

LEGAL ASPECTS IN PALLIATIVE CARE

HANDBOOK

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Acknowledgments

Kenya Hospices and Palliative Care Association (KEHPCA) would like to thank all individuals and organizations who contributed towards the development of the legal aspects in palliative care handbook.

Special thanks go to KELIN, an NGO working closely with KEHPCA, for its input and the expertise in review of the final draft of the handbook and advice accorded to KEHPCA on legal issues in palliative care.

Sincere appreciation goes to Open Society Initiative for East Africa, Open Society's Institute International Palliative Care Initiative (IPCI), and the Open Society Institute Law and Health Initiative (LAHI) for their support towards the development of this handbook.

Introduction

This handbook has been designed as a guide for use by health care professionals and non - health care workers, lawyers and paralegals offering care and support to patients and family members facing problems associated with life threatening illnesses in Kenya. With the number of people suffering from life threatening illnesses rising to alarming numbers, there is an urgent need to integrate palliative care services in our health care system. Palliative care as a health concern derives meaning from the World Health Organization (WHO) 1946 Constitution which defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity” Palliative care thus focuses on: quality of life, control of pain and other distressing symptoms, attention to the psychosocial, emotional and spiritual needs of the patient. Among the psychosocial needs of the patient are legal concerns which include delegation of decision making and powers of attorney, property inheritance and how to make a will, patient rights and responsibilities, and palliative care as a human rights issue obtaining from the right to health.

The Kenya Hospices and Palliative Care Association (KEHPCA), which is a national association, was formed to represent all palliative care service providers in Kenya. Its mission is to scale up palliative care services to bridge the very significant gap between those who receive services and those in need. This encompasses addressing issues of accessibility, affordability and quality of palliative care services. KEHPCA carried out a needs assessment survey in 3 member hospices to establish the issues affecting patients in need of palliative care and found that there is limited skilled resource in terms of numbers of service providers and the level of skill.

There are largely 3 palliative care challenges in Kenya attributable to the law:

- a). **Availability** - there are very few palliative care service provision sites in the country. Most of these do not provide all the components of palliative care and the only health care workers legally allowed to prescribe opioids are doctors, who are few in number.
- b). **Accessibility** - opioids do not reach patients as the majority of healthcare workers within easy access of patients are prohibited by law to prescribe opioids.
- c). **Affordability** - very few patients can afford opioids. Tight legal controls on narcotics hinder the supply of opioids which results in high prices.

What Is Palliative Care?

World Health Organization (WHO) has defined 'palliative care' as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illnesses, through the prevention and relief of pain and suffering by means of early identification and impeccable assessment of pain and other problems, physical, psychological and spiritual. Patients with cancer, HIV & AIDS and life-threatening illnesses suffer from severe pain and many symptoms that need to be controlled. Pain is a common symptom that can be managed but is mostly ignored or untreated. Palliative care is provided by a multidisciplinary team of health care providers including doctors, nurses, community caregivers, among others and it can be delivered in different settings; hospital, clinic, hospice, home, etc

Some examples of life-threatening illnesses are – cancer, leukaemia, hepatitis B, HIV/AIDS, etc.

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.

Palliative Care Rights

Palliative care embraces human rights that are recognized in national laws and international human rights treaties/conventions.

Palliative Care Rights Include:

- Pain relief
- Symptoms control for physical and psychological symptoms
- Essential drugs for palliative care
- Spiritual and bereavement care
- Family centred care
- Care by palliative care professionals
- To receive home-based care when dying and to die in dignity
- To access legal services
- Treatment of disease and to have treatment withdrawn
- Information about diagnosis, prognosis, and palliative care services
- Name a health proxy for decision making
- Not to be discriminated against in the provision of care because of age, gender, national status, or means of infection.

Definitions

A **'patient'** is a person who is waiting for, is receiving, or has received health care services.

'Patient care' refers to the prevention, treatment and management of illnesses and the preservation of physical and mental well-being through services offered by medical and allied health professionals.

'Human rights' refers to entitlements that all human beings have by virtue of the

fact that they are human beings. The entitlements are in the form of fundamental rights and freedoms.

Human Rights in 'Patient Care'

The provision of quality and appropriate health care is part of the Human Right to the highest attainable standard of Health. Palliative care is a holistic approach that improves the quality of life for patients and their families by addressing the psychosocial, legal, and spiritual problems associated with life-threatening illness. Hence, it is fundamental to health and is a basic human right. Rights that determine the highest attainable standard of health in patient care include:

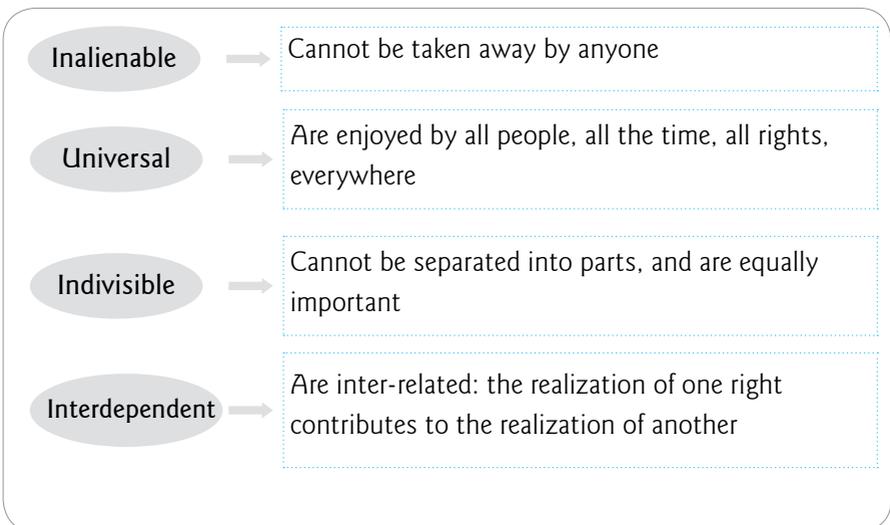
- Right to free choice which includes right to informed consent
- Right of access to services
- Right to respect for patients' time
- Right to privacy and confidentiality
- Right to freedom from torture
- Freedom from cruel, inhuman and degrading treatment
- Right to observance of quality standards
- Right to safe medical practices and facilities
- Right to avoid unnecessary suffering and pain
- Right to personalised treatment
- Right to complain
- Right to a remedy for infringement of rights
- Right to personalised treatment
- Right to complain

Human Rights and Palliative Care

What are 'Human Rights'?

Human rights are entitlements that all human beings have by virtue of the fact that they are human beings. They are necessary for human beings to live a life of dignity. Everyone has human rights, regardless of their age, sex, race, colour, language, tribe, social or economic class, religion or political beliefs. However, it is important to remember that rights are human constructs: they are seen through the eyes of human beings and exist for the benefit of humans only. They are also moral codes in all societies on what is right or wrong, permissible or not permissible. They protect all people from exploitation and dominance by more powerful people.

Characteristics of Human Rights



International human rights instruments and palliative care

General Human Rights are embodied in 3 instruments collectively referred to as the International Bill of Rights. These are:

1. The Universal Declaration of Human Rights (UDHR);
2. The International Covenant on Civil and Political Rights;
3. The International Covenant on Economic, Social and Cultural Rights.

The Universal Declaration of Human Rights (UDHR) was adopted by the United Nations General Assembly on 10 December 1948 in Paris. The Declaration arose directly from the experience of the Second World War and represents the first global expression of rights to which all human beings are inherently entitled. The UDHR binds all nations of the world as customary international law.

The International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights were both adopted by the UN General Assembly on 16 December, 1966. Both bind Kenya as a state party to the treaties.

Palliative Care as a human right:

Palliative care has not been expressly mentioned in any international instruments. However, palliative care as a right can be implied from the overall international human right to health, as well as freedom from torture and cruel, inhuman, and degrading treatment. Palliative care also affirms the right to life.

Article 25.1 of the Universal Declaration of Human Rights 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.

The ICESCR Article 12.1 asserts that: The State Parties to the present Covenant recognise the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

Both the UN Special Rapporteurs on Health and torture have cautioned against the failure to ensure access to medicines for pain relief as a human right violation.

