2012

Hospice
Palliative
Care
Association
of South Africa

no end to caring

UPDATED
FULL COLOUR
EDITION

HOSPICE PALLIATIVE CARE ASSOCIATION OF SOUTH AFRICA

Legal Aspects of Palliative Care

Legal Aspects of Palliative Care

Hospice Palliative Care Association of South Africa

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no end to caring

OPEN SOCIETY FOUNDATIONS

This book is available online at www.hpca.co.za/legal resources; www.osf.org.za; www.soros.org/issues/health

The HPCA thanks patients, families, staff and others connected with hospice who kindly provided permission to use their photographs or their stories in this book.

Published by the Hospice Palliative Care Association of South Africa (HPCA)
PO Box 38785, Pinelands, South Africa
Tel: 021 531 0277
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www.hpca.co.za

First published 2009
Revised edition 2012

ISBN 978-0-620-54210-4

A catalogue record for this book is available from the South African National Library

Produced by sarahscottdesign www.sarahscottdesign.co.za

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Unfortunately, in end-of-life care, we do not have a vocal constituency:
The dead are no longer here to speak,
The dying often cannot speak,
And the bereaved are often too overcome by their loss to speak.

Professor Harvey Chochinov, one of Canada's leading palliative care experts
during his address to the Canadian Senate in 2000

FOREWORD

Patients with life-limiting illness and their families face many painful problems. Some of these need legal interventions. These legal issues can increase emotional stress at a difficult time, and impact on the way families and friends cope with the illness. Palliative care aims to prevent and relieve suffering. Palliative care also aims to enhance quality of life - but this enhanced quality is restricted while patients' legal problems remain unresolved.

Patients and families - especially from poor communities - have limited awareness of their human rights and limited access to and little experience of legal services. The book helps hospice staff to develop awareness of legal issues and gather information on legal problems to enable early identification and referral where necessary. This will help relieve suffering.

For legal practitioners the book aims to enhance their understanding of the needs of patients in palliative care, and to encourage them to extend their services to this vulnerable group.

This updated edition of the law manual was funded with support from the Open Society Foundation. The update affects content and layout. It is supplemented by training exercises for practical purposes. This book I am happy to say is now more attractive to the reader. There is a sidebar for notes, extra resources at the end, and full-colour photos throughout.

The book will be of interest to readers working with patients and clients struggling with two issues concurrently: the challenges of life-threatening illness and with parallel legal problems.

The original version was published in 2009. This updated edition remains unique worldwide in that writers from two disciplines, palliative care and law, came together to work in pairs to articulate and respond to issues raised by those working in the field: the legal challenges of patients in palliative care. Collaborative work by each pair of co-writers developed into individual chapters. So the book addresses the problems from the two perspectives throughout.

The opening three chapters explain the ethos behind palliative care, and look at palliative care from a rights perspective and then tackles ethical issues in palliative care.

Thereafter chapters cover the legal requirements for palliative care organizations to register and be recognized under South African law, the challenges in accessing care and medication in palliative care, the challenges of poverty and financial issues, debt, the rights of the child in palliative care, palliative care for older persons, and marginalized groups. A chapter is devoted to the role and status of community caregivers in South Africa.

The penultimate chapter explains estate planning and what happens when someone dies without a will, giving tips on what to include when writing your will. The closing chapter covers dying from the palliative care perspective.

A wealth of expertise and experience in the areas of palliative care and the law has provided a unique document that expands the realms of both disciplines.

Edwin Cameron
Constitutional Court
May 2012

ACKNOWLEDGEMENTS

Much of the original content of this book has been greatly revised in this updated edition. The basic foundation was laid in the first edition of 2009, and the publisher, HPCA and the funder, the Open Society Foundation, wish to acknowledge the original authors and also acknowledge those who revised and contributed greatly to this update.

To the editing team for revising and updating much of this edition, including the addition of new content, case studies and training exercises, with grateful thanks to:

Sue Boucher
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With thanks to the following people for supplying additional material or reviewing aspects of this edition:

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Richard Perkins, Financial Officer, HPCA

Marlise Richter, Wits African Centre for Migration and Society

Jo Vearey, Wits African Centre for Migration and Society

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For copy-editing and proof-reading with grateful thanks to **Erica Bethke.**

For project-management of this book with grateful thanks to **Nicky GunnClark.**

For acknowledgment of the original authors and editors of the 2009 edition please see the next page.

ACKNOWLEDGEMENTS

Acknowledgement to the Original Authors And Editors

HPCA, the funders and the publisher would like to thank the following people and organisations in particular for their contributions as editors or authors to the original edition of this book:

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CHAPTER 1

Introduction to Palliative Care

“The essence of palliative care is the relief of suffering”
Derek Doyle

WHAT IS PALLIATIVE CARE?

The World Health Organisation defines palliative care as an 'approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.'

WHO August 2002

Terms you will find in this chapter

Advocate: to speak on behalf of another person or group

Continuum of care: a gradual transition of care without abrupt changes in care or cessation of care

Dichotomy: separation between two different approaches

Existential: relating to or affirming human existence, concerned with one's place in the world

Non-derogable: those rights in a treaty which states cannot violate under any circumstances

Peremptory norms: are standards of international public policy which impose limits on the behaviour of governments and politicians

Any person of any age who has a life-limiting condition in South Africa qualifies for palliative care. The most common life-limiting conditions are cancer, AIDS and TB. The three "trigger" questions on page 6 provide good guidance as to when people should seek palliative care.

The World Health Organisation definition also states that palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten nor postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- Will enhance the quality of life, and will also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are implemented to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

WHO August 2002

The fundamental purpose of palliative care is to improve quality of life, so it can be argued that palliative care lends itself to the recognition of the human rights of patients and their families.

Among the features of palliative care that make it conducive to a human rights approach are:

- The goal of palliative care is quality of life. Quality of life relates to an individual's subjective satisfaction with life and a quality of life assessment usually looks at four domains: physical, social, emotional (psychological) and spiritual (existential). Quality of life changes as an individual's experience and expectations change.
- The unit of care is the patient and family. Patient-centred care requires open and honest communication with the patient, respect, sharing of information in words the patient understands, mutual agreement on the goals of care and treatment options. The family's views are important but should not supersede the patient's wishes.
- Palliative care provides total care: physical, psychosocial and spiritual. No one element of care is more important than another, although it is true that when a patient is in severe pain, it is difficult for the patient to focus on psychosocial issues until the pain is controlled.

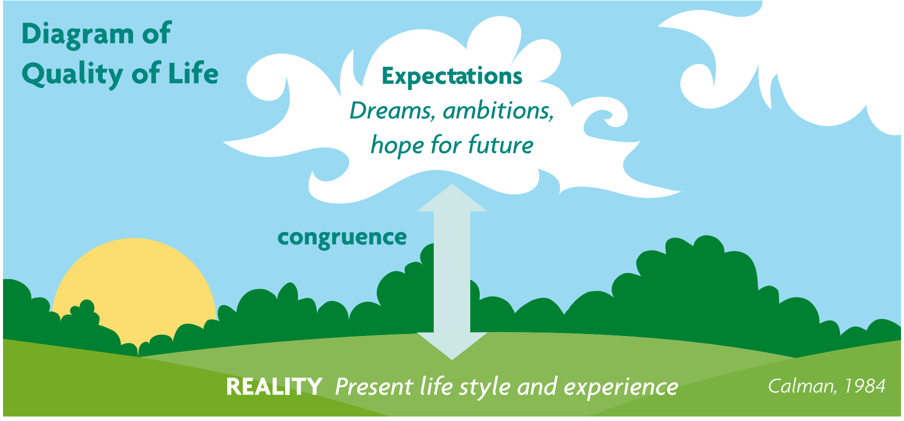


Diagram by Dr Michelle Meiring, Big Shoes Foundation, adapted from K. C. Calman (1984). Quality of Life in Cancer Patients - An Hypothesis. Journal of Medical Ethics 10 (3):124-127

PALLIATIVE CARE AND HUMAN RIGHTS

International law

Certain rights have been considered so important that they are non-derogable.

These rights are also known as peremptory norms of international law.

What rights are these?

- the right to life

- the right to be free from torture and other inhumane or degrading treatment or punishment.

- the right to be free from slavery or servitude

South African Constitution

Under the South African Constitution certain rights are entirely protected and non-derogable. (meaning the right is absolute and cannot be suspended even in a declared state of emergency) Rights in the Constitution may be limited generally if the limitation is reasonable and justifiable (Section 36).

Section 11 – the right to life

Section 12 – the right to freedom and security of the person which includes the right:

- not to be tortured in any way;
- and not to be treated or punished in a cruel, inhuman or degrading way.

Everyone has the right to bodily and psychological integrity, which includes the right to make decisions concerning reproduction;

to security in and control over their body; and not to be subjected to medical or scientific experiments without their informed consent.

In addition, the South African Constitution absolutely protects the right to Human Dignity.

Section 10 - Everyone has inherent dignity and the right to have their dignity respected and protected.

Relevance in Palliative Care

How can palliative care recognise the human rights in our Constitution and under international law?

Palliative care calls for the recognition of the patient's right to access palliative care and pain control.

Palliative care is about quality of life:

- respect for life
- recognition of the whole person
- including family and loved ones

The UN Special Rapporteur on the Right to Health and the Special Rapporteur on Torture, after reviewing the inadequacies of pain management and Palliative Care around the world, stated in a joint statement that:

"The failure to ensure access to controlled medicines for the relief of pain and suffering threatens fundamental rights to health and to protection against cruel, inhuman and degrading treatment."

Palliative care is concerned with the alleviation of human suffering.

Derek Doyle describes suffering as the distress associated with events that threaten the intactness or wholeness of the person.

Palliative care respects the dignity of patients and family members regardless of stage of illness or any other consideration.

"You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die."

Dame Cicely Saunders

WHAT PALLIATIVE CARE INCLUDES

Derek Doyle describes suffering as the distress associated with events that threaten the intactness or wholeness of the person and describes the appropriate response to suffering as multidisciplinary palliative care.

Notes

Palliative care includes all aspects of care, medical and non-medical, and as such is described as total care.

This aligns with the WHO definition of health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. The requirement for a multidisciplinary team is clear in order to be able to provide this comprehensive care. Many healthcare professionals have viewed palliative care as a 'soft option' and equate it with withdrawal of care. However, palliative care is active therapy, assessing and managing difficult symptoms and psychosocial and spiritual issues. Appropriate assessment of patient problems enables the care team to develop an individualised care plan for each patient in consultation with the patient.

The WHO definition was developed with the care of patients with advanced cancer in mind, so that chemotherapy and radiation therapy are identified as important therapies intended to prolong life that should be offered in conjunction with palliative care. With other diagnoses, therapies that should be considered include: antiretroviral (ARV) treatment for HIV/AIDS, anti-failure medication for heart failure and renal dialysis for renal failure.

Palliative care can best be understood in its fundamental sense as a response to suffering – the suffering of patient and family members when faced with the diagnosis of life-threatening illness. Inasmuch as both are concerned with the alleviation of human suffering, palliative care has much in common with the modern human rights movement.

PALLIATIVE CARE FOR CHILDREN

Palliative care is not only concerned with the care of adults. Palliative care for children is of enormous importance in the work of hospices around the country. The founding statement of the International Children's Palliative Care Network (ICPCN) in Seoul, South Korea, in 2005 stated: **"We ask that the voices of children and young people be heard, respected and acknowledged as part of the development of palliative care worldwide."**

WHO Definition of Palliative Care for children

The WHO definition of palliative care, appropriate for children and their families, is as follows (the principles apply to other paediatric chronic disorders):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres, and even in children's homes (the child's own home, community home or institution).

Quinton was 12 when diagnosed with osteosarcoma. He had limb-sparing surgery and chemotherapy but developed cardiac failure with a poor prognosis. Quinton spent eight months in and out of hospital and wanted to stay at home. Home was a municipal flat in a gang-ridden area.

This was a sad family. His father could not cope with the imminent death of his beautiful, life-loving son. His only son who just wanted to go back to school. Quinton was concerned about his family and their sadness and did not know how to comfort them. He did not want to go back to hospital, he understood he was dying, and he wanted to assist his family to let him go.

The hospice team was mobilized and the palliative care nurse with the hospital paediatric palliative doctor doing symptom management. His loss of weight, appetite and energy worried his mother; so Quinton's food preferences were discussed and a plan formulated. His pain was managed with a low dose of Morphine but he developed abdominal discomfort and his breathing was not easy. Solutions were sought, and by ensuring regular bowel movements, much of the discomfort was lifted. Quinton controlled his medication himself and with support, managed it well. His father said knowing there was someone close, who visited, cared and gave advice, made the time at home very special; they could relax and enjoy each other's company.

The social worker had family meetings and many chats with Quinton about his illness, fears, hopes and dreams. Quinton and his mother had open and honest conversations about dying and the future. Quinton needed to be busy so home-caregivers in the area, visited often, with playful banter and board games. The hospice teacher helped with school-projects, new games and crossword puzzles. The physiotherapist kept Quinton mobile with exercises and taught these to the home-carers. Quinton loved swimming, so almost every Saturday his family took him to the local swimming pool.

The community rallied around. School friends, neighbours and teachers visited. Quinton knew he was dying. On the morning Quinton died, his father tells how Quinton said it was time to go and that he wanted to say goodbye. He thanked everybody for their help and love. He thanked hospice and the hospital team for making it possible for him to spend time at home.

Quinton is not his real name

BARRIERS TO PALLIATIVE CARE

The Gold Standards Framework in the UK suggests a method of identifying patients that would benefit from palliative care using 3 practical "triggers" for palliative care:

1. **The surprise question:** 'Would you be surprised if this patient were to die in the next 6 - 12months?'
2. **Patient choice or patient need:** the patient with advanced illness makes a choice for comfort care only; or the patient is in special need of supportive or palliative care.
3. **Clinical indicators:** general and specific indicators of advanced disease. General indicators include weight loss >10% over 6 months, general physical decline, reducing performance status. Specific indicators for cancer, organ failure and frailty are described.

Often infected patients are reluctant to disclose their status. One patient asked the caregiver to say she was his girlfriend so that his neighbours would think that was why she visited him so often.

Although it appears to be a straight-forward exercise to ensure accessibility of palliative care to all patients requiring this service, there are still a number of significant barriers to access to palliative care.

Clinical staff, doctors and nurses may not have the necessary training to understand or to provide palliative care. They do not see their role as providing palliative care and they see referral to a hospice service as 'giving up' on the patient. Many doctors do not have the communication skills to compassionately address end-of-life issues, although this is changing as these skills are now taught in medical school and many doctors avail themselves of continuing professional development opportunities to develop these skills. There is a lack of institutional standards for the provision of palliative care.

Patients may continue in denial of the severity of their illness. They may have unrealistic expectations of disease response. There may be patient and family disagreement about treatment options and there may be lack of advanced care planning.

Social factors that are barriers to palliative care include:

- discrimination against minorities and disempowered groups such as refugees, prisoners and homeless people.
- there may be language barriers in accessing palliative care.
- hospices may not have been established in rural communities.
- Access to palliative care may be denied both to patients whose care is paid by medical aid, and to more wealthy patients whose doctors choose to continue active treatment even when futile.

There are other access factors that are barriers to the provision of palliative care:

- transport costs to health care facility for seriously ill patients
- no government subsidies for palliative care and no physician reimbursement for palliative care
- there may be inefficient procurement processes in remote clinics/hospitals
- some palliative care drugs may not be held at Community Health Centres in spite of their being on the Essential Drug Lists.

These barriers need to be addressed if all patients requiring palliative care are to access that care.

This requires:

- education of healthcare workers and policy makers
- raising awareness of the benefits of palliative care within communities
- addressing patient and family concerns

The outcome of accessible palliative care is:

- better quality of life for patients
- compassionate support for patients and families
- development of caring communities
- enhanced personal and professional satisfaction for the healthcare worker.

PROVISION OF PALLIATIVE CARE

Where is palliative care provided?

In South Africa, palliative care has traditionally been provided by hospices.

This has lead many people to view palliative care as end-of-life care. While hospice care and terminal care are important aspects of palliative care, palliative care starts from the moment of diagnosis of a life-threatening illness. Palliative care can be delivered in the most appropriate setting for the individual patient and his/her family, as is specifically described in the definition of palliative care for children. The majority of patients are cared for in their own homes, but palliative care can also be carried out in hospitals, clinics, the frail care setting, hospice in-patient units and prisons (if the prisoner is not released home for terminal care). Patients do not need to travel to a facility to access palliative care. Palliative care staff can take the care to the patient. Palliative care can be delivered as in-patient care, out-patient care and home care.

Continuity of care depends on good communication between healthcare workers in the different settings and on co-ordination of care, usually by the patient's home care nurse. HPCA is a national membership association operating in all nine provinces of South Africa with member and affiliated hospices countrywide.

When does palliative care start?
....Where is it provided?

Palliative care starts from moment of diagnosis

In prisons

Palliative care is provided:
- *in hospitals*
- *in clinics*
- *in frail care settings*

In the patient's home

In children's homes, community health centres, tertiary care facilities

Palliative care staff take the care to the patient

In hospice In-Patient Units

Notes

Exercise on Provision of Palliative care

Who provides palliative care?

The World Health Organisation definitions describe palliative care on:

- page 2
- page 5

Consider these statements, and describe who provides palliative care.

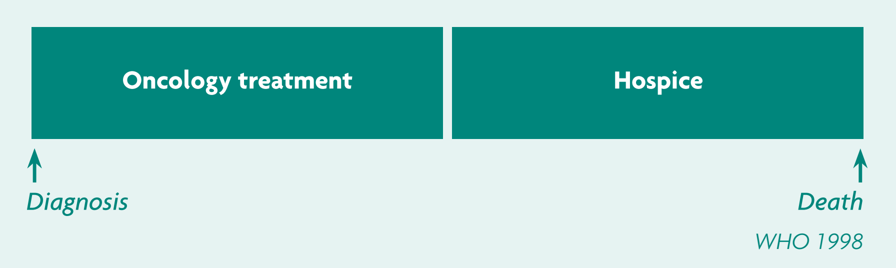
Notes

1. Continuum of care:
Traditional view of palliative care

The traditional view of palliative care, which was developed in the 1960s, has to be challenged. Traditionally patients were told, 'there is nothing more we can do', before being referred to a palliative care service. Disease-oriented care and palliative care are, however, not an 'either-or' option, but a 'both-and' option.

The separation of the two led to patients experiencing a sense of abandonment by their doctors and the doctors themselves experiencing a sense of failure. The 'false dichotomy' between disease-modifying treatments for HIV/AIDS or cancer and palliative care must be overcome. In the HIV setting, even patients near death from AIDS may recover and lead functional lives with ARV therapy. Furthermore, uncomfortable symptoms in AIDS patients are sometimes best treated with ARV therapy or aggressive treatment of opportunistic infections, while pain and symptom control may improve adherence to ARV therapy and quality of life.

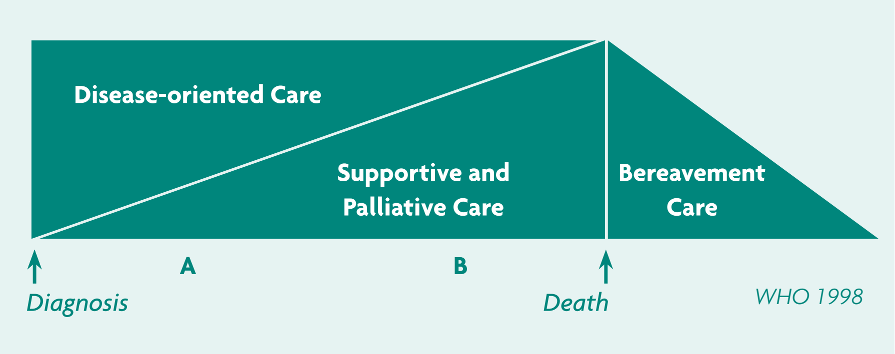
Continuum of care: Traditional View of Palliative Care - Diagram 1



2. Continuum of care:
Palliative care in the developed world

In the developed world, supportive and palliative care is (ideally) offered to patients alongside disease-oriented and life-prolonging care. Care is holistic and patient and family-centred. This results in better patient care, better bereavement outcomes and a more satisfactory professional experience. All clinicians are trained in palliative care and can provide this care to patients at the same time as providing disease-oriented care. So the oncologist will prescribe pain medication as well as chemotherapy. The HIV clinician will manage the pain of oesophageal candidiasis and nutritional support as well as prescribing fluconazole as an antifungal treatment.

Continuum of care: Palliative Care in the developed world - Diagram 2



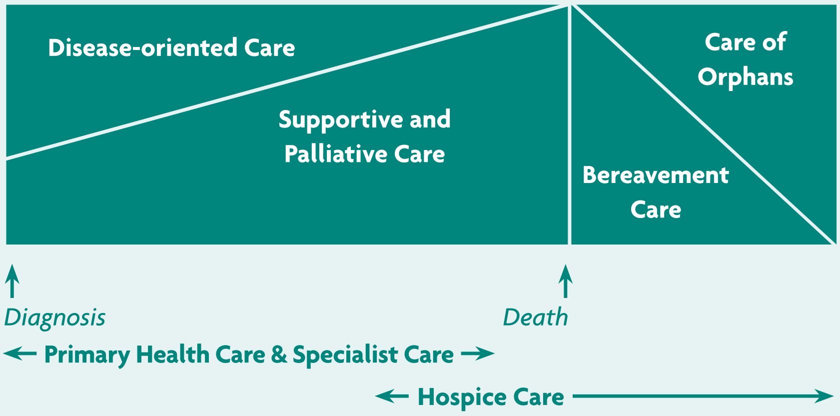
3. Continuum of care: Palliative care in the developing world

In the developing world, with its limited resources, fewer disease-oriented treatment options are available for patients and their families so that supportive and palliative care is an increasingly important part of holistic patient care. With more healthcare professionals training in palliative care, this can be integrated earlier into the caring relationship, creating better results for patient, family and healthcare professional. Palliative care is then provided in other care settings and not only by hospices, although hospices remain the specialist centres for providing palliative care, whether in the patient's home or in a hospice in-patient facility.

The result of early intervention, with active palliative care, is better quality of life for patients and families, a peaceful and dignified death for the patient and better bereavement outcomes for the family. The professional satisfaction of effective compassionate care results in a rewarding experience for the healthcare worker, both personally and professionally, and a lower incidence of burn-out.

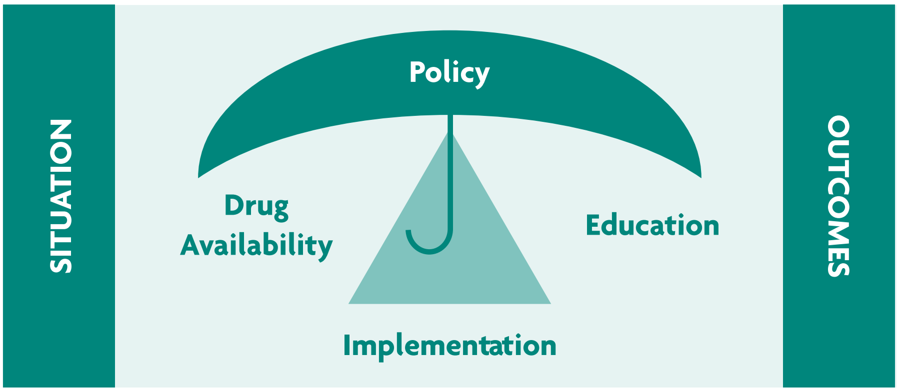
The diagram also illustrates that disease-oriented care (chemotherapy, radiotherapy, antiretrovirals) is often not available to many people at the time of diagnosis, because of limited resources which results in discrimination against the poorer members of society. This discrimination in the provision of health resources requires urgent attention, and efforts to improve palliative care must be linked to, or accompanied by, efforts to simultaneously pilot and improve comprehensive HIV/AIDS care, including ARV therapy or cancer control programmes.

Palliative Care in the developing world -Diagram 3



Adapted from WHO Defilippi, Gwyther 2002

WHO Public Health model

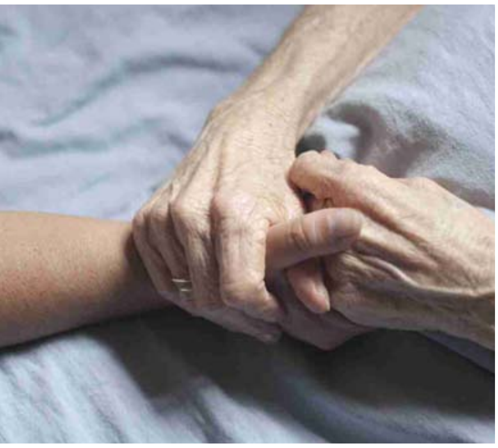


The WHO public health model for the implementation of palliative care

In an attempt to increase access to palliative care for patients and families facing the diagnosis of life-threatening illness, the World Health Organisation has identified a public health strategy for effective national palliative care programmes that consists of four parts:

1) National palliative care policies and guidelines that incorporate palliative care into the public health system
2) Laws and regulations that make readily and responsibly available opioid analgesics and other essential palliative care drugs
3) Education in palliative care for healthcare providers, government officials, patients and caregivers
4) Implementation of clinical palliative care programmes

CONCLUSION



The time is right for the South African government to develop and implement a palliative care strategy to promote access to quality palliative care for all patients with a diagnosis of a life-threatening illness. The skills and expertise to achieve this are available within the palliative care community of South Africa, and as described in Chapter 2, the foundation for palliative care as a human right has been established.

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CHAPTER 2

Introduction to Human Rights and Palliative Care

HUMAN RIGHTS AND PALLIATIVE CARE

Both palliative care and human rights are based on the principles of the dignity of the individual and of universality and non-discrimination. To palliative care personnel, this creates a self-evident premise that palliative care is a human right.

A closer look at the history of the development of human rights and human rights covenants gives a deeper understanding of palliative care as a human right.

What are Human Rights?

"All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood."

Article 1 UDHR

Why was the United Nations (UN) started?

After World War 2, countries decided a new international organisation was needed to promote international peace and security. The United Nations was created in 1945 to protect future generations from the scourge of war and to promote fundamental human rights and the dignity and worth of the human person. After founding the UN, a committee was charged with the writing of an International Bill of Rights which emerged in December 1948 as the Universal Declaration of Human Rights. The term 'Human Rights' refers to the rights and freedoms to which all humans are inherently entitled.

The International Bill of Rights

In 1948 the United Nations General Assembly adopted the Universal Declaration of Human Rights (UDHR) .

The UDHR, together with two binding treaties:

- the International Covenant on Civil and Political Rights (ICCPR)
- the International Covenant on Economic, Social and Cultural Rights (ICESCR)

make up the International Bill of Rights.

While the UDHR is a resolution of the UN General Assembly, the ICCPR and ICESCR are legally binding treaties that have been *ratified* by nearly every nation on earth.

The provisions of the International Bill of Rights are reflected in many national constitutions and are enforceable at the national level through litigation.

Their provisions are also enforceable at the regional international level through a variety of treaty-monitoring mechanisms, complaints procedures, and courts.

In addition to the ICCPR and ICESCR, there are:

- *specialised treaties*
  (such as the Convention on the Rights of the Child, the Convention on the Elimination of All Forms of Discrimination Against Women)

and

- *regional treaties*
  (such as the African Charter on Human and People's Rights, and the European Convention for the Protection of Human Rights and Fundamental Freedoms)

which contain provisions and procedures that further strengthen the argument that palliative care is a human right.

Terms you will find in this chapter

Breaches in pain care: failure to keep to or obey the established guidelines for pain care

Covenant: an agreement that is binding on all parties

Defendant: the accused person who has to answer the charges brought against him/her

Disproportionately burdened: unequally/unfairly burdened compared with those around them.

Inalienable element: absolute part (of healthcare) which cannot be taken away or challenged

Indigenous populations: people who are the original/local inhabitants of a region or country

Inherently entitled: to have the right to have/do things by the very fact of being human

"inter alia": Latin phrase meaning "among other things"

Lack of compliance: not doing what you have agreed to do

Litigation: the process of bringing or opposing a case in a court of law

Minimum Core: a minimum standard that the United Nations apply to make sure everyone has the basics to survive

Plaintiff: a person who accuses someone else of wrongdoing in a civil court

Potable water: clean and uncontaminated water which is suitable for drinking

Preamble: that which comes before/introduces/leads up to a report, speech or formal document

Ratified: to have confirmed/agreed to a treaty negotiated by someone else

Standard of reasonableness: an objective test that the Courts use to see if governments or people carry out their duties to a certain standard.

Universality: affecting/relating to everyone in the world

What does it mean to ratify a document?

When a country *ratifies* a document, it agrees to be bound by the rules in the document and makes the document part of its own laws.

If a country *signs*, but does not ratify it, this means that the country supports the rules in the document and promises not to commit acts that would defeat the purpose of the document.

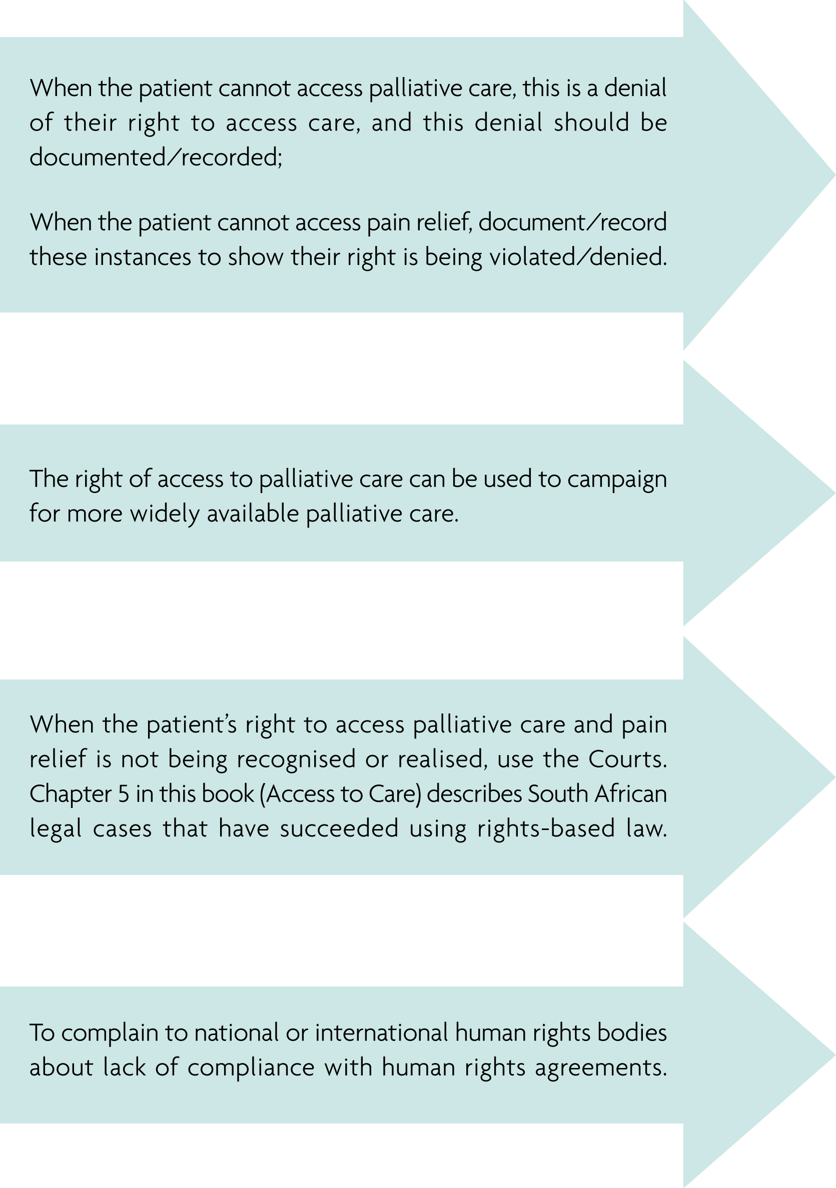
South Africa has signed and ratified the International Covenant on civil and political rights and monitoring is done by the SA Human Rights Commission.

South Africa has not ratified the ICESCR. Black Sash sees this as 'South Africa engaged but not married'.

The Child Gauge 2009-2010 recommends that amongst other steps the government should ratify the ICESCR and publicly debate the implications of implementing this treaty.

From LIFE Before Death © Moonshine Agency

How can we use human rights to benefit patients?



When the patient cannot access palliative care, this is a denial of their right to access care, and this denial should be documented/recorded;

When the patient cannot access pain relief, document/record these instances to show their right is being violated/denied.

We can use examples of violated rights, to draw attention to the plight of patients who are not receiving palliative care or not receiving pain medication.

The right of access to palliative care can be used to campaign for more widely available palliative care.

If your campaign is successful, more patients will receive palliative care as it will be more widely available.

When the patient's right to access palliative care and pain relief is not being recognised or realised, use the Courts. Chapter 5 in this book (Access to Care) describes South African legal cases that have succeeded using rights-based law.

Courts can enforce patients' rights and ensure provision of palliative care services.

To complain to national or international human rights bodies about lack of compliance with human rights agreements.

Further pressure brought to bear on decision makers to provide for the needs of palliative care patients.

THE HUMAN RIGHT TO HEALTH

What does *progressive realisation of the right to health* mean?

Progressive Realisation - means your rights are not absolute but are dependent upon your government's available means. These socio-economic rights are not absolute, they are qualified rights. In South Africa the extent of the state's obligation with regard to economic and social rights is defined by three key elements:

- the obligation to *take reasonable legislative and other measures*
- in order *to achieve the progressive realisation* of the right
- and to do this *within available resources*.

The right to the highest attainable standard of health is evident in extracts from the following legally enforceable documents.

- Article 25.1 of the UDHR states: *"Everyone has the right to a standard of living adequate for the health of himself and his family, including food, clothing, housing and medical care and necessary social services"*
- Article 12.1 of the ICESCR asserts that: *"...the States Parties to the present Covenant recognise the right of everyone to the enjoyment of the highest attainable standard of physical and mental health."*
- Article 12.2 of the ICESCR stipulates the steps to be taken by States Parties....to achieve the full realisation of these rights.

  The ICESCR recognises that, in resource-constrained settings, these rights may not be immediately attainable but... States Parties that are signatories of the ICESCR commit to progressive realisation of the right to health over a period of time and to reporting on the steps taken to reach this goal.

The Committee on Economic Social and Cultural Rights (CESCR)

The Committee on Economic Social and Cultural Rights (CESCR), which is the United Nations body responsible for overseeing government compliance with the ICESCR, also recognises that the right to health is dependent on a number of other:

- social,
- economic
- cultural rights:

"...such as food and nutrition, housing, access to safe and potable water and adequate sanitation, safe and healthy working conditions, and a healthy environment".

While this raises the challenge of how to prioritise a population's socio-economic needs in working towards the realisation of the rights articulated in the ICESCR, it affirms that rights are interdependent and should not be pitted against one another. In August 2000 the CESCR drew up General Comment No. 14 where the right to the highest attainable standard of health was addressed in terms of Article 12 of the ICESCR.

- General Comment No. 14 asserts that: *"In particular, States are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons, including prisoners or detainees, minorities, asylum seekers and illegal immigrants, to preventive, curative and palliative health services;"*
- It further describes, (in the section on Older Persons) : *"Attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity."*

How has palliative care been adopted regionally as a human right?

Palliative care is included in the rights guaranteed by the International Bill of Rights.

Some countries have taken this right further, and included references to palliative care as a human right in official documents.

In 2000, a Standing Committee of the Canadian Senate proclaimed that: *"end-of-life care was a right of every citizen."*

In 2003, the European Committee of Ministers adopted a Recommendation which stated, in part: *"palliative care is... an inalienable element of a citizen's right to health care."*

In February 2011 a report on Belarus from the UN Committee on the Rights of the Child, identifies government responsibility to support children's palliative care in line with Articles 4, 6 and 24 of the UN Convention on the Rights of the Child. This also applies to the South African government with respect to their obligations towards children.

Guideline 6 of the International Guidelines on HIV/AIDS and Human Rights includes the comment that:

"States should... take measures necessary to ensure for all persons, on a sustained and equal basis, the availability and accessibility of quality goods, services, and information for HIV prevention, treatment, and care and support..., including preventive, curative and palliative care of HIV and related opportunistic infections and conditions."

In considering these obligations with regard to palliative care, there is an opportunity for palliative care professionals to engage with government to ensure:

- a national policy for palliative care
- education in palliative care for all healthcare professionals
- provision of palliative care in the public health system alongside the NGO sector programmes.

In this way, we can ensure that all those with life-threatening or life-limiting illness who require palliative care will have access to this service.

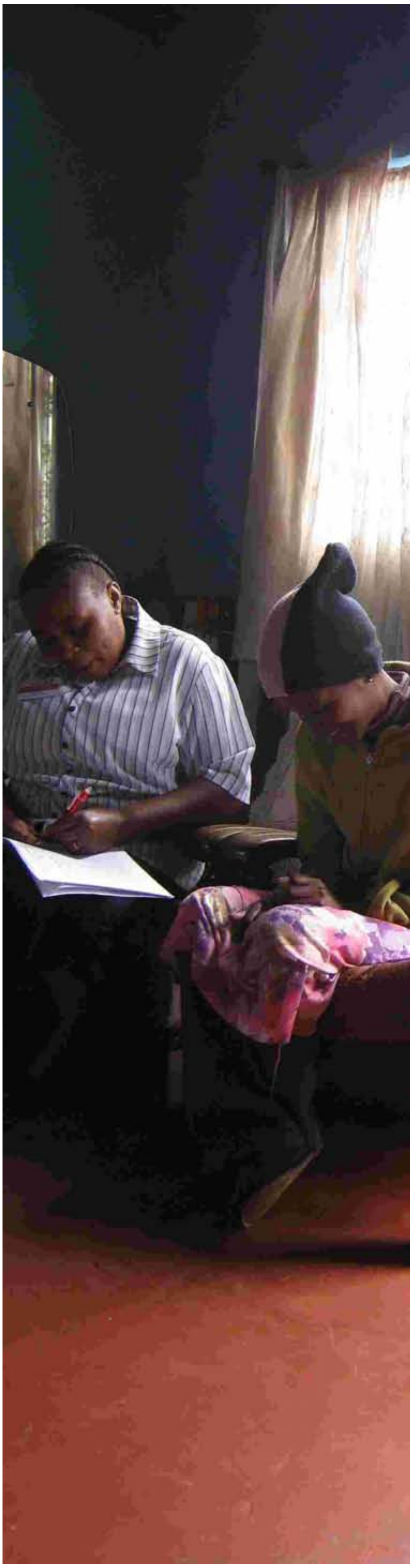
The South African Department of Health's Patients' Rights Charter describes access to healthcare as follows:

"Everyone has the right of access to healthcare services that include:

iii. Provision for special needs in the case of... patients in pain, persons living with HIV or AIDS patients;

v. Palliative care that is affordable and effective in cases of incurable or terminal illness."

Notes



THE RIGHT TO ADEQUATE PAIN RELIEF

The facts in *Giurelli v Girgis* were:

The plaintiff sustained a broken leg which was operated on by the defendant orthopaedic surgeon, who fixed a steel plate to the front outer surface of the tibia. The plaintiff complained on a number of occasions about serious pain in the leg and an inability to put any weight on the leg. The surgeon took the view that the plaintiff was a difficult patient, with a propensity for histrionics, who exaggerated his complaints. When the steel plate was removed and the plaintiff attempted to put weight on the leg, it gave way. A further operation was required to repair the fracture.

White J held that the surgeon was liable, because he had failed to take into account the possibility that the fracture was not uniting satisfactorily and had dismissed the plaintiff's complaints without making any proper investigation. The plaintiff was not believed or given sufficient time or opportunity to describe his symptoms, or the defendant did not ask sufficient questions. He had allowed only five to ten minutes for consultations, but "pressure of time did not justify the risks of not listening and inquiring".

Through the use of different international instruments, the right to adequate pain relief can be justified.

The United Nations Committee on Economic Social and Cultural Rights indicated that access to:

"essential drugs, as defined by the WHO Action Programme on Drugs"

is part of the minimum core content of the right to health.

When we review the WHO Essential Drug List it is evident that fourteen palliative care medications are currently on this list.

In addition to the right to health, the UDHR in Article 5 states in part:

"no one shall be subject... to cruel, inhuman or degrading treatment".

This statement is typically applied to the treatment of prisoners but has been used to encompass patients' rights to pain relief and in legal cases, claiming negligence in the failure to relieve patients' pain adequately.

An unreasonable failure to provide adequate pain relief may constitute negligence.

Breaches in reasonable pain care may be:

- an unreasonable failure to take an adequate pain history;
- an unreasonable failure to adequately treat the pain.
- in the context of uncontrolled pain, an unreasonable failure to secure expert consultation.

Negligence cases against health professionals and hospitals, based on these principles, have resulted in multimillion dollar judgments the following cases illustrates.

In the case of Giurelli v Girgis 1980 the judge decided there had been an unreasonable failure to take an adequate pain history.

See the facts in the shaded box below.

The judge in the North Carolina case of Estate of Henry James v. Hillhaven Corporation 1991 decided that there had been an unreasonable failure to adequately treat the pain. This was the first negligence lawsuit where a healthcare provider was held liable for failure to treat pain appropriately. The jury awarded $15 million in damages to the family of Henry James, whose dying days were made intolerable by the decision of a nurse and her employer, a nursing home, to withhold or reduce pain medication ordered by the patient's physician. The lawsuit focused on healthcare providers' responsibilities to ensure the proper administration of pain medications in appropriate doses.

Henry James, a 75 year old man with metastatic adenocarcinoma of the prostate, was admitted to a nursing home. His pain had been well controlled by regularly administered opioids. A nurse documented both her impression that the patient was addicted to morphine and her intention to wean the analgesic regimen and substitute a mild tranquilizer. In unilaterally deciding to wean the patient from opioids, the nursing staff did not consult the doctor. In his summary statement approving a final settlement in favor of the plaintiff, the judge emphasized the potentially serious legal consequences faced by healthcare providers when they negligently fail to provide patients with adequate analgesia.

OTHER INTERNATIONAL HUMAN RIGHTS CONVENTIONS

In addition to the International Universal Bill of Rights, other important international and regional conventions exist and are referred to in this manual.

These include:

- Convention Relating to the Status of Refugees, 1954
- Convention on the Elimination of All Forms of Racial Discrimination, 1969
- Convention on the Elimination of All Forms of Discrimination Against Women, 1981
- Convention on the Rights of the Child, 1990
- The African Charter on Human and People's Rights, 1986
- African Charter on the Rights and Welfare of the Child, 2000

The right to non-discrimination and equality is a foundational principle under both the South African Constitution and international law.

Under the South African Constitution: *"Everyone is equal before the law and has the right to equal protection and benefit of the law."*

This echoes the ICCPR:
"All persons are equal before the law and are entitled without any discrimination to the equal protection of the law."

This fundamental principle is further highlighted in the preambles to international human rights conventions. The CESCR has explained how this right to equality applies to the delivery of health services. Health facilities, goods, and services have to be accessible to everyone without discrimination *"especially to the most vulnerable and marginalized sections of the population."*

The UN Committee has urged particular attention to the needs of *"ethnic minorities and indigenous populations, women, children, adolescents, older persons, persons with disabilities and persons with HIV/AIDS."*

Moreover, health facilities, goods, and services: *"must be affordable for all,"* and *"poorer households should not be disproportionately burdened with health expenses."*

What does the *Right of Access to Health Care* mean?

South Africa's Constitution provides a right of access to health care.

What does this mean?
What must government do?

- Government must act accordingly in order to make it possible for you to access health care.
- Government must remove the obstacles that may prevent people from accessing health care.
- At the same time the state must manage these claims so that state finances or resources are not overextended.
- In addition government must provide the SA Human Rights Commission with information outlining the steps that have been taken to progressively realise these rights.

Where the international documents might apply a minimum core approach, in South Africa it appears that the Courts are following the notion of reasonableness in their application of progressive realisation.

THE SOUTH AFRICAN CONSTITUTION

South African courts have interpreted progressive realisation of rights to mean…

In the case of Grootboom (Government of Republic of South Africa and Others v Grootboom and Others 2000 (11) BCLR 1169 (CC), the Court mentioned the provision of maintenance grants and other material assistance as one of the ways… the State would meets its Section 27 obligations.

Sandra Liebenberg, a Human Rights expert from Stellenbosch University argues that the Court's analysis in this case shows its reluctance to interpret the socio-economic rights provision in the Constitution as allowing individual claims for direct material assistance from the State.

In the Minister of Health & Others v Treatment Action Campaign & Others 2002, the Court's central enquiry [was] whether the constitutional standard of reasonableness in section 27(2) had been met.

The Child Gauge 2009-2010 looks at the courts' track record in enforcing children's rights and finds that the TAC judgment and the resultant roll-out of comprehensive PMTCT have saved thousands of babies' lives. The Child Gauge argues that this progress would not have happened without the activism of health professionals and civil society.

But the Child Gauge continues 'on the negative side, the Constitutional Court has been criticised for:

- failing to give content to the meaning of socio-economic rights
- failing to hold the State to the delivery of a minimum core…
- The Court has instead adopted a procedural approach ("the reasonableness test") that promotes a process of accountability and that leaves defining the content of socio-economic rights to the Executive and the Legislature. '

CONCLUSION

> "Unfortunately, in end-of-life care, we do not have a vocal constituency:
>
> The dead are no longer here to speak, the dying often cannot speak,
>
> and the bereaved are often too overcome by their loss to speak"
>
> *Harvey Chochinov, testimony before the Subcommittee, 28 Feb 2000, Canadian Senate*

South Africa's 1996 Constitution was hailed as one of the most progressive constitutions in the world. It provides access to a number of political and socio-economic rights such as housing, health care, education, water, and electricity. However, ensuring the realisation of these rights has proven to be one of the greatest challenges facing South Africa.

As service providers, we are in a unique position to contribute to the future of the country by ensuring the successful realisation of these rights in our respective fields. In some cases, particular population groups may face greater barriers to realising their rights and by being aware of such barriers we can tackle them as they arise. We have the opportunity to promote access to palliative care for patients and family members facing the diagnosis of life-threatening illness and to act as advocates for this group of people, who because of their illness or grief, have not had the capacity to demand the services they need.

The human rights approach to advancing palliative care development emphasises the fact that care of patients with life-threatening illness is a fundamental responsibility of governments, society and health professionals.

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CHAPTER 3

Ethical Issues in Palliative Care

INTRODUCTION

Terms you will find in this chapter

Alleviation: to make something such as pain or hardship more bearable or less severe

Distributive justice: fair distribution of resources for all

Duress or Coercion: the use of force or threats to make somebody do something

Euthanasia: active killing at a person's request

Legal justice: according to the laws of the land.

Maximal (comfort): the best or greatest possible (comfort)

Paternalistic approach: an approach where the authority figure makes decisions on behalf of others supposedly in the other's best interest but depriving the others of their choice

Prevail: to prove to be stronger and more effective

Proxy: somebody authorised to act for another person

Social justice: based on the concepts of human rights and equality, involving a greater degree of economic equality through progressive taxation, income redistribution, or even property redistribution

Vegetative state: a wakeful but unconscious/unaware state usually due to brain damage

What is bio-ethics?

Bio-ethics, also known as medical ethics, is the study and employment of moral values in medical science. This includes clinical care and clinical research.

Individuals working in the field of medicine are faced daily with moral dilemmas and difficult decision-making such as :

- when life begins and when life ends
- the withholding or withdrawal of treatment
- the allocation of scarce medical resources
- the accessibility of resources

Practical decision-making is often influenced by the beliefs of family and community (including other healthcare professionals) about what is right and wrong. Many of the contemporary debates in bio-ethics are the direct result of advancement in scientific and medical knowledge and technology. With these new advances, the human race is not only morally challenged as to the basic nature of life and death, but also about the power the social structure can assert over those in need who do not have the means to pay for it.

Medical decision-making is guided by the four bioethical principles of:

1. respect for autonomy
2. beneficence
3. non-maleficence
4. justice

These principles were initially described by two US authors, Beauchamp and Childress, to assist clinical decision-making in medicine. We recognise the Western emphasis on the individual (autonomy) compared to an African emphasis on community autonomy so that certain countries such as South Africa may apply a different emphasis on the principles set out above.

In caring for patients with life-threatening illness, there are often complex decisions to be made and it is helpful to have a good understanding of the application of bioethical principles to assist decision-making. The South African Health Professions Council has clear General Ethical Guidelines for the Health Care Professions to assist this understanding.

Ethical Decision-making in Palliative Care

There are some concerns regarding the application of bioethical principles. These principles provide a guide to decision-making, but they may fail to take into account the individual and family members' personal preferences and context. In palliative care it is always important to consider:

- each patient individually and to develop a care plan relevant to the individual
- the stage of the illness
- the person's preferences and the family's wishes. Shared decisions discussed in an understanding and compassionate way allow for appropriate patient care, with patient and family involvement.

So now let us consider the four bio-ethical principles in more detail.

1. Respect for Autonomy

The concept of autonomy – from the Greek meaning self-rule – describes the ability to make a decision for oneself based on deliberation. This presumes a decision maker who has the required information, capacity and circumstances to make rational decisions. Respect for autonomy requires the doctor to provide full information in language and wording that promote patient understanding. The ethic of respect for autonomy contrasts with the ethic of paternalism which sees the patient as a passive recipient of care.

Respect for autonomy underpins the concepts of informed consent, confidentiality and truth-telling about prognosis, treatment options and side effects. The Hospice Palliative Care Association Code of Ethics recognises that the fundamental principle underlying all care practices is respect for the worth, dignity and human rights of every individual; and that respect for human dignity requires the recognition of patient rights, particularly the right to self-determination.

The capacity to make decisions depends on a person's mental competence which may be compromised as illness progresses. If a patient lacks the capacity to make decisions, a proxy decision-maker should be consulted. A person may have written his wishes for future care in a Living Will or Advance Directive. If there is no proxy, decisions should be made in the patient's best interests, taking into account his known values and in accordance with society's norms and values.

Informed consent

The autonomous person is well informed about the risks and benefits of each technique or treatment and can make an unbiased, informed decision, without being pressured in decision-making. It is the duty of the medical practitioner or researcher to disclose all available information to the individual – whether adverse or not.

The right to information is enshrined in both the South African Constitution and international and regional human rights conventions. Under the South African Constitution (Section 32), "Everyone has the right of access to:

(a) any information held by the state; and

(b) any information that is held by another person and that is required for the exercise of protection of any rights."

This right to information plays a central role in health care. Only when an individual is properly informed by having received all information available on the subject matter, can he/she give informed consent to start or continue with the treatment he/she is receiving on a voluntary basis. The decision to receive treatment or not to receive treatment can be changed at any time as the individual reviews his/her decision.

The right to information entails both the right of access to health information from the state, so that citizens can play an active role in the formulation of health policy, and the right to information from health services concerning treatment.

Decisions in the palliative care setting are often made in an environment of emotional distress. The doctor should be sensitive to the 'human vulnerability, dependency and fragility' of the patient who is critically ill and to the family member acting as proxy.

Notes

Notes

Patient Rights

Patients have the moral and legal right:

- to determine what will be done with their own person
- to accept, refuse, or terminate treatment without undue influence, duress, coercion, deceit, or penalty
- to be given necessary support throughout the decision-making and treatment process. This includes the opportunity to discuss and make decisions with family, significant others, knowledgeable personnel and other health professionals
- to be assisted with weighing the benefits, burdens, and available options in their treatment, including the choice of no treatment
- to be given accurate, complete, and understandable information in a manner that facilitates an informed decision

Respect for human dignity, described in the HPCA Code of Ethics, requires the recognition of patient rights.

In many settings, medical care takes a paternalistic approach, where the doctor decides on the treatment without providing adequate information and without discussion with the patient. Legally and ethically, the patient may even make decisions contrary to the advice of a medical practitioner, with possible detrimental effects, as long as that patient has been informed properly beforehand. It is clear that the information given to the patient should be accurate and understandable to that patient.

Within our African context it is important to remember that support of autonomy also includes the recognition that some cultures place less weight on individualism and choose to defer to family or community values in decision-making.

Informed consent: Women and children

The fact that social norms assign primary responsibility for care to women and decision-making to men, means that women may not have autonomy in decision making. In particular in the circumstances of communal decision-making, women's opinions may be discounted, over-ruled or not even obtained. Clinicians should ensure that women are informed about their care and that they take part in the decision, even in circumstances where their culture adopts a communal decision-making process. In the care of children, a child should receive age-appropriate information and should assent to medical care.

See the chapter on palliative care for children later in this book.

Case Study

Peter has AIDS and has been taking antiretrovirals for 2 months. He has bad side effects from the drugs. Peter is now depressed and wants to stop all treatment. He says that he doesn't care if he dies. He becomes very ill and is admitted to a hospice. The doctor there explains to him that there are a number of different antiretrovirals and that there are some with fewer side effects than the drugs that he is taking. Peter did not know that he had other options. After hearing about the different antiretroviral regimens, Peter decides to try a different set of drugs. He is now improving and no longer experiences side effects from the new medication.

Question

Which bioethical principle is the doctor demonstrating here?

Guidance to facilitators

The doctor supported Peter's right to autonomy, but also provided information about treatment options so that Peter could make an informed decision about his care. The doctor was practising the principle of beneficence.

Notes

Advance care planning and Advance directives

What is Advance care planning?

It is the process of discussing and documenting a person's wishes for care in the event of their not being able to communicate this in the future. In this way, medical personnel can encourage patient self-determination by discussions with patients and their identified proxies' on their wishes for future care.

What is an Advance Directive or a Living Will?

It is a document to guide medical and healthcare decisions.

It is not a legal binding document but a document indicating a person's preferences for care.

The importance of the Advance Directive or Living Will is that the person drawing up this document, in discussion with family and healthcare providers, indicates their preferences for care while they are able to discuss these preferences, and that the discussion takes place and is documented.

This will guide families and healthcare professionals to make decisions relating to the person's future care.

A simple example of a Living Will

ADVANCE DIRECTIVE / LIVING WILL

To my Family and my Physician:

This declaration is made by me ____________________ at a time when I am of sound mind and after careful consideration.

If the time comes when I can no longer take part in decisions for my own future, let this declaration stand as my directive.

If there is no reasonable prospect of my recovery from physical illness or impairment, expected to cause me severe distress or to render me incapable of rational existence, I do not give my consent to being kept alive by artificial means. I request that I receive only the drugs and intravenous fluids that may be required to keep me free from pain or distress even if the moment of death is hastened.

I hereby request and authorise my spouse, children, partner or any member of my family to apply to the Supreme Court for a Court Order to compel compliance of this directive should any medical practitioner or hospital refuse to give effect to the said directive.

This declaration is signed and dated by me in the presence of the two under-mentioned witnesses.

SIGNED: ____________________ Date: ____________________

Witnessed by: ____________________ ____________________

SIGNATURE: ____________________ Date: ____________________

Name: ____________________ ____________________

Address: ____________________ ____________________

SIGNATURE: ____________________ Date: ____________________

Name: ____________________ ____________________

Address: ____________________ ____________________

Another example of a Living Will comes from SAVES the Living Will Society. Further details can be found on their website: *www.livingwill.co.za*

> If the time comes when I can no longer take part in decisions for my own future, let this declaration stand as my directive.
>
> If there is no reasonable prospect of my recovery from physical illness or impairment expected to cause me severe distress or to render me incapable of rational existence, I do not give my consent to be kept alive by artificial means, including any pacemaker, nor do I give my consent to any form of tube-feeding when I am dying; and I request that I receive whatever quantity of drugs and intravenous fluids as may be required to keep me free from pain or distress even if the moment of death is hastened.
>
> DO NOT RESUSCITATE: I do not give my consent to any person's attempt at resuscitation, should my heart and breathing stop and my prognosis is hopeless.

Another **example of wording in a Living Will**:

> "If I am in a coma or persistent vegetative state, and in the opinion of my physician and two consultants, have no hope of regaining awareness or higher mental functions, then my wishes would be for all treatment and artificial feeding to stop. I direct that only medication directed at relieving pain should be provided."

Bear in mind that depending on the circumstances of the patient, it may not be feasible to consult more than one physician.

The importance of Confidentiality

All medical personnel have a duty to maintain the confidentiality of all patient information. Trust between patient and medical personnel can be destroyed by unauthorised access to patient information or by the inappropriate disclosure of patient information. The rights, well-being, and safety of patients should be the primary factors when making professional judgments concerning the sharing of confidential information whether oral, written or electronic. Relevant data should be shared only with those members of the medical team who have a need to know. Information pertinent to patients' treatment and welfare is disclosed only to those directly involved with their care.

However, duties of confidentiality are not absolute and may need to be modified to protect the patient and other innocent parties.

The right to privacy is enshrined in the South African Constitution (Section 14):

"Everyone has the right to privacy, which includes the right not to have *the privacy of their communications infringed."*

SAVES recommends that:

Three (or more) original Living Wills should be signed when of sound mind and after careful consideration, in the presence of two witnesses.

It is imperative to share this decision with anyone who may have to implement The Living Will i.e. your doctor/s; and family and friends who must be told where you keep your Living Will.

BENEFICENCE AND NON MALEFICENCE

Balance the benefits and risks

Topic
for discussion

1) When should a referral for palliative care be made?
2) When to treat and when not?

2. Beneficence

The principles of beneficence (providing benefit to the patient), and non-maleficence ('first do no harm') are often considered together.

What is beneficence?

According to the guidelines presented by the Medical Research Council (MRC), beneficence refers to the practice of treating individuals in an ethical manner, not only by respecting their decisions and protecting them from harm, but also by making efforts to secure their wellbeing.

The moral obligation of beneficence is paramount to ethics, since actions are weighed for their possible good against the costs and possible harm. Beneficence provides benefit to the patient and balances the benefits against risks and costs.

An imperative when acting within the ethic of beneficence, is for medical personnel to keep abreast of modern medical knowledge, including the knowledge and understanding of palliative care. If the doctor is not able to manage severe or refractory symptoms, it is important to refer the patient to a qualified palliative care specialist or hospice. Any treatment embarked upon should be with the intent to benefit the patient, taking into consideration the intended benefit and the burden or discomfort of the treatment. If the treatment will not benefit the patient at this stage of his illness, it would be a sound clinical decision to withhold or withdraw treatment after discussion with the patient, family members and other members of the care team. Such decision-making would be considered both legal and ethically acceptable.

3. Non maleficence

What is non maleficence?

Non maleficence describes the bioethical principle of 'do no harm' and is closely related to beneficence and the balancing of risk and benefit. For example, one should not embark on futile treatment that is unlikely to benefit the patient, as when 'treatment results in preserving permanent unconsciousness'. Another example is the initiation of CPR in a dying patient. This kind of situation can be prevented by advance care planning that may include a "Do Not Attempt Resuscitation" order, so that the treatment offered is appropriate to the individual situation.

Futile Treatment

If a patient's condition continues to deteriorate and treatment is ineffective, it may be that life-prolonging treatment is no longer appropriate. This requires careful assessment and evaluation and a review of the goals of care in discussion with the care team including patient and family members. Futile treatments are assessed as:

- those that are bound to fail
- those that may not restore a patient to independence or at least to an acceptable quality of life
- treatments that may simply be prolonging the dying phase

It is unethical to subject patients to futile treatments. The challenge comes when clinicians are uncertain or disagree whether the treatment is effective or futile.

Withholding and withdrawing treatment

Consideration of withholding or withdrawing treatment developed as a consequence of the availability of advanced medical technology and the resultant ability to prolong life. In some cases this leads to prolonging the dying process, even if it is a sound clinical decision. This prolongation of life may occur without allowing for patient perspectives such as:

- quality of life
- being close to family members at a critical stage of life
- the implications of providing end-of-life care in the alien environment of the hospital or intensive care unit

The key is to be able to identify when active treatment will improve quality of life and prolong life, in contrast to active care and medical technology which will not positively influence the course of the illness, but merely prolong the dying process. Twycross makes the statement that a doctor has neither the right nor the duty to prescribe a lingering death.

Benatar *et al.* of the University of Cape Town Bioethics Centre wrote a comprehensive and considered statement on withholding and withdrawal of life-sustaining therapy, providing clear guidelines and recommendations, and making the unequivocal statement that withholding or withdrawing treatment 'is regarded as distinct from participating in assisted suicide or active euthanasia *'neither of which is supported by this statement'*.

It is important to consider the rights and needs of the patient, who may, for example, decide to discontinue treatment for a life-threatening illness, preferring to die with dignity while still mentally competent to make that choice. The clinician should ensure that the patient has the information required to make an informed choice and should support the patient in his/her decision.

4. Justice

Justice is a debatable concept with no clear definition. It is often used interchangeably with the notion of fairness. Essentially justice is about treating people equally in relation to criteria acknowledged to be morally relevant – such as treating people equally in relation to their needs, rights, ability to benefit, or autonomous desire.

Because of the notion of equality, particularly when considering justice in the South African context, justice can be seen as distributive justice (where there is fair distribution of resources for all). A further notion that is highly debated currently is the notion of social justice which can be seen as largely grounded in distributive justice. The ethical principle of justice also includes rights-based justice (equal access to health care), and legal justice according to the laws of the land.

Discrimination in access to health care and health insurance, combined with dramatic increases in the costs of health care and the allocation of scarce resources, have fuelled debates about what social justice requires. Problems of distributive justice arise in resource-poor settings and this highlights the concern about an unfair distribution of burdens, which includes inequitable access to therapies (due to geographical, financial or even political reasons) and the prioritising of allocation of scarce resources.

The South African government is addressing this problem of equity in health care. One of the methods for improving equity is National Health Insurance. In South Africa, there is currently, a dual health care system. Private health care is provided to those who have the ability to pay either directly or indirectly through insurance. However, those who do not have the means to pay are forced to go without and become part of a "vulnerable" community. The debate surrounding the existence or absence of a moral responsibility to protect the vulnerable of society and to give them access to the benefits of therapies, even though they cannot afford to pay for them, continues. The NHI aims to improve equity in the health system which should lead to greater access to quality health services by vulnerable groups and in underserved areas.

In a society where justice prevails, the aim is therefore for all citizens to have access to health care. In such a society the benefits of medicine would be for all and not a selected few.

Case Study

TAC vs Minister of Health (Nevirapine)

The case brought by the Treatment Action Campaign, which dealt with the provision of drugs for the prevention of mother-to-child transmission of HIV/AIDS, came before the Constitutional Court. TAC launched legal action to demand broader access to Nevirapine in 2001. In December 2001 Judge Botha of the Transvaal High Court declared that *"a countrywide PMTCT programme is an ineluctable obligation of the state".* The High Court's order instructed the government to allow Nevirapine to be prescribed where it was "medically indicated" and where, in the opinion of the doctors, acting in consultation with the medical superintendent, there was capacity to do so. The High Court also ordered the government to develop "an effective comprehensive national programme to prevent or reduce MTCT" and to return to the court with this programme for further scrutiny before 31 March 2002. The Minister of Health appealed this ruling directly to the Constitutional Court. Unanimously, the Constitutional Court decided that the government's policy had not met its constitutional obligations to provide people with access to health care services in a manner that was reasonable and took account of pressing social needs. The Court said that the government was wrong to restrict access to the antiretroviral medicine, nevirapine, which is effective in reducing the risk of mother-to-child HIV transmission. It ordered the government to make the medicine available to pregnant women living with HIV.

ETHICAL DECISION-MAKING IN PRACTICE

Case Study

Sourced from CME July 2011 Vol.29 No.7 p274-276 Ethics & Palliative Care

Mr James Petersen is 68 yrs old with pancreatic carcinoma and liver metastases.

Treatment options were discussed with him and his wife at the oncology clinic and he opted for palliative measures, stating that he wished for treatment to enable him to live as comfortably as possible without "useless" medication interventions.

