REPUBLIC OF KENYA

MINISTRY OF HEALTH

NATIONAL PALLIATIVE CARE GUIDELINES

2013

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Foreword

Kenya like other countries in Sub- Saharan Africa is still faced with the enormous burden of the HIV and AIDS pandemic as well as that of cancer. According to the 2007 National Survey, HIV and AIDS prevalence rates were estimated at 7.4 % among the 15 to 49 years age group. The London declaration on Cancer Control in Africa in 2007, states that 'African countries will account for over a million cases of cancer per year' with an estimated 88-95%of cancer patients presenting late or at end stage of disease. Patients and their families have identified effective pain relief as a main priority to improve their quality of life, and this priority is central to palliative care. It is also estimated that 30- 80% of patients will have pain in the terminal phase of their disease, and that 25% of AIDS patients suffer severe pain during their terminal illness. (Katabera 1998, Moss 2000). Pain in patients with HIV/AIDS is often under diagnosed and under treated.

There is also much suffering caused by other symptoms including psychological and spiritual distress. These patients urgently require palliative care services, which has been highlighted as an urgent need for patients with both HIV/AIDS and cancer.

Non-Communicable Conditions (NCCs) are leading causes of morbidity and mortality globally. They contribute to over 60 % of total global mortality, out of which 80% of these deaths occur in middle and low income countries. By 2030, it is estimated that 8 0f 10 leading causes of death will be linked to NCCs. The World Health Organization (WHO 2002) report on non-communicable diseases indicates that NCCs are becoming a major burden in developing counties much more so than in the developed counties and the burden is growing bigger each year. WHO estimates that by 2015-2020, the number of deaths from the four leading NCCs (Cardiovascular disease, cancer, diabetes and hypertension) would increase by 21%.

Kenya is faced with impending epidemic NCCs. According to WHO report (2002), total mortality due to NCCs was about 32%. For the period 2005-2007 NCCs contributed over half of the top ten leading causes of morbidity in the country (MOH, 2007). Over 37% of the Kenyan population has high blood pressure, and 12% are suffering from heart diseases, while 10% have diabetes. Every year, over 28,000 new cases of cancer

are diagnosed in our hospitals while 22,100 die of cancer each year. NCCs are the cause of over 55% of all deaths recorded in our hospitals while they contribute to 50% of all hospital admissions in our public hospitals.

Implementation of palliative care services is regulated by international declarations like the Cape Town Declaration (2002) and the Korean Declaration of (2005). Up to 2010, Palliative care services were being championed by Non Governmental Organizations. To demonstrate government commitment for development of palliative care services, on 29th July 2010, the Director of Medical Services released a circular to 10 Level Five and Provincial Hospitals directing them to integrate palliative care services. Before then, palliative care services have been coordinated mainly by free standing hospices and a few mission hospitals. Development of these national palliative care guidelines will provide direction in the provision of palliative care services.

The Ministry of health is appealing to all government facilities, Mission Hospitals, all institutions providing health care and Non Governmental organizations providing palliative care or wishing to open palliative care sites and those currently providing palliative care services to operate in line with these guidelines.

James W. Macharia
Cabinet Secretary,
Ministry of Health

Executive Summary

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Kenya like other countries of the world is experiencing a rising number of patients suffering from non communicable conditions like cancer, diabetes, cardiac diseases, renal failure, and chronic obstructive pulmonary disease among others. The country is still being faced with HIV/AIDS epidemic and all these patients require palliative care. It is estimated that there are 1.4 million Kenyans living with HIV (KAIS 2007) and 28,000 new cases of cancer annually.

In 2005, the WHO projected that Africa will experience the largest increase in death rates from cardiovascular diseases, cancer, respiratory diseases and diabetes by 2015. Majority of patients present late and cure is not possible hence the need for palliation. These guidelines were developed by various knowledgeable stakeholders with an interest in palliative care.

Vision, Mission and Goal

The National palliative care guidelines envisions an effective and efficient national palliative care program in order to achieve the goal of providing holistic and quality palliative care services to patients and families faced with life threatening illnesses throughout the country.

Key Interventions

This guideline identifies the following key areas and suggests interventions in order to promote provision of holistic quality palliative care in Kenya. The list is not exhaustive and more strategies can be included as new challenges and innovations arise:

- To provide direction for the establishment and implementation of quality palliative care services in institutions and communities.

- To promote access to quality palliative care services, including pain and symptom control.
- To promote quality pediatric palliative care services.
- To provide a basis for ensuring availability, accessibility, safe handling and rational use of opioids for pain management, and other palliative care medications
- To provide basis for the development and implementation of palliative care standards in Kenya.

A list of essential palliative care medicines is provided in Annex 1 as well as useful patient assessment tools.

Conclusion

The Ministry of Health hopes that these guidelines will contribute positively to the development of palliative care. The guidelines will ensure that services offered are standard with an aim of improving the quality of life of patients in the best way possible.

The MoH also recommends the adoption of these guidelines and remains committed to providing technical support through these processes.

Dr. Francis Kimani
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Acronyms & Abbreviations

AIDS	Acquired immune deficiency syndrome
APCA	African Palliative Care Organization
ART	Anti-retroviral therapy
ARV	Anti-retroviral
CBO	Community Based Organization
CD	Controlled Drugs
CHAK	Christian Hospitals Association of Kenya
CO	Clinical Officer
CPD	Continued Professional Development
EOL	End of Life
FBO	Faith Based Organization
GoK	Government of Kenya
HBCC	Home Based Community Care
HIV	Human Immunodeficiency Virus
HPCT	Hospital Palliative Care Team
KEHPCA	Kenya Hospices and Palliative Care Association
KEMSA	Kenya Medical Supplies Agency
KEPH	Kenya Essential Package for Health
M, E & R	Monitoring, evaluation and Reporting
MO	Medical Officer
MOH	Ministry of health
NASCOP	National AIDS and STD Control Program
NCCs	Non-communicable Conditions
NGO	Non-governmental Organisation
ORS	Oral Rehydration Salts
PC	Palliative Care
PLWHA	People Living with HIV and AIDS
PTB	Pulmonary Tuberculosis
WHO	World Health Organisation

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Notes

CHAPTER 1

Introduction and Background

1.1 Introduction

Goal

The goal of the guidelines is to streamline the provision of PC in Kenya, through the elaboration of key steps/processes required for quality service provision.

Objectives for the Guidelines

- To provide direction for the establishment and implementation of quality palliative care services in institutions and communities.
- To promote access to quality palliative care services, including pain and symptom control.
- To provide a basis for lobbying availability, accessibility, safe handling and rational use of opioids for pain management, and other palliative care medications
- To provide basis for the development and implementation of palliative care standards in Kenya.

