



THE REPUBLIC OF UGANDA
Ministry of Health

HUMAN-RIGHTS, ETHICAL AND LEGAL ISSUES IN PALLIATIVE CARE:

A GUIDE FOR HEALTH CARE PROVIDERS



*Do you want to provide better support to your patients
who have needs related to legal and human-rights issues?
Here is your guide*



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The Ministry of Health Uganda would like to acknowledge its appreciation of these partnerships in advancing palliative care as a human right.

Foreword

Palliative care is founded on ethical values relating to a person, human care and treatment that together afford a patient with a serious illness a good quality of life, dignity in death and support for the family to cope. Palliative care is fundamental to health and human dignity and is a basic human right. Dehumanizing, excessive, yet avoidable pain and suffering is a serious breach of fundamental human rights. The care received must ensure that there is excellent pain and symptom control; psychosocial and spiritual support for the patient and family; Informed decision-making, and coordinated services across the continuum of care – communication, information sharing, patient preferences, advanced care planning, bereavement care.

The Government of Uganda has made efforts in advancing palliative care and making it accessible for all Ugandans. Health care workers have an obligation to provide quality palliative care services to patients and their families, in a manner that observes the ethical principles of care, upholds their human rights, and ensures support in meeting their legal needs.

The Government of Uganda, in collaboration with its partners has developed a simple guide which helps health professionals understand their obligation and role in providing such care. The guide provides insights into common legal and human rights issues they are bound to meet while dealing with patients receiving palliative care and their families and how they can support these patients.

The guide offers a list of contacts for legal and human-rights service providers in Uganda that health workers can collaborate with to ensure that the legal and human-rights needs of their patients and their families are met.

I highly recommend this guide to all those involved in the care of patients.

A handwritten signature in black ink, appearing to read "Ondo". The signature is fluid and cursive, with a large initial "O" and a trailing flourish.

Hon, Dr. Ondo D. J. Christine

Minister for Health

Section 1: Defining important terms

“Palliative care is fundamental to health and human dignity and is a basic human right”¹

“To leave a person in avoidable pain and suffering should be regarded as a serious breach of fundamental human rights” (Somerville, 1995)

1.1 What are human rights?

Human rights can be expressed in three different but overlapping ways:

- Human rights are basic rights and freedoms to which all humans are entitled; they are inherent and they accrue to every human being simply because they are a human being.
- Human rights are God-given and not granted by the state; however, they are enshrined in the Constitution of the Republic of Uganda and in other international documents. Uganda has ratified these documents and this makes them legal and enforceable.
- Human rights must be enjoyed by everybody irrespective of their skin colour, ethnicity, race, disability, age, gender, health status, religion, political beliefs and so forth.

Examples of human rights are:

- The right to life
- The right to the highest standard of physical and mental health
- The right to personal liberty
- The right to privacy
- The right to fair hearing
- The right to respect
- The right to property.

1.2 What are legal rights?

Legal rights are entitlements a person has by virtue of enacted law or statutes or other law prevailing under a given country. For example land law in Uganda gives legal rights to a wife to claim ownership over her matrimonial home. Such laws are enforced in courts of law and protect persons from being abused; they apply to all persons in the same way

¹ Public Health Fact Sheet: ‘Palliative care as a human right: open society public health program’, May 2011.

1.3 What is palliative care?

The World Health Organization (WHO) defines palliative care as: ‘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.’² The main principles and tenets of palliative care, as set out by the WHO in 2002, are that it:

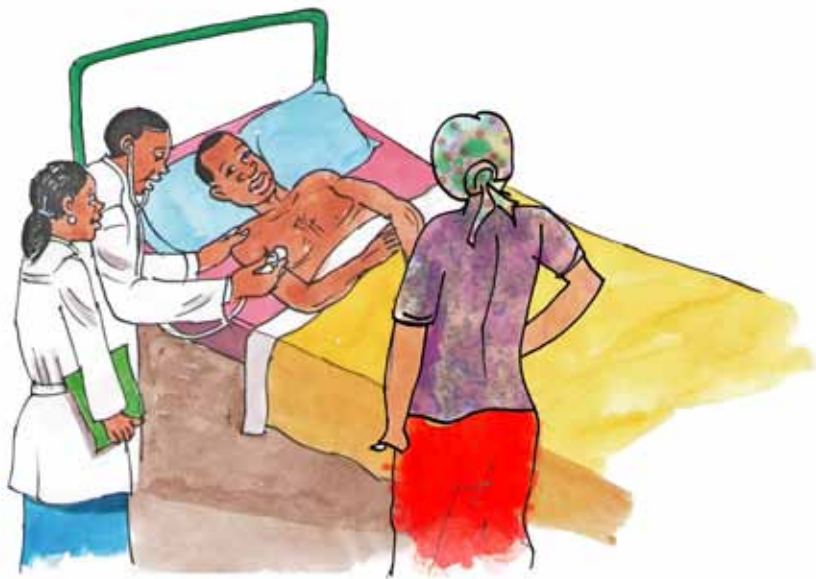
- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten nor postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until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

1.3.1 Palliative care for children

The WHO’s definition of palliative care appropriate for children and their families is as follows:

- Palliative care for children is the active total care of the child’s body, mind and spirit, and also involves giving support to the family.
- Palliative care begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.

2 WHO definition of palliative care www.who.int/cancer/palliative/definition/en



- Health providers must evaluate and alleviate a child’s physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children’s homes.

1.4 What are the principles of palliative care?

The principles of palliative care are provided in Table 1 and relate to both the attitude to care and the care itself.

Table 1: Principles of palliative care

<p>1</p>	<p>Attitude to care</p>	<p>A caring attitude – this involves sensitivity, empathy and compassion, and demonstrates concern for the individual.</p> <p>Consideration of individuality – the practice of categorising patients by their underlying disease, based on the similarity of the medical problems encountered, fails to recognise the psychosocial features and problems that make every patient unique.</p> <p>Cultural considerations – ethnic, racial, religious and other cultural factors may have a profound effect on a patient’s suffering.</p> <p>Consent – the consent of a patient, or those to whom the responsibility is delegated, is necessary before any treatment is given or withdrawn. This applies to children as well.</p>
<p>2</p>	<p>The care provided</p>	<p>Clinical context and appropriate treatment – all palliative treatment should be appropriate to the stage of the patient’s disease and the prognosis.</p> <p>Comprehensive multidisciplinary care – the provision of total or comprehensive care for all aspects of a patient’s suffering requires a multidisciplinary team.</p> <p>Care excellence – palliative care should deliver the best possible medical, nursing and allied health care that is available and appropriate. Care is provided at home, in hospitals, hospices and through outreach programmes.</p> <p>Consistent medical care – an overall plan of care should be established, and regularly reviewed, for each patient to make sure they have consistent medical management.</p> <p>Coordinated care – involves the effective organisation of the work of the members of the multidisciplinary team, to provide maximum support and care to the patient and their family.</p> <p>Continuity of care – the patient should receive care for their physical symptoms and other needs from the time they are first referred until death. Care should also be extended to bereavement care for the family members.</p>

	<p>The care provided</p>	<p>Crisis prevention – good palliative care involves careful planning to prevent or minimise the physical and emotional crises that can occur with a progressive disease.</p> <p>Caregiver support – the relatives of patients with advanced disease are subject to considerable emotional and physical distress, especially if the patient is being managed at home, and they too need to receive support.</p> <p>Continued reassessment – this is a necessity for all patients with advanced disease for whom increasing and new clinical problems are to be expected.</p>
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1.5 What are the ethical principles in palliative care?

“Ethics apply to all professional care but assume greater importance when caring for people with life-threatening illnesses. Ethical care is human rights based.”³

“Ethical issues in palliative care centre on decisions that ensure that our care will be guided by moral values that will enable us to satisfy the criteria for a peaceful and dignified death.”

[Bruera et al, 2004)



In order to make sure that patients are cared for in a way that is moral and respects their rights, there are standards to guide the actions of people providing palliative care. There are four main ethical principles which they should follow, as outlined below.