He requires opioid analgesia, laxatives and anti-emetics and over the course of the illness loses weight and becomes weaker and bedfast. He is nursed at home by his wife, Susan. In the later stages of his illness, his daughter, Rachel, a palliative care nurse, comes home to assist with his care and is determined to carry out her father's wishes to remain at home throughout his illness.

Following a period of nausea and vomiting, his medication is now administered subcutaneously via a syringe driver, morphine sulphate 30mg and haloperidol 2.5mg over 24 hours which achieves good symptom control. His oral intake declines markedly.

You are called to see him, as he has developed myoclonus and confusion over the last 2 days. His son, Mike, an intensive care physician, has returned home from the USA and is very concerned that his father is severely dehydrated and requests hospital admission for rehydration.

In applying bioethics to a practical situation, it is necessary to identify the ethical dilemma; to engage in discussion with the patient, family and care team; to explore assumptions; and to present factual information. The bioethical principles provide a foundation for the discussion and assist in reaching a decision for the immediate care plan. There is also opportunity for further discussion and review of the care plan as the illness progresses (or improves).

Topic for discussion

What is the ethical dilemma?

The ethical dilemma revolves around the fact that Mr Petersen's wife and daughter have been caring for him during this illness, have experienced the progression of his illness to this advanced stage and are determined to respect his wishes to remain at home and to die at home.

His son believes his condition is reversible and he insists on hospital admission to reverse the dehydration and improve his father's condition. This is a very emotional time and an emotional situation with heated disagreements possible.

The son may also harbour feelings of guilt at not having been present to advise on his father's care. His assumption is that his father's condition can be improved and that he is dying of 'neglect'.

The wife, daughter and palliative care team recognise that Mr Petersen is in the final stage of a terminal illness. The palliative care team recognise that the myoclonus and confusion experienced by Mr Petersen are probably due to the build up of morphine metabolites as his renal function declines in the last stages of his illness.

Discussion

- How would the care team promote autonomy for family members?
- What are the important issues to consider when deciding on a balance between beneficence and non-maleficence?
- Describe the different discussions members of the care team need to have with family members
- What possible emotions may members of the family experience?
- How can a family meeting be facilitated to assist the family's decision-making and how can the care team acknowledge the emotions and support family members?

Some suggestions might be the following:

- The son might appreciate a one-on-one discussion with the palliative care team doctor
- The social worker and professional nurse might invite the entire family to come together with them as a group to talk things through

Autonomy

Mr Petersen no longer has the capacity to express his wishes, but these were discussed in detail with his wife and his GP. It would be helpful to have a Living Will or Advance Directive although these are documents to guide decision-making and not legally binding documents under South African law.

His wife would be seen as his proxy decision-maker, but may be swayed by her son with his clinical knowledge, expertise and authority. Her daughter supports her father's wishes.

Beneficence

Is there treatment that at this stage of the illness could benefit Mr Petersen?

As it is likely that morphine metabolites are causing the myoclonus and possibly the confusion, it is recommended that analgesic medication be changed from morphine sulphate in the syringe driver to transdermal fentanyl. It may be that additional fluid would assist in eliminating the morphine metabolites. Does this require IV rehydration or can it be achieved through subcutaneous infusion of normal saline – hypodermoclysis? This procedure can be instituted at home. Will it improve his comfort? There is no certainty about this, but we could do a trial of hypodermoclysis and Mr Petersen's response to this intervention assessed. Current evidence suggests that artificial hydration is a futile treatment at this stage of advanced cancer.

His son may not feel this treatment is enough and the physiological processes that occur at the end of life would need to be explained to him. "In the terminal phase of progressive illness there is virtually always a profound loss of appetite (and therefore an absence of hunger). The literature is clear that the body cannot use calories to become stronger or to gain weight. Instead, it breaks down its own energy stores (muscle, fat, carbohydrates) regardless of caloric intake. Efforts to improve caloric intake by enteral or parenteral means have no role in addressing comfort, functional status, or survival in such end-of-life scenarios". (Harlos M, 2010)

Beneficence also extends to the family to support Mrs. Petersen and her daughter in following his wishes. Assisting the family to agree on Mr. Petersen's care will improve bereavement outcomes following his death. Empathetic counselling of the son may assist him in coming to terms with his father's irreversible condition and impending death.

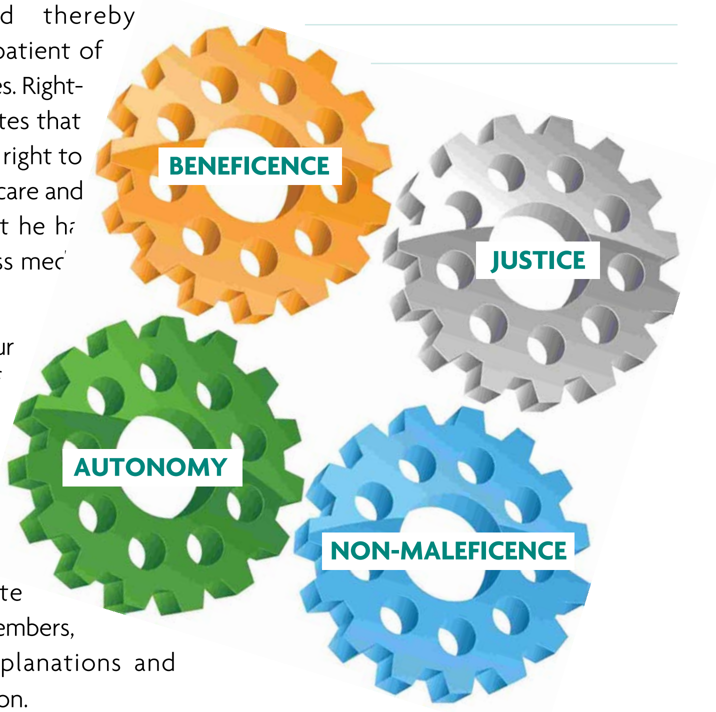
Non-maleficence:

'Harm' would be caused if Mr Petersen was admitted to hospital, going against his wishes and those of his wife and daughter to provide care at home, in a familiar loving environment. There are also a number of disadvantages to IV hydration: an IV cannula is uncomfortable and a barrier to contact with the family, there may be incontinence due to increased urine output, a urinary catheter may be required and fluid overload may result in pulmonary oedema.

Justice

If we consider the fair allocation of resources, it is clear that Mr Petersen should not be in hospital if there is no hospital treatment that will improve his condition, and thereby depriving another patient of the hospital resources. Right-based justice indicates that Mr Petersen has the right to choose his place of care and to refuse treatment he h described as "useless med interventions".

In conclusion, the four principles of bioethics are a valuable foundation for clinical decision-making an must be combi with compassionate support of family members, including clear explanations and sharing of information.



Notes

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Euthanasia and Physician (doctor) Assisted Suicide

These topics are included in this book because HPCA recognises the importance of the societal discussion on euthanasia and assisted suicide. However, HPCA opposes euthanasia and physician assisted suicide on the basis that quality palliative care intends neither to hasten nor to postpone death and that the goal of palliative care is to improve quality of life for patients and family members affected by life-threatening illness.

The philosophy of palliative care includes holistic assessment and management of a person's needs, paying attention to the multidimensional aspects of the whole person. The expressed desire for euthanasia needs to be explored holistically as an expression of existential suffering. This is done by engaging the person in dialogue with active listening and empathy, and exploring the following themes:

1. *Reality of the disease progression.*
2. *Exploring and understanding the person's goals for care (including advance care planning).*
3. *Perceptions of their suffering and sense of burden to others.*
4. *Anticipation of the dying trajectory.*
5. *To explore the timing of desired death (this is often seen as sometime in the future – not yet).*
6. *The desire for good quality end-of-life care.*
7. *The care and support that is or can be offered by good health care and supportive significant others.*
8. *The possibility of clinical depression as co-morbidity.*

Definitions

Euthanasia means killing on request and is defined as a doctor intentionally killing a person by the administration of drugs, at that person's voluntary and competent request. In euthanasia the intention is to kill the patient, the procedure is to administer a lethal drug and the successful outcome is immediate death.

Assistance in suicide means knowingly and intentionally providing a person with the knowledge or means or both required to commit suicide, including counseling about lethal doses of drugs, prescribing such lethal doses or supplying the drugs. Physician Assisted Suicide is defined as a doctor intentionally helping a person to commit suicide by providing drugs for self-administration, at that person's voluntary and competent request.

Most commentators make no formal ethical distinction between euthanasia and assisted suicide since in both cases the person performing the euthanasia or assisting the suicide deliberately facilitates the person's death. There is disagreement about whether euthanasia and assisted suicide should rightly be considered "medical" procedures.

None of the following should be seen as euthanasia

- withholding futile treatment
- withdrawing futile treatment
- palliative sedation

Withholding or withdrawing treatment is a sound clinical decision when reached in discussion with the patient (if competent), the family and the care team. It is important to identify when active treatment will improve quality of life and prolong life, and when active treatment is futile without the likelihood of improving the condition and merely prolonging the dying process as described earlier in this chapter.

Palliative sedation is defined as the use of sedative medication to relieve intolerable suffering in palliative care. In palliative sedation the intention is to relieve intolerable suffering, the procedure is to use a sedating drug for symptom control and the successful outcome is the alleviation of distress. The level of sedation is guided by the level of patient distress and the aim is to calm the patient without causing unconsciousness, so that the patient is able to interact with the family. Occasionally, deep sedation is required to relieve severe distress but this should be a temporary measure.

In Summary

When a person`s medical diagnosis precludes the hope of health being restored or maintained and the death of the patient is inevitable, the physician, the care team, the patient and the family are often faced with a complex set of decisions regarding medical interventions. The duty of doctors is to heal, where possible, to relieve suffering always and to provide care that benefits the patient without causing harm. There shall be no exception to this principle even in the case of incurable disease. The primary responsibilities of the doctor and care team in end-of-life care are to assist the patient in maintaining an optimal quality of life, through controlling symptoms and addressing psychosocial and spiritual needs, and to enable the patient to die with dignity and in comfort.

Healthcare practitioners must ensure decisions are properly documented including clinical findings, discussions with the patient or others involved in decision-making and details of treatment. Records of these discussions and decisions reached should be legible, clear, accurate, unambiguous and accessible to team members. The care team commit to ongoing compassionate care and non-abandonment of the person deemed to have incurable illness.

CONCLUSION

The aim of palliative treatment is to obtain symptom control and a high quality of life, even if life expectancy may be relatively short and the patient's health may be poor. In essence, palliative care is an affirmation of life, even in the face of impending death. There is thus a shift of goals from the cure and prolongation of life to the alleviation of psychological and spiritual suffering, the relief of pain and other symptoms, and the enhancement of the meaning and quality of the patient's remaining life. Palliative care therefore utilises every relevant component of modern medicine to achieve maximal comfort, to alleviate fear and anxiety, to establish security and trust, and to encourage patient autonomy.

Physicians and hospice healthcare workers have the responsibility to give comprehensive palliative care to terminally ill patients and their families and to make every effort to explore, understand, and address suffering that persists despite their best efforts.

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CHAPTER 4

The NPO Sector

INTRODUCTION

This chapter refers to Non-Profit Organisations (NPOs) and the legislation that relates to their establishment, registration and operation. In this chapter, attention will also be drawn to the new Companies Act 71 of 2008 that came into effect from 1st May 2011 thus replacing the 35 year old Companies Act of 1973. This new Act fundamentally rewrites South African company law, extensively impacting on the way in which companies may now conduct their business in South Africa.

In this chapter when we refer to:	we will call this:
the new Companies Act 71 of 2008	'the new Companies Act'
the old Companies Act 1973	'the old Companies Act'
a Section 21 Non-Profit Company	a Not-for-Profit Company (NPC) to reflect the changes in the new law. The name of a non-profit company incorporated under the new Companies Act will end with 'NPC'. Therefore certain regulatory requirements apply to both existing Section 21 Companies and NPCs
Other non-profit organisations	These will remain listed as such.

Although the new Companies Act was not specifically written for NPO's, it has some impact on the formation, operation and future accountability of Non-Profit Company (NPC). For example, from now on, an NPC will have a legal nature of it's own.

For further information

Further information on how to find out the current status of South African legislation can be found in the Resources Section at the end of this book, along with information on how to access other publications by South African legal experts.

The new Companies Act introduces new terms:

When the terms board, trustees and directors are used they refer to the governance (accountable oversight) level of the organisation.

When the terms CEO, general manager, management team or manager are used they refer to the management (daily operations) level of the organisation.

Terms you will find in this chapter

Altruistic: unselfish concern for welfare of others

Ancillary objective: extra, less important aim. Of less importance than the main objective but still relevant or additional to the main objective.

Annexed: attached/added to something larger

Beneficiary: someone entitled to money or property from a trust, will or insurance policy

Corps: group of people who work together

Entity: the form your organisation takes

Founding documents: contains information on why the organization was formed and what its structures are e.g. main objective and how many people should be on the board. Can be called a constitution or memorandum and articles of association or trust deed depending on how the organization is registered.

i.t.o: in terms of

Liability: legal responsibility for costs or debts

Mandatory requirements: official or compulsory requirements

Narrative report: report of events in the order in which they happened

Organogram: an organisation's chart of human resources

Philanthropic: devoted to helping other people

Prescribed period: period of time set down by organisation or law

Quorum: minimum number of committee members to conduct business

This chapter discusses issues relating to the legal structure and compliance requirements of an NPO in terms of the current legislation. It sets out to explain the process of NPO registration, the challenges that may be encountered and preventative steps that may need to be taken to avoid the many potential pitfalls. It will also look at issues relating to governance and management particularly with respect to palliative care within South Africa.

What are NPOs?

Non-Profit Organisations (sometimes called non-governmental organisations (NGOs) include all organisations whose main aim is not to make a profit for its members but rather to serve some common or public interest.

Types of legal structures

The three types of registered non-profit organisations are:

1. Voluntary associations
2. Trusts
3. Non Profit Companies with or without members as introduced by the Companies Act 71 of 2008.

Why an NPO should have a legal structure

Having a legal structure protects and formalises the relationships that an NPO has with it's members, the community and donors.

The benefits of a legal structure for an NPO are that it:

- provides a framework and rules which is useful in understanding the responsibilities, obligations and rights of the individual members.
- makes sure that the members and the management of the organisation accountable to the community they serve.
- enhances the organisation's credibility to potential donors.

Do we have to register our NPO?

NPO registration is not required in terms of the NPO Act however it is advisable to register in order to access funding from private as well as government department donors. The important aspect of NPO registration is that it legally establishes an entity. Being registered as an NPO is often the first step in securing on-going funding.

Registering your structure with the Department of Social Development (DSD)

Regardless of which structure you choose, all NPOs should think about registering with DSD as a NPO. See page 37 of this chapter for how to register with DSD.

An organisation can choose to be a voluntary association and not register with the Department of Social Development although this is not recommended.

Notes

THE NON-PROFIT ORGANISATIONS ACT, 71 OF 1997

Sample constitutions

Examples of constitutions of Non-Profit Organisations can be found on the HPCA website but these may be subject to change from time to time.

www.hospicepalliativecaresa.co.za/starting_a_hospice.html

The Department of Social Development and the Legal Resources Centre also have examples of Model Constitutions. See the box on page 40 later in this chapter.

The Non-Profit Organisations Act, 71 of 1997, came into effect on 1 September 1998. The Act aims to create an enabling environment for NPOs as well as to set standards of good governance, accountability and transparency within the NPO sector.

The Act set out a definition of a Non-Profit Organisation and also explains how such an organisation can register if it wants to.

Section 1 (x) "a trust, company or other association of persons:

(a) established for a public purpose ; and

(b) the income and property of which are not distributed to its members or office bearers except as reasonable compensation for services rendered;" Section 1(x)

This means that a NPO need to be created for public purpose and not for profit.

Requirements for registration:

If you want to register your NPO you need to fulfil certain requirements that must be met in terms of the law. The law expects your organisation to set down various points that you have thought about before you start your organisation, such as your organisation's name, objectives, staff profile and so on.

The documents you develop from these initial thoughts are your founding documents. The mandatory requirements are laid out in Section 12(2) of the Act. You will also see in this section of the Act it speaks about a constitution.

A constitution explains:

why an organisation was created	the vision, mission and objectives e.g. to provide palliative care
who will do what	Board and management structure and authority
what activities will be undertaken	to achieve the mission
The rules that will outline **how** the organisation will operate	to provide care according to : • law • scope of practice • Hospice Palliative Care Association standards and guidelines

Section 12(2) is as follows:

"(2) Unless the laws in terms of which a non-profit organisation is established or incorporated makes provision for the matters in this sub-section

The constitution of a non-profit organisation that intends to register must

(a) state the organisation's name;

(b) state the organisation's main and ancillary objectives;

Examples of main and ancillary objectives are:

main objective:

To provide home-based care and other caring services for patients in our community

ancillary objectives:

- To provide a palliative care service for patients with a life-threatening illness and bereavement care for their families
- To provide nutritional support through food gardens
- To assist the Department of Health with medication management of chronic patients
- To assist patients in accessing grants
- To provide health education in the community

(c) state that the organisation's income and property are not distributable to its members or office bearers, except as reasonable compensation for services rendered;

(d) make provision for the organisation to be a Body corporate and to have an identity and existence distinct from its members or office-bearers;

(e) make provision for the organisation's continued existence notwithstanding changes in the composition of its membership or office-bearers;

(f) *ensure that the members or office bearers have no rights in the property or other assets of the organisation solely by virtue of them being members or office-bearers;*

(g) *specify the powers of the organisation;*

(h) *specify the organisational structures and mechanism for its governance;*

(i) *set out the rules for convening and conducting meetings, including quorums required for and the minutes to be kept of those meetings;*

(j) *determine the manner in which decisions are to be made;*

(k) *provide that the organisation's financial transactions must be conducted by means of a banking account;*

(l) *determine a date for the end of the organisation's financial year;*

(m) *set out procedure for changing the constitution;*

(n) *set out procedure by which the organisation may be wound up or dissolved;*

(o) *provide that, when the organisation is being wound up or dissolved, any asset remaining after all its liabilities have been met, must be transferred to another non-profit organisation having similar objectives"*

So for example, if the organisation providing palliative care is dissolved, any assets remaining after debts have been paid, e.g. furniture, computers must be transferred to an organisation that follows the same purpose (i.e. palliative care).

How to register your NPO with Department of Social Development

You can go to the DSD website – *www.dsd.gov.za/npo/index.php* to download an application form to register as an NPO. The application form needs to be completed by a minimum of three members from the Management Committee. When completed, send it to The Directorate for Non-Profit Organisations at Private Bag X901, Pretoria, 0001. Remember to include all the documentation they ask for, such as two copies of your NPO constitution.

Duties and Obligations of a registered NPO

As soon as the NPO is registered and the certificate issued to the NPO, it needs to comply with certain requirements in terms of the NPO Act. The following are the sections in the Act that list the duties and obligations of a registered NPO:

- Section 16(3)
  Reflect its registered status and registration number on all its documents.
- Section 17(1)(a) and (3)
  Keep and preserve accounting records and supporting documentation for the prescribed period.
- Section 17(1)(b)
  Within six months of the end of its financial year, draw up financial statements which include a statement of income and expenditure and a balance sheet.
- Section 17(2)
  Arrange for an accounting officer to compile a written report within two months after drawing up its financial statements confirming that the financial statements are consistent with the accounting records; the accounting policies are appropriate and applied, and that the organisation has complied with the financial reporting requirements of the Act.
- Section 18 (a)
  Submit to the Directorate a narrative report in the prescribed form together with its financial statements and the accounting officer's report within nine months of the end of the financial year.
- Section 18 (1)(b-e)
  Submit to the Directorate the contact detail of its office bearers, even if they were reappointed within one month of their appointment; the NPOs physical address for service of documents and notice of any change of address one month before it takes effect, any other prescribed/ information reasonably required by the Directorate for the purposes of ascertaining whether the NPO is complying with the material provisions of its constitution and the Act.

Notes

Exercise in small groups

If six of you want to set up a small group to provide food for the elderly in your community, what non-profit structure would you choose?

How would you register your group (a Voluntary Association, a Trust or a Company)?

Give your reasons

Notes

The implications of registration as a NPO

Once the NPO is registered, the Directorate of Non-Profit Organisations places the organisation's details on a database of registered NPOs in South Africa. A certificate of registration will be issued when all the requirements are met and will serve as proof that the organisation is indeed an NPO registered with the Directorate. The certificate also serves to confirm that the NPO is a Body Corporate, which means that it exists separate from its membership. If the membership changes, the NPO continues to exist. The NPO will be able to enter into agreements in its own name, without the members incurring personal liability.

An NPO once registered remains registered until the Directorate deregisters it either:

- For contravention of regulations, or
- On request from the NPO

Contravention means that the NPO has not performed in terms of the Act, for example not sending an annual NPO report to the Directorate. It could also refer to any criminal activity that may have occurred.

NPO deregisters

The NPO needs to send a resolution by the Board of Directors stating that:

a) There is an intention to deregister the NPO, and;

b) reasons are provided for deregistration in terms of Section 23 of the Act. They must also state the date of deregistration and this must be two months after date of notice.

c) The organisation must also file the narrative and financial report of the previous financial year end up to the date on which notice was given.

LEGAL STRUCTURES USED BY NON-PROFIT ORGANISATIONS

Which Structure is appropriate?

These questions may help you to decide which structure is most appropriate.

Founder: We are trying to decide which structure is appropriate for our organisation. Can you advise me?

Advisor: Yes I can try. In legal terms, as you are the main person running your organisation you are called the Founder and your organisation is called an entity. You need to decide on the most appropriate form your entity should take, for it to be recognised in law. You also need to consider the size, capacity and complexity of your organisation to help you choose the most appropriate form for your entity.

Advisor: So let's look at your situation. In terms of size - is your organisation run by you and two or three other people? In other words are you a group?

Founder: Yes, there is a group of us.

Advisor: So you and your group may decide you want to be an entity governed by members.

Founder: OK - if we want to be members, what's the best structure for that?

Advisor: Well, a membership-based structure. You could choose a Voluntary Association or a non-profit Company **with members**, either is suitable.

Founder: ...And if we don't want to be members – is there any other structure we could choose?

Advisor: You could choose an entity such as a trust or a non-profit company ***without members.***

Founder: If we decide to choose a Trust or a non-profit Company without members will that mean we have no freedom to make decisions?

Note: A Non-Profit Company is not required to have members but it can choose to have members. It may therefore suffice for the Non-Profit Company to elect to have only a Board of Directors to manage its affairs.

Advisor: No but you need to choose a structure that allows you to manage your organisation in the best way to achieve your goals. Let's look at it in terms of capacity and complexity. As the founder, do you prefer to decide on the management and operation of the organisation?

Founder: Yes

Advisor: Then you are looking for a more flexible approach, where you are able to draft your founding documents based upon your needs. A Voluntary Association is a more suitable option.

Founder: ...So a Voluntary Association seems to be a flexible structure allowing you more control to make decisions? But sometimes it feels safer to just follow directions.

Advisor: Then you may prefer to have a more rigid entity where the management and operational guidelines are prescriptive and you need only follow the requirements.

Founder: Mmmm this could be more appropriate for us, but I am not sure...

Advisor: Well if you want an entity with a rigid or prescriptive outlook where you are happier following directives, then a company or a trust is a more suitable option.

The requirements for the establishment of: a Trust or a Voluntary Association are **less** complex.	The requirements for the formal establishment of the current Non-Profit Company structure are **more** complex. And the continued regulatory requirements of the current Non-Profit Company structure are more complex.
The most common structure for small, newly established NPOs is...	The most common structure for larger well established NPOs with large budgets, complex programmes and a large staff contingent is...
... a Voluntary Association	**... a Trust or Non-Profit company,** and is the structure recommended for members of the Hospice Palliative Care Association.

Resources:

The Department of Social Development has a Model Constitution available that can be used as a guide in order to draft a Constitution for a Voluntary Association. This Model Constitution can be obtained from the offices of the Department or from their website at *www.dsd.gov.za*

The Legal Resources Centre, a non-profit, public interest law firm, which also specialises in assisting NPOs, also has a Model Constitution available on their website at *www.lrc.co.za*

Also see page 36 earlier in this chapter for a link to HPCA's example constitutions.

1. Voluntary Associations

A Voluntary Association is created when three or more people decide to form an organisation in order to reach shared non-profit objectives.

Voluntary Associations are governed by common law, which requires that the Association's objectives are lawful and not primarily for gain or profit for its members.

Voluntary Associations are suitable entities for small community-based organisations, which do not require:

- management of large amounts of money
- intricate financial policies
- ownership of land
- valuable assets or property

in order to reach their objectives.

The founding document of a Voluntary Association is a Constitution which regulates the governance of the Association. The Constitution will appoint a group of people and bestow management or executive powers on them, on behalf of the Association, in order for them to manage its affairs.

Constitutions of different types of Voluntary Associations may vary in style and content, but should the Association decide to register as a Non-Profit Organisation it is important to comply with the Section 12 (2) requirements discussed above.

2. Trusts

A trust is best described as an arrangement, which is set out in a written document (trust deed) in which an owner or founder hands over property/funds to a group of people (trustees) who administer the assets for the benefit of other people (beneficiaries) for a stated objective.

Board of Trustees: Powers and Duties

A trust is governed by a Board of Trustees and their powers are normally widespread to enable them to achieve the stated objectives of the trust.

In terms of legislation, trustees are expected:

- to exercise their duties with care, diligence and skill, which can be reasonably expected of a person who manages the affairs of others.
- to be aware of a conflict of interest, where their personal interest and that of the Trust is not the same.
- to receive reasonable remuneration for the work done, as long as this is not expressly prohibited by the Trust Deed.

How to establish a Trust

In order to establish a Trust it is advisable to seek the assistance of an attorney to draft your Trust Deed as this can be complicated.

The attorney will also assist with filing the original copy of the application with the Master of the High Court.

The trust must be registered with the Master of the High Court in whose area of jurisdiction the greatest portion of the trust assets is situated

For your nearest Master's office see *www.justice.gov.za*

Once with the Master's Office:

1. The Master will register the Trust and issue Letters of Authority to the trustees, formally appointing them to act on behalf of the Trust.
2. The Master may request that the Trustees provide security for the proper performance of their duties. This can be arranged through an insurance company. If you want to do away with the request for security, a clause exempting the Trustees from furnishing security must be included in your Trust Deed document.

In order for the Master to register the Trust and issue Letters of Authority the following documents must be submitted:

- Original trust deed or a notarial certified copy.
- Proof of payment of fee to the Master.
- Completed Acceptance of Trusteeship by each trustee.
- Bond of security by the trustees (if required by the Master)
- All the requirements listed on the Master's Form (JM21)
- An undertaking by an Auditor (see below).

The Trust will need an auditor

The Master of the High Court will require the appointment of an auditor who will confirm in writing to the Master that he or she will audit your books. The auditor must also provide an undertaking to inform the Master:

1. Should he or she cease to act for the Trust.
2. The name of the new auditor should he/she be aware thereof.
3. Should the trust not have been administered in accordance with the terms and conditions of the Trust Deed.
4. Of any substantial addition to the capital of the trust and the value thereof.

Notes

Notes

3. Non-profit Companies

Schedule 1 of the Companies Act 71 of 2008 as amended (the new Companies Act) allows for a not-for-profit company (NPC) which has replaced the Section 21 Company as from 1 May 2011. The name of a non-profit company incorporated under this Act will end with 'NPC'.

The Act defines the non-profit company as incorporated for public benefit or other object relating to one or more cultural or social activities or communal or group interests.

The income and property of a company is not distributable to its incorporators, members, directors, officers or persons related to any of them. The NPC must use all of its assets and income, however derived, to advance its stated objects as stated in its Memorandum of Incorporation.

An NPC has a legal personality separate from its members and directors.

What does this mean?

This means the NPC can:

- sue in its own name
- be sued in its own name
- own property.

An NPC does not have shares therefore its members are not called shareholders. Unlike other forms of companies in the Companies Act, a non-profit company is prohibited from distributing its profits by way of dividends to its members.

At the dissolution of a NPC, current or past members or directors are not entitled to any part of the net value of the company after its liabilities have been satisfied. The entire net value of the company must be distributed to one or more non-profit companies, external non-profit companies carrying on activities within the Republic, Voluntary Associations or non-profit Trusts with similar objectives.

A NPC is not required to have members, but it can choose to have members. However, if the NPC chooses to have members, it is permitted to have two classes of members, namely, voting members and non-voting members. It may therefore suffice for the NPC to elect to have a Board of Directors to manage its affairs.

Complying with Legal Obligations

It is important for the governing boards of NPOs to realise that they are obligated to adhere to the legal obligations imposed on them by the founding documents of the NPO, common law and the legislation that governs the NPO structure. For the different structures discussed above the legal obligations may differ, which is why it is critical for NPOs and their governing boards to ensure that they are aware of the legal obligations.

Certain legal obligations are applicable to all NPO governing bodies:

- Act in good faith and in the best interest of the NPO.
- Do not allow personal interest to conflict with the interest of the NPO.
- Do not act beyond the powers of the NPO/Governing Board or the limitations placed on such powers in terms of the founding document.
- Exercise the degree of skill that may be reasonably expected from such a person of his/her knowledge. It is however important to note that members are not required to have exceptional intelligence and will not be liable for errors of judgment.
- Apply his/her mind to decisions and exercise an independent discretion.
- Give intermittent, not continuous attention to the affairs of the NPO.

See page 37 of this chapter where sections of the NPO Act are explained. The following lists the obligations that a registered NPO must comply with in terms of the NPO Act:

- *Reflect its registered status or registration number on all its documents – section 16(3).*
- *Keep accounting records – section 17(1)(a).*
- *Draw up financial statements – section 17(1)(b).*
- *Arrange for an accounting officer to prepare a written report – section 17(2).*
- *Preserve its books of account, supporting vouchers, membership records and financial records and documents – section 17(3).*
- *Submit to the Director of Nonprofit Organisations:*
    - *A narrative report – section 18(1)(a).*
    - *Details of any changes of its office-bearers - section 18(1)(b).*
    - *Details of any changes of its address at which it will receive documents – section 18(1)(c).*
    - *Details of any changes in its constitution or its name – section19.*

The Legal Resources Centre Information Series No 6, **Legal Obligations of Members of Non-Profit Organisation Governing Bodies** can be downloaded free from the LRC website at *www.lrc.co.za*

King Committee on Governance

The King Committee was established to investigate corporate governance in South Africa. They published their first report in 1994 and their second in 2002. King III was released in 2009 but only came into effect one month after the New Companies Act. The King Report is a code of conduct that is meant to guide Boards of companies in accountable and acceptable behaviour. The contents of King Reports have been used as supportive evidence in legal cases and indirectly become part of law.

Judge Mervyn E King, writes in his introduction to King III:

"In contrast to King l and King ll codes, King lll applies to all entities regardless of the manner and form of incorporation or establishment. We have drafted the principles on the basis that, if they are adhered to, any entity would have practised good governance. For that reason, we have not focused on or discussed the implementation of the code and each entity should consider the approach that best suits its size and complexity"

(Report on Governance for South Africa; Institute of Directors; 2009)

The Governing Body of an NPO (of any form) should be aware of the contents of the King III report. A group of NPOs have reviewed King III and claim:

"NPOs are a distinct category of organisation and warrant and need a separate and distinct Code of Governance..., NPOs are by nature, committed to a number of values and principles that are distinct and very different from those applicable in the corporate sector. The primary difference of purpose is that an NPO exists to serve the common good, and promote a public benefit, rather than to ... advance self-interest, which is the purpose of for-profit entities."

(Pages 2 & 4 of the Voluntary Independent Code of Governance Draft for Comment, 2012)

The group in consultation with the King Committee have developed a voluntary Code of Governance for Nonprofit Organisations and want the code to be in the public domain and not belong to any one or more organisation. They hold the code has the backing of the Non-Profit Directorate and also wide support from the donor community. The code was launched in July 2012 and is available at:

www.governance.org.za/the-independent-code

1. LEGAL OBLIGATIONS OF VOLUNTARY ASSOCIATIONS

Registration and setting up a Voluntary Association (VA)

- No registration of the Voluntary Association is required. You can choose to register the name of the Voluntary Association (in terms of Section 7 (2) of the Heraldry Act, 1962).
- A Voluntary Association is founded on a contractual basis. Any 3 or more people wishing to form the Association have to agree on the objectives and character of the Association for it to be incorporated under Common Law.
- A group of people with executive powers must be appointed.
- A constitution needs to be drawn up to govern how the organisation will function.
- If you wish to register your VA with the NPO Directorate, your VA constitution needs to comply with the NPO Directorate's requirements.

Where can I find the legal obligations of Voluntary Associations set out?

There is no specific Act that sets out the legal obligations of members of a Voluntary Association's Governing Body. The legal obligations are to a large extent found:

- within the constitution of the V A
- further principles applicable to a V A are provided by the Common law

Obligations which apply to members of Voluntary Association Governing Bodies

Some of the key legal obligations which apply to members of Voluntary Association Governing Bodies are that:

- The Members must be familiar with the content of the Constitution and ensure that they give effect to the provisions as far as they are lawful and effective,
- Members are limited to act in terms of the Constitution and are not allowed to act beyond the powers delegated to them by the constitution,
- Members have a duty to act in good faith toward their fellow board members,
- Members have a duty of care to the association and other members as they accept the responsibility of managing the affairs of the association,
- Where a conflict of interest arises, members have a duty to declare the conflict and to place the interest of the association before their own,
- Members can become personally liable if they have acted beyond the scope, powers and limitations of the constitution,
- When the organisation cannot pay its debts, the members of the Association are not liable for these debts. So the Voluntary Association protects its members, however, when members have acted fraudulently or recklessly they can be held personally liable.

2. LEGAL OBLIGATIONS OF TRUSTS

Law that regulates a Trust

The Trust as a legal structure is regulated by two areas of law:

1. The Trust Property Control Act 57 of 1988, and;
2. common law

Lodging the Trust Deed with the Master - Legal Obligations i.t.o the Trust Deed

- An attorney must draw up the Trust Deed;
- The First Trustees must lodge the Trust Deed with the Master of the High Court;
- Trustees must ensure that they are familiar with the content of the Trust Deed and are able to give effect to the provisions therein;
- Trustees must lodge amendments of the Trust Deed with the Master of the High Court.

Legal Obligations of Trustees

Trustees can only act in their capacities as trustees once authorised to do so in writing by the Master of the High Court. Once authorised:

- Trustees must furnish the Master of the High Court with security if they are not exempted from payment thereof;
- Trustees must act with the care, diligence and skill which can be reasonably expected of a person who manages the affairs of another;
- Trustees must exercise an independent discretion;
- Trustees must provide the Master with an undertaking that they will:
  - Account to the Master for their administration and disposal of the trust property,
  - Deliver to the Master any book, record, account or document relating to their administration or disposal of the Trust property,
  - Answer honestly and truthfully (to the best of their ability) any questions put to them by the Master in connection with the administration and disposal of the trust property.
- Resigning trustees must notify the Master of the High Court and the beneficiaries of their resignation.
- Trustees can be held personally liable, if the Trust has not been registered as a NPO with the NPO Directorate.

Please note that these bullets are not a closed list of legal obligations, which is why it is important that trustees familiarise themselves with the relevant legislation.

3. LEGAL OBLIGATIONS OF NON-PROFIT COMPANIES

Registration of Non-Profit Companies

If you want to set up your non-profit organisation as a Non-Profit Company then you need to register it with the Companies and Intellectual Property Commission established by Section 185 of Companies Act 71 of 2008. Forms are obtained from *www.cipc.co.za/Companies_Forms.aspx*

In order to register with the Companies and Intellectual Property Commission the following is required:

- A company name. (You need to apply to reserve a company name).
- A notice of incorporation
- At least 3 directors, who sign consent to act as directors and thereby accept the obligations, responsibilities and rights of the appointment.
- An independent auditor
- The Memorandum of Incorporation for non-profit companies with members, this must be on Form CoR15.1E.
- The Memorandum of Incorporation for non-profit companies without members, this may be in either:
  - the 'short form' CoR 15.1C, or
  - the 'long form' CoR 15.1D.

Dealing with NPC documentation

Any documents, accounts, books, records or other information that the non-profit company is required to keep in terms of the Companies Act must be kept:

- in written form, or;
- in any other form that allows the document to be converted to written form within reasonable time.

This documentation must:

- be kept for a period of seven years, or any longer period, if specified in public regulation.
- be accessible at or from the company's registered office or another location(s) within the Republic.

Additionally if this location changes or if the records cannot be accessible from the company's registered office, then notice of this must be filed with the Commission.

The following are some of the duties and obligations.

The Memorandum of Incorporation and Articles of Association:

- Each company must maintain its Memorandum of Incorporation and any amendments or alteration thereto.
- The company must send to every member at his/her request and on payment of the prescribed fee:
  - a copy of its memorandum and articles, or shall, if so requested,
  - afford to a member or his duly authorised agent adequate facilities for making a copy of such memorandum and articles

    (these copies must include all the amendments made thereto)
- If the company has taken a special resolution altering the memorandum, it must, on written request from the Registrar, submit a copy of its amended memorandum to the Registrar.

The Register of Members:

Every Company must keep a register of its members in one of the official languages of the Republic, and shall enter therein:

- The name and address of each member
- The date on which his/her name was entered onto the register as a member
- The date on which he/she ceased to be a member.

When registering your NPC and when dealing with your duties and obligations relating to the NPC - seek legal assistance

Notes

General Legal Obligations of Non-Profit Companies

According to the Companies Act Schedule 5, all companies that existed at the time when the new act came into operation, shall continue to exist as if they have been incorporated in terms of the provisions of the new Act.

Therefore even if a company is registered under the old Companies Act, the provisions of the new Companies Act will now apply.

The following regulatory requirements will apply to both existing Section 21 Companies and NPCs:

- The Company must appoint auditors and inform the Commission of any change in auditors;
- The Company must appoint a registered address and inform the Commission of any change of address;
- The company must keep an updated register of members and directors;
- The company must keep accurate and complete accounting records;
- The Directors must ensure that proper minutes and attendance registers are kept;
- The company must hold an annual general meeting;
- The company must prepare annual financial statements within six months of the end of its financial year and must present the statements at the AGM;
- The non-profit company may not 'amalgamate or merge with, or convert to, a profit company'
- The Company must keep a record of its directors including details of any person who has served as director for a period of seven years after the person ceases to serve as director.
- The Company must keep copies of all reports presented at the annual general meeting of the company for seven years after the date of the meeting.
- The Company must keep copies of all financial statements for seven after the statement was issued.
- The Company must keep copies of all accounting records for the current financial year and for the previous seven completed financial years of the company.
- The Company must keep copies of all meetings and resolutions of the directors' committee or audit committee if any, for a period of seven years after the date of such meetings or the date when such resolutions were passed.

GENDER CONSIDERATIONS

In many hospice NGOs, the Board of Directors comprise more men than women, while there are more women than men on the management staff. Social norms assign primary responsibility for care to women and decision-making to men. The outcome of this is that the strategy for the hospice is often set without sufficient consideration of management perspectives. There may also be an imbalance of leadership skills, with business and financials skills being considered more important than people skills. At strategic planning meetings, the nursing services' manager, for example may be reticent about questioning financial issues, as this is not her area of expertise. It is important for directors and senior staff to develop skills, including the skills of financial management, relationship skills, communication skills and strategic planning skills.

Hospices are charity organisations which often started with a strong volunteer corps. Hospice directors often still view professional staff in a volunteer or honorary capacity so that staff salaries may not be market related.

Hospices can also be preferred places of employment for women, as they can negotiate flexible working hours to be able to take children to school, or job sharing so that they can work half days to suit their family responsibilities. It is clear that these family-care tasks are gendered in our current society. Some women take advantage of policies regarding maternity leave. If there are no policies to engage replacement staff, the burden of work is then taken up by the other staff in the job.

Notes

TABLE OF COMPARISON

The table below provides a quick summary and comparison of each of the three legal structures:
Voluntary Association, Trust and Non-Profit Company

Which type of structure is best for your Non Governmental Organisation?

	Voluntary Association (VA)	Trust	Non-profit
ADVANTAGES and DISADVANTAGES	• Simple process for simple, small organisations. • Registration is voluntary i.e. It is not a requirement • VAs have all the powers of Non-Profit Companies and Trusts. • When a VA cannot pay its debts, the members are not liable for these debts. But members will be held liable for fraud or reckless acts.	• Greater degree of credibility with funders. • If Trust is not registered with NPO Directorate, trustees can be personally liable. • Very structured • Highly accountable to Master of the High Court • Complex reporting required. • Audited financial statements required.	• Greatest degree of credibility with funders. • Complex requirements to start a non-profit company. Separate Legal Entity registered i.t.o the Companies Act, with statutory control by the Company Registrar. • Very structured. • Highly accountable to the community. • Freedom of internal management and day-to-day running. • Complex annual reporting requirements. • Significantly improved risk profile compared to VAs and Trusts, due to the requirements for accountability, disclosure and an independent audit. • Directors held accountable for their actions and the company has recourse i.t.o Company Law against Directors who fail in their duty of care.
LEGAL REQUIREMENTS	• No registration required. • Can choose to register the name. • Founded on a contractual basis with 3 or more people to be incorporated under common law.	• Attorney to draft trust deed. Deed to be lodged with Master of the High Court. • Trustees to be aware of all their responsibilities	• Registration with Companies and Intellectual Property Commission. • 3 directors to accept the obligations, responsibilities and rights of the appointment. • Memorandum of Incorporation.
APPLICABLE LEGISLATION	• Largely governed by own constitution. • Common law.	• Trust Property Control Act 57 of 1988. • Common Law	• Companies Act 71 of 2008
WHERE TO GO FOR HELP TO SET UP THE ENTITY	• Any lawyer or approach the Legal Resources Centre, a non-profit organisation that helps NPOs. *www.lrc.co.za*	• Any lawyer or approach the Legal Resources Centre, a non-profit organisation that helps NPOs. *www.lrc.co.za* • Trust to be registered with the Master of the High Court in whose area of jurisdiction the greatest portion of the trust assets is situated.	• Any lawyer or approach the Legal Resources Centre, a non-profit that helps NPOs. *www.lrc.co.za* • The non-profit company must be registered with the Companies and Intellectual Property Commission.
FORMS TO FILL IN	• It is not compulsory but advisable to register with the DSD	• Acceptance of Trusteeship by each trustee. • Bond of security by the trustees, if required by the Master. • All the requirements in Master's Form JM21 • An undertaking by an auditor, if applicable	• Application for reservation of name. Notice of Incorporation Memorandum of Incorporation • Notice of change of registered office and the effective date of change (which must be within at least five business days of filling the notice). • Notification of location or change in the location, of any company records that are not located at its registered office.

NEW TAX LAWS FOR NPOS

When considering tax law, South African law recognises two main benefits for NPOs.

The two benefits are:

1. Income Tax Exemption
2. Donor Deductions

1. Income Tax Exemption

This is exemption from paying certain taxes.

Quite apart from the NPO Act, another piece of legislation, the Income Tax Act Act 58 of 1962 creates a public benefit organisation (or PBO).

Public Benefit Organisations are referred to in Section 10 (1)(cN) of the Income Tax Act and are dealt with through the South African Revenue Service, separate from the NPO Act.

A PBO is therefore not a legal entity, but a structure with a certain type of accreditation from SARS. Remember that a PBO can be any one of the three types of NPOs - a Voluntary Association, a Non-Profit Company or a Trust.

PBO status allows the organisation to be declared a public benefit organisation. PBO status is an additional accreditation that:

- allows the organisation to be exempt from paying certain taxes
- allows the organisation to issue invoices to donors which they can use to claim a tax break

Due to the nature of the work done, hospices should generally qualify for PBO status in terms of the Ninth Schedule to the Act.

All NPOs can and should apply to be PBOs because of the tax benefit this confers. However, the NPO will need to be a registered legal entity before it can apply for PBO status.

For example a trust needs to be registered with the Master of the High Court before applying for PBO status.

What is a Public Benefit Organisation (PBO)?

Definition

A Public Benefit Organisation (PBO) is defined as any organisation of a public character:

- Which is a non-profit company, trust or association;
- The sole object/s of which are to carry on one or more of the listed Public Benefit Activities (PBAs) subject to certain trading restrictions and in a manner where:
  - Such activities are carried out in a non-profit manner and with altruistic and philanthropic intent
  - The economic self-interest of any fiduciary or employee of the organisation, is not indirectly or directly promoted, except by way of reasonable remuneration payable to that fiduciary or employee
  - At least eighty-five percent (85%) of such activities (measured in time or cost), are carried out for the benefit of persons in the Republic, unless the Minister, directs otherwise, but if donations are received from persons outside of South Africa, such donations may be used for the benefit of people outside of South Africa
- Which complies with one of the following requirements:
  - Each activity should be for the benefit of, or be widely accessible to the public at large, including any sector thereof,
  - Each activity should be for the benefit of or readily accessible to the poor and the needy
  - The organisation is at least eighty-five percent (85%) funded by donations, grants from any organ of state or any foreign grants.

Notes

Do your activities match the list of Public Benefit Activities (PBA)

A list of Public Benefit Activities can be found in Part I of the Ninth Schedule of the Income Tax Act. This is a list published by the Minister of Finance for purposes of income tax exemption. The Minister may make additions to the list from time to time by means of a notice.

Part I lists 63 activities under 11 headings (the Revenue Laws Amendment Act 45 of 2003 extended the list of activities by adding the activity which provides for the 'promotion of free speech and access to media')

- Welfare and humanitarian activities
- Health Care
- Land and Housing
- Education and Development
- Religion, Belief or Philosophy
- Cultural activities
- Conservation, Environmental and Animal Welfare
- Research and Consumer Rights
- Sports
- Providing assets or other resources
- General

NPOs have to carefully consider the list in order to determine whether the activities of their organisation match the list.

If the NPO activities fall within the definition of a PBO and their activities can be matched to Part I of the Ninth Schedule, the NPO will be registered as an approved PBO and exempt from income tax.

Further requirements must be met in order to qualify

There are however further requirements in terms of Section 30(3) of the Act that the NPO will need to meet in order to qualify such as:

- Any conditions prescribed by the regulator
- Submissions of a copy of the founding document which provides for the following:
    - Three unconnected persons must accept positions of fiduciary responsibility and no single person should directly or indirectly control the decision-making power of the organisation
    - It is required to utilise its funds solely for its primary purpose
    - Surplus funds may only be invested in certain prescribed investments
    - Investments (other than business undertaking and trading activities) acquired by way of donations, bequests or inheritance may be retained in the form so acquired e.g. a donation in the form of a building may be retained and the organisation would not be required to sell the building
    - On dissolution, it must transfer its assets to a similar approved PBO, an institution established by law as defined, or a department of state as defined
    - It may not trade except under certain circumstances set out in the Act
    - It is prohibited from accepting certain donations which are revocable or conditional under certain circumstances
    - It must furnish SARS with copies of any amendments to its founding documents
    - It must not be party to a tax avoidance scheme
    - Remuneration to employees, office bearers, members or other person must not be excessive and no person should benefit from the Organisation in a manner that is inconsistent with the Act
    - It must conform to certain reporting standards
    - Where the PBO provides funds to non-approved PBOs, it must take reasonable steps to ensure that

the funds are used for the purpose for which they have been provided

  - It must be registered in terms of Section 13(5) of the Non-profit Organisations Act, unless exempt
  - Not use its resources to directly or indirectly support, advance or oppose any political party

The new law prohibits PBOs from trading except as provided for in the four categories prescribed in Section 30 (3)(b)(iv), namely:

- A deminimis rule that provides that gross income from trade may not exceed the greater of 5% of gross receipts or R50 000,00. Although this limitation has recently been increased (from R25 000,00 to R50 000,00), organisations need to engage in more [large scale] trading activities in order to supplement their limited donor contributions.
- Related trading activities, substantially the whole of which are directed towards cost recovery and which do not cause unfair competition in relation to taxable entities.
- Unrelated trading activities which are of an occasional nature and which are substantially carried out with voluntary assistance without compensation.
- A list of undertakings or activities which the Minister of Finance may approve having regard to certain criteria set out in Section 30(2)(b)(iv)(dd).

2. Donor Deductions

Section 18A of the Income Tax Act allows for the deduction of donations to certain organisations. Donors can use invoices from PBO to claim a tax break.

Part II of the Ninth Schedule of the Income Tax Act

makes provision for PBOs which conduct Public Benefit Activities to qualify for donor deductible status.

Part II of the Ninth Schedule previously only listed 17 activities, but a further 26 activities has now been added.

The annual limits for individuals and companies have now been equalised at 5% of annual taxable income. The limit to the amount of R1,000,00 has now been removed from the legislation. All taxpayers, companies or individuals, are entitled to a 5% deduction from their taxable income should they donate to a PBO with donor deductible status.

NPOs applying for PBO status in terms of the tax laws

It is advised that you complete the application forms with either a legal or financial advisor. The following steps serve as a brief outline:

1. In consultation, check:

a) Part I of the Ninth Schedule and any gazetted schedules, if any, to ascertain whether the activities of your NPO are listed on it, for income tax exemption.

b) Part II of the Ninth Schedule and any gazetted schedules, if listed on it, for donor deductible status.

2. If the activities of your NPO are listed on the relevant Schedule, then check that the founding document of your NPO complies with the provisions of the NPO Act as well as the new tax law. If not, the document needs to be amended accordingly.
3. Ensure that your NPO is registered with the Directorate of Non-profit Organisations in terms of the Act.
4. Complete the application form (Form EI 1), which is available at your nearest SARS office or on the SARS website: *www.sars.gov.za*. You are required to submit the application along with a copy of the organisation's founding document as well as a narrative of the activities of your organisation.
5. If you have not amended or cannot amend the founding document so that it complies with the provisions of the new tax law, then in addition to the application form, complete and submit the SARS Letter of Undertaking (Form EI 2) which is available from your nearest SARS office or on the website.

Notes

Exercise

What could some of the problems in managing an NPO be?

Discuss in small groups and list your ideas.

What is *an important step* to follow when establishing an NPO?

It is essential to word the founding document simply and clearly.

The founding document must:

- Give an explanation of how you plan to run the organisation
- Describe the roles and responsibilities of the Board and Management
- Show how the roles and responsibilities of the Board and Management differ but complement each other

See further points on founding documents on pages 36-37 and pages 40 and 55 of this chapter.

The Board of Directors has responsibility for:

- strategy
- financial oversight
- sustainability
- good governance

Management and personnel (staff and volunteers) focus on the day-to-day work of hospice and interaction with patients, guided by community needs and medical and psychosocial support.

Case Study

Beautiful Gate

A case study of governance with integrity

A Development Officer's experience:

If I had to say what the most valued aspect of a Board of Directors is I would have to say integrity. The Board of Beautiful Gate a non profit and faith based organisation working with children in Phillipi in the Western Cape have this quality. They have not got everything right or in place but they know this and are striving to improve.

As a group of people they are proud of their faith and what it brings to their role as a board. They consciously strive to live by the values of the organisation. Their board manual contains a statement of faith that is manifest in the vision and mission. The values are embraced by the Board and encouraged in the staff.

By living these values which include respect, team work and accountability they have delegated the authority to manage and operate the organisation to their CEO who is a member of their Board and respected for his knowledge and experience working daily in the organisation. But at the same time they do not shy away from their role as the governors of Beautiful Gate and are aware of the challenges being faced.

When facilitating a training session with this group of board members I was struck by their thankfulness for an opportunity to re-examine their board manual and be led through a re-affirming of their roles and responsibilities. They really are an example to be followed.

Maria Demjan – August 2011

The following are possible management ptifalls and suggested ways to avoid conflict.

GOVERNANCE & MANAGEMENT PITFALLS	GOVERNANCE & MANAGEMENT SUGGESTIONS
1. The overlapping of the Board of Directors (BoD) and Management Committee functions and responsibility. This could result in the Manager and management committee having many bosses with individual ideas. The Directors may experience a lack of control, information and relevant knowledge, which should be available to assist with making decisions. The role of the Directors, Manager or Heads of Departments could be undermined if lines of communication and responsibility are not clear. The one party experiences the other as interfering in their business.	Clear negotiated guidelines on roles and responsibilities need to be documented as part of policies. This may be called a “scope of practice” or be a part of the job descriptions. Clear lines of communication need to be identified in line with the Organogram. The governance function and operational management should be separate, clearly defined and documented. Training to the Board and senior management should be made available to ensure understanding of the different roles and responsibilities in general and how this applies to the organisation specifically. The founding document should outline who the management committee is but if this is not documented then the Manager should make this decision. The Manager would chair this committee. The composition of the management committee should include heads of departments and or relevant volunteers /community members who will ensure that the strategic plan of the Hospice is implemented and managed on a day-to-day basis. For example the BoD approves a budget and the Manager and management committee implement it. Directors and managers need job descriptions, orientation and regular evaluation. Disciplinary code and grievance procedure should include all levels of the organisation from the Chair of the Board to the lowest level of staff. This should allow for disciplinary action against board members and a structure for staff to raise grievances against the board. The role and responsibility of Board Sub-committees and management committee need to be clarified. Minutes of all meetings which include all decisions made, are to be kept, signed and dated.

GOVERNANCE & MANAGEMENT PITFALLS	GOVERNANCE & MANAGEMENT SUGGESTIONS
2. The Board of Directors may lose touch with the organisation as it evolves to meet the changing needs of the community e.g. changed profile of patients and changed systems of health care. This may result in a conflict of interests, mistrust and lack of mutual respect, frustration and an inability to adequately perform tasks as requested by the BoD. Fundraising and funding opportunities may be missed, if the Hospice is not prepared to adapt to changing trends and embrace funding opportunities, which could bring about change. Job satisfaction of staff may be negatively impacted as frustration levels build over the lack of responsiveness to community needs. The needs of the community may not be addressed making the organisation a "white elephant".	To ensure awareness of the changing needs in the community Directors should be suitably and fully representative of the community. They should be passionate and informed about the service delivery. The CEO could be a member of the Board, also possibly other senior managers (NOTE – the staff on the Board should be less than one third of the total Board). Senior managers, who are not Board members, should attend Board meetings to encourage transparency and communication. Board orientation should not be a once off but at least annual activity with regards to connecting with the community that is served by the organisation. Good communication between HPCA and the Hospice BoD around the changing environment and prediction of trends will provide the necessary information. A Board sub-committee should be established with the function of identifying and recruiting Directors.
3. If board members are allowed to serve unlimited terms and are not challenged about their involvement they can develop a complacent attitude and become an institution unto themselves Directors may be continually unopposed and re-elected to fill a vacancy because of reluctance to offend them. When the only members are the Directors the re-election pattern remains unchanged Directors may feel they do not need to familiarise themselves with the changing environment and needs of the organisation. Directors may discourage growth and adaptation to changing needs to limit potential risk and disruption to the organisation.	The founding document of the organisation should clearly define terms of office, election and re-election processes for Directors. Those responsible for identifying, recruiting and electing Directors should be empowered to fulfil their role and responsibility in this regard. The election of new Directors should be staggered to retain continuity of expertise i.e. on a board of nine directors, if three directors resigned and were replaced each year, there would be a balance of new ideas and experience on the board. Directors should be held to a code of conduct that requires them to attend, be prepared for and participate in all Board meetings. Where they habitually fail to do this they should be asked to resign.

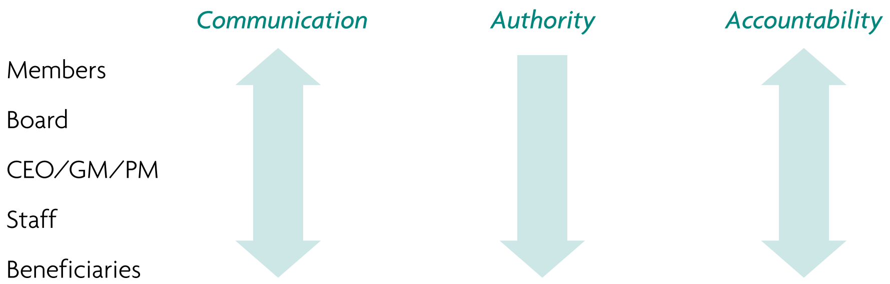
GOVERNANCE & MANAGEMENT PITFALLS	GOVERNANCE & MANAGEMENT SUGGESTIONS
4. The possible 'take over' of Hospice resources and mission by the community could be a real threat if not managed proactively E.g.: A renegade group could hijack the Hospice for their own needs. The emphasis of the Main Business could be diluted to benefit a small group interests such as job creation, housing etc.	A selection committee must approach and approve potential new Hospice members. The Main and Ancillary Business stated in the founding document needs to be concise and tight within the parameters of palliative care. The founding document must meet the requirements of the applicable legislation (e.g. Companies Act) with regard to quorum requirements for special resolutions (such as when wanting to change the constitution or mission of the organisation).
5. Loss of focus on the core business, the mission and vision of the Hospice could be the result of poor communication between the manager and the Board. This may result in not enough attention being paid to the core function at Board level. Sustainability needs and anxiety may overshadow service delivery requirements.	Yearly strategic planning should be done and an operational management programme made and implemented by management and supervised by the BoD. The mission, vision and strategic objectives of the organisation must guide decisions. Ask the question: "How will this affect patient care delivery?" and let that be the yardstick to base decisions on. Decisions must be made in committee and not by individuals.
6. Adjusting to and managing the changing goals and demands of funders and government strategy e.g. Re-engineering of primary health care; focus on TB, management of orphans and vulnerable children, mentorship, training, accreditation, the expanded scope of palliative care and paediatric palliative care, health systems strengthening and partnerships.	The Board and management should remain knowledgeable with regard to the changing environments, current community needs and health care trends. This will assist Board and management in deliberating the scope of involvement and the impact on the palliative care organisation. Directors have a responsibility to maintain awareness of current trends. Management reports to the board should include current issues. Directors are encouraged to attend sector meetings, e.g. regional hospice meetings, conferences. Major strategic direction changes should be thoroughly discussed and jointly made by Directors, management committee, key volunteers and interested parties.

GOVERNANCE & MANAGEMENT PITFALLS	GOVERNANCE & MANAGEMENT SUGGESTIONS
7. Duties regarding development, approval and implementation of policies and procedures should be clear to avoid uncertainty and overlap of roles.	The Board of Directors should delegate the authority to management to develop operational policies and procedures. The Board of Directors must oversee the Financial and Governance policies and have the responsibility to ratify policies and procedures developed by the management committee. Human resource policies are guided by Labour Law. No policy or procedure should be in conflict with any legislation.
8. Manager who controls the Board either intentionally or by default when the Board is not fulfilling their governance role. • Gives unfair responsibility to the manager • Can allow the strategic direction of the organisation to be driven by one / few individuals • Abdication of governance is allowed	Chairperson of the Board and Manager should meet regularly to discuss roles and responsibilities in terms of current operations and governance in the context of the specific organisation. Board should be evaluated at least annually and held accountable when they have not fulfilled their roles. Manager should at least annually be assessed by the chair of the board. Both the manager and Chairperson of the Board should have integrity to stay within the scope of their roles.

GOVERNANCE & MANAGEMENT PITFALLS	GOVERNANCE & MANAGEMENT SUGGESTIONS
9. Service delivery may be compromised because of sustainability specifically relating to funding. • An overcautious board that will not use reserve funds for operations. • Unrealistic hope that past funding will continue. • Unwillingness to change with funders trends.	The financial committee and the fundraising committee need to work closely together guided by the strategic plan, mission and vision of the organisation. Financial committee and/or board should work in line with policy that lays out when reserve funding should be used and for what. Fundraising should not only be left to fundraisers but remains a joint responsibility of the Board, managers and fundraisers. The fundraiser takes the main role of co-ordinating the function. The funding market should be continually scanned for trends and to be aware of changes and impending change. It is essential that the Manager and Department Heads remain in touch with latest trends to ensure the sustainability of the Hospice. Therefore they should be involved with HPCA, other NPOs, CBOs and the DoH. Networking ensures that the responsibility of care is not only your organisation's responsibility. Board and management should negotiate formal partnerships to share the costs of care and/or growing community needs.

Notes

Organisational Effectiveness



Principles of Governance

Governance in any organisation must be built on sound principles.

These principles are critical organisational effectives. These principles can be described as follows:

- Leadership
- Authority
- Power
- Accountability
- Transparency
- Communication

Organisational effectiveness is also dependent on constant interaction between the different stakeholders.

Seven Disciplines for governance excellence

These 7 principles will contribute to excellence in governance

1. NGOs should continuously strive towards excellence in governance
2. Protect the interests of the owners/stakeholders
3. Respect owners'/stakeholders' expectations
4. Reflect on organisational results
5. Select prominent leadership
6. Expect great board-management interaction
7. Connect for healthy board relations

OPERATING AN NPO WITHIN THE LAW

Besides the laws that govern how you register your NPO, there are many sectors of law that have to be considered on a daily basis.

The context of this book is not broad enough to discuss all of these in detail. However, bringing them to your attention is a starting point. The following list may be of assistance:

AREA OF OPERATION	LEGISLATION
Finance & fundraising	• Public Finance Management Act No. 1 of 1999 • Income Tax Act No. 58 of 1962 • The Companies Act No. 61 of 1973 • The Non-profit Organisation Act No. 71 of 1997 • Second Hand Goods Act No. 6 of 2009
Staff	• Labour Relations Act No 66 of 1995 • Basic Conditions of Employment Act No. 75 of 1997 • Compensation for Occupational Injuries & Diseases Act No.130 of 1993 • Occupational Health & Safety Act No.85 of 1993 • Unemployment Insurance Act No.63 of 2001 • Skills Development Act No.97 of 1998
Patient care	• Medication & Harmful Substances Amendment Act No. 72 of 2008 • Childrens Act No. 38 of 2005 • Health Professions Amendment Act No. 29 of 2007 • Traditional Health Practitioners Act No. 22 of 2007 • Nursing Act No. 33 of 2005 • National Health Act No. 61 of 2003 • Pharmacy Act 53 of 1974
Equipment & vehicles	• Administration Adjudication of Road Traffic Offenses Act No.24 of 2000
General	• Consumer Protection Act No 68 of 2008 • Broad Based Black Economic Empowerment Act No. 53 of 2003 • Promotion of Access to Information Act No. 54 of 2002

It should be noted that legislation is regularly amended and that the amendments should be viewed alongside the initial Acts.

CONCLUSION

This chapter has explained the law relating to the non-profit sector with its specific focus on the Palliative Care sector. It describes the various NPO entities that can be established and registered as well as the legal requirements for each entity. We trust that the Chapter will be useful in assisting the founders over the initial hurdle of deciding which NPO entity to establish, as well as providing information on the registration process of the entity in question. As highlighted in this chapter, different entities come with their own challenges, and it is for the founders to decide which entity is most appropriate for the long-term sustainability of their organisation.

BIBLIOGRAPHY

These resources will provide you with more information on the laws that govern non-profit organisations:

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The Guide to the Companies Act and Regulations, Originally Compiled and Edited by T. Schoeman, Revising Editor Walter D Geach, Published by Juta & Co, LTD, 1992.

The Legal Resources Centre *Legal Obligations of Members of Non-profit Organisation Governing Bodies Information Series No6.*

The Legal Resources Centre *Legal Structures Commonly Used by Non-profit Organisations Series No1*

The Legal Resources Centre *New Tax Law for South African Non-profit Organisations Series No3*

RELEVANT LEGISLATION

- The Companies Act 71 of 2008
- The Income Tax Act, No 58 1962
- The Non-profit Organisation Act, No 71 1997
- The Trust Property Control Act, No 57 of 1998

POST SCRIPT
NEW INFORMATION HOSPICES SHOULD BE AWARE OF

New information has come to light recently and hospices should ask these important questions:

- Are you using your tax exemption status?
- Have you amended your Constitution as required by the Tax Exemption Unit?
- Are the three people with fiduciary responsibility in your organisation – unconnected to each other?
- Do you need training to support your compliance with the new Companies Act?