Placing The Right To Palliative Care In The Kenyan Context

Supportive provisions in the Constitution of Kenya

The 2010 Constitution of Kenya, currently in force, was promulgated on 27 August 2010. The Constitution contains an advanced Bill of Rights that incorporates a wide range of human rights and among other things recognizes Socio-Economic rights of the Kenyan citizens.

The protection of fundamental rights and freedoms of the individual is guaranteed under the Kenyan Bill of Rights, Chapter 4 of the Constitution. The following are some rights which are determinants of a person's physical and mental health in Kenya:

- Article 26** - The right to life
- Article 27** - Right to freedom from discrimination
- Article 28** - Human dignity
- Article 29 (d) and (f)** - Right to freedom from torture, cruel, inhuman or degrading treatment
- Article 31** - Right to privacy
- Article 35** - Right to information
- Article 40** - Right to property
- Article 43(1)** - Right to health
- Article 46** - Consumer rights

The Kenyan Constitution 2010 can be found on the following website;

www.kenyalaw.org

Understanding these Constitutional provisions in the context of palliative care

Article	Relevance to palliative care in Kenya
2 (4) Supremacy of the Constitution	Outlaws any practice that is inconsistent with the provisions of the Constitution
Article 2(6) Supremacy of the Constitution	International instruments ratified by Kenya form the laws of Kenya; and can be enforced in court to support integration of palliative care
Article 10 National Values and principles of Governance	Decisions on laws and policies will take into account relevant principles and values of human rights
Article 26 Right to life	Right to life includes the right to a good quality of life that is comfortable and free from pain
Article 27 Equality and Non- Discrimination	Prohibition of discrimination on the basis of several grounds including health status means that people with life-limiting conditions deserve equal access and allocation of resources
Article 28 Human Dignity	Patient with conditions such as Cancer, HIV and TB have the right to be treated with respect ; free from avoidable suffering and pain
Article 31 Right to Privacy	Patient medical information is confidential and cannot be disclosed without his consent; unless necessary for medical care
Article 41 Labour relations	Patients are entitled to fair working conditions and adequate remuneration. Protects against unfair termination
Article 43 Economic and Social Rights	The right to the highest attainable standard of health care would entail sparing patients from unnecessary pain. It also includes ensuring access to pain relief medication
Article 46 Consumer Rights	PLHIV should be entitled to have access to effective drugs and treatment.

How Kenya can Respect the Right to Health

- *By refraining from denying or limiting equal access to health care for all persons;*
- *By abstaining from enforcing discriminatory practices as a State policy;*
- *By abstaining from imposing discriminatory practices relating to women's health status and needs;*
- *By adopting legislation ensuring equal access to health care and health related information and services provided by all;*
- *By ensuring that medical practitioners and other health care professionals meet appropriate standards of education, skill and ethical codes of conduct;*
- *By taking measures to protect all vulnerable or marginalised groups of society especially women, children, adolescents and older persons, in light of gender-based expressions of violence.*

How Kenya can Fulfil the Right to Health

- *By giving sufficient recognition to the right to health in the national political and legal systems;*
- *By recognising the right to health as a constitutional guarantee;*
- *By recognising other determinant rights of the right to health as constitutional guarantees.*

How Kenya can Protect the Right to Health

- *By documenting violations of the right and addressing them accordingly*
- *By advocating for the respect of the right to health by all persons*

Application of International law in Kenya

International law together with general rules of international law and treaties ratified by Kenya form part of the law in Kenya by virtue of **Article 2 (5)** and **2 (6)**.

While palliative care is not expressly mentioned under Kenya national law, it is specifically referred to in interpretation of the International Covenant on Economic, Social and Cultural Rights binding on Kenya.

The Committee on Economic, Social and Cultural Rights, which is the body that monitors and guides implementation of ECOSOC rights by state parties to the treaty, has in its General Comment No. 14 interpreted the right to the highest attainable standard of health as including palliative care.

General Comment No. 14 issued by the CESCR on the interpretation of the right to health 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***

General Comment No. 14 further describes, (in the section on older persons) the obligation of state parties to ICESCR to give 'attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity'.

The Committee on Economic, Social and Cultural Rights has also 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. 14 palliative care medications are currently on the WHO Essential Drug List

Guideline 6 of the International Guidelines on HIV&AIDS and Human Rights comments 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.*

Key components of the right to health in the context of palliative care:

1. **Available.** This includes the availability of palliative care services and goods such as opioids used in pain management without discrimination. Sufficient health personnel of adequate skill should also be available.
2. **Accessible.** Palliative care must be physically accessible and economically affordable. This also includes the right to information on palliative care and access to palliative care services from all levels of health facilities
3. **Acceptable.** This means that medical ethics must be respected and palliative care services offered should be culturally appropriate.
4. **Good quality.** Goods and services provided at palliative care facilities must be of good quality. At the minimum, this requires skilled medical personnel, scientifically approved drugs including opioids for the control of moderate to severe pain, hospital equipment, safe water and adequate nutrition.

Cases of Human Rights Violations In Palliative Care

Scenario 1 in Kenya

Musa a 35 year old man is married with 3 children. He works at Utubora hotel as a cook and a cleaner when the work load is less. He has had a recurring problem with boils on different parts of his body for the last 3 years. As a routine provision by his employer, Musa took the annual medical check up which coincided with his annual leave for 21 working days. Upon return to work, he found a new cook and cleaner at his duty station and upon seeking allocation of a duty station, his boss gave him money equivalent to a month's salary and terminated his employment.

Musa was shocked and unable to know what to do next. He went home very depressed, never told his wife about their fate and that evening went out to the local beer den to drink his problems away. He found a fellow colleague at the den who was shocked to see Musa, but wishing for another drink and knowing Musa had received some money earlier, the colleague shouted to Musa that since he was soon going to die of HIV, he should enjoy his last days with him!

Musa could not believe these words from a colleague, in a bar! He got so angry and wanted to know why he was terminated from work. The colleague volunteered that at Utubora Hotel, everybody knew Musa was HIV+ and no client wanted to eat food handled by a HIV+ person. The following morning Musa decided to confront his boss with this information.

but on his way to work; his landlord stopped him at the gate and told him to vacate his premises within 24 hours as he did not want a HIV+ person using his house. On hearing this, Musa's wife, Confused and dumbfounded, confronted Musa wanting to know if he had infected her as well and a commotion ensued. Before things could get worse, they saw their first-born child approaching. He had had a fight at school with some kids who accused him of having a HIV+ dad and said that they never wanted to play with him anymore as their parents had warned them not to.

Human Rights Violations in Musa's case:

(The contravention of the human rights law which obligates respect, protection and fulfilment of human rights is termed violation)

- Right to information
- Right to privacy and confidentiality
- Equality and Freedom from discrimination
- Freedom of association
- Right to employment and fair labour practices

The human rights abuses:

(The effects of such contravention on the victim is termed as human rights abuse)

- Disclosure of Musa's status to third parties without his consent
- Failure to get information on the outcome of his diagnosis
- Discriminatory acts by the employer, colleagues at work and landlord due to stigma
- Unfair treatment that results in the loss of employment, work and home
- Isolation of Musa and his family

What can Musa do at a personal level?

- Officially request his former employer for written reasons for his dismissal
- Seek reinstatement at his place of work.
- Musa could seek legal counsel through an organization that provides pro-bono legal support.
- File a case for unfair termination, discrimination at the place of work on grounds of health and seek compensation.
- Seek damages for breach of confidentiality due to injury caused to him by his health status being disclosed to third parties without his consent, his colleagues knowing his health status before him and the negative spread of information to his landlord and his neighbours which has resulted in his loss of accommodation and his children being ridiculed at school. He is also likely to lose his wife as a consequence.
- File a complaint to the medical board or sue the examining doctor for failing to respect professional ethics by sharing personal information without the consent of the examined client.
- Seek medical support from a medical practitioner for advice on how to address his condition and any other health-related concerns.
- Seek psychosocial support to address his wife and children about his HIV+ status, have them counselled and examined
- Join a support group

Scenario 2 in Kenya

Lucas was a senior sales consultant with a multinational company for many years. He had made good savings and invested in a big house in an upmarket suburb in one of Nairobi's posh Estates. He was married and with a daughter who was attending an international school while the wife attended to their needs at home.