1.5.1 Respect for autonomy

Respect for autonomy acknowledges each patient’s rights to self-determination, without prejudice. It recognises the right and ability of an individual to make decisions for themselves, based on their own value system, beliefs and life span.

This means:

- Treatments can only be given with a patient’s informed consent or to those whom responsibility has been delegated to e.g. in children

3 African Palliative Care Association: A Handbook of Palliative Care in Africa

- A patient has the right to be given full information in order to make decisions
- It is the patient's right to decide what treatments they do or do not wish to have
- Health care workers have an obligation to provide honest and complete information when it is requested
- This framework applies not only to medical treatments but also to matters such as where a patient receives care, and who will provide that care.

1.5.2 Beneficence

Beneficence means the production of benefit, doing good and always acting in the best interests of the patient. This requires that the health care team prevents or removes harm, while doing or promoting good. It is the most commonly used principle in the application of care. It implies that the health care team should do positive acts in maximising the benefits of treatment. This means:

- Whatever is done or said must be for the patient's good
- Beneficence includes being honest with patients, which in nearly all circumstances will be to the patient's benefit
- Patients should not be subjected to unnecessary medical investigations
- Patients should not be subjected to unnecessary or futile therapies
- Beneficence applies not only to physical good but also to psychological, social and existential well-being and it must be distinguished from paternalism ('doctor knows best').

1.5.3 Non-maleficence

Non-maleficence means not being malicious; not doing harm. It supposes that 'one ought not to inflict harm deliberately'. Violation of this principle may include offering information in an insensitive way, providing inappropriate/wrong treatment for pain or other symptoms, continuing aggressive treatment when it is not suitable for the patient's condition, providing unwanted sedation, or withholding or withdrawing treatment without consent. This means that:

- Whatever is done or said must not harm the patient, physically or psychologically
- The principle includes being honest with patients – lying to patients or telling only part of the truth will very probably cause harm
- For every intervention, the potential benefits must be weighed against possible adverse effects

- Treatments should not be prescribed unless there is a strong chance that they will help the patient with only a small chance of unpleasant adverse effects.

1.5.4 Justice

Justice relates to fairness in the application of care. It implies that patients receive care to which they are entitled medically and legally. Justice can be translated into ‘give to each equally’, ‘to each according to need’ or ‘to each his due’. This means that care provision should not be based on wealth, class, creed or colour of skin.

Quality care is therefore provided by healthcare workers who:

- Endeavour to maintain the dignity of the patient, their caregiver(s) and family
- Work with the strengths and limitations of the patient and their caregiver(s) and family to empower them in managing their own situation
- Act with compassion towards the patient and their caregiver(s) and family
- Consider equity in the accessibility of services and in the allocation of resources
- Demonstrate respect for the patient, their caregiver(s) and family
- Advocate on behalf of the expressed wishes of patients, their caregivers, families and communities
- Are committed to the pursuit of excellence in the provision of care and support
- Are accountable to patients, their caregivers, families and the community.

1.5.5 Maintaining the ethical principles of care

In order to ensure that high-quality, patient-focused and evidence-based services are available to meet patient needs, primary care and specialist providers, and other health care professionals, should also:

- Follow established practice standards and requirements for quality management, such as leadership and governance, human resource management, safe practice, information management and continual quality improvement
- Adhere to professional and organisational codes of practice and ethics
- Reflect on and evaluate current practice, and incorporate new evidence into protocols, policies and procedures

- Participate in continuing professional development in the knowledge, attitudes and skills required to deliver quality palliative care as pertaining to the standards in this document.

1.6 Response of the Government of Uganda to palliative care

Uganda has received international acclaim for its leadership in Africa on the advancement of palliative care in practice. To ensure that this health-based human right is achieved, the Government of Uganda has established a supportive environment for the provision of palliative care through its health-related national policies, strategies and the constitution.