In terms of Section 18A of the Income Tax Act, hospices and other NPO's can issue receipts to donors which will enable the donor to qualify for a tax deduction on personal tax returns. Currently some hospices are not using this benefit – and could lose out on important funding opportunities.

Does your organisation have tax exemption status ie written proof and a certificate of its exemption status?

Registration as a NPO does not mean you have automatic tax exemption status. Tax exemption and section 18A status must be applied for through the SARS Tax Exemption Unit in Pretoria. Tax exemption status does not mean that an organisation also has Section 18A status. This status must also be applied for by ticking the relevant box on the application form provided by the SARS Tax Exemption Unit. This is important to remember when applying as government officials are not allowed to just issue Section 18A status, since it ultimately means government will be deprived of tax revenue. So you have to apply and make sure you meet the requirements.

Once tax exemption status has been granted to your organisation you will receive a letter confirming this from the Tax Exemption Unit. You need to pay close attention to Clause 2 and ensure that you respond to the requirements therein. Clause 2 usually means you need to review your existing Constitution. Andre Wagner of HPCA's Organisational Development has found that ninety percent of hospice organisations within the association do not respond to Clause 2. He warns that failure to submit an amended Constitution runs the risk of attracting a substantial penalty. The penalty may involve the Tax Exemption Unit requesting the return of all tax breaks given in previous years. For some hospices who have enjoyed significant tax breaks to date, this penalty can run into millions of rands.

Hospices need to be aware that once they have achieved tax exemption status this means they also need to submit a tax return annually for their organisation.

Amending your Constitution – to maintain your tax exemption status

For hospices needing assistance to amend their Constitution, there is a new model Constitution available from an NPO attorney, Ricardo Wyngaard. This generic constitution can be compared to your existing constitution and amendments made to ensure you meet the requirements for tax exemption.

Important funding opportunities are currently being overlooked

It has been found that currently many hospices are not actively using their Section 18A status. This is a very important opportunity that is being overlooked. Donors who support your organisation need to ask you for a Section 18A receipt. This tax saving for your donor/s could support your ongoing relationship with them. Equally the tax saving could present a significant corporate funding incentive for new funders you approach.

Fiduciary responsibility – three unconnected persons at your hospice

The provisions of Section 30(3) of the Income Tax Act stipulates that :

At least three persons who accept fiduciary responsibilty for the public benefit organisation, will not be connected persons in relation to each other, and no single person directly or indirectly controls the decision making powers relating to such organisation.

Hospices therefore need to be careful who they appoint in key leadership positions in their organisation as this can present a conflict of interest in terms of the Income Tax Act. For example a hospice where the husband is the Chair of the Board and the wife is the Hospice Manager presents a conflict of interest in terms of the Act (This comment fits in with the advice given earlier in this chapter on page 50 under the title headed *Further requirements to be met to qualify for status of a Public Benefit Organisation*: three unconnected persons must accept positions of fiduciary responsibility.

Is your hospice compliant with the new Companies Act?

The new Companies Act was promulgated on 1 May 2011, and hospices who are existing Section 21 Companies or who are now NPCs under the Act, have one year remaining in which to ensure their organisation meets the requirements of the new legislation. HPCA has invited the NPO lawyer Ricardo Wyngaard to run workshops for hospices in all provinces, outlining the requirements of the new Companies Act and the implications for hospices.

Interested hospices should contact Andre Wagner at HPCA on 021 531 0277 or *andre@hpca.co.za*.

NOTES

CHAPTER 5

Access to Care

INTRODUCTION

Terms you will find in this chapter

Delirium: extreme restlessness, confusion caused by fever etc

Discrimination: unfair treatment because of race, age, religion or gender

Dyspnoea: difficulty in breathing, often caused by heart or lung disease

Family respite: a brief period of rest or recovery from tiring and difficult home care

Ineluctable obligation: inescapable obligation – it must be done

Primary healthcare: care at community level such as at a clinic, GP practice, community health centre

Peripheral clinics: those not in the towns, but out in the rural or more inaccessible areas

Rationalisation of institution: made more efficient/profitable, e.g. by reducing workforce

Stigma/Stigmatisation: the shame/disgrace attached to illness not socially acceptable

Tertiary healthcare: care at a specialist hospital

In a matter before the Port Elizabeth High Court, a two-week-old baby boy was given the chance of life when a High Court judge ruled in favour of a blood transfusion, against the religious beliefs of his Jehovah's Witness parents. This means that not even a child's parent can prevent him/her from accessing existing health care services.

The UN Universal Declaration of Human Rights conceptualises human rights as based on inherent human dignity. Death is inevitable. The provision of good health care at the time of death is less so. Throughout the world there are wide disparities in the capacity, resources, and infrastructure devoted to the care of people who are dying.

The right of access to healthcare in South Africa

The Constitution of the Republic of South Africa gives every person the right of access to health care services. This implies that all South Africans have the right to the provision of good health care throughout the course of an illness, including the end of life.

In terms of the National Health Act of 2003 every person in South Africa has a constitutional right to access health care services. In order to fulfil this right, the necessary conditions for people to access health care must be created by providing:

1. positive assistance to patients
2. health care benefits and
3. health care services

Government has an obligation to promote health by providing hospitals, clinics, medicines and the relevant, necessary staff.

In order to fulfil this right, the Government and all citizens must respect the right of access to health care services by not unfairly or unreasonably obstructing people accessing existing health care services, whether in the public or private sector.

In the face of the current HIV and TB pandemics, and social attitudes that result in stigmatisation and discrimination against people who are HIV positive, healthcare workers have a responsibility to provide equitable health care to people living with HIV without discrimination. Managers of health care institutions should ensure that their staff are adequately trained in clinical care of patients and are supported in developing compassionate attitudes towards care.

In terms of the National Health Act 2003, Chapter 2, Section 5, a health care provider, health worker or health care establishment may not refuse a person emergency medical treatment. Should this occur, that person has recourse to the Department of Health or the Public Protector. A court can review and set aside the decision to refuse to treat the patient.

The Health Professions Council of South Africa (HPCSA) Guidelines say that healthcare professionals are obliged to treat all patients equally. Several booklets have been developed by the HPCSA outlining ethical guidelines for good practice in healthcare professions.

Government has a responsibility to protect the right of access to health care by developing and implementing a comprehensive legal framework to facilitate individuals realising this right and to limit those who obstruct others from accessing health care.

National Health Insurance

In November 2009 the South African Government set up an expert advisory committee to explore the implementation of a National Health Insurance (NHI) Scheme. In February 2011 the South African Minister of Health, Dr Aaron Motsoaledi, submitted the finalised NHI policy document to Cabinet.

Currently South Africa has two types of health care services

1. The Private Health Care System in which the individual carries the responsibility of health care with assistance from various medical schemes.
2. The State Health Care System in which the state provides health care for those unable to afford adequate medical cover.

According to Dr Olive Shisana of the Ministerial Advisory Committee, the South African Government believes this two-tiered health care system is inequitable, with proportionately more resources serving a minority, and an under-resourced public sector serving a large majority of the population. The NHI policy document has been accepted by Cabinet, and the Department of Health aims to develop National Health Insurance for the benefit of all.

The presentation by Dr Shisana dated 12 August 2011, on the National Health Insurance Green Paper makes clear the government's intention to provide equity so that those with the greatest need are prioritised. Services are to be procured at affordable cost, and the duplication of administrative structures at national, provincial and district sphere eliminated.

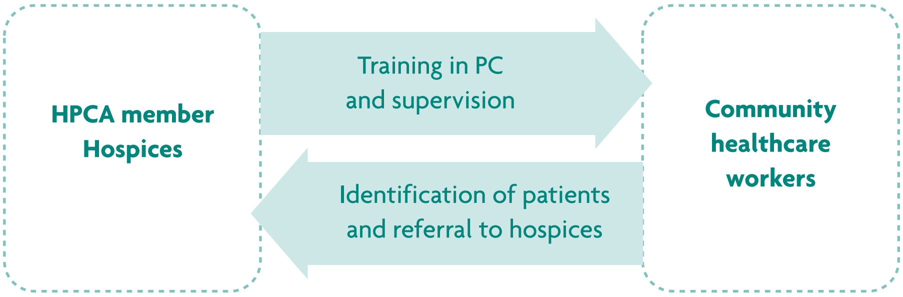
NHI AND RE-ENGINEERING PRIMARY HEALTH CARE

NHI and Re-engineering Primary Health Care

In the National Health Insurance Green Paper the government outlines the socio-economic benefits of NHI, arguing that each extra year of life expectancy raises a country's GDP per person by 4% in the long run and thus a healthier population contributes to better wealth creation. The new NHI policy is seen as part of the socio-economic benefits of health spending. To successfully implement the NHI, the current health system is to be completely transformed, and this involves re-engineering primary health care.

Access to health care depends on access to doctors, nurses, dentists and pharmacists. In South Africa, as well as internationally, there are several different crises confronting human resources within health care services, including:

- Personnel shortages in rural areas and poor urban areas.
- Many healthcare workers leaving the public health system and going to countries where payment and conditions are better.
- The impact that HIV and TB have on the capacity of the health system by greatly increasing the numbers of people in need of care.



Hospice services relevant to Re-engineering of Primary Health care

HPCA welcomes the National Department of Health initiative in the Re-engineering of Primary Health Care. Hospice services that are relevant to the PHC re-engineering initiative include:

- Professional nurse supervision for home-based carers and support in patients' homes
- A strong focus on prevention messages
- HPCA standards and star rating system to measure quality of service delivery supported by the African Palliative Care Association Patient Outcome Score (APCA POS) surveys for quality of care
- The partnership project to strengthen district health systems
- HPCA and member hospices have effective mentorship for developing organisational strength in governance, management and the provision of palliative care
- HPCA training courses include the Leadership Development Programme and Palliative Care training for all levels of healthcare workers i.e. doctors, nurses, social workers, community healthcare workers and medical students
- Palliative Care training in hospital settings including TB hospitals
- Palliative Care training for traditional healers

HPCA and member hospices support the success of the re-engineering of Primary Health Care. For instance, member hospices train community healthcare workers in palliative care so that patients in need of palliative care at home are identified. Once patients have been identified, they can be referred to HPCA member hospices for palliative care. Member hospices thus provide supervision of community healthcare workers in the provision of palliative care.

The re-engineering strategy focuses on promotive and preventive health which supports the right to health. However there is a gap in the strategy in that it does not address the issue of people who may be sick in the home and dying in the home. There is an opportunity for hospices to engage with DOH at district and provincial level to address this gap. Hospices link with existing services at local level and are an important component of PHC and have the opportunity to be part of NHI. HPCA is one of the founding members of the recently formed joint-PHC forum to ensure palliative care reaches those who are sick and dying in the home.

See Chapter 11 of this book where the implications for hospices of government's re-engineering policy is also mentioned.

Specific ways HPCA and member hospices support re-engineering of Primary Health Care

Specific ways HPCA and its member hospices support the Re-engineering of Primary Health Care are the:

- Sharing of training curricula, supervision and support of home-based carers
- The use of Monitoring & Evaluation systems to gather information on care worker activities and capturing this data on Hospice Data Management System (HDMS)
- Revival or set up of health forums to allow local communities to contribute to health planning and provision, identifying existing services, identifying gaps in services and duplication of services. This HPCA initiative to map the District Health System (Health Systems Strengthening project) supports efficient referral systems and enhances community awareness of health campaigns.

Encouraging new statistics have come to light which indicate major developments in the fight against HIV

The tide is starting to turn, and although there is still a long way to go, enormous strides have been made.

Antiretroviral treatment in South Africa

At the end of 2009, an estimated 37 percent of infected people were receiving treatment for HIV, according to the latest WHO guidelines (2010). In mid-2011, following the launch of the HCT (HIV Counselling & Testing) campaign in early 2010, it was announced that the number of people on antiretroviral treatment had increased significantly from 923,000 in February 2010 to 1.4 million in May 2011.

According to the South African government, provision of HIV treatment for children has greatly increased in recent years. In 2007, more than 32,000 children were receiving antiretroviral therapy, a 250 percent increase on 2005's figure, though still only meeting half of the estimated need.

In 2009, 86,270 children were receiving treatment. According to the latest WHO guidelines, this means that 54 percent of children in need of HIV treatment in South Africa are receiving it.

... since the beginning of 2010 there have been some notable improvements regarding the delivery of antiretroviral treatment. For example, only 490 health centres provided ARVs in early 2010 compared with 2205 health centres in late May 2011.

AVERTing HIV & AIDS International HIV & AIDS charity www.avert.org/aidssouthafrica.htm

Life unexpected

Despite the savage effects of HIV, infected South Africans are living longer.

There has been a marked increase in the life expectancy of South Africans over the past five years, according to the model of the Actuarial Society of South Africa (ASSA) ... The average for males was 51.8 in 2005 and for females it was 57.2. That improved to 54.5 for males in 2010, and 60.8 for females.

The greater rollout of antiretrovirals (ARVs) and the increased provision of prevention of mother-to-child transmission of HIV have probably added at least three years to life expectancy, particularly for females, says Rob Dorrington, a professor of Actuarial Science at the University of Cape Town.

... Dr Brian Brink, chief medical officer at Anglo American, says greater investments in health, particularly in preventing or fighting HIV and Aids, tuberculosis and malaria ... had a major impact on the improvement in South African life expectancy.

Leadership in HIV/Aids is supported by the South African Business Coalition on HIV/Aids, (Sabcoha),

www.hivaidsonline.co.za/index.php/antiretroviral/161-life-unexpected

The right to receive care

In terms of the South African Constitution, The Health Act, The International Covenant on Economic, Social and Cultural Rights (ICESCR), it is widely accepted by our Courts that there is no absolute right to most of the socio-economic rights in the Constitution, but that there must be a progressive realisation of this right as resources become available.

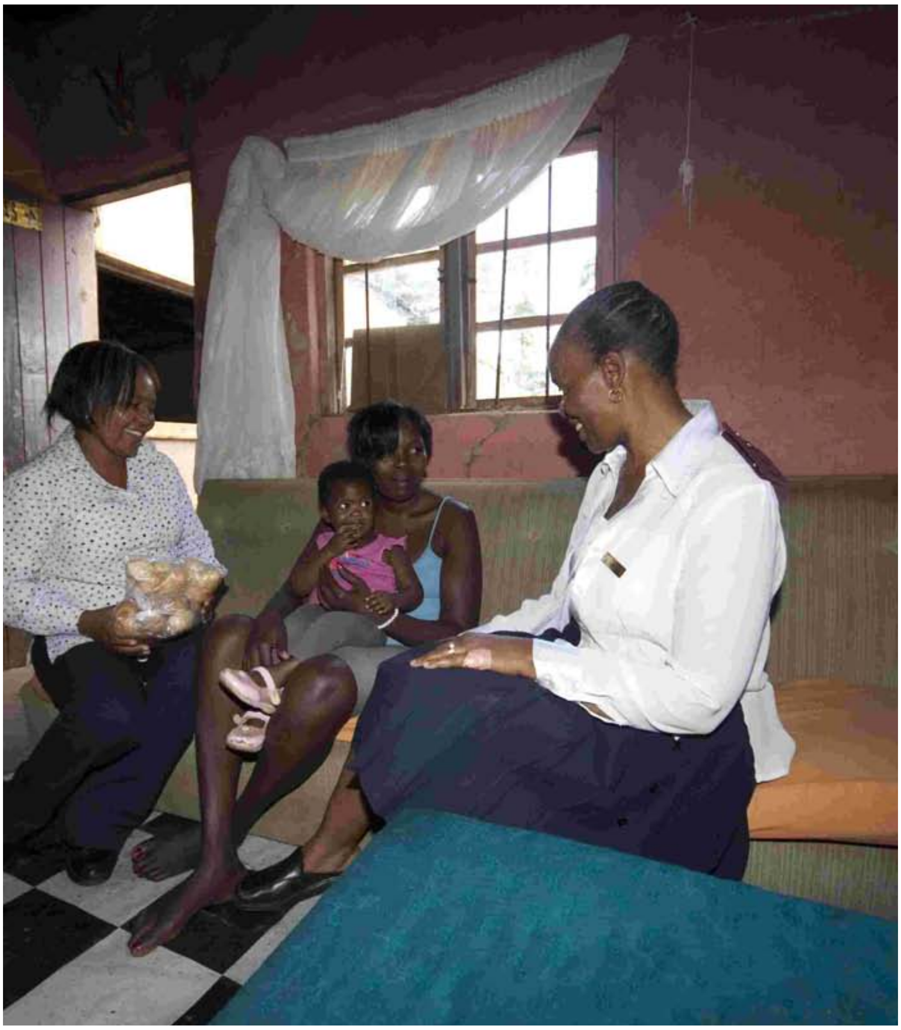
No express right to care

The rights described in ICESCR are termed aspirational rights. This means that there is no express right to care, but that Government must strive to gradually increase the right to health services in a manner which will uphold and develop the rights enshrined in the Constitution and that the government agrees to core obligations towards the realisation of these rights. The provision of palliative care is one part of a continuum of health care for all persons. Therefore, an argument can be made that a right to palliative care can be implied from the overall international human right to health. General Comment 14, from the Committee for ICESCR, documents palliative care as a human right.

Access to palliative care is impacted by:

- the lack of palliative care training for all healthcare professionals,
- the current lack of integration of palliative care into the formal health care sector.

In 2011 South African hospices cared for 3.29% of the total population of people in need of palliative care. What was the experience for the patients who died without this care?



The rights described in ICESCR are termed aspirational rights and these rights are also in the South African Constitution.

Notes

CHALLENGES TO THE PROVISION OF PALLIATIVE CARE

Notes

Understanding and awareness of palliative care

There is a significant lack of understanding regarding Palliative Care in South Africa. Many healthcare professionals and communities consider palliative care to be terminal/end-of-life care. The WHO definition of palliative care emphasises that palliative care is applicable early in the course of the illness, in fact from the time of diagnosis of the illness. Palliative care should be provided alongside disease-oriented care. This lack of understanding means that patients are referred late to hospice care. They suffer unnecessarily, alone in their homes. Family members who are not equipped to deliver palliative care then have the burden of care placed on them at a time when they themselves need care and support.

This might be due to misconceptions about hospice or to the lack of information relating to services offered by Palliative Care organisations. To overcome these challenges, more marketing and lobbying for palliative care needs to be done, for example in social media such as Facebook, Twitter, and on blogs. This information needs to be found in all government departments, for example within the Departments of Health, Social Development, Defence and Correctional Services so as to assist patients, their families, carers and health personnel. More Palliative Care campaigns are needed to provide the necessary information and to influence attitudes. We need to make this information available to other role-players, for example faith-based organisations and traditional healers who are looking after patients who have life-threatening illnesses.

The structural arrangement of a health care system can also contribute to problems concerning palliative care and its administration. Many primary health clinics and private and public hospitals do not have staff trained in palliative care. The lack of designated palliative care beds or wards also contributes to patient distress.

If more staff in these institutions could be trained in palliative care, there would be a change in attitudes towards life-limiting illnesses, death and dying. Patients would benefit from better symptom control and management of their pain, and care would be more holistic. Family members would also receive better support throughout the progression of the illness and during bereavement.

Palliative care education

Until recently, training programmes at South African medical and nursing schools did not include palliative care in their curricula. This has resulted in the lack of knowledge of palliative care, and in particular, pain management.

Palliative care is an integral part of every healthcare professional's role. This means that training in palliative care is an essential part of preparation for doctors and nurses. Traditional medical and nursing training focuses on cure, so that healthcare professionals are not equipped to deal with the clinical and emotional issues which arise during the care for patients for whom cure is no longer an option. These patients often have severe symptoms and emotional distress. Healthcare professionals need to develop the skills and knowledge to provide compassionate care and to commit to non-abandonment of patients.

In addition to including palliative care in health sciences curricula, financial support is needed to conduct research to assess the awareness of health professionals in relation to palliative care and to develop evidence-based practice. Hospices and hospitals need to have good working relationships so that hospices can become mentors for those hospitals which need to expand their practical experience of palliative care.

Place of care

Certain barriers exist with respect to palliative care, even for patients who have access to the hospice system. Hospices provide services through:

- home-based care
- day hospices
- a limited number of in-patient units (IPU)

however barriers to palliative care remain as this comparison between Home Based Care and care in an IPU shows.

When is Home Based Care appropriate?	When is an IPU admission appropriate?
• Patients are more comfortable to be attended to, in their own homes. • Most hospice programmes deliver care to persons who are dying in their own homes. This is appropriate for the South African setting and acknowledges patient preference for home care. • However home-based care is not appropriate for patients with symptoms of dyspnoea and delirium, and terminally ill patients requiring intensive nursing. These patients need admission to a hospice IPU, and will not be able to access appropriate care where their local hospice does not have an IPU.	• Admission to an in-patient hospice unit (IPU) is appropriate for symptom and pain control. • Admissions are appropriate for intensive nursing of the terminally ill. • Appropriate for bouts of dyspnoea and delirium. • Provides respite for the family and patient.
• Home Based Care is available during office hours only, as travelling at night can be dangerous for staff.	• 24 hour palliative care is available
• When a patient has problems at night, advice can be given over the phone (if the hospice has this service)	
• Hospice Day centres operate well since they provide access to the services of doctors, professional nurses and social workers.	• The IPU provides access to clinical and 24 hour nursing services, and access to the hospice multidisciplinary team.
• More cost effective means of care	• Very few hospices can afford in-patient units, and those that do exist, have a limited number of beds due to funding constraints. • More costly means of care

Notes

The failure to provide morphine to terminally ill patients leads to unnecessary suffering and breaches patients' right to human dignity. There are benefits in allowing nurses to prescribe morphine which results in better quality of life for the patient, and a peaceful and dignified end to life.

Shortage of resources

Member hospices within the Hospice Palliative Care Association (HPCA) of South Africa have experienced increasing numbers of patients from the year 2000 onwards. Professional staffing for South African hospices is a continuing challenge. The recruitment and retention of professional staff requires hospices to compete with public and private sectors with regard to staff salaries. Hospices are primarily funded through donations, which creates an ongoing challenge to meet professional salaries. Staff shortages may mean that hospices have to limit the number of patients they can care for. With the advent of the HIV pandemic, patient numbers at hospices have increased and hospice services now include prevention strategies, treatment support, holistic palliative care, poverty alleviation, food security and care of orphaned and vulnerable children.

The social problems resulting from HIV/AIDS include unemployment and child-headed households. Hospices provide holistic care which involves responding to patients' needs, so that addressing these social problems has become a significant part of hospice care.

A further challenge to the provision of palliative care is the shortage of staff and medication at clinics and hospitals. This often means that there is no doctor to write a prescription and medication is sometimes not available.

Pain relief and access to opioids

Pain can be controlled by careful assessment and management, addressing psycho-social and spiritual factors that impact on the pain experience and using relatively inexpensive oral medications. Pain that is difficult to control, such as neuropathic pain in HIV, can still be improved through the WHO approach to pain management. This recommends using non-opioid medication for mild pain, weak opioid for moderate pain and strong opioids, such as morphine, for severe pain.

Denial of pain relief

In many parts of the world, particularly in developing countries, there is inadequate access to morphine and other opioids and, as a result, people are being denied adequate pain relief. In South Africa, legislation as currently implemented, restricts the prescribing of opioids to medical practitioners. In light of the shortage of doctors and the need to provide care for seriously ill patients in the home, this logistically restricts access to pain medication for these patients. The failure to provide morphine to terminally ill patients as part of palliative care leads to unnecessary suffering and painful deaths. This breaches patients' constitutional right to human dignity contained in Section 10 of the Constitution. This is soon to change to allow nurses to prescribe and dispense opioids.

Legislation to allow nurses to prescribe opioids

When fully implemented, new nursing legislation will provide the opportunity for the inclusion of Schedule 6 substances in the list to be prescribed by nurses registered as authorised prescribers. The South African Nursing Council and civil society worked on the necessary legislative steps to enable this option. New draft nursing regulations were released for public comment by the National Department of Health on 14 December 2011.

Palliative care organisations including HPCA, submitted comment on the proposed regulations in March 2012 and the regulations in their final form are awaited. The Minister of Health intends to make the regulations which will be called Regulations relating to the keeping, supply, administering, prescribing or dispensing of medicine by registered nurses.

The WHO position on palliative care and the Cape Town Declaration

The World Health Organization has recommended that:

- all nations should have a national policy for the implementation of palliative care services,
- the care of people with life-limiting illnesses should enjoy equal standing with all other health issues.

In 2002 a group of palliative care educators met in Cape Town and produced the Cape Town Declaration which states that:

> *"Palliative Care is the right of every adult and child with a life limiting disease;*
>
> *Appropriate drugs including strong opioids, should be made accessible to every patient requiring them in every sub-Saharan country and at all levels of care, from hospitals to community clinics and homes."*

Policy change will only occur if governments understand the importance of palliative care and accept the need to increase access to drugs for palliative care within their countries.

Although the South African government recognises the administration of morphine for pain relief is an important aspect of primary health care, terminally ill patients do not have a right of access to pain relief. As a result their ability to get pain relief depends on the accessibility of doctors and pharmacists. Consequently people who are poor (in rural areas or with limited access to healthcare services), are often unable to obtain pain relief when terminally ill.

Licensing of qualified professional nurses to prescribe pain relief

Licensing of suitably qualified professional nurses to prescribe palliative care medication would improve access to pain relief for patients at home. Currently nurses are concerned that they are not able to deliver true palliative care, since they cannot prescribe the appropriate analgesics.

Dispensing laws in South Africa – what about home-bound patients?

South African dispensing laws need to take into account the question of access to medication for home-bound patients.

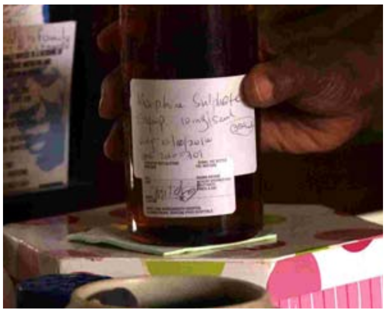
Pain control is achievable when patients are cared for by practitioners trained in pain management and palliative care. In the light of current constraints in human resource capacity within the health sector, the solution for adequate management of patients with life-threatening illness in the home is the licensing of palliative care professional nurses to prescribe Schedule 6 medication.

Experience in Uganda has proven that there are benefits in allowing nurses to prescribe Morphine which results in better quality of life for the patient and their family members, and a peaceful and dignified end to life. This benefits not only patients and their families, but also the clinical teams who have previously had to witness the intense and unnecessary suffering of patients.

Integrated Community Health Care: a solution to facilitate access to medication

Once referred to a hospice, patients continue to be cared for in partnership with the referring public health facility according to the Integrated Community Health Care (ICHC) model. *(See diagram Chapter 11).* Ideally, they should continue to access their medication through the public health facility.

In the case of bed-bound patients unable to access medication from a public health facility, an effective partnership between the hospice and the formal health care sector would facilitate continued access to the necessary medication.



Notes

Topic
for discussion

1. Do you believe this case was handled appropriately?
2. Suggest other ways in which this case could have been handled in order to have ensured a better outcome for the patient.

Notes

Case Study

I went to see a patient in a township; he was referred to me by a concerned neighbour. He had a small shack between two low cost houses.

He was lying on a mattress outside in the sun. He lived with his mother, who was an informal trader — selling sweets outside a local school. She left a cup of water and a plate of porridge covered with a plate in the shack for him. When I arrived it was about 10h00, and the food and water were untouched.

He tried to sit up to greet me, but was groaning with pain and grimacing. I told him to lie down. After a chat, I learned that he had been a long distance driver, and had contracted HIV. He learned of this 11 months before, but had never attended a clinic or hospital.

He complained of diarrhoea, and severe abdominal pain and headaches, On clinical examination, he was emaciated, dehydrated and his abdomen was swollen and tender to touch. He was unable to walk without assistance. He said he waited for his neighbour if he needed to go to the toilet, although I noticed the mattress was soiled. His voice was strained and he battled to talk. He had Panado tablets from the clinic, which his mother had obtained for him; which were not helping.

Without intervention and ARV medication, it was clear to me that this man would die. The most difficult thing to witness was the extreme pain he seemed to experience. Advice was given to the neighbour regarding hygiene and managing the diarrhoea. Nutritional advice was also given to improve his physical condition; his mother appeared to care for him, and tried her best to keep him comfortable in her absence. What he needed urgently was pain control, and admission to hospital because it was also urgent that he start on ARVs.

I had to travel back to the office to consult a doctor telephonically for a script for pain medication.

The doctor was unavailable. The next day, when I spoke to the doctor he was unwilling to prescribe anything stronger than Brufen without seeing the patient, and was unwilling to travel to the patient's home.

I travelled out to the patient again, arming him with a referral letter to the government hospital. I also gave him travel money from hospice.

The following week, at the home visit, the patient was not there, The neighbour came out to greet me. The patient had passed away on the weekend. He had not been able to make the trip to the hospital; they had tried taking him to the taxi rank in a wheelbarrow, but he cried with every bump, so much so that they carried him home before even reaching the rank. The neighbour had been with the patient and his mother throughout the last two days. She said he groaned a lot and didn't want anyone to touch him because his whole body hurt so badly. In the last few hours he became still and unresponsive (possibly a coma), and then had taken a deep breath and died.

I knew that had I had morphine syrup, I would have been able to relieve him of some if not most of his pain. The agony he and his mother and neighbour went through are unimaginable and could have been prevented if only I could have given him something stronger for his pain. I felt hopeless and deeply saddened by this case, I have seen a number of cases similar to this, and every time I wonder, am I really helping at all?

DIFFICULTIES IN ACHIEVING ACCESS TO CARE

When it comes to accessing care there are a number of difficulties and challenges that face communities, particularly in rural areas such as...

1. Geographic Challenges

Geographical barriers to access to care in rural areas are a big problem for a number of reasons:

- The infrastructure is bad e.g. poor road conditions and poor or non-existent public transport.
- Home-based teams often cover large, sparsely populated areas, limiting the number of patients that can be seen each day and adding to the cost of care.
- When it rains, access to patients becomes difficult. Conditions become worse, roads become muddy, rivers overflow and in some instance poor bridge construction means that the team cannot cross the river and reach their patients.
- Some of the areas do not have proper physical addresses, which makes it difficult for the Palliative Care team to find the patient after he/she has been referred to a hospice.

2. Cultural and Social challenges

- Seriously ill people or their families are often reluctant to contact hospice at an early stage because of the stigma that may be attached to the illness. There may be denial and difficulty in accepting the severity of the illness until a very late stage.
- People may delay contacting hospice because they fear stigmatisation should a hospice vehicle be seen outside a home. Other people may see illness as a business opportunity, taking advantage of vulnerable people by offering assistance in return for financial gain.
- Some families prefer to care for their loved ones on their own or may not be aware of the services that hospices can provide, resulting in delayed referrals.
- Many communities associate hospice with death and are reluctant to approach hospice as this means acknowledging that their loved one may be dying.
- Different languages used in South Africa present a problem, as communication between care-givers and patients speaking different languages or from diverse racial groups present barriers to proper care.
- In some cultures it is not acceptable for people to talk about death which then leads to non acceptance of the illness and a delay in accessing palliative care.
- Religious beliefs can act as a barrier to care, as some people believe in the power of prayer and are unwilling to accept medical treatment.

3. Gender considerations

- Care and nurturing are seen as part of the woman's role and this can place a burden on the female members of the family when a patient requires care.
- Most health facilities are only open during working hours, making it difficult for working people to access them.
- Healthcare staff, especially in the nursing profession, are generally women and men may be reticent to take health problems to a female healthcare provider. Hospices have found good uptake of services when male carers and counsellors are employed, and an after-hours Voluntary Counselling & Testing service (VCT) and ARV clinic is more accessible to men in the town.
- Women are often tested for HIV at antenatal clinics. Under these circumstances women are offered ARVs earlier than men, who often present with more advanced HIV and a lower CD4 count at first testing, with more severe opportunistic infections.
- Some male patients do not present for care themselves, but send their wives and then take their wives' medication.

Notes

4. Child-headed households

A child-headed household has no adult living in the home. The children live together in the house and the oldest child is the head of the home. This gives rise to many challenges, including:

- Lack of income, perpetuating the cycle of poverty.
- Children in child-headed households tending to have many roles. They are expected to care for their siblings, to make sure that there is something to eat and also have other responsibilities.
- The responsibility is an onerous one on a child and is made worse if one of their brothers or sisters is on medication. They may get the dosage incorrect or forget to ensure that medication is taken. Poor treatment compliance is a big problem in these families.
- Uncertainty in knowing whom to approach for assistance when there are problems in the home such as when one of the siblings is not well.
- Transport is problematic as the responsible child in many cases needs to ensure that siblings are transported to clinics or hospitals. The lack of transport money or somebody to accompany the child to health facilities is a reality.
- The stigma and burden associated with caring for a terminally ill family member contributes to the isolation that children experience as heads of households. The fear of being ostracised from community and peers leaves long-lasting emotional scars.

Traditional Healers

In KwaZulu-Natal, the eThekwini Municipality managers work closely with traditional healers. They believe patients must have the freedom to access both western and traditional medicine. It is important that patients are not discouraged from going back to the traditional healers after attending western facilities. In the eThekwini district some of the traditional healers have developed referral forms, which they use when they refer patients for western medicine. The traditional healers' concern is that nurses and doctors don't take these referral forms seriously; they ignore or don't acknowledge them and patients are not treated.

Traditional healers are still very much part of everyday health care for many South Africans. They are respected by the communities they live in and therefore find it relatively easy to treat community members. Traditional healers have a long history of providing treatment and care and therefore understand the patient culture within their communities. In remote rural areas, where western health facilities are few and far between, traditional healers are available and able to care for patients.

Once it has been established that there is no curative care and the patient is removed from the hospital setting, the traditional healer may be involved as the sole provider of health care and acts as adviser to the patient and the family. In Africa, 80% of people consult traditional healers. Some patients believe in both traditional and western medicine. Others opt for only contacting the palliative care team after they have already contacted traditional healers. HPCA is collaborating with traditional healers to provide them with appropriate training in palliative care. This training will enhance the quality of care which patients receive from traditional healers.

Palliative care and traditional healers dialogue

A dialogue discussion between a palliative care team and a group of traditional healers has generated new initiatives. Each side shared their perspective on their work and developed a new understanding of the other's work and looked at the possibility of cross-training. A working group has developed a 5 day traditional health practitioners course to enable traditional healers to incorporate palliative care into their care for people with life-threatening illnesses. This course has also looked at how to network with other palliative care providers to promote the well-being of their patients, thus enhancing their practice.

AN EXAMINATION OF CASE LAW DEALING WITH ACCESS TO CARE

Case Study

Interrupted care delivery

On 11 June 2007 the Department of Health dismissed 41 healthcare workers in Khayelitsha for participating in the public sector strike. Before the industrial action started on 1 June, Khayelitsha's clinics were already seriously understaffed. The strike exacerbated the staff shortage, but the dismissals made it impossible for at least two of Khayelitsha's three health facilities to offer adequate care. At all times before the dismissals in Khayelitsha, essential services were being provided and workers who participated in industrial action did so peacefully, without any destruction to property or endangering patients' lives.

Most of the workers were dismissed from Site B Clinic. On 31 May, workers at this facility, in conjunction with the facility manager, agreed to a skeleton staff system that ensured that treatment for patients with chronic illnesses would still be available, as well as emergency services.

Following a meeting with some of the remaining health workers at Site B, the Treatment Action Campaign (TAC) together with five patients who use Khayelitsha's health services, proceeded with urgent litigation in the Cape High Court to compel government to restore health services in Khayelitsha, including re-instating the dismissed workers.

The Cape High Court granted an interim interdict ordering the Western Cape Provincial government and the Ministers of Health and Public Works and Administration to restore the reasonable functioning of health care services in Khayelitsha. It found that they acted unconstitutionally by violating the rights of patients. The evidence of doctors and nurses who work in Khayelitsha demonstrated to the Court that service provision had been affected because of the dismissals.

Judge Desai in his judgment found that the dismissals in Khayelitsha disrupted the delivery of health services and that this constituted a violation of the constitutional right to access to health care service.

Case Study

Access to treatment for prisoners

Since October 2005, the TAC and the AIDS Law Project (ALP) have assisted HIV positive inmates at Westville Prison in acquiring ARVs which have routinely been refused to them by prison authorities. Situated in KwaZulu Natal, one of the provinces most severely affected by HIV/AIDS, Westville Prison had steadfastly prevented TAC or other NGOs from conducting treatment workshops, treatment literacy programmes, or any form of HIV awareness training. When this case came before the Court, Judge Pillay cited various precedents where government has been forced to uphold the rights of prisoners dating as far back as 1912, and concluded relatively early on that there was no dispute and that these fifteen prisoners, as well as any others in a similar condition, should have been receiving ART. The Government was given leave to appeal this decision, but the court ordered the interim implementation of the Court order. Judge Pillay indicated that the irreparable harm being inflicted by the sustained lack of treatment for HIV positive inmates necessitated the implementation of the initial order.

The final hearing took place two months later, in which Judge Nicholson not only ruled that the respondents immediately provide ART for the applicants and other HIV positive prisoners, but also found that they were in contempt of court as a result of failing to implement the interim order of Judge Pillay. According to the Annual Report 2010 of the Department of Correctional Services, South Africa has 240 prisons with 22 sites accredited to provide ART, being roughly 9% of prisons, thus the majority of prisoners in South Africa are not likely to have access to ART in prison.

Shining Stars prison choir singing at World Hospice & Palliative Care Day event at Dept of Correctional Services, KZN.

PALLIATIVE CARE IN PRISONS

The HPCA Department of Correctional Services project was launched in KwaZulu-Natal at Durban Westville and Pietermaritzburg prisons in October 2009 to allow access to palliative care. This project has since rolled out in four provinces with member hospices in KZN, Gauteng, Western and Eastern Cape working to provide palliative care to local prisons in their areas. More information on this initiative can be found in the Marginalised Groups chapter.

CONCLUSION

Section 27 of the Constitution of the Republic of South Africa gives every person the right of access to health care services.

The South African Patients' Rights Charter states that "Everyone has the right of access to health care services that include... the provision for special needs in the case of... patients in pain... palliative care that is affordable and effective in cases of incurable or terminal illness."

In order to realise these rights, there needs to be government policy regarding palliative care for all persons living with life-threatening illness, training of all healthcare professionals to provide palliative care and access to essential palliative care medications. Palliative care should form part of comprehensive health care and should be integrated into the formal as well as informal health care sector.

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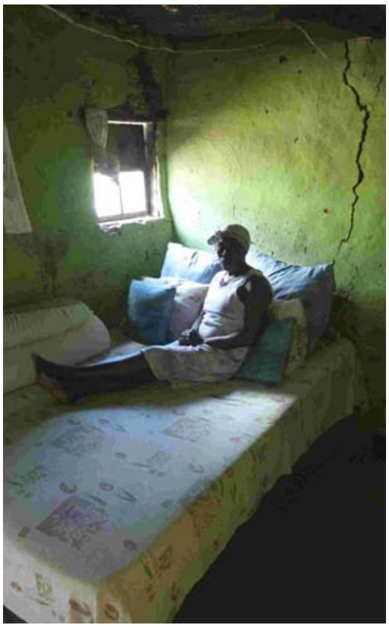
CHAPTER 6

Poverty, Financial Issues and Social Development

INTRODUCTION

> "Incredible changes have occurred, but unless we examine the lived experiences of our poor, we will never be able to address the inequalities in our society"
>
> *Ehrenreich 2007*



Since 1994, much has been achieved in South Africa such as access to clean water sources and clinics for many people, availability of electricity for new government housing in urban and peri-urban areas and opportunities at grass roots level for people to develop themselves through education and training.

However, many would argue that too little has been done, that the poor are becoming poorer and that services are lagging far behind the needs of the people. People living in rural areas are still deprived of amenities taken for granted in urban areas. Unemployment in many communities is unacceptably high, adults and children go hungry and crime leads to feelings of insecurity and fear. Children are particularly vulnerable, especially those who have no adult to protect them.

Overcrowding in dwellings leads to the spread of diseases such as tuberculosis, and drug resistant TB is an increasing problem. HIV/AIDS continues to threaten those who should be providing for young families although anti-retroviral therapy is prolonging the lives of the many who are motivated to stay on the treatment.

This chapter identifies some of the challenges of poverty faced by patients receiving palliative care, and the impact on their daily lives. The human rights and human dignity of those who are disadvantaged are considered in terms of the South African Constitution. The problems inherent in applying for a birth certificate when no proof of birth is available are addressed, as well as current resources in terms of social grants, and documentation needed to apply for them. Strategies for social development are discussed.

The chapter draws on the experience of hospice social workers in Soweto, Gauteng; South Coast, KwaZulu-Natal; Port Elizabeth, Eastern Cape; and Ladybrand, Free State. The experience of caregivers, members of NGOs and hospice staff - present at discussions and focus groups held by Desia Colgan of Street Law during 2007 - has also been a valuable source of reference. Many questions and suggestions from participants at multi-disciplinary pilot groups, held at the end of 2011 to assess responses to this chapter, have also been addressed.

Terms you will find in this chapter

Abridged certificate: shortened/ reduced certificate

Affidavit: a written statement made on oath before a Commissioner of Oaths eg Police

Alleviation of poverty: helping to reduce poverty/making it more bearable

Arbitrarily discriminate: treat differently and unfairly, depending on personal bias

Beneficiaries: those who benefit with money or property

Condonation: to approve or grant in spite of failure to meet requirements

DSD: Department of Social Development

Entrepreneurial: starting or financing new businesses/enterprises

Exacerbate effects of poverty: to make the effects of poverty worse

Informal sector: unregulated business

Lapsed policy: a policy which has expired or been stopped

Means Test: examination of someone's income and savings to determine whether a grant is needed.

Migration: moving from one region or country to another

Minimum Core: a minimum standard that the United Nations apply to make sure everyone has the basics to survive

Motivational letter: a letter giving reasons why a certain action should be taken

NGO: Non-Government Organisation

Paralegal: someone with legal training who assists a qualified lawyer

Peer group: a group of people who are of the same age, education or social class

Potable water: water suitable for drinking

Pro bono services: services of a lawyer for the public good without expecting payment

Prohibition of unfair discrimination: the legal banning of unfair treatment

Remunerative work: work that brings in money

Respondent with regard to maintenance: the person against whom the claim is brought

SASSA: South African Social Security Agency

Standard of reasonableness: an objective test that the Courts use to see if governments or people carry out their duties to a certain standard

Summons with regard to maintenance: an instruction from Court requiring a parent to come to Court in a maintenance matter.

Suspension of grant: the stopping of a grant for a period of time

Violation of human rights: depriving a person of their rights/privileges

Poverty

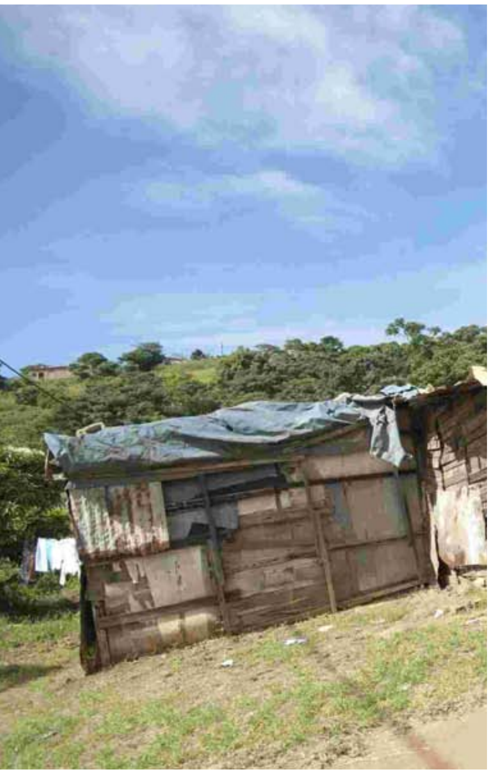
At the end of 2007, a short questionnaire was completed by hospice social workers from the areas mentioned above. The following tables reflect their experience and appear to continue to reflect many people's current experience at the end of 2011.

Some causes of unemployment	Impact on daily living
Illiteracy because of no schooling, insufficient schooling or poor quality schooling	Limits job possibilities
Lack of job opportunities	Lack of income Leads to frustration, discouragement, possible crime.
Lack of both entrepreneurial and technical skills	Lack of income Limits job possibilities
Illness through HIV/AIDS and TB limits the ability to work	Lack of income Poor care/possible neglect of children Access to grants is compromised Children caring for parents are not in school – so affecting their later possibilities in the job market Children acting as prostitutes or 'sex slaves' to gain food for themselves and the family
Migration of people from rural to urban areas and from other parts of Africa, seeking work in competition with locals	Can increase the pool of unemployed in some areas and lead to suspicion of 'foreigners' and possible violence

Other issues of poverty	Impact on daily living
Housing shortage	Leads to overcrowding in the home Poor sanitary conditions Lack of secure shelter for orphaned children and loss of shelter for adult family members *(see chapter 12: Dying and the Law)*
There are many orphans especially in deep rural areas	A grandmother over 60 may be feeding several children on her own Old Age Grant. (Now Older Person's Grant) Under 60, she may have little, if any, income
Crime	Poverty and unemployment both lead to an increase in crime
Debt	Cycle of poverty See table on needs and social work planning in section on social development in palliative care later in this chapter. See Ch. 7, Debt.
Lack of knowledge about available local resources	Inability to source state and other assistance
Breakdown of extended family who might have helped with finances or care, due to family deaths from AIDS and related family expenses	Lack of a support system for families

Poverty also has spiritual and cultural components. One of the participants in a group who met with Desia Colgan, when discussing the rise in the number of orphans being encountered in communities (Pietermaritzburg), expressed concern about what sort of values orphaned children were learning and wondered who was going to be there for them when their 'grannies' or caregivers 'moved on'.

Notes



Human Rights and Poverty

As discussed in Chapter 2, the UDHR together with the ICCPR and ICESCR make up the International Bill of Rights. In addition, the United Nations has drafted a variety of instruments dealing with the rights of vulnerable groups such as women, children and indigenous people.

Human rights have traditionally been seen as falling into two categories: civil and political rights on the one hand, and economic, social and cultural rights on the other.

Examples of economic, social and cultural rights include the following:

- The right to an adequate standard of living, including adequate food, housing and clothing
- The right to education
- The right to take part in cultural life
- The right to the highest attainable standard of physical and mental health
- The right to work, form trade unions, to enjoy safe and healthy working conditions

Recent legal developments such as the passing of the South African Constitution and rulings from the United Nation's Committee on Economic Social and Cultural Rights have shown that economic, social and cultural rights can and should be enforceable within domestic courts.

The South African Constitution is unique in including civil, political and socio-economic rights. The inclusion of socio-economic rights in our Bill of Rights goes a long way towards addressing the alleviation of poverty. Some of the most important sections of the Constitution for people living in poverty are:

- Section 26 gives everyone the right of access to adequate housing
- Section 27(1)(a) gives everyone the right to access health care services
- Section 27(1)(b) gives everyone the right to access sufficient food and water
- Section 27(1)(c) gives everyone the right of access to social security, including appropriate social assistance if they are unable to support themselves and their dependants.
- Section 28(1)(c) gives special emphasis to children's rights.
- Section 29(1)(a) gives the right to "a basic education"

Traditionally poverty has been associated with lack of resources, lack of adequate money or lack of income. Lack of income to meet fundamental human needs such as food, potable water and shelter. But poverty is about more than money. Poverty is a manifestation of historical, social, political, and legal disadvantage. This disadvantage arises, at least in part, from policies and laws adopted by governments. In South Africa this disadvantage is exceptionally severe: apartheid has left the country with one of the most uneven wealth distributions in the world. Unfortunately, although discriminatory laws have been replaced, their legacy lives on in the form of poverty and the uneven distribution of resources.

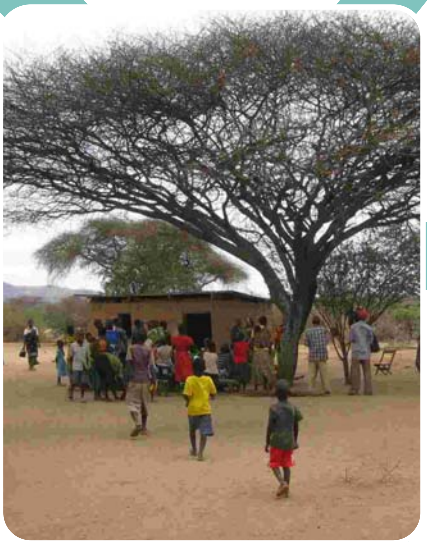
The impact of poverty on people's lives

Poverty intersects with human rights at every possible juncture; both the civil and political and the economic, social and cultural rights of the poor are affected. The table below illustrates the impact of poverty on people's lives:

May lack access to food and adequate shelter.

May face greater risk of disease.

Are often not registered with Home Affairs or do not register their children, and so may experience difficulties in obtaining social grants or registering their children for school.



May be forced to accept dangerous working conditions.

Are less able to participate in, or influence, political decision-making.

May be excluded from the justice system because they are unable to hire a lawyer to represent them or because they are hindered by illiteracy, lack of self-confidence and mistrust of the system.

The denial of access to the fundamental rights of adequate food, housing, health and education for people living in poverty is apparent. Because poverty so disproportionately affects vulnerable groups such as women, children, and particular socio-economic groups, poverty must also be seen as a denial of people's right to equality.

Gender and Poverty

The term 'feminisation of poverty' refers to an increase in the relative levels of poverty among women and/or female headed households. Traditionally, social norms and values assign primary responsibility for reproduction and care to women and decision-making to men. The reality that the primary responsibility for care of the family is placed on women means that their job opportunities are limited. In addition, women's income when they work is more likely to be allocated to the welfare of their children. Historically, women face greater difficulty in being rewarded with a good income for their work. Gender norms and practices tend to exacerbate the effects of poverty so that poor women enter the labour market with lower levels of health, nutrition, education and skills than men. There is both active discrimination against women and unconscious biases that face women in the workplace. The result is that women are assigned to less well-paid jobs than men or are paid less for the same job.

Increased access to paid work often does not translate into improved family wellbeing because of the woman's increased workload. Women often rely on older children to look after younger children at home – usually this responsibility falls to girl children and impacts on their educational prospects and their ability to escape the cycle of poverty. The difficulties faced by impoverished women are exacerbated if the man deserts or abandons the family.

Cycle of poverty particularly impacts women, children and the elderly

Illness aggravates poverty, as the sick are often unable to work to earn an income or to undertake domestic tasks. Sick people also require care which is usually provided by family members who may need to take time off from work. When the burden of care falls on children, it impacts on their education and future opportunities for employment.

The AIDS epidemic has had a particularly negative impact on the income-generating and child-rearing age group. Sick adults are not able to earn an income and often turn to their mothers for care and assistance with the care of their children. Many grandmothers take on this burden with limited resources to sustain the extended family.

Human Rights-based approach to Poverty

Before 1997 most United Nations development agencies pursued a 'basic needs' approach. They identified basic requirements for beneficiaries and tried to improve services to fulfil these basic needs. In contrast, the United Nations has now adopted a rights-based approach, which translates peoples' needs into rights. Using a rights-based approach, individuals are regarded as active rights holders; governments have duties and obligations to these rights holders. This is an important distinction. A need that is not fulfilled results in deprivation and dissatisfaction. A right that is not fulfilled results in a legal violation that may be addressed in court. However in South Africa we have not managed to secure a right to food and a right to employment. These are two fundamental rights that continue to evade poor people.

Importantly, the Constitutional Court rejected the international law principle that the South African government must meet a "minimum core" obligation to ensure the satisfaction of minimum essential levels of each right to everyone. Instead, in South Africa, the Constitutional Court will consider whether the government's measures to realise social rights is "reasonable". Reasonableness can be seen as a standard or measure for evaluating government action or inaction with respect to socio-economic rights.

In Government of the Republic of South Africa and Others v Grootboom and Others 2000 the Constitutional Court held that: "to be reasonable, measures cannot leave out of account the degree and extent of the denial of the right they endeavour to realize. Those whose needs are the most urgent whose ability to enjoy all rights is therefore most in peril, must not be ignored by the measures aimed at achieving the realization of the right."

The case of Grootboom says that minimum core is government's obligation to deliver on a socio-economic right, rather than a minimum standard to ensure everyone has the basics to survive. **There is a difference in the positions of those who can afford to pay for services and those who cannot. State policy must take account of these differences.**

The case of Khosa and Mahlaule challenged the constitutionality of some of the provisions of the Social Assistance Act 59 of 1992 for excluding permanent residents from eligibility for social grants. The Court found that "in addition to the rights to life and dignity, the social-security scheme put in place by the state to meets its obligations under section 27 of the Constitution raises the question of the prohibition of unfair discrimination". The Court held that the decision to exclude a particular group must be consistent with the Constitution as a whole, and there must be compelling reasons to limit such benefits to citizens only. This case means that the government cannot arbitrarily discriminate against a particular vulnerable group of people when meeting its obligations under the Constitution.

These cases demonstrate the way in which people living in poverty may approach the court for assistance when their human rights have been violated. Where a violation has been found to exist, the court has decided that the government has a clear duty to implement reasonable programmes to address the rights of those in desperate need as quickly and efficiently as possible.

> "A human rights-based approach means that the situation of poor people is viewed not only in terms of welfare outcomes but also in terms of the obligation to prevent and respond to human rights violations. For example, any action that excludes a specific group of children from school or discriminates against girls constitutes such a violation. The human rights approach aims to empower families and communities to secure assistance and advocates a fair and just distribution of income and assets."
>
> (UNICEF (2000))

Case Study

An example of a case where poor people were able to use the Constitution to insist on the fulfilment of certain rights is The Minister of Health v Treatment Action Campaign (TAC). In that case the TAC challenged a government programme which was supposed to address the Mother-to-Child Transmission of HIV/AIDS. The programme made an anti-retroviral drug available only to 10% of mothers needing the intervention. TAC argued that this violated section 27(1)(a) of the Constitution which gives everyone the right to access to medical care. The Court held that although the primary obligation to provide basic health care services for children rests with parents, the mothers and children in this case could not afford to access private medical care and were therefore dependent on the government to make such health care services available to them. The Constitutional Court found that the government's policy was unreasonable and unconstitutional.

BARRIERS TO ACCESSING SOCIAL GRANTS

Notes

In order to access any of the social grants, a bar-coded Identity Document (ID) is needed. Application for an ID requires a Birth Certificate. Many Birth Certificates are not available because:

- the birth was never registered
- the Birth Certificate has been lost
- documents have been destroyed e.g. by a shack fire or flood
- theft of documents.

The absence of the correct documentation is a huge problem, especially when trying to obtain identity documentation for a child or young person whose birth has never been registered. In cases where the child's parents are deceased, the child may not know his or her place of birth and therefore is unable to obtain a birth certificate.

Registration of births

The Births and Deaths Registration Act, (51 of 1992) states that the birth of a child must be reported and registered within 30 days. This assists Home Affairs to update their records and to create a reliable and accurate Population Register in the country. It also helps with obtaining other documents such as a duplicate Birth Certificate, ID Book, Death Certificate etc.

How do you register a birth?

To register a birth, the BI-24 (Notice of Birth) form must be completed and submitted to the nearest Home Affairs office. If the applicant is abroad, he or she should submit the application at the nearest South African Mission or Consulate.

Requirements for Birth Registration

It is important that:

- one of the parents or the legal guardian provides the Notice of Birth.
- If neither of the parents or the guardian is able to do this, a person, requested by the parents or the guardian, may give notice on their behalf. This person must have their written permission.

What happens to the birth registration when parents are not married?

A child born out of wedlock is:

- registered under the surname of the mother.
- the child may also be registered under the surname of the natural father if he agrees that he is the father. Both father and mother must agree to the registration of the child under the father's surname in the presence of a Home Affairs' official.

For further information

See the Resources Section at the end of the manual for what to do when registering a birth within 30 days, after 30 days, after one year, and after 15 years of age.

Birth registration of an abandoned or orphaned child

What happens if the parents cannot be found?

When the child's parents and/or relatives cannot be traced, and you need to register the child, the following steps should be taken according to the Department of Home Affairs:

Collect and fill in A Notice of Birth form (B1-24 form) from the Department of Home Affairs

Obtain a report from a Social Worker which states that information on the parents is not available

Register the birth of the child with the Department of Home Affairs

An Abridged Birth Certificate will be issued free of charge.

Helping adults to access Birth Certificates

In the case of adult applicants, the experience of hospice social workers and patients (Western Cape) is that the Department of Home Affairs requires at least one, and sometimes more than one, of the following:

- Clinic card – proof that the adult attended the clinic when they were a baby and small child. Most adults will not have this.
- Baptismal certificate – sometimes available, but problems arise if any names on the document are mis-spelt
- Affidavit by someone who has known the adult for more than ten years – not always possible, especially when people relocate from other areas.

Experience in the field

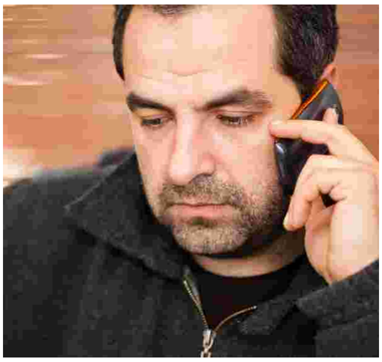
The following are responses to the questionnaire sent out at the end of 2007 to hospice social workers:

"It is very difficult for abandoned children and those born on farms and whose parents passed on before registering them to get Birth Certificates and/or Identity Documents" (Ladybrand, Free State)

This social worker found that a motivational letter from the Social Worker at the Department of Social Development, confirming that the child is a South African citizen, *"always helps to facilitate the process."*

A hospice social worker from Soweto reported the following:

"Due to the high rates of HIV and AIDS deaths, most children are left by their parents and caregivers without proper documents. Problems arise because of Home Affairs' administrative mistakes, (such as misspelling a name or giving a male instead of a female number). The Department of Home Affairs is not giving people sufficient information and then not taking responsibility for that."



Government help lines

It is worth noting that the South African Government Information website states that:

Government has a number of help lines and call centres through which you can:

- **get information** about services and programmes
- **report problems** or **make complaints**
- **provide tip-offs** to authorities about fraudulent or criminal activities.

The **Presidential Hotline 17737** should be used when all your attempts to get assistance from a government department, province, municipality or state agency have failed. It is not only a complaints line. You can call to share your views or provide solutions to the challenges in your community.

Department of Home Affairs

General Enquiries: for identity documents & travel documents
Tel 0800 2044 76
email *csc@dha.gov.za*

Ministerial hotline for complaints and/or compliments
Tel 0800 6011 90
email *minister@dha.gov.za*

Difficulties obtaining Birth Certificates and ID Applications

The following case study demonstrates difficulties which were encountered by a terminally ill mother in Gauteng when trying to obtain a birth certificate for her child:

Case Study

Margaret was 38 when I first met her. She was a hospice patient suffering from cancer of the breast which spread to brain and lung. She worked as a domestic worker and could no longer work. Her employers very kindly allowed her to go on living in the room on their property. Margaret shared the room with her 11 year old son Joe and her brother Tony, 32 years of age, who works in Johannesburg. Joe was at the local high school and doing well.

Joe's birth had never been registered and his father had died before he was born. This was of great concern to Margaret. An added complication was that Margaret's own ID document was incorrect. Her surname had been incorrectly spelt. We applied for a new ID but she died before the application could be completed. Margaret had applied for a disability grant and her application was accepted and she received her disability grant monthly until her death.

Margaret tried to put things in place before her death so that Joe could get an ID document. She and her sister Anna, who was with her when Joe was born, made sworn affidavits at the local police station, that Joe was born in the servant's quarters and that there was therefore not a hospital record of his birth. Margaret also managed to get a letter from the nursery school that Joe attended. She died not having been able to get a record of his clinic card.

Margaret died in the hospice In Patient Unit and Joe, now aged 16, wanted to get his ID document. I accompanied him to a branch of the Home Affairs Department. Having completed all the necessary forms we were told to see a "supervisor". This difficult lady told us that none of the documents we had were valid and could all be falsified, and how did she know Joe was born in South Africa and she would not recommend that he be issued with an ID document. Joe had done very well at school and showed her his school report allowing him to go into grade 11. The supervisor scoffed and said she was not interested. We needed a clinic card and a record from a hospital.

I have contacted another branch of Home Affairs and the officials are more accommodating. They have agreed to interview Joe and his aunt Anna in the New Year (2008)

It has so far proved very difficult, seemingly impossible, to get Joe an ID document as his birth was never registered.

Jill Knott, formerly Principal Social Worker, Wits Hospice

Identity Documents

Providing there is a Birth Certificate and other necessary documentation, this process of obtaining an Identity Document should be straightforward. The applicant applies at the nearest Department of Home Affairs.

Identity documents prove that people are who they say they are .

To obtain an Identity Document

1. Go to your nearest Department of Home Affairs or service point
2. Complete form BI- 9
3. Take the following with you:

- Copy of your birth certificate or previous ID book
- Reference book or a copy of the TBVC (Transkei, Bophuthatswana, Venda and Ciskei) ID or travel document
- Two identical photos
- Your marriage certificate, if applicable
- Your permanent residence permit or SA citizenship certificate and your passport, if applicable

4. Your fingerprints will be taken for recording in the National Population Register.

Note: You can no longer receive your ID book in the post but have to collect it at the office where you made the initial application.

Timeframe

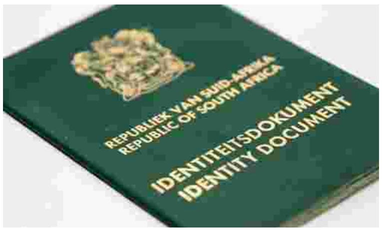
- It takes about six to eight weeks to process your ID application
- Temporary ID - same day (this is valid for three months)

Note: To receive an update on your ID application status, SMS the word 'ID', followed by your ID number e.g. (ID 1212127891082), to 32551.

How much does it cost

- First ID application – Free
- Replacement of an identity book – R140
- Temporary identity book – R140

NB The cost of applying for an identity book does not include the photographs.



An ID is needed when?

To access :

- housing,
- education,
- health care services
- To enter business agreements/ partnerships
- To register for examinations

To apply for :

- a driver's license,
- a job
- a payout from the Unemployment Insurance Fund (when you have no job).
- Identity documents are also used for voting in national, provincial and local elections.

Who qualifies to apply for an Identity Document?

You can apply for an ID if:

- you are 16 years or older
- you are a South African citizen or a permanent resident
- your ID is lost, stolen or damaged
- your personal particulars have changed
- you have changed your surname
- your citizenship status has changed
- you are temporarily residing abroad and have previously had a South African ID.

SOCIAL DEVELOPMENT

> "Most of the initiatives out there are pre-conceived agendas – they don't come from the communities, so they don't own them. "
>
> *NGO participant, Pietermaritzburg*

Social development projects are intended to uplift the community. Effective social development has its roots in the community; ideas and dreams which start there can be fostered and partnered and come to fruition. There needs to be a close working relationship between government, non-government organisations (NGOs/NPOs) and people in communities in terms of developing skills, resources, and income-generating projects. Communities need to feel that they own the various initiatives. Unfortunately many social development projects do not get off the ground or are obstructed by in-fighting.

Social development in palliative care

Hospice social workers investigate and identify needs with the client.