Millions of people affected by NCCs live and die with severe pain and other debilitating symptoms and can be effectively treated at low cost, however, they do not have access to medicines, technologies and palliative care services. Health care focuses on acute care and care of chronic patients with stable illness but patients with progressive illness are a neglected group Health services abandon patients

sending them home often without medication when “there is nothing more we can do for you” in hospitals. This is a time when patients have critical clinical, psychosocial and spiritual problems

Palliative Care is an approach that improves the Quality of Life of Patients and their families facing the problems associated with a life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual

- Provides relief from pain and other distressing symptoms
- Integrates the psychological and spiritual aspects of patient care (holistic nature)
- 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 counseling, 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

Benefits of palliative care

- Causes patients to spend more time at home and reduces the number of hospital inpatients days
- Improves symptom management
- Provides patient, family and care takers satisfaction
- Reduces overall cost of disease
- Prolongs survival
- Improves quality of life of patients and family

We should not just focus on preventing avoidable deaths but also on preventing avoidable suffering. Positioning palliative care within a continuum of care for

NCCs is a must. Palliative care has a role in patient & community education for prevention messaging and to present early for treatment in supporting treatment and helping patients cope with side effects of treatment and in end-of-life care. The provision of palliative care services is a fundamental component of the continuum of care for people with NCCs and those affected. Palliative care is required throughout the course of illness regardless of access to disease modifying treatment. It covers a variety of responses including providing physical, psychological, social, legal and spiritual support, supporting both people with NCCs and their carers throughout the course of the illness. Palliative care is a cross cutting issue that is a vital component of an effective and functioning health system and is key to ensuring the quality of life and productivity of people living with life-limiting conditions and their carers. It is a necessity in the response, not a luxury – both for the people living with the conditions and the health system as a whole.

Palliative care service delivery is guided by the following WHO declarations:

Political declaration of the high level meeting of the general assembly on the prevention and control of non communicable diseases – September 2011.

Strengthening National Policies and Health Systems

Screening, diagnosis, and treatment of non-communicable diseases and prevention and control, and to improving the accessible to the safe, affordable, effective and quality medicines and technologies, including through the development and use of evidence-based guideline for the treatment of non-communicable
45- (L) According to national priorities, give greater priority to surveillance, early detection, diseases, and efficient procurement and distribution of medicines in countries; and strengthen viable financial options and promote the use of affordable medicines, including generics, as well as improved access to preventive, curative, palliative and rehabilitative services, particularly at the community level;

55. Foster partnerships between Government and civil society, building on the contribution of health-related NGOs and patients` organisations, to support, as appropriate, the provision of services for the prevention and control, treatment, care, including palliative care, of non-communicable diseases;

1.2 Background

1.2.1 Situation analysis of Palliative Care services in Kenya

Kenya, like other countries in Sub-Saharan Africa, is tackling the enormous burden of HIV and AIDS pandemic and looming epidemic of cancer and other non communicable diseases (NCCs). There are more than 1.6 million people living with HIV and 57,000 deaths per year are attributable to AIDS . It is estimated that more than 28,000 Kenyans live with cancer and there are countless others with other diseases for which there are no curative treatments available at this time. The majority of patients who need palliative care live in rural areas, often far away from the nearest health facility. In the public sector, oncology services are available in Kenyatta National Hospital, Moi Teaching and Referral Hospital and Coast Provincial General Hospital. There is only one public radiotherapy service available at the Kenyatta National Hospital and two private centers at the Cancer Care Kenya Center and the Aga Khan University Hospital. All these centers are in Nairobi.

Management of patients with cancer from the time of diagnosis requires a palliative care approach with optimal pain and symptom control. Morphine (syrup) and other essential medicines for palliative care are intermittently available, and research has shown that some health professionals have continued fears about prescribing opiates (Harding 2002).

By June 2012, there were over 2,300 trained service providers of all categories representing 45% of nurses and 11% of clinicians. Palliative care services are being delivered at 32 sites; which include 11 Government Level five Facilities, 16 hospices and palliative care centers, 6 mission hospitals 2 Tertiary public hospitals and 4 Non Governmental Organizations.

1.2.2 Rationale for the Palliative Care guidelines

The rationale for setting palliative care guidelines is to enhance the provision of quality services as part of the national health sector response to the HIV and AIDS pandemic and life threatening conditions such as cancer and other non-communicable diseases (NCCs). They will provide guidance and direction towards the implementation of a Palliative Care policy in Kenya. These guidelines are applicable to both the public and private health sector.

The guidelines for PC will be implemented in conjunction with other relevant policies and guidelines such as the HIV&AIDS policy and Guidelines for anti-retroviral therapy in Kenya, National Cancer Control strategy, National Infection Prevention and Control Guidelines for Health Care Services in Kenya, Clinical Guidelines For Management And Referral Of Common Conditions etc

Notes

CHAPTER 2

Palliative Care Guiding Principles

Palliative care is patient and family centered care. It optimizes quality of life by active anticipation, prevention and treatment of suffering. It emphasizes use of an interdisciplinary team approach throughout the continuum of illness, placing critical importance on the building of respectful and trusting relationships. Palliative care addresses physical, intellectual, emotional, social and spiritual needs. It facilitates patient autonomy, access to information and choice.

2.1 Guiding Principles

Guiding principles of comprehensive palliative care service delivery shall include:

2.1.1 Access to care

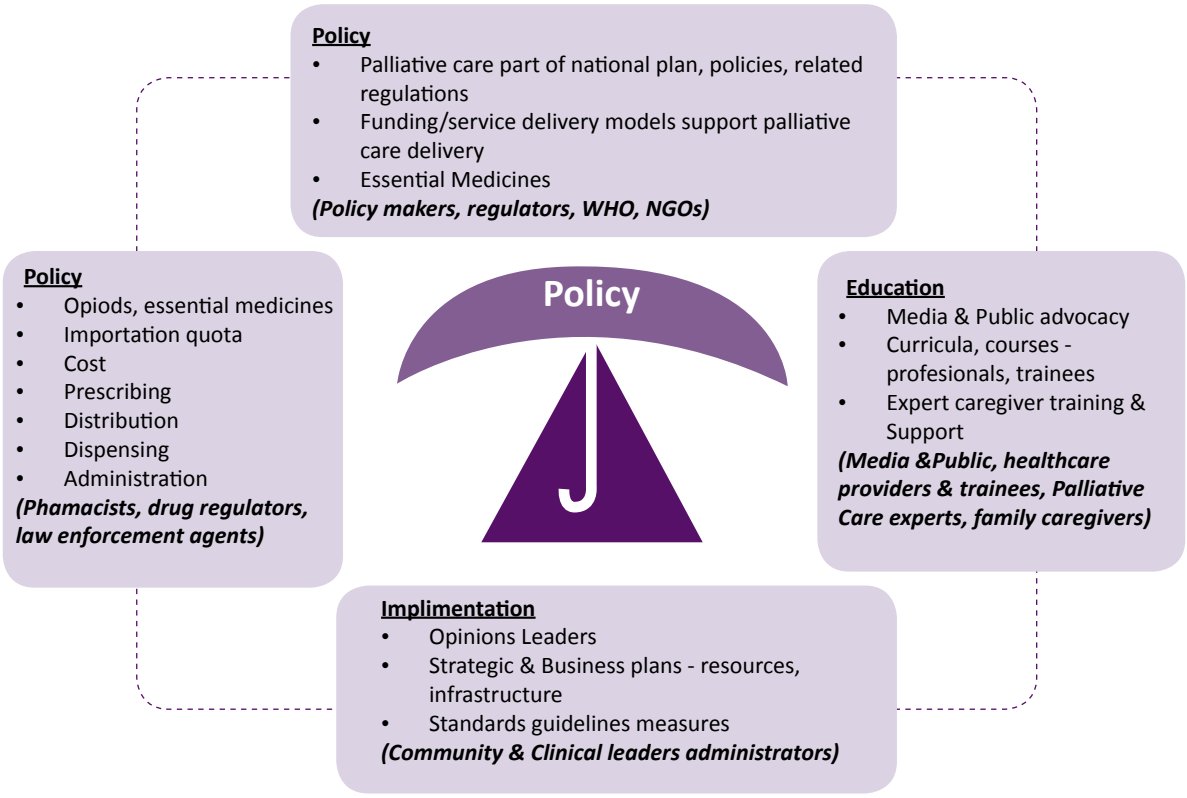
- Palliative care is a right of every adult and child therefore, it should be included in the Kenya Essential Package for Health (KEPH)
- Patients and their families shall access holistic palliative care which aims to meet their physical, psychosocial and spiritual needs within their cultural context.
- Palliative care patients shall be referred to appropriate levels of health care service delivery

2.1.2 Multidisciplinary team approach

- Palliative care shall be provided by an multidisciplinary team.
- Where an interdisciplinary team is not available, a core team shall be oriented on palliative care to ensure that all needs are met.
- Members of the team shall communicate and network the care of the patient and family through regular meetings to discuss case studies in order to share experiences, understand problems and identify appropriate solutions.

2.1.3 Service Delivery Model.

Institutions, guided by the WHO Palliative Care Program Principles, shall choose a suitable model depending on their setting and resource availability without compromising quality of services.
The model shall be:



- Developed as a comprehensive and public health approach
- Integrated within existing health care delivery systems in both public and private sector for scale up of the continuum of care for chronic , life-threatening illnesses
- Tailored to the specific cultural and social context.

2.1.4 Ethical and Legal Aspects of Care

- The intention of palliative care is to improve the quality of life of patients and family therefore care and support shall be provided for the benefit of the patient and family whilst causing them no harm.
- The patient's goals, preferences and choices shall be respected according to the laws of Kenya, and shall form the basis for the plan of care.
- Rights and ethical consideration for the patient shall be observed as outlined in Kenya National Palliative Care Training Curriculum for HIV&AIDS, Cancer and other life threatening illnesses.
- When a child's wishes differ from those of the adult decision-maker, appropriate professional staff members shall be made available to assist the child.

2.2 Provision Of Palliative Care Services

2.2.1 Palliative care plan

A patient requiring palliative care should have a detailed holistic assessment and care plan developed by the palliative care provider in collaboration with the patient and family in order of priority.

2.2.2 Pain control

Total pain is a concept commonly used in palliative care and encompasses physical, psychological, social and spiritual aspects of pain.
Effective pain control is central to palliative care using both pharmacological and non pharmacological measures. Providers shall be able to control physical pain according to WHO analgesic ladder (Annex 7)

2.2.2.1 Pharmacological Measures

- The WHO analgesic ladder (Annex 7) is the fundamental approach to all types of pain including nociceptive and neuropathic pain , and should be used as the standard approach to the management of pain
- Pain control drugs should be administered regularly –by the clock, by the ladder, by the mouth and for the individual patient
- Opioids are indicated for the control of moderate-to-severe pain among patients with HIV&AIDS, cancer as well as other painful disease conditions.
- Prescription of opioids shall be carried out according to the laws of the Government of Kenya
- Supply, storage, prescription, dispensing, receipts and consumption of opioids shall follow the legal provisions and regulations as stipulated in the Narcotic and psychotropic drugs act

2.2.2.2 Non Pharmacological Measures

Non-pharmacological pain management is the management of pain without medications. This method utilizes ways to alter thoughts and focus concentration to better manage and reduce pain. Methods of non-pharmacological pain management should include:

- Education of the patient and family / carer on the condition to provide insight and support.
- Psychosocial therapy/care - companionship, music, art, aromatherapy, yoga, drama , and group therapy
- Physical care may involve the following: Exercises, heat/cold application, lotions/massage therapy, positioning, occupational therapy, physiotherapy, etc
- Spiritual care such as meditation, prayer and religious counseling
- Palliative surgery and chemotherapy.

2.2.3 Symptom Control

The general approach to symptom control in palliative care shall include:

- Assessment for the cause and severity of the symptom;
- Anticipate multiple symptoms- which may include physical, psychological, social and spiritual
- Treatment of reversible causes;
- Initiation of disease/symptom-specific medicines and non-drug measures;
- Involvement of the patient and family on the management plan

2.2.4 Medicines and Supplies

- Medications for symptom control including essential medications for opportunistic infections should be made available for palliative care service provision in each health facility.
- Medicines, equipment and consumables required shall be made available and accessible as outlined in the essential palliative care drugs list *(Annex 1&2)*

2.2.5 Nutrition

- Nutrition support has been shown to benefit palliative care patients by reducing physical deterioration, improving quality of life, and preventing the emotional effect of "starving the patient to death."
- Palliative care patients of all age groups should be educated and encouraged to consume the following food groups (carbohydrates, proteins, vitamins, minerals, fats & oils, dietary fibre and water)
- The successful management of these medicine-food interactions requires understanding clients' individual food access as well as eating habits. Locally available foods are recommended.
- Management of patients shall include assessment and counseling on feeding with regard to the nutritional needs specific to the stage of the illness.
- Patient and carers shall be counseled on appropriate feeding according to the stage of the illness

2.2.6 Infection Prevention and Control

Palliative care services shall operate in accordance with National Infection Prevention and Control Guidelines for Health Care Services to minimize the risk of infections in patients, families and care providers in order to promote a safe caring environment.

Core infection prevention and control interventions shall include use of:

- Hand hygiene
- Personal protective equipment
- Isolation precautions
- Aseptic technique
- Cleaning and disinfection and
- Sterilization

2.2.7 Care of Carers

- The palliative care team shall be assisted to recognize the difficult situations they encounter, personal limitations and ways of utilizing effective coping strategies.
- Carers shall be provided with adequate resources for patient care. Regular team meetings and social gatherings shall be promoted to help reduce stress and burnout.
- Supervision, training and support shall be provided to health workers, family and community members.