Lucas was diabetic and on follow-up. Due to long travels and work demands, he got so stressed by his work that he began to drink a lot. He was rarely at home. Recently he started complaining of diarrhoea, severe abdominal pain and headaches. His wife escorted him to the hospital but was not involved nor informed about her husband's management since Lucas always liked going into the consultation room alone. His health deteriorated and after about six months of being in and out of hospital, he was diagnosed with cancer of the liver. One day Lucas suddenly fell ill. His wife rushed him to one of the best hospitals in the country and upon clinical examination, he was found to be emaciated, dehydrated and his abdomen was swollen and tender to touch. His liver was palpable and hard. He was unable to walk without assistance. The doctor recommended immediate admission and treatment commenced but his condition deteriorated very fast. Several consultants were called in and tests, drugs and more tests were recommended.

After 3 days of admission, the insurance company raised concern that Lucas' insurance cover was not up to date and hence the company could not cover for his expenses. The hospital asked his wife to settle the medical bill or make an undertaking to pay. The bill stood at Kshs.2 million. She could not share this with her husband who was now in the intensive care unit. His kidneys had also failed and he needed dialysis, 3 sessions each week would amount to about Kshs 20,000 per session. Upon consultations with a few relatives, they decided to check with his bank but only Kshs.500,000 was available. They

decided to sell his car which could only fetch Kshs.700, 000. By that evening, Lucas went into a coma. The hospital recommended that due to the high bills the family was incurring daily, the government hospital could help with life support as chances of Lucas getting out of the coma were very low. The family, fearing to risk 'killing him', requested to have this transfer but they had to pay the bill first. The solution was to sell his house.

For 3 days, Lucas remained on life support in the government hospital until he was pronounced dead. His wife and daughter were left destitute and had to be accommodated by friends and relatives. The daughter is now attending a government public school and the wife selling vegetables at a local market.

Human Rights Violations in Lucas' case:

- Right to access information
- Right to consent to particular treatment
- Right to respect for patients' wishes within the available resources
- Right to avoid unnecessary pain and suffering
- Right to affordable medical care
- Right to make decisions based on expert information

Model scenario:

The Patient and family needed to;

- Be informed with the complete and accurate diagnosis
- Have detailed discussions about treatment options, risks including success or failure
- Be referred to the nearest palliative care facility
- Have his symptom management, especially pain
- Encourage Lucas to involve his family in his care

- Receive Counseling
- Recommend legal Support for him and his family
- Psychosocial, Spiritual and emotional care

Palliative care respects the goals, likes, and choices of the ill /dying person. It...

- Respects patient's needs and wants as well as those of their family and other loved ones
- Finds out from the patient who they want to help plan and give care
- Helps patients understand their illness and what they can expect in the future
- Helps patients figure out what is important
- Tries to meet patient's likes and dislikes: where they get health care, where they want to live, and the kinds of services they want
- Helps patients work together with their health care provider and health plan to solve problems

Palliative care looks after the medical, emotional, social, and spiritual needs of the ill/ dying person. It;

- Knows that dying is an important time for the patient and their family
- Offers ways for the patient to be comfortable and ease pain and other physical discomfort
- Helps the patient and their family make needed changes if the illness gets worse
- Makes sure the patient is not alone
- Understands there may be difficulties, fears, and painful feelings
- Gives the patient the chance to say and do what matters most to them
- Helps the patient look back on their life and make peace, even giving them a chance to grow

Palliative care supports the needs of the family members. It;

- Emphasizes that families and loved ones need help, too
- Offers support services to family caregivers, such as time off for rest, and advice and support by telephone

- Knows that care giving may put some family members at risk of getting sick themselves. It plans for their special needs
- Finds ways for family members to cope with the costs of care giving, like loss of income, and other expenses
- Helps family and loved ones as they grieve

Palliative care helps gain access to needed health care providers and appropriate care settings. It;

- Uses many kinds of trained care providers--doctors, nurses, pharmacists, clergy, social workers, and personal care givers (multidisciplinary)
- Makes sure, if necessary, someone is in charge of seeing that patient's needs are met
- Helps the patient to use hospitals, home care, hospice, and other services, if needed
- Tailors options to the needs of the patient and their family

Palliative care builds ways to provide excellent care during illness and at the end of life. It;

- Helps care providers learn about the best ways to care for ill /dying people. It gives them the education and support they need
- Works to make sure there are good policies and laws in place

Human Rights and Access to Care

- All patients have a right to be treated with respect
- Health care workers must not treat patients who are living with HIV or cancer differently to other patients
- Employers should not terminate the employment of people who have life-limiting illnesses unfairly
- Landlords should not refuse housing to people with life-limiting illnesses
- Health care, education, and access to goods and services should be accessible

Some challenges to Access to Care

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

Human Rights Violations in Kenya's Health Care System

- Patients detained in hospital for their inability to pay bills
- Patients' information is open to all hospital staff, including those not involved in patient care
- Patients are forced to disclose their medical diagnosis to their employer in order to obtain sick leave from work
- Medical examinations take place in public wards
- Government fails to provide information on various health care services e.g. availability of pain medication
- Sometimes clinical performance does not measure up to acceptable standards of quality
- Waiting lists compromise availability and accessibility of health care services
- Physicians fail to comprehensively explain to patients the facts related to their condition
- Physicians fail to provide patients with information about treatment options and the potential risks and benefits of each procedure

Challenges to the Provision of Palliative Care in Kenya

- Legal restrictions to opioids availability and access causes people with life-limiting illnesses (e.g. cancer and AIDS patients) to suffer unnecessary pain
- Fearing prosecution for handling classified drugs, a doctor refuses to prescribe morphine to relieve a patient's pain

- Laws prohibit the prescription of morphine by other health care workers except physicians
- Laws prohibit the prescription of morphine to drug users. A former drug user in the advanced stages of AIDS who suffers great pain is denied the right to pain relief

What patients and health care workers can do when palliative rights are violated

KEHPCA encourages the hospices and palliative care units to work closely with lawyers and paralegals trained in legal aspects of palliative care. KEHPCA and KELIN have trained several lawyers across the county who been offering pro-bono legal support to patients on various matters. Some guide the patients, family members or community members to understand the nature of the violations and the legal options available for redress. They may also support filing of cases in court, others are willing to represent patients in court while others have assisted patients draft wills and donate power of attorney. The legal practitioners are also key allies in advocacy, lobbying for and ensuring a legislative and policy environment that is supportive of access to essential palliative care commodities and services.

The Constitution provides for easier implementation of human rights in High court by prioritizing human rights cases, eliminating technicalities and court fees. The Constitution also permits one to easily represent himself or a group of people in court to enforce fundamental human rights.

Palliative Care and Access to Controlled Medicines

World Health Organization (WHO) estimates that 80% of the world's population, including tens of millions of people worldwide who suffer from moderate to severe pain, does not have adequate access to pain treatment. This includes 5.5 million terminal cancer and 1 million end-stage AIDS patients. Much of their suffering could be prevented if morphine, an inexpensive, effective and safe medication that is generally not difficult to administer were available. However, in more than 150 countries around the world, access to morphine is virtually non-existent. One of the key reasons for this unacceptable state of affairs is a failure by many governments around the world to take reasonable steps to ensure the availability of this essential medicine.

- Morphine and codeine are on the WHO List of Essential Medicines (This list has been adopted for use in Kenya)

Countries have to:

- Provide these medications as part of their core obligations under the right to health;
- Make the medications available physically in adequate quantities and financially accessible to those who need them;
- Put in place an effective procurement and distribution system; and
- Create a legal and regulatory framework that enables healthcare providers in both the public and private sector to obtain, prescribe and dispense these medications.

Any regulations that arbitrarily impede the procurement and dispensing of these medications violate the right to health.

Pain Relief as a Human Right

Chronic pain is one of the most significant causes of suffering worldwide and a common symptom of HIV and cancer (some of the world's leading life limiting conditions). Pain has a profound impact on the quality of life and can have physical, psychological and social consequences. Access to pain relief is an essential human right.