Where there is no social worker, a Community Health Worker (CHW) might help with practical matters and, together with the client, plan to meet these needs. Conversations between clients and palliative care and legal staff should be on an equal basis, where power is shared and the expertise of the client recognised. There is always a danger of creating added dependency when the helping person provides solutions instead of encouraging action and initiative on the part of the client, in partnership with the helper.

Needs expressed by patient or family	Social work planning with the client
Financial	
a) to source income	a) Discussion re any monies due to the patient: • Unemployment Insurance (UIF) • Any relevant insurance policies re sickness benefits • Maintenance money from father of a child or children Documentation towards application for a Social Grant is addressed, if the above monies do not exclude this. • Reduction in school fees or exemption (see section below on school fees) • Sourcing of interim food parcels for patient and family if necessary and possible
b) to plan re debts	b) Informing creditors of current financial situation • No rash promises should be made re payments at this stage, but an undertaking that the client is doing his/her best to source income to pay. • Possible referral to a debt counsellor. *(See chapter 7 of this book)*
c) to keep up payments on a funeral policy or attempt to restore a lapsed policy	c) Assist client/family member to talk to funeral policy manager. • Talk with other family members to see if they can contribute. • See if the client's church can help.
Emotional Fears that neighbours might discover the patient has HIV and/or TB.	• Counselling re fears and concerns. • Exploring together advantages/risks of disclosure
Alcohol or drug abuse The patient is receiving antiretroviral therapyor TB treatment but has started drinking or taking drugs again.	• Exploring together what has happened and what the client puts this down to. • What are his or her hopes for the future and for the family? • How could staying healthy contribute to these hopes? • Possible referral to specialist organisations providing treatment for drug/alcohol addiction.
A child of the patient is addicted to the drug TIK. The patient requests counselling for him.	The social worker plans to see the child. Later, a family meeting might be held and referral to a specialised agency dealing with drug addiction arranged, if treatment is available.
Spiritual The ill person believes he is being punished by God or has been bewitched.	Counselling conversation and possible referral to spiritual leader or traditional healer of the patient's choice.

Unemployment Insurance Fund (UIF)

The Unemployment Insurance Act and Unemployment Insurance Contributions Act apply to all employers and workers, except for the following:

- workers working less than 24 hours a month for an employer
- learners
- public servants
- foreigners working on contract
- workers who get a monthly State grant; or
- workers who only earn commission

Domestic employers and their workers have been included under the Act since 1 April 2003.

When workers are unable to work due to illness, they may claim their unemployment insurance in the form of 'illness benefits'. All workers should claim within 6 months of becoming ill/becoming unemployed/applying for deceased benefits (by family member).

Delaying making a claim for UIF benefits usually leads to a denial of the benefit. It is possible to request condonation for, or acceptance of the late application, but this complicates the process and late applications are often not allowed.

Mrs Y was living on a farm with her husband. Her husband was employed and contributing to the UIF when he died. She was entitled to certain benefits as his widow. She only found out about this seven months after her husband died. When she went to the Department of Labour, they incorrectly refused to allow her to claim. They should have assisted her with a condonation application. She then sought advice from her local advice office. The advice office did not keep a copy of her condonation application and when she sought advice from a lawyer, the lawyer was told that her condonation application had been refused. Without copies of the condonation application, no further legal action could be taken. The delay in lodging the claim unnecessarily complicated Mrs Y's ability to make the claim for benefits that were due to her.

Topic
for discussion

Angie, a single parent with one child, 10 years old, has advanced cancer.

Angie has been working until two months ago but is now unable to work due to illness.

Discussion Question

- Would Angie be entitled to apply for Unemployment illness benefits?
- How would she claim for these?

How long will it take and how much will you get from UIF?

The system of claiming is usually straightforward and payment is over several months or until the individual's benefits are exhausted. The percentage of salary paid out will depend on how long the person has been consistently working, whilst paying into the Fund, and when he last claimed unemployment benefit. The first payment should be made about 6 weeks after the employer/medical form has been accepted.

What should the client be told?

Information to all clients should stress:

- the importance of lodging claims within six months
- that copies of all completed forms for illness benefits or anything else should be made
- that these copies should be kept in a safe place together with any relevant correspondence

How to claim UIF illness benefits

The worker or family member collects the prescribed claim form U1-19 from the nearest office of the Department of Labour and requests the employer to complete it.

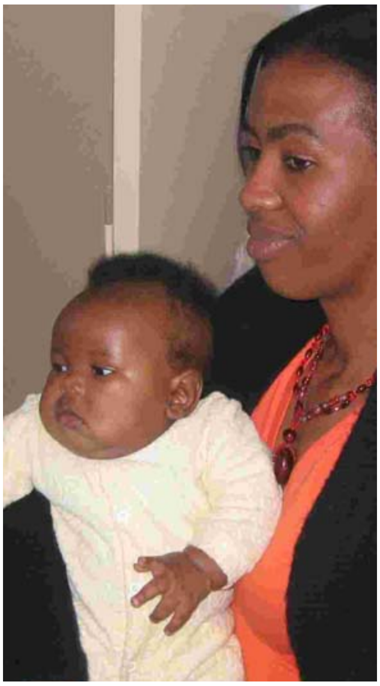
A doctor must complete the medical section of the form. ***The client should see that the doctor's name is clearly readable and that the doctor's practice number is on the form, otherwise the claim will be rejected by the Department of Labour in Pretoria.***

The claimant must have a bar-coded ID and proof of residence.

The worker returns the form to the local Department of Labour.

Applying for a Maintenance Order

- Legally, both parents have a duty to support their children, but if parents cannot support the child, one can look to the grandparents for support.
- The applicant must be caring for the child/children
- Those applying for maintenance are more often single mothers, but could be fathers, grandparents or others caring for the children
- Maintenance Officers are usually based at the local Magistrateís Court building
- Once a Maintenance Court has issued a Court Order instructing a parent to pay child support, it is a criminal offence not to pay.



How to apply for maintenance at the Magistrate's Court in the district where you live.

- Go to the court and complete Form A: Application for a maintenance order
- Submit proof of your monthly income & expenses, such as:
  - receipts for food purchases,
  - electricity and /or rent payments,
  - together with Form A

- The court will serve a Summons on the respondent to appear in court on a specific date to discuss the matter.
- If the respondent agrees to pay the maintenance as claimed, the magistrate will review the documentation and make an order.
- If the respondent does not consent, he or she must appear in court, where evidence from both parties and their witnesses will be heard.

Take Note – tracing agent

The process of applying for maintenance relies on the contact details of the respondent being known. When the whereabouts and place of work of the person alleged to be liable to pay are not known, the process can be a lengthy one. It may be possible to assist clients in appointing a tracing agent to locate the respondent on a NO TRACE, NO FEE basis.

- If the court finds the person liable to pay maintenance, payments must be made.
- Money can be paid in :
  - at the local magistrate's office
  - directly into the bank account of the person concerned or to that person
- by an order which directs the employer to deduct the money from the salary of the person employed (in accordance with the Maintenance Act of 1998)

School Fees

Through the South African Schools Act of 1996, the national Department of Education has made educational attendance compulsory for all children aged seven to fifteen (or the completion of Grade 9). The State accepts the responsibility to ensure that schools are accessible and affordable. Some schools have been certified 'no fee schools' and the parents do not have to pay any fees. Other schools charge a limited fee based on the income of the parent group. Some schools charge fees that are too high for parents to pay and they may, in certain circumstances, apply for a partial or full fee exemption.

The School Fee Exemption Policy

The policy applies to learners from Grade R to Grade 9.

The Exemption of Parents from the Payment of School Fees Regulations of 1998 sets out a means (income) test for the granting of exemptions:

- If the combined annual gross income of the parents is less than ten times the annual school fees per learner, the parent qualifies for full exemption.
- Partial exemptions are available for those whose income is more than ten times but less than thirty times the annual fees.

Eligibility for full and partial school fees is worked out on the basis of parental income in relation to the fees.

Regulations released in October 2006 take into account the number of school-going children supported by a caregiver and provide clear guidelines for working out the amount of partial exemption.

***Example:** The breadwinner's annual salary is less than 10 times the amount of the school fee*

Monthly salary	Annual salary	Annual School Fees
R800	R9600	R1000

In the above example, there will be exemption from school fees for a single parent.

***Example:** The combined income of the mother and father is less than 30 times the annual school fee*

Monthly combined salary	Annual combined salary	Annual School Fees
R1500	R18000	R700 30 x annual fee= R21000

The couple above will qualify for a partial reduction of fees

Exercise

A palliative care social auxiliary worker visits a man who has advanced cancer. His wife earns R1400 per month and says she cannot afford to pay school fees for their two daughters, aged 9 and 10 years.

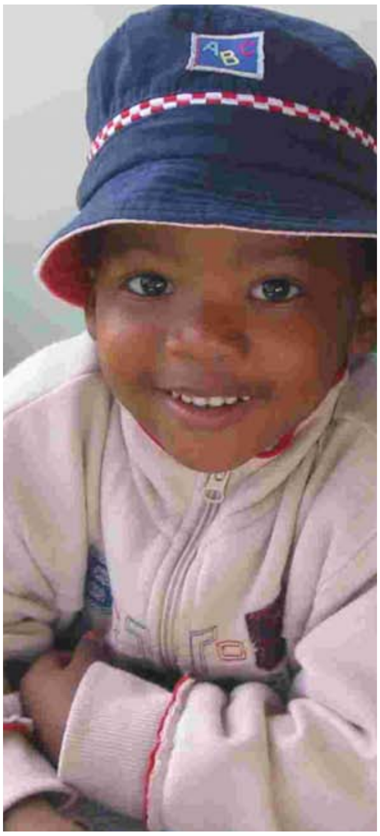
There is no other income.

Consult the above table to answer the following question:

Would this family qualify for a reduction in school fees?

Certain categories of children are exempt from paying school fees, such as:

- Child Support Grant beneficiaries
- foster children
- children in Child-headed Households



Notes

How can parents apply for a reduction in school fees?

In practice many schools will not accept learners if their parents are not able to pay the fees, but once your child is in the school it is possible to apply for a fee exemption. The process to follow is as follows:

- Write a letter to the School Governing Body requesting to be exempted in part or totally from fees.
- Provide a payslip or letter from the employer(s) explaining how much the parent(s) earns.
- Where the parents are unemployed or self-employed, they should make an affidavit saying what they earn or how they support the child (pension, child care grant etc.)

Housing

Local authorities have an annual budget for subsidised housing. Unfortunately there is an overwhelming demand for housing which exceeds the budget each year. In Cape Town, the housing list has 500,000 names; the number of houses which can be built each year is 8,000 to 9,000.

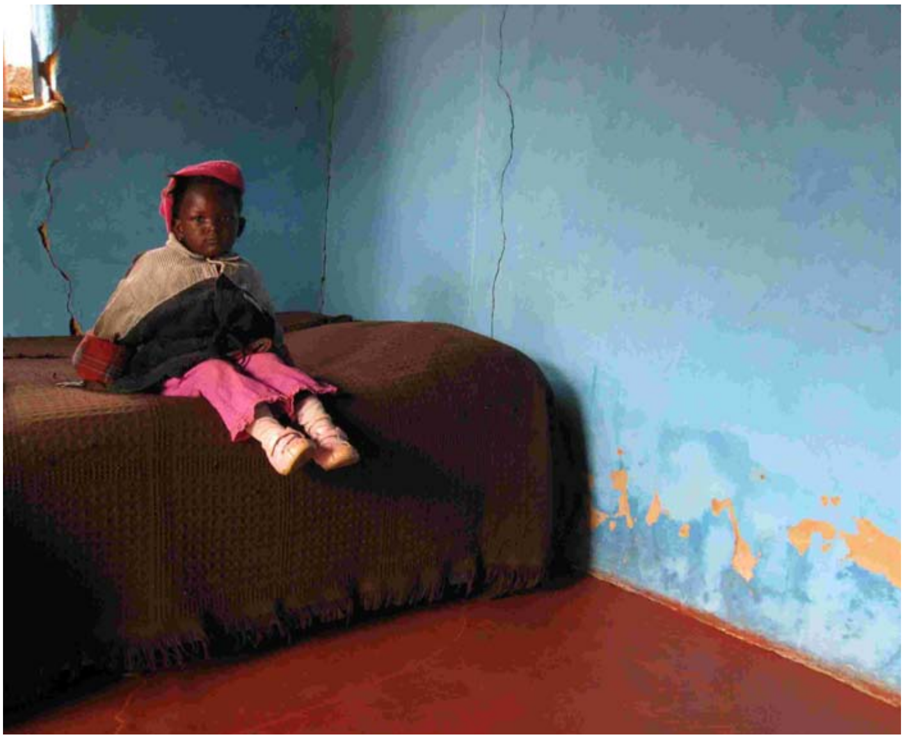
How to apply for a subsidised house

- Approach the nearest housing office
- Request that your name be entered on the housing list

If people struggle to pay their municipal accounts (rent, rates, electricity and water), through retrenchment, unemployment, illness for instance, what should they do?

Municipal Accounts

They should immediately inform the municipality and try to come to an arrangement with the accounts department.Find out if assistance may be available in some form. The City of Cape Town has a Housing Indigent Grant and will assist with housing debt management.



Social Assistance is an income transfer in the form of grants or financial award provided by government.

From 1 April 2006, the responsibility for the management, administration and payment of social assistance grants was transferred to the South African Social Security Agency. SASSA is a public entity and focused institution responsible for ensuring that government pays the right grant, to the right person, at a location which is most convenient to that person.

Most adult patients in palliative care will be applying for Disability Grants, although some may have an Older Person's grant. An adult is only allowed to receive one social grant. One of the problems when applying for Older Person's and Disability Grants is accessibility to an office of SASSA; elderly and sick people often cannot travel to the nearest office, which can be miles away. SASSA officials will help the patient at home, hospital or in frail care with applications for grants, although this process can be slow at times.

Once grants have been authorised, collection from the relevant pay-out points can also be problematic.

A Disability Grant can take up to 3 months to be authorised.

If a person is chronically ill and bed-fast, how can they apply for a grant?

Authority for someone else to fetch a grant: giving a Power of Attorney

- Ask a family member or friend to represent them in terms of the grant.
- This person is known as a procurator and has to be authorised to do this by a SASSA official.
- The procurator must be over 18 years but need not be a South African citizen or permanent resident.
- The nominated person must sign the grant application form and provide their thumbprints.
- When collecting the grant, the procurator must produce his/her own identity document/passport/driver's license as authorisation. This Power of Attorney to draw a Social Grant is also mentioned in the last chapter of this book, *Chapter 13, Death and Dying.*

Qualifying requirements for grants

See tables on the following pages for adult grants and child grants.

Take note: Those who are casual workers, working for only some months of the year, should be assisted to work out an average monthly income for the year, so that they do not receive a smaller grant than they are entitled to.

In order to benefit their patients and families, it is a sound idea for social workers and social auxiliary workers to build relationships with SASSA officials and to set up a meeting with those persons. Officials are likely to be more helpful when they know with whom they are talking and also know of the organisation and staff working in the community concerned.

Topic for discussion

A palliative care worker visits a family living in a shack. The mother, Mrs. Ndolo, has advanced cancer and cannot work. The daughter, ten years old is physically disabled and the whereabouts of the father of this child are unknown.

Questions:

- What social grants would this family be entitled to?
- What documents would the mother need?
- How would she apply for the grants?

Refer to the material in this chapter as you need to.

For further information

For Asset and Income Table, current amounts of grants in 2011 and 2012, and toll-free hotline for SASSA, see pages 214,215 and 233 of the Resources section at the end of the manual.

SOCIAL GRANTS

Adult Social Grants

Grant	Requirements	Documents
Older Person's	SA citizen/Permanent Resident Must be resident in South Africa Over 60 years of age (F and M) Means test for both spouses Not resident in a State Institution Not receiving another social grant	13 digit bar-coded ID Marriage Certificate or Certificate of Divorce or Death Certificate if applicable Tax certificate Bank statements for 3 months Proof of residence 13 digit bar-coded ID Marrriage Certificate or Certificate of Divorce Death Certificate if applicable Tax certificate Bank statements for 3 months Proof of residence
Disability	SA citizen/permanent resident or refugee Resident in South Africa 18-59 years of age Means test for self and spouse Not in a State Institution Not in receipt of another social grant	13 digit bar-coded ID Medical Assessment report from clinic/hospital doctor confirming disability Marriage certificate Tax certificate (if pay tax) Bank statements Proof of residence Proof of refugee status
War Veteran's	South African citizen/permanent resident Resident in SA 60 years and over or disabled from Second World War or Korean War Means test Not in a State Institution Not in receipt of another social grant	13 digit bar-coded ID Proof of war service Medical Assessment if disabled Marriage certificate Tax certificate Bank statements Proof of residence
Grant-in-aid	For those receiving Older Persons, Disability or War Veteran's Grant, who are unable to care for themselves. Must require full-time care (physical or mental) Must not be cared for in an institution that is subsidised by the State for such care	Proof of receipt of one of the above grants

Application for a Disability Grant (DG)

This Grant applies to those in financial need whose illness or disability prevents them from being employed. At the age of 60 years, the person's DG will be automatically converted to an Older Person's Grant.

How to obtain a Disability Grant

- Patient should ask their clinic doctor to write a note saying the doctor is willing to complete the authorised medical assessment form for a Disability Grant.
- The patient goes to the SASSA office and obtains the Disability Grant forms together with a list of documents/ proofs needed.
- The patient returns to SASSA to deliver the completed forms and documents.
- SASSA collects the completed medical form from the clinic or hospital.

The most important document for a Disability Grant is the medical report.

The medical assessment of the disability will determine if a Disability Grant is given for six months or for longer.

A temporary Disability Grant granted for six months or up to one year will only require:

- a new application
- a new medical certificate

Before the grant is discontinued, SASSA will send the patient a notification letter giving three months in which the patient can re-apply. If it is believed the disability will last more than one year, permanent disability may be awarded; it is not a grant for life and re-application and re-assessment will be needed at some stage.

Child Grants

Name of Grant	Requirements	Documents
Child Support Grant	Applicant must be the primary caregiver of the child/children and a SA citizen/permanent resident Both applicant and child must reside in South Africa Child must be under 18 years Means test for applicant & spouse Application for not more than 6 non-biological children Child cannot be cared for in State institution	Birth Certificate of child Clinic card ID of applicant Letter from school principal for school-going children Proof of income Proof of residence Letter from employer if adult applicant is working
Foster Child Grant	The applicant and child must be resident in South Africa A court order indicating foster care status Foster parent must be a SA citizen, permanent resident or refugee The child must remain in the care of the foster parent(s)	13 digit bar-coded ID of applicant Marriage certificate Birth certificate of child Report from school principal Clinic card Proof of refugee status if applicable
Care Dependency Grant	The applicant must be a SA citizen or permanent resident The applicant and child must reside in South Africa The child must be under 18 years Medical report confirming permanent, severe disability Applicant and spouse means test (except for foster parents) The care-dependent child must not be permanently cared for in a State Institution	13 digit bar-coded ID (applicant) Birth Certificate (child) Medical assessment of the child Bank statements (applicant) Marriage certificate if applicable Proof of residence

Foster Child Grant

If the child is disabled, the following persons who receive Foster Grants for that child may also apply for the Care Dependency Grant :

- South African Citizens
- Permanent Residents
- Refugees.

Foster parents are not means-tested.

Applying for a grant – if you are not the parent

If a child is to be placed in the care of someone who is not the parent:

- An investigation is carried out by a statutory social worker, working within a child and family NGO or in the Department of Social Development.
- An assessment report is submitted to the Children's Court.
- An order from the Children's Court is needed.
- There is usually a long delay in getting the Court Order, but once obtained, the grant should follow shortly thereafter.
- Allow a minimum of 1 year for the court order and 3 months for the grant following the court order.

Note that the Child Support Grant is available to permanent residents only.

- Refugees
- Asylum seekers
- Migrant workers

cannot receive the Child Support Grant unless they are permanent residents of South Africa.

How does an adult apply for a child grant when he/she is not the parent?

An adult applying for a child grant, who is not a parent of the child, would need:

- Death Certificates of the child's parents.
- Birth Certificate of the child.

What happens when the parent is still alive?

When children are in the care of someone other than the parent ,and the parent is still alive, the parent has to make an affidavit stating that she/he has placed the children with the other person before a child grant can be accessed.

Where to apply for a Grant?

- At the nearest SASSA Office
- The applicant has to be seen by an official of SASSA and finger-prints taken. Officials visit some communities on a regular basis.
- Sometimes an official will come to the home for a very ill or disabled patient, but in rural areas it is doubtful if this would happen.
- The receipt from the official of SASSA is the proof of application and must be safeguarded. It is issued when all requirements are met for the grant to be received.
- If the grant is approved, the recipient will be paid from the date of application.
- SASSA Toll-free telephone number: 0800 601 011 to check progress of the grant application.

Exercise

Mrs. Erasmus is fostering a child who is physically disabled but has no social grant for her disability.

- Could Mrs. Erasmus apply for a Care Dependency Grant for this child?
- Would a means test be part of the application for these foster parents (Mr. and Mrs. Erasmus)?

Child-headed households

When the oldest person living in the house is under 16 years, a supervising adult is required to mentor the children and to apply for any grants to which they are entitled. This adult must ensure that the money is used for the children's needs (Black Sash 2010).

Sometimes a grant is abused by the adult and the child does not benefit.

Abuse of children's grants

There is anecdotal evidence that the child care grant given by the Department of Social Development is often used by the mothers of the children. In some cases children are left with grandparents, without the intended financial grant being given to the grandparent for the child's upkeep. In other cases, when a grandmother has managed to secure a grant for the upkeep of a child, the mother of the child has kidnapped him/her from the grandmother's care so that the grant can be paid to her. Many grandmothers, once the parents of a child have died, apply to foster the orphan which entitles them to a substantial foster care grant. Rarely is the money used solely for the child. It is used for the purchase of food for the whole household (Nelia Drenth, 2011).

How long before a decision is made on the application for a grant?

Draft Regulation 3(3) provides that

"[t]he Agency *may*, within 90 days of receipt of an application", either uphold or dismiss the application.

The permissive language (using the word 'may') means that SASSA is not obliged to finalise the application within 90 days but may do so within its discretion.

How will you know if the application is not approved?

If the application is not approved by SASSA, the person must be informed with reasons in writing.

What happens if the application is rejected?

There is a right of written appeal:

1. First to SASSA - then to the Minister of Social Development, explaining why the applicant disagrees with the decision to refuse the grant.
2. First SASSA will reconsider the rejection of a grant.
3. In terms of the Draft Regulation 2(2), the applicant is obliged to make copies at his or her own cost of a proof of receipt issued by SASSA, as well as the letter of rejection also issued by SASSA.

What happens if SASSA rejects the application again?

If upon reconsideration, SASSA dismisses the application for a disability grant it can be referred to the Independent Tribunal who must finalise the application within 90 days of receiving it.

It is a matter of public record that there is a significant backlog of appeals in the social assistance system. There was a recent settlement of the case dealing with the backlogs in appeals brought before the Eastern Cape High Court by the Black Sash Trust. The applicants in that case sought to compel the Department of Social Development to develop a programme to deal with the backlog in appeal cases. Many of the applicants had been waiting for their appeal applications to be finalised for many years. In terms of the court order obtained by consent, DSD is obliged to develop a programme to address current and future backlogs and to decide on the backlog appeals by the end of July 2011. In reality this is a hollow victory for many appellants who have kept on applying for grants. To have their appeal decided now is not likely to affect them that much.

Many appeals will be, and have been disposed of, and decided against the grant applicant.

The appeal system is an important tool, but without sufficient medical evidence to demonstrate a disability, it will not lead to a grant.

Methods of payment of grants

- Cash payments at specified pay-points and authorised institutions
- Banks, including Postbank

If the recipient is unable to collect the grant, he or she may choose to give a Power of Attorney to another person to collect it. This would need to be done through a SASSA Grant's official.

Suspension of Grants

The following may result in the suspension of a grant:

- Changes in circumstances (financial and/or medical)
- Outcome of a review
- Failure to co-operate when a grant is reviewed
- Committing a fraudulent activity or misrepresentation
- Where the grant was approved in error

An application must be made for restoration of a grant within 90 days of the suspension.

Main reasons for lapsing of grants

- Death
- Admission to a State Institution
- If the grant is not claimed for 3 consecutive months
- When the period of temporary disability has lapsed (six months or one year)
- The grant recipient is absent from the Republic
- The recipient ceases to be a refugee

Period of Social Relief of Distress (SROD)

This is a temporary provision of assistance intended for persons in such dire material need that they are unable to meet their or their families' most basic needs. It is issued monthly for a maximum period of three months. An extension for a further three months may be granted in exceptional cases.

It appears that the SROD is seldom granted, very difficult to access and unreliable. SROD is administered by the Department of Social Development and not SASSA.

No person who is in receipt of a Social Grant may receive Social Relief of Distress.

In order to qualify for SROD, the applicant must comply with one or more of the following conditions:

- The applicant is awaiting permanent aid
- The applicant has been found medically unfit to undertake remunerative work for a period of less than 6 months
- The breadwinner is deceased and insufficient means are available
- The applicant has been affected by a disaster, and the specific area has not yet been declared a disaster area
- The applicant has appealed against the suspension of his or her grant
- The person is not a member of a household that is already receiving social assistance
- The person is not receiving assistance from any other organisation.

Vouchers are issued, no money is given. In practice it is usually a food parcel or a voucher.

Transport expenditure may be paid in exceptional cases where:

- the applicant is referred for treatment by a medical officer and no other transport arrangements can be made
- the applicant must travel to a specific destination to accept employment where he or she will not be dependent on further State Aid.

Responsibility of the beneficiaries of a grant

It is the responsibility of beneficiaries to keep SASSA informed of changes in their circumstances and means.

For further information on Social Grants

See the Resources Section at the back of the manual:

SASSA
Tel: 0800 60 10 11
Website: www.sassa.gov.za

Black Sash Help Line on 072 663 3739 for free paralegal advice and support.

Notes

NETWORKING

Case Study

Lydia has only her Disability Grant as income but she owns an RDP (Government Reconstruction and Development Programme) house. She has six adult children and cannot leave the house to only one of them. The hospice social worker arranges for her to see a lawyer. A will is made in which Lydia stipulates that on her death, the house is to be sold and the proceeds divided equally amongst her six children.

Patient Support Groups

Patients often benefit by having their own group, facilitated by a social worker or social auxiliary worker and carers, where they can discuss any concerns they may have. Unfortunately, in deep rural areas, distances and transport difficulties of patients may stand in the way of support groups.

Benefits of a support group to those who attend:

- The group can provide an environment where there is acceptance
- Friendships are made and sometimes people who have been rejected by their family, or have no immediate family, grow to experience the group as 'family'
- The group can become a community of care
- People know that everyone in the group is living with the same condition, for example HIV/AIDS - 'We are all in the same boat'
- There is peer-group exchange of information and personal expertise with regard to diet, medication and other matters. This is often experienced as very supportive.
- Professional information is given and discussion facilitated around healthy eating, starting a vegetable garden, treating infections promptly, treatment adherence, condom use, sexuality, disclosure, use of antiretroviral therapy
- People can be empowered by being encouraged to take responsibility for their own health and in taking an assertive and active role in the decision-making about their treatment
- Information is given about resources available to people, such as applying for Identity Documents, Disability and other grants
- Healthy refreshments or a meal may be given
- Second-hand clothing may sometimes be available
- Activities may be offered which teach skills. Sometimes articles made can be sold for extra income
- Life skills may be taught, such as conflict resolution, negotiation and other ways of self-empowerment
- If funding is available, business skills may be taught. Working in the informal sector of the economy or operating a small business can generate the income a family needs to survive.

Networking

The palliative care social worker, social auxiliary worker or community health worker liaises with other organisations in the different communities in which she works in order to source help for clients:

Food parcels: Other organisations may be issuing these and the client can be referred. Churches and individuals in some areas may sponsor food parcels.

Burial: Some churches may subsidise this for their members. See also the section on funerals in Chapter 13, Death and Dying.

Legal Assistance: Confidentiality of the client is always to be respected and referrals made only with their consent. Community paralegals can give legal assistance and are often mediators, e.g. in disputes between neighbours, and others are skilled at pursuing missing Birth Certificates, ID etc. However some clients may not wish to be helped by someone in their immediate community. Local paralegals have access to lawyers for more complex problems. Such lawyers work at legal clinics at universities, at Justice Centres, at the Legal Resources Centre and as private lawyers, doing some of their work for free (pro bono). Other organisations such as Black Sash, Lawyers for Human Rights and Pro Bono.Org may also provide legal assistance. If local legal assistance is not immediately available, other NGOs, local branches of political parties and trade unions will have access to this information.

Networking to assist clients

Food parcels	Other organisations may provide these
Subsidised burial	Some churches do this
Encouraging learners to get back to school	Social workers liaise with parents, learners and with educators
Skills training	• Sourcing possible training • Learning bead-work, jewellery or soft-toy making to sell for income • Cooking, waitron skills, household skills • Sponsors for further education and training in building, electrical, plumbing etc. • Consult Sector Education & Training authorities (SETAS – part of the SA Qualifications Authority structure) about possible courses
Encourage home industries and vegetable gardens to generate income for the family	Look for a donor for seeds, compost, garden implements.
Foster Child Grants	The social worker liaises with a child & family welfare organisation or with the Department of Social Development.
Encourage clients to get involved in community projects	Some patient support groups start a choir or a dance or drama group. They may perform for others in different communities for a fee.
Access legal assistance for clients	Legal assistance can be sourced via community paralegals, at legal aid clinics or through pro bono services of private lawyers.

It should be noted that more educators in schools with expertise in mathematics and science subjects are desperately needed, in order to equip learners to work in technical and industrial sectors of the country. In addition, the apprentice system, equipping school-leavers with a range of artisan skills, needs to be accelerated.

For further information

Refer to the Useful Contact Numbers under the Resources Section on pages 235 – 238 for a list of contact details for legal organisations

CONCLUSION

This chapter has discussed poverty amongst palliative care patients from the practical experience of social workers in hospices in South Africa. The legal rights of disadvantaged people have been clearly explained and an indication has been given of resources which may be available to those struggling with illness, who are also experiencing financial, emotional and social concerns.

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CHAPTER 7

Managing Debt in the Context of Illness

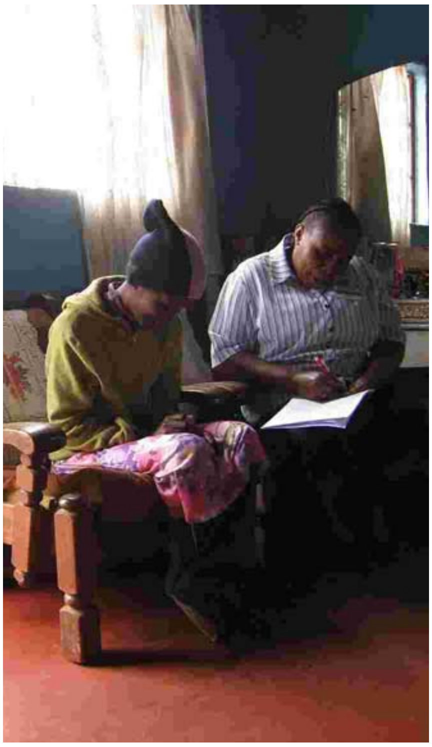
INTRODUCTION

> “ People become sick because they are poor, they become poorer because they are sick, and they become even more ill as their poverty increases”
>
> W. Kwadwo Asenso-Okyere, World Health Forum

Palliative care addresses the needs of the whole patient and we are aware of the conundrum that “the sick become poor and the poor become sick”.

In order to fully assist patients and family members, hospices provide quality palliative care free of charge to those unable to contribute towards the cost of care, assist patients in accessing social grants and may offer programmes that promote economic empowerment. However, many people who are helped by hospice often worry about the fact that they are in debt. This is a problem that many carers also face in the current economic situation.

Many people today owe money as a result of the purchase of goods or the loan of money, as they do not have sufficient funds to pay for what they have bought. Some people prefer to avoid getting into debt, and try to save money before buying what they want. In this way they avoid paying interest on outstanding debt, but rather earn interest on their savings. But many people with a very low income feel that they have no choice but to borrow money or to buy on credit, and for them debt is a daily reality. These transactions are called credit agreements, which come at a great price, often not fully understood by the unwary consumer.



Terms you will find in this chapter

Contempt of court: the crime of deliberately failing to appear in court or to respect the authority of a court of law

Credit agreements: agreements by which buyers can take possession of something and pay for it later or over time, usually in monthly instalments

Credit bureaux: organisations that keep records of credit owed by every citizen

Default judgement: judgement taken without opposition by the customer usually based on the failure of the customer to meet payments

Emoluments attachment order: the legal instruction given to your employer to deduct the money you owe from your salary

Initiation fees: the fees charged for starting/initiating the credit process

Pre-agreement disclosure: sharing of all the facts, interest to be charged and hidden costs with the customer before they sign any credit agreement

Pro rata basis: a debt administrator can pay what you owe to your various creditors according to a fixed proportion e.g. a bigger portion to the one who is owed the most.

Service fees: the monthly fees charged for handling the credit process

To attach assets: to seize property or salary legally for non-payment of debts

Warrant of execution: a legal notice informing the debtor that certain assets will be removed.

CREDIT AGREEMENTS

The cost of credit

Credit providers (sellers of goods or lenders of money) charge interest on outstanding debt, as well as other fees, the most important of which are initiation and monthly service fees. Although the National Credit Act 34 of 2005 has placed limits on the cost of credit, the total cost is still extremely high and must be carefully calculated. The smaller the amount of money borrowed, the more expensive it is likely to be to repay. The cost of small loans in particular is exorbitant. The maximum interest rate that money lenders may charge is 5% per month, but many lenders unlawfully charge interest much higher than this, some as much as 100% per month.

Consumer Rights and Duties

The National Credit Act provides many measures to protect consumers who purchase or borrow on credit, such as:

- the right to pre-agreement disclosure;
- the right to protection against certain marketing practices;
- the right to a cooling off period.

Consumers' prospects of obtaining credit are influenced by their credit record, and credit records are kept by certain credit bureaux.

For further information

For leaflets on the Cost of Credit, Consumer Rights and Duties, The Credit Bureaux and Debt Management Tips and Advice, see the Resources Section at the end of this book.

Reckless credit

Before entering into a credit agreement, the credit provider must assess the consumer's:

- understanding of the risks and costs of the proposed credit
- debt repayment history
- financial means, prospects and obligations

A credit agreement is reckless if the credit provider fails to do this, and a court may set aside or suspend all, or part of the consumer's rights and obligations (e.g. the consumer might not have to repay the credit provider).

The unlawful use of identity documents, bank cards or PIN numbers

Frequently identity (ID) books or bank cards (credit, debit or ATM cards) are held by credit providers (e.g. money lenders) as security for debt. Money lenders also use these documents to collect a debt for example:

- Money lenders control ID documents in order to recover the proceeds of the borrowers' social security grants (e.g. Older Persons' Grants).
- Money lenders use bank cards and PIN numbers to withdraw money directly from borrowers' bank accounts (frequently money lenders withdraw far more than they are entitled to, leaving borrowers with little to live on).

These practices are not just unlawful, but are criminal offences. If consumers who are victims of these practices report them, such money lenders should be arrested, charged and convicted, which could stamp out these widespread unlawful practices. Unfortunately this does not happen frequently enough.

Topic for discussion

Story

Elsa was struggling to feed and clothe her three children. Then her mother died. There was no funeral insurance, but Elsa wanted her mother to have a good funeral. She borrowed money from a money lender. The lender told her that she would have to leave her Identity Document in his safe-keeping until she had paid off the debt.

Question in small groups

- Was the money lender entitled to take Elsa's ID?
- What could Elsa have done differently?

Topic for discussion

Story

Ansie was receiving a social grant. She reported to her carer that the person she had borrowed money from kept her SASSA card and only gave it to her when she collected her grant money. This man would wait outside the SASSA pay-point and take the money from her and just give her a small amount each month. Because she did not have enough to live on, she was accumulating more and more debt. She despaired of ever being free of this situation.

Question in small groups

What action could be taken in this situation?

ENFORCEMENT OF DEBT

Notes

The letter of demand

The collection of debt usually begins with a letter of demand addressed to the debtor (a "default notice" in the case of credit agreements), requiring payment within a stated time or by a date indicated. It is essential that debtors respond by the due date, either personally or through a legal representative. This response could be payment of the debt or an offer to pay off the debt in specified instalments (unless, of course, the debtor has a defence to the claim). Failure to respond could result in a summons being served on the debtor. This will also lead to an increase in legal costs that can be avoided by proactive behaviour on the part of the debtor.

Summons and judgement

Court action is started by the issue of a summons. A summons is the legal document that initiates legal proceedings in court. It is issued by the court and served on the defendant (the debtor) by the Sheriff of the Court. In the case of credit agreements, summons may not be issued until:

- the debtor has been in default for 20 business days
- 10 business days have passed since the credit provider delivered the default notice (these periods may run concurrently).

It is essential that the debtor seeks legal advice or obtains proper assistance from elsewhere when he/she receives the summons. The debtor must respond within 5 court days (business days) of receipt of the summons by:

- paying the debt, or
- negotiating payment of the debt in instalments, or
- formally defending the action

Failure to respond will almost certainly result in a default judgement being granted against the debtor, without the need for a court hearing, and the debtor will be ordered to pay the judgement costs. For this reason it is essential that the debtor acts immediately on receipt of a summons.

Debt collection

Once judgment is obtained, the judgment creditor has three options to recover the judgment debt:

(a) Attach and sell attachable assets (movable or immovable property) by way of a warrant of execution. This method is preferred if the debtor has attachable assets.

(b) Give notice to the debtor to appear in the debtor's court for a financial enquiry, when the court may order the debtor to pay off the debt in instalments which he/she is able to afford. This method will be used if the debtor has no assets, but has a steady income. *(Note that if the debtor fails to appear in court as required, he/she may be arrested for contempt of court).*

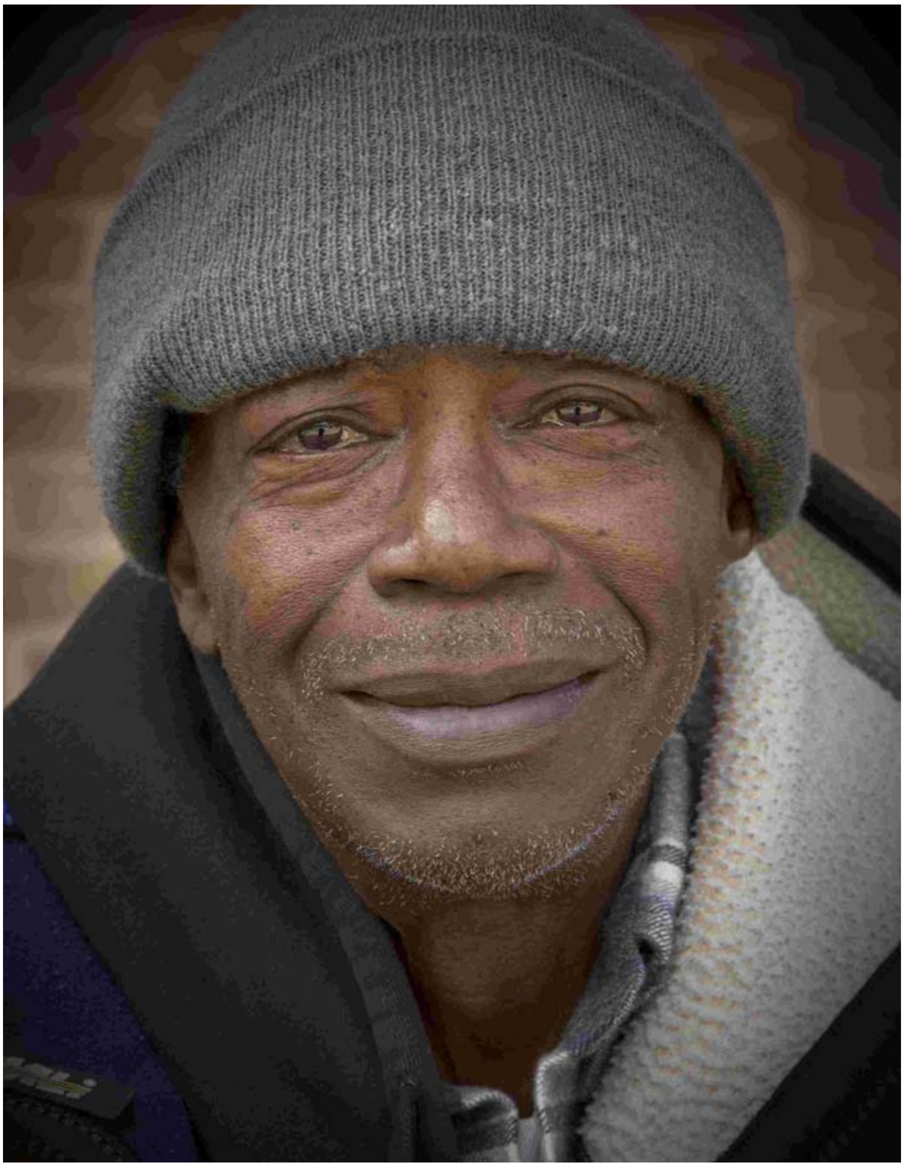
(c) Obtain an emoluments attachment order in terms of which the employer of the debtor is required by the court to deduct from the debtor's salary a specified amount each month and pay it to the creditor. This method is preferred by creditors to (b) above if the debtor is in secure employment.

Administration orders

It is possible for a debtor, who has a lot of debt which he/she is struggling to pay off, to have him/herself placed under administration by the court. This can also be initiated by a creditor. The debtor is ordered to pay a certain monthly sum to an administrator appointed by the court, who then distributes the proceeds of these payments to all creditors on a pro rata basis. An advantage of this process for the debtor is that no creditor may take independent action against the debtor to enforce the debt. A major disadvantage, is that the administrator takes a large fee for the work done, and the debtor is further impoverished as a result. For this reason, administration orders are not recommended to debtors.

Debt re-structuring

In any court proceedings involving a credit agreement, a court may declare a consumer to be over-indebted, usually upon the recommendation of an independent debt counsellor. The court can then order that one or more of the debts be re-structured (e.g. by extending the period of time within which the debt must be paid and requiring smaller payments, and/or by postponing the dates of payments). This is a new provision of the National Credit Act which is being used increasingly, and depends to a large extent on the availability of a registered debt counsellor.



Notes

WHAT HAPPENS TO DEBT UPON THE DEATH OF THE DEBTOR?

For further information

Refer to page 169 of Chapter 12 and page 197 of Chapter 13 for information about what happens to your debt and your assets when you die.

www.michalsons.co.za/category/consumer-protection

National Consumer Forum
www.consumerfair.co.za/

National Consumer Commission
0860 266 786
www.nccsa.org.za

Refer to the ***Resources Section*** on page 215 for training exercises for this chapter.

A person's debt is also known as a "liability". Upon death, all assets and liabilities "vest in" (become part of) the deceased estate. A new legal entity comes into being (e.g. Estate Late Dhlamini) which owns the assets and is responsible for payment of the liabilities. The Executor or estate representative is responsible for the payment of all liabilities of the deceased estate from the proceeds of the assets in the estate. Once all liabilities are paid, the balance of the assets is distributed to the heirs in accordance with the Will or the laws of intestate succession (if there is no Will).

If the liabilities in the estate exceed the assets, then the creditors of the deceased estate will be paid on a pro rata basis, with preference being given to certain creditors (e.g. former employees of the deceased). Note: the heirs of the deceased never become personally responsible for the debts of the deceased (whether or not the assets exceed the liabilities); rather, the deceased estate is responsible for such debts prior to the estate being wound up.

A credit provider may require a consumer to take out life insurance cover for the outstanding amount due in terms of the credit agreement. Indeed, it is advisable for consumers to maintain insurance cover in order to protect their heirs. Upon death, the insurer will pay out to the credit provider the outstanding amount due under the credit agreement. Insurance premiums are usually paid monthly together with the monthly instalment in re-payment of the capital and credit costs (interest and fees).

A credit provider may also require a consumer to take out life insurance cover for immovable property (e.g. a house) subject to a mortgage bond, or against loss or damage to any other property which is the subject of the credit agreement (e.g. furniture).

The Consumer Protection Act

The Consumer Protection Act has had a huge impact on virtually every business in South Africa. This new act came into force on 31 March 2011 and was signed by the President in April 2009. The full name of the act is the Consumer Protection Act 68 2008.

What does this mean?

Consumers in South Africa are now well protected. This will have a potential impact on all those offering products and services to consumers, as they must comply with the Act. A few examples of the impact of this law:

- all consumer agreements must be written in plain and understandable language;
- consumers will now be protected by warranties and indemnities in terms of the Act;
- standard form contracts must be interpreted in favour of consumers.
- there are various mechanisms for consumers to enforce their rights;
- the Consumer Protection Act does not affect employment contracts;
- the refund policy of various businesses will have to change in terms of the Act.

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CHAPTER 8

Legal Rights of Children in Palliative Care

INTRODUCTION

This chapter describes legal rights of children, including neonates and adolescents, within the context of palliative care provision. Children may be affected either as patients receiving palliative care or as family members of palliative care patients.

In order for children to achieve their rights, adults' rights must be met, because children are dependent on adults.

Overview of palliative care for children

Palliative care for children is the active total care of the body, mind and spirit of the child with a life-threatening, chronic, life-limiting illness or severe disability, and includes support for the family into the bereavement period. The aim of palliative care is to improve quality of life and relieve suffering. For children this also includes support of optimal childhood development, formal education, and developmental stimulation to enable the child, at every age, to live the best life possible. For children before and immediately after birth, support to the mother is an essential part of perinatal and neonatal palliative care.

Children have the same right to palliative care as adults. While children are inherently vulnerable and varyingly dependent, they are also inherently capable in a number of different ways during different stages of their lives and in different circumstances. Consequently the realisation of any child's rights must take into account a number of factors based on the expression and nature of that child's capabilities, vulnerabilities and dependencies.

Life-limiting illnesses increase the vulnerability of children. They also change the capacities and dependency of that child. Palliative care services reaching children in their homes, through daycare programmes and in residential care facilities, have the potential to improve the quality of life of these children and those around them and to relieve suffering with skilled and compassionate interventions.

Terms you will find in this chapter

Advocacy:	active vocal support for those who may not have the ability to represent themselves.
Analgesics/Analgesia:	medication that relieves pain
Asylum:	protection granted by a government to someone who has fled from another country
Children's care:	The day-to-day care and personal growth of a minor child. Making sure the child is fed, clothed, healthy, loved and nurtured.
Cognitive developmental challenges:	challenges to develop thought processes and thus acquire knowledge
Contact:	Keeping in touch with the child, developing a personal relationship with the child. A parent who no longer lives at home with the child should still keep in contact with the child in order to maintain their relationship.
Designated:	In terms of legislation certain people are given the power to choose who may be responsible to carry out certain tasks. Generally in terms of the Children's Act the official would be the Director-General and he or she can choose a particular department to carry out certain functions in terms of the law.
Disclosure:	information that is revealed which has been secret e.g. HIV status
Exemption:	permission not to do what others are required to do e.g. exemption from school fees
Historically unprecedented:	this is the first time it has happened (no record in history)
Holistic care:	care which takes into account all of the patient's physical, mental and social conditions
Jurisdiction:	the authority to enforce laws or pronounce legal judgments in a certain area
Muscular dystrophy:	a medical condition with gradual wasting and weakening of the skeletal muscles
Neonate:	a newborn child up to the age of four weeks
Succession:	inheritance of position or possessions from deceased parents

CHILDREN'S RIGHTS

A children's rights approach underlies effective paediatric palliative care programming.

The essential requirements of childhood are outlined in the rights of children to:

- healthcare and a healthy environment,
- parental and family care,
- education, access to information, participation, play, friends,
- identity, privacy, dignity and protection from harm.

Children's rights also address what needs to be done when things go wrong in a child's life (such as the loss of parents), or in the world around that child (such as living in poverty, in war or other conflict).

These rights are set out in international documents such as:

- the United Nations Convention on the Rights of the Child (UN CRC) and
- the African Union's African Charter on the Rights and Welfare of the Child.

South African legal protections are entrenched in the Constitution and laws, especially the Children's Act 2005 and the Children's Amendment Act 2007, and policy documents such as the National Strategic Plan on HIV and AIDS and STIs (Sexually Transmitted Infections) which are updated from time to time.

In 2011 a report on Belarus from the UN Committee on the Rights of the Child, identifies States responsibility to support children's palliative care in line with Articles 4, 6 and 24 of the UN Convention on the Rights of the Child (February 2011). This also applies to the South African government with respect to their obligations towards children.

Section 28 of the South African Constitution

(1) Every child has the right:-

(a) to a name and a nationality from birth;

(b) to family care or parental care, or to appropriate alternative care when removed from the family environment;

(c) to basic nutrition, shelter, basic health services and social services;

(d) to be protected from maltreatment, neglect, abuse or degradation;

(e) to be protected from exploitative labour practices;

(f) not to be required or permitted to perform work or provide services that-

(i) are inappropriate for a person of that child's age; or

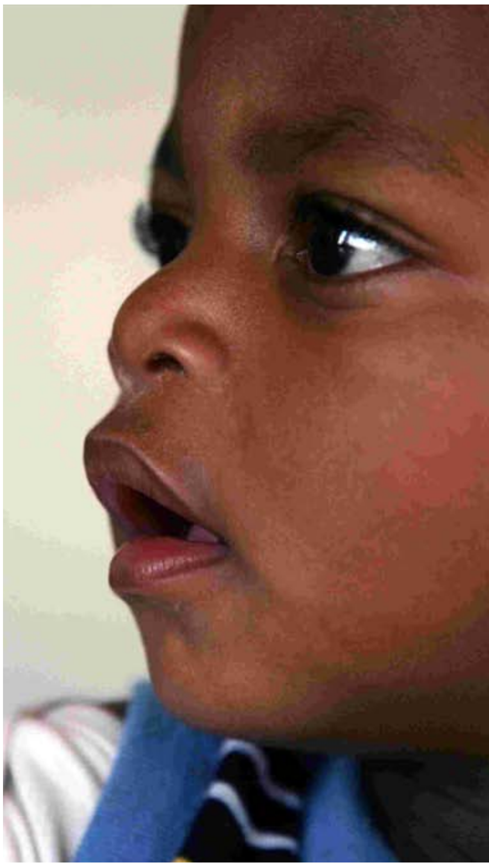
(ii) place at risk the child's well-being, education, physical or mental health or spiritual, moral or social development;

(2) A child's best interests are of paramount importance in every matter concerning the child.

(3) In this section 'child' means a person under the age of 18 years.

The guiding principles in realising children's rights are outlined in the Children's Act 2005 read together with the Children's Amendment Act 2007, and these are as follows:

- The best interests of the child must always be taken into account
- Recognition of child's needs with special provision for special needs and the creation of an enabling environment for children with disabilities.
- All rights for all children (equity and non-discrimination) and recognition of the inherent dignity of all children
- Ethical, meaningful child participation in critical areas of their lives including decision-making
- Taking the whole child into consideration including physical, social, emotional, cognitive and spiritual aspects
- Recognising the uniqueness of each child and that child's individual characteristics
- Regard for the situation at any point in time and their developmental stage, recognising the child's need for development. Engage in play and other recreational activities appropriate to a child's age,
- The changing context, needs, dependencies and abilities of each child.



Notes

GENERAL PRINCIPLES AND CHILDREN'S RIGHTS RELEVANT TO PALLIATIVE CARE

Why is play important?

All children have the right to play, and should be given an opportunity to do so every day. It is a basic need of human development and well-being as vital as food, water and rest. It is essential for a child's quality of life. It improves health of both mind and body. Play is children's way of engaging with and making sense of the world around and within themselves. Through play children develop competencies, self-perceptions, social skills and relationships. It is a key to learning life lessons about respect, inclusion, leadership, co-operation and more.

What is the relevance of play for palliative care?

If a child is not playing – they should be checked for pain or other problems. Children with life-limiting illnesses often experience pain, sadness and suffering for short and intense periods. However, they can often be distracted by play, music, storytelling and art. Children's palliative care services need to recognise this and integrate these activities into holistic care programmes, including supporting play in the home. Where programmes focus on clinical interventions only, the child's right to play may be compromised.

Best interests of the child

Sections 7 and 9 of the Children's Act 38 of 2005 reinforce the constitutional principle that the best interests of a child are paramount. This means that when making a decision that will affect the child 'the best interests' of this particular child need to come first. The Act wants people who are responsible for the care of a child to always think about what is best for the child. The Act is concerned about a child's legal welfare, his or her personal relationships, health needs or emotional and intellectual needs. In the past people often focused on the needs of the adult parent or caregiver before the needs of the child. The Children's Act has changed this perspective and is concerned about the whole child – taking into consideration both the child's developmental needs and the child's need to participate in age appropriate activities.

That is why Section 6(2)(e) of the Children's Act states that all proceedings, actions or decisions concerning a child must recognise a child's need for development and to engage him/her in play and other age-appropriate recreational activities.

The child's right to education

Section 29 of the Constitution of South Africa points out that everyone has a right to basic education. No child may be denied education on the basis of being unable to pay school fees or on the basis of their health status. Any child living in a child-only household is exempt from paying school fees. Children who are forced by circumstances to live in child-only households will need support in ensuring that this right is realised. School fee exemptions must be offered by the school, and the school must assist those requiring such exemptions to apply for them.

Chapter 6 of the Children's Act also highlights the importance of Early Childhood Development (ECD) and says in section 91(1) that ECD is 'the process of emotional, cognitive, sensory, spiritual, moral, physical, social and communication development of children from birth to school going age'. There are a large number of ECD services that range from pre-primary schools, nursery schools, day-care centres to parent support and education programmes, partial care facilities and child and youth care centres (refer to s93(4) Children's Act 2005).

Children's Right to Education including ECD while in palliative care

Young children in need of palliative care will benefit from attending Early Childhood Development programmes and ordinary schooling with other children. Those who are too frail and need protection may need to have these rights fulfilled by having educational services provided at home. The principle of a child's best interest should guide these difficult decisions, balancing a child's rights to socialise, to education, and to inclusion. Some children may be able to attend school most of the time, but may have multiple or extended periods of absence. Palliative care workers will need to work with other service providers to ensure that a child's right to education is realised.

A child with a chronic condition must be supported by the school so that during any absence, arrangements are made to receive any work that may have been missed. The hospice needs to play an active role in ensuring this continuity of education.

Gender Issues in Children

Section 9 of the Constitution speaks of the right to equality of all people in South Africa and points out that no one may 'unfairly discriminate directly or indirectly against anyone' on grounds such as race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language or birth.

Unfortunately cultural and social factors may affect the realisation of the right to gender equality, both in the way society perceives the needs and roles of girls, boys and inter-sexed or trans-gendered children, and in the expectations related to the provision of care and support in households where the parent/primary caregiver may be absent, sick or elderly. The burden of caring for themselves and their siblings in these households often falls on girls, whose rights to education, play and protection may be violated when carrying out this caring role.

Services for children are legally and ethically obliged to protect the rights of each child, no matter what the child's gender and they need to be able to identify, intervene and report cases of child neglect, abuse and exploitation.

Topic for discussion

Do you agree or disagree with the statement above?

Often in communities the primary caregivers of children are female and they may also be single, living in poverty and/or elderly. These factors may limit the ability of children's services to promote gender equality in communities where culturally and socially boys are seen as more important than girls.

Case Study 1

Cindy is 12 years old and lives with her mother, 15 year old brother Thomas, and 17 year old brother Neo who has muscular dystrophy. Her mother has a job and cannot care for Neo who requires full-time care as he is in a wheelchair and cannot feed himself. The children's granny helps when she is not working, but Cindy has to stay away from school to care for Neo at least twice a week and has fallen behind with her schoolwork. She is also frightened that something will happen to Neo when she is alone with him; and gets angry that she cannot spend time with her friends.

Life-limiting conditions affect not only the child with the illness, but also all family members. Palliative care addresses not only the needs of the child with the illness, but also the needs of other family members, helping them to cope with all the stresses and emotions they experience.

Notes

Topic
for discussion

Discuss in small groups

- What support could be given to the family to care for Neo?
- How could one help Cindy to address the issues bothering her?

Topic
for discussion

Discuss in small groups

- What are Lizzie's needs?
- What are the needs of her brother and sister?
- What would be a helpful intervention in terms of the school fee problem?
- What should be done about the grandmother's request to take on the guardianship of Lizzie?

The Children's Act 38 of 2005 section 10 provides a legal obligation to ensure Child Participation and states:

> "Every child that is of such an age, maturity and stage of development as to be able to participate in any matter concerning that child has the right to participate in an appropriate way and views expressed by the child must be given due consideration."

Furthermore, such information must be given in a way that the child can understand and express their opinions and feelings, which in turn must be taken into account in any decision-making. This means that even when the child is dependent on his/her parents and they may consent on the child's behalf, the child still has a right to participate in the decision. A child should be provided with important information in a child-friendly manner and his/her opinion still needs to be heard and considered.

Case Study 2

Lizzie is a bright and happy 8 year old girl with a chronic, genetic heart condition. As she is an orphan, she stays in a child-only household with her older siblings (14 and 17) who are very caring, feed and clothe her well, and make sure she attends clinic appointments and that she takes her medication properly. They live in a small house that belonged to their mother, who did not leave a will. The 17 year old boy does gardening on Saturdays to generate extra income and the 14 year old girl sees to all the housework and cooking, often missing school to carry out these activities. Due to her condition, Lizzie requires frequent hospitalisation or admission to a hospice in-patient unit which disrupts her schooling. This meant that she started school late and has had to repeat Grade one. The school also complains when Lizzie's siblings cannot pay school fees for her or themselves, even though they are exempt from paying school fees under the law. When her siblings are writing exams they find having Lizzie at home makes it difficult for them to study properly and request the hospice to admit her over these periods, which further disrupts her schooling. Her grandmother has now asked for guardianship of Lizzie, but not of the other siblings, as she does not want the responsibility of adolescents. The mother's family also claim that the house in which the children live belongs to them. Lizzie and her siblings would rather stay together in their mother's house with support from the hospice. Since palliative care considers the child within the family unit, and provides social, spiritual, emotional and developmental support to both the patient and their family, the educational and emotional needs of all the children were identified and a family plan put into action to ensure adult supervision in their home; and care of Lizzie at home, and when needed in the in-patient hospice. This ensured that all the children had access to education.

Child participation

Section 10 of the Children's Act states that every child has the right to participate and to be heard. This means that every child should be involved in any matter that concerns their care and well-being depending on age, abilities and maturity.

Age of majority

Section 17 of the Children's Act states that the age of majority is now 18 years and not 21 years, as it was in the past. The age of majority is the age at which a person is no longer regarded as a child and this means that they will, generally, have all the rights and responsibilities of an adult. A person over the age of 18, who is no longer dependent on his/her parents, is now able to sue and be sued and enter into legally binding agreements. A person under the age of 18 usually needs parental consent to enter into an agreement that is binding in law.

Access to information on health status and treatment

Section 13 (1) of the Children's Act gives children, depending on their age and level of maturity, the right to know enough about issues related to their health so that they are able to make an informed decision about their treatment.

Co-operation is built on trust. Children need to believe that the adult carers have their best interests at heart. They need to trust that carers will provide ongoing and consistent care and protection. Trust depends also on honesty. While children should never be told a lie – they do not need to be told everything about their health status all at once. What they are told, needs to be as much as they will understand and what they can cope with at that time. But whatever they are told it must be the truth. If they find out that a person has lied to them, they will feel betrayed and will no longer trust that person.

What does this mean for palliative care?

It is important to be honest when discussing their health status with a child. "Disclosure to a child is a process and not an event" is the most often repeated advice. Who decides to tell what, and how and when this information is conveyed are decisions that the primary caregiver should make with the help and support of the healthcare worker. Palliative care providers need to be included in this process.

Relevance in palliative care

In palliative care, children who are partners in their own health care should know the basic facts about their illnesses or condition. They have been given important information that has been communicated in appropriate ways. They know what treatment and care they should have and how important it is. They have the skills to put their knowledge into practice - for example the skills of washing hands thoroughly. They are involved in decisions about their health care, and are listened to and respected.

Right to confidentiality

Section 13 also refers to the right of a child to keep his or her health status confidential as long as respecting a child's right to confidentiality remains in his/her best interests. If there is a time that the health professional makes a decision to breach a child's right to confidentiality, he or she should talk openly to the child about the decision and give an understandable reason as to why it will be in their best interest to breach confidentiality.

What does this mean for palliative care?

Relevance in palliative care

The dignity of the child must be respected in all situations. This means that information about their health status should remain confidential and only shared with people who need access to this information in order to provide the best possible care.

For example, written documents which include information on a child's health status need to be kept in a locked cabinet with access given only to people who have the right to access this information. People with this information are obliged to maintain confidentiality and should be aware that breach of confidentiality could result in legal action being taken against them.

Children with disability or chronic illness

Section 11 of the Children's Act states that a child with a disability or who is chronically ill must be given every opportunity to take part in social, cultural, religious and educational activities. The right to dignity and self-worth is very important to children living with a chronic illness or disability. Even if a child has a disability or is chronically ill, he or she should be encouraged to live a life full of possibility, and opportunities for growth and development.

Pain and symptom management

- Section 10 in the Constitution deals with inherent dignity of the individual
- Section 12(1)(e) of the Constitution highlights the right not to be treated in a cruel, inhuman or degrading way.

What does this mean for palliative care?

Relevance in palliative care

These sections are both relevant when one considers the management and relief of pain and other distressing symptoms. Pain and symptom management are essential elements of palliative care and the failure to provide adequate pain relief may also constitute negligence.

The effectiveness of pain interventions depend on:

- strong, practical patient care skills,
- adequate assessment of the child's pain,
- active communication with the child,
- the availability of palliative care drugs and analgesics (including morphine),
- access to these medications,
- non-pharmacological interventions,
- health professionals trained and skilled in pain and symptom management.

Pain is a common experience in children; however it is often overlooked, not properly assessed or ranked low in care priorities.

Case Study Yandelwa's story

I am Yandelwa Matiwane, I am 17 years old and lived in Khayelitsha, Cape Town. I began getting ill in 2004. By 2010, the cancer had spread to my whole body and the doctors said they could not operate anymore. This is when my family was introduced to the palliative care team – the doctor, nurse and social worker. The palliative care team kept in touch with my mother and me. I liked receiving calls just to find out how I am and what I was up to. This made me forget how sick I was. In March 2011 my illness took a turn for the worse. [I went to Eastern Cape with my paternal family for a traditional ceremony]. This is the time that I saw for myself what role the palliative care team played. They phoned my aunt, doctors, nurses and everyone who was around me and all the time they were making sure that I did not have pain. They made arrangements for me to be transferred from one hospital to a better one. The palliative care team contacted my father and spoke about my wish to return to Cape Town.

This is an extract from Yandelwa's story by Linda Ganca, a Paediatric Palliative Care Social Worker, in consultation with Yandelwa's mother and sister. If you want to see Yandelwa's full story, see *"Touching Rainbows – Acknowledging the Child's Voice in Palliative Care"* Published by the International Children's Palliative Care Network 2011.

Minimising or eliminating pain and suffering in children has a positive effect on everyone, including other children in the household and the caregiver. However, the assessment of pain in babies and even in older children can be difficult when they cannot describe their pain, and different skills and tools are required and available. Pain assessment tools must also take into account cultural differences and factors that influence interpretation of the tool.

Health practitioners are often afraid of prescribing morphine for children, and children are left in pain rather than having effective analgesia administered. When morphine is correctly prescribed, fears that the child will become "addicted" or their breathing will be suppressed, are unfounded. According to Amery et al "Generally, opioids are very well tolerated in children. With the exception of infants, children metabolise opioids faster than adults and are more resistant to respiratory suppression."