2.2.8 Psychosocial care of patients and their families

Psychosocial interventions are an integral part of pain management.

- Patients and their families/carers shall be informed of common psychosocial issues facing palliative patients including anxiety, depression, advanced care plans, care of children, finances, will, community support, and family relationships. Each of these areas will be assessed and recorded.

- The palliative care team, in conjunction with the patient and family/carer will prioritize psychosocial needs of the patient and family and these will be included in the care plan.
- Counselling and psychosocial support can be given by any care provider trained in counseling – nurse, other clinician, volunteer, CHW, spiritual care provider.
- Difficult cases shall be referred to a counselor with specialized skills.
- Grief and bereavement counseling is part of palliative care for every family/carer. This is to be provided in a safe comforting place to enable family to express their feelings thoughts and needs as they experience bereavement.

Psychosocial Care of Palliative Care team

- Palliative care team shall be assisted to recognize the difficult situations they encounter, personal limitations and ways of utilizing effective coping strategies.
- Carers shall be provided with adequate resources for patient care. Regular team meetings and social gatherings shall be promoted to help reduce stress and burnout

Spiritual Care

- Spiritual care involves being a compassionate presence to patients even as they suffer. It recognizes that emotional and spiritual healing can take place even though a physical cure is impossible.
- As a patient approaches end of life they often begin to think about the meaning and purpose of life and feel the need to mend broken relationships by forgiving and being forgiven.
- Areas of life that can generate spiritual peace or spiritual distress are, relationship with God/Creator/Higher Being, with self, with others, and with the world around them.

2.2.9 End of life care

- Health care providers shall prepare both the patient and the family on the impending death

- Care provider shall be honest, attend to emotional responses and spiritual needs.
- Care providers shall maintain presence and talking to the patient even if he/she is unconscious.
- Comfort measures shall be provided depending on the presenting signs and symptoms of impending death.
- End-of-life concerns, hopes, fears, and expectations shall be openly and honestly addressed in the context of social and cultural customs in a developmentally appropriate manner.
- Care providers shall discuss issues regarding advanced directives with patients giving guidance as well as enquire about the presence of an ethical will
- Palliative care practice shall be guided by the medical-ethical principles of autonomy, beneficence, non-malficence and justice

2.2.10 Grief and Bereavement

- Grief and bereavement risk assessment shall be done routinely throughout the illness trajectory
- Care providers shall offer a safe, comforting place to the bereaved family to enable them express their feelings, thoughts and needs as they are going through bereavement.
- Customary and religious rituals shall be respected to help the family cope with death.

2.2.11 Paediatric Palliative Care (0- 16 YEARS)

Palliative care for children focuses on enhancement of quality of life for the child and support to the family. Emphasis shall be on pain assessment & management, psychosocial & emotional support and communication, which shall be appropriate for the age and developmental stage of the child.

2.2.11.1 Paediatric Pain Control

- Pain assessment tools should be age appropriate (Annex 8).
- Aspirin is contraindicated in children under 12 years.
- Dosages shall be calculated in kilogram per body weight (Annex 2)

2.2.11.2 Special needs for children

- Special needs shall be identified through comprehensive assessment and addressed holistically.
- Children shall be involved in decisions about their own care. Appropriate information according to age shall be communicated in clear and simple language at their pace
- Children shall be allowed to lead a normal life that includes access to education within the limitation of their illness. School teachers, community members including other children shall be encouraged to support and deal sensitively with the affected child
- Recreation activities shall be encouraged like play activities, drawings, poems or songs.
- Palliative care providers shall take into consideration the needs of orphans and vulnerable children and shall refer them to appropriate services for care and support

2.3 Maintaining Best Practice

- The palliative care team shall seek to maintain up to date skills in their area of work through Continuing Professional Development (CPD), refresher courses, regular clinical meetings – e.g. case conferences, seminars, workshops and journal clubs; personal reading, case study review and research.
- Palliative care providers shall always adhere to standard operating procedures (SOPs) as provided
- Treatment decisions shall be based on goals of care, assessment of risk and benefit, best evidence, and patient/family preferences.
- Treatment alternatives shall be documented and communicated clearly to permit patient and family make informed choices.
- Continuous monitoring and evaluation shall be provided at all levels.

2.4 Education and Training

- Palliative care service providers shall be trained in palliative care. Training shall be appropriate for the cadre and their role in the interdisciplinary team.
- Palliative care concept shall be incorporated in the pre-service curricula for health training institutions
- Post-graduate training to specialization in palliative care / medicine shall be encouraged
- The ***National Palliative Care Training Curriculum For HIV&AIDS, Cancer And Other Life Threatening Illnesses*** shall be used during the introductory course
- Trainings shall be coordinated and certified by MOH

CHAPTER 3

Responsibilities and Authority

MOH in collaboration with relevant stakeholders shall establish resource centers and organize refresher courses to update service providers.
There are various levels of responsibility regarding the implementation of palliative care; the roles and responsibilities shall be as outlined:

3.1 Ministry of Health

The Ministry of Health

- Shall provide leadership and coordination of palliative care services.
- Shall identify and prioritize specialized training needs in palliative care
- Shall establish partnership in provision of palliative care services
- Shall regulate policy formulation

3.2 County Medical Team

- Shall be responsible for monitoring adherence to the guidelines at all levels

- Shall supervise, monitor and evaluate the implementation of palliative care services
- Shall offer tertiary palliative care services
- Shall network with home based care groups and other health facilities for referral
- Shall keep appropriate records and compile monthly reports

3.3 Health Facility

- Shall develop a palliative care team with involvement of their local communities (including community volunteers) to provide services
- The team shall be responsible for identification, management, follow up and referral of patients
- Shall keep appropriate records and compile monthly reports which shall be submitted to the county health office

3.4 Pharmacy and Poisons Board (Medicines Regulating Authority)

- The board shall be responsible for regulating and reporting on the importation of morphine and other opioids used for palliative care.
- The board shall review legislation on a regular basis to improve access to opioids and other medicines

3.5 KEMSA and facility pharmacy

- Shall be responsible for availability and accessibility of all essential palliative care medicines including morphine
- Shall be responsible for supervision of safe handling, warehousing, storage and reporting of opioids at provider sites
- Shall keep accurate records of all transactions on opioids

3.6 STAKEHOLDERS

In collaboration with MOH:

- Shall provide supervision to implementing sites
- Shall provide support for training of trainers
- Shall identify resources for Continued Professional Development.
- Shall advocate for palliative care services
- Shall conduct biennial conferences on best practices and update members on emerging issues in palliative care.
- Shall provide technical support for palliative care services
- Shall collaborate with national and international palliative care bodies
- Shall monitor adherence to palliative care guidelines and standards

3.7 Patients, families and communities

- Shall be actively involved and participate towards self care
- Shall work in collaboration with health professionals and CBOs / FBOs / NGOs in their catchments area.
- Shall participate in palliative care service provision
- Shall advocate for better access to palliative care

Notes

CHAPTER 4

Monitoring and Evaluation of Palliative Care Programs

Monitoring and evaluation shall be used as advocacy tool for use of evidence based decision making.