The right to pain relief is incorporated in the interpretation of Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR). Health is defined broadly and includes the health of people with life-limiting illnesses. The right to pain relief as a human right can be implied from the right to life and freedom from torture, cruel, inhuman and degrading treatment established under the Articles 6 (1) and 7 of the International Covenant on Civil and Political Rights. General comment No. 14 on ICESCR asserts that “... *attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity.*”

On 13 November 1964 Kenya became the fortieth country to accede to the Single Convention on Narcotic Drugs, 1961 which obligated countries to work towards universal access to the narcotic drugs necessary to alleviate pain and suffering. Despite this many cancer and AIDS patients continue to suffer pain without treatment. The Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment sites denial of pain treatment as a human rights abuse. The report recommends full access to palliative care and overcomes current regulatory, educational and attitudinal obstacles that restrict availability to essential palliative care medications, especially oral morphine.

Research shows that pain can be controlled with careful assessment and management of pain, addressing psychosocial 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 which describes using non-opioid medication for mild pain, weak opioid for moderate pain and strong opioids such as morphine for severe pain.

However there is inadequate access to morphine and other opioids for pain relief in many parts of the world. Many people are being denied adequate pain relief – the majority (but not all) of these people are in developing countries. In Kenya, current legislation restricts **opioids prescription to doctors**. In the light of 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.

- Policy change will only occur if governments understand the importance of palliative care and the need to increase access to drugs for palliative care within their countries.
- Terminally ill patients do not have access to pain relief as a right and their ability to get pain relief depends on the accessibility of doctors and pharmacists.
- Licensing of suitably qualified professional nurses to prescribe palliative care medication would improve access to pain relief for patients at home.
- Under Kenyan law nurses are not able to deliver true palliative care since they cannot prescribe the appropriate analgesics.

Current prescribing legislation constitutes a failure of the Kenyan Government to take steps to progressively realise the right to health care services.

Common barriers to pain treatment availability include the failure by states to;

- Ensure a functioning supply and distribution systems for opioids medications;
- Enact adequate palliative care legislative framework;
- Develop effective policies and guidelines on pain management;
- Ensure relevant education and training for healthcare workers;
- Reform excessively strict drug-control regulations;

- Address widespread fear of legal sanctions for prescribing opioids medications among healthcare workers; and
- Take steps to ensure the affordability of morphine and other pain medications. Failure by states to take reasonable steps to remove these barriers violates right to health.

Common problems:

- Kenya does not recognize palliative care and pain treatment as priorities in health care, have no relevant policies, have never assessed the need for pain treatment or examined how well that need is met and have not examined the barriers to such treatment.
- Narcotic drug control regulations or enforcement practices impose unnecessary restrictions that limit access to morphine and other opioid pain relievers. They create excessively burdensome procedures for *procurement, safekeeping, and prescription* of these medications and sometimes discourage health care workers from prescribing narcotic drugs for fear of law enforcement scrutiny.
- Medical and nursing school curricula do not include instruction on palliative care and pain treatment, meaning that many health care workers have inaccurate views of morphine and lack the knowledge and skills to treat pain adequately.

These failures result in unnecessary suffering for people with moderate to severe pain and their families.

Causes of poor availability of pain relieving drugs

- Failure to put in place functioning supply and distribution systems;
- Absence of government policies to ensure their availability;
- Insufficient instruction for healthcare workers;
- Excessively strict drug-control regulations; and
- Fear of legal sanctions among healthcare workers.

Kenya Controlled Medicines

NOTE: to handle 'controlled medicines' in Kenya, one must:

- Follow the WHO essential drugs list as approved by the Minister for Health
- Follow Ministerial guidelines under the Public Health Act, Cap 242,
- Possess a licence under the Pharmacy and Poisons Act, Cap 244
- Comply with regulations under the Dangerous Drugs Act, Cap 245
- Hold a licence under the regulations of the Medical Practitioners and Dentists Board Act, Cap 253
- Comply with regulations under the Food, Drugs and Chemical Substances Act, Cap 254,
- Be a registered medical practitioner under the Medical Practitioners and Dentists Board Act, Cap 253.

In response to the vast range of drugs that had become available, the World Health Organization formulated a model core list of drugs essential and relevant to health care needs. This Essential Drug Concept was formalised with the publication of the first WHO Model Essential Drug List in 1977. Kenya was one of the first countries to recognise the importance of the concept and made its own list in 1981 based on the WHO model list.

The Kenya Essential Drugs List was for all levels of health care but was initially used for the rural health institutions and also formed the basis of the drug kits.

Essential Drugs are those that satisfy the health care needs of the majority of the population; they should therefore be available at all times in adequate amounts and appropriate dosage forms.

1. *Essential drugs are those that satisfy the needs of the majority of the population.*
2. *There should be adequate data supporting their efficacy and safety.*
3. *The drugs were assessed if they were used routinely and on their performance in routine practice.*

Dangerous Drugs Act – Cap 245

3. (1) No person shall import or export raw opium or coca leaves except under licence and into or from prescribed ports or places.

(2) If at any time the importation of raw opium or coca leaves into a foreign country is prohibited or restricted by the laws of that country, there shall, while that prohibition or restriction is in force, be attached to every licence which is issued under this Act authorizing the export of raw opium or coca leaves from Kenya such conditions as may appear to the licensing officer to be necessary for preventing or restricting, as the case may be, the exportation of raw opium or coca leaves from Kenya to that country during such time as the importation of raw opium or coca leaves into that country is so prohibited or restricted, and any such licences issued before the prohibition or restriction came into force shall, if the Minister by order so directs, be deemed to be subject to the same conditions.

7. No person shall import or export prepared opium.

8. A person who -

- a) Manufactures, sells or otherwise deals in prepared opium; or
- b) Has in his possession any prepared opium; or
- c) Being the occupier of premises, permits those premises to be used for the purpose of the preparation of opium for smoking or the sale or smoking of prepared opium; or
- d) Is concerned in the management of premises used for any such purpose; or
- e) Has in his possession any pipes or other utensils for use in connexion with the smoking of opium, or any utensils used in connection with the preparation of opium for smoking; or
- f) Smokes or otherwise uses prepared opium, or frequents a place used for the purpose of opium smoking, shall be guilty of an offence.

- 14.** (1) The drugs to which this Part applies are -
- a) Medicinal opium;
 - b) An extract or tincture of Indian hemp;
 - c) Morphine and its salts, and diacetylmorphine (commonly known as diamorphine or heroin) and other esters of morphine and their respective salts;
 - d) Cocaine(including synthetic cocaine) and ecgonine and their respective salts, and the esters of ecgonine and their respective salts;
 - e) A solution or dilution of morphine or cocaine or their salts in an inert substance whether liquid or solid, containing a proportion of morphine or cocaine, and a preparation, admixture, extract or other substance (not being such a solution or dilution as aforesaid) containing not less than one-fifth per centum of morphine or one-tenth per centum of cocaine or of ecgonine;
 - f) A preparation, admixture, extract or other substance containing a proportion of diacetylmorphine;
- 15.** Licences, permits or authorities for the purposes of this Act may be issued or granted by such person on such terms and subject to such conditions (including in the case of a licence the payment of a fee) as the Minister may prescribe.

Family Law and Palliative Care

The Constitution in Article 45 (1) provides that the family is the natural and fundamental unit of society and the necessary basis for social order. The family is a crucial component of palliative care because palliative care seeks to improve the quality of life of patients and their families. Kenya is currently in the process of developing, reviewing and amending its laws to ensure compliance with the provisions of the Constitution.

Some of the legislative provisions discussed below may change over the next few years. The Marriage Bill, Matrimonial Property Bill and Protection Against Domestic Violence [or previously titled the Family Protection Bill] will significantly affect family rights in Kenya.

The Matrimonial Property Bill seeks to clarify ownership and division of ancestral land and the cultural home. It also seeks to make specific provisions to ensure equitable division of matrimonial and other property in polygamous marriages giving guidance on the rights of each wife over property acquired with her husband as against the rights of other wives.

The Marriage bill 2012 seeks to repeal 7 acts of parliament relating to various regimes of marriage and attempts to consolidate the different systems into one.