Where possible and reasonable, children should be offered real choices about their care and treatment. For children under 12 years, decisions on treatment rest finally with the parent or guardian and the healthcare worker. There are certain choices which adults need to make for the child, according to the child's best interests. If an adult is going to decide, then the child should not be offered the illusion of choice, but should be provided with meaningful information and an opportunity to ask questions and process their feelings.

It is better if a child agrees to the treatment or gives assent even if the decision is taken by adults. When this occurs, the child is less anxious, experiences less pain, manages pain better and is more resilient overall, even if there has to be a painful procedure.

This assent and co-operation depends on children understanding and accepting their need for the procedure and/or medication and is a major part of their participation in their own health care. They need to know the facts and to accept them, to assimilate them into their lives and to put them into practice as far as they can. If there is medication to be taken or if procedures or surgery are required, these need to be explained to the child in ways, and with words he or she can understand and with processes that help children to communicate their questions and concerns. For children with disabilities, there should be appropriate communication, including sign language when required.

Ages of consent – Section 129 of the Children's Act

Taken from The Children's Act Explained (Unicef) Booklet 3

A child over 12 years can consent to all medical procedures as long as he or she has the maturity and capacity to understand what he or she is doing.

Need parental consent	If under 12 years of age	If over 12 years of age
Medical treatment	Yes	No – own consent
HIV testing	Yes	No – own consent
Disclose HIV status	Yes	No – own consent
Ask for contraception	Yes	No – own consent
Surgery	Yes	Yes

HIV testing of children

According to section 130 of the Act, a child may be tested for HIV, if testing is in the child's best interests and consent is given by the child or the child's parent or caregiver. According to the Department of Health's HIV Counselling and Testing (HCT) Policy Guidelines 21 "an HIV test will be in the best interests of the neonate, infant or child if it is clear that the test will provide access to the continuum of care and promote a child's physical and emotional welfare".

Pre- and post-counselling for HIV testing

Pre- and post-testing counselling must be provided to the child. Section 132 of the Act, states that testing may only be done after proper counselling by an appropriately trained person. The HCT Policy Guidelines stipulate that "where children are counselled and tested, staff should have appropriate understanding or specific training in child development, communication with children, and appropriate counselling guidelines". The parent or caregiver must also be counselled if they have knowledge of the test or have consented on the child's behalf.

Confidentiality of information on HIV/AIDS status of children

A child has the right to choose whether or not to disclose his or her HIV status but this right is limited. Section 133 provides that information on a child's HIV status must be kept confidential. Breaching confidentiality without consent is an offence with a penalty of a fine or imprisonment for up to 10 years. This could create problems if a child under 12 years can consent to take an HIV test and the results are positive. A child under 12 cannot consent to treatment, but can refuse to disclose the results to the parent or guardian. In this case, the health professional should encourage the child to disclose to the parent, guardian or caregiver.

Case Study

A young girl called Naomi had advanced stage cancer and needed pain medication. She was offered Valeron and after taking this for a few days refused to take any more, as she said she did not like the taste. She was then offered oral morphine to which she had the same objection. The nursing sister (Joan) placed the Valeron in a spoon and the oral morphine in a syringe and said that she had to have medication, but she could choose the one she wanted and how she took it i.e. either on the spoon or the medicine syringed into her mouth. She chose to have the oral morphine in the syringe and never complained about it again. When it came time for her to be placed on a syringe driver, she was again given the choice of continuing to have the medicine administered orally via the syringe or to have the syringe driver. She chose to have the syringe driver.

Take Note: If all attempts to persuade the child to disclose his/her status to the parents or caregiver fail, the health professional has two options:

- to approach a court if the child is unreasonably withholding consent and disclosure is in the best interest of the child;
- the superintendent of the hospital can consent to the treatment if treatment is urgent.

There is no case law or definitive ruling on such a case and doctors are advised to approach such matters with extreme caution.

PROTECTION OF CHILDREN FROM HARM

Notes

Levels of violence against children are high in South Africa, so child protection is an issue that palliative care workers are likely to encounter. Child Protection includes protection from abuse, neglect and exploitation. Abuse may include physical, emotional, intellectual, social, and/or sexual harm. Neglect may be deliberate or as a consequence of the ill-health, incapacity or mental state (such as depression) of a caregiver.

Categories of abuse

Taken from 'The Children's Act Explained (Unicef) Booklet 3

Types of abuse	**Type of behaviour** *(what to look out for)*
Physical abuse	Bruises, scars, burns, etc.
Sexual abuse	Touching a child in the wrong place or letting someone else touch a child, having sex with a child or letting someone else have sex with a child.
Emotional abuse	Calling the child names all the time, making the child feel scared or stupid, pushing the child away, threatening the child
Deliberate neglect	Letting a child starve, always leaving a child alone without protection, letting a child get cold or face harm in some way.

Healthcare workers are ideally placed within the community to identify possible neglect or abuse. They have the opportunity to educate families on how to strengthen parenting skills, on the use of positive and non-violent discipline, on care of children with disabilities, and developing good communication within the family. They must also intervene in such situations by reporting abuse, neglect and exploitation.

Section 150 (1) of the Children's Act:
How to identify children in need of care and protection

Taken from 'The Children's Act Explained (Unicef) Booklet 3

Physical or emotional neglect or abuse when they:	**Living away from home when they:**	**Unsafe or dangerous conditions when they:**
Live in a home where they are not safe and could be harmed if they stay there	Have been abandoned or orphaned with no visible means of support.	Behave in an out of control manner that the parents cannot cope with.
Are being mentally, physically or emotional neglected or abused by a parent of caregiver.	Live or work on the street or are begging on the street.	Drink too much or take drugs and there is no support or help.
Live in a home where there is exploitation or where they may be at risk.		

Mandatory reporting of abused or neglected children

Section 110(1) of the Children's Amendment Act. This section in the Act increases the range of professionals who are legally obliged to report the abuse of children, yet the type of abuse that they must report is limited to more serious cases of abuse and neglect such as:

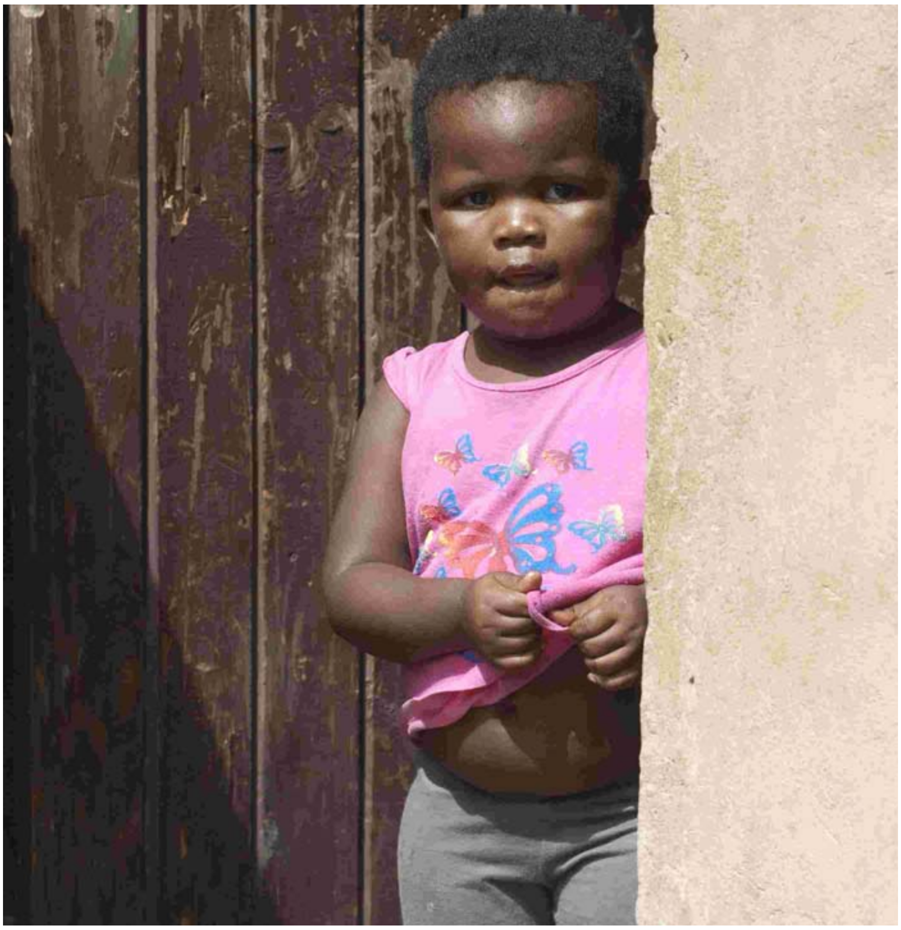
- physical abuse causing injury;
- sexual abuse,
- deliberate neglect.

Section 110 (1) reads as follows:

"Any correctional official, dentist, homeopath, immigration official, labour inspector, legal practitioner, medical practitioner, midwife, minister of religion, nurse, occupational therapist, physiotherapist, psychologist, religious leader, social service professional, social worker, speech therapist, teacher, traditional health practitioner, traditional leader or member of staff or volunteer worker at a partial care facility, drop-in centre or child and youth care centre, who on reasonable grounds concludes that a child has been abused in a manner causing physical injury, sexually abused or deliberately neglected, must report that conclusion in the prescribed form to a designated provincial department of social development or a police official."

There are steps that need to be followed in the case of abuse or neglect

1. Report the abuse to the police who are duty bound to ensure the safety of the child.
2. Within 24 hours, inform the Department of Social Development (DSD) or an organisation like Child Welfare.
3. The Social Worker ensures that the child is safe and the information in the report is accurate and honest.



Take note: Children are not always removed from the family when a report has been made. This is only done when the child's life is under threat. These decisions are made with the best interests of the child in mind, and wherever possible families and children should be involved in the decision.

A hospice social worker reports:

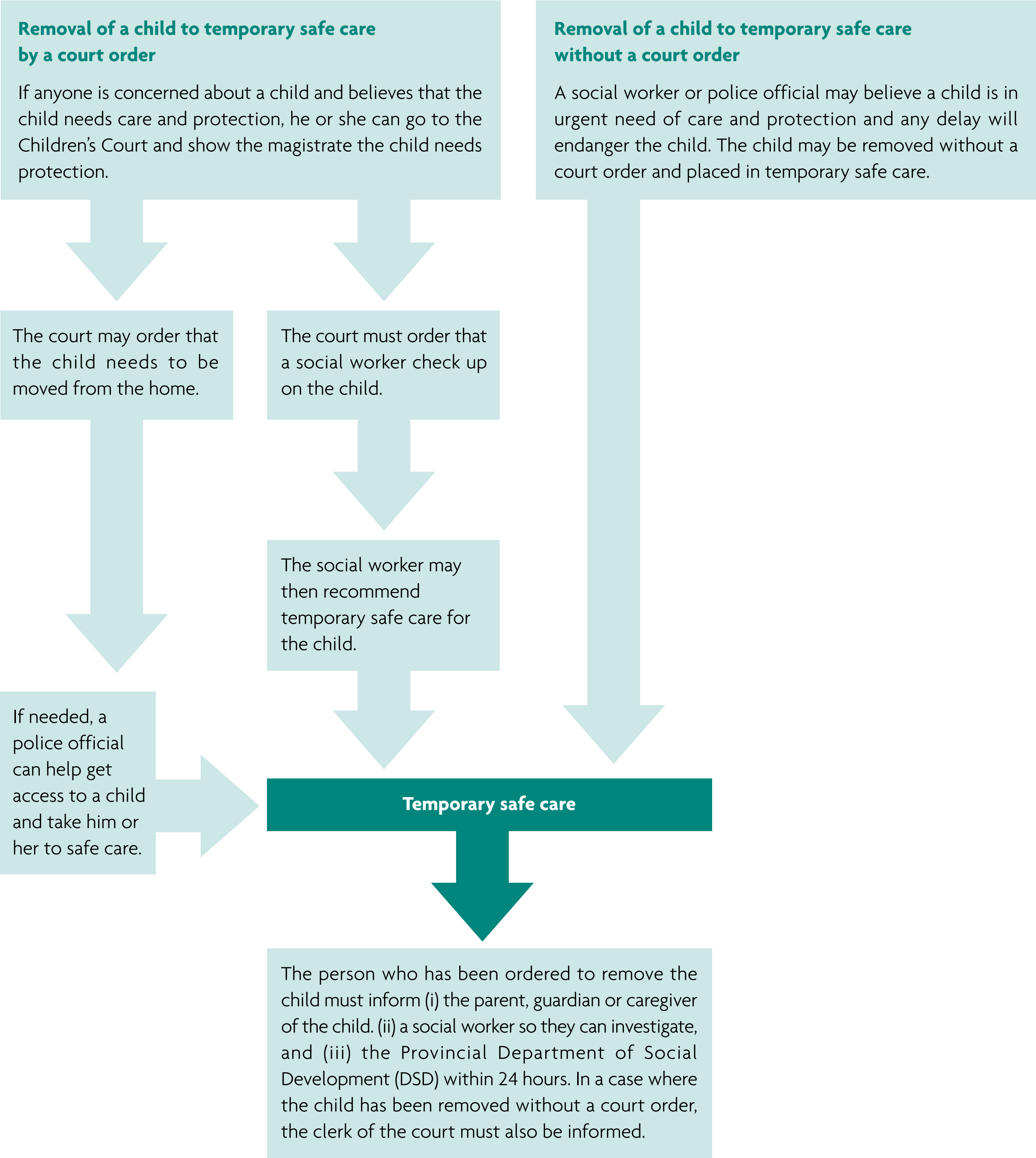
The statutory social worker is supposed to investigate. If its severe neglect/abuse, and it is an emergency, she can remove a child/children with a Form 36. It's a crisis intervention, and the child is removed to an alternative place of safety either with a family who have been screened first or to a Place of Safety facility. And then the social worker takes the case to the Children's Court Commissioner, saying this is why the child was removed, now it needs to be investigated. Then she's got 3 months in which to investigate. Then she returns to Court to say: Now this is what I assessed.

Please Note: *Form 36 (authority to remove a child) can be completed by social workers or police officers. As far as travelling in a car with a child is concerned, the organisation should ensure that the child's guardian has signed an indemnity form; this will indemnify anyone within the organisation who is transporting children.*

PROTECTION OF CHILDREN FROM HARM

Removal of a child to temporary safe care with or without a court order

Section 151 and 152 of the Children's Act (The Children's Act explained, Unicef/DSD)



Removal of a child to temporary safe care by a court order

If anyone is concerned about a child and believes that the child needs care and protection, he or she can go to the Children's Court and show the magistrate the child needs protection.

Removal of a child to temporary safe care without a court order

A social worker or police official may believe a child is in urgent need of care and protection and any delay will endanger the child. The child may be removed without a court order and placed in temporary safe care.

The court may order that the child needs to be moved from the home.

The court must order that a social worker check up on the child.

The social worker may then recommend temporary safe care for the child.

If needed, a police official can help get access to a child and take him or her to safe care.

Temporary safe care

The person who has been ordered to remove the child must inform (i) the parent, guardian or caregiver of the child. (ii) a social worker so they can investigate, and (iii) the Provincial Department of Social Development (DSD) within 24 hours. In a case where the child has been removed without a court order, the clerk of the court must also be informed.

The National Child Protection Register

Section 111 to Section 128 of the Children's Act 2005 sets out direction for the establishment of a National Child Protection Register to ensure that all reports and convictions regarding the abuse and neglect of a child are recorded.

Part A is a record of all reports and convictions of persons abusing or deliberately neglecting a child, and all findings by a Children's Court regarding an abused or neglected child.

In terms of Section 115 only the Director-General and officials of the designated department have access to Part A of the Register.

Part B is a record of all persons who are unsuitable to work with children. As a result, certain persons such as managers in recognised organisations can access Part B of the Register.

Part B includes information about people who are not allowed to work with children as a result of a conviction of a crime such as murder, rape or indecent assault against a child or an accusation of these crimes without a conviction, due to mental illness or when an official forum has made a decision to say that such a person is not suitable to work with children.

Police clearance of staff and volunteers working directly with children

There are two reasons for police checks and clearance:

1. Any NPO not acting according to the law, when employing a person who will work with children, could jeopardise their organisation by not undertaking the necessary investigations. If a child is molested or physically abused and this employee has a history of abusing children, this could lead to legal action being taken against the hospice.
2. Doing proper screening of staff working directly with children, is one of the measures which we could use in the prevention of abuse of children on our programmes by staff/volunteers.

The law states that you have to screen staff working directly with children.

There are two Acts that refer to the importance of screening prospective staff.

1) Sexual Offences and Related Matters Amendment Act 2007, chapter 6 section 40-53

2) Children's Act 38 of 2005.

This means there are two registers that exist at the moment which results in some confusion. For the purposes of this chapter, we have focused on the Children's Act.

In terms of the Child Protection Register as found in the Children's Act, the procedure to follow according to the Department of Social Development (as at 6 Dec 2011) is that all staff who have access to children, voluntary or permanent, need to be screened against the Child Protection Register.

This means that all professional staff such as doctors, nurses, teachers, social workers affiliated to their professional bodies, still require a clearance certificate, in terms of the law, to work directly with children.

An individual can ask for this information using Form 30 and they are not obliged to reveal the outcome, or the Employer can do so, using Form 29. Organisational requests should be on an authentic letterhead. Together with copies of their letter, the employer should include a certified Identity document of the employee.

Requests should be sent to:

Mr Selema Mashiane, Child Protection Register, Dept of Social Development, Private Bag X901, Pretoria, 00012 , and marked as confidential. Currently there is a six month backlog on response time.

Topic
for discussion

Whilst the Child Protection Register is in the process of being set up, there are certain procedures that could be followed by organisations such as hospice.

Discuss the advantages of following these procedures:

PROCEDURE A - Provide the SAP with a list of staff members' names and their IDs. This means you could get a general letter from the SAP clearing the staff members or a certificate for each individual.

PROCEDURE B - When a person applies for a job working directly with children, they would be responsible for providing their own police clearance at their own cost.

Think of other measures hospices can put in place to protect children. Remember that police clearance is not the ultimate solution against child abuse.

Please Note: Although professional staff such as doctors, nurses, teachers, social workers are accountable to their professional bodies for ethical conduct, they will also be required to obtain this clearance certificate if they will be working directly with children.

Notes

An overwhelming number of South African children live in extremely difficult circumstances. They experience poverty and inequality and many are exposed or subjected to violence, abuse, neglect or exploitation. Most children live with only one parent or in households headed by a grandparent. HIV/AIDS has added to the challenges faced by children and their families, communities and service providers. This has resulted in historically unprecedented numbers of children of all ages either requiring palliative care, and/or living with someone who is in need of palliative care.

Case Study 3

Benny was three years old when referred to a hospice programme by a hospital. He is an orphan, cared for by his maternal grandmother who is employed as a domestic worker, and living in a shack in an informal settlement area. Admitted to a children's in-patient unit with HIV-related disease, severe malnutrition, hearing loss from frequent and untreated ear infections, unable to speak or to eat solid food, he was also severely developmentally delayed.

Grandmother did not visit the child, despite frequent attempts by the hospice community nurse to get her to do so. She continued to receive the foster care grant.

Benny stayed in the in-patient unit for 15 months and developed a strong relationship with a hospice volunteer who was able to get the child to eat solid foods and obey simple instructions, and who expressed a desire to foster Benny. The volunteer also bought all Benny's clothes and toys and took him out for a day each week.

Despite her offer to foster him, the Department of Social Development felt it was in the best interest of the child for him to be returned to the grandmother. The hospice insisted that the grandmother receive training in giving ART before the placement, and expressed their concern, both verbally and in writing, to the Director that Benny would again be neglected by his grandmother.

On follow-up of Benny, it was found that his grandmother had left him alone in the shack, had not taken him for his follow-up visit to the ART clinic, and had not been giving Benny his ARVs. This was immediately reported to the Department of Social Development who have been slow to respond. The hospice and the volunteer have made frequent visits to Benny to ensure that he has clothes and food as well as a bed to sleep on and have taken the child for ART follow-up. Benny is now living with his caring volunteer, but the legal guardianship remains with his granny who continues to receive his foster care grant.

However, it must be noted that many grandmothers and elderly caregivers, strive to provide loving homes for these orphaned children, often at great personal cost.

Children in households headed by vulnerable people

Section 137 of the Children's Act as amended by the Children's Amendment Act 2007 legally recognises and makes provision for child-headed households. In terms of the Act a child-headed household is seen as a home where there are no adults present for a number of reasons.

Children with life-limiting conditions often live in households where the primary caregiver is also vulnerable. Hospices are required to assist in accessing support for children, elderly relatives or sick parents who may be unable to access social support, either through lack of knowledge, lack of finances or their own age or health status. Children in child only households may not be able to complete their own schooling as they need to find resources to assist them to care for the family, or may need to be at home to care for babies and very young children or sick parents. The child or the elderly person running a household may also lack the knowledge and skills to provide safe and effective care. Hospices need to provide training, and access special resources for them, such as cots and baby feeds; as well as access to education and grants. The Children's Act provides for mentoring of children in child only households. Palliative care workers play an important role in identifying such children and ensuring either mentoring or effective referral for such mentoring, and other support.

Also see chapter 6 for advice on accessing grants for children, and the elderly and how to apply for exemption from school fees.

Non-compliance with ARV regime

A social worker from a hospital reports:

But how many times have the parents come to the hospital and said: "We've had enough, we can't carry on like this, so we have decided to stop the ARVs. Do you know how much money it costs to come to the hospital, how much money it costs to go to the clinic to fetch the medication?" There are monetary reasons that they decide the child must die. And the child comes into the hospital acutely ill and dies. And we are seeing this very often and nothing gets done about it, because you can stop your child's medication. Now you have a difficult decision – do you remove the child who has a strong bond with parents and family so they suffer emotional harm? Or do you allow the child to stay and at least they will die with parents and family around? And these children are often too young to make this decision themselves. Often the parents don't decide to not comply, they are just not responsible enough to be compliant.

Non-compliance and hospice training on compliance

A social worker at Cotlands reports:

" We found that where children have been removed due to non-compliance, and referred from DOTS clinics and hospitals, we give that compliance training to the parents. Often we find the parents say afterwards that for the first time they understand so it has helped. Often the counsellors at clinics and hospitals don't do the training properly but often if we do it, it makes a big difference. We see this when we follow up with the HBC afterwards. If there is a problem again, they do training again. If we do training and we see really it's not working, then we will refer for alternative placement, but that's the minority.

Our training takes a few hours and we give information about HIV, about ARVs, about compliance, about immunizations, about hygiene, about stimulation, the whole care of the child, infection-control, symptoms and side-effects of ARVs."

The photo above is of Zinhle at the time she was admitted to Bambano Baby Sanctuary, Wychwood near Germiston. The photo below shows Zinhle again and she is now at home with her family.

Notes

Hospices are often ideally placed to raise awareness of the needs of children for whom they care. However, as they have no legal standing to remove children or to place them in foster care (apart from hospice social workers using a Form 36 for temporary Place of Safety placement - *see above flow chart*). Hospices are dependent on the actions of government services or other authorised organisations such as Child and Family Welfare agencies, who are often dealing with a huge backlog of cases. Once children are placed in hospice in-patient units for holistic care and nutritional therapy, they often improve dramatically, leaving the hospice as physically healthy children without suitable care in the community. Decisions concerning guardianship also place hospices in a vulnerable position when acquiring consent for admission to hospice programmes and treatment. This has led to children's in-patient units also having to register as Child and Youth Care centres, resulting in these hospices carrying out a responsibility other than palliative care. (Cotlands Hospice is a registered Place of Safety. It admits children from 0-6 years to the In-patient Unit and children from 0-12 years are visited by the home-based care team at home)

What do you do if you have a child in need of care?

If this issue is not within your area of expertise, contact an established child care programme in your region, to ensure that the best interests of the child are met.

What do you do if you have a child in need of care, and there is no responsible adult, and you don't know who the guardian is? Do you just leave them?

This hospice social worker responded:

No, you phone them (DSD) every week, you don't have a choice, you phone their supervisor. Phone the next person. It's hard work getting things done. A lot of people don't follow up. They refer and don't follow up, I don't believe in that, because a child is suffering. So I will follow up and follow up and follow up, and go and see them, and follow up again. Sometimes I do the work myself, write the whole report, and just get them to finalise with the Court, please sign here. Because it's about the best interests of the child. Most organizations just refer and then forget. Those kids get lost, that's the reality.

What do you do when you find a problem, and nothing seems to be happening?

Step 1

Escalate the referral of the child at risk to:

- Supervisors, Managers and Directors.
- Note and follow up every communication
- Forge closer relationships with local district level statutory social workers.

- Invite them to hospice training days, hospice meetings and events.
- Make personal contacts so reports of children at risk can take priority.

Step 2

Alert the local Magistrate who is also the Presiding Officer of the Children's Court and known as Commissioners of Child Welfare in the Children's Court. Magistrates need to know there are children at risk who are neglected. How?

- Ring the local Magistrate's Court and speak to the Clerk of the Court.
- Explain the problem and where the problem is in their geographical area.

If these relationships with local role-players are not bearing fruit, two further steps are suggested.

Don't remain silent!

Step 3

Contact the local branch of the Legal Aid Board, children at risk may be from indigent families, and legal aid is available. The role of Legal Aid Board is to facilitate the relationship between hospice and the statutory social worker on a case-by-case basis.

Step 4

If the process of referrals of individual cases is not successful, legal advice should be sought on the systemic problems, with a view to litigation of the issues.

A lawyer suggests:

To enhance the protection of children:

- network with all relevant organisations in your area.
- Don't rely on the legal system which is overburdened and slow.
- Explore other alternatives.
- Develop a strong network of like-minded people and organisations.
- Invite participation in the network from strong child advocacy organisations to help keep you up-to-date on children's rights.
- Include this network as part of your developing relations with the statutory bodies for children.

Don't remain silent!

If there is a decision of the Children's Court that you don't agree with:

- Fight the decision you don't agree with.
- Find someone who can represent the child.
- Contact your network of like-minded people and organisations. They may have links to lawyers who are passionate about children's rights.
- Appeal the decision.
- By contacting the network, you can get both the lawyers and the network involved. The collective voice is very powerful.
- Refer to the Public Prosecutor. See contact details under Resources, where the role of this public body is explained.

Talk to the child

"The best interest of the child means that the child comes first, so you have to talk to the child."

Case Study

In the story of Yandelwa Matiwane, who was 17 at the time, the importance of listening to the child is clear.

...We never spoke about my illness with my parents. They avoided the subject. I remember the day I think the doctor must have told them [my parents] the cancer was beyond being cured. When they returned, my mother couldn't look me in the eye, She was crying and when I wanted to know what the doctor had said, my father said he had told him that he could take me home for Christmas. I was very upset and angry because I knew that the doctor had said something other than that. I started crying too and I just wished someone would tell me the truth! I knew that I was going to die...

The palliative care team kept in touch with my mother and me. I liked receiving calls just to find out how I am and what I was up to. This made me forget how sick I was. In March 2011 my illness took a turn for the worse. I went to the Eastern Cape to attend a traditional ceremony but at this time I wanted so much to go back home to Cape Town. This is the time that I saw for myself what role the palliative care team played. They phoned my aunt, doctors, nurses and everyone who was around me and all the time they were making sure that I did not have pain. They made arrangements for me to be transferred from one hospital to a better one. My mom arrived at that stage and I was very relieved. The palliative care team contacted my father and spoke about my wish to return to Cape Town. It was a relief to be back in Cape Town on 23 May 2011. At this stage I did not want any visitors except my immediate and extended family.

Yandelwa's story is taken from "Touching Rainbows – Acknowledging the Child's Voice in Palliative Care" Published by the International Children's Palliative Care Network 2011

Notes

CHILDREN AND INHERITANCE

South African law provides some protection for children's inheritance in a situation in which someone has not left a will. However in practice this law is not able to protect all children. A combination of factors dispossess children: lack of awareness of children's legal rights, the complexities of the legal system and little knowledge about the law of succession and important role that the Master's office plays in winding up deceased estates. In addition there is often a conflict of interest between the relatives who may, as legal guardians, feel entitled to the deceased's property and the heirs who have a right to the property. The customary law of inheritance has also recently changed with the introduction of a new act called the Reform of Customary Law of Succession and Regulation of Related Matters Act 2009. Not many communities which are directly affected are aware of the change in the law (Colgan, 2007).

Refer to Chapter 12 on Dying and the Law for further information.

Non-South African children

Not all children in South Africa are South African citizens.

Refer to Chapter 10 for guidance on dealing with Marginalised Groups.

The Bibliography on the next page lists useful guidance on the Children's Act and in addition refer to:

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CONCLUSION

POINTS TO REMEMBER

- Palliative care for children, including neonates and adolescents, may be provided over many years and includes a wide range of conditions often not found in adults.
- A children's rights approach underlies effective paediatric palliative care policy, programming and practice. These rights must be based on an understanding of child development and the best interests of the child.
- Where appropriate, children should be involved as partners in their own palliative care.
- Children and their caregivers need more information and support in accessing their right to health, education and social support, including birth registration, early childhood development programmes, schooling, grants, social and psychological services.
- Pain, discomfort and suffering in children of all ages can be relieved.
- Early diagnosis and treatment of children for disabilities, and chronic, life-limiting illnesses and conditions can make a significant difference to a child's quality of life.
- It is the responsibility of all professionals, including healthcare workers to identify children at risk for harm and in need of protection from violence, abuse, neglect, exploitation, poverty, and stigma.

It is important to learn about, use, monitor and support existing legislation and plans such as the Children's Act and the National Strategic Plan.

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"You and Your Child with HIV Living Positively" by Noreen Ramsden, Children's Rights Centre, 2007. www.crc-sa.co.za

Relevant Legislation

The Children's Act No. 38 of 2005 as amended by the Children's Amendment Act 41 of 2007 and the corresponding regulations came into effect as of 1 April 2010. See www.ci.org.za for a copy of the Act and its Regulations, and Note 17 at section 150(1)(o) which provides that a child is in need of care and protection if, the child has been abandoned or orphaned and is without any visible means of support.

CHAPTER

9

Palliative Care for Older Persons

INTRODUCTION

Notes

"The human race is characterized by a long childhood and by a long old age. Throughout history this has enabled older persons to educate the younger and pass on values to them; this role has ensured man's survival and progress. The presence of the elderly in the family home, the neighbourhood and in all forms of social life still teaches an irreplaceable lesson to humanity. Not only by his life, but indeed by his death, the older person teaches us all a lesson. Through grief the survivors come to understand that the dead do continue to participate in the human community by the results of their labour, the works and institutions they leave behind and the memory of their words and deeds. This may encourage us to regard our own death with greater serenity and to grow fully aware of the responsibilities towards future generations."

(Extract from the Vienna International Plan of Action on Ageing 1982)

It is important that social policies recognise ageing as an integral part of human life and development. This implies that the specific needs of older persons should not be denied or ignored.

This chapter will focus both on the needs of the elderly caregiver and on the needs of older persons requiring palliative care.

Terms you will find in this chapter

Anecdotal evidence: based on the account of someone, not on scientific evidence or direct experience

Autonomy: respecting the right for people to make their own personal informed decisions

Collaboration: working together with one or more people to achieve a goal

Cumulative negative effect: the increasing and stronger effect of successive negative occurrences

Custody: the legal right to look after a child

Derealisation: A feeling of disconnection from the world around you.

Disenfranchisement: to deprive a person of the right to vote, but in this chapter, the right to grieve

Intra-familial: relationships within the family

Misconception: a mistaken view resulting from a misunderstanding

Phenomenon: something that is out of the ordinary and creates interest and curiosity

Proactive: acting rather than reacting to events – taking the initiative

PALLIATIVE CARE FOR THE OLDER PERSON

Significant linkages exist between palliative care and geriatrics e.g.:

- frailty syndrome
- elderly cancer
- neurodegenerative disorders
- end-stage organ failure
- elderly with chronic pain
- the bereaved elderly

As Lo and Woo (2006) note:

> Both palliative care and geriatrics focus on patient-centred holistic care, emphasizing quality of life, adding life to days when days can no longer be added to life. Both specialities take a patient-centred rather than an organ-based approach, carefully considering the benefits and burdens of intervention and treatment in advanced disease and age... Both geriatricians and palliative-care physicians attend to families' needs, e.g. ameliorating bereavement and stress associated with caregiving for the demented and the terminally ill... Older people are [also] more likely to face bereavement, for which counselling and support should be available.

Many areas of palliative care for the elderly are yet to be explored, such as their attitudes toward their own death; their reactions to the death of others; the meaning and impact of multiple deaths; and the bereavement coping styles of older persons.

It is difficult to predict the timing of death or the quality of life at the end of life for people with chronic or terminal illness. Moss, Moss and Hansson (201: 249) state that terminal decline in cancer tends to be relatively predictable, but fewer than one fourth of older persons die of cancer. Most people die from other chronic diseases which are not as predictable. The approaching death of an older person is often viewed as a normal process of life; emotions attached to this process may be overlooked and the grief of the dying person, family or friends disenfranchised. In this way the right of the older person to die with dignity and the rights of loved ones to grieve the death of the deceased may not be upheld.

Pain experienced by older persons

Using Dame Cicely Saunders' concept, the potential components of 'total pain' experienced by the aged are shown in Table 1.

Table 1: Potential components of total pain in elders *(different components may overlap)*

Physical Pain	Psychological Pain	Social Pain	Spiritual/existential Pain
Pain from cancer	Worry	Poor living conditions	Indignity
Pain from metastases	Anxiety	Financial Hardship	Meaning of suffering
Pain from treatment	Fear	Inadequate communication	Meaning of life
Pain from joints	Negativity	Inadequate information	Purpose of life
Pain from trauma	Low self-esteem	Loneliness	Value of life
Pain from wound	Despair	Isolation	Sanctity of life
Pain from sores	Depression	Neglect	
Pain from immobility	Demoralisation	Abuse	
Pain from poor oral/ dental hygiene	Derealisation	Burden on family/carers	
		Family disharmony	
		Discharge placement	

RIGHTS OF OLDER PERSONS

Notes

There is a growing recognition globally of the need to establish closer links between palliative care and older persons.

The theme for the 2007 World Hospice and Palliative Care Conference was *Across the Ages: From children to older persons*, emphasising that people of all ages need access to hospice and palliative care, either as:

- patients
- family members
- informal carers of people facing progressive, life-limiting illness

Rights of Older persons

The Older Persons Act, No 13 of 2006 and the Constitution of South Africa constitute some of the guidelines regarding the rights of older persons. The aim of the Older Persons Act is to:

> "deal effectively with the plight of the older persons by establishing a framework aimed at the empowerment and protection of older persons and at the promotion and maintenance of their status, right, well-being, safety and security; and to provide for matters connected therewith."

National Action Plan

This is South Africa's National Action Plan For the Protection and Promotion of Human Rights (NAP). It was lodged with the United Nations on 10 December 1998, International Human Rights Day and on 50th Anniversary of The Universal Declaration of Human Rights.

The National Action Plan (NAP) is a national initiative, whereby the South African Government responded to the call for a detailed policy and legislative programme to realise the fundamental rights and freedoms enshrined in the Constitution. The NAP affirms that no one shall be unfairly discriminated against on the basis of age. The NAP also refers to the right of access to justice, and as a result, the Department of Justice ensures that courts are made more accessible for older people (Justice Vision 2000). The older persons are also protected under the Right of Access to Health Care Services. The NAP encourages the following to be addressed at provincial level:

- Providing adequate state funding
- Establishing homes and frail care centres
- Providing funding for home-based care
- Improving the quality of care in homes and frail care centres.

South Africa is a member of the United Nations and has adopted the UN principles for older persons (UN Resolution 46/91). The authors have added some suggestions on how palliative care may be able to contribute to these principles.

UN Principles (UN Resolution 46/91)

PRINCIPLE OF INDEPENDENCE

The UN stipulates that older persons should have access to adequate food, water, shelter, clothing and health care through the provision of income, family support and community support and self-help.

Older persons should have the opportunity to work or have access to other income-generating opportunities.

Older persons should be able to participate in determining when, and at what pace, withdrawal from the labour force takes place.

Older persons should have access to appropriate educational and training programmes.

Older persons should be able to live in environments that are safe and adaptable to personal preferences and changing capacities.

Older persons should be able to reside at home for as long as possible

PRINCIPLE OF PARTICIPATION

Older persons should remain integrated in society, participate actively in the formulation and implementation of policies that directly affect their well-being and share their knowledge and skills with younger generations.

Older persons should be able to seek and develop opportunities for service as volunteers in positions appropriate to their interest and capabilities.

Older persons should be able to form movements or associations of older persons.

How can palliative care assist?

Palliative caregivers assist by identifying the needs of the elderly and providing resources to a certain extent and within the means of the relevant Hospice.

A well known hospice in the Eastern Cape directs its training and education efforts via Grandmother and Teenager support groups in areas served by the hospice.

Older persons in the employ of Palliative Care Organisations should be included in this decision-making process.

Palliative care training programmes are a means of empowering the healthy elderly to become involved in care-giving in the community and to advocate for palliative care amongst all population groups.

Palliative care assists patients with all aspects of their well-being including adjustments to their environment.

The wish of the dying older person to die at home should be respected by palliative caregivers.

Palliative care aims to include patients and clients in all decisions relating to their care and to keep them within their community wherever possible.

Palliative care organisations offer volunteer work for the retired and elderly.

Hospice patients often benefit from having their own groups, facilitated by a social worker, where they can discuss concerns, share information and allow friendships to develop. Where there is acceptance, the group can become a community of care.

UN Principles (UN Resolution 46/91)

How can palliative care assist?

PRINCIPLE OF SELF-FULFILMENT

Older persons should be able to pursue opportunities for the full development of their potential, even when they have been diagnosed with a terminal illness.

Older persons should have access to the educational, spiritual, and recreational resources of society.

Palliative care will enhance the quality of life, and will also positively influence the course of illness.

The goal of palliative care is quality of life. A quality of life assessment usually looks at four domains: physical, social, emotional (psychological) and spiritual (existential).

PRINCIPLE OF DIGNITY

Older persons should be able to live in dignity and security and be free of exploitation and physical and mental abuse.

Older persons should be treated fairly regardless of age, gender, racial or ethnic background, disability or other status, and be valued independently of their economic contribution.

Palliative care offers patient-centred care, honest communication with the patient, respect, mutual agreement of goals of care and treatment options.

Hospice has a philosophy of care that believes every person with a life-threatening condition has a right to quality of life and dignity in death.

PRINCIPLE OF CARE

Older persons should have access to health care to help them to maintain or regain an optimum level of physical, mental and emotional well-being and to prevent or delay the onset of illness.

Older persons should benefit from family and community care and protection in accordance with each society's system of cultural values.

Older persons should be able to utilise an appropriate level of institutional care providing protection, rehabilitation and social and mental stimulation in a humane and secure environment.

Older persons should have access to social and legal services to enhance their autonomy, protection and care.

Older persons should be able to enjoy human rights and fundamental freedoms when residing in any shelter, care or treatment facility. These should include full respect for their dignity, beliefs, needs, privacy and the right to make decisions about their care and the quality of their lives.

In palliative care the unit of care is the patient and family. The care offered is patient-centred care, with mutual agreement on goals of care. The family's views are important but should not supersede the patient's wishes.

Older people, because they are reaching the end of their lives, and at times are perceived to be of less value to society, are one of the most neglected groups in South Africa in terms of rights and care. The responsibilities of older women, with regard to caring for others, are increasing when they should be decreasing. The role of older women is changing from being grandmothers to be cared for, to becoming 'mothers' again who have to care for orphaned and vulnerable children, often without the financial and emotional support they need.

The Older Person's Act No 13 of 2006 states that a woman is an older person at the age of 60, whereas a man is an older person at the age of 65. However, both men and women can access an Older Person's grant at the age of 60 (see chapter 6) so are treated equally in this respect.

This chapter discusses key issues facing older persons in South Africa, which are often made worse by the burden of disease. The case study of a grandmother living in a township illustrates how HIV/AIDS, poverty and family pressures affect the way in which she is able to cope with all that she has to do each day, by virtue of being the head of her household. Her situation is not uncommon, with aspects of her life being shared by many other older people living in poverty.

The current environment in South Africa is overshadowed by the devastating effects that the HIV/AIDS epidemic is having on the lives of families. Coupled with the sickness and death of younger people, poverty, crime, elder abuse and lack of education, older people have to find ways of meeting the challenges that face them every day. The effect of the AIDS pandemic in South Africa is such that the burden of care of orphans falls on older people. There is not sufficient acknowledgement of this phenomenon, nor sufficient attention to developing the capacity of older persons and supporting their efforts. Universal recognition that the future of South Africa is in the hands of older people has not taken place and consequently much more emphasis needs to be put on their needs.

Some of the difficulties facing older caregivers are illustrated in the story of Nonnie's life and her story is serialised through this chapter.

Case Study Nonnie Part 1

Nonnie grew up in rural Eastern Cape and had three daughters. In 1970 when she was 31 and her husband died, she moved to Cape Town. She got a job as a domestic worker and was the main breadwinner. She had two more daughters while living in the Cape.

Nonnie owns a one-bedroomed home in Khayelitsha where she cares for her youngest daughter, Priscilla, who at age 26 has end-stage AIDS. In 2002 Priscilla was diagnosed as being HIV+ when she gave birth to her first son. Nonnie looked after the little boy until his father stepped in.

Nonnie is now 69 years and no longer working. She has fourteen grandchildren, five of whom have died. She has a five year old grandchild with AIDS and a newborn baby grandchild with TB, who is also HIV positive. Both these children and their mother, Priscilla, live with Nonnie.

Questions for training groups:

- Identify some of Nonnie's possible problems
- What questions would you ask Nonnie and Priscilla if you were Priscilla's Home-based Caregiver?

Refer to the end of this chapter where you will find the answers

Notes

Notes

Case Study Nonnie Part 2

Nonnie's fourth daughter, Mary, died in 1998 at the age of 21. At that time Nonnie did not know where to turn in her grief and also did not dare to talk to anyone about the "mysterious illness" that had caused her daughter's death, for fear of what the community might think and might do to her. She became depressed and isolated from her circle of support, her neighbours and fellow church members.

Group discussion

- What feelings do you think Nonnie may be experiencing?
- What is she thinking?
- What does she do?
- As a caregiver, how could you help her?

The death of an elderly parent is to some extent expected by the younger generation, although it may still be feared. There is, however, the anticipation that the parent will die before the child and not that the child will pre-decease the parent.

Nonnie's grief is disenfranchised or disallowed by others (family, neighbours, church) because of the stigma of HIV/AIDS.

A helpful approach by the visiting caregiver would be to sit down with Nonnie and Priscilla and listen to whatever concerns they wish to share.

Old age is a time of multiple and sequential losses, thus exposing the elderly to the risk of bereavement overload and a cumulative negative effect. It is a regular occurrence that people view the older person's normal responses to bereavement, such as fatigue, social withdrawal and confusion, as problems of old age. Loss of siblings, spouses, parents and grandchildren have particular meaning for older persons and should certainly be addressed in bereavement programmes.

Case Study Nonnie Part 3

Towards the end of every month money runs out in Nonnie's household and there is no food in the house. In order for Lindiwe, her 5 year old grandson, to take his medication for AIDS, a neighbour provides a bowl of porridge for him before he sets off for preschool. Nonnie's response to the lack of food in the house was to say "God will provide".

So, in all, Nonnie cares for Priscilla who has AIDS, Lindiwe with AIDS, and the newborn baby will live with her as well, if the baby survives. Nonnie receives a state pension. Two of her daughters occasionally bring her gifts of food, but they too live in a state of poverty. Nonnie is nursing Priscilla as she is desperately ill and close to death. A home-based caregiver, under the supervision of a professional nurse, visits Priscilla on a weekly basis.

Nonnie has the following concerns:

a) She finds it difficult to forgive Priscilla for her promiscuous life which has caused so much suffering.

b) She also worries that she will die before her grandson and does not know who will take care of him after her death.

c) In 2007, on the way to her sister's funeral in the Eastern Cape, Nonnie was involved in a bus accident. When she arrived back home she was unable to walk. Friends and neighbours, from GAPA (The NGO, 'Grandmothers Against Poverty and Aids), helped where they could, doing the washing, fetching chronic medication and housework. Today Nonnie walks with difficulty and also suffers from cardiac disease and hypertension.

Question for group discussion

What assistance does Nonnie need now?
Discuss what assistance Nonnie needs in terms of issues: a) b) and c)

AIDS is referred to as "the grandmothers' disease", because elderly women so often assume the role of caregivers, tending for their dying son or daughter, and then the children left behind (Kelso in Alpaslan & Mabutho, 2005: 283).

The impact of the AIDS epidemic extends well beyond persons with HIV or AIDS. Most adults who die of AIDS have parents who survive them, who are affected in several ways by the illness and the death. "Since adults with AIDS are typically in their 20's and 30's, their parents tend to be in their 50's, 60's and 70's, and they constitute a substantial population of older persons who are directly impacted by the epidemic." (Knodel & Van Landingham, 2002:77)

The UN AIDS Report 2010 states that treatment scale-up is saving lives: between 2004 and 2009, AIDS-related deaths decreased by 20% in sub-Saharan Africa. However the death of the parents places an immense burden on the shoulders of the grandmothers, predominantly, as they become the primary caregivers, often without financial and emotional resources. In addition the grandmother often has to take care of the children from more than one household, when more than one of her own children die of AIDS-related illnesses. The grandmother thus has to cope with her own multiple losses, as well as caring for grieving and often infected, children. She has to prepare herself emotionally for perhaps losing and grieving for these grandchildren eventually as well. She finds herself in a constant grieving environment.

Research into the plight of grandmother-headed households living on the Cape Flats in 2000, showed that grandmothers were ill equipped to deal with the effects of the AIDS epidemic (Ferreira, M. Keikelane, M. J. and Mosaval, J. 2001). Grandmothers found that they were faced with the deaths of their children and grandchildren after a relatively short period of progressive weakening, weight loss and being bedridden. Their normal channels of support such as neighbours, other family members and communities closed as everyone feared the possible consequences and stigma of being associated with the disease, the origin of which is clouded by misconceptions in many communities.

Grandmothers reported in the study that they were becoming poorer because of the additional costs of caring for a sick person; their pensions being now the only income for their households and their responsibilities for caring for grandchildren being now full time. Furthermore the grandmothers did not have any knowledge of HIV/AIDS and were powerless to begin to know how to care for their sick children and grandchildren.

Older people are considered to be the "keepers of the culture" and because of the huge expense of a culturally correct funeral, household income could drop considerably as grandmothers often borrow money from neighbours and friends to pay for the funerals of their children and grandchildren.

Grandchildren still at school relied on their grandparents' income to keep them at school after the death of their parents. Although there might be relief in some schools from paying fees, the children still need uniforms, pens, pencils, files, glue etc and still have to pay for outings or they are excluded. Children, below school going age, have to remain in their grandmother's care everyday, as there is no money to pay for crèche or preschool fees. Grandmothers found that they had no time for themselves, having to line up at hospitals and clinics from the very early hours of the morning with small children while they waited for their medication or doctor visits. No provision is made for the children or the older people at the hospitals.

The stress of loss of children to HIV/AIDS, lack of money, their own chronic illnesses, presence of small children all day and night, lack of understanding about the illness and lack of neighbourly support diminished the older people's sense of worth resulting in widespread depression and thoughts of suicide.

Grandmothers who foster children are faced with many challenges as shown below:

- Financial implications;
    - Limited or lack of income prevents grandmother caregivers from providing orphan's basic needs.
    - Poor support from Government
    - No/poor support from the children's fathers and the extended family
- Emotional strains resulting from negative community reactions towards the fostered grandchildren, or worries about the cost of childcare
- Physical strain and exhaustion resulting from taking care of infants and younger children, as well as from additional work required to cover the escalating cost incurred by taking care of the grandchildren.
- Elderly grandmother caregivers face the challenge that the AIDS orphans in their care often do not accept their authority.
- Reduced participation in social activities, due to the community's fear of including the infected children. Intra-familial relations may become strained in the event of conflict over custody, or if the grandparents judge other family members to be negligent about sharing responsibility.
- The grandmother's own health status
- Decreased opportunity to grieve

Rights of older caregivers

There are no specific rights, recognised in the Older Persons Bill 2006, for older persons who find themselves in a care-giving role. However, in order to afford older persons the right to remain in their communities for as long as possible, which is a clearly stated right, they should have access to support programmes. If they become frail while in a care-giving role, then provision should be made for home-based care.

It is common to discover that older people in South Africa suffer from low self-esteem and consequently feel that they are unable to think of solutions to problems concerning life choices. Often they are not proactive in seeking help outside their communities. The reason for this may be that they have spent most of their lives living under the apartheid system, when their movements, their educational opportunities, their access to health facilities and work opportunities were all controlled by the state. This system continuously eroded their sense of self-esteem, creativity and problem-solving ability.

Human Rights Education for older persons

Older people, when exposed to education on human rights, are encouraged to take a hard look at their lives. This reflection leads to the recognition that they have been disadvantaged. Furthermore, they realise that this previously enforced environment fostered feelings of lack of self-worth and helplessness. Once older persons recognise that they need not remain quiet or compliant, a large obstacle to their taking charge of their lives and demanding their human rights disappears.

Notes

Case Study Nonnie Part 4

Nonnie, encouraged by her two non-infected daughters, pays each month for a burial policy for herself, her daughter Priscilla and another HIV+ daughter, who is not yet sickly. The baby's funeral costs added up to R2 000. It is very important to her that burials are done in the correct manner and she is prepared to do without food in order to pay the premiums. She said that she has to pay "because our sons and daughters are careless – they don't care". It would be a "disgrace in the neighbourhood and rude if there is not a proper funeral."

Nonnie is worried about the fact that all the cemeteries in Khayelitsha are full and families have to go further and further away from their homes to find a burial plot. She has come to terms with the fact that she will have to be buried in Cape Town, rather than the Eastern Cape, because her family will not be able to afford to transport her body "home". Nevertheless all the other burial and funeral traditions have to be carried out according to custom.

For further information

GAPA
021 364 3138
& 021 361 8326 (Office)

You will also find contact details for GAPA under the Useful Contact Numbers in the Resources Section at the end of this book

Notes

Case Study Nonnie Part 5

In 2001 Nonnie heard about Grandmothers Against Poverty and AIDS – GAPA - in Khayelitsha where she met other grandmothers who had lost family members to AIDS. She received education about the disease and learned to cope with her emotions. In time she became a peer group leader, counselling and assisting other grandmothers to understand and cope with the results of the AIDS epidemic. Participation in the group meant that she and the group members had an outlet for their grief, and at the same time were able to earn extra money by making craft items which they sold.

AVAILABLE SUPPORT STRUCTURES FOR OLDER PEOPLE

Since 2001 - when a pilot project by the Albertina and Walter Sisulu Institute of Ageing in Africa at the University of Cape Town and a group of NGOs was run in Khayelitsha to educate grandmothers about HIV/AIDS and coping skills - worldwide interest has been awakened to the potential capacity of grandmothers to successfully step into the role of carers, mothers to orphans and educators of their communities.

Benefits of educational workshops

It was found that grandmothers, when taught in their own language, benefited greatly from educational workshops on a number of related subjects. The subjects were HIV/AIDS knowledge, home nursing, food gardening, human rights, bereavement and very basic business skills.

Benefits of Psychosocial groups

Furthermore, the formation of psychosocial groups where grieving grandmothers were counselled by their peers was very successful in curing depression and lessening stress levels. The manufacture of handicraft by the groups not only attracted grandmothers to the groups, but contributed to their self-esteem and the household income.

The important role that grandmothers have to play in the maintenance of family structures and their capability to run households has been recognised worldwide.

AVAILABLE SUPPORT STRUCTURES FOR OLDER PEOPLE IN SOUTH AFRICA

In South Africa, many organisations make provision for the education and support of the older population.

ACVV

In the Free State, the ACVV has organised grandmothers' groups.

Age in Action

A national body, operating in all provinces, with more than 800 NGOs caring for older persons. It can be accessed at www.age-in-action.co.za. Age in Action also promotes the training of older people about HIV/AIDS.

GAPA

In Cape Town, they are including older people in their training programmes.

Ikamvalabantu

In the Western Cape, they are including older people in their training programmes.

Muthandane Society for the Aged

In Kwazulu Natal, they are including older people in their training programmes.

Gender considerations

The role of caring often falls upon women's shoulders. Most older people and most of their carers are women, since women have a longer life-expectancy than men. Women are perceived as nurturers and in the event of an older man becoming ill, his wife will usually look after him at home. Caring is not seen as a male role and most men do not perceive themselves as having the skills for nursing. If the wife becomes ill, the husband may feel inadequate in the caring role. Often this means that women are admitted to a care home or to hospital rather than being cared for at home. In addition to the distress of being moved from home, there are financial implications for the cost of care.

It is also true that generally more men than women remarry after the death of their spouses. This, in addition to the longer life-expectancy of women, means that more elderly women are on their own than elderly men. In relationships where there was inequality or a sharp division of roles, such as the man paying the accounts, the woman, now on her own, may not have the skills to take on these tasks. Similarly, the man may not have learned how to cook and finds himself without the skills to produce a meal.

As described earlier in this chapter, the AIDS epidemic has impacted heavily on the elderly. Grandparents (usually the grandmother) often suffer the distress of caring for their adult children who are sick and may be dying, as well as caring for their grandchildren who are orphaned.

Elder Abuse

Elder abuse is a growing phenomenon worldwide and is emerging as a growing social problem. The responsibility for dealing with elder abuse is no longer a function of the Department of Social Development (South Africa) and has now become the responsibility of the community and other non-governmental sectors. The Department of Health took the lead and formed a committee for the Development of Elder Abuse Strategy in 1998. This was in collaboration with key departments and NGOs. The Department of Social Development, in the Older Persons Act of 2006, focused on the protection of older persons in the community and in residential facilities.

Older persons in need of care and protection are defined as follows:

- Older people who have their income, assets or old age grant taken from them against their wishes or suffer other forms of economic abuse.
- Older people who get removed from their property against their wishes or are unlawfully evicted from property.
- Older people who are neglected or abandoned without any visible means of support.
- Older people who live or work on the streets or beg for a living.
- Older people who abuse a substance or are addicted to it and are without any support or treatment for such substance abuse or addiction.
- Older people who live in circumstances likely to cause or be conducive to seduction, abduction or sexual exploitation.
- Older people who live in circumstances which may harm them physically or mentally.

Data on Elder abuse and neglect in South Africa are not collected systematically. An opinion poll done by the National Department of Health reported that there is a widespread awareness of abuse of older persons in South Africa. Concealment of abuse occurs due to the stigma attached to it and fear of victimisation. There is therefore a lack of accurate and current figures for the abuse and neglect of the elderly, and more specifically, elderly females, in South Africa.

When discussions are conducted with the patient about his/her wishes concerning the placement of minor children after death, assessment should be made of the grandmother's capacity to handle the additional responsibility.

It should not be assumed that she will be able to shoulder this burden.

Note: If you as an older person experience any of these issues, you can call on the Older Persons Act to support you.

For further information

Halt Elder Abuse (HEAL)
0800 00 3081

A telephonic help-line for older people who are being abused is manned by counsellors from the organisation, Halt Elder Abuse (HEAL). The line can also be used by the general public to report cases of abuse.

*You will also find HEAL's free-phone number at the end of this book under **Useful Contact Numbers**.*

What is Advance Care Planning?

It is the process of discussing and documenting a person's wishes for care in the event of their not being able to communicate this in the future. In this way, medical personnel can encourage patient self-determination by discussions with patients and their identified proxies' wishes for the future.

Also see Chapter 3 Ethical Issues for Advance Care Planning.

Notes

The profile of older persons who are likely to be abused and neglected is summarised by the National Strategy on Elder abuse as follows:

Older persons who:

- Are dependent on one person for all or part of their care
- Exhibit difficult or inappropriate behaviour, confusion or memory loss as a result of previous mental or psychological disturbances, or due to more recent conditions such as impairment through some kind of illness
- Have communication problems
- Have longstanding negative personality traits
- Have feelings of low self-esteem
- Have a background of conflict and tension
- Have limited social contact and networks

The above-mentioned profile is of vital importance in the palliative care environment, as it assists in the identification of the vulnerable elderly and in the approach towards care.

What should one do if there is abuse of an older person?

- It is the responsibility of all people to report cases of abuse. (Older Persons Act 2006)
- At a local level, abuse should be reported to a social worker or a police official.
- Abuse of older persons must be brought to the attention of the Director General of the Department of Social Development.

Some older people are cared for in the community while others are in care-homes, but may suffer serious neglect and lack of pain management. If a patient is not cared for properly, the family could sue the institution.

The Court, when considering the institution's duty of care, will decide what is a reasonable measure of care in the circumstances.

CONCLUSION

The worldwide role of older persons, as sources of accumulated knowledge and guardians of moral values, takes on new dimensions in South Africa. Many grandparents do not have the luxury of watching their children rearing their grandchildren, visiting them occasionally, helping out where needed and offering guidance or insights about family history.

The time has come when a number of older people have to take on the total responsibility of young families because their children have died from AIDS-related diseases. At the same time grandparents are themselves becoming frail due to age-related disease.

The challenges for grandparents in coping with all that comes their way cannot be met without the assistance of agencies that interact with older people. These agencies need to offer insight and information into human rights, education about HIV/AIDS, education on age-related diseases and psycho-social support for older people. The state-run agencies need to provide basic necessities of living such as housing, water, health and protection against abuse.

Case Study Answers to Nonnie - Part 1

What were some of Nonnie's possible problems?

- Finance
- At 69, Nonnie is an elderly caregiver to her daughter and grandchildren. Her energy will be limited.
- She may be grieving her daughter Priscilla's loss of health

The Home-based carer could ask the following:

- Does Nonnie have an Older Person's Grant?
- Does Priscilla receive a Disability Grant?
- Does Priscilla receive Child Support grants for her two children?

See Chapter 6 for further information about Social Grants.

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CHAPTER
10

Marginalised Groups

INTRODUCTION

Exercises for training purposes

Start the training session with a brainstorm/icebreaker on attitudes to marginalised groups, how people are treated according to the label they are given.

Ask participants to share personal stories of being marginalised, as this will make the plight of marginalised groups more real.

This chapter specifically addresses some of the barriers facing refugees, asylum seekers and migrants, sex workers, drug users, prisoners and sexual minority groups in accessing various forms of health care. Some of these groups have previously been stereotyped as being 'high risk groups' for HIV transmission and infection. It is such prejudice, along with other issues, that we need to tackle in order to ensure equitable access to health care in compliance with existing South African law. Another group of people who are being stigmatised and marginalised are those with multi drug-resistant or extensively drug-resistant TB.

Cross-border migrants face the additional challenge of xenophobia. In 2011, "xenophobia and incidences of xenophobic violence are not decreasing. Many of these incidents do not receive coverage in the mainstream media, and this creates the impression that xenophobia is no longer a problem. The truth is far from that... There is a pressing need for legislation specifically targeting hate speech and intolerance. This needs to be partnered with an active citizenry who are monitoring and reporting incidences and outbreaks of violence to the police, so that these criminal elements of our society are rooted out" (CoRMSA, 2011: 9).

Many healthcare workers may initially feel uncomfortable assisting some of the categories of people described in this chapter. These are categories of people who may experience prejudice on a number of fronts and it would not be uncommon for some healthcare workers to share such prejudices, including xenophobic sentiments. These groups may face severe challenges to their human rights regarding access to health care as well as other services. This chapter aims to help healthcare workers negotiate and challenge some of the prejudices experienced by these groups. In the case of those in prison, it is also important to note that they will be entirely dependent on prison officials to provide access to health care and hence can be additionally vulnerable for this reason.

The palliative care approach sees each person as unique, with their own needs and their own stories. Palliative care encourages an empathetic, non-judgmental approach to patient and family members. Palliative care practitioners assist patients to become active members of the care team and to make informed decisions about their health care as best fits their own context and need.

Terms you will find in this chapter

Asylum Seeker: someone who has fled from political oppression in their own country and is seeking protection in another country. In South Africa, asylum seekers are granted a Section 22 permit.

Cross-border migrant: somebody who has moved and crossed a border/borders.

Disempowering: to have power or influence taken away from you

Foreign national: somebody who does not have South African citizenship.

Incarceration: putting somebody in prison or a place of confinement

Marginalised groups: groups which are kept away/excluded from the centre of influence, power or acceptance

Migrants: people who move from one place to another, often for employment or economic improvement. This can include those who move within a country as well as those who cross borders.

MSM: men who have sex with men.

Non-national: somebody who does not have South African citizenship.

Post-exposure prophylaxis (PEP): a short, intense course of antiretroviral treatment to prevent potential infection following exposure to a risk of HIV infection eg after a sexual assault, needle-stick injury

Refugee: someone who has been granted asylum. In South Africa, refugees are granted a Section 24 permit.

Unaccompanied minor: Children who have arrived in South Africa without their parents

Undocumented migrant: somebody who does not currently possess the documentation required to be in the country legally.

Xenophobia: an intense fear or dislike of foreign people, their customs and culture

REFUGEES, ASYLUM SEEKERS AND MIGRANTS

Refugees

In South Africa, refugee status and the rights this provides are governed by the 1998 Refugees Act. Although this is a very progressive piece of legislation, there are still many challenges in implementing all the measures it provides for. The Department of Home Affairs (DHA) determines who qualifies for refugee status and issues and renews the documents provided to refugees. It is well documented that the DHA has experienced many challenges in issuing documents to South African citizens, and those applying for refugee status face even more extensive delays.

The Refugees Act 130 of 1998

In terms of the Refugees Act, to be granted refugee status is to be given the right to remain in the country and to have the protection of the South African government.

Refugee status also provides for most of the rights granted to South African citizens, such as the right to work, study, access health care and have freedom of movement in accordance with the Bill of Rights. The key right refugees are not granted, is the right to vote. Refugees are also not entitled to receive a social grant until they have received refugee status. (See Chapter 6: Poverty and Social Development.) Refugees are now entitled to claim a Disability Grant and parents or guardians of disabled children may apply for a Care Dependency Grant. If refugees are foster parents in South Africa they may claim the Foster Care Grant.

The Refugees Act provides refugee status for someone who can demonstrate "a well founded fear of persecution" in his or her own country and could not rely on the protection of his/her own government. This persecution is usually due to factors such as race, ethnicity, nationality, religion, political opinion or membership of a particular social or gender group. A person can also be granted refugee status if there is war or a similar generalised threat affecting the whole or the specific part of the country where they were based. A person with refugee status will be issued with a Section 24 permit and can apply for a refugee ID.

Asylum Seekers

A person who has applied for refugee status, but has not yet had his or her application finalised, is called an 'asylum seeker'. Although the law states that the process of applying for refugee status should be a rapid one, in practice it takes a long time. Many people wait for a number of years before being told whether their applications have been approved or rejected. In the meantime, asylum seekers are allowed to work and study as well as access health care. Asylum seekers will be issued with a 'Section 22 permit'.

Renewal of documents

Whilst both refugee and asylum seekers' documents have expiry dates, the recent expiration of such a document should not be reason to deny a refugee or asylum seeker access to the services to which they are legally entitled. Refugees and asylum seekers are required to renew their documents at the Refugee Reception Offices run by the DHA. However, the challenges faced by the DHA mean that no one is guaranteed access to a Refugee Reception Office on any given day, and therefore it is likely that documents may expire before the bearer is given the chance to renew them. Because of these challenges, many foreign nationals in South Africa remain without documents, or are in possession of expired documentation.