Monitoring shall be conducted at all levels using appropriate indicators

- Reviews shall be done annually to assess programme performance by comparing baselines against set target

4.1 Palliative Care Indicators

Process Indicators	Definition of indicator/ Measurement	Method of data collection	Frequency
Percentage of health professionals (nurses, doctors, clinical officers) trained and providing palliative care services	Numerator: Number of trained professional health workers providing palliative care services Denominator: Total number of professional health workers trained in palliative care	Training records	Annually

Process Indicators	Definition of indicator/ Measurement	Method of data collection	Frequency
Number and percentage of palliative care sites with minimum staff norms (1 trained nurse and 1 trained clinician)	Denominator – total number of sites currently providing palliative care services	Supervision reports	Annually
Number of medicines-day availability in reference to the WHO analgesic ladder	Denominator 365 days	Supervision reports	Biannually
Total number of patients receiving palliative care services	Denominator – total number of patients registered for palliative care	Quarterly reports	Quarterly
Percentage of palliative care sites supervised at least twice a year	Denominator – Total number of sites currently providing palliative care		Biannually
Percentage of palliative care health facilities with resources (minimum of guidelines, pain medications, essential supplies)	Numerator: Number of PC accredited health care facilities with resources Denominator: Total Number of PC accredited Institutions	Structured Audit tool with on-site inspections	Baseline/ Quarterly
Output Indicators	**Definition of indicator/ Measurement**	**Method of data collection**	**Frequency**
Proportion of patients seen at home	Numerator: Number of palliative care patients seen at home Denominator: Total number of palliative patients on home care	Health care records	Baseline/ Monthly/ Quarterly
Percentage of patients seen as inpatients in a health facility	Numerator: number of palliative care patients seen as inpatients Denominator: Total number of inpatients	Health facility/ Palliative care unit records	Baseline/ Monthly/ Quarterly

Output Indicators	Definition of indicator/ Measurement	Method of data collection	Frequency
PC coverage: Percentage of recognized palliative care health facilities providing minimum package of services	Numerator: Number of recognized palliative care health facilities Denominator: Total number of health facilities capable of providing minimum package of palliative care services	Ministry of Health and Palliative care association records (Health service records)	Baseline/ Quarterly
Impact			
Quality of palliative care services	Qualitatively	Client and family questionnaires	Every 2-3 years

4.2 Reporting Systems

Community services providers shall compile reports monthly to the nearest health facility, who will then submit to the county offices of health which shall submit quarterly to the Ministry of Health using the Standardized forms (annex 4). KEHPCA shall obtain a copy from the MOH.

Notes

Annex 1: ESSENTIAL PALLIATIVE CARE MEDICINES LIST

Drug Name	Properties	Clinical Uses	Alternative Drugs
Paracetamol	Non opioid Analgesic Antipyretic	Fever Pain	
Aspirin	Non opioid Analgesic Antipyretic Anti-inflammatory	Pain Fever Sore Mouth	
Ibuprofen	NSAID	Pain (esp. bone pain) Fever Anti inflammatory	Diclofenac Indomethacin
Tramadol	Weak opioid Analgesic	Pain	Codeine
Morphine liquid	Strong opioid Analgesic	Pain Introduction Breakthrough pain Difficulty swallowing children Breathlessness Severe Diarrhoea	Morphine slow release tablets
Morphine (slow release tablets)	Strong opioid	Pain Severe diarrhoea	Morphine liquid
Dexamethasone	Corticosteroid Antinflamatory	Painful swelling and inflammation Poor appetite	Prednisolone
Amitriptyline	Tricyclic Antidepressant	Neuropathic pain (nerve pain)	Carbamazepine Phenytoin
amitriptyline	Tricyclic antidepressant	depression	imipramine
Hyoscine Butyl bromide (Buscopan)	Antimuscarinic Antispasmodic	Abdominal pain (Colic)	propantheline
Diazepam	Benzodiazepine Anticonvulsant	Muscle spasm Seizure Anxiety sedation	Lorazepam

Drug Name	Properties	Clinical Uses	Alternative Drugs
Phenobarbitone	Anticonvulsant	Seizure	Diazepam
Metoclopramide	Antiemetic	Vomiting	Haloperidol Domperidone promethazine
metoclopramide	Pro-kinetic	Abdominal Fullness	
Chlorpromazine	Antipsychotic	Hiccups	Metoclopromide Nifedipine
Magnesium Trislicate	Antacid	Indigestion Gastro-oesophageal reflux gastritis	Aluminium Hydroxide Magnesium Hydroxide Ranitidine cimetidine
Loperamide	Antidiarrhoeal	Chronic diarrhoea	Codeine Morphine
Bisacodyl	Stimulant laxative	Constipation	Sennakot
ORS	Rehydration Salt	Diarrhoea Rehydration	
Chlorpheniramine	Antihistamine	Drug reactions	Promethazine
Flucloxacillin	Antibiotic	Chest infection Skin infection	Erythromycin
Cotrimoxazole	Broad Spectrum Antibiotic	PCP treatment and prophylaxis Infective diarrhoea in HIV/AIDS Urinary Tract Infection	Ciprofloxacin Amoxicillin, nitrofurantoin,
Metronidazole	Antibacterial for anaerobic infections	Foul smelling wounds Gingivitis Dysentery Vaginal discharge	Nalidixic acid
Lumefantrine artemether(LA)	Anti- malarial	Malarial treatment	Quinine sulphate
Chloramphenicol eye ointment/ drops	Antibacterial	Eye infections	Tetracycline, Gentamycin, ointment & drops
Fluconazole	Antifungal	Oral and Oesophageal candidiasis Cryptococcal meningitis	Triconazole Miconazole
Acyclovir	Antiviral	Herpes zoster	

Drug Name	Properties	Clinical Uses	Alternative Drugs
Clotrimazole 1% Cream	Topical antifungal	Fungal Skin Infection	Whitfield ointment Miconazole. Griseofulvin
Nystatin Suspension and pessaries	Antifungal	Oral and vaginal candidiasis Prophylaxis for patients on steroids	Clotrimazole pessaries Triconazole Miconazole GV paint
Petroleum jelly Potassium permanganate	Skin moisturizer and protection. Drying agent Antiseptic	Dry skin Pressure area care. Oozing lesions Wet skin	Emulsifying ointment
Gentian Violet Paint	Antimicrobial Astrigent.	Bacterial & fungal skin infection	Clotrimazole pessaries Nystatin Triconazole Miconazole
Chlorinated Lime	Disinfectant	Infection prevention	Chlorine
Calamine Lotion	Itch	Rash	Aqueous Cream 10% salicyclic acid