Legal Basis of the Family

The family is based on Article 45 (2) of the Constitution that provides that *'every adult has the right to marry a person of the opposite sex, based on the free consent of the parties'*. Laws that govern marriage, separation and divorce, custody of

children, maintenance and division of matrimonial property vary depending on the “personal law” of the individual concerned. The family law system is made up of the following regimes under which marriages can be contracted:

1. Marriage Act, Cap 150 (proposed repeal)
2. African Christian Marriage and Divorce Act, Cap 151 (proposed repeal)
3. Mohammedan Marriage, Divorce and Succession Act, Cap 156 (proposed repeal)
4. Hindu Marriage and Divorce Act, Cap 157 (proposed repeal)
5. Customary law marriage (proposed repeal)

There are certain requirements that must be fulfilled in order for parties to contract a valid marriage under any of the 5 marriage law regimes. The Constitution provides the basic requirements which apply to all the regimes that the parties must be a man and woman who have freely consented to marry. Marriages under the Marriage Act, African Christian Marriage and Divorce Act and the Hindu Marriage and Divorce Act are strictly monogamous. Islamic marriages are potentially polygamous up to a maximum of 4 wives whereas customary marriages are potentially polygamous with no limit to the number of wives one can marry.

Contraction of a valid marriage is the basis for founding a family. The family is relevant to legal aspects of palliative care because the following palliative care rights have a bearing on the family:

- Right to receive family-centred care
- Right to receive home-based care when dying and to die at home if desired
- Right to name a health care proxy for decision-making
- Right to spiritual and bereavement care
- Legal services in palliative care that may be influenced by family include:
 - Disposal of property by will to provide for dependants
 - Considerations and decisions on custody and guardianship of children

Disposal of property and custody of children are usually the issues of major concern in family law and palliative care. Taking care of these issues is crucial to the psychosocial support of the patient, which gives the patient peace of mind.

The disposal of property in Kenya

Inheritance in Kenya is guided by the Law of Succession Act Cap 160 of the Laws of Kenya. Under this Act, a person may either die testate or intestate. A person dies testate when he has made a valid will on how his property should be distributed on his death. A person dies intestate when he has not made a will on how his property will be distributed on his death or his will has been invalidated.

Testate succession: If a person is of sound mind, then under Section 5 of the Law of Succession Act, he may dispose of all or any of his free property by will and may thereby make any disposition by reference to any secular or religious law that he chooses. However, if a dependant is left out of the will of his provider, Section 26 of the Law of Succession Act allows for him to apply for reasonable provision out of the estate of the deceased.

Intestate succession: In a case where a person dies intestate, the Law of Succession Act considers two scenarios. The Act provides for both monogamous and polygamous situations. In case a monogamous person dies and leaves a spouse and a child or children, the relevant sections of the Act are sections 35 and 37. In such a situation, the spouse is entitled to the personal and household effects of the deceased person absolutely and a life interest in the whole of the residue of the net estate. Section 3(1) defines personal and household effects to mean clothing, articles of personal use, furniture, utensils, appliances, pictures, ornaments, food, drinks and all other articles of household use and decoration normally associated with a matrimonial home. This does not include anything related to the deceased's business or profession. The surviving spouse enjoys the residue of the estate in her lifetime and it then devolves to their children when she dies. Under the proviso to Section 35(1), if the surviving spouse is a widow and she remarries, then the life interest in the property terminates.

Section 3(5) of the Law of Succession Act provides that regardless of the provisions of any other written law, a woman married under a system of law which permits polygamy is a wife for the purposes of inheritance and her children are entitled to inherit even if her husband has contracted a previous or subsequent monogamous marriage. Other women claiming to be the wives of a deceased may be entitled to inherit his property together with their children. However, this is conditional on their proving that they underwent some ceremony of marriage in a system that permits polygamy.

Making a Will: When one is faced with a life-threatening illness, it is prudent to make a will securing the property interests of their dependants, especially children. A will is defined under section 3(1) of the Law of Succession Act as the legal declaration by a person of his intentions or wishes regarding disposition of his property after his death. It can be oral or written.

Characteristics of a will

- It has no legal effect until the maker dies;
- The wishes expressed in it are only intended to take effect on death – where there is nothing in the document showing reference to the death of the person making it, it cannot take effect as a will;
- A will only operates as an expression of intention - it does not fetter the maker's freedom to deal with the property as he pleases during his lifetime;
- A will is ambulatory – it is capable of dealing with property acquired after the date of the will;
- A will is always revocable – because it does not take effect until death and it is merely a declaration of intention.

Why should one make a will?

- A will enables the maker to maintain control over their property even in death. This is especially important for a person with a spouse and children who may otherwise be disinherited by greedy relatives;
- A will enables the deceased's property to be well administered since its maker personally appoints a person he/she trusts believes to be capable of managing the property properly;
- Full disclosure of the deceased's property is enabled by the will, without which undisclosed property could be lost if the family never knew of its existence;
- A will gives the family peace of mind and avoids disputes over the sharing of the deceased's property;
- It is only through the will that one can benefit persons outside the immediate family circle;
- A will enables a parent who has young children to appoint guardians to take parental responsibility for the children should he/she die while the children are minors.

Creating a Valid Will

The maker of a will must be an **adult of sound mind**

The will must be made **voluntarily** without any duress/coercion, undue influence or mistake

The will must comply with the following formal requirements:

1. Oral will

- It must be made in the presence of two or more competent witnesses;
- It cannot be valid unless the maker dies within three months after it is made.

2. Written will

It must be signed by the maker or affixed with his thumb print or be signed by some other person in the presence of and by the directions of the maker of the will;

The signature of the maker or the person signing for him must be made or acknowledged by the maker in the presence of two or more competent witnesses

See sample will below:.

GUIDELINES TO MAKING A WILL

This is the last Will and treatment of (Name).....

Currently residing at (full address).....

Made on (date)

- 1. I hereby revoke all my former Wills, Codicils and Testaments made by me and declare this to my last Will.
- 2. I testify that I am an adult female/male of sound mind and holder of national identity card (ID. Number).....
- 3. I hereby declare this to be my last and final will
- 4. I appoint (name).....

Currently residing at (full address and name).....

to be the joint executors and trustees of this my last will and testament but if anyone or more of the above named persons should refuse to act, die before me, or die before the trusts hereof have been fully performed, then I appoint (name).....

Currently residing at (full address).....

to be the executor of my Will and Testament in the place and instead of any one or more of the above named persons, and the expression "my Trustee";

used throughout include the trustee for the time being, whether original or substitutional.

5. I direct the administrator to pay my just debts (as listed in Codicil II), funeral and other testamentary expenses, all succession duties, inheritance and death taxes, and all expenses necessarily incidental thereto, to be paid and satisfied by my Trustees as soon as is convenient after my death; to collect all my debts and outstanding

6. I give, devise and bequeath all my real and personal property of every nature and kind to the following:

(List) All my property as listed here, to the following:

Examples of properties to be distributed:

- a. Land parcel Ruiru/Block I 8/9999 to.....(Name)
- b. Unsurveyed plot at Kayole share No. XYZ to.....(Name)
- c. Shares in Kenya Airways to.....(Name)
- d. Motor vehicle registration No. KKD 100 to.....(Name)
- e. All my clothes, jewelry, ornaments to.....(Name)

7. I give the following properties to the following dependants

- 1. My wife/wives/husband.....(Name(s))
- 2. My father..... (Name)
- 3. My mother..... (Name)
- 4. My son (s) (name).....List them.....
- 5. My daughter(s)(name).....List them.....

8. I nominate, constitute and appoint (name).....
Currently residing at (place).....

.....
To be the guardian of my minor children. I direct the guardian of my minor children to raise them as Christians/Muslims according to the rules, customs, and teachings of the Bible/Islam.

9. In the event that any of my heirs should predeceases me, then my estate should be divided among my remaining heirs according to (7) above.

10. It is my most earnest request. to my heirs that if any differences of opinion should arise between them as regards any of my assets whatsoever or as the

ownership, character, value or otherwise, of the same or as to the meaning or true interpretation of anything contained in my Will, or, Codicils, thereto, they shall settle amongst themselves first, if not, the Trustees before resort to court.

In witness, whereof I, the said..... (Your name).....