Four aspects need to be mentioned, as follows:

- Palliative care is included in the mission statement for Uganda's National Health Policy: 'to provide the highest possible level of health services to all people in Uganda through delivery of promotive, preventive, curative, palliative and rehabilitative health services at all levels'⁴
- Palliative care is a component of Uganda's Minimum Health Care Package and is one of the priority interventions in the National Health Sector Strategic Plan. This means that, as a health care worker, you have an obligation to provide the service to your patients and their families.
- In 2002, statutory instruments relating to the National Drug Authority (prescription and supply of certain narcotic analgesic drugs) were adjusted to enable specially trained palliative-care nurses and clinical officers to prescribe opioids, especially morphine, so as to effectively control pain in patients with life-threatening illness.
- Through the Ministry of Health, the Government of Uganda has made oral morphine available at no cost for patients experiencing moderate to severe pain.

⁴ The Republic of Uganda, Ministry of Health, Second National Health Policy; July 2010

Section 2: Palliative care as a human right

Palliative care is borne out of human value and dignity. It's about human rights. Understanding the human rights of patients is central to providing palliative care. Both palliative care and human rights are based on principles of human respect, dignity, non-discrimination and universality. But palliative care goes much further than physical care. It 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.

Palliative care, when seen through the lens of fulfilling the rights of the patient, will adhere to the ethical principles of care and professionalism; it will also take into consideration the legal needs of the patient that render them or their close family insecure – such as property issues, succession and estate planning, and the custody of children.

Human rights consideration will require that the patient is central to the care, such that:

- Ethical principles are adhered to
- The patient's welfare and interests are paramount and always sought
- The patient's opinion is valued and respected
- Their needs and fears are taken care of, including legal needs.

The human-rights approach to advancing palliative-care development emphasises the fact that the care of patients with life-threatening illness is a fundamental responsibility of governments, society and health professionals. Ethical and legal aspects of care (e.g. documenting patient preferences for goals of care, treatment options and the programme of care; and planning required care in advance, among other directives) are important in palliative-care provision.

Palliative-care providers are in a good position to discuss legal issues with patients living with life-threatening illness.

The responsibility for the human-rights approach to palliative care exists on three levels:

- The government
- The health care workers
- The family and community.

This means that all three levels have obligations and roles to play. Failure to respect the human rights and other ethical issues of individuals creates liability

on the part of the three responsible entities. And in cases of breach, three different circumstances could arise:

- Breach of human rights – could attract proceedings in a human-rights tribunal at national, regional and international level
- Breach of ethical principles or a dishonouring of an established code of conduct –can be taken as admissible evidence in a legal proceeding against a care provider, although they may not have so much legal force as the first instance above.
- Breach of legal provision is an automatic contravention of the law, which could lead to criminal and civil procedures in municipal courts.

2.1 *Children’s rights within palliative care*

“Human rights based care for the child with chronic illness with provided conditions that ensure dignity, promote self-reliance and facilitate active participation in the community; and also providing the child with the necessary support services” (Paraphrase of s.11 of Children Act, South Africa)

In Uganda, a child is defined as a person who is below 18 years of age. This definition is according to the nation’s Constitution and the Children’s Act.



Children may be affected either as patients receiving palliative care or as family members of palliative care patients. All human rights and legal rights apply to adults and children. However, children are not little adults. While children are inherently vulnerable and varyingly dependent, they are also inherently capable in different ways at different stages in their lives and in different circumstances. Consequently the realization of any one child’s rights must take into account a number of factors based on the expression and nature of children’s Vulnerabilities, dependencies and capabilities:

- health care and healthy environment,
- parental and family care, education,
- access to information,
- participation, play,
- friends, identity,
- Dignity and protection from harm.

Children have special needs as they tend to have a broader range of people involved in their care. So palliative care for children should be provided in a way that upholds the ethical and legal rights of the child. All decisions must be made with the best interest of the child at the centre.

Children's rights also address what needs to be done when things go wrong in an individual child's life (loss of parents), or in the world around that child (living in poverty or in war or other conflict).

A Key guide in realizing Children rights is the Best welfare principle as provided by the Law on children.