Consumables

Cannulas, brannulas
strapping
Disinfectant
infusion fluids
Catheters/condom catheters
Incontinence pads
Plaster
Needles, syringes
Gauze
Bandages
Cotton wool
Crepe bandage
Gloves
Colostomy bags
IV giving sets

These doses are given for guidance, taking into account the formulations most commonly available. Where liquid formulations are available, more accurate dosing using mg/kg is advised

***** High doses are used for spinal cord compression and raised intracranial pressure. Lower doses (given above by weight) are used for reducing tumour mass causing obstruction, oedema or nerve compression. Short courses are advised, which can be repeated. If given for more than a week, steroids should be tailed off gradually. In some cases a maintenance dose may be necessary; this should be the lowest dose needed to control symptoms. Cover with antifungals in the immunosuppressed and those on long courses.***

Annex 3: SUPERVISORY CHECK LIST FOR PC IMPLEMENTING FACILITIES

Name of Facility_____

Name of facility palliative care coordinator: _____

Contact address:_____

Phone number of facility coordinator_____

1.0 Capacity Building

1.1 Do you have a palliative care Team? Y N

If no state reasons _____

_____

_____

_____

If yes, give Composition of the Palliative care team by cadre and gender:

Cadre	Total	Number Trained	Trained And Providing Services	No. Trained This Year
Dr.'s				
CO's				
Nurses				
Social workers				
Physiotherapists				
Pharmacy technicians				
Pharmacists				
Nutritionist				
Others (specify)				

1.2 Number of palliative care team meetings conducted in this quarter?
(Verify by checking minutes)

_____

_____

2. SERVICE PROVISION:

2.1 Indicate model of care by ticking in the box.
In patient care { } Outpatient { } Day care { } Home based care { }
Others-please specify

_____

_____

2.2 Indicate conditions and number of patients cared for during the quarter)?
Report children separately

CANCER		
AGE	**MALE**	**FEMALE**
0-5 YEARS		
6- 12 YEARS		
13- 40 YEARS		
> 40 YEARS		
TOTAL		
HIV/AIDS		
0-5 YEARS		
6- 12 YEARS		
13- 40 YEARS		
> 40 YEARS		
TOTAL		

Other conditions (please specify)

_____

_____

2.3 Number of patients referred to other services (specify type of service)

_____

_____

2.4 Mention type of support and organization and/or institutions networking with.
Please Specify names of institutions/ organizations and type of support:

Management support _____

Transport for supervision _____

Drugs and supplies _____

Financial support _____

2.5 Mention Challenges experienced in the implementation of palliative care services: _____

_____

_____

2.6 Achievements _____

_____

_____

_____

_____

_____

_____

Annex 4: REFERRAL FORM FOR HEALTH SERVICES IN PALLIATIVE CARE

Date:	Patient number	
Name of patient		
Sex	Age	Religion
Occupation		Marital status
Physical address of patient./ Telephone number		
Name of carer		
Relationship to patient		Telephone number
Diagnosis (specify)		
Patient aware of diagnosis Y/N		
Carer aware of diagnosis Y/N		
Main problems		
Current treatment		
Referred from: (Full Address / phone number)		
Referred To:		
Reason for referral		
Referred by		Authorized Signature
Phone Number		
(Name and Designation)		

Annex 6: PALLIATIVE CARE HOLISTIC ASSESSMENT FORM

Patient No	Date referred:
Patient Name:	Date seen:
Age:	Contact Tel
Sex:	Physical address
Marital status:	
	Religion
Next of Kin/Carer	Refered from:
Relationship with Patient	CHBC ( )
Contact Tel:	Health Centre ( )
	OPD ( )
	Hospital ward ( )
	MOH ( )
	FBO ( )
	Private ( )
History from: Patient ( ) Carer ( ) Other ( )	Refered by: Clinician ( ) Nurse ( ) Volunteer ( )
Specify	Other specify
Reason for referral: Pain control ( ) Symptom control ( ) Psychological support ( )	HIV status: Positive ( ) Negative ( ) Unknown ( )
Other specify	If unknown offer counseling and testing services
Diagnosis of patient (if available/histology results if cancer)	Diagnosis discussed with patient and carer Yes ( ) No ( )
Past Medical and surgical history:	Previous treatment history
	History of drug allergy/adverse drug reaction
Present medications (all medications including ARVs, Prophylaxis, Opiods)	History of present illness and treatment to date (include description of symptom noted and main concern)

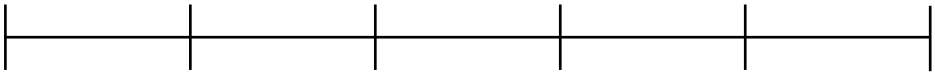
Symptoms Assessment Tool

Pain and symptom history

Symptoms: 0 absent; + mild; ++ moderate +++ severe

Symptom	0	+	++	+++	Comments (incl onset)	Symptom	0	+	++	+++	Comments
Anorexia						Dry mouth					
Nausea						Skin Rash					
Vomiting						Constipation					
Dysphagia						Edema					
Painful Swallowing						Arthralgia *(specify joints)*					
Sore Mouth						Fatigue					
Dyspnoea						Confusion					
Cough						Drowsiness					
Headache						Diarrhea					
Paralysis						Other					

Simple Descriptive Pain Intensity Scale[1]

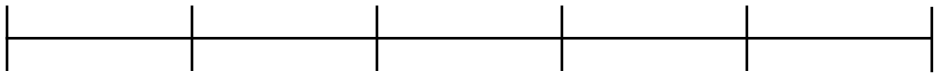


No pain | Mild pain | Moderate pain | Severe pain | Very severe Pain | Worst possible pain

Measuring Pain- Various Scales For Assessing Pain.

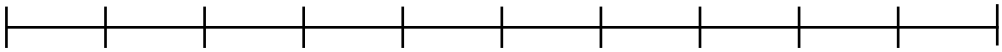
Visual Analogue and numerical Pain Rating Scales

Simple Descriptive Pain Intensity Scale[1]



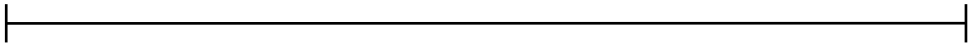
No pain	Mild pain	Moderate pain	Severe pain	Very severe Pain	Worst possible pain

0-10 Numerical Pain Intensity scale[1]



0	1	2	3	4	5	6	7	8	9	10
No pain					Moderate pain					Worst possible pain

Visual Analogue Scale (VAS)[2]

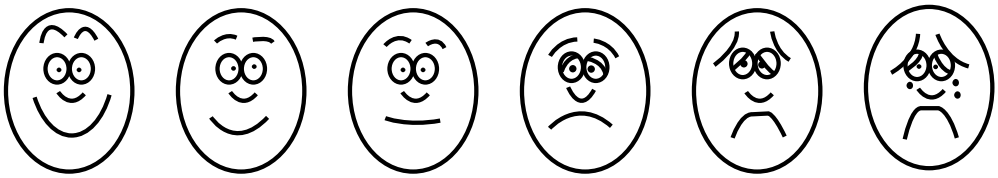


No pain	Pain as bad as it could possibly be

[1] If used as a Graphic rating, a 10-cm baseline is recomended.