Have signed my name on this.....(Date).....

Signed by the said.....

Signed by the Testator and published and declared as his/her last Will and Testament, in the presence of us both present together and in his presence and in the presence of each other have hereunto subscribed our names as witnesses. (The witness can be the same person as the Executor/Trustee.)

Signature of witness (1).....

Name.....

Address.....

Signature of witness (2).....

Name:.....

Address:.....

Codicils I, II and III are part of this will

A codicil is a document (a testamentary instrument) that amends, rather than replaces, a previously executed will. Amendments made by a codicils may add or revoke small provisions (e.g. changing executors), or may completely change the majority, or all, of the gifts under the will.

Codicil I

List of all my Property/Assets

Note: The Codicils are part of your Will. Since the Codicils are likely to change over time the Codicil which has the latest date and which is attached to this

Will, forms part of the Will and revokes all former Codicils made by you. Therefore the dates on the Codicil may not necessarily correspond with the date on the Will. Please ensure that you sign your latest Codicils and date it.

(Here make a list of all your property including: cash, bank accounts (local and foreign), off shore accounts, life assurances, real estate, jewelry (kept for the purpose of investment), shares/stocks, lockers and others)

Name of Property/estate	Location	Comments

Signature..... Date.....

Codicil II

List of Debts and Property of other to whom! have to pay/Return

(Here list all your debts and property you have of other people)

Name of Property owed	Amount/Property owed	Comments

Signature..... Date.....

Codicil III

List of Debts and Property that belong to me and I have to collect

(Here list the people who owe you and the property that others are keeping for you)

Name of person who owes	Amount/Property owed to me	Comments

Signature..... Date.....

NOTE:

- A competent witness is an adult of sound mind, who is receiving no benefit under the will,
- The marriage of the maker of a will automatically revokes the will made prior to the marriage except where the will is expressed to be made in contemplation of marriage with a specified person.
- A person making a will is required by law to make adequate provision for their dependants to avoid the will being challenged in court. One should not for instance will away their property to charity while leaving dependants destitute.

Disposal of property under rules of intestacy

Intestacy arises where someone dies without making arrangements on how his or her property will be disposed of after his or her death. It may be partial, where a person fails to include all of his or her property in a will, or full in the case of a person who does not make a will at all. In the case of partial intestacy, the property not covered by the will should be governed by the rules of intestacy under the Law of Succession Act.

Where a person dies without leaving a will, the law makes provision for distribution of their property under both monogamous and polygamous unions. Where the intestate leaves a spouse and a child or children, the spouse is entitled

to the personal and household effects plus an interest as long as he or she lives in the rest of the property. If the surviving spouse is a woman, her interest in the rest of the deceased's property terminates when she remarries. A surviving husband is however free to remarry without loss of their life interest in the property of their deceased wife. Upon death or remarriage of the surviving spouse, the property is divided amongst the surviving children equally. She may also distribute the estate while she is still alive or unmarried, so long as it is done fairly and reasonably. Any aggrieved child is entitled to petition the High Court for a variation or redistribution.

Where the deceased had more than one wife, the personal and household effects of the deceased and the rest of the deceased's property are divided between the various houses in proportion to the number of children in each house with the wife of the house added as a unit. The spouse in each house has a life interest in the share of the property allotted to her house as long as she lives and does not remarry her children inherit the property from her upon death or remarriage.

Where a widow has no children, she will be entitled to personal and household effects of her deceased husband absolutely. She will then get the first Ksh. 10, 000 or 20% of the rest of the deceased's property, whichever is greater, and a life interest in the remainder which terminates on remarriage.

Administration of estates

Upon the death of a person, if he or she had left a will, the executor (if one was appointed) should apply for probate. In the case of intestate succession, the most well-placed person in the succession line should apply for grant of letters of administration (the law gives priority to a surviving spouse). Temporary letters are always issued and are conformed after some time. It is an offence punishable under the law for anyone to administer an estate without letters of administration or to make false statements in the application for letters of administration.

Where it is proved that a grant of letters of administration was obtained through fraud, it will be annulled and the property will revert to the rightful person in the succession line. If there is no one in the succession line to the sixth degree of blood relation, the property will revert to the state.

General comments on Succession Law in Kenya

The Law of Succession 1981 does not adequately provide for widows in both monogamous and polygamous marriages. The Act also unfairly gives priority to fathers over mothers in inheritance and does not give adequate protection to children born out of wedlock.

The Commission on the Implementation of the Constitution (CIC) has recommended that laws that have a bearing upon the implementation of the Family Law Bills should be reviewed to facilitate uniformity and avoid contradiction with the proposed family laws and compliance with the Constitution.

The revised provisions of the amendments to the Law of Succession Act includes provisions that give the surviving spouse an absolute interest in the entire matrimonial home, personal and household effects, and one third of the residue estate, rather than mere life interest in the home and an absolute interest only in the personal and household effects.

Palliative Care and Children

Who is a child?

The Constitution in Article 260 defines a child as an individual who has not attained the age of 18 years. The Children's Act 2001 also gives the same definition.

Upon death, often children under 18 are left behind with no relatives or with ruthless relatives who end up taking advantage of these vulnerable kids. In order to ensure that all the rights of children are protected, the Law of Succession and the Children's Act have made specific provision for children. **Kindly note that the Commission on the Implementation of the Constitution (CIC) has recommended the review of both laws to ensure compliance with the Constitution and consistency with the proposed family bills already discussed above.**

Children and Succession

The Law of Succession Act in Section 3(2) defines adopted, legitimate and illegitimate children as children for the purposes of inheritance. This means that they have the right to inherit the property of their parents on an equal footing with biological children born within wedlock.

Where the deceased is survived by a spouse and/or children, no other relatives are entitled to benefit from the estate. The only way they can benefit is by making an application to the court as a dependant of the deceased immediately before his death. The Office of the Public Trustee was created to facilitate performance of duties related to custodianship and administration of deceased's estates and minors' trusts. Property devolving upon children as sole heirs should be held in trust for them by a court appointed.

NB: The proposed amendments to the Law of Succession Act provide that children will inherit immediately in equal shares to make sure that they are afforded adequate care and protection.

Custody and Guardianship of Children

What is Custody?

Custody is defined by the Children's Act in section 81 as parental rights and duties as relate to possession of a child. The guiding principle for the award of an order of custody by the courts is the best interest of the child.

Guardianship

Section 102 of the Children's Act defines a guardian. A guardian is a person appointed by will or deed by the parent of a child or by an order of the court to assume parental responsibility of the child upon the death of the child's parent. There can be appointed a sole guardian or a guardian in conjunction with the surviving parent of the child as the constitution imposes parental responsibility on both parents of the child, whether they are married to each other or not.

Custody can be conferred by guardianship. Palliative care patients can by their wills appoint guardians for their children to assume parental responsibility when they die. This helps patients to have peace of mind in their last days.

Section 23 of the Children Act defines parental responsibility over a child to mean all duties, rights, powers, responsibilities and authority that by law a parent has in relation to the child and the child's property in a manner consistent with the evolving capacities of the child. A parent or guardian is under duty to:

- Maintain the child with respect to adequate diet, shelter, clothing, medical care and education;
- Protect the child from neglect, discrimination and abuse;
- Give the child parental guidance in religious, moral, social and cultural values;

- Receive, recover, administer and otherwise deal with the property of the child, for the benefit and in the best interests of the child;
- Arrange for the burial or cremation of the child upon death.