Because a person does not have valid documents to be in South Africa does not mean that he or she is not deserving of refugee status. Many are forced to become self-reliant, but service providers can assist them by helping to ensure their access to the services they provide.

For further information

A number of organisations who can assist foreigners in South Africa are listed in the Useful Contact List at the end of this book.

Attitudes to Marginalised Groups

When a person such as a drug user, sex worker or refugee arrives at a healthcare institution seeking assistance, some healthcare workers may be too quick to identify what they think are the real needs of the person, based on their assumptions about that person. The beliefs of the healthcare worker may be completely inaccurate. This may prevent the healthcare worker from actually hearing what it is the person is requesting. The process of delivering health care should be seen as a partnership between the person and the healthcare worker, in which both are able to provide input on the course of treatment to be followed. Should a person have additional needs - that are beyond the mandate of a healthcare worker - the healthcare worker should be able to provide an appropriate referral (for instance social work assistance, drug and alcohol rehabilitation).

In this way, no healthcare worker is dealing with such difficult issues in isolation. If a healthcare worker does not know the best advice to offer, such partnerships and referrals can be valuable in then being able to provide a service which is relevant to the particular need. At the same time, given the stresses healthcare workers face on a daily basis, a supportive network for possible referrals can reduce feelings of isolation. By working in partnership with other specialised professionals, stresses can be alleviated and healthcare workers can avoid 'burning out'.

Exercise

What do you think of the argument made here in Attitudes to Marginalised Groups?

Does this reflect your own practice? What else do you do when dealing with someone from a marginalised group?

FOREIGN CHILDREN

In giving effect to South Africa's obligations both nationally and internationally, the "best interests of the child" principle must be applied to all children regardless of their nationality.

Foreign children who are unaccompanied minors are protected by Section 150 and 151 in the Children's Act. This means that an unaccompanied minor who is at risk, can be removed to a temporary place of safety, using a form available from the police or a social worker.

Notes

Unaccompanied Minors

Adults who are in South Africa as foreigners fall under different categories:

- refugees
- asylum seekers
- migrants
- illegal immigrants

Children who have arrived in South Africa without their parents are known as 'unaccompanied minors' and face additional risks without the care of a guardian.

Unaccompanied minors can apply for refugee status

In terms of the law, unaccompanied minors may apply for refugee status in the same way that an adult may. In the same way then, the provisions for refugees and asylum seekers also apply to unaccompanied children. It is therefore evident that South African legislation and subsequent policies and directives have become more inclusive. No person who finds him/herself in the jurisdiction of the Republic is excluded from access to health care.

Whatever their status, all children living in South Africa, have basic rights and are protected by:

- international law
- regional agreements
- the South African Constitution
- national law

Government and service providers have a duty to fulfil children's rights to:

- protection,
- social services
- education
- and health care of which palliative care is an integral part

Any child who is a refugee, asylum seeker, unaccompanied minor or undocumented immigrant cannot be denied the right of:

- entry to school
- provision of social assistance
- health care including ARVs

What happens if a child from another country has no adult carer with them?

The Refugees Act 130 of 1998 points out that any child who has a refugee claim and is in need of care must be brought before the Children's Court. The Court will order that the child be assisted in applying for asylum, and places the child in a state-approved foster home in order to provide protection, care and financial assistance.

Case Study
Foreign Children

In the case of the Centre for Child Law v Minister of Home Affairs, 2005 a group of unaccompanied foreign children were being held in Lindela repatriation centre. The children were being detained along with adults at the centre and were facing imminent deportation. Deportation would be effected by loading the children into trucks and transferring them to trains, to go by train to their country's border and by truck again to the nearest police station in that country. The Centre for Child Law managed to prevent the Minister of Home Affairs deporting the children who were then moved to Dyambu Youth Centre pending a Children's Court enquiry.

The Department of Social Development (DSD) social workers did not act until, in a precedent-setting judgment of the High Court, Judge Annemarie de Vos ordered DSD to bring the children from Dyambu to the Children's Court for an enquiry into their circumstances, and to report within 15 days of her order.

The Court held that:

Persons within our territorial boundaries have the protection of our courts and the Constitution. The Court is upper guardian of all minors.

- All unaccompanied foreign children found in need of care should be dealt with in accordance with the provisions of the Children's Act (2005), which includes refugee children.
- If they are found to be in need of care, they must be brought before a Children's Court for an enquiry to be conducted into their circumstances.
- The South African government is directly responsible for providing for the socio-economic needs of unaccompanied foreign children in South Africa, including health and education.

The Judge pointed out that there was an ongoing responsibility of the State to provide these children with the rights and protection set out in Section 28 of the Bill of Rights of the Constitution. Amongst other rights, this section of the Constitution affords every child the right to basic nutrition, shelter, basic health care services and social services.

To summarise the judge's further remarks:
'I agree with the view held by Liebenberg that this suggests that the State is under a direct duty to ensure basic socio-economic provision for children who lack family care as do unaccompanied foreign children. There is thus an active duty on the State to provide those children with the rights and protection set out in Section 28.'
The judge is referring to Sandra Liebenberg writing in the Economic and Social Rights Review Sept 2004. Although it appears here that unaccompanied children have a right to claim direct material assistance, Professor Liebenberg states that:

'The current jurisprudence has not resolved whether children have a direct entitlement to the socio-economic services in section 28(1)(c)

Rights of Adults are different to children

Note that the rights of adults are different to the rights of children.

For adults the Constitution states:

Section 27 (1) Everyone has the right **to have access to**

(a) healthcare services

(b) sufficient food and water;

(c) social security...

For children the Constitution states:

Section 28 (1)(a) Every child has the right-

(a)... (b)...

(c) to basic nutrition, shelter, basic healthcare services and social services;...

The best interests of the child are paramount in South Africa.

For further information

*Refer to Chapter 2 of this book, where the **Right of Access to Health Care** and **Progressive Realisation** are explained on page 17. Page 167 of Chapter 11 also explains **Access to Healthcare**.*

ACCESS TO HEALTH CARE

The previous National Strategic Plan (2007 – 2011) specifically included refugees and migrant groups, sex workers, sexual minority groups and prison populations.

Readers are encouraged to refer to the new National Strategic Plan for South Africa (NSP 2012 - 2016) to ascertain what it says about marginalised groups, and the way forward.

Notes

When considering healthcare for foreign nationals its useful to consider their rights to healthcare under international law. Chapter 2 of this book refers to the United Nations General Comment 14 which refers to governments' obligations to uphold the rights of asylum seekers and illegal immigrants to preventive, curative and palliative health services.

The South African Constitution guarantees access to health care for all and everyone within the country is assured access to life-saving health care. In the context of HIV, this guarantee extends to HIV services, including access to antiretroviral therapy (ART).

According to Section 27 (g) of the 1998 Refugees Act, a refugee is "entitled to the same basic health services and basic primary education that the inhabitants of the Republic receive.

Refugees and Asylum Seekers do not have to pay for ARTs

For asylum seekers the situation was less clear, until the National Department of Health (NDOH) issued a directive in 2007.

Importantly, this directive clarifies that refugees and asylum seekers – with or without a permit – shall be exempt from paying for ART services, irrespective of the site or level of institution in which these services are rendered.

The National Department of Health (NDOH) has also clarified that patients do not need to be in possession of a South African identity book in order to receive ART. According to the directive from the NDOH, undocumented migrants should have the same access to basic health care as refugees and asylum seekers, given the state's decision not to discriminate on the basis of documentation. This is a welcome move that allows all people in South Africa to be included in prevention and treatment services. Without support from all public health practitioners, the intentions of the Directive, and supporting guidelines, may not be met.

Case Study
Gender Issues

Ritsepile's story

"It's either you have sex with me or you get deported." Living a life like this is far away from the hopes I had growing up in Zimbabwe, dreaming of becoming a doctor. My dreams were shattered when my father passed away before I even finished school. Partly out of desperation, I fell in love with an old businessman in our village. I thought I loved him. He promised to take care of my mother and me, and to pay for my school fees. He took advantage of me, impregnated me and dumped me. I dropped out of school. Since I had no qualifications, my only choice was to find a job as a maid so that I could fend for my old mother and my unborn child. Under all this pressure, I gave birth to an immature baby at six months. I had to stay in hospital until he was old enough to get out. My stepsister down here in South Africa felt sorry for me and asked me to come and look for something here, since there are few opportunities in Zimbabwe. I entered the country illegally, and stayed at home, afraid of being deported. I respected my sister's husband. He looked like a good, caring husband and father, until all hell broke loose. It started one day when I was coming out of the bathroom. I got inside the house to realize he was back from work earlier that usual. I had only a towel around me. As I took my clothes so that I could go and dress in the bathroom, he moved faster towards the door and locked it from the inside. He became aggressive – I could not take his hands off me. He pushed me on the bed. He touched me everywhere, kissed me and forced me to have sex. This happened for almost three weeks and I suffered in silence. One day I related the whole story of her abusive husband to my sister. Instead of comforting me, she became angry and even accused me of seducing her husband. She told me I was loose and that is why I had a child at home out of wedlock. She threw me out of the house and this is how I ended up on the streets. I am asking for help. I would like to enroll and train so that I get a certificate, I want to be able to stand on my own feet, spread my wings and fly higher.

This story is part of the I Stories series produced by Gender Links Opinion and Commentary Service for the 16 Days of Activism on Gender Violence.

Gender Issues

In addition to the significant losses experienced by refugees (loss of country, home, possessions) health workers need to be aware that women, especially, are vulnerable to sexual exploitation and loss of dignity as described in this very moving account by Ritsepile Pretty Mlauzi in the Sunday Argus of 30 November 2008

Topic
for discussion

If Ritsepile Mlauzi was diagnosed with HIV and TB and was referred to a palliative care service, what challenges would her care present in terms of addressing physical, social, emotional and spiritual needs?

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Ingrid Palmary at the African Centre for Migration and Society at Wits University comments:

Mlauzi's story echoes the experiences of many women who travel far from home to seek opportunities and livelihoods they cannot find in their home country. Both women and men who migrate face a number of challenges, but the nature of these challenges and their impact is very different. Problems often begin for women as soon as they decide to leave their country. The border post is one of the most dangerous places in a woman's journey. Syndicates of smugglers based at the borders are responsible for widespread violence against women.

Moreover, added to the risks of sexually transmitted diseases and unwanted pregnancy, survivors of these attacks often face social stigma and exclusion, rather than support. The stigma attached to victims of sexual violence is what makes it a particularly effective way to harm women. This is one reason why during times of conflict, including the xenophobic attacks of May 2008, rape is such a common and effective weapon used against foreign women.

Once a woman crosses the border, she faces a number of challenges. Overall, women, who bear the primary responsibility for the care of children, find migration with children extremely difficult and more expensive than migrating alone. On arrival in South Africa, they have greater difficulty in finding work given their childcare responsibilities. They may even have greater difficulties finding low-cost accommodation that will accept children. Research also shows women who migrate with their children tend to earn less than those who do not. As with all poor women, they also face difficulty in finding safe and affordable childcare for their children while at work.

Like men, many women arriving in South Africa find themselves unable to get the documents needed to legalise their stay in the country. However, the effects can be much more serious for women than for men, as lack of documentation makes women particularly vulnerable to violence. Undocumented women migrants who experience domestic violence, or any other form of gender-based violence so widespread in South Africa, are unlikely to report it to the police or make use of other social services.

Research by the Forced Migration Studies Programme shows that xenophobia and discrimination from service providers acts as a significant barrier to getting services for women who are in abusive relationships. In addition, abusive men use women's migrant status to justify their abuse, and their inability to go to the police was a reason for their ongoing abuse.

In her story, Mlauzi recounts how she was first afraid to tell of being raped by the brother-in-law in her home, and later how she endured abuse because she had no money and nowhere to go. Fear of repercussions means these women are not only unable to seek justice, but also do not get access to psychological and health support, such as post-exposure prophylaxis for HIV.

Ingrid Palmary is Acting Director with the African Centre for Migration and Society at Wits University.

This story is part of the I Stories series produced by Gender Links Opinion and Commentary Service for the 16 Days of Activism on Gender Violence.

Access to ART

Refugees are often incorrectly stereotyped as 'disease carriers', particularly in relation to HIV. In fact refugees often move from countries in conflict with relatively low rates of HIV to more stable countries with higher rates of HIV.

The memo circulated by the NDOH in the first quarter of 2007 provides important clarification that not being in possession of a South African identity booklet should not prevent an individual from accessing ART, providing that all other conditions are met. This has positive implications for both non-citizens and citizens without identity booklets who are in need of ART.

The September 2007 Directive goes further and indicates that refugees and asylum seekers – with or without a permit – shall be exempt from paying for ART services, irrespective of the site of level of institution where these services are rendered.

HIV is a public health issue and ensuring the free provision of ART to all individuals within South Africa who are in need of treatment, will have a public health benefit, particularly from an infectious disease control perspective. Whilst the numbers of non-citizens within South Africa are small, they are significant. It is important to ensure that individuals are able to access treatment early, as the burden upon the health system will be greater for untreated, sick individuals. The burden within society will also increase if communities have to care for the sick and dying.

Topic
for discussion

You are caring for a refugee who has HIV and TB. You want to know if refugees and asylum seekers can access TB medication from state healthcare services and if they are exempt from paying for TB treatment.

Who would you contact to help you answer this question?

Notes

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Fees for Health Services

The NDOH directive BI 4/29 REFUG/ASYL 8 2007 announced that refugees and asylum seekers "with or without a permit that do access public health care shall be assessed according to the current means test". Refugees and asylum seekers therefore fall into the same categories as South Africans in terms of paying fees according to their income. This means that those without income will pay minimal fees, whilst only those with a high level of income will be classified as 'Private Patients' and pay the maximum fees.

Because the NDOH directive does not discriminate against asylum seekers who have not yet been issued with documentation, the same means test, which is applied to South Africans, will determine the fees they pay.

In terms of the 1998 Refugees Act, refugees and asylum seekers should not be classified as 'foreigners' and asked to pay the R1800 deposit required of other non-nationals (such as those on work or study permits). Because the NDOH does not discriminate between asylum seekers with or without documentation, if a person is unable to provide identification documents they must then be charged in terms of the same means test structure as South African citizens.

In practice, foreign nationals experience a number of barriers to accessing the health care to which they are entitled under South African law. For example, public hearings held by the South African Human Rights Commission in June 2007 on the issue of access to health care, revealed that refugees are denied access to services due to inconsistent application of the relevant policies and laws. More recent discussions and symposiums show that refugees and asylum seekers continue to face challenges in accessing healthcare. Some hospitals have indicated to service providers that whilst they recognize the requirements of the NDOH directive to provide health care to those without documents, they do not intend to comply with the directive, stating that this is due to the limited budget with which their institution is provided.

Barriers to general health care for refugees and asylum seekers are:

- Lack of documentation issued by the Department of Home Affairs due to the large queues and limited services being provided by the Refugee Reception offices.
- Unaccompanied minors experience further obstacles due to the additional challenges they face in accessing documentation from the DHA.
- Undocumented nationals facing additional obstacles due to their constant vulnerability to arrest and deportation whatever their circumstances. They may be unwilling to present themselves at hospitals or clinics for fear of being reported to police and deported.
- Negative attitudes of healthcare staff who might refuse services to refugees and asylum seekers. Refugees reported that treatment was more likely to be provided once contact had been made with a doctor. In addition, it was suggested that xenophobia was heightened towards refugees with disabilities
- Confusion by healthcare service providers over the rights of different categories of foreign nationals. Many service providers are unaware of the legal status of refugee documents and asylum seeker permits and are fearful of getting into trouble for assisting someone with such documents.
- Confusion over the fees to be paid by the different categories of foreign nationals. Until the NDOH directive, it was generally unclear as to how asylum seekers were to be charged.
- Poverty, as some refugees and asylum seekers were not employed and thus experienced financial barriers to accessing health care. Healthcare staff's uncertainty about fee structures contributed to this, as some foreign nationals were charged higher fees than they should have been in terms of the law.
- Language issues, as translators were often not available to assist foreign nationals in explaining their illness to healthcare service providers.

Barriers to accessing ART

- Institutions may wrongly demand an ID booklet. People without an ID booklet are refused treatment, and referred out of the public sector and into the NGO sector. This not only increases the burden on a resource-limited (and externally funded) NGO sector, but prevents the public health system from fulfilling their obligations to provide health care to all.
- A previous lack of clarification from the NDOH regarding the rights of asylum seekers to access ARTs. The new policy directive issued by NDOH will go a long way towards tackling this issue, but there will still be challenges in ensuring there is wide-spread awareness of this new measure.
- A fear of approaching the police regarding post-exposure prophylaxis (PEP). A number of foreign nationals have reported negative experiences in dealing with the various South African police services. Many foreign nationals also appear unaware that they can present themselves at a public hospital for this service (PEP) and healthcare providers are obliged to keep clinical information confidential.
- The challenges of providing information to non-national populations in an accessible and appropriate way. Refugee and migrant populations live in many different areas and it is difficult to communicate with them all. Many non nationals are therefore not aware of initiatives such as the prevention of mother to child transmission of HIV (PMTCT).
- Stigma in non-national communities around HIV. Such stigma challenges common support structures such as 'treatment buddies' or support groups. Instead it has been found that foreign nationals often prefer to be part of such support structures located outside of the communities where they live.

Case Study Access to Antiretroviral Therapy

Jean (not his real name) arrived in South Africa in 1998. He left the Democratic Republic of Congo (DRC) in order to escape violence and conflict. He travelled to Johannesburg where he applied for, and received refugee status. Although he did have refugee papers, these were stolen in 2001. He has applied for a replacement but is still waiting and currently has no documentation. Jean has been working informally since his arrival, he currently mends shoes. He lives in the inner-city and shares a flat with other people he met there who came from the DRC. Jean had a South African girlfriend for several years, but she has now left Johannesburg; he does not know where she is.

In 2006, Jean started to become unwell, and developed a bad cough. When he was too sick to work, he went to the local government clinic. He was diagnosed with TB and started on treatment. He was advised to test for HIV, which he did at the clinic. He found out that he was HIV positive and was referred to the closest ART rollout site. There, they tested his CD4 count and found that it was 194. The counsellor explained that he must finish his TB treatment before he could commence ART. However, once Jean had completed his TB medication, he was then told that he could not receive ART because he did not have a green South African identity booklet. He explained that his refugee booklet had been stolen but the counsellor said that he needed a green South African identity booklet. At this point, although feeling better, Jean was still very weak; he was still unable to work and his friends were no longer able to support him.

The counsellor at the ART site referred Jean across the city to an NGO site that provides ART. They did not ask him for any documentation. They checked his CD4 count and found it was 120. He received adherence counselling and then started ART. Jean has been receiving ART at this site since 2006 and is currently well. Jean has to travel far to the NGO site to receive his medication and to have his CD4 count monitored and the taxi fare is expensive. He is eligible to receive ART at his local government ART rollout site (that is in walking distance) but unfortunately, the right to access ART is not being upheld.

Jean is a refugee and has the right to access ART. The September 2007 Directive confirms that refugees and asylum seekers – with or without a permit – are entitled to free ART.

In South African hospices, palliative care is provided regardless of citizenship and is free of charge, so refugees can access palliative care if they are in an area that has a service.

Across Africa NGOs provide palliative care to those in need regardless of citizenship. Dr Faith Mwangi-Powell of the African Palliative Care Association talks of providing palliative care to people on the move and one of the photos the care team is seen resting on the back of a bakkie, after providing care to people walking across rural Namibia.

Palliative care on the move - Providing care to migrating people

Addressing the Challenges

- **Know the rights** of refugees, asylum seekers and migrants and inform your colleagues of these.
- **Challenge prejudice against foreign nationals** where you see it. Remember that the law is on your side and it is the duty of all healthcare services to provide fair healthcare access in terms of the law.
- **Maintain communication with legal organisations** who can offer advice and assistance if specific challenges emerge. Key organisations such as:

- Lawyers for Human Rights (Johannesburg, Pretoria and Durban),
- Wits Law Clinic (Gauteng), SERI (Johannesburg),
- UCT Law Clinic (Cape Town) and
- the Legal Resources Centre (Cape Town, Grahamstown, Durban and Johannesburg)

can provide clarity on any legal concerns regarding non-national access to health care.

- **Create a relationship between your organisation and an organisation offering interpreter and translation services.** Local migrant and refugee service providers may be able to assist you in this regard.

Case Study

Living with HIV, how I treat myself

Story told by Diputo Lety to Elsa Oliveira. A short story about being a sex worker in Hillbrow

Diputo Lety's story

I became infected with HIV as a result of a rape. In 2004, I was coughing and losing a lot of weight so I decided to go to the Sex Worker Project in Hillbrow, and get tested for Sexually Transmitted Infections [STIs]. The Sex Worker Project is run by the Reproductive Health & HIV Research Unit (RHRU) in Hillbrow.

Since the clinic started in 1997, sex workers have had a safe place to go for health treatments and preventative health exams. It was during this time that I found out that I was HIV positive. When the nurse at the clinic told me about my status she announced it to me in the hallway, in front of everyone. I felt angry and embarrassed that she did this, and at the time, I did not realize that I could report her. Fortunately, my experiences with health care services have improved after this experience!

At that time, I did not know anything about what it meant to be HIV positive. I did not know what I needed to do to take care of myself. All I remember was that I felt a lot of fear, and that I was reluctant to start ARV treatment. When I look back at that time, I can say that being humiliated in front of people at the clinic did not help me to want to learn more about my treatment options. All I knew was that I was not ready to go on ARVs so instead I took vitamins and tried to eat lots of fruits and vegetables.

These are the ARVs that I take to improve my CD4 count, as well as lowering the viral load that weakens the immune system. I've been taking ARVs for six months now, and there has been great improvement in my health.

Photo: Lety/Market Photo Workshop/ Working the City

Topic
for discussion

- How should the health care professional have shared this news with the client?
- Where?
- What principles were violated in terms of communication?

Notes

Lety/Market Photo Workshop/ Working the City

Diputo's story continues…

In 2008, I became a peer educator at RHRU. As a peer educator, I helped educate other sex workers about prevention, STIs, and encouraged them to come to Sisonke[2] for support services for sex workers. During this time, I began to learn more about HIV and I realized that my life was not over because of my status. I learned that I could be healthy and live a long life. In 2009, I began ARV treatment. I was ready. Because of the support services of Sisonke, the caring nursing staff at the Sex Worker Project, and my work as a peer educator, the stigma of being HIV positive was replaced by my desire to live a healthy life.

Although my family does not know that I am a sex worker, or how I contracted HIV, they are very supportive of me as a woman living with HIV. Both of my parents work as hospice workers with people living with HIV so they understand what it means to be HIV positive better than a lot of people.

They really encourage me to stay healthy and take my ARV treatment. In fact, they call me everyday to remind me to take my ARVs. This kind of support is wonderful and I feel blessed to have them in my life. I think that it would be much harder if my family were not supportive. When I am not feeling well I go back home so that I can rest and recuperate and this makes a big difference in my life. My sprits are high because of their love and encouragement.

As a sex worker, I make sure that I am protected and protect my clients by wearing condoms - after all - My Body is My Business! When there are clients that don't want to wear a condom I use a female condom. Many clients do not know about STIs so when I see that one of them has an STI, I encourage him to go to the clinic to get tested. Sometimes they tell me that they are afraid, and other times, they tell me that they don't care about their health. I, myself, have gone with clients to the clinic so that they can get tested for HIV. I support them by accompanying them to the clinic because I know from experience that it is not easy to go alone.

I have been taking ARVs for two years now, and while at times the side effects are hard to deal with, I take them anyways. I know that they are helping me to stay healthy and strong. I continue to eat healthy and make sure that I get enough rest because I know that all of these efforts help me, my body, and my treatment to work more effectively. I am also working as a peer educator for Sisonke where I continue to educate other sex workers about health and human rights issues and why it is so important for sex work to be decriminalized. Many sex workers are afraid to get tested because the stigma of being a sex worker is so high, and because they are scared that health care workers may discriminate against them. As a peer educator, a sex worker, and a woman living with HIV I have the opportunity to challenge some of the myths of HIV by sharing my personal story and telling others- specifically sex workers- that they should not be afraid to test for HIV and to seek treatment.

It is my hope that my story serves as an example of the ways in which sex workers are supporting one another, and how sex workers are uniting. My story is just one example, but it is my wish that it positively impacts social and political change for sex workers, and that more sensitive and non-judgmental health services will be rolled out in South Africa.

These photos were part of a collaborative project between eleven migrant women involved in sex work in Johannesburg, and Sisonke Sex Worker Movement, the Market Photo Workshop and the African Centre for Migration and Society (ACMS) at Wits University. An exhibition of migrant women's experiences in Joburg took place in October 2010.

Photo: Lety/Market Photo Workshop/ Working the City

For further information

Information about Sisonke Sex Worker Movement can be found in the Resources Section at the end of this book.

Notes

Barriers to healthcare for Sex Workers

Sex workers face a number of potential barriers to health care. Due to their employment choice they are among the most marginalised and stigmatised in our society. This is a crucial issue that requires a lot of self awareness and sensitivity from healthcare workers, who should avoid making judgements based on their own values. A number of sex workers have spoken of feeling judged and being lectured to by service providers who have effectively ignored the reasons why the sex worker came to seek assistance.

Service providers have an ethical duty to be approachable and friendly to all people from all walks of life. The Constitution protects the rights of all within South Africa and sex workers have the same rights as everyone else to access to healthcare services, dignity, privacy and non-discrimination.

Suggestions for service providers

- Treat all people who seek health care with dignity and empathy regardless of their occupation or livelihood. Reserve your comments and opinions as these may hurt the person and cause him or her to become more reluctant to seek out healthcare assistance in the future.
- Do not tell others about their health status unless they have given you permission to do so. Treat sex workers with the same respect and confidentiality that you would give to any other person.
- Avoid talking to sex workers in a manner that may interpreted as 'preaching' with regard to their choice of employment. In the same way you would not tell a teacher or a nurse to change their job, do not tell sex workers to change their jobs, unless they have explicitly asked you would not tell them of other work opportunities. Whilst you may feel that you are trying to help, in fact the person is likely to feel judged, humiliated and not heard.
- Many sex workers experience high levels of violence – whether from their clients, the police or their partners. Screen your patient for potential abuse and refer appropriately.
- Challenge prejudice where you see it.
- Listen to what the person is asking for and assist where you can.
- Organisations should consider undergoing stigma training workshops for working with marginalised people. Refer to the list of Resources at the end of this book
- Sex workers may approach healthcare workers with multiple needs or questions. In such cases, healthcare workers can play a key role by contacting, or referring patients to organisations that are better equipped to provide for specialised needs.
- Many people know what they need when approaching healthcare services, but might not know how to ask for it or how to get what they want. Be patient, compassionate and give the person time and space to think through what they need, even if at times these needs seem contradictory.

Photo: Lety/Market Photo Workshop/ Working the City

Section 35(2)(e) of the Bill of Rights of the South African Constitution provides for the rights of prisoners to have "adequate medical treatment" whilst Section 35(2)(f) provides for a detainee to be visited by his or her chosen medical practitioner. If the state is unable to provide a particular treatment, it needs to demonstrate that it cannot afford this treatment or that such treatment would place an unwarranted burden on the state. Furthermore, section 11 of the Bill of Rights provides for the right to life, and Section 10 for every person to have their dignity respected and protected.

Section 12 of the Correctional Services Act 1998 and the accompanying Regulations stipulate specific requirements regarding health care for prisoners. Health care for prisoners in South Africa is regulated by the Department of Correctional Services (DCS) rather than the NDOH. This can pose challenges in ensuring that a consistent standard of health care is available to all South Africans across the country. In June 2006, the Durban High Court ordered the DCS to provide ART to prisoners in Westville Prison in accordance with public sector policy. Prior to this ART was being denied to prisoners. Whilst the state has been criticised for the slow speed at which it has sought to rectify this, the DCS has managed to increase the number of sites providing ARV treatment.

In practice

The DCS faces significant challenges in providing health care for prisoners including a lack of medical staff, overcrowding in prisons and poorly resourced prison hospitals. In one prison, an acute shortage of staff was discovered, whilst pregnant patients were being kept in the same accommodation space as TB patients and had no access to gynaecological services. In addition only limited screening of newly-admitted prisoners took place and prisoners with infectious diseases were not isolated from the rest of the prison population. The DCS Annual Report of 2009/10 reveals a high level of vacancy for nursing staff (27%) and medical practitioners (26.7%) within the Correctional Services system and this is likely to put further pressure on the ability of the system to meet inmates' needs. The DCS recognised the shortage of skilled staff in the form of professional nurses, medical practitioners, psychologists and pharmacists and the impact this was having on the health care it was able to provide for prisoners. It committed itself to taking steps to rectify this situation. Further major challenges to the health care of inmates are the presence of gangs inside many prisons as well as practices relating to the use of tattooing in prisons. Access to PEP for those who have been sexually assaulted inside prisons can also prove a significant challenge.

Medical Parole

Section 79 of the Correctional Services Act 1998, states that any sentenced offender may be considered for placement on medical parole if they are diagnosed by a medical practitioner as being in the final phases of a terminal illness. This is to allow for a prisoner to die a 'consolatory and dignified death'.

Medical parole has long been a contentious issue and recent legislation has changed the definition of medical parole.

Despite the legal provision, in practice medical parole involves a lengthy and bureaucratic process. In some cases, the condition of prisoners worsens and some die before being released. In *Stanfield v Minister of Correction Services and Others* the Court judgment declared that "the overriding impression gained from [the state's] attitude in this regard is that the applicant must lose his dignity before it is recognized and respected".

Notes

The new Correctional Matters Amendment Act 2011 amends the definition of medical parole and states that:

79. (1) Any sentenced offender may be considered for ...medical parole ...if:

a) such offender is suffering from a terminal disease... so as to severely limit daily activity or inmate self-care

b) the risk of re-offending is low

c) there are appropriate arrangements for the inmate's supervision, care and treatment within the community to which the inmate is to be released.

2) An application for medical parole shall be lodged by:

i) a medical practitioner

ii) a sentenced offender

Notes

The new Correctional Matters Amendment Act 1998 Section 79(7) provides that no placement on medical parole may be cancelled merely because of the improved medical condition of an offender.

However before a medical team can even assess a prisoner for medical parole, the first step under the Correctional Matters Amendment Act requires a medical practitioner or the offender to initiate the application for medical parole.

This amendment has now shifted the duty to initiate the process of application for medical parole to the prisoner, whilst it is in fact the duty of the DCS to promote and protect the dignity of the prisoner, which would include initiating the application process for medical parole.

For prisoners locked up in small and rural facilities without regular access to a doctor, the chances are slim of a doctor seeing a prisoner, and equally slim that a prisoner will be able to make a medical parole application and find the necessary supporting medical report for this. The law around medical parole clearly remains in need of improvement if only 5.5% of prisoner deaths in 2008 were after release on medical parole.

Additionally, significant delays occur in the process of applying for medical parole. Such delays occur due to:

- Reluctance by family members to accept a terminally ill family member back home.
- A potential lack of skills on the Parole Board to assess complex medical conditions, resulting in the rejection of applications due to incorrect consideration of the circumstances.

Lukas Muntingh of the University of Western Cape's Civil Society Prison Reform Initiative notes that prisoners eligible for release on medical parole are frequently identified at a very late stage and die before they can be placed on medical parole.

Continuation of Care after Release

It is vital that preparations are made for prisoners undergoing treatment for when they are released from prison. Whilst some prisoners may have been able to have good access to treatment whilst inside the prison, their release may pose challenges for the way in which they now have to access care.

For those on a course of ART, it is critical that planning is co-ordinated between the DCS and NDOH, as well as the patient's support structures, to ensure the patient is able to maintain access to ART.

It appears that currently there is limited support to ensure continuity of care after release, and this is a major area that needs to be addressed. Where the prisoner's family is unable to care for the prisoner at home, appropriately qualified and experienced doctors assisting Parole Boards need to be aware of palliative care services and make enquiries to establish what services might be available for such prisoners on release.

Palliative Care in Correctional Centres

HPCA has advocated for seriously ill prisoners to have better access to palliative care on a broad scale. The HPCA DCS project was launched in KwaZulu-Natal at Durban Westville and Pietermaritzburg prisons in October 2009 and has now expanded to 8 prisons across the country. The project has involved palliative care training for DCS health staff, advice on implementation of palliative care and DCS staff members having regular contact with their hospice mentors. Offenders and parolees can receive assistance from hospice, and palliative care beds have been set up in prison with a palliative care doctor from local hospice coming to do a monthly ward round. On a national level, it has been noted by HPCA that the medical team making decisions on medical parole policy should be trained in palliative medicine. The DCS has requested that palliative care be rolled out in Gauteng, KwaZulu-Natal, Eastern and Western Cape.

Background

Drug addiction has been recognised internationally as a disease that is manageable rather than curable. As a primary and progressive disease, it is the addiction itself that is the key problem rather than its consequences, and it can become worse over time. Key characteristics of the disease can include withdrawal, shame, loss of control, manipulation and lying, and drugs becoming the main focus in the person's life.

Addicts can be ambivalent about their situation, with part of them recognising the destructive impact of drugs on their lives, but with another part attached and attracted to their drugging for different reasons. Service providers can play a useful role by supporting the addict who wants to stop.

A key palliative care perspective is that the drug user in pain requires higher doses of opioid analgesics because of the effect of drug use on speeding up the metabolism of these analgesics. This can result in discrimination, as the requirement for higher doses is seen as an expression of addiction and manipulation. Also, problems occur with previous drug users who have now stopped using and are afraid to take medication for pain control for fear of slipping back into addiction. So both situations are challenging to the palliative care practitioner as the patient still requires and should receive adequate pain management.

Roles to Avoid and to be Aware of as Service Providers

- The Rescuer: by attempting to 'rescue' an addict to make him or her feel 'safe' and 'loved' can have the effect of sheltering the addict from experiencing the negative effects of his or her actions and thus slowing down the healing process.
- The Persecutor: by punishing the addict by denying him or her services or privileges, you do not stop the addictive behaviour, you give the addict a person to blame for his or her behaviour and thus avoid dealing with the problem.
- The Victim: this is a role that can be played by the addict when he or she wants something. Essentially, the addict avoids taking responsibility for the issue and instead shifts the blame for his or her behaviour onto others.

As a service provider, it is important to avoid the roles of the rescuer or persecutor as these roles can reinforce that of the 'victim' and allows the addict to continue his or her behaviour. Instead, service providers could play a supportive rather than rescuing role, and a limiting rather than a persecuting role. In this way they can assist by helping set appropriate boundaries or limits.

If a service provider does not have the appropriate skills to assist and counsel drug addicts, it is important, with permission from the client, to involve a specialist service provider and work as part of a team in dealing with issues of addiction.

The Vienna Declaration

Global Opposition to the War of Drugs approach

Recently the Vienna Declaration has highlighted that anti-drug laws have caused an escalation in HIV infection rates. At the 18th International Aids Conference in Vienna, the international scientific community launched the Vienna Declaration which outlines the harm done by the criminalisation of illicit drugs.

The Vienna Declaration seeks an evidence-based approach and states that the over reliance on drug law enforcement has resulted in overwhelmingly negative health and social consequences

According to Toronto's Globe and Mail, the Vienna Declaration slammed the criminalisation of illicit drugs as a major factor fuelling HIV infection rates. The authors of the Vienna Declaration called on policy-makers around the world to refocus their approaches to illegal drugs and HIV-AIDS prevention – especially in light of new statistics that show HIV infection rates have climbed back to 1982 levels, largely thanks to infection in injection-drug users.

Since the Vienna Declaration, Toronto has claimed to be the first city in the world to endorse the declaration as part of its commitment to fighting drug addiction and Evan Wood, founder of the International Centre for Science in Drug Policy, commended Toronto's commitment to fighting drug addiction in more nuanced ways than a "war-on-drugs" stance.

LESBIAN, GAY, BISEXUAL & TRANSGENDER PEOPLE

Exercises

Working in small groups

Exercise 1

1) choose one particular marginalised group that is discussed in this chapter
2) develop your own checklist of questions when assisting a person from this marginalised group in need of specialist assistance.

Exercise 2

1) choose one particular marginalised group that is discussed in this chapter
2) pick out how the chapter defines this particular marginalised group, their challenges and the legal approach for this group.

Exercise 3

Working in small groups, discuss together any new information you learned from this chapter. Pick out from this chapter information that you agree is new and relevant to your work in the palliative care sector and develop a questionnaire.

This questionnaire could be used to measure how much people know about the issues discussed in this chapter and could be used at the beginning and end of a training session.

Former South African President Nelson Mandela appointed Edwin Cameron as acting judge and later a judge of the High Court. In 1999-2000 he served for a year as an Acting Justice at the Constitutional Court. In 2000 he was appointed a Judge of Appeal in the Supreme Court of Appeal a position he held until 2009 when he was appointed as Justice to the Constitutional Court of South Africa.

A study conducted by OUT Well-being in 2004 found that many black gay men and black lesbians had been refused access to health care due to their sexual orientation. Although the law is clear, prejudice on the part of service providers can inhibit access to key services. Such prejudice can present in a number of ways. It could be overt in the form of direct refusal of services or it could be less obvious in the form of behaviour that makes the person uncomfortable, such as insensitive questions and comments.

Healthcare providers and support staff need to distinguish between people's identities and their behaviour. A person may be gay but that may not impact upon their specific healthcare needs. If a male patient has sex with men, then it is this behaviour that may be more relevant for preventative measures or treatment being addressed by the healthcare practitioner. Many people believe in "curing" people with 'deviant' sexual behaviour, and therefore some sexual minority patients may misinterpret referrals to psychologists or counsellors as being for the same purposes.

Case Study

Story from Constitutional Court Judge Edwin Cameron

My first contact with hospice was in the early 1980s, at a time when the AIDS epidemic first manifested itself in this country. Amongst the first people to be struck by the disease were gay men like myself, felled in their midlife or in the peak of their lives. The initial demography was not the mass heterosexual epidemic that we later came to see.

When the disease struck, this group was very marginalised and stigmatised – with the result that AIDS was immeasurably worse than other life-threatening illnesses.

What did Hospice do? Their response was principled, correct and true according to its own mission. That was at a time when all too many doctors were fearful of treating people suffering from the effects of HIV. I know this because together with others I had to fight Wits surgeons at Bara and Johannesburg General Hospital on what care people with HIV were entitled to. Many people were fearful and condemned those with HIV.

By contrast, Hospice took people into its shelter, its loving care, into its embrace and gave them what they deserved: no end to caring.

I have a particular passion and interest in the work of Hospice Palliative Care Association of South Africa.

First, many of my friends were cared for and died at Houghton Hospice. Later, when I was at the Supreme Court of Appeal in Bloemfontein, Ladybrand Hospice asked me to get involved and I did so willingly and gratefully. Now, as a Patron of HPCA, it is with equal willingness and joy that I respond.

It's an honour to be associated with the work you do. Your association is of the greatest importance to this country.

Thank you for the work you do and for standing true at a moral moment in our country's response to disease. Fortunately when I myself contacted HIV in 1997 I had access to medications that saved me from death. Now, nearly fifteen years since starting antiretroviral therapy, I am privileged to lead a vigorous full and highly energetic life.

But my experience of AIDS – when I myself might already have needed your final care – has made me carefully attentive to and aware of the vital work you do.

CONCLUSION

This chapter has illustrated that there continue to remain significant barriers in South Africa to the provision of equitable access to health care that does not alienate marginalised groups. Many of these challenges relate to attitudinal barriers to accessing health care, and for this reason it is vital that staff in all healthcare institutions are made aware of the effect their attitudes can have on patients. Further challenges involve ensuring that staff members are aware of the current legislation with regard to providing health care for foreign nationals, with or without documents. Access to health care in prisons remains tenuous, and the reliance of inmates on prison officials for access to health care increases the inmates' vulnerability. By addressing the challenges outlined in this chapter, healthcare providers can improve the standard of health care offered to marginalised groups.

Notes

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CHAPTER 11

Community Health Workers and Home Based Carers

INTRODUCTION

Various terms are used to describe those who do care work in the community, including:

- Community Health Worker (CHW),
- Community Caregiver,
- Community Based Health Worker (CBHW),
- Home Based Carer (HBC),
- Ancillary Healthcare Worker,
- DOTS Supporter
- Onompilo

In the document outlining the re-engineering of the Primary Health Care (PHC) system, the preferred term is **Community Health Worker (CHW)**. The term **Home Based Carer (HBC)** is still used by hospices to identify those who are providing home-based care to patients in the community.

There are many community workers who play a key role in empowering people with healthcare knowledge and access to Primary Health Care (PHC) services and assist with healthcare delivery. They have no formal, professional healthcare qualifications.

In 1978, South Africa was one of the signatories to the declaration of Alma Ata which outlined the goal of "Health for All" and focused attention on primary health care as the means of achieving this goal.

The AIDS Law Project's publication *Health and Democracy* highlights that "since 1994, many new policies and laws have been introduced that aim to transform the health system. There have also been important programmes to build new clinics, revitalise hospitals and improve the training of health workers".

It is also acknowledged that "the government faces great challenges in fulfilling its duty to ensure that all people are able to access health care services. These involve improving the social conditions that influence health and restructuring the management of the health service itself".

Topic
for discussion

Look at the declaration of **Alma Ata** at the end of the book and in small groups discuss what achievements you think have been made so far in reaching the goal of "**Health for All**"

Terms you will find in this chapter

Attrition rate: the number of people who leave their work in a period of time

Community Health Worker: A non-professional person who is part of a team providing preventive and promotive primary health care in the community

Crucial prerequisites: essential requirements

Decentralise care: to move care from a health care facility into the homes and community

DOTS: Directly Observed Treatment Short-course

Disparities in remuneration: a lack of equality in payment for services

Enrolled nursing auxiliary: a person with 1 year of nursing training who works under the supervision of a professional nurse

Ethical responsibility: responsibility to act in a correct, moral manner

Home Based Carer: Non-professional care worker at a hospice/ palliative care organization/community organization who provides a range of home care services to patients and families in the community

Interdisciplinary team: a team of people with various clinical skills from the hospital, hospice, clinic and community

Primary carers: the main caregivers, usually family or community members

Reciprocal benefits: something that benefits both parties

Re-engineering of Primary Health Care: The initiative of the Department of Health to address primary health care needs in the community

Reimbursement: to pay someone back for money spent or as compensation

Stipend: money paid in place of a salary for services in the caregiver setting often below a living wage

The impact of HIV/AIDS and TB has meant that there has been a dramatic increase in the number of people requiring care and support. With rising costs of care and hospitals not able to cope with the demand for beds, the aim is to decentralise care to the community level, placing the responsibility, on Primary Health Care Clinics, Non-Government or Non-Profit Organisations (NGOs/NPOs), Community Based Organisations (CBOs), CHWs, HBCs and family carers. The reality is that many patients who are discharged from hospital do not have family members to care for them within a home setting or, if the primary caregiver has to go to work, the sick person is left alone. Even when family members are available, many do not have the required skills and knowledge and some are simply unwilling to care.

Human rights are normally divided into two groups namely:

Civil and political rights, which include such rights as:

- the right to life
- the right to dignity
- freedom of speech
- freedom of association
- freedom of movement

The United Nations International Covenant on Economic, Social and Cultural Rights (ICESC) include:

- the right to have access to adequate food and housing (Article 11 ICESC)
- the right to have access to social security (Article 9 ICESC)
- the right to education (Article 13 ICESC)

The purpose of socio-economic and cultural rights is to ensure that all persons have access to resources and services that are needed. Socio-economic and cultural rights are important for the very poor and vulnerable people in our society. The government provides these rights according to what it can afford. Very often people say that socio-economic and cultural rights are provided within the available resources of the government.

Chapter 2 of this book outlines United Nations General Comment 14 and the obligations of states in terms of Article 12: the right to the highest attainable standard of health.

The costs of private doctors, hospitals and medical aids are very high and some people cannot afford to pay these costs. Section 27 of the South African Constitution guarantees everyone the right of access to health care services, including reproductive health care services. Children are regarded as being vulnerable and every child is given the right to basic health services. This section places a duty on the state to provide children with basic health care. Section 28 also places a constitutional duty on parents, who are financially able, to provide for their children's basic needs. The Constitution also states that no one may be refused emergency medical care. Emergency health care must be distinguished from access to health care services, which is a socio-economic right.

Despite the rights provided for in the Bill of Rights, stigma is still rife within many communities. People living with HIV/AIDS (PLWHA) and/or TB are often discriminated against and neglected by their families. Many people present late for treatment at PHC clinics, leading to added pressure on organisations or people providing home care. In some cases, where sick people are left on their own, HBCs have become the primary carers, assisting with household chores and even spending their own money to provide food or transport to PHC clinics. Many home care organisations are also providing care and support for an increasing number of orphans as well as for children who are HIV positive and who have TB. Much time is spent in facilitating the placement of children, helping to secure relevant grants and seeking programmes which provide paediatric care.

It is important to realise that the right to health care does not mean that a person can demand whatever type of health care they want. The government is responsible for ensuring that the money that is spent on health is spent fairly and reasonably.

What do the Courts consider Access to Healthcare to mean?

In *Soobramoney v Minister of Health, Kwazulu Natal* (1997), the court decided that the Government does not have to provide free health care services to everyone. The court said that if a hospital or clinic has a limited budget, the hospital may prioritise who will receive treatment. Any decision taken by the hospital or clinic must be reasonable and justifiable in the circumstances.

In terms of the court's decision in the *Minister of Health and others v Treatment Action Campaign* (2002), the Government must aim to have plans in place that will ensure the progressive realisation of the rights of access to health care.

Topic
for discussion

Look at the Patients' Rights Charter at the end of this book and discuss how you can be involved in promoting patient rights.

RE-ENGINEERING PRIMARY HEALTH CARE

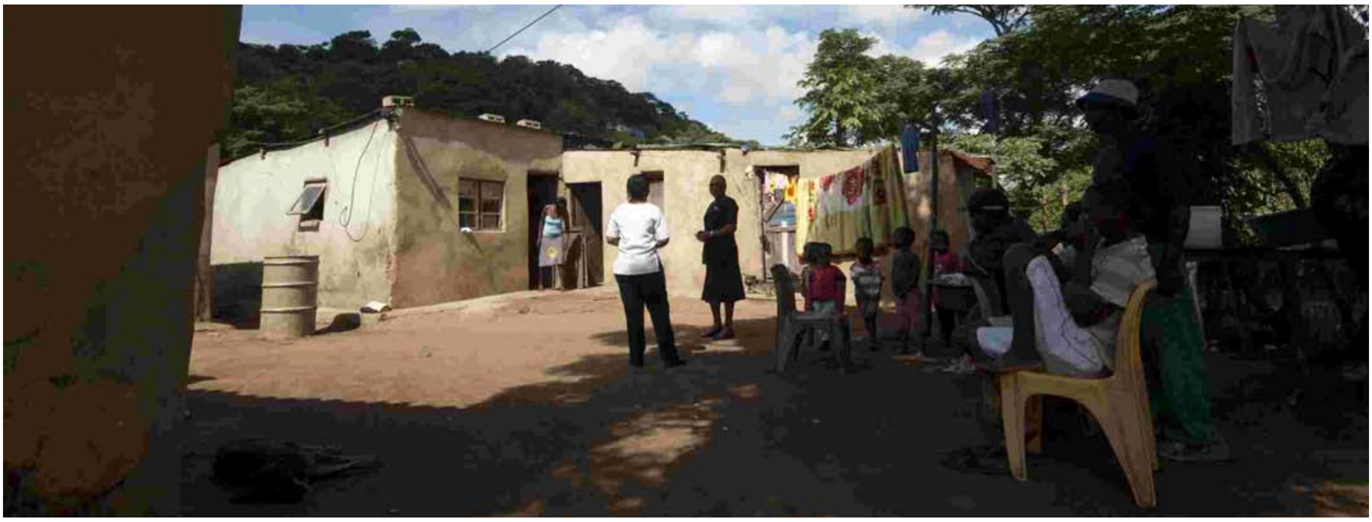
Implications for hospices of the Re-engineering PHC policy

It would seem that provinces are taking different approaches to the implementation of the re-engineering programme. It is important that the Hospice Palliative Care Association (HPCA) member organisations liaise with Department of Health (DoH) managers responsible for health at district and provincial levels to establish how they fit into the overall plan for health delivery in the local community.

Two key recommendations in the Government's re-engineering strategy are the strengthening of the district health system and the focus on community-based services, which include health teams where CHWs play a significant role. It is acknowledged that all organisations working in the health sector will need to collaborate in the provision of primary health care. The importance of a well-functioning referral system from community to clinic to district hospital has been stressed and it is recommended that emergency services and transport form part of a smooth referral process.

The two fundamental differences to the current PHC approach are:

- Responsibility and accountability for the health of the district lies with the DHS.
- The emphasis is on a proactive, team-based outreach into communities, with a focus on health promotion and the identification of those at high risk. Primary Health Care teams operating from the local clinic and made up of a professional nurse, a staff nurse and CHWs, will take responsibility for a number of households within a geographical area.



THE ROLE OF THE COMMUNITY HEALTH WORKER

Topic for discussion

Imagine that you have been appointed as a new District Health Manager.

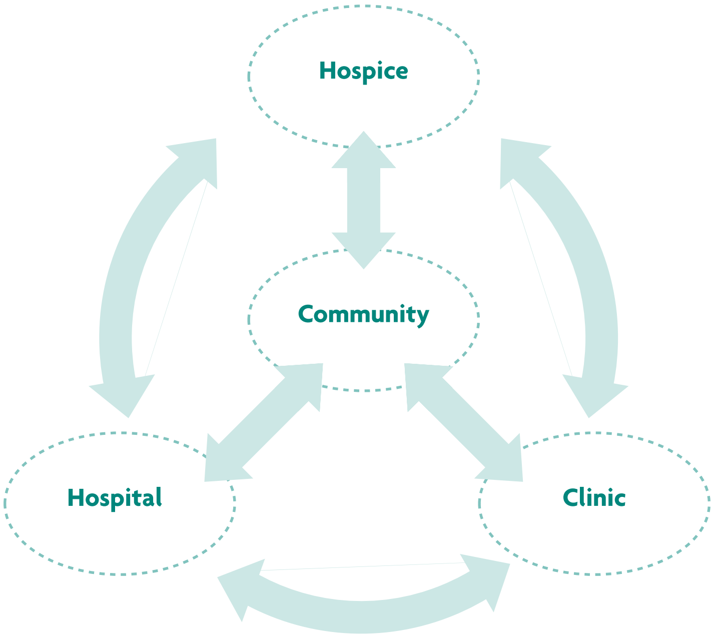
Make a list of the things you will do to make sure that the households in your district receive quality health care.

It is proposed that each CHW will take responsibility for 250 households and that a PHC team will consist of 6 CHWs, 3 staff nurses and 1 professional nurse.

The CHWs will have a wide range of roles which focus on health promotion. These include:

- Drawing up a map and profile of the community
- Doing household assessments, identifying health problems and making appropriate referrals
- Providing information and education to families
- Providing psychosocial support
- Participating in community campaigns and screening programmes in the community.

HOME BASED CARERS AND COMMUNITY HEALTH WORKERS WITHIN THE CONTEXT OF PALLIATIVE CARE



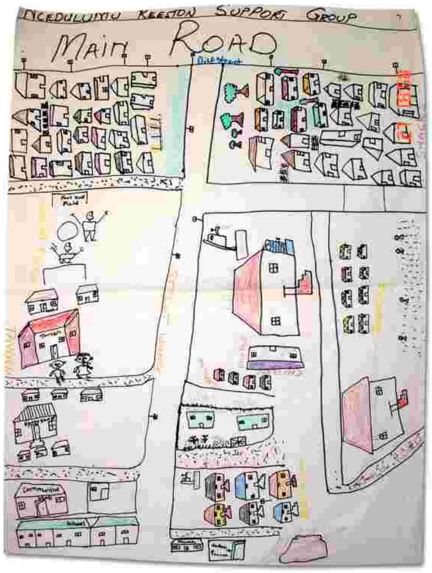
CHWs and HBCs - a key resource in local communities

Within a palliative care context, HBCs form part of a hospice's interdisciplinary team whose focus is on providing holistic home-based care in line with the World Health Organization (WHO) definition of palliative care. The Integrated Community Home Care Model, promoted by the Hospice Palliative Care Association, regards HBCs and CHWs as key resource personnel within the community.

COMMUNITY MAPPING

This activity below involves identifying all the organisations in the community that are involved in providing or supporting care and making a map of their positions in relation to your service.

The community maps below were made by HBCs working in the Eastern Province.



Topic for discussion

Make a community map of the area where your organisation works

- Which organisations do you network with?
- Are there others that you could build a relationship with?
- How will you liaise with the PHC teams in your area?

CARE-GIVING ACTIVITIES

Topic for discussion

Within the re-engineering of PHC, palliative care is seen as the role of "lay workers"

What could you do to promote the role of palliative care in the community?

A home-based carer and professional nurse visiting a patient in the community

Notes

HBCs visit homes in the community, often walking long distances in the heat or the cold, to assist with:

- Physical care such as bed bathing, mouth care, wound care, cleaning those with frequent bouts of diarrhoea, etc.
- Emotional support
- Training on infection control and waste disposal
- Training family members how to care for the sick person at home
- Securing relevant grants
- Referrals to clinics, hospitals and hospice programmes

When CHWs and HBCs become well known in their communities, there is a danger that the demands made on them, often after hours, exceed their skills and ability to cope. Their own families begin to suffer and the cost of care becomes too great to sustain.

Although many Community Based Organisations (CBOs) claim to provide palliative care, lack of resources within these programmes usually means that care is limited to basic nursing or supportive care. In order to provide palliative care in line with the WHO definition, it is essential that the following are in place:

- Training of home-based carers which needs to include home care, palliative care for both adults and children, infection control, psycho-social support as well as record keeping
- Job descriptions, contracts and remuneration
- Adequate equipment and supplies
- Professional supervision
- A referral system which ensures the availability of medication
- Caregiver support and on-going training

Friedman points out that often "lip service is paid to the importance of community-based programmes without a willingness to provide the type of support lent to hospital and clinic -based services". Where CBOs are expected to operate without any of the essentials mentioned above, it is little wonder that very basic support only can be provided.

Although they are collectively responsible for the bulk of the 'hands on' care provided in the community, HBCs and CHWs are currently not regulated by any professional council. This means that their work has to take place without the guidelines that a mandatory scope of practice provides. The ethical responsibility of promoting safe practice therefore falls upon the organisation to which they belong. The South African Nursing Council recognises the following categories of nurses:

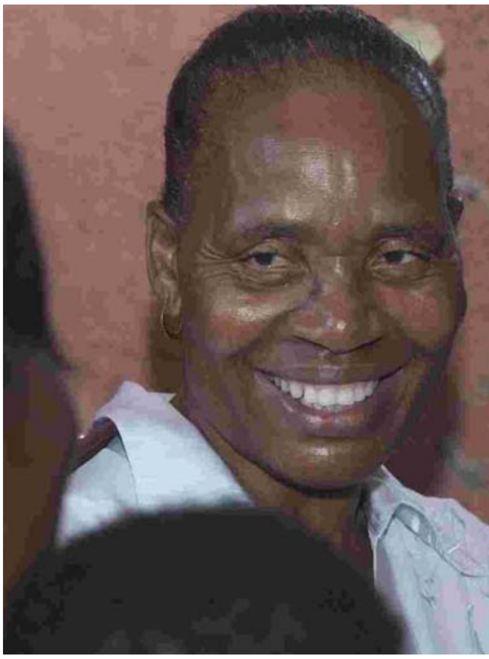
1. The registered professional nurse, who on completion of a minimum of three years training linked to a tertiary education institution, is awarded a diploma or degree and is allowed to practice independently within a prescribed scope of practice.
2. The staff nurse, who on completion of two years of dedicated training, works within a scope of practice that allows for very basic nursing interventions only to be provided without supervision by a professional nurse. The professional nurse retains accountability for the activities that she has delegated.
3. The enrolled nursing auxiliary, who after 1 year of training, is not permitted to provide even basic nursing care without professional supervision.

It is therefore apparent that to safeguard themselves as well as those entrusted to their care, HBCs and CHWs should be given adequate training, reimbursement, professional supervision and a proper job description.

PROFESSIONAL SUPERVISION AND MENTORSHIP

In order for any organisation to claim to provide palliative rather than supportive care, those providing home-based care need to be able to deal with issues of pain and symptom control. While HBCs and CHWs play a key role in identifying and referring distressing symptoms, pain management is beyond their scope and it is, therefore, essential that HBCs and CHWs are supervised and supported by professional nurses. The supervision of trained non-professional caregivers by professional nurses has assumed paramount importance in Africa. It is ethically inconceivable to accept that this category of healthcare worker should be allowed to function independently. It is the professional nurse who is responsible for the first assessment of the patient and for developing the care plan which the HBCs are involved in implementing. She is also responsible for supervising, supporting and teaching the HBCs and CHWs so that together they provide holistic patient care and family support.

When one considers the issue of professional supervision /mentorship and the benefits it provides for HBCs and CHWs, it is important to ensure that organisations train and support professional nurses in this role. Many nurses are unfamiliar with the scope of practice of HBCs and CHWs and they also report that while it is easy to give praise, it is a challenging task to discuss and deal with areas of conflict.



WHO PAYS FOR CARE?

While some Community Based Organisations receive funding from the Departments of Health or Social Services at national or provincial level, there remain many informal CBOs providing a range of health care services within their communities without any form of remuneration. Even when care is provided by volunteers, it is a mistake to regard it as a cheap option. The physical and emotional costs for those, usually women, providing care that is unpaid and under-valued are enormous. Whether it is acceptable to encourage unemployed people in poor communities to work as volunteers remains a contentious issue. As Friedman points out:

> *It is not surprising therefore that worldwide, most schemes which involve volunteerism are situated in predominantly industrialized countries or among upper/middle classes in developing countries, where people can afford to volunteer. Crucial prerequisites to this volunteering are time and money. A secure economic and social life makes voluntarism possible, even attractive... The reverse applies among volunteers from poorer settings where they are driven by the hope that it will lead to paid work or some other benefits ... Based on the burden that volunteerism tends to place on the poor, many view the intentional use of this strategy by health services as a form of exploitation.*

Friedman also makes the point that in small rural communities, there might be reciprocal benefits in helping one's neighbour but within an urban setting, driven by a cash economy, survival depends on some sort of monetary payment. As Margaret Legum, the Chairperson of the SA New Economics Network points out:

> *They [Governments] can intend, and effect, that people are paid closer to what they are worth, rather than what they must take because they have no alternative.*

Organisations providing care to people living with HIV/AIDS (PLWHA) and orphans and vulnerable children (OVCs) are unable to charge a fee for services and therefore are reliant on funding from donors, many of whom are reluctant to fund salaries. This point is illustrated by one care provider who recounted that when they included stipends in their proposal, the donor insisted that this budget item be removed or else the funding would not be granted.

At the time of writing, HPCA member hospices either employ HBCs directly or channel government stipends to the HBCs. Remuneration can therefore vary between a stipend of R500 and a salary of approximately R2000 per month. Viewing HBCs as employees means that they then have contracts, job descriptions and are bound by the policies and procedures of the organisation. This is particularly significant when one thinks of areas such as confidentiality, a key concern for PLWHA. An additional advantage is that attrition rates are lower, reducing the need for constant initial training of new HBCs.

CONFIDENTIALITY

In a landmark court ruling, *Jansen van Vuuren v Kruger* (1993), the court ordered a medical doctor to pay damages to a patient whose HIV status he had disclosed to another person without the patient's consent.

"It has changed because I can now tell people that when they have tested positive, it does not mean they are going to die, look at me, I drink ARVs but I am still alive, if you can have support, your families and not think that this is the end, you will be fine. I share my experiences with them and tell them how the treatment has helped me."

Refer to page 113 of Chapter 8 where there is also discussion of the rights of the child to keep their health status confidential.

Notes

It is imperative that the HBCs and CHWs are educated about the patient's right to privacy. Where the HBC or CHW works for an organisation and breaches the privacy of a patient during the exercise of her duties, the organisation may be held liable for the damages suffered by the patient. Section 14 of the Constitution provides that everyone has the right to privacy. Legal rules require that doctors, nurses, dentists, psychologists and other healthcare workers keep patient information confidential. Details about a patient's health status can only be disclosed to someone else, provided that the patient has provided his or her informed consent.

Lay counsellors also have to respect a patient's confidentiality even though they are not registered with a professional body. The common law of South Africa provides that all persons have the right to privacy, and this requires all persons to respect the privacy of information belonging to another person.

When can the patient's information be shared with someone else?

In South Africa, a patient's information can only be given to another healthcare worker if:

a) The patient consents

b) A court orders a healthcare worker to disclose the HIV status of the patient

c) An act of Parliament requires a healthcare worker to make a disclosure

d) After the death of a person, when the next of kin has given permission

e) A healthcare worker is allowed to disclose the status to another healthcare worker if the disclosure is for a legitimate purpose within the ordinary scope of the duties of the healthcare worker and where the disclosure is in the best interest of the patient.

"... our patients are alive because of counselling. We tell them about ARV [antiretroviral] drugs and now we have patients that were on wheelchairs but not anymore. Patients love us and appreciate what we do; they tell and refer other patients to us."

Community healthworker

COMMUNITY HEALTH WORKERS VOLUNTEERS OR EMPLOYEES?

One area of confusion is that there are conflicting messages from the Department of Health, which insists that the CHWs are volunteers, when stipends are paid via hospices, and the Department of Labour, which maintains that they are employees. The Department of Labour's Expanded Public Works Programme is one of the government's short-to-medium term programmes aimed at the provision of additional work opportunities coupled with training. Allowance is made for Expanded Public Works Programme projects to pay below the minimum wage as gazetted in the Code of Good Practice for Employment under the Special Public Works Programme, as this is a form of training on the job. However there is a concern that the lower rate of pay is applied not only to CHWs in training, but also to experienced CHWs who have completed training.

An employee is defined in the Labour Relations Act 66 of 1995 as:

- any person, excluding an independent contractor, who works for another person or for the State and who receives, or is entitled to receive, any remuneration
- any other person who in any manner assists in the implementation or conducting of the business of the employer.

Persons who do not receive remuneration will be excluded from the definition of employee.

Remuneration includes:

- payment in kind, which would include providing accommodation, food and other supplies
- non-cash payments or benefits given in return for services rendered

A person working in a charitable institution will only be regarded as a volunteer if such a person does not get paid. In terms of the scenario sketched above where CHWs and HBCs are either employed directly by the organisation or receive government stipends, which are channelled through the hospice, the relevant individuals will be regarded as employees in terms of the law and will be entitled to the protection afforded by the South African labour legislation.

The Caregivers Action Network was convened during the United Nation's 53rd Commission on the Status of Women, to ensure that community-based home-based caregivers were recognized in this annual governmental conference focusing on the Equal Sharing of Responsibilities between Women and Men, including caregiving in the context of AIDS. HPCA is a member of CAN which campaigns for better working conditions for community health workers.

For further information

See further details in the Resource Section.

"Sometimes they come and present with social problems, some will tell me about conflict in the house at home. I am a member of the community policing forum so I do assist where I can, but sometimes the problem will be food, we sometimes get food parcels because I am part of the municipality committee, so I help people where I can."

Community healthworker

ISSUES OF GENDER

See also Chapter 5 of this book for Gender considerations.

> *"The thing is we now have patients on ARVs, so we do follow-ups for those who miss return dates. We also do counselling, home-based care and drug readiness [training]. We rotate, for example if I do home-based care today, I do counselling tomorrow, just like that."*
>
> Community healthworker

Notes

1. The role of women is undervalued

Because women's activities are generally invisible in national income accounting systems, there is an assumption among ordinary people as well as policy makers that the supply of women's labour is unconstrained and flexible. It is assumed that women can adjust their time easily and rapidly between market work and household production. Thus, it is often assumed that in response to crises or illnesses, women's labour will be the adjusting variable (Elson 1994). When women are the primary carers in the household or work as volunteers in an organisation, the value of the time and effort required to perform this unpaid work is not taken into account in economic terms, despite its key contribution to communities and to the economy.