[2] A 10-cm baseline is recomended for VAS scales.

Source: AHCPR, 1992.



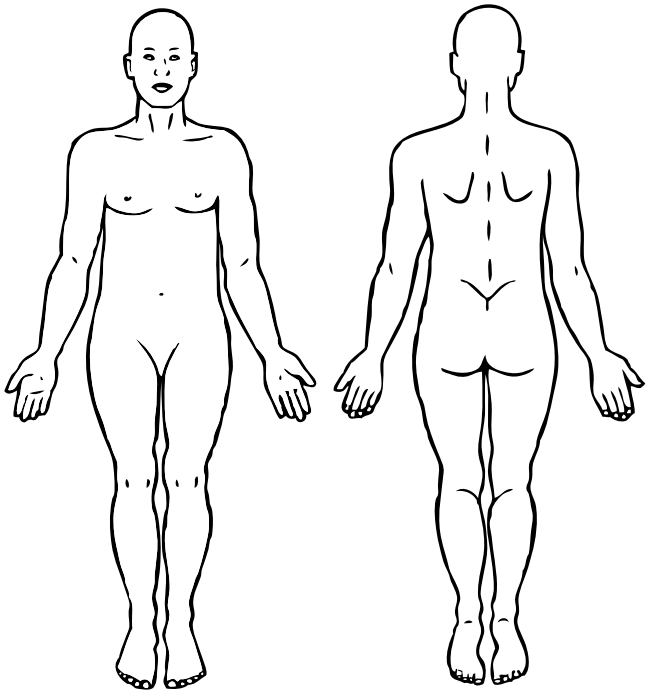
0	2	4	6	8	10
No hurt	Hurts a little bit	Hurts a little more	Hurts even more	Hurts a whole lot	Hurts worst

Explain to the person each face is for a person who feels happy because he has no pain (hurt) or sad because he has a lot of pain. Face 0 is very happy because he doesn't hurt at all. Face 2 hurts just a little bit. Face 4 hurts a little more. Face 6 hurts even more. Face 10 hurts as much as you can imagine, although you don't have to be crying to feel this bad. As the rating scale recommended for persons age 3 and older.

Source: Wong DL, Hockenberry-Eaton M, Wilson D, Wilkenstain ML, Schwatz P. Wong's Essentials of Paediatric Nursing, 6th ed St. Louis: Mosby, Inc, 2001. Copyrighted by Mosby, Inc. Reprinted by permission.

Palm pain scale (1- mild pain and 5 severe pain)

Indicate the location of the pain on the body charts.

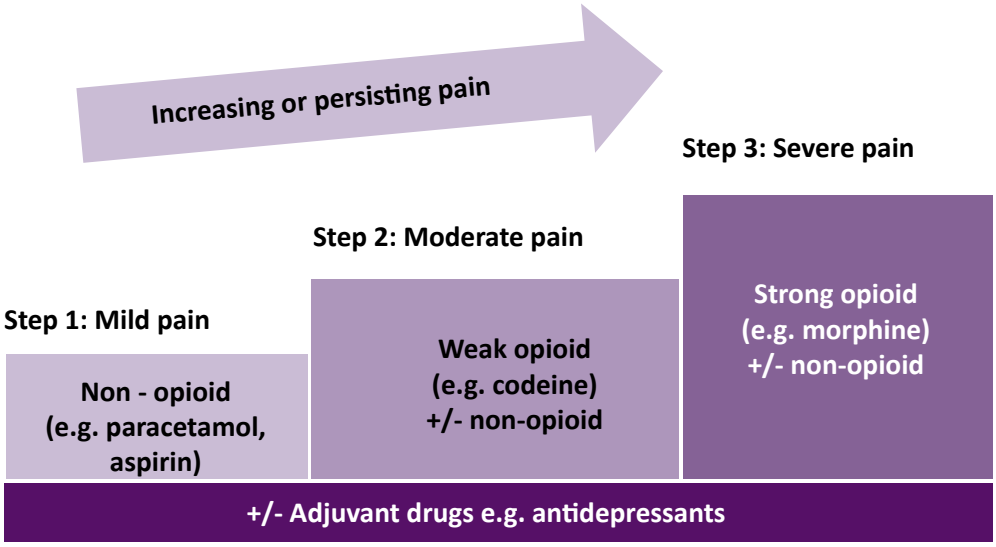


Pain and symptom history

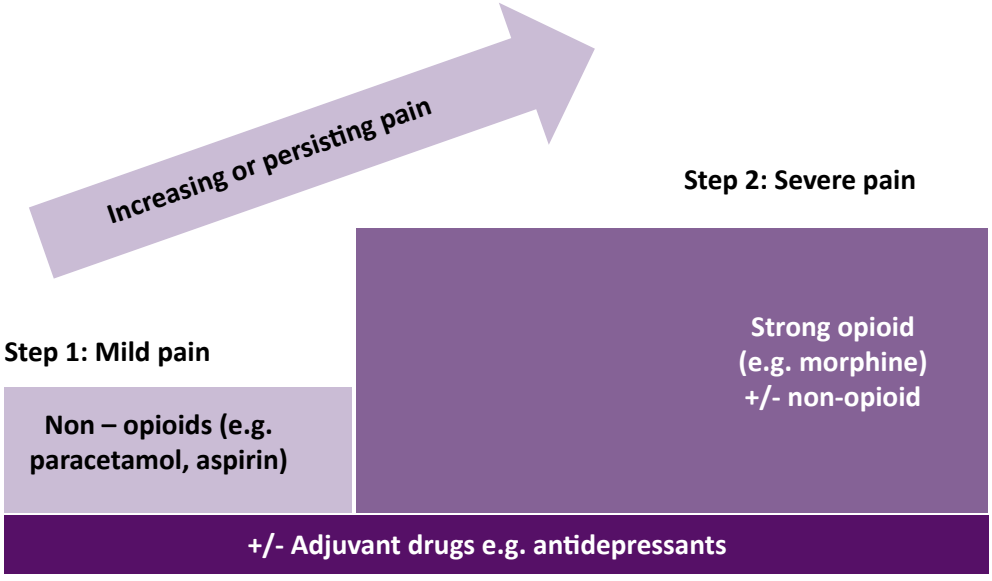
Symptoms: 0 absent; + mild; ++ moderate +++ severe