Child Rights in Palliative Care

Children fall under the ambit of palliative care either as patients receiving palliative care or as family members of palliative care patients. The aim of palliative care is to improve quality of life. For children, this includes support of optimal childhood development and formal education which are rights obtaining from Article 53 of the Constitution. The right of the child to be protected from all forms of violence and inhuman treatment as stipulated in Article 53 (1) (d) and the right to healthcare have palliative care implications that oblige the state to promote, protect and fulfil palliative care rights for children.

i). The Right to Participation

The Children's Act (2001) Section 4(4) avails children this right in the following words:

“in any matters of procedure affecting the child, the child shall be accorded an opportunity to express his opinion, and that opinion shall be taken into account as may be appropriate taking into account the child's age and degree of maturity”

In the context of palliative care, the right to participation for child has been established to have the following effects:

- When only parents and guardians are consulted, important and insightful perspectives of the affected children that could improve care quality are missed;
- When children are partners in their palliative care, they:
 - Are happier
 - Feel included and cared for
 - Take on appropriate responsibilities
 - Talk about their hopes and worries
 - Cope better

ii). Children in need of Care and Protection

The Department of Children's Services of the Ministry of Home Affairs is in charge of coordination of protection services for children in special need. The Children's Act in section 119 (1) (l) recognizes children with terminal illness or a child whose parent is terminally as children in need of care and protection. Section 120 provides for children officers to attend to the safety of such children as appropriate. Information on children in need of care and protection should be shared with the nearest available children's officer for their further action and intervention.

Power of Attorney

A power of attorney is a written document in which one person (the principal/donor) appoints another person to act as an agent (attorney) on his or her behalf, thus conferring authority on the agent to perform certain acts or functions on behalf of the principal. A power of attorney is a legal document that can let the patient appoint someone else to make decisions on their behalf when they are unable to make decisions for themselves.

- Daily routine (e.g. diet, visitors)
- Treatment options, medical care and access to such information
- Ending treatment and moving to home care
- Life-sustaining treatment

Through a power of attorney, the patient can also appoint someone to make decisions about money and property, e.g.:

- Paying bills
- Collecting benefits
- Disposal of property

What is the Power of an Attorney?

A power of attorney is a document in which you state that you give someone else (usually a relative or friend) the authority to make certain decisions and act on your behalf.

The person to whom you give these powers is called an “agent”

You are called the “principal.”

Just because the word attorney is used does not mean that the person you give authority to has to be a lawyer

Executing a power of attorney does not mean that you can no longer make decisions; it just means that another person can act for you also.

For example, you may be hospitalized for a brief period of time and need someone to deposit your checks in the bank or pay your bills. As long as you are capable of making decisions, the other person must follow your directions. You are simply sharing your power with someone else. You can revoke the agent’s authority under the power of attorney at any time if you become dissatisfied with what they are doing.

The type of power of attorney provided for the elderly sick is a power of attorney which means that, your agent can continue to make decisions for you if you become incapacitated. The agent will still be obligated to act in your best interest, making decisions and using your money and property only for your benefit.

By establishing a power of attorney, you are giving the agent some of the following powers:

- To spend your money, cash checks, and withdraw money from your bank accounts
- To sell your property
- To pursue insurance claims and legal actions

How do you choose agents?

If you do not establish a power of attorney and you become mentally incapacitated, it may be necessary for a court to appoint a guardian or conservator for you.

An agent is the person you have designated to act on your behalf or assume certain duties and responsibilities. The most important obligation of the agent is to act in your

best interest. This means they must always follow your instructions. The agent is a “fiduciary”, which means that he or she must act with the highest degree of good faith on your behalf.

Although your agent is supposed to make decisions in your best interest and to use your money and property only for your benefit, he or she has great freedom to do as he or she pleases. Therefore, it is essential to choose someone whom you trust when you sign a power of attorney. Before selecting an agent or attorney-in-fact, ask yourself the following questions:

- Do I trust this person?
- Does this person understand my feelings and my point of view? Will he or she follow my wishes if I am ever incapacitated?
- Is this person willing to do the work and spend the time handling my affairs?
- Is this person available to visit me or to keep in contact by phone?
- Is this person knowledgeable about finances? If not, would this person seek the help of experts?

Is my Power of Attorney Effective when I die?

No. A power of attorney ends upon your death. Thereafter your will, or the law of intestacy, governs the handling of your estate. A power of attorney document is not a substitute for a will.

Does an agent get paid?

This depends on the relation of the agent and the principal and the duties involved. Normally, in family situations where the attorney-in-fact’s duties are simple, no payment is provided.

A sample power of attorney

I/We..... (name/s and address)

.....

Do hereby nominate and appoint
.....(Name/s and address).....

with full power of substitution and revocation to be my/our true and lawful agent and attorney for me/us and in my/our name to apply for and obtain in Kenya

.....
.....
.....

and for the aforesaid purpose in my/

our name to sign and lodge documents which they in their aforesaid capacity may deem necessary or desirable; to alter and amend such documents; to attend wherever necessary and defend my/our application from opposition; and I/we hereby confirm and ratify whatsoever said agent substitute or substitutes may lawfully do by virtue of these presents.

I/We hereby revoke all previous authorizations, if any, in respect of the same mater or proceeding.

I/We also authorize the said agent to complete the entry of an address for service as part of any registration under the above authorization.

Thus done and signed at

.....

This day of.....

Signature.....

Before Me

Notary/Commissioner for Oaths

.....

Or

Witnessed by.....

Dated this.....

Other Issues that may require legal intervention include:

- Legal capacity in medical decision making (transferring power of attorneys)
- Accessing social benefits for orphans and older persons
- Domestic violence (physical, emotional and psychological)
- Medical negligence
- Creating sales agreements
- Discrimination in work place and health care services

Why do we need to integrate legal services in palliative care?

- To help patients with terminal diseases die peacefully and with dignity
- To protect the dependents of the patient
- To keep families together in hard times, reduce family disputes and inheritance wrangling
- Lobby for a legal and policy framework supportive of palliative care including access to quality pain medication

Appendix I

Know your palliative care Rights

You may have at one time in your life had an awful experience at the health care facility be it from delay in health care service, an undignified treatment or denial of the same but had no idea of your rights as a patient. If you know your rights, you are empowered to claim

Be empowered; know your rights

The Kenyan Patients' Rights Charter

Majority of people experience either denial or violence of fundamental human rights to health care services. To ensure the realization of these rights of access to health, the World Health Organization (WHO) requires all health service providers to make a commitment to upholding, promoting and protecting this rights. In 2013, Kenya came up with the **Kenya National Patients' Rights Charter** and chapter 1 states that every person, patient or client has the right to access health care; Health Care shall include promotive, preventative, curative, reproductive, rehabilitative and palliative care as a common standard for achieving the realization of this rights.

Palliative care services are included in health care services and therefore should be provided to all who need them.

Your rights as a patient are:

- A healthy and safe environment
- Participation to decision-making
- Information on one's health condition
- To be treated by a named health provider
- Privacy and confidentiality
- Access to health care
- Have information of your health condition
- Have informed consent
- Continuity of care
- Complain about health services
- Free choice
- Highest attainable standard of health
- Equality and freedom from discrimination
- Human dignity
- Emergency medical treatment.

What is palliative care?

Therapy intended to relieve the suffering of people who are living with an incurable illness by improving their quality of life.

What are palliative care rights?

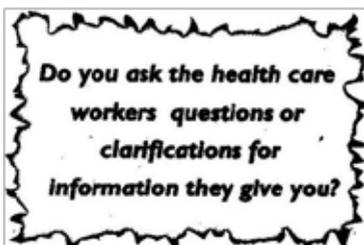
Palliative care embraces human rights that are already recognized in national laws, international human rights documents, and other consensus statements.

Palliative care rights include the right to:

- Pain relief
- Symptom control for physical and psychological symptoms
- Essential drugs for palliative care
- Spiritual and bereavement care
- Family-centered care
- Care by trained palliative care professionals
- Receive home-based care when dying and to die at home if desired
- Treatment of disease and to have treatment withheld or withdrawn
- Information about diagnosis, prognosis, and palliative care services
- Name a health care proxy for decision making
- Not be discriminated against in the provision of care because of age, gender, national status, or means of infection.
- The right to a dignified death
- The right to write a will
- The right to protect and dispose your property
- The right to plan for your children and dependants
- The right to secure access to health and social benefits
- Empowering others to make medical decision on your behalf

Your responsibilities as a patient are:

- To enquire about the related costs of treatment and/or rehabilitation and to arrange for payment
- To take care of health records in your possession.
- To take care of your health.
- To care for and protect the environment.
- To respect the rights of other patients and health providers.
- To utilize the health care system properly and not abuse it.
- To know your local health services and what they offer.
- To provide health care providers with the relevant and accurate information for diagnostic, treatment, rehabilitation or counseling purpose.
- To engage in healthy lifestyles for example; always eating a balanced diet living a life free of excessive alcohol, not smoking, not engaging in unprotected sex. To complete dosage as instructed at the health care facility
- To advise the health care providers on your wishes with regard to your death.