2. Burden of care falls on girls and women

An evaluation of home-based care in southern Africa found that 91% of caregivers are women. In addition to the burden of care, women have had to forego earning opportunities, resulting in a continued state of poverty within the family. Even when a HBC or CHW does receive a salary, it is often the only income supporting the family, and is low in comparison to rising costs. In addition, there is often uncertainty about continued funding for HBC and CHW stipends or salaries, creating anxiety about the lack of job security.

3. Loss of educational opportunities for young girls

Many young girls are forced to leave school to care for a sick family member, thus forfeiting the chance of an education and future employment prospects. In terms of section 29 of the Constitution, everyone has the right to basic education. Where young children are forced by circumstances to leave school to look after ill family members, these learners have no hope of exercising their right to education. In terms of the South African Schools Act 84 of 1996, children are compelled to attend school from the year in which they reach the age of seven to the last school day of the year in which they reach the age of 15 or the ninth grade, whichever occurs first. The problem with these rules is that the Department of Education is not monitoring whether the children, who are compelled in terms of the law to attend school, are in fact in school. If the Department monitored the situation, there would be a much clearer perception of the number of children who are not attending school. It is also necessary to recognise the impact of placing the emotional burden of care and household duties on children who are too young to assume these responsibilities. Involving more boys and men in care responsibilities would make a significant contribution to changing traditional attitudes towards what are perceived as gendered responsibilities and thereby lessening the burden on girls and women.

4. Difficulties as a result of cultural norms

Regardless of how well trained HBCs and CHWs are, it can be awkward for a young black woman to provide care to an older man because of cultural norms and expectations. It is particularly unacceptable for her to suggest to a man that he engage in safe sexual practices. In the rare cases where there is a male caregiver on a hospice team, it is not unusual for him to feel that he should assume seniority and ask his female counterparts to do the more menial tasks, simply because of his gender.

CARING FOR CARERS

There is a crucial need to recognise that HBCs and CHWs need support to deal with their own emotional needs. The fact that many of those providing care are, themselves, HIV positive, with similar needs to their patients, means that the need for support is even more crucial.

The stress and fatigue that these carers experience is heightened by:

- stigma and discrimination
- the emotional stress of repeated losses
- the physical strain of having to walk long distances to reach patients
- the lack of adequate training, protective clothing and gloves

Caring for caregivers can consist of many interventions to reduce stress such as:

- providing training so that HBCs and CHWs feel more confident
- providing leisure time
- providing reasonable payment so that financial burdens are lessened
- organising debriefing and team-building sessions
- empowering them by allowing them to participate in the decision making process

> "Who cares for the carers, and why is it taken for granted that women provide, and will continue to provide, care and support to family members and loved ones, with no sense of the cost and value of this work to society and the economy in general?"

Topic
for discussion

What does your organisation do to care for its carers?

CAREER PATHWAYS

The National Qualifications Framework (NQF) makes provision for various levels of training, including home care, palliative care, caring for people with disabilities as well as health promotion. It is hoped that when the re-engineering of Primary Health Care is implemented, there will be career options for those currently working as Home Based Carers or Community Health Workers.

> *"We are working so hard, we make sure we do our work perfect but no one sees that. Yes, we are volunteers but we need someone to say thank you for what we are doing. We need to be appreciated, that alone will mean a lot to us."*

CONCLUSION

The proposed re-engineering of primary health care will have a significant impact on the provision of health care at community level. It is essential that organisations providing palliative care position themselves within the district health model, so that palliative care is included in the services available to households. Home Based Carers and Community Health Workers play a vital role in the provision of care to many who would otherwise have little access to any form of assistance. However, this care comes at a cost to the patient, the family, and to all the carers, which makes it is essential that government and donors

- firstly acknowledge the critical role that caregivers, particularly women, are playing
- secondly provide the financial support needed so that palliative care for all who need it becomes a reality.

Comments by community healthworkers quoted in this chapter were taken from the research paper by Schneider et al, 2008: *Community health workers and the response to HIV/AIDS in South Africa: tensions and prospects.*

See the Bibliography for further information.

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CHAPTER 12

Dying and The Law

INTRODUCTION

‘Because people do not like to talk about death, especially their own death, their silence causes lots of problems.’

‘The stigma of having HIV affects the way people talk to their families and this means that they don’t make any plans for when they are not around. The sick person says to us as their caregivers, `Don’t tell them (the family) that I am HIV until I die, even if they ask you every day don’t tell them anything.’

Caregivers’ stories from Soweto and Pietermaritzburg

Topic
for discussion

In small groups, 2-3 people per group, read the stories and answer these questions:

a) Have you ever come across similar experiences in your work?

b) What do you think of the different approaches taken in each of these stories?

c) Do you think it is important to build a trust relationship in similar circumstances to those described above, why?

Death is an inevitable fact that we will all need to face at some point in our lives, be it our own death or the death of a loved one. What is also inevitable is the grief that we will encounter as a result of losing someone who is close to us.

Because we all cope differently with loss, it is important to think about ways in which we can protect ourselves and our loved ones from the additional administrative and financial burden that occurs after someone has passed away.

It is also important to encourage family and friends to start talking about ways in which families and loved ones can prepare for the loss of their loved one.

Families and friends should think of building a network of support; where there are people they can rely on and trust during times of loss and sadness.

Talking about Death

Sometimes people are not comfortable talking about death and this can have a negative impact on sorting out a person’s affairs before they die. Here is a short exercise to rate your own response to the topic of death.

1) Consider the question `*I can talk quite openly about death.’* Answer yes or no to this question.

2) Now using a scale of 1-10, rate how comfortable you will be in each of the following situations:

A I can talk quite openly about the death of a stranger/someone I do not know.

B I can talk quite openly about my own death.

C I can talk openly about the death of my parent or loved one.

Building a Trust Relationship

Home-based palliative care services support patients and their families in preparing for the death of a loved one. This support is most effective when the patient and family have developed a relationship of trust with their carers, since without this trust relationship many problems can arise.

The following stories were told by caregivers who were working in Soweto and in Pietermaritzburg:

Story 1

‘Hey this one is a big problem (when people are not talking about death) you will find that the parents, when they passed away, they don’t even tell the family where the children are supposed to go. They die and the children are left in the house and sometimes you find that, most like, the uncles they come to fight for the property. They want to take away the property. Others they want to chase the children away, you find those children living in the street.’

Story 2

‘Just from a family point of view they are sitting with a dilemma where the mother is terminally ill and preparing the children will normally happen after the death of the mother. So before the mother dies we test the process to find out what it would be like, because it’s very painful on that day. We try to prepare the child in the context of the mother not being around any more, like we may send the child to the father beforehand, so that the child can gradually get used to the father and the father’s home.’

Estate Planning – putting proper plans in place

Often after the death of a family member, people are confronted with overwhelming and confusing administrative challenges.

One of the most simple, yet common challenges facing the family of a deceased person is the lack of correct documentation such as a missing:

- identity document
- birth certificate
- marriage certificate
- Insurance policy

Not having the correct documentation adds to the administrative burden of the deceased's family because they will need to sort out the missing documentation after the person has died.

If proper plans are put in place when we are well and our minds are still clear, the stress of coping with such challenges is greatly reduced. Simple preparation before death – called estate planning – helps with making decisions about:

- What documentation is necessary
- Where your important documents are to be kept.
- What you would like to have in place for your loved ones after you are no longer around to care or provide for them.
- The importance of having a will /or not. At least providing adequate instructions about the property that you own, your savings accounts and other financial investments such as a pension or insurance.

> 'The old man never had an ID so when he was killed the mortuary treated his body with no respect and they refused to keep his body at the mortuary. We had to run around and find the chief in his area who would allow the old man to be buried quickly because the mortuary wanted to throw him out. Luckily we found his birth certificate.'

Terms you will find in this chapter

Administration: organising and taking care of paper work and office tasks

Assets: property you own such as your house, your car, your furniture, your books and your money. Your assets can help to pay off any outstanding debts.

Best interests of the child: If there is a conflict between the child's interest and the parents' rights then the child's interest comes first

Burial order: an order that is made once the death has been registered. This allows the person to be buried.

Care: The day-to-day care and personal growth of a minor child. Making sure the child is fed, clothed, healthy, loved and nurtured.

Customary succession: inheriting according to traditional African law.

Death notice: a government form that needs to be filled in by someone who knows the personal details of the deceased and is able to identify the deceased.

Death certificate: this is a government form issued by the Department of Home Affairs. A funeral director or undertaker can help you get one.

Debt: money you owe to someone, referred to as liabilities when dealing with deceased estates

Estate: all the things and the money owned by the person who has died – sometimes referred to as a deceased estate

Executor: the person, appointed by the Master of the High Court, who winds up and administers the deceased estate, helping with the distribution of the property. making sure your property is divided up according to your wishes as set out in the will. See executor's duties.

Formalities: set rules that must be followed to make something legal

Freedom of testation: people have the freedom to decide what they want to do with their property after they die

Guardianship: the legal responsibility of a minor child.

Heirs: a person who inherits

High Court: the supreme guardian of all children

Inheritance: property, belongings or money left to someone by a deceased person

Intend: you mean to do something and you understand what you are doing

Intestate: dying without a will

Marital regime: the type of marriage contract that you have entered into with your spouse (see inset below)

Master of the High Court: government official with the duty to oversee the proper administration or proper winding up of deceased estates. There is a Master's Office in every province

Spouse: the person to whom the deceased was married. This will be the husband or wife, or partner in a same sex marriage

Testate: dying with a will

Trustee: a person appointed by the High Court to take care of a child's/person's estate

Winding up: closing down a person's estate, a person's property

Notes

Dying with or without a will

After someone has died, there are two ways in which the law provides for the distribution of the deceased person's property.

One is when a person prepares a will before his/her death.

This is called testate succession.

The other is when a person dies without a will and we call this intestate succession.

Leaving a will is very important if :

- you have your own property
- if you have young children

When preparing a will

When preparing your will it is important that you write out your wishes with great clarity and care. Remember you are putting your wishes down in writing so that any person reading the will can understand it after you are gone.

If certain legal requirements are not met, then the Master of the High Court could reject your will and he or she will use the law of intestate succession (explained later) to distribute your possessions. This is why you have to be very careful about making a will.

If you write your will properly there will be no arguments after your death and members of your family will not be forced to go to court to sort out any problems as a result of an unclear will.

Freedom to give your property to anyone is not absolute

The law recognises that people have a right to give their property to anyone they choose and this right is called the person's `freedom of testation'. These rights of `testation' are not absolute, as there are certain legal provisions that need to be followed and applied when minor children or spouses are involved. This is because, in South African law, a minor child and a surviving spouse are able to claim maintenance from a deceased estate – that is if there is any money in the deceased estate after the bills have been paid.

If you die without a will, the executor or the Master of the High Court will not be able to follow your wishes even if you spoke to your loved ones about your property before you passed away.

This means that if your wishes are not written down and certain set formalities have not been followed, legal rules will apply and your property will be distributed in terms of the Intestate Succession Act of 1987, as amended.

In this next section we are going to discuss what the law says and what preparations should be in place when faced with death. We will also look at some problem situations and some new changes to the law, particularly the law dealing with customary rights and marriage.

Case Study

Mrs. Laher, a car guard, tried for many years to secure maintenance from her husband for herself and her three children. Eventually the court ordered that his furniture be attached and the rental income from one of his properties be paid to Mrs. Laher to recoup the maintenance monies he owed. Before this order could be enforced, Mrs. Laher's husband died. After his death, his family came and took all the furniture out of the house and took over the property so that Mrs. Laher could not access it.

Topic
for discussion

Solve the problem:

Read the story and break into groups of 3-5.

In your groups discuss:

a) Whether Mrs. Laher has any legal rights

b) What steps can Mrs Laher follow in order to solve her problem?

DYING WITH A WILL - TESTATE SUCCESSION

As already mentioned, every person who owns property or has minor children should have a will as this will protect their loved ones from the additional worry of dealing with legal or administrative problems at a time when they are grieving. A will is a legally recognized document that formally sets out a person's wishes. This means that in a will you can put down:

- who you want to leave your property/money/belongings to,
- the amount you wish to leave to each person,
- specific instructions about your burial or cremation,
- who you will entrust with the administration of your estate after your death.

People need a will that has been properly drafted and executed and it must be drawn up before you die. This means that it must be in writing and must follow the formalities that have been set out in the Wills Act 7 of 1953, as amended. Having a will in place can go a long way toward reducing stress and giving a person peace of mind because there is this understanding that his/her wishes will be followed after his/her death. Although making a will is an important legal act it can be a relatively easy exercise.

If your wishes are simple and uncomplicated you DO NOT have to ask an attorney or a bank to help in writing up your will.

Everyone over the age of 16 years can prepare a will, as long as they know and understand what they are doing. You also need to be mentally capable of understanding what you are doing at the time you draw up your will. This means that you are clear headed and can remember who you are, what you own and to whom you want to leave your belongings after your death. You also need to make sure that you sign your will in front of two witnesses who are over the age of 14 years and who can sign the will in front of you as well. (see formalities on page 171 of this chapter).

Making a proper will needs careful planning and writing. A will does not have to be typed and it can be in any language as long as it can read clearly by someone else. In a will you can leave anyone your property/belongings. Firstly you need to make sure that the property is yours to give away. You also need to think about any debts you may have. If you have not paid off your debts, the money you owe will be taken out of the estate first and then the remaining amount – if any – will be paid to your heirs.

You need to ask yourself a number of important questions before sitting down to write your will:

1. Whether you have minor children (children under the age of 18 years) or dependents. If so, what plans do you have for their care and future wellbeing?
2. Who you would trust to take care of the administration of your estate after your death? This person will make sure your property is divided according to your wishes after your death and is called an executor or administrator. Their duties will be discussed a bit later on in this section.

Whether you are married, and if so; your marital regime: are you married in community of property; are you married in terms of an ante-nuptial contract, a civil union or do you have a customary law marriage? *(see box – What do we mean by marital regime?).*

What do we mean by marital regime?

In South African civil law there are three matrimonial property systems/regimes. They are:

- Marriage in community of property where both parties share a joint estate. This is the system that automatically applies if you do not draw up an ante-nuptial contract.
- Marriage out of community of property where both parties have separate estates. You have to draw up an ante-nuptial contract before the marriage.
- Marriage out of community of property with accrual -you have to draw up an ante-nuptial contract before the marriage. The difference is that both parties have separate estates, but to stop any unfairness they share in the accrual at the end of the marriage. Accrual is the accumulated profits they may make during their marriage.

Note:

1) Customary law marriages are recognised in our law. The Recognition of Customary Marriages Act of 1998 gives full legal recognition to customary marriages as long as they are registered at Home Affairs. (A customary law marriage is not `the same' as a civil law marriage)
2) Same-Sex Unions are now also recognised in our law. The Civil Unions Act No 17 of 2006 states that a civil union is, `the voluntary union of two persons who are both 18 years of age or older, which is solemnised and registered by way of either a marriage or a civil partnership, in accordance with the procedures prescribed in this Act, to the exclusion, while it lasts, of all others'.

Topic for discussion

Do I need help to write my will?

Guidance for discussion

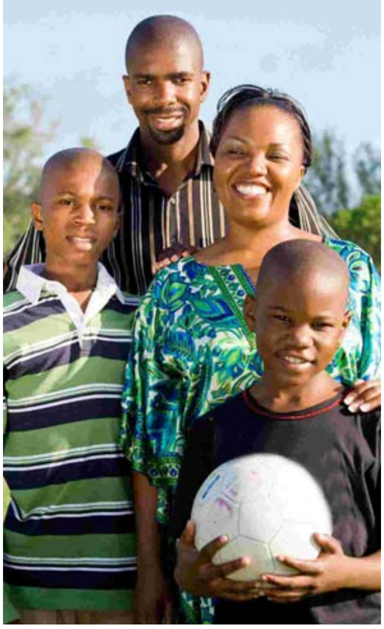
Think about your own situation when responding to this question:

- Do you have children, a spouse, property that is in your name?
- Is your personal situation quite complicated or very simple?
- Your responses can determine whether you will need help or not in writing up a will.

For further information

Legal Aid Adviceline
0860 534 258 / 0800 110 110
(Toll free from a landline)

Refer to the Resources section at the end of this book, for a list of contact details for legal services.



Seeking assistance to draw up a will

Wills may be very simple or may be very detailed. The detail depends largely on the number of assets that you own.

In what circumstances do I need help to draw up my will?

- If you have a number of assets
- You are worried about tax implications
- You plan to set up a trust to take care of your children

then you really do need to seek the assistance of an expert, usually an attorney.

Who can help me draw up my will?

1) Attorneys
2) Legal Aid
3) Banks

If you need help or advice about drawing up your will, there are several places where you can go to seek expert advice. Some experts may charge a fee to draw up your will, some will not.

1) Attorneys

If it's a simple will, an attorney should not charge you very much and you can and should discuss beforehand the amount they will charge.

2) Legal Aid

There are various services available for people who cannot afford to pay for lawyers. Unfortunately not all these services will help with drawing up a will or winding up a deceased estate. You will need to check with them first. These are:

- Legal Aid SA and Justice Centres
- Law clinics at various universities in South Africa
- Legal Resources Centre
- Community law centres and/or paralegal advice offices
- Black Sash

3) Banks

A bank can help you draw up your will but the bank may charge you for this service. A bank may charge less to help draw up your will, if you nominate the bank as your Executor or if you request that the bank assist your Executor.

If the bank acts as your Executor they may charge an annual fee to keep a copy of the will for safe keeping and you should keep the duplicate copy in a safe place of your choice.

If your will is simple

You can:

- Draw it up yourself
- Ask one of your children or friends who you trust to help you.

You are not obliged to leave them something in your will just because they helped you in the writing of the will.

An important note: Always be careful of people who offer to help write up your will for free and then suggest you leave them something in your will.

Changing your will

You may change your own will at any time before you die.

How can I change my will?

You can either:

- cross something out and add something into your will
- or make a new will.

If you cross something out and add something into your will then you and two witnesses must sign as close to the change as possible.

If you make a new will, in other words, you replace your old will with a new one, then the proper way of doing this is to state, in the new will, that all previous wills are cancelled or revoked.

A testator (the person whose will it is) can even destroy his/her will any time before his/her death.

The person changing, destroying or making a new will must:

- want to make the change
- not be persuaded or forced to do so
- he/she should also be mentally alert at the time the changes are made.

Formalities of a valid will

A will must comply with the following formalities:

- The person writing the will (testator) must be 16 years or above.
- The will must be in writing.
- The will must be signed by the testator and if there is more than one page the testator must sign every page.
- The testator must sign the will in front of two witnesses.
- The two witnesses must also be of sound mind and over the age of 14 years.
- The witnesses must sign the will in front of the testator and they should not be due to inherit anything from this will.

Drawing up a will

- Give your full name with your identity number and your address.
- Say what your marital status is, and if married, state your marital regime. Give the name and identity number of your spouse.

Are you single, married, divorced or widowed?

- Write down that this is your last will and testament and that you revoke (cancel) all other wills that you have made before this one.
- Name someone you trust to take on the administration of your will (carrying out your wishes) – an executor. You should ask the person first before naming them as your executor in the will. If you do not select someone, or if the Master thinks that the person you have chosen will not be able to do the administration properly, then the Master may select someone for you.
- You must also say that the executor does not have to pay any money when she/he accepts the position of executor. This is called an `exemption from paying security'.
- Make it clear how you want your property to be dealt with. Write down who will inherit each of your possessions. Give details such as their full names, addresses and whether they are male or female, married or unmarried.
- Always think of your minor children. If you have minor children, you need to think of someone you trust who can act as their guardian. This person must be able and willing to be their guardian. If it is possible, an expert such as a bank manager, an accountant or a lawyer should be consulted when there are minor children.
- When you are finished, write the date and sign the will, in full, in front of the two witnesses – you must sign the will as closely as possible to the last line of writing in the will. This is to stop anyone from adding anything onto your will.

WARNING
A person cannot inherit if s/he signs as a witness. This is to stop people from committing fraud or the court thinking that they may have committed a fraud.

- Both witnesses must sign, in full, after your signature on the last page.

Unless your will includes an 'exemption from paying security', the Master will normally require the Executor to submit a bond of security. This is because the Executor is responsible for your assets. If you appoint your parent, your child or your spouse as your Executor, they do not have to submit a bond of security. Remember that despite your wishes in your will, the decision to request a bond of security is at the Master's discretion.

Example of a simple will

LAST WILL AND TESTAMENT OF Kase Mdu (ID number)
of 25 Malibongwe Drive, Randburg, Johannesburg.

1. I hereby cancel all wills made by me before this time,
2. I appoint as executor of my estate my sister, Suni Sunn, of 10 Moss Street, Burgersfort. I do not want my executor to pay any security.
3. I leave R5 000.00 to my friend, Sbu Khosa, of 9 First Avenue, Malvern, Johannesburg.
4. I leave my car to my daughter, Akhona Mnisi, of 201 Green Street, Acornhoek, Limpopo Province.
5. I leave the rest of my property to my wife, Agnes Mdu, with whom I have a customary law marriage which is registered in terms of section 4(1) of Act 120 of 1998, and if she does not survive me, I leave the rest of my estate to my brother, Gideon Mdu,
6. Should my wife die before me, I would like to appoint my brother, Gideon Mdu, as the guardian of my minor son, Mpho Mdu.
7. I would like that, on my death, any of my organs to be used for purposes of transplant to help another living person. I direct that my executor may have the authority to decide in this matter.
8. I would like to be cremated.

Signed by Kase Mdu on this day of 29th October 2006 as the testator of this will in the presence of two witnesses.

Testator. ______________________

Witness 1. ______________________

Witness 2. ______________________

Note: as long as the heirs are clearly identified, a will remains valid.

Even if the date, identity numbers or addresses are left out the will remains valid.

The problem is that the Master of the High Court will then have to ask for the addresses of the heirs and if the date is missing it may be difficult to find out when the will was written.

Notes

Topic
for discussion

These may be considered controversial

1) Does organ donation save lives?
2) There is a shortage of land for burials. Wouldn't it be better if we were all cremated?
3) What do you think of having a video will?

Note: If the Testator (person writing the will) thinks their Executor may need help to administer the will, then this clause should be included in the will: I direct that my Executor shall have the power to appoint a professional to assist him/her.

DYING WITHOUT A WILL: INTESTATE SUCCESSION

When a person dies without a will, the law of intestate succession provides a number of steps that must be followed by the Master's Office in order to distribute the deceased person's property and possessions. The Intestate Succession Act of 1987, can be a very difficult Act to follow if it is not clearly explained.

A short excerpt of the Intestate Succession Act is given below:

1.(1) If after the commencement of this Act a person (hereinafter referred to as the`deceased') dies intestate, either wholly or in part, and-

(a) is survived by a spouse but not by a descendant such spouse shall inherit the intestate estate:

(b) is survived by a descendant, but not by a spouse, such descendant shall inherit the intestate estate;

(c) is survived by a spouse as well as a descendant-

(i) such spouse shall inherit a child's share of the intestate estate or so much of the intestate estate as does not exceed in value the amount fixed ....by the Minister of Justice... whichever is the greater; and

(ii) such descendant shall inherit the residue (if any) of the intestate estate;

(d) is not survived by a spouse or descendant, but is survived-

(i) by both parents, his parents shall inherit the intestate estate in equal shares; or

(ii) by one of his parents, his surviving parent shall inherit one half of the intestate estate and the descendants of the deceased parent the other half, and if there are no such descendants... the surviving parent shall inherit the intestate estate; or

(e) is not survived by a spouse or descendant or parent, but is survived –

(i) by –

(aa) descendants of his deceased mother who are related to the deceased through her only, ...by descendants of his deceased father who are related to the deceased by him only; or

(bb) descendants of his deceased parents who are related ...through both such parents; or

(cc) any of the descendants mentioned in...(aa) as well as ...(bb), the intestate estate shall be divided into two equal shares...

And so on... .

The surviving spouse will receive the same share of the property as the children or R125 000.00, whichever is the most, and the children will share the rest.

Note: *This means that if you have no will your spouse (wife/husband/partner) will get all the money if you have the amount of R125 000 or less.*

What happens if you die without a will
The Intestate Succession Act explained

A simple explanation of the Intestate Succession Act is as follows:

- If you are married but you have no children then your surviving spouse will inherit everything.
- If you have children but no spouse then your children will inherit equally.
- If you have a spouse and children then the children and your spouse will inherit equally depending on how much money you have left after following a formula set down in law: Remember that children means all children, including illegitimate children – children born outside a legal marriage.
- If you have no spouse or children the estate will be equally divided between your parents.
- If you have no spouse, no children and no parents your estate will be equally divided between your brothers and sisters.
- If you have no spouse, no children and no brothers and sisters then your estate will be equally divided between the blood relatives who are closest to you.
- If you have no spouse, no children, no brothers, no sisters and no relatives your estate will go to the state.

Exercise

Read the following stories

Scenario 1

Mr Sibanda dies without drawing up a will. He left:

- his wife, Mary
- three children, Nkhosi, who is 5 years old, Bernard, who is 10 years old and Thandi, who is 19 years old.

After all his debts have been paid off, his estate adds up to R260 000.

Question

How much will Mary, Nkhosi, Bernard and Thandi inherit?

Note: *In this example the marital regime has already been sorted out, the exercise is only looking at the intestate estate.*

Scenario 2

Kevin forgets to make a will. After his death the Master has to devolve his deceased estate.

Kevin never married and he had no children. He did have a brother and a sister, Connie and Brandon, and a half brother Martin, who was his mother's son from a previous marriage. Although his father has passed away, his mother is still alive. Kevin leaves an estate of R700 000.

Question

Who will inherit?

After reading the above scenarios

a) Draw a diagram showing the lines of inheritance for each senario.

b) Give reasons for the answers you gave to Scenario 1 and Scenario 2 i.e. Who do you think will inherit and how much will they inherit?

Answers to Scenario 1

Follow the procedure step by step:

i) Mr Sibanda has left a wife and three children. In terms of the law the surviving spouse, Mary, will either get an equal share of the property, as a descendant, or R125 000, whichever is the greatest amount.

ii) If you divide 260 000 by 4 (wife plus 3 children) = 65 000. This is an amount that is less than R125 000. Check the law. The wife must get the greater amount.

iii) The wife Mary will therefore get R125 000. The three children will share the remaining amount in equal shares

iv) 260 000 – 125 000 = 135 000, which is the remaining amount. This amount must now be divided by 3 which equals R45 000.

v) Each child will receive R45 000.

Answers to Scenario 2

Follow the procedure step by step:

i) Kevin has no spouse and no children but has one surviving parent and descendants of a predeceased parent.

ii) The surviving parent inherits half of the estate. The estate is divided in half: R700 000 divided by 2= R350 000. Kevin's mother inherits R350 000.

iii) The remaining R350 000 will be divided amongst the descendants of the predeceased parent. This means that Connie and Brandon will share R350 000 equally and receive R175 000 each.

iv) Martin is related to Kevin through his mother Mary and will inherit nothing.

Notes

CUSTOMARY LAW OF INHERITANCE

Intestate succession in terms of African Customary Law is based on the principle of primogeniture. What primogeniture means is that:

Only a male, who is related to the deceased through the male-line, is entitled to inherit.

An example of this is where the eldest son of the senior wife or his descendant, if he is dead, usually takes over as the head of the house when the head of the house dies. In this way, the formal customary law of succession discriminates against women and children by excluding them from their rightful inheritance.

Often what happened was that, after the death of the adult male, the widow and the children were thrown out of the family home and the widow had very little legal protection.

> A will written by the adult male before he dies protects his wife and children from such a practice. See page 183 and the example of a Simple Will on page 184 for guidance on drawing up a will.

In response to the unfairness that was the result of certain discriminatory situations, changes have recently taken place that directly impact on the customary law of inheritance and the rights of women and children.

In the Constitutional Court decision of Bhe and Others v Magistrate Khayelitsha and Others 2005 (1) SA 580, a ruling was made that certain laws, dealing with the administration of black estates, were unconstitutional because they discriminate against women. This decision has had a far reaching impact on the future administration of black estates, and new laws have been developed and debated. In South Africa a new Act has been recently passed and is called the Reform of Customary Law of Succession and Regulation of Related Matters Act 2009.

Notes

Case Study

Bhe and Others v Magistrate Khayelitsha and Others 2005

The Bhe case concerned two young girls, aged 9 and 2. The customary rule of primogenture that prevented them from inheriting their father's property, because of their female gender, was challenged on their behalf.

The girls had been living in Khayelitsha with their parents until their father's death. Even though the parents had been together for twelve years, the parents were not legally married. After their father had died, the family continued to live on the property until their grandfather told them to leave.

The grandfather claimed that under African customary law, the house should now be the property of the eldest male relative of the father's children. This meant that, in terms of the rule of primogeniture, the family house would become his property and he then planned to sell it.

The court decided in favour of the girls and against the grandfather since this was a clear case of African females being discriminated against. The two girls were declared to be the sole heirs of their father's estate and were given the right to inherit equally.

Topic
for discussion

What do you think of the outcome of this case?

The Court decided that certain laws, dealing with the administration of black estates, were unconstitutional because they discriminate against women. This decision has had a far reaching impact on the future administration of black estates, and new laws have been developed and debated. In South Africa a new Act has been recently passed and is called the Reform of Customary Law of Succession and Regulation of Related Matters Act 2009.

TAKING CARE OF THE CHILDREN

'People want to grab children when there's a funeral - because there's money attached to a child - and there's no-one to monitor whether the children go to school or not because the social workers does not go out there. NGOs do their best to monitor, but really they cannot help much. Its very complicated that's when you need the legal process to keep an eye on things and make sure the children are being taken care of.'

Notes

The Guardian's Fund falls under the Master of the High Court and the fund is to protect the the financial and property interests of minor children.

If you decide to draw up a will you need to provide for a legal guardian or even find a trustee for your minor child. The Children's Act 2005 says a person can become a child's guardian if elected in a will that was written by the parent/s or primary caregiver, as long as that selected person is a 'fit and proper person'.

Remember that before you nominate a person in your will you should consult with your family and also with the person you would like to nominate.

Explain clearly what you want for your child or children, always thinking about what would be in the best interests of the child. Keep your child's birth certificates, medical records, school reports with your will or with all your other documents such as identity documents (IDs), work information and insurance information.

Do not leave your money or property directly to minor children, unless there really is no-one you trust or no-one who is prepared to help with the children. If you put your property directly in the hands of your minor children and do not name a guardian to take care of their affairs, then the state will administer their property through the Guardian's Fund. This means that each time the children need money, the person who is caring for them, will have to write a letter to the Guardian's Fund motivating why they need the money. This caregiver will also have to show proof of all the expenses. It can be a very time consuming and frustrating process.

If you do have some money and you would like to leave it to your minor children, then plan what you would like to do in advance. Go to a lawyer or a bank and ask them about creating a trust for your minor children.

A trust can provide the following for your children (if there is enough money):

- Day-to-day care of the children
- Education needs

Maintenance Claims of Minor Children

Both parents are responsible for the maintenance of their minor children. If a parent dies this responsibility for maintenance continues and is then shared between the surviving parent and the estate of the parent who has died. When this happens that child's guardian, as the child's representative, will claim maintenance from the executor of the deceased estate. The claim usually takes the form of an agreement between the guardian and the executor and must be approved by the Master and/or the court.

There are many ways to claim the maintenance from the deceased estate. Payment can be made in the form of a single lump sum (which is usually paid into the guardian's fund where it will be administered for the child's benefit), or by forming a trust if a court order provides for it. As soon as the child is able to maintain him or herself or becomes a major, usually when reaching majority (18 years) the duty to pay maintenance falls away.

Winding up the deceased estate

The administration of a deceased estate is a step by step process that needs to be followed in an organised manner as it is not an easy process. If each step is carefully followed, the estate can be wound up fairly quickly.

The estate must be wound up (closed down) by the Master's Office of the High Court in the province where the deceased lived. There are 14 Master's offices in South Africa and there are also service points at all magistrates' courts throughout the country. These service points are responsible for the administration of small simple estates. The first steps that need to be taken by family or friends after a person has died are as follows:

1. After reporting the death to Home Affairs you will receive the appropriate documentation to proceed with the burial or cremation of the deceased. Once the burial/cremation has taken place you will then need to start sorting out the property of the deceased person.
2. If the person who has died has left some property behind, you are expected to report his/her death to the Master's Office. This needs to be done within 14 days after the person has died. You need to send a death notice to the Master's office. A family member or friend can do this. If the death did not take place at home, then the official from the building where the death occurred can do this.
3. A death certificate needs to be issued if the person who signs the death notice was not present at the death or did not identify the body after the death.
4. The Master's Office will give the family forms to fill in, these are necessary for winding up the estate of the deceased. The Master's Office will also require certain documents from the family such as the deceased's identity document, a marriage certificate (if married) and a will, if there is one.
5. The Master will then decide whether an executor or administrator will be needed to assist in winding up the deceased estate.
6. If the estate is a small estate and is less than R50 000, a family member or some other representative can wind up the estate on their own.
7. If the estate is worth more than R50 000 but under R125 000, the Master will decide whether an executor should be appointed to help with winding up the estate.
8. If the estate is more than R125 000 the Masters Office usually says that an executor must wind up the estate.
9. If an executor has not been appointed, the Master will appoint one.

When is an Executor or Administrator appointed?

If the estate is not complicated or is a small estate falling under R125 000 the appointment of an executor is not always necessary. This is when an administrator can be appointed by the Master of the High Court and we call this a section 18 (3) appointment (informal process). The Master of the High Court will issue 'letters of authority', giving this person the power to administer the deceased estate. This means the administrator acts as the Master's representative and will administer the deceased estate by collecting together all the assets and debts for the deceased person. Winding up a small estate is very simple and the Master leaves this entirely up to the administrator to complete. The Master is still able to ask for proof of how the estate was sorted out. Once the Master is satisfied with the administration of the estate, the Master will close the account.

When a person dies, the property of the deceased person does not go immediately to the heirs. It must first go to the executor or administrator who will then pay off the debts and then divide the rest of the inheritance between the heirs.

Notes

A death notice and a death certificate must not be confused with one another, they are different documents.

Administrator's duties

For estates that too small for an executor to be appointed an administrator is appointed instead. The Master will issue section 18(3), 'letters of authority', which will give this person the authority to administer the estate – meaning that he/she can collect together all the money owed to the estate, pay of the debts, sort out the banking and then finally pay off the heirs. The procedure is very simple, but if the Master has any concerns about the process he/she can ask the administrator to show proof of how the estate was finally sorted out. This means that the administrator will have to give the Master receipts, invoices, statements and affidavits showing how he/she administered the deceased estate. Once the administrator has supplied the Master with all the necessary proof, and the Master is satisfied with the administration, the account will be closed.

If an executor needs help, he can ask for assistance from someone who knows. This could be a lawyer, an accountant or the manager of a banking institution. He can even hire a lawyer to assist with the above duties and responsibilities. This person will usually charge a fee or a percentage of the value of the estate

For further information

For information regarding the forms that the Master's Office will need, please refer to the resources section at the back of the book.

The executor's duties – a step by step process

The nominated executor needs to meet with the family to collect relevant documents and information such as the deceased's:

- identity documents,
- banking details
- property details – including title deeds
- any policies and
- any debts that the deceased may have had.

These details are important for the family members to gather together as they will help in sorting out the inventory that the Masters Office will need.

The executor then reports the estate to the Master with the relevant documents such as:

- the death notice,
- death certificate (if needed) and,
- the original will, if there is one.
- The inventory,
- A form stating acceptance of trust as the executor.

The Master will then appoint the executor by sending him/her 'letters of executorship'.

- The executor must then arrange for a valuation of the estate.
- The executor puts a notice in the paper and asks all the creditors to come forward. The creditors have 30 days to come forward.
- The executor must open a bank account for the deceased estate and deposit all the money from the estate into this account.

After the executor has gathered together all the information regarding the property in the deceased estate, the executor will be able to decide if the deceased person's assets are more than his/her debts and that s/he is therefore solvent.

Finally the executor needs to start planning to liquidate the deceased estate:

- The executor contacts the beneficiaries and explains the procedure to them and asks for their opinion on certain matters about the estate.
- The debts are then subtracted from the total amount of the assets. All of the debts are then paid.
- There are also death duties on estates – these are death taxes. If the estate is small there are no costs or they are minimal.
- The executor sends the final account to the Master of the High Court. The account lies at the Master's Office to allow people to inspect it.

If there are no objections to the account and the Master is satisfied, the executor can then pay the heirs their inheritance.

- The executor must then send the Master copies of receipts from the heirs showing that they have received their inheritance.
- The executor is then released from his/her duties by the Master.

WHEN SOMEONE DIES AT HOME

When someone dies at home, the caregiver or family members need to be careful about taking care of themselves at this time – both emotionally and physically. When someone dies, and there is no doctor or nurse there to help, certain things need to be done or someone trustworthy asked to assist.

- Close the person's eyes and contact someone who can help you – it will be better if that person is your home-based carer, a nurse or a doctor.
- If there is going to be a delay until a doctor, funeral director or SAPS can get to you, then the body may need cleaning.
- Cover any wounds or sores, taking care to cover your hands with gloves or plastic bags.
- Put a cloth between the legs and up under the buttocks.
- Put clean clothes on the deceased person, if you are able.
- Remove all pillows.
- Straighten the body and limbs (arms and legs).

If a medical practitioner arrives he/she needs to give you the medical certificate of death. This will explain the cause of death. This is not the death certificate. The medical practitioner will hand the documents to next-of-kin or to the funeral undertaker. If a medical practitioner is not available then you should contact a funeral company as soon as possible as you will need someone to help you remove the body and prepare it for burial. In rural areas the traditional leader or SAPS can assist in dealing with the removal of a deceased person.

The funeral director may need the following documents from you:

- the deceased's ID document or
- an official document that will show the deceased's date and place of birth and place of death
- details of any hazardous work that the deceased was employed to do – if relevant
- details of any funeral policies, burial societies or pre-paid plans
- the medical certificate issued by the medical practitioner.

Notes

FUNERALS AND PLANNING

Note: Where there is no Home Affairs office in the area then the nearest police station will be appropriate.

Notes

The death must be reported to the Registrar of Births and Deaths (Home Affairs) as soon as possible. If the death takes place in the city, the notice of death must be handed to the registrar within 24 hours. If it takes place in the rural areas, it should be handed in within 14 days. After registration of the death the family will receive a death certificate and a burial order. This allows them to proceed with the burial of their family member.

After the necessary documents listed above have been handed in and the funeral director has been instructed as to the family's wishes, he/she will then assist with a number of decisions to be made.

When someone dies,the family has to make many decisions. Some of these are listed below:

- They will need to decide whether they want to arrange a burial or a cremation, according to their beliefs. If there is a will, sometimes the deceased will give specific instructions about this. For those of the Muslim or Jewish faith, there will be a sense of urgency to arrange the burial.

Then:

- Christians will need to consider where the funeral service should be held - in the local church, at a crematorium chapel, even in the home or at the graveside.
- Muslims will need to gather the mourners for the funeral prayers, traditionally said outside in a courtyard or outside the mosque, before the men only proceed to the graveside. After the burial there will be three days of mourning.
- Jews will want to accompany the body to the graveside in a procession called the "levayah" and afterwards organise the "shivah" or seven days of mourning.
- African Traditional religions will need to arrange the burial for a time when the family and the community can gather for several days of mourning at the ancestral home of the deceased, if at all possible.
- Who will officiate (run the service or prayers)? This is usually a church minister, the Rabbi or the Imam. Family and friends may also want to say something at the funeral.

Burial

After the registration of death and the issuing of a burial notice, the burial can take place at an approved burial site as it is illegal to bury people on your own property or in an open plot of land. Burials cost money so you need to find out about the costs and select the burial that you can afford. Do not spend money that you do not have.

Pauper's Funeral (Burial)

Some people may be unable to afford to pay for the burial of a loved one. Many people belong to burial societies, or they have an agreement with a funeral parlour. If there is no money for the burial, the family may apply to the municipality (under cemetries) or the department of health for a pauper's funeral. This is a very simple funeral with a simple coffin made of pine and no tombstone is put on the grave. You may also find that in certain provinces the body may be cremated.

Be careful: Having an expensive funeral is not always advisable. Families need to show their love and respect for the departed but sometimes people take advantage of this wish and it may place an unnecessary burden on the relatives of the deceased.

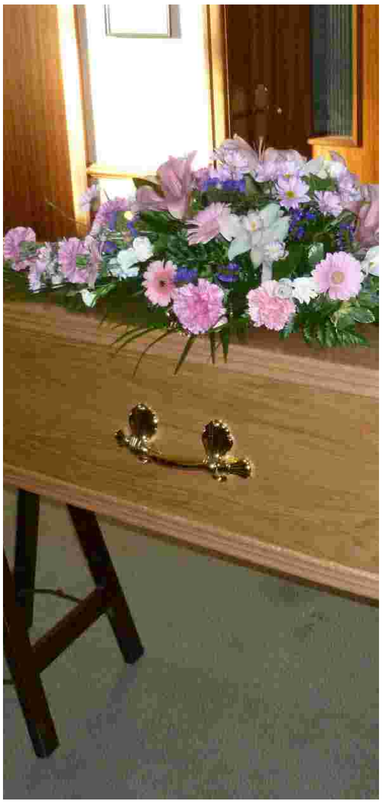
FINAL CHECK

It is very difficult to be a careful consumer when you are mourning the loss of a loved one, but there are some matters that people need to be careful of:

- being persuaded to spend all your money on an expensive coffin or an expensive tombstone
- spending money on an expensive flower arrangement, or even several flower arrangements.
- spending too much money on refreshments
- being persuaded, by any of the service providers, shop owners or funeral parlours, to sign a blank form or a form where the numbers have been penciled in
- not checking up on the hidden costs involved – hidden costs like storage of the body, transport and so on.

What you should do if you are uncertain is

- Pay for what you can afford – respect or love for the deceased can be shown in many other ways. The words you say at the funeral, the way in which the service is held are all ways of showing respect and love for the person who has died.
- Make careful enquiries about all the costs involved. Do not let people intimidate or confuse you.
- Do not be embarrassed to ask if you are not sure what you are signing.
- Contact the nearest legal aid office, advice office or Pro Bono.Org office if you have any problems.



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Jamneck J (ed) and Rautenbach C (ed). The Law of Succession in South Africa, Oxford Uni Press 2009

The Master's Office. http://www.justice.gov.za/master/about.htm

RELEVANT LEGISLATION

Intestate Succession Act of 1987

Law of Succession Amendment Act 1997

The Children's Act 2005

Wills Act 1953, as amended

NOTES

Notes

CHAPTER

13

Death and Dying

INTRODUCTION

> "The most precious possession any human being has is his spirit – his will to live, his sense of dignity, his personality. We must never lose sight of the person we are treating."
>
> *Dr. Paul Brand*

Terms you will find in this chapter

Debriefing: an interview in which a person discusses a task or event after it has happened

Power of Attorney: the legal authority to act for another person in legal and business matters

Letters of Executorship: letters authorising a person to carry out the instructions in the deceased's will

Taboo: forbidden to be used, mentioned or approached because of social, cultural beliefs

Incontinent: unable to control the bladder or bowels

Living Will: a document signed while in good health, which specifies the medical treatment to be undertaken when the patient is no longer able to communicate his/her wishes – usually includes instruction that they are not to be kept alive artificially by life-support systems

Stokvel: an informal savings society in which members contribute regularly and receive payouts in rotation

Pauper's Burial: burial of a person without any income or relatives - usually undertaken by the municipality

Thinking about death and meeting people who are terminally ill can be challenging and even scary to those who are new to palliative care or who are called upon to provide a legal or financial services to seriously ill people and their families. This can include administrative staff who assist newly bereaved family members with account queries and other ancillary staff. It also includes lawyers and law students providing legal services.

Our society as a whole does not prepare us for the trauma of losing a loved one or for contemplating our own deaths. There is an expectation that the bereaved should "be over it" after a few weeks, when the reality is that grieving often continues for many months and sometimes years.

Support by those more experienced in the field of palliative care and training is required to equip newcomers with knowledge and understanding of the needs of patients and family members at this time of their lives. The main supporters of legal practitioners in the palliative care workplace are social workers. Where there is no employed social worker, the support task would fall on the nursing staff.

One lawyer said at debriefing that she was not prepared for the emotional impact of the situation when she went to draw up a Power of Attorney, given by a patient to a family member. She felt that knowledge about the different diseases, especially cancer and HIV/AIDS, would be useful.

When providing a legal service, preparation is important for:

- the current physical and mental state of the person to be encountered
- and the effect on the family of the illness and anticipated loss.

This chapter will discuss end-of-life issues such as communication with the terminally ill person and bereaved family and the implications of cultural and spiritual diversity with regard to illness and funerals. The importance of thorough debriefing of both palliative care and legal people is addressed. Cross references to other chapters in the manual will be given when appropriate.

Who is 'the dying patient' in palliative care?

- The person who presents with late stage illness for whom cure is not possible. (and in the case of HIV/AIDS or TB where treatments have failed).
- The person who has been treated actively for cancer and has now reached the stage where the extent of the disease has exhausted curative options and the focus is now on symptom control and keeping the person comfortable.
- The person living with HIV and currently seriously ill who begins antiretroviral therapy. If response to treatment is successful, this individual may eventually move into a status of chronic rather than terminal illness and may no longer need palliative care.

When should legal aspects be addressed in palliative care?

The answer to this is:
as early in the disease process as possible.

It is not advisable to arrange the drawing up of a will in the last days of a person's life, when the latter does not have the energy to think through his or her wishes properly and may at times be confused.

The nursing assessment, when the first contact with the person is made, or early in the caring relationship, should include a question such as:

- Can I ask if your affairs are in order, do you have a will?
- Have you given Power of Attorney to someone?"
- Where there is a social grant, it is important to ask if the person has given Power of Attorney to anyone to access the money for him.

These questions should be on the nursing assessment form and ticked off. The replies should be recorded. When assistance is needed, immediate referral to the social worker should be made to access legal assistance as well as social grants.

Notes

Case Study

Mr. Daniels was in a hospice in-patient unit.

He was terminally ill, bedridden and had little energy.

His nephew and wife had taken him into their home when it was apparent that he had nowhere else to go. He had been divorced for years and said he had lost contact with his children.

The nephew requested legal assistance so that Mr. Daniels could draw up a will. Although weak, he was mentally lucid.

The nephew was present at the bedside with the lawyer during the process of establishing his uncle's wishes. Mr. Daniels had a sum of money in a savings account which he had intended to leave to his children, but now felt he would like to leave to his nephew.

The will was drawn up and duly signed, but the lawyer felt uncomfortable with the conversation which was led by the nephew. The lawyer was also concerned that the will could be contested by Mr. Daniel's children after his death.

Discussion

The pressure in this situation was that this very ill person was close to death, so there was some urgency when he wanted to make a will. This caused stress to the palliative care staff and to the lawyer.

Should the lawyer have refused to proceed with the will, if he felt uncomfortable with the discussion which took place?

This emphasises the point that, where possible, people should be encouraged to make wills earlier on in the disease process. Unfortunately many people are referred at a late stage of illness.

Response in this situation:

In a case like this, it would be appropriate for the palliative care worker to call the lawyer aside, and to suggest that he consults the client and drafts the will without the nephew being present, if the lawyer has not already expressed this to the nephew.

Notes

What legal needs may an ill person or family member have?

Some common requests for legal assistance by patients and their relatives:

A General Power of Attorney to manage a person's affairs	The granting of a General Power of Attorney to another person to manage the person's affairs.
Power of Attorney to draw a social grant	Power of Attorney is needed so that another person is empowered to collect the patient's social grant.
Drawing up a will	The person wishes to make a will – see Chapter 12 on Dying and the Law.
Legal protection to prevent eviction	The person needs legal protection from other family members who want to evict him from his own house – see case study below.
Guardianship of children	Guardianship of children – see Chapter 8 on the Rights of the Child.
Advance Directives	Advance Directives – see Chapter 3, Ethical Issues.

Case Study

Problems over house ownership

Mr. Africa, who was receiving hospice care, complained that other family members had threatened to put him out of his own house.

In small groups, discuss:

If you are a member of the palliative care team, how would you handle this request for help by Mr. Africa?

What actually happened?

Mr. Africa was referred to the hospice social worker, who visited him at home.

He advised the social worker that some of his family members wanted him evicted.

The social worker asked to see the last municipal account and Mr. Africa's Identity Document. The account was addressed to Mr. Africa and there were no other names on the account.

The social worker asked if he would like her to call round and gather all the family together to discuss this matter. He was in favour of this.

A family meeting was held and discussion took place about what exactly had been said to Mr. Africa about being put out of the house and how this threat had arisen. Family members present were of the opinion that it had been said by one of their number who had been under the influence of alcohol at the time. They said they would not let this happen and that they knew that the house was the property of Mr. Africa.

The meeting ended amicably and the problem did not recur.

Note: If this matter had not been resolved in a satisfactory manner, legal assistance would have been needed.

Legal assistance which might be required after death

Please note: If this chapter is being used for training purposes, the facilitator could use each of the situations below as discussion topics in small groups.

Case Study 1

A man dies early in the month before his social grant has been paid out. The nearest family member wishes to apply for that month's payment to put the money towards funeral costs.

Response to this situation

Applying for the social grant after a death

If the recipient of a social grant or pension dies before the grant has been paid out for that month, the closest family member may apply to a grants' officer at the nearest branch office of SASSA for that month's pay-out. Documentation in support of this application is the following:

- Identity Documents of the deceased and the claimant
- Marriage certificate or proof of relationship
- Death Certificate
- Funeral account

This money will take about three months to come through.

Case Study 2

The brother of the deceased applies for Letters of Executorship and offers the widow an amount of money which she believes is less than she is entitled to in terms of the will.

Mrs. M. was being visited by a hospice bereavement volunteer. In her culture the men of the family take charge after the death of a brother (Mrs.M.'s husband.) Her brother-in-law had been appointed executor of the estate. He had the original will and Mrs. M. had a copy of the will. In terms of the will, Mrs. M. was not satisfied with the amount of money being granted to her by her brother-in-law.

Response to this situation

After consultation with the hospice social worker, the volunteer took Mrs. M. to the Master's Office of the High Court to report her situation. A lawyer, acting pro bono for the hospice was also consulted.

Case Study 3

The widow or widower wants the house, which was joint-owned, to be put in her/his name. There is no will.

Answer: You will find the answer to this scenario at the end of this chapter on page 209

See also Chapter 12, Dying and the Law for what happens to your assets when you die without a will.

Notes

INTRODUCTION

'Because people do not like to talk about death, especially their own death, their silence causes lots of problems. And there's one big problem... we find that the parents, when they passed away, they don't even tell the family where the children are supposed to go.'

Notes

Case Study 4

Minor children are left without guardians

Response to this situation

In terms of The Children's Act of 2005, care must be provided for children under the age of 18 years.

If the wishes of the deceased single parent are not known, a social worker from a child and family agency or from the Department of Social Development can investigate the circumstances of the children and any family support available to them.

For instance the family might get together to:

- decide who is going to care for the children
- the wishes of the children would also be taken into consideration.

An assessment by the social worker would be submitted to the Children's Court (usually situated at the local Magistrate's Court). The Children's Court Commissioner would then make a ruling about the children's care.

The children might be placed:

- in the foster-care of family members or others
- placed elsewhere

A guardian might have to be appointed by the court.

If the parent left money to the children in a will, this money would be placed in the Guardian's Fund (See Chapter 12 Dying and the Law).

See also Chapter 8 on the rights of children in palliative care.

POWERS OF ATTORNEY

A person may wish to give another the power to act as their representative or agent to conduct their affairs for practical reasons (illness, disability etc.) The person making the Power of Attorney retains overall legal power in any decision-making. There are two main types of Power of Attorney, General Power of Attorney (GPA) and Special Power of Attorney (SPA). These are outlined below. Remember that before institutions will recognise the representative acting on behalf of the person, both the person and the representative must inform everyone who needs to know, about the existence of the Power of Attorney and give them copies of the signed document. Institutions will not deal with the representative unless this step has been taken first. The person who acts on behalf of the person is known as the recipient in the points below.

There are two main types:

General Power of Attorney (GPA)

- You can buy a standard form *General Power of Attorney* from CNA and some stationery shops, but please fill in only the clauses that apply to your situation. If you use a shop-bought GPA, then get a lawyer or legal advisor to check it.
- You may decide to consult a legally qualified person
- Or simply draw up the form yourself
- The GPA lapses on the death of the person

Special Power of Attorney (SPA)

This is a specific power rather than general power to conduct the affairs of another person.

Banks require an SPA if the financial matters of the account holder are to be handled by another person. Banks have their own forms and will require the following documentation:

- Identity Document of the account-holder and the recipient of the SPA
- Proof of residence: A recent account in the name of the recipient with the current address of the recipient.

Power of Attorney to draw a Social Grant

See Chapter 6 on Poverty under Social Grants, Authority for someone else to fetch a grant on page 93. An official of SASSA (South African Social Security Agency) will issue this to the person who will collect the grant of an ill or disabled client. It is best to apply for it at the initial application for the grant, but may be obtained later as well. Fingerprints will be needed.

For further information

See the Resources Section at the end of this book, where the Power of Attorney for Future Medical Treatment/an Enduring Power of Attorney is discussed.

Notes

COMMUNICATION WITH THE DYING PERSON AND FAMILY

Lawyers, paralegals and law students should ask these questions before, during and after contact with the patient:

1. Are you prepared for each unique situation?	• Legal staff who visit, should see that they have basic information before they set out, about : - the patient, - the illness - the family situation • They can request a non-confidential summary of the situation from the patient's home-care nurse or doctor. • Be prepared with the usual legal documents/forms required for a dying person and his/her family.
2. Is an interpreter required?	• The interpreter should preferably be a palliative care staff member or someone with whom the legal person chooses to work.
3. Is there as much privacy as the ill person requires?	• This is difficult to achieve in an open ward or in a small shack with other family members present. The ill person is consulted about this. If the person is mobile, the staff member's car may be used for privacy.
4. Is the person comfortable?	• Someone in pain will not be able to concentrate on important legal issues or on anything else. It is up to the palliative care professional nurse to help with pain control.
5. Have you used simple language and checked that what you have said has been understood?	• Reflect back the person's wishes where necessary – to see that both of you are talking about the same thing.
6. Did you show respect for cultural and belief systems?	• Conversations about death may be taboo for certain people, who see talking about death as 'inviting death in'. For further discussion about culture and beliefs see the section below and refer to Chapter 5: Access to Care
7. When should you refer?	• If you are a legal practitioner, you are not expected to answer questions the patient or family ask about the illness or other matters. If you are visiting without a palliative care staff member, tell the patient/family member you will ask the hospice sister to contact them. • Stick to the legal brief, but show caring and compassion. • If you do not feel comfortable to proceed, in terms of legal ethics and boundaries, explain this simply to all concerned and withdraw.

The appearance of a very ill person

- Colour may be very pale
- The person may be breathless. Listen carefully, and go at his/her speed. Allow pauses in the conversation, so that he/she can recover his/her breath and have time to think
- The person may have rashes, pustules or other disfigurements on the face
- A person who is very close to death may not be able to hold a train of thought and may nod off to sleep frequently
- A person who has lost the power of speech may be able to write or to use a communication board
- A very deaf person may require you to write down questions or comments
- This may be the ill person's first encounter with a legal practitioner and may feel intimidated. He/she may be anxious about the importance of what he/she is about to do in terms of this visit.

It is helpful if the professional person approaches the ill person and family showing the following attitudes

- Respect – acknowledging that the person is the expert on his or her life
- Compassion – caring and commitment to the needs of the person
- Empathy – putting oneself in the other person's shoes.

  Thinking, "If this were me. how would I be feeling? How is this person probably feeling?"
- Acceptance of the person's looks (he/she may be disfigured in some way), of the smell (he/she may be incontinent) and of the person's general appearance and way of talking
- Acceptance of language, culture and belief systems
- Knowledge of one's own inner thoughts. The legal person identifies what he/she is thinking whilst talking with the person/family member and is able to put these thoughts on one side in order to focus on the other's needs
- A tentative approach – such as "Am I understanding you correctly? "Are we talking about what you want to talk about?"

There is an invitation to share thoughts and feelings:

"What did you want to put in your will?"

"I want to be sure I understand you. Are you saying...?"

After a period of silence from the person, the lawyer might ask: "I am wondering what you are thinking about at the moment?"

Topic
for discussion

How to approach the patient and family

In small groups, imagine that you are a legal practitioner or a law student who has not previously been in contact with those who are seriously ill and dying and discuss what your feelings might be.

Response to this situation

In the palliative care situation, it is the responsibility of:

- the social worker
- the professional nurse

to sit down with the legal person and prepare him/her for the encounter with the patient/family member. The social worker or nurse should have the patient's Identity Document to hand or have arranged that he/she will bring it.

Where Power of Attorney is to be given, the Identity Document of the recipient should also be available. Any concerns should be discussed.

The legal practitioner must be given an outline of the family structure, especially those family members closest to the patient.

The lawyer prepares him/herself emotionally for the interview.

The interview may take place in the community (a very ill or bedfast person); at the hospice or hospital (in as private a situation as can be arranged).

Notes

Communication guidance for legal personnel

Starting off

Don't be intimidated by the illness. Address the ill person as you would anyone else.

The lawyer introduces himself:

"Good morning. My name is … . I am a lawyer. I understand you would like to draw up an Advance Directive ('Living Will' may be the term some people are familiar with)?"

Sit down if possible in a position where the person can see you easily without turning his/her head too much. The light from a window or other should not be shining in his/her eyes.

When the lawyer wishes to establish exactly what the person means, the following might be said:

- Tell me a little more about that.
- Could you help me understand what you mean?
- If I'm hearing you correctly …
- Am I right in thinking…?
- What has made you think you might need a Living Will?

Ending the conversation

- Summarise what has been decided by the person and repeat it if necessary
- Plan to see the person again as soon as possible for signing of the documents which have been drawn up. Time may be short and someone with a terminal illness may die at any time.

Debriefing

The lawyer may be faced with emotional distress, or family members overwhelmed with grief following the death of a loved one. After such an interview, it is important for the lawyer to recognise the emotions which have been transferred from the person to him/herself. Once identified, he/she realises that these emotions do not belong to him/her and need to be released. This is a vitally important action. Negative emotions (pain, suffering, grief) can be taken up unknowingly from others and stored in the recipient's body to the detriment of the receiver. A sign that this has happened, would be when the receiver feels very drained and tired at the end of the day.

This releasing process should be conducted daily by back-tracking and remembering who has been seen during the day.

Law students and lawyers doing work in palliative care can request time with the social worker, when needed, to help with debriefing.

Other useful practices:

- Caring for yourself by eating healthily, exercising, having enough sleep
- Thinking positive thoughts about yourself and rejecting the negative thoughts
- Asking for help when you need it
- Preparing and debriefing properly

CULTURAL AND SPIRITUAL DIVERSITY AND THE IMPLICATIONS FOR CARE AND FUNERALS

Some understanding of the culture and belief systems of others is helpful, so that people don't talk past each other.

In this chapter we shall outline the practices of African people only.

The African spiritual tradition

- For the African person, belief systems and culture are experienced as being interwoven.
- All of life is seen as inter-connected and all fall under God.
- Those who have gone before, the ancestors or 'living-dead', retain an interest in their families. Since God is a distant divine being, they are the mediators between God and the family. Their function is to see that traditional rules and rituals around life and death are adhered to. When the rituals are not performed, a warning may be received from the ancestor in the form of a dream or vision. If the family member does not search his spirit to find out what the problem is or consult a Traditional Healer to help him, he may experience an accident or a breakdown in his health.
- There is continuity between life and death, but the accent is on life and health. The healthy African person experiences a balance within himself, between himself and the community, and between himself and the spiritual world.
- There is a strong attachment to the soil and a sense of belonging to the place of birth
- People see themselves through their relationships with others (the community) rather than regarding themselves as separate individuals
- People are able to be members of other religions whilst at the same time observing the rituals of Traditional African Religion
- Death is feared, and any discussion or preparation for approaching death is often strongly discouraged. There is a fear that by using the words 'death' and 'dying', death may be invited into the room.
- In palliative care, family members may sometimes require a senior member of the family grouping or clan to be present when decisions have to be made regarding the person who is ill.

Case Study

A Xhosa-speaking man was admitted to a hospice in-patient unit in an urban area. He was terminally ill.

The man's son took responsibility for both of his parents.

The son requested that staff in the unit should not have any discussions about death and dying with his father or mother.

This request was respected and no conversations about death or dying took place, except with the son. Conversations focused rather on the patient's comfort.

It was explained to the son that his father was close to passing and he was asked if he wished this to happen at home or elsewhere. The son said he wanted his father to continue to receive care in the hospice.

When his father died, the son made all the funeral arrangements.

However, for many families who come from the Eastern Cape or other rural areas in South Africa and now live in urban areas, it is important to be buried in the place where they were born. Sometimes people feel that the time has come to return to the place of their birth, and they return of their own accord or with family members.

Clues to Culture 2005 by Elion and Strieman is recommended for an informative and concise overview of cultural and spiritual diversity in South Africa.

Registering the death

This is normally done by the funeral undertaker.

The funeral

Financial implications

Where tradition is vitally important, African families are prepared to go heavily into debt in order to satisfy the ancestors and the living family by proceeding with the necessary rituals at the place of birth. There are transport costs for those of the family who will attend the funeral; a beast must be slaughtered (a goat for an ordinary family, an ox for a wealthy family); extra cooking pots bought for the food to be cooked.

Saving for the funeral

- African families often pay into a stokvel or a burial group. A stokvel is similar to the English word 'co-operative'. People come together and pay in for various purposes, not necessarily for burial. For instance they may do it during the year to have money at Christmas. African people, who move from rural areas into towns, often form a burial group with others from the extended family or clan. The members of the group meet once a month and pay in an arranged amount of money. This money is then used to pay for burials for any member of the group. Funerals of members who die are financed out of this fund. If several members of an extended family die within a short space of time, the fund may be insufficient.
- Borrowing money from a micro-lender or a bank. Large amounts of money are needed and it will take many months to repay the amount with interest.
- People may take out funeral insurance and pay the premium each month

  See the story in Chapter 7, Managing Debt in the Context of Illness.

The wider significance of the funeral

- As well as the ancestors, the community and neighbours have to be satisfied with the way in which this particular family has completed all necessary rituals after the death of a family member.
- If arrangements are not well made, the entire extended family and clan may be ashamed and may suffer emotionally and spiritually as well as socially.
- Other communities in South Africa would also feel that they had lost face in the eyes of friends, church people and the larger community if they provided a cheap funeral and not much in the way of refreshments to honour their family member who had died.
- The funeral can thus be seen as an investment in the future lives of those left behind, even if they struggle financially to repay loans.

PAUPER'S FUNERAL

When people have died alone at home, on the street or in a Night Shelter and are apparently without relatives or income, a Pauper's Funeral is provided by the health district or large municipality.

If the destitute person dies in the provincial hospital or in an ambulance, then the province and not the municipality is responsible for the cost. The following steps are taken to access a Pauper's Funeral:

- The cemetery department of the municipality (Health department of a smaller municipality) is contacted.
- A municipal council member or SAPS member determines whether the person was destitute and will complete the necessary forms.
- The body is collected when authorisation is given by the municipality (Cemetery office) to the funeral undertaker who holds the municipal contract.
- The municipality does not pay storage costs if the body has been removed before this process has been completed.