	Pain 1	Pain 2	Pain 3	Pain 4
Duration of pain				
Character/ description of pain				
Numerical Rating Scale (0-5)				
Periodicity (constant/ intermittent)				
Precipitating Factors				
Relieving Factors				
Does pain affect sleep? Y/N				
Does pain affect mobility? Y/N				
Effect of current medication-None, partial, complete control				

Annex 7: THE WHO ANALGESIC LADDER FOR ADULTS



Who Analgesic Ladder For Paediatrics

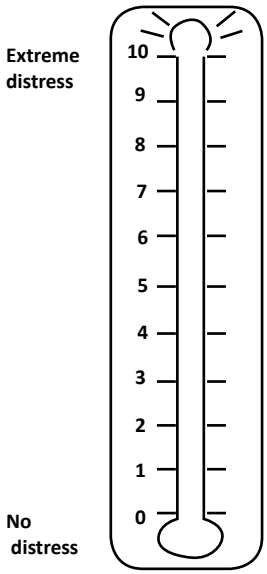


NB: step 2 drugs in adult WHO ladder are not used in paediatric age group due to severe side effects. Patients with moderate to severe pain are managed with strong opioids with or without Adjuvants.

Psychosocial Assessment Tool

SCREENING TOOLS FOR MEASURING DISTRESS

Instructions: First please circle the number (0 - 10) that best describes how much distress you have been experiencing in the past week including today.



Second, please indicate if any of the following has been a problem for you in the past wee including today. Be sure to check YES or NO for each.

YES	NO	Practical Problems
☐	☐	Child Care
☐	☐	Housing
☐	☐	Insurance/Financial
☐	☐	Transportation
☐	☐	Work/School

YES	NO	Family Problems
☐	☐	Dealing with Children
☐	☐	Dealing with Partner
☐	☐	Ability to have Children

YES	NO	Emotional Problems
☐	☐	Depression
☐	☐	Fears
☐	☐	Nervousness
☐	☐	Sadness
☐	☐	Worry
☐	☐	Loss of Interest in usual activities

YES	NO	Spiritual/religious concerns
☐	☐	

YES	NO	Physical Problems
☐	☐	Appearance
☐	☐	Bathing/Dressing
☐	☐	Breathing
☐	☐	Changes in Urination
☐	☐	Constipation
☐	☐	Diarrhea
☐	☐	Eating
☐	☐	Fatigue
☐	☐	Feeling Swollen
☐	☐	Fevers
☐	☐	Getting Around
☐	☐	Indigestion
☐	☐	Memory/Concentartion
☐	☐	Mouth Sores
☐	☐	Nausea
☐	☐	Nose dry/congestion
☐	☐	Pain
☐	☐	Sexual
☐	☐	Skin dry/itchy
☐	☐	Sleep
☐	☐	Tingling in hands/feet

Other Problems: _____

_____

_____

_____

_____

_____

Annex 9: GUIDELINES TO WRITING A WILL

A Sample Will

This is the last will and testament 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 be 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) _____

   _____

   _____

   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 anyone 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, device and bequeath all my real and personal property to the following: (list) All my property as listed here to the following:

Examples of properties to be distributed;

a) Land Parcel Ruiru/Block 18/9999 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 _____

      _____

      4. 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 to raise them as Christian/ Islam.
9. In the event of any of my heirs predecease me, then my estate should be divided among my remaining heirs according to (7) above.
10. My most earnest request to all my heirs that if any differences of opinion arise between them as regards any of my assets whatsoever or as the ownership, character, value or otherwise, of the same or as to meaning or true interpretation of anything contained in my Will, or codicils, thereto, they shall settle it amongst themselves first, if not, the Trustees before resort to court.

I 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 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

_____

_____

Definitions of Terms

Addiction:

Is defined by aberrant changes in behavior. Addiction is compulsive use of drugs for nonmedical reasons; it is characterized by a craving for mood altering drug effects, not pain relief. Addiction means dysfunctional behavior, in sharp contrast to the improved function and quality of life that result from pain relief.

Analgesic Ladder:

A three-step approach of administering the right drug in the right dose at the right time in the following order: non-opioids (aspirin and paracetamol); then, as necessary, mild opioids (codeine); then strong opioids such as morphine, until the patient is free of pain.

Bereavement:

The period of grief and mourning after a loss or death.

Patient:

In this document it means person requiring palliative care services BREAKTHROUGH, Pain

Community Home Based Care:

Care given to an individual in his/her own natural environment not only provision of the physical and health needs, but also the spiritual, material and psycho-social needs Palliative Care: is 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 by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (WHO 2002)

Day Care:

Caring for patients for the day away from their usual environment, where they can share with others, receive medical care and other therapies if available, a meal and entertainment.

End of life:

Special time before death when the patient and family require holistic support.

Evaluation:

Systematic process of attributing outcomes to their causes.

Grief:

Normal process of reacting to a loss expressed through mental (anger, guilt, anxiety, sadness and despair), physical, social or emotional reaction.

Health professionals:

All cadres of health care workers registered by their respective professional bodies

Home Based Palliative Care:

Provision of palliative care for the patient and family in the home.

Indicator: a unit of information, measured over time that documents change

Inpatient model shall use a dedicated unit in a general ward/specialist hospital, identified room within the hospital setting or a separate free standing unit within a hospital complex or a free - standing unit geographically separate from any other hospital and have appropriately qualified multidisciplinary staff trained in palliative care committed to offer 24 hours palliative care services

Monitoring systematic process of collecting, analyzing and using information to track performance of an organization in achievement of goals

Opiates:

Substances having “addiction-sustaining liability similar to morphine”.

Opioid:

All drugs either natural or synthetic with morphine-like actions - e.g. morphine, codeine etc.

Physical Dependence:

Physical dependence is the physiological adaptation of the body to the presence of an opioid. It is defined by the development of withdrawal symptoms when opioids are discontinued, when the dose is reduced abruptly or when an antagonist (e.g., naloxone) or an agonist-antagonist (e.g., pentazocine) is administered.

Pseudo-addiction:

Describes what happens when healthcare workers perceive as addictive behavior a pain patient's requests for more or stronger pain medications. In fact, the patient's behavior may be a response to inadequate pain management. Pseudo-addictive behavior is pain-relief seeking behavior.

Reporting *systematic and timely provision of useful information at specific periodic intervals*

TOLERANCE:

Tolerance is a physiological state characterized by a decrease in the effects of a drug (e.g., analgesia, nausea or sedation) with chronic administration.

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Notes

REPUBLIC OF KENYA

MINISTRY OF HEALTH

Diana

The Work Continues

KEHPCA

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for all

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The True Colours Trust