Appendix 2

Patient Information

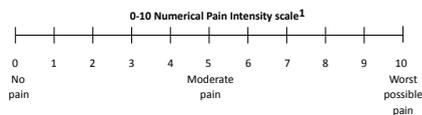
What is palliative care?

Therapy intended to relieve the pain and suffering of people who are living with incurable illnesses by improving their quality of life.

Are you in pain?

Most people suffer from pain. The good news is that most pain can be treated. It is your right to have your pain treated. Talk to your clinician about your pain. You can rate and tell your clinician where your pain is using the scales below.

Numerical rating (NRS)



Choose a number from 1 to 10 that best describes your current pain. **0 is no pain, 10 is the worst possible pain.**

Or

You can rate your pain by choosing the face that best describes how you feel. The far left face indicates **'No hurt-no pain'** and the far right indicates **'Hurts worst-worst pain'**. Document the number below that face chosen.

Faces rating scale (FRS – recommended for children)



Help your clinician to help treat your pain by talking about your pain.

What are Palliative Care Rights?

Palliative care embraces human rights that are already recognized in national laws, International human rights documents, and other consensus statements. Palliative care rights include the **right to:**

- Pain relief
- Symptom control for physical and psychological symptoms
- Essential drugs for palliative care
- Spiritual and bereavement care
- Family-centered care
- Care by trained palliative care professionals
- Receive home-based care when dying and to die at home if desired
- Treatment of disease and to have treatment withheld or withdrawn
- Information about diagnosis, prognosis, and palliative care service
- Name a health care proxy for decision making
- Not to be discriminated against in the provision of care because of age, gender, national status, or means of infection.

Appendix 3

Hospices and Palliative Care Units in Kenya - Contact List 2014

	HOSPICE/PCU	E-MAIL	TELEPHONE
1	Meru Hospice	pdirector@meruhospice.or.ke	+254 064 30 109
2	Nairobi Hospice	info@nairobihospice.or.ke ceo@nairobihospice.or.ke	+254 732 690 077 +254 020 2712361
3	Kisumu Hospice	kisumuhospice@hotmail.com	+254 057 530 091 +254 020 2393565
4	Coast Hospice	info@coasthospice.or.ke	+254 020 3577026 +254 707 239 603 +254 041 221431
5	Nyeri Hospice	info@nyerihospice.org ceo@nyerihospice.org	+254 061 2030382
6	Eldoret Hospice	info@eldorethospice.org	+254 053 2062049 +254 020 2410800
7	Nyahururu Hospice	nyahuhospice@yahoo.com	+254 065 22114 +254 711 2145741
8	Nakuru Hospice	nakuruhospice@gmail.com	+254 737 079707 +254 722 771401
9	Thika Hospice	unisnjeri@yahoo.com	+254 721 354 681
10	Embu-Mbeere Hospice	embumbeerehospice@yahoo.com	+254 722 930887
11	Kakamega Hospice	kakamegahospice@gmail.com roseotera@yahoo.com	+254 725 828829
12	Catherine Mc Auley Hospice - Muhoroni	gabriellemnerty@gmail.com	+254 734 958 228
13	Murang'a Hospice	murangahospice2010@gmail.com	+254 721 271172 +254 721 961865 +254 710 705049
14	Pope John Paul II Huruma Hospice - Nanyuki	jphuruma@gmail.com	+254 720 708023 +254 721 389763
15	Baraka Medical Centre - Nairobi Thika Road	germandocs@wananchi.com vincent.germandocs@gmail.com barbara.hueki@gmx.de	+254 20 2048468
16	Siaya Roselyne Hospice: Siaya	celline1952@yahoo.com hospice.siaya@gmail.com	+254 721 569662

	HOSPICE/PCU	E-MAIL	TELEPHONE
17	Laikipia Palliative Care Centre Nanyuki Town	laikipiapcc@hotmail.com mariaki67@yahoo.com	+254 20 2494148 +254 716 862762
18	Machakos PCU	emmusau@yahoo.com machakospcu@gmail.com	+254 713 833782
19	Malindi Hospice Palliative Care Unit		+254 070 8553762
20	Kimbilio Hospice - Kipkaren	juli@livingroominternational.org sawe@livingroominternational.org infokenya@livingroominternational.org	+254 728 278411 +254 700 151190
21	VIAGENCO Mbita	mokowuor@yahoo.com boswago@gmail.com	+254 711 896062 +254 720 808654
22	Our Lady Hospice Thigio: Limuru	thigiohospice@gmail.com	+254 20 0531084 +254 734 644649
23	Shepherds of life – Tharaka: Meru Town	shepherdsoflife@yahoo.com info@solkenya.org jwachieni@yahoo.com	+254 720 974311
24	Cancer Care Kenya: Nairobi	info@cancercarekenya.com stellahwarui@yahoo.com	+254 20 3740132 /0227/0153
25	Busia Hospice	periswandra@yahoo.com	+254 722 454111
26	Webuye Palliative Care Unit	drlaktabai@yahoo.com	+254 722 685542
27	FRACODEP-Kisumu	pam.oduor@yahoo.com fracodep.org@gmail.com palleta2009ke@yahoo.com	
28	AIC Kijabe Hospital	palliative.kh@kijabe.net meddir.kh@kijabe.net wgithinji2007@yahoo.com palldoc.kh@kijabe.net	+254 736 507666 +254 736 205549 +254 020 3246453/500
29	AIC Litein Mission Hospital: Liten	liteinpalliative@gmail.com chebetsarah73@yahoo.com	+254 052 54026 +254 52 54260 +254 723 089784 +254 728 488536
30	Chogoria Hospital	pcuchogoria@yahoo.com	+254 064 22620 +254 720 640495
31	Tenwek Mission Hospital	manchesters@tenwek.com evengeno@gmail.com tenwek@tenwek.com hospice@tenwek.com	+254 725 575133- Eveline +254 736 644070- Dr. Steve +254 20 2045542 +254 052 22495/6

	HOSPICE/PCU	E-MAIL	TELEPHONE
32	Maua Methodist Hospital	stevegito@yahoo.com	+254 064 21003 +254 064 21107 +254 733 361286
33	Mutomo Mission Hospital: Kitui	johnamollo@hotmail.com	+254 0721 647696
34	PCEA Kikuyu Hospital	palliative@pceakikuyuhospital.org	
35	Catholic Archdiocese of Mombasa (Health)	health@mombasacatholic.org	
36	Integrated AIDS Program - Thika Assumption Sisters	asninte@gmail.com	+254 722 580224
37	Nazareth Hospital	maryjollypaul@gmail.com	
38	Moi Teaching and Referral Hospital (MTRH) and AMPATH Oncology Institute - Palliative Care	suekipsang2008@yahoo.com ampath.palliativecare@gmail.com phanicejepkemoi@yahoo.com	
39	Kenyatta National Hospital PCU	drcege@wananchi.com	+254 722 848114
40	Embu PGH	judymutune@yahoo.com cnmarete@gmail.com	+254 720 553893 +254 720 483818
41	Nyeri PGH	wambuikaguora@yahoo.com	+254 722 295458
42	Kakamega PGH	sbokoth@gmail.com wpgh15@yahoo.com japwelch@yahoo.com adomisiani@yahoo.com	+254 725 951924
43	Coast PGH	mandareirine@yahoo.com egetambu@yahoo.com	+254 723 028726 +254 726 816559
44	JOOTRH	stephensewe@yahoo.com jennyobor@yahoo.com	
45	Machakos Level 5	chabimartin@yahoo.com	
46	Meru Level 5	stellakathambi@yahoo.com	
47	Thika Level 5	tl5palliativecareunit@gmail.com	+254 726 645920
48	Nakuru PGH	mercywachiuri@gmail.com zephkip@yahoo.com	+254 700 767636
49	Kisii Level 5	marylwanga@yahoo.com obaemary07@yahoo.com	+254 722 521459
50	Garissa PGH		
51	Homabay DH	lirumeshack@gmail.com	