Implications of Pauper's Funeral for Palliative Care

The need for a pauper's funeral may arise within the context of palliative care. However, there are concerns and decisions about this type of funeral which should not be taken lightly:

- The ill person may have been living on the street, but in fact has savings which he has not disclosed.
- He may have a will, which specifies how he wants his remains to be disposed of, and this is not known to others at that time
- He may have relatives, but has broken off contact and tells staff that he has no family.
- In an African community, others may be prepared to contribute towards a funeral.
- Months later, a member of a traditional family may arrive and require some soil, from the place where the person was buried or the ashes scattered, to take back to the place of birth, so that the proper rituals may be carried out for their relative in order to appease the ancestors.

Notes

PROPERTY GRABBING

Colgan reports that some home-based carers she met in Soweto in 2007 spoke of property being grabbed by adult relatives after the funeral; and that sometimes orphaned children are seen as being a potential source of money through social grants.

See Chapter 12 on Dying and the Law and
Chapter 8 on the Rights of Children and Young People in Palliative Care

Notes

Continued communication guidance for legal personnel

Palliative care includes practical assistance and counselling for bereaved family members. Research has shown that individual and family breakdown can be prevented at this time if support is available to those who need it. Bereaved family members may need legal assistance.

Very often the spouse or partner of the person who died will be the one consulting the legal practitioner, in terms of the will.

- An adult son or daughter may be the main beneficiary of the deceased
- Or an adult son or daughter may accompany their parent to give support
- Parents of a deceased adult child may come forward with problems accessing a life policy made out to them

It is important to remember that grieving people may be 'off-balance' after a death. Judgement and perception may be affected for a while and people say and do things which, a year later, they might regret. Bereaved people are emotionally stressed and are trying to survive; at the same time they are called upon to make an extra effort at a time when they feel most vulnerable and exhausted. We know that grieving saps a person's physical and emotional energy.

The lawyer or caregiver can help the person to face the reality of the legal and financial situation in a gentle, patient, calm and compassionate way. He/she can explore with the client whether there is another family member who might be able to assist and support them.

Where possible, in practical terms, clients can be advised not to make over-hasty decisions and to give themselves six to twelve months before making major changes.

The following may occur after a loved one has died:

- The grieving client forgets an appointment or gets the time wrong.
- The client cannot locate documents needed or only brings some of the documents. Many telephone calls may be necessary to some clients before all is in order.
- The client bursts into tears and overwhelms the lawyer with sadness and despair.
- The lawyer worries about something he/she may have said which provoked fresh grief from the client.
- The lawyer thinks the person should have 'got over their grief' by this time.

WHY IS IT ADVISABLE TO OBTAIN SEVERAL COPIES OF THE DEATH CERTIFICATE?

A certified copy of the Death Certificate will be needed in the following instances:

- For pay-out of any insurance policy ceded to the claimant
- For the cancelling of debts where there is no liability to pay by family members - such as a son or daughter

In the past under 'universal succession' the heirs stepped into the shoes of the deceased to inherit the debt, but this no longer happens. When the deceased dies, the debt is paid out of their estate, the heirs will not inherit the debt. The heirs will inherit the assets, if there are any, after the debt is paid.

CONVERTING THE HOUSE INTO THE NAME OF THE SURVIVING SPOUSE OR PARTNER, WHEN IT IS JOINT-OWNED BY THE DECEASED AND THE PARTNER

Answers to Case Study 3 on page 199

The widow or widower wants the house, which was joint-owned, to be put in his/her name. There is no will.

Answer:

The house must be converted into the name of the surviving spouse/partner, when it is joint-owned by the deceased and the partner. The following must first be completed:

- If the person died intestate, a letter of authority is required from the Master of the High Court. This is a completed form from the Master's office stating when the person died and that there was no will.
- The municipal account must be fully paid up.
- Application can then be made through the municipal housing office.

CONCLUSION

- Legal issues should be addressed as early in the illness process as possible
- The most common legal requests, in palliative care before the death of a person, are for powers of attorney, wills, housing issues, guardianship, advance directives.
- After death, legal advice may be required for any disputes about the will, house transfer and children's issues.
- The legal practitioner should be prepared by palliative care staff and have sufficient information before seeing an ill person or family member
- Cultural knowledge of diversity is required and an attitude of respect
- It is essential that both palliative care and legal practitioners debrief properly after distressing encounters in their work.
- Some understanding of the feelings of the bereaved and the importance of the funeral is helpful knowledge.

The provision of legal advice to those receiving palliative care and their families empowers individuals and restores hope. It is heartening to know that lawyers, university law departments and law students are willing to be of service at a time when families are in crisis.

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CHAPTER 14

Resources

Resources for Chapter 4

Resources for Chapter 6

Resources for Chapter 7

Resource for Chapter 8

Resources for Chapter 11

Resources for Chapter 12

Resource for Chapter 13

Leaflets

FREQUENTLY ASKED QUESTIONS

Notes

20 Frequently Asked Questions for readers

1. *A hospice in-patient requests euthanasia. How would you counsel this client?*

   See Chapter 3.

2. What bio-ethical principles guide clinical decision-making in palliative care?
   See Chapter 3.

3. How do you express your preferences for care in the future, if you are no longer able to express your choices?
   See Chapter 3.

4. What might be the barriers to accessing good palliative care?
   See Chapter 5.

5. How would you assist a client to apply for Maintenance?
   See Chapter 6.

6. What determines access to reduced school fees?
   See Table, chapter 6.

7. How is a late birth registration made?
   See Chapter 6 and Resource for chapter 6

8. Can foster parents apply for more than one grant for the child they are fostering?
   See Chapter 6.

9. What advice can you give when your client is in debt?
   See Chapter 7 and leaflets in Resources.

10. What is the disadvantage of an Administration Order when a client is in debt?
    See Chapter 7.

11. What are the guiding principles concerning children's rights?
    See Chapter 8.

12. Should a child of six years be informed about his illness?
    See Chapter 8: Consent and Assent.

13. What happens to grandmothers' rights as older persons when they have to care for grandchildren after the death of the children's parents?
    See Chapter 9: Rights of older caregivers.

14. What are the rights of child migrants (non-South African citizens)?
    See Chapter 10: Rights of non-South African child migrants..

15. Can clients who are not South African citizens and who do not have Permanent Residence status, have free health care, including HIV and TB medications?
    See Chapter 10: Fees for Health Services.

16. Primary Health Care in South Africa is being re-engineered. What changes do you expect to see at local level?
    See Chapter 11.

17. What staff will comprise a primary health team?
    See Chapter 11: The role of the community health worker in the community.

18. What is a customary law marriage? Where is it registered?
    See Chapter 12: What do we mean by marital regime?

19. Who should not be a witness to the signing of a will?
    See Chapter 12: Formalities of a valid will.

20. What are the implications for the next of kin when a person dies without a will?
    See Chapter 12: Dying without a will: Intestate succession.

RESOURCES FOR CHAPTER 4

THE NPO SECTOR

How to find out the current status of South African legislation

The Parliamentary Monitoring Group, (PMG) is an information service, established in 1995 according to its website. The PMG was started as a partnership between Black Sash, Human Rights Committee and Idasa with the aim of providing a type of Hansard for the proceedings of the more than forty South African Parliamentary Committees for these three advocacy organisations. This was because there is no official record publicly available of the committee proceedings - the engine room of Parliament - and this type of information is needed by civil society to lobby the Parliament of South Africa on pieces of legislation, matters of democratic processes and parliamentary oversight of the executive.

Contact details for the Parliamentary Monitoring Group (PMG) can be found in the Useful Contact List.

How to access information about publications by South African legal writers

Juta Law Catalogue | *www.jutalaw.co.za/products*

The Juta Law Catalogue is provided free of charge by the publishers, Juta's. The catalogue is an online list of publications by legal writers writing on a variety of legal topics and the listing includes information on authors, price and date of publication and brief content outlines.

RESOURCES FOR CHAPTER 6

POVERTY

How to register a birth

Births notified within 30 days after birth

According to the Home Affairs website, all children born in South Africa must be registered within 30 days of their birth (in terms of the Births and Deaths Registration Act, 1992). A parent, parents, guardian or any other person legally responsible for the child must complete Form BI-24 (with black ink) and submit the form to the nearest office of the Department of Home Affairs if you are in South Africa, or the nearest South African embassy, mission or consulate if you are overseas.

Although the Births and Deaths Registration Act (Act 51 of 1992) requires that the birth of a baby must be registered within 30 days after birth, special circumstances may make this impossible. Notices of birth after 30 days are called late registrations and are all free of charge.

Births notified after 30 days but before one year

- Form BI-24 must be completed and submitted along with written reasons why the birth was not registered as required by the Births and Deaths Registration Act.
- If successful, the application will then be forwarded to the DHA Head office for the allocation of an identity number and for archiving.

Births notified after one year but before 15 years

Form BI -24 must be completed and attach written reasons why the birth was not registered as required by the Births and Deaths Registration Act. In addition, provide documented proof in the form of:

- The identity and status of the child - an affidavit by the parents
- If the parents are deceased, an affidavit by a close relative at least 10 years older than the child who is familiar with the circumstances of the child's birth
- Any other documents which could help establish the identity of the child.

The following documents are required to ensure the quick processing of the application:

- A certificate by the hospital or maternity home where the child was born. The certificate must be signed by the person in charge and must have the institution's official stamp
- Confirmation of the child's personal details as extracted from the school register of the first school attended by the child.

The confirmation must be on the school's official letterhead, be signed by the principal and must have the school's official stamp

- The child's baptismal certificate
- In the case of abandoned children, a social worker report must be submitted
- A clinic card
- School reports
- Any other documentary evidence that may assist in proving the child's identity and status.
- Upon application, you will be interviewed and your fingerprints will be verified against the national database.
- If successful, your application will then be forwarded to the DHA Head office for the allocation of an identity number and for archiving.

Births notified after 15 years

- You must complete Forms DHA-24, DHA-24/A x 2 and DHA-288 for the registration of birth.
- You must be a South African citizen or permanent residence permit holder with a valid South African Identity Document.

How does the Means Test work?

Assets and Income Threshold and Grant amounts (How much you receive in a grant)

To find out if a person qualifies to receive a grant, the South African Social Security Agency makes use of an Asset and Income Table. It is most important to be sure you are looking at an up-to-date version of the table because in most years the table is adjusted. The most recent table can be found on the SASSA website under Social Grants or by phoning the SASSA toll-free number listed in the Useful Contact List.

Every year the amount of money in a grant changes – why?

In order to keep up with inflation, and to ensure people get enough money, the government adjusts the amounts payable and the income threshold below which people qualify for a grant. So a person needs to be sure that they are looking at the latest tables available. The table below shows how between 1 October 2011 and 1 April 2012 the amounts for qualifying assets and income have changed.

Asset and Income Threshold for Social Grants

WARNING!
Be sure you are looking at an up-to-date table when checking these amounts.
Refer to SASSA for current information.

Space for you to enter new amounts

Asset Threshold	1 October 2011	1 April 2012	1 April 2013
Older Person, Disability and War Veterans Grant			
Single person	R752 400	R792 000	
Married person	R1 504 800	R1 584 800	
Income Threshold			
Older Person, Disability and War Veterans Grant			
Single person	R44 880	R47 400	
Married person	R89 760	R94 800	
Child Support Grant			
Single person	R32 400	R33 600	
Married person	R64 800	R67 200	
Foster Child Grant Child	No means test	No means test	
Care-dependency Grant Parent/PCG: Single Parent/PCG: Married	R136 800 R273 600	R144 000 R288 000	
Care-dependency Grant Child	No means test	No means test	

How much you will receive in a grant (paid out to recipient)

Space for you to enter new amounts

Grant Amounts	1 October 2011	1 April 2012	1 April 2013
Older Person's Grant	R1 140	R1 200	
Older Person's Grant (above 75)	R1 160	R1 200 + R20	
Disability Grant	R1 140	R1 200	
War Veteran's Grant	R1 140 + R20	R1 200 + R20	
Grant-in-aid	R270	R280	
Child Support Grant	R270	R280	
Foster Child Grant	R740	R770	
Care-dependency Grant	R1 140	R1 200	
State-aided Institution (25%)	R285	R300	

RESOURCES FOR CHAPTER 7

DEBT

Exercise 1

Read Bongani's story and work out the calculations below:

Bongani goes to Lewis Stores and sees a very nice, very large Supermax Fridge with lots of compartments and an icemaker. It costs R14 000 but he decides he wants to buy it. He speaks to the salesman and signs a credit transaction agreement. In the agreement he agrees to pay off the R14,000 over a period of a year and a half (18 months). The agreement states that Bongani must pay interest on the debt of 40% per year. He goes home and tells his wife Thembi about the fridge and she is pleased and excited. The fridge arrives next day and they love it and start using it immediately. A week later Thembi attends a workshop at hospice, and the audience is asked to calculate the cost of any recent credit transaction they have entered into.

Calculate what Thembi and Bongani must pay each month to pay off the cost of the fridge over 1.5 years?

Year 1 interest is =	Year 2 interest is =
R14,000 fridge	40% current rate of interest per year over 18 months

Note: the facilitator can say: Now this does not include service fees and basic insurance for the fridge and other costs.
Year 1 paying R19,600 and in year 2 = R16,800

R19,600 + R16,800 is just the interest. R36,400 for a R14,000 fridge, reduced because it is a payment plan of under 24 months, after which the maximum interest of 44.2% could be charged.

Exercise 2

Budgeting

The skill of working with money can be taught to children at quite a young age, at their level of understanding. An adult needs to be able to balance money coming into the house against expenditure, for the family. Any excess income could be saved.

A simple budget, as an example, for a family of 2 parents and 2 Primary School aged children for teaching the skill, might be the following:

Family income per month:	R3,500.00
Expenditure	
Municipal account with rent:	R600.00
Meter electricity:	R200.00
Food:	R1,800.00
School Fees for 2 children:	R70.00
Clothing:	R200.00
Transport:	R450.00
Funeral policy:	R50.00
Cell phone:	R130.00

Notes

RESOURCES FOR CHAPTER 7

The following exercises may also be used in training

Material adapted from : *Chioma, University of Cape Town, Street Law Workshop 2008, Black Sash ETU Paralegal Manual, adapted by Nicola GunnClark, HPCA*

Exercise 3

Ntombi buys furniture costing R2,000. She doesn't have R2,000 in cash, so she agrees with the shop that she will pay the money in instalments every month until the full R2,000 is paid. This is called an instalment sales agreement (hire purchase).

Later Ntombi falls ill and hasn't paid her instalments for 3 months. One day when she is out at the clinic, her house is broken into by people who say they are from the furniture shop. When she comes home she finds the door and lock are damaged and the furniture that she was paying each month, has been taken away. And her radio that she paid cash for is also gone. You are a carer visiting Ntombi because she is sick. When you visit Ntombi she tells you her house was broken into and her things taken. She asks if this is illegal and what she can do.

Remember that the following are considered UNLAWFUL ACTIONS BY MONEY LENDERS:

- Using a fake summons
- Breaking into someone's house
- Damaging the house/property
- Taking other things that belong to the person
- Threatening the person, saying that they will tell other people that the person hasn't paid his debt, or threatening to tell the person's employer about their debt problem

Use of fake Summons

Exercise 4

Vusi goes to an electronics shop because he wants to buy a television. Vusi does not have cash to buy the television, but he promises the shop that he will pay the full amount in cash within one month. He goes home with the television. For the next two months he uses the television but he does not pay the amount he owes to the shop. One day whilst you are visiting Vusi at his house, he receives a document which has the words SUMMONS printed on the top. The document was not issued by the court, but it says if he does not pay the amount of R1,500 immediately, then a court order for his arrest and imprisonment will be obtained. Vusi is very worried that he will go to prison, and he asks you what he should do and if the document is legal. Is the document a real summons and what can Vusi do about this?

Answers to Exercise 3

- Breaking into someone's house is illegal. Even a money lender or debt-collector cannot do this – it is housebreaking and trespassing.
- Damaging the door and lock is called malicious injury to property – it is also illegal.
- Taking her radio – is theft.

What can Ntombi do?

- If you are not sure what Ntombi can do – ask Ntombi if you may ask your supervisor at hospice what should be done.
- Ntombi can go to the police and lay a charge for housebreaking, trespass, malicious injury to property and theft. If possible she will need to give the name, address or place of work of the person/people who broke into her house. She must get a case number from the police when she lays the charge.
- Ntombi could ask a paralegal to help her to claim for the damage to her door and lock and to claim back her radio from the shop. Give Ntombi the phone number of a local paralegal. *Refer to the Useful Contact List later in this chapter.*
- Money lenders are only allowed to take back the furniture (called repossession) if she agrees (with her consent) or with a Court Order. They are not allowed to use unlawful/illegal ways to take the furniture back. If the money lender has a Court Order, only the Sheriff of the Court can come and take the furniture back (not the money-lender themselves).
- The money lender must keep the furniture for 30 days before reselling it, and Ntombi can try to borrow money from friends/family to pay the 3 months of instalments that she didn't pay before (arrear instalments) and get the furniture back. Then the agreement remains in force and she must continue paying the instalments until the full R2,000 is paid.

Answers to Exercise 4

- If you are not sure what to do, ask Vusi if you may ask your hospice supervisor
- Any document with the words 'Summons' will only be official if it has been rubber stamped by the Magistrate's Court or High

Court. So it must have a stamp on it from the Court and it must also have been signed by the Clerk of the Court or Registrar of the High Court.

- If the document has a Case Number in the top corner and also states the name of the court, Vusi can phone that Court and ask them to look up that Case Number on the court list of cases. He can ask if his name is mentioned for that case number.
- If the court does not have any record of a Summons against him, Vusi should take the document to the police station and ask them to lay a charge of fraud against the electronics shop.
- Vusi can take the document to a paralegal or a university legal aid clinic and ask them to help him. *See Useful Contact list.*
- A person may not be put in prison if he can't pay his debt - but he can go to prison if he ignores an official order from the Court.
- A proper Summons will usually order a person to appear in Court on a certain date to answer the charge that he owes money. Vusi should never ignore an official Summons from a Court, because the Court will make a decision in his absence if he is not there to give his side of the story.

See also the leaflets on consumer rights, debt management and cost of credit later in this section.

RESOURCE FOR CHAPTER 8

CHILDREN

The role of the Public Protector

As explained on its website, the Public Protector has the power to investigate any conduct in state affairs, or in the public administration in any sphere of government, that is alleged or suspected to be improper, or to result in any impropriety or prejudice. The Public Protector is appointed by the President, on the recommendation of the National Assembly. The Public Protector is subject only to the Constitution and the law in terms of Section 181 of the Constitution.

Following such an investigation, the Public Protector has to report on the conduct concerned and he/she can take appropriate remedial action. The Public Protector is neither an advocate for the complainant nor for the public authority concerned. He/she ascertains the facts of the case and reaches an impartial and independent conclusion on the merits of the complaint. Citizens can approach the Public Protector with any complaints about government services or conduct.

The Public Protector website states: If you are unsure whether your problem is something the Public Protector will investigate, or if you cannot write, you can phone the Public Protector's office. There are trained professional staff members who will listen to a complaint, big or small, and conduct investigations. In some cases the staff can help people to find quick solutions to their problems. The staff can also tell you where to complain if the Public Protector cannot help you.

Contact details for the Public Protector can be found in the Useful Contacts List.

RESOURCES FOR CHAPTER 11

COMMUNITY HEALTHCARE WORKERS

Declaration of Alma-Ata

International Conference on Primary Health Care, Alma-Ata, USSR, 6-12 September 1978

The International Conference on Primary Health Care, meeting in Alma-Ata this twelfth day of September in the year Nineteen hundred and seventy-eight, expressing the need for urgent action by all governments, all health and development workers, and the world community to protect and promote the health of all the people of the world, hereby makes the following

Declaration:

I

The Conference strongly reaffirms that health, which is a state of complete physical, mental and social wellbeing, and not merely the absence of disease or infirmity, is a fundamental human right and that the attainment of the highest possible level of health is a most important world-wide social goal whose realization requires the action of many other social and economic sectors in addition to the health sector.

II

The existing gross inequality in the health status of the people particularly between developed and developing countries as well as within countries is politically, socially and economically unacceptable and is, therefore, of common concern to all countries.

III

Economic and social development, based on a New International Economic Order, is of basic importance to the fullest attainment of health for all and to the reduction of the gap between the health status of the developing and developed countries. The promotion and protection of the health of the people is essential to sustained economic and social development and contributes to a better quality of life and to world peace. **IV** The people have the right and duty to participate individually and collectively in the planning and implementation of their health care.

V

Governments have a responsibility for the health of their people which can be fulfilled only by the provision of adequate health and social measures. A main social target of governments, international organizations and the whole world community in the coming decades should be the attainment by all peoples of the world by the year 2000 of a level of health that will permit them to lead a socially and economically productive life. Primary health care is the key to attaining this target as part of development in the spirit of social justice.

VI

Primary health care is essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of selfreliance and self-determination. It forms an integral part both of the country's health system, of which it is the central function and main focus, and of the overall social and economic development of the community. It is the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process.

VII

Primary health care:

1. reflects and evolves from the economic conditions and sociocultural and political characteristics of the country and its communities and is based on the application of the relevant results of social, biomedical and health services research and public health experience;
2. addresses the main health problems in the community, providing promotive, preventive, curative and rehabilitative services accordingly;
3. includes at least: education concerning prevailing health problems and the methods of preventing and controlling them; promotion of food supply and proper nutrition; an adequate supply of safe water and basic sanitation; maternal and child health care, including family planning; immunization against the major infectious diseases; prevention and control of locally endemic diseases; appropriate treatment of common diseases and injuries; and provision of essential drugs;
4. involves, in addition to the health sector, all related sectors and aspects of national and community development, in particular

agriculture, animal husbandry, food, industry, education, housing, public works, communications and other sectors; and demands the coordinated efforts of all those sectors;

5. requires and promotes maximum community and individual self-reliance and participation in the planning, organization, operation and control of primary health care, making fullest use of local, national and other available resources; and to this end develops through appropriate education the ability of communities to participate;
6. should be sustained by integrated, functional and mutually supportive referral systems, leading to the progressive improvement of comprehensive health care for all, and giving priority to those most in need;
7. relies, at local and referral levels, on health workers, including physicians, nurses, midwives, auxiliaries and community workers as applicable, as well as traditional practitioners as needed, suitably trained socially and technically to work as a health team and to respond to the expressed health needs of the community.

VIII

All governments should formulate national policies, strategies and plans of action to launch and sustain primary health care as part of a comprehensive national health system and in coordination with other sectors. To this end, it will be necessary to exercise political will, to mobilize the country's resources and to use available external resources rationally.

IX

All countries should cooperate in a spirit of partnership and service to ensure primary health care for all people since the attainment of health by people in any one country directly concerns and benefits every other country. In this context the joint WHO/UNICEF report on primary health care constitutes a solid basis for the further development and operation of primary health care throughout the world.

X

An acceptable level of health for all the people of the world by the year 2000 can be attained through a fuller and better use of the world's resources, a considerable part of which is now spent on armaments and military conflicts. A genuine policy of independence, peace, détente and disarmament could and should release additional resources that could well be devoted to peaceful aims and in particular to the acceleration of social and economic development of which primary health care, as an essential part, should be allotted its proper share.

The International Conference on Primary Health Care calls for urgent and effective national and international action to develop and implement primary health care throughout the world and particularly in developing countries in a spirit of technical cooperation and in keeping with a New International Economic Order. It urges governments, WHO and UNICEF, and other international organizations, as well as multilateral and bilateral agencies, nongovernmental organizations, funding agencies, all health workers and the whole world community to support national and international commitment to primary health care and to channel increased technical and financial support to it, particularly in developing countries. The Conference calls on all the aforementioned to collaborate in introducing, developing and maintaining primary health care in accordance with the spirit and content of this Declaration.

This Declaration was sourced from: www.who.int/publications/almaata_declaration_en.pdf

The South African Patients Rights Charter

For many decades the vast majority of the South African population has experienced either a denial or violation of fundamental human rights, including rights to health care services. To ensure the realisation of the right of access to health care services as guaranteed in the Constitution of the Republic of South Africa (Act No 108 of 1996), the Department of Health is committed to upholding, promoting and protecting this right and therefore proclaims this PATIENTS' RIGHTS CHARTER as a common standard for achieving the realisation of this right.

This Charter is subject to the provisions of any law operating within the Republic of South Africa and to the financial means of the country.

A healthy and safe environment

Everyone has the right to a healthy and safe environment that will ensure their physical and mental health or well-being, including adequate water supply, sanitation and waste disposal as well as protection from all forms of environmental danger, such as pollution, ecological degradation or infection.

RESOURCES FOR CHAPTER 11

Participation in decision-making

Every citizen has the right to participate in the development of health policies and everyone has the right to participate in decision-making on matters affecting one's health

Access to healthcare

Everyone has the right of access to health care services that include:

i. receiving timely emergency care at any health care facility that is open regardless of one's ability to pay;

ii. treatment and rehabilitation that must be made known to the patient to enable the patient to understand such treatment or rehabilitation and the consequences thereof;

iii. provision for special needs in the case of newborn infants, children, pregnant women, the aged, disabled persons, patients in pain, person living with HIV or AIDS patients;

iv. counselling without discrimination, coercion or violence on matters such as reproductive health, cancer or HIV/AIDS;

v. palliative care that is affordable and effective in cases of incurable or terminal illness;

vi. a positive disposition displayed by health care providers that demonstrate courtesy, human dignity, patience, empathy and tolerance; and

vii. health information that includes the availability of health services and how best to use such services and such information shall be in the language understood by the patient.

Knowledge of one's health insurance/medical aid scheme

A member of a health insurance or medical aid scheme is entitled to information about that insurance or medical aid scheme and to challenge, where necessary, the decisions of such health insurance or medical aid scheme relating to the member.

Choice of health services

Everyone has the right to choose a particular health care provider for services or a particular health facility for treatment provided that such choice shall not be contrary to the ethical standards applicable to such health care providers or facilities, and the choice of facilities in line with prescribed service delivery guide lines.

Be treated by a named health care provider

Everyone has the right to know the person that is providing health care and therefore must be attended to by clearly identified health care providers.

Confidentiality and privacy

Information concerning one's health, including information concerning treatment may only be disclosed with informed consent, except when required in terms of any law or an order of the court.

Informed consent

Everyone has the right to be given full and accurate information about the nature of one's illnesses, diagnostic procedures, the proposed treatment and the costs involved, for one to make a decision that affects any one of these elements.

Refusal of treatment

A person may refuse treatment and such refusal shall be verbal or in writing provided that such refusal does not endanger the health of others.

Be referred for a second opinion

Everyone has the right to be referred for a second opinion on request to a health provider of one's choice.

Continuity of care

No one shall be abandoned by a health care professional worker or a health facility which initially took responsibility for one's health.

Complain about health services

Everyone has the right to complain about health care services and to have such complaints investigated and to receive a full response on such investigation.

Every patient or client has the following responsibilities:

- to advise the health care providers on his or her wishes with regard to his or her death.
- to comply with the prescribed treatment or rehabilitation procedures.
- to enquire about the related costs of treatment and/or rehabilitation and to arrange for payment.
- to take care of health records in his or her possession.
- to take care of his or her health.
- to care for and protect the environment.
- to respect the rights of other patients and health providers.
- to utilise the health care system properly and not abuse it.
- to know his or her local health services and what they offer.
- to provide health care providers with the relevant and accurate information for diagnostic, treatment, rehabilitation or counselling purposes.

This was sourced from: http://www.doh.gov.za/docs/legislation/patientsright/chartere.html

RESOURCES FOR CHAPTER 12

DYING AND THE LAW

Information the Master of the High Court will need when a Deceased Estate is being wound up

The Master may require different documents, depending on the value of the estate (how much the property is worth), if there is a will or if there are young children. The documents can be obtained from the nearest Master's Office or they can be downloaded from the internet at: *www.justice.gov.za/master.forms.html*

The most common reporting documents needed are listed below:

For estates less than R125 000

- Death notice form (J294)
- Original or certified copy of the death certificate
- Original or certified copy of marriage certificate
- Original will (if any)
- Affidavit of Next-of-kin if there is no will (J192)
- Inventory form (J243)
- Undertaking and acceptance of Master's directions (J155)
- Declaration confirming that the report has not been made at another Master's Office

For estates less than R50 000 reported to service points/no will

- death notice form (J294)
- Certified copy of Death certificate
- Certified copy of marriage certificate
- Identity documents of beneficiaries
- Affidavit of Next-of-kin (J192)
- Inventory form (J243)
- Written nominations for the Master's representative by heirs
- Undertaking and acceptance of Master's directions (J155)
- Declaration confirming that the report has not been made at another Master's Office

RESOURCES FOR CHAPTER 12

Summary of Steps

1. If the value of the estate is more than R125 000, the Master will appoint an executor and the full legal process must be followed.
2. If the value of the estate is worth less than R125 000, the Master may decide to appoint a Master's Representative instead. The Master will issue section 18(3) letters of authority and the process followed is less complicated.
3. If the value of the estate is worth less than R50 000 and if there is no will, the estate can be reported at service points throughout the country.

You can find offices of the Master of the High Court in:

Pretoria
Cape Town
Pietermaritzburg
Grahamstown
Mthatha
Bloemfontein
Kimberley
Mafeking
Johannesburg
Polokwane
Port Elizabeth
Thohoyandou

The phone numbers for the Office of the Chief Master are to be found in the **Useful Contact List.**

RESOURCES FOR CHAPTER 13

DEATH & DYING

A Power of Attorney for Future Medical Treatment

This extra information relates to the section in Chapter 13 on Powers of Attorney.

Our law says that a power of attorney falls away when a person becomes mentally incompetent. So, this means that our law does not allow you to appoint a power of attorney when you are in good health, to make medical decisions for you in the future when you are not able to make decisions yourself.

When you become mentally incompetent, someone can apply to the court to appoint a curator to take care of your personal affairs and to make medical decisions for you.

The South African Law Commission (SALC) looked into this matter and recommended that the law should be changed so that people can make an enduring power of attorney – in other words, a power of attorney that carries on even when a person becomes mentally unable to make decisions anymore. The draft bill as outlined below, was drawn up in 1999 but has not yet been debated by Parliament.

Case Study

An Enduring Power of Attorney

Eddie has a long-term relationship with Phumi, but they are not married. Eddie wants to write a power of attorney giving Phumi the right to make decisions about his medical treatment if he becomes too ill to do so. He is worried that his family may try to make those decisions without Phumi.

At present in South Africa we do not have law on this issue however we do have policy. A Living Will (Advance Directive) is not legally binding but guides healthcare decisions. Therefore it is not possible to go to court to enforce a Living Will or Advance directive.

Case Study

Clarke v Hurst 1992(4) SA 630 D

The patient, Dr Clarke, had been a member of SAVES (The Living Will Society) and had signed a living will, requesting that he be allowed to die rather than live by artificial means. Later during medical treatment, he suffered extensive brain damage. Three years after this tragedy, his wife applied to court to be appointed as Mr Clarke's curatrix personae, with specific powers to decide to withdraw naso-gastric feeding. Mr Clarke's two sisters and four children supported Mrs Clarke's application.

The Attorney-General opposed this application, arguing that Mrs Clarke was effectively asking for a declaratory order to end a life, and declined to undertake not to prosecute if this should transpire.

The Judgment

The court looked at the quality of life of the patient and whether the steps Mrs Clarke proposed would be in the best interests of Mr Clarke. The court although being strongly in favour of preservation of life, felt that it did not mean life should be maintained at all costs, irrespective of its quality. The court felt that the patient's wishes as expressed when he was in good health should be given effect to.

The Court found that Mrs Clarke could refuse naso-gastric feeding of Mr Clarke without incurring liability, even should such action shorten the life of Mr Clarke. So the Court did not express itself on the legal standing of a living will. It appointed the patient's wife as curatrix to authorise cessation of medical treatment by taking into account several factors, one of which was the patient's wishes as expressed in his living will.

For further information, see Chapter 3, Ethical Issues

For further reading on the case of Clarke v Hurst see:

Botha Grové, Lourens. Framework for the implementation of Euthanasia in South Africa, Uni of Pretoria, Faculty of Law 2007 http://upetd.up.ac.za/thesis/available/etd-07102008-131712/unrestricted/dissertation.pdf

Assisted Decision-making: Adults with Impaired Decision-making Capacity. Discussion Paper 105, Project 122. The South African Law Commission January 2004 http://www.justice.gov.za/salrc/dpapers/dp105.pdf

Euthanasia and patient's right to refuse treatment http://www.nortonrose.com/knowledge/publications/44188/euthanasia-and-patients-right-to-refuse-treatment

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A simple example of a Living Will

Advance Directive / Living Will

To my Family and my Physician:

This declaration is made by me ______________________ at a time when I am of sound mind and after careful consideration.

If the time comes when I can no longer take part in decisions for my own future, let this declaration stand as my directive.

If there is no reasonable prospect of my recovery from physical illness or impairment, expected to cause me severe distress or to render me incapable of rational existence, I do not give my consent to being kept alive by artificial means. I request that I receive only the drugs and intravenous fluids that may be required to keep me free from pain or distress even if the moment of death is hastened.

I hereby request and authorise my spouse, children, partner or any member of my family to apply to the Supreme Court for a Court Order to compel compliance of this directive should any medical practitioner or hospital refuse to give effect to the said directive.

This declaration is signed and dated by me in the presence of the two under-mentioned witnesses.

SIGNED: ______________________ Date: ______________

Witnessed by: ______________________ ______________

SIGNATURE: ______________________ Date: ______________

Name: ______________________ ______________

Address: ______________________ ______________

SIGNATURE: ______________________ Date: ______________

Name: ______________________ ______________

Address: ______________________ ______________

____

Drawing up a will

- Give your full name with your identity number and your address.
- Say what your marital status is, and if married, state your marital regime. Give the name and identity number of your spouse.

Are you single, married, divorced or widowed?

- Write down that this is your last will and testament and that you revoke (cancel) all other wills that you have made before this one.
- Name someone you trust to take on the administration of your will (carrying out your wishes) – an executor. You should ask the person first before naming them as your executor in the will. If you do not select someone, or if the Master thinks that the person you have chosen will not be able to do the administration properly, then the Master may select someone for you.
- You must also say that the executor does not have to pay any money when she/he accepts the position of executor. This is called an `exemption from paying security'.
- Make it clear how you want your property to be dealt with. Write down who will inherit each of your possessions. Give details such as their full names, addresses and whether they are male or female, married or unmarried.
- Always think of your minor children. If you have minor children, you need to think of someone you trust who can act as their guardian. This person must be able and willing to be their guardian. If it is possible, an expert such as a bank manager, an accountant or a lawyer should be consulted when there are minor children.
- When you are finished, write the date and sign the will, in full, in front of the two witnesses – you must sign the will as closely as possible to the last line of writing in the will. This is to stop anyone from adding anything onto your will.
- Both witnesses must sign, in full, after your signature on the last page.

WARNING

A person cannot inherit if s/he signs as a witness. This is to stop people from committing fraud or the court thinking that they may have committed a fraud.

Unless your will includes an 'exemption from paying security', the Master will normally require the Executor to submit a bond of security. This is because the Executor is responsible for your assets. If you appoint your parent, your child or your spouse as your Executor, they do not have to submit a bond of security. Remember that despite your wishes in your will, the decision to request a bond of security is at the Master's discretion.

Note: If the Testator (person writing the will) thinks their Executor may need help to administer the will, then this clause should be included in the will: I direct that my Executor shall have the power to appoint a professional to assist him/her.

Example of a simple will

LAST WILL AND TESTAMENT OF Kase Mdu (ID number) of 25 Malibongwe Drive, Randburg, Johannesburg.

1. I hereby cancel all wills made by me before this time,
2. I appoint as executor of my estate my sister, Suni Sunn, of 10 Moss Street, Burgersfort. I do not want my executor to pay any security.
3. I leave R5 000.00 to my friend, Sbu Khosa, of 9 First Avenue, Malvern, Johannesburg.
4. I leave my car to my daughter, Akhona Mnisi, of 201 Green Street, Acornhoek, Limpopo Province.
5 I leave the rest of my property to my wife, Agnes Mdu, with whom I have a customary law marriage which is registered in terms of section 4(1) of Act 120 of 1998, and if she does not survive me, I leave the rest of my estate to my brother, Gideon Mdu,
6. Should my wife die before me, I would like to appoint my brother, Gideon Mdu, as the guardian of my minor son, Mpho Mdu.
7. I would like that, on my death, any of my organs to be used for purposes of transplant to help another living person. I direct that my executor may have the authority to decide in this matter.
8. I would like to be cremated.

Signed by Kase Mdu on this day of 29th October 2006 as the testator of this will in the presence of two witnesses.

Testator. ____________________

Witness 1. ____________________

Witness 2. ____________________

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YOU
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YOUR MONEY

THE COST OF CREDIT

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The National Credit Act prescribes limits on interest rates for all forms of credit, including micro-loans. However, the Act introduces other fees (the initiation fee and the service fee) which cause the total cost of credit to remain extremely high. No longer is it sufficient to consider only interest rates. Interest rates **and** initiation **and** service fees must all be carefully calculated in order to work out the **total cost of credit** for borrowers.

Since 1 June 2007 credit is MORE EXPENSIVE in most cases. Not just interest, but also **initiation and service fees** must be considered when calculating the total cost of credit.

INTEREST

Agreements of up to R8000 that must be repaid within 6 months have a maximum interest rate of **5% per month or 60% per year**.

Unsecured agreements (agreements for more than R8000 and/or repayable over more than 6 months) currently have a maximum interest rate of **32.1% per year**. This is more than DOUBLE the previous maximum.

Secured bank loans, credit cards or cheque accounts now have a maximum interest rate of **22.1% per year**.

INITIATION FEE

This is a one-off fee payable when you enter into the agreement, or payable in instalments. The maximum amount is R150 per agreement AND 10% of the amount of the debt that is more than R1000, but never to exceed R1000 nor 15% of the debt

SERVICE FEE

This is a monthly or periodic fee for routine administration. It may be a maximum of **R50 per month** or R600 per year, which is a huge fee for smaller credit agreements.

The combined impact of interest, the initiation fee and the service fee

In the table below, the total cost of credit is applied to a number of loan amounts and loan periods. The total monthly cost of credit is indicated in rands, and then this rand amount is indicated as a monthly and annual percentage of the initial loan. These percentages give the most accurate possible indication of the total cost of credit in each case.

	Amount of initial agreement (e.g. loan)	**Duration of agreement**	**Interest** 5% pm (R)	**Initiation fee** pm, when paid in instalments (R)	**Service fee** always R50 pm (% of the initial loan)	**Total cost of credit** interest + initiation fee + service fee (R and %)
1	R200	1 month	R10 pm	R32 pm	25% pm	R92 pm 46% pm (552% per year)
2	R500 (average size 30-day loan)	1 month	R25 pm	R79 pm	10% pm	R154 pm 31% pm (372% per year)
3	R500	6 months	R25 pm	R15 pm	10% pm	R90 pm 18% pm (216% per year)
4	R1 000	1 month	R50 pm	R158 pm	5% pm	R258 pm 26% pm (312% per year)
5	R1 000	6 months	R50 pm	R30 pm	5% pm	R130 pm 13% pm (156% per year)
6	R8 000 (max size short-term loan)	6 months	R400 pm	R167 pm	0,6% pm	R617 pm 8% pm (96% per year)

The National Credit Act has made great strides towards consumer protection, and the new limits on interest rates will provide welcome relief for many borrowers. The total cost of credit on small loans will, however, remain exorbitant. This will have a devastating negative impact on poorer individuals and communities.

FOLD ALONG THE DOTTED LINES

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10. Statements of account

Credit providers must give you statements of account, usually once per month (once every two months for instalment sale agreements).

Credit providers must also give you statements of account on request, at no charge. Consumers may choose how the statement must be delivered:

- orally in person, or by phone; or
- in writing (in person, by sms, mail, fax or email – provided the credit provider has these facilities). Credit providers do not need to give written statements on demand more than once every three months.

11. Duty to report location of goods

In the case of instalment agreements, you get ownership ONLY when all instalments are paid. Consumer must inform credit provider of changes in :

- business or residential address
- the premises where the goods are kept
- the name and address of any other person who has possession of the goods

If requested, you must also give to the credit provider or Sheriff the address where the goods are kept and the name and address of the landlord of the premises.

12. Duty to pay credit providers

This is the consumer's MOST IMPORTANT duty. It will prevent legal action being taken against you.

Also, maintaining a good credit rating will make it easier for you to get credit in future

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YOU
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CONSUMER RIGHTS & DUTIES

The last provisions of the National Credit Act of 2005 came into effect on 1June 2007. All consumer credit law is contained within this Act and it applies to all credit agreements and all credit providers.

1. Right to pre-agreement disclosure

- Before entering into a credit agreement the credit providor MUST give you a statement and quotation for FREE.
- At this stage there is NO AGREEMENT: you do not have to sign anything or pay any fee
- The statement and quotation must tell you:
  - the amount of credit provided
  - the number and amount of instalments payable
  - interest and other fees
  - deposit required
  - credit insurance

You have 5 days to accept or reject the quote. This gives you time to look around for better or cheaper credit.

Only when you accept the quotation is the credit agreement concluded and you are bound by it.

DO NOT PAY ANY FEES BEFORE CONCLUDING YOUR AGREEMENT!

2. Right to apply for credit and non-discrimination

- Every adult can apply for credit, but no-one has the right to be granted credit.
- A credit grantor can refuse to give you credit for reasonable business reasons, but
- may not refuse to give you credit because of your race, religion, marital status, ethnic or social origin, gender, sexual orientation, age, disability, culture, language etc.
- you MAY ask for reasons why you were refused credit. The credit provider should give you these reasons in writing.

3. Right to understandable language

You have the right to be given a quotation and credit agreement in an official language you understand, if this is reasonable. If documents don't have a set form they should be in plain language that an average person can understand.

4. Right to information held by credit bureaux

When you apply for credit, the credit provider will check your credit report before deciding whether or not to give you credit.

- You have the right to access information held by credit bureaux about your credit worthiness.
- You can dispute the correctness of this information
- You can have information about rescinded judgments removed from credit bureaux records.
- The credit bureau or NCR MUST investigate and correct any incorrect information FREE of charge.
- A credit provider must advise you before reporting information about you to a credit bureau.
- You have the right to a free credit bureau report once per year during your birthday month.
- After that it will cost R20 per enquiry.

Two IMPORTANT credit bureaux are:

TransUnion ITC
Tel: 086 148 2482 | Fax: 011 388 9963
Email: freecreditreport@transmission.co.za
www.mycredit.co.za

Experian
Tel: 086 110 5665 | Fax: 011 707 6700
Email: consumer@experian.co.za.
www.experience.co.za

5. Right to protection against marketing practices

The Act contains a number of rules regarding marketing practices:

(a) The advertising and marketing of credit must contain prescribed information on interest and all other charges you will have to pay

(b) Negative option marketing is not permitted (in terms of which an agreement will automatically come into existence unless the consumer declines an offer).

(c) Advertisements must not be misleading, fraudulent or deceptive.

(d) Credit providers may not harass, force or persuade you to apply for credit.

(e) Credit sales at a person's home are strictly prohibited, unless:

- the sale occurs during a meeting that you pre-arranged for that purpose ; or
- you are given credit on the sale of goods or services.

(f) A credit provider may require that you have credit life insurance during the time you have a credit agreement with them; but they have a duty to ensure that suitable options for insurance cover are offered to you.

6. Right to confidentiality and privacy

Credit bureaux must protect the confidentiality of consumer credit information that they hold or report on.

Credit providers must give you the option of being excluded from telemarketing campaigns, marketing or customer lists sold or distributed, and mass distribution of email or sms messages.

7. Right of cooling-off

Leases and instalment agreements

You may terminate these agreements (in writing and properly delivered) within five business days of signing them. You must then return the goods you bought. The credit provider must refund the money you paid within seven days of termination, less the following:

(a) reasonable costs of return and repair of damages after sale;

(b) rent for use of the goods, unless they are still in their original packaging; and

(c) compensation for depreciation in value of the goods (by agreement or court order only).

8. Right to early settlement and repayments

You MAY settle your debts before they are due, and credit providers must accept early payment. Amounts paid early will be used first for unpaid interest and fees, and second to reduce the principal debt.

In the case of SMALL agreements (less than R15 000) you do not need to give notice to the credit provider if you want to do this. Interest and other fees are payable only until the date of settlement.

i.e. YOU CANNOT BE PENALISED FOR PAYING EARLY

In the case of LARGE agreements (eg mortgage bonds) you must give 3 months notice to the credit provider. If you cancel a mortgage bond, you will be liable for the bond cancellation costs.

9. Surrender of goods

You can take the goods you bought on credit back to the credit provider at ANY time (whether you are in default or not). The credit provider must then sell the goods and use the money it gets from the sale to settle your account. If the amount the credit provider receives from selling the goods is less than what you owe, you will have to pay it the amount that is outstanding.

FOLD ALONG THE DOTTED LINES

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What can I do if the information on my credit report is incorrect?

The National Credit Act has prescribed a process for managing consumer disputes with the credit bureau. If you believe that the information on your credit report is incorrect, you should do the following:

- Contact the Credit Bureaux and inform them that you wish to register a dispute.
- The Credit Bureaux will investigate the dispute and respond within 20 business days. Credit providers will be notified that there is a dispute on your record but will not be able to view the disputed information during this investigation period.
- Should the information prove to be incorrect or unsubstantiated it will be removed immediately.
- Credit providers will be notified of the correction.

Should you not be satisfied with the resolution of your query you may contact the office of the

Credit Information Ombud
on 0861 66 28 37

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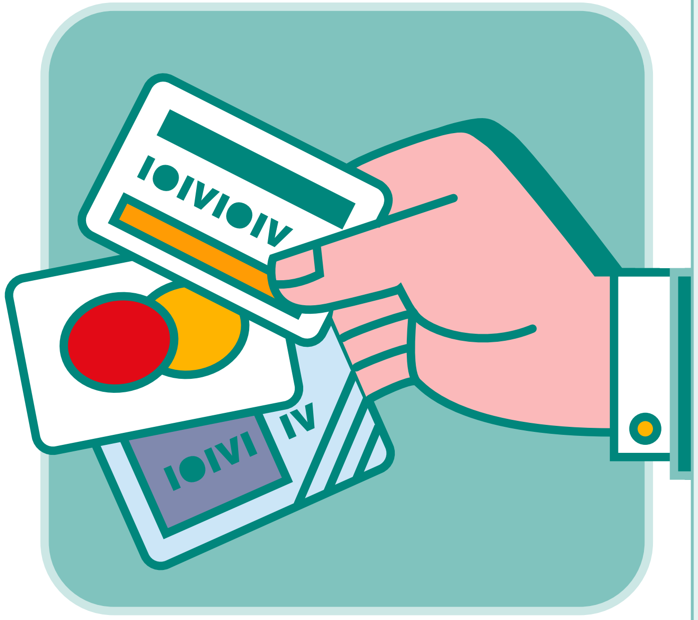
THE CREDIT BUREAUX



Rights regarding information held by Credit Bureaux

Whenever you apply for credit, the credit grantor checks your Credit Report before deciding whether to approve or decline your application.

A Free Credit Report is available once a year, as of 1 September 2006. This gives the Debtor access to all the information that credit grantors can access, including the debtor's paying habits, credit history and any other credit enquiries. Note that this free credit report is only available in the month of the debtor's birthday. You can now check that your personal information, like your ID number, address and employer's details, are correct and up to date. You can also see information relating to how you pay your accounts and how it is represented on your Credit Report.

The two main Credit Bureaux are:

- Trans Union ITC and
- Experian

A. Free Credit Report through TransUnion ITC

There are three main methods:

- Internet
  Log into *www.mycredit.co.za*
- Email
  freecreditreport@transmission.co.za
- Fax
  011 388 9963

A reply to your application will be sent to you within 48 hours.

Should you have already received your Free Credit Report for the year, you can purchase another copy for only R20 from the Personal Credit Products section of this website.

B. Free Credit Report through Experian

To request your free credit report the following procedure must be followed:

- Complete a Request a free credit report form which can be downloaded at *www.experian.co.za*
- Fax it (together with the required documentation) to 011 707 6700
- Or email the above completed report to *consumer@experian.co.za*

A reply to your application will be sent to you within 48 hours.

Please note that any further copies of your credit report will be charged at R22.80 (R20 + VAT). For any further queries contact Experian's Consumer Relations desk on 0861 10 56 65.

You are required to provide the following information when making an application with both Credit Bureaux:

- Proof of your full names
- Date of birth
- Identity number (by providing a copy of your national identity document)
- Or, if your identity document is un-available, a copy of your passport and full birth certificate or a valid driver's licence and other credit-related information

What information is on a credit report?

A credit report includes:

- information about previous credit enquiries.
- account repayments including poor payer information.
- judgments

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DEBT MANAGEMENT

TIPS AND ADVICE

If someone has a problem with debt, he or she should not say "I can't pay", otherwise they would be legally regarded as insolvent and the insolvency process would then apply. This legal process might result in them losing their house. The person should rather say: "I am sick and have not been able to work, or 'I am unemployed at present but looking for a job."

Before legal action is taken against the Debtor (who may be your patient/client) :

1 If you not sure what to do, ask the patient's permission for you to refer the problem to your supervisor.

2 Contact the Creditor to make an arrangement to pay off the debt over time. It must be put in writing and each payment recorded.

3 If the patient doesn't want to contact the Creditor directly, contact a local Advice Centre or a Legal Aid Clinic for help. They might be referred to a Debt Counsellor who will help draw up a budget and suggest a distribution. Remember a Debt Counsellor may charge for assistance.

4 Suggest that they ask their friends or family if they would agree to pay the debt.

5 If a person cannot afford an attorney, they should contact a University Law Clinic or a Justice Centre or an NGO offering free legal services to find out if they qualify for free legal assistance.

If a Court Order is issued for **Repossession of Goods:**

Items can only be repossessed with a court order or with your permission. The Sheriff of the Court must show you the Court Order before removing the goods from your home.

If a Garnishee Order is issued:

It is only allowed when the item you purchased can't be repossessed (it was lost, damaged, stolen). This only applies to goods purchased through an instalment sales agreement (Hire Purchase Agreement). The money to pay the debt is taken directly out of your wages/salary.

If a Letter of Demand or a **Summons from the Court** is received

1 **DO NOT IGNORE IT.**

2 If you not sure what to do, refer it to your supervisor – but do not delay.

3 Call an Advice Centre/Legal Aid Clinic/Attorney immediately

4 Contact the attorney for the Creditor immediately to make an arrangement to pay. Get everything in writing.

5 If you dispute the debt and want to go to Court to explain, fill in the "Notice of Intent to Defend" on the back of the Summons and take it to Court.

A real summons letter always has the name of the Clerk of Court and the Case Number on the top.

Other Options:

- Seek the Court's Help.
- Ask at a library for the phone number of your local Magistrate's Court. Apply to the Magistrate's Court for a "distribution" order
- Apply to a High Court for Insolvency. This should be a last resort because it has serious consequences.

FOLD ALONG THE DOTTED LINES

Remember that the following actions by debt collectors are considered to be crimes.

CRIMES

If a creditor...

- Threatens or harasses you
- Comes at night to take away items
- Enters your private property without permission

This is **INVASION OF PRIVACY AND TRESPASSING**
If a creditor...

- Breaks a door, window or lock in order to enter a debtor's property
- Threatens violence

This is **MALICIOUS INJURY TO PROPERTY AND ASSAULT**

Call the police and report the creditor for the crime

USEFUL CONTACT LIST

MAIN OFFICE	NATIONAL CONTACT DETAILS	IMPORTANT LOCAL NUMBERS
Bigshoes In partnership with government and other organisations, Bigshoes is committed to improving the quality of life of vulnerable children through health care interventions	011 484 0792/3 031 309 464 053 021 685 8826 admin@bigshoes.org.za www.bigshoes.org.za	
Cancer Association of South Africa (CANSA) A non-profit organization set up to fight cancer and offer support to cancer sufferers.	0800 22 66 22 (toll free) 011 616 7662 info@cansa.org.za www.cansa.org.za	
Cape Town Drug Counselling Centre	021 447 8026 www.drugcentre.org.za	
Caregivers Action Network Campaigning for better working conditions for community healthcare workers	www.caregiversactionnetwork.org	
Child Welfare South Africa (CWSA) Represents more than 263 member organizations and forms the largest non-profit, non-governmental organization in the country in the fields of child protection, child care and family development.	011 452 4110 011 452 5229 info@childwelfare.org.za www.childwelfaresa.org.za	
CHOC Children's Haemotology Oncology Clinics, started by a parent group, now with branches in five provinces.	086 111 350 headoffice@choc.org.za www.choc.org.za	
Civil Society Prison Reform Initiative A research and advocacy project focusing on prisons in the African region, with the aim of furthering constitutional and human rights imperatives within these settings.	021 959 2950/2951 cspri@uwc.ac.za www.cspri.org.za	
Companies & Intellectual Properties Commission Customer Contact Centre	086 100 2472	
Department of Home Affairs General Enquiries for identity documents and travel documents	0800 204 476 csc@dha.gov.za	
Ministerial hotline For complaints and compliments Update on ID application status	0800 601 190 minister@dha.gov.za SMS the word 'ID' and your ID number eg. ID 121212781082 to 32551	
Ehospice For the latest news, commentary and analysis on hospice, palliative and end of life care – delivered by regional and national hospice and palliative care organisations worldwide.	www.ehospice.com launching in October 2012	

USEFUL CONTACTS

MAIN OFFICE	NATIONAL CONTACT DETAILS	IMPORTANT LOCAL NUMBERS
Gold Standards Framework UK based - Enabling a gold standard of care for all people nearing the end of life.	www.goldstandardsframework.org.uk +44 (0) 1743 291891 info@gsfcentre.co.uk	
Gauteng Centre of Excellence for Palliative Care The objective of the centre is to light the way for a pain free journey through the provision of an integrated pain management programme in public health.	011 933 4916 / 4031 info.palliative@wits.ac.za www.wits.ac.za/academic/health/clinicalmed/internalmedicine/divisions/palliativecare/9472/contact_us.html	
Grandmothers against AIDS and Poverty (GAPA) For details of other organisations supporting older persons look at Chapter 9 – Palliative care for Older Persons.	021 364 3138 021 361 8326 info@gapa.org.za www.gapa.org.za	
Halt Elder Abuse (HEAL) A telephone helpline for older persons who are being abused.	0800 003 081	
Hospice Palliative Care Association (HPCA) A national organisation operating in all 9 provinces in South Africa with member and affiliated hospices countrywide.	021 531 0277 info@hpca.co.za www.hpca.co.za	
International Children's Palliative Care Network (ICPCN) ICPN believe that every life-limited child deserves a high standard of total care, wherever they live in the world.	info@icpcn.co.za advocacy@icpcn.co.za 082 897 4420	
Legal services See Legal Services at the end of this list		
Master of the High Court Offices of the Chief Master can be found in major cities in South Africa. Executors need to contact the Master of the High Court when winding up a Deceased Estate.	Pretoria 012 315 1220 Cape Town 021 410 8300 Johannesburg 011 220 2500 Durban 031 306 0175 Port Elizabeth 041 502 7407 www.justice.gov.za/master.forms.html	
Palliative Care Society of South Africa (PCSSA) Aims to become a national voice for palliative care in South Africa, to foster and promote palliative care for people with a progressive and terminal illness & their families, among service providers, caregivers and the community at large.	www.palliativecaresociety.co.za	
Parliamentary Monitoring Group (PMG) See further details about this group on page 213, Resource for Chapter 4.	021 465 8885 info@pmg.org.za www.pmg.org.za	

MAIN OFFICE	NATIONAL CONTACT DETAILS	IMPORTANT LOCAL NUMBERS
Presidential Hotline For use when all attempts to get assistance from a government department, province, municipality or state agency have failed.	17737 (1 PRES) Fax: 086 681 0987 / 012 323 8246 president@po.gov.za	
Public Protector To investigate complaints against government agencies or officials. See further details about the Protector, under Resource for Chapter 8 earlier in this chapter.	0800 11 20 40 012 366 7000 www.pprotect.org/index.asp	
SASSA toll-free hotline To check progress on your grant application.	0800 601 011 www.sassa.gov.za	
Sisonke Sex Worker Movement To unite sex workers, improve living and working conditions and to fight for equal access to rights.	0782 403 651 pamelachakuvinga@yahoo.com workingthecity.wordpress.com/sisonke-sex-worker-movement/	
South African government information website	www.info.gov.za	
World Wide Palliative Care Alliance (WPCA)	www.thewpca.org	
Triangle Project Challenging homophobia Appreciating sexual diversity	021 448 3812 Helpline: 021 712 6699 (between 1pm to 9pm) www.triangle.org.za	

LEGAL SERVICES

When looking for legal assistance, remember:

- The confidentiality of the client is always to be respected.
- Get the client's consent before making a referral for them to receive legal assistance.
- Community paralegals can give legal assistance, for instance by mediating in disputes between neighbours, helping to find missing birth certificates or ID, or helping with debt problems.
- Many paralegal advice centres operate within what is known as a cluster which is a referral network of paralegals, university law clinics and government justice centres.
- Remember that some clients may not wish to be helped by someone in their immediate community.
- Paralegals have access to lawyers for more complex problems. Such lawyers work at legal clinics at universities, at government Justice Centres, at legal NGOs such as the Legal Resources Centre, Black Sash, Lawyers for Human Rights and Pro Bono.Org, all listed below. Private lawyers do some of their work for free (pro bono) as part of their commitment to community involvement.
- Besides accessing lawyers through paralegals, university law clinics and legal services NGOs, you can also contact the Law Society of South Africa for access to attorneys registered in the various provincial law societies.
- Law24.com (launched by Lexis-Nexis) offers a one-stop website with simple legal information, expert opinions grouped into various categories: work, money, personal and family, and property and home. Visit www.law24.com
- If legal assistance is not accessible locally, other NGOs, local branches of political parties, trade unions will have access to legal information.
- Legal fees may be charged if the person seeking legal assistance has an income, whilst some lawyers will provide assistance pro bono (for free) to those without means of payment.

Some of the organisations listed here have contributed to writing this manual. The list on the next page is not comprehensive but offers pointers on how to find legal services operating in local communities in South Africa.

USEFUL CONTACTS

CONTACT DETAILS FOR LEGAL SERVICES

MAIN OFFICE	NATIONAL CONTACT DETAILS	IMPORTANT LOCAL NUMBERS
Association of University Legal Aid Institutions (AULAI) Will help you find a law clinic in your area or you can contact your local university to find out if they have a law clinic.	051 448 5940 018 297 5341 secretary@aulai.org.za www.aulai.org.za	
Black Sash Helpline Can assist to find a paralegal in the Western Cape. The Black Sash assists with useful information about social grants and also produce the Paralegal Manual and Paralegal Advice website.	072 663 3739 help@blacksash.org.za www.blacksash.org.za www.paralegaladvice.org.za	
Justice Centres and The Legal Aid Board of South Africa Provide legal representation to indigent persons at State expense.	08610 Legal (53425) 011 877 2000 communications2@legal-aid.co.za www.legal-aid.co.za	
Legal Aid Advice Line Or request assistance from the Legal Aid Officer at a Magistrate's Court.	0800 110 110 0860 534 258	
Lawyers For Human Rights (LHR) Provide free legal services to vulnerable, marginalised and indigent people, both non-national and South African, who are victims of unlawful infringements of their Constitutional rights. LHR have offices in Johannesburg, Pretoria and Durban.	012 320 2943 www.lhr.org.za	
Legal Resources Centre With 65 lawyers working from four regional offices (Cape Town, Grahamstown, Durban and Johannesburg). Working for justice for the vulnerable and marginalised, including poor, homeless, and landless people who suffer discrimination by reason of race, class, gender, disability or by reason of social, economic, and historical circumstances.	011 836 9831 011 838 6601 011 403 0902 www.lrc.org.za	

MAIN OFFICE	NATIONAL CONTACT DETAILS	IMPORTANT LOCAL NUMBERS
National Alliance for the Development of Community Advice Offices (NADCAO) Can assist to find a paralegal situated anywhere in SA	021 6866952 www.nadcao.org.za	
Pro Bono.Org.za An NGO working with the private legal profession to provide pro bono legal services to the poor.	011 339 6080 erica@probono.org.za odette@probono.org.za www.probono.org.za	
Rhodes University Law Clinic Providing free legal services to the indigent people of Grahamstown and surrounding areas & providing support, training and back-up legal services to paralegal advice offices throughout the Eastern Cape.	046 622 9301 www.ru.ac.za/lawclinic	
Section 27 Incorporating the Aids Law Project Towards the progressive realisation of socio-economic rights, with a particular focus on the right of access to health-care services	011 356 4100 info@section27.org.za www.section27.org.za	
Socio-Economic Rights Institute (SERI) A law clinic and public interest law centre	011 356 5860 sanele@seri-sa.org www.seri-sa.org	
Street Law Provides practical understanding of law, the legal system and Constitution to all learners. Street Law offers legal training to NGOs and CBOs nationally.	031-2601291 info@streetlaw.org.za www.streetlaw.org.za	
The Law Society of South Africa Represents the attorneys profession comprising 20 000 attorneys and 5 000 candidate attorneys as at August 2010.	012 366 8800 LSSA@LSSA.org.za www.lssa.org.za	
Treatment Action Campaign (TAC) Campaigning for the rights of people with HIV/AIDS. Contact TAC for stigma awareness training.	021 422 1700 www.tac.org.za	

USEFUL CONTACTS

MAIN OFFICE	NATIONAL CONTACT DETAILS	IMPORTANT LOCAL NUMBERS
University of Cape Town Law Clinic Refugee Rights Unit training to guide asylum seekers and refugees through asylum procedure and the rights that are available to refugees as well as the systems that have been put in place to assist refugees.	021 650 3775 021 650 5390/5632/2678/5652 /5581/5493 uctlawclinic@uct.ac.za refugeelawclinic@uct.ac.za www.uct.ac.za/faculties/law/research/lawclinic/study	
University of the Western Cape Law Clinic Provides legal services in a range of legal matters to the poor and marginalized communities in the surrounding Cape Metro, Boland and West Coast Region.	021 959 2756 www.uwc.ac.za	
University of Witwatersrand Law Clinic One of the biggest law clinics of its kind in South Africa, and is renowned for its work, particularly in areas of public interest law and claims against the State as a result of police brutality.	011 717 8562 www.wits.ac.za	

CHILD LAWYERS

MAIN OFFICE	NATIONAL CONTACT DETAILS	IMPORTANT LOCAL NUMBERS
Children's Institute Activities focus on four areas critical to children's well-being: child rights, child poverty, child health services, and care in the context of HIV/AIDS.	021 689 5404 www.ci.org.za	
Community Law Centre Includes the Children's Rights Centre.	021 959 2950/2951 www.communitylawcentre.org.za	
Childline Works collectively to protect children from all forms of violence and to create a culture of children's rights in South Africa.	0800 055 555 011 645 2000 infogauteng@childline.org.za www.childlinesa.org.za	
Women's Legal Centre Litigates on behalf of poor women, particularly black women, focus areas include access to healthcare.	021 424 5660 www.wlce.co.za	

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Hospice Palliative Care Association
of South Africa
no end to caring

WHAT IS PALLIATIVE CARE?

The World Health Organisation defines palliative care as an ‘approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.’

Palliative care respects the dignity of patients and family members regardless of stage of illness or any other consideration.

“You matter because you are you, and you matter to the end of your life.
We will do all we can not only to help you die peacefully,
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- Dame Cicely Saunders

ISBN: 978-0-620-54210-4

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