It means that:

- all decisions must be made with the best interest of the child at the centre.
- A child will be treated according to his special need or special condition
- A child will enjoy all rights; all rights will be for all children (equality and non-discrimination)
- Ethical, meaningful child participation in critical areas of their lives including decision-making.
- The child is seen as a whole child
- Each child's individual characteristics (like personality in particular) are taken into consideration
- The situation at any point in time and the child development stage should be assessed and analyzed to fit the response
- The uniqueness of each child
- The changing needs dependencies and abilities of each child.

The application of this principle in practice requires adults to be taken into account.

Children need to be involved in their care and they need to be provided with appropriate information about the care they are receiving. Involving children in their care improves their quality of life- they are happier, they cope better, feel included and cared for, healthier, take on appropriate responsibilities, talk about their hopes and worries.

Children who are partners in their own health care know the basic facts about their illnesses or condition. They have important information that has been communicated in appropriate ways. They know what treatment and care they should have and how important it is. They have the skills to put their knowledge into practice for example the skills of washing hands thoroughly. They are involved in decisions about their health care, and are listened to and respected.

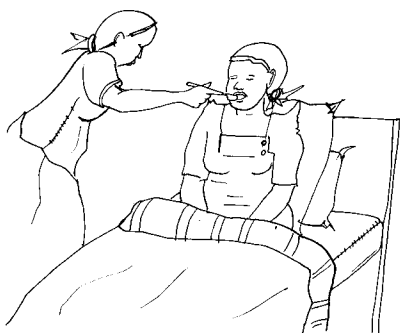
While children should never be told a lie – they do not need to be told the whole truth. What they are told, needs to be as much as they will understand and what they can cope with at that time

Children who are carers

Most times, in resource constrained families, children or young people are the carers of older patients facing life threatening illnesses. Such children are faced with traumatic conditions of witnessing their loved ones undergo pain and the ailments of their conditions; they do the cleaning and toileting. Being children, they are not fully composed to carry this weight of pain and confusion. As much as possible they need to be protected from the trauma and the effect of seeing loved ones suffering. An alternative carer should always be sought after (i.e. an adult carer and not a child). Government, palliative care programmes and services for children should protect the rights of each child, whether female or male; be able to identify, intervene and report cases of child neglect, abuse and exploitation.

2.2 The rights of women within palliative care

Human rights recognise all persons as being equal before the law and all should be protected by the law. However, women and girls – mainly as a result of socio-cultural norms, deep rooted attitudes and practices that influence the general way of life and decision making – are not usually afforded the same rights or opportunities as men. In that regard, women are vulnerable and need special consideration, support and protection to make sure their full rights are respected.



The constitution of Uganda recognises women and men as equal and enjoying equal rights.⁵ In relation to ethical care, human rights and legal issues, the following areas should be given keen attention:

Respect for autonomy, privacy and confidentiality: The need to respect this right may be more significant for women because usually they are not the decision makers. Patients who are women should be given an opportunity to decide about, and to get involved in, their own treatment

5 Article 33 of the Constitution of Uganda

and care planning; their views must be respected. What a woman shares with a health care worker should not be shared with third parties without her consent because this could hurt her best interests.

Domestic setting of care: It is important to take into account the domestic setting where a woman patient is being cared for. Are there any issues of violence or familial disputes that need addressing?

Property issues: A large number of women will have property ownership struggles and conflict due to custom or culture. They will have worked for property or have a major interest over land, but will not always be recognised as having ownership rights. Guidance on how to make a will is important in view of such circumstances. For example where property she may want to distribute in the will is jointly owned, the will should clearly say that it's jointly owned property. Sometimes women have user rights over property but not ownership rights. Alternative protection and succession planning can be achieved in other ways, such as calling family meetings where the woman's views are recorded and witnessed by several others. It is good to invite a lawyer and a friend to the meeting to witness what takes place, for future reference.

2.3 The rights of special-needs groups within palliative care

As stated in Section 1, human rights are inherent: each human being ought to enjoy the same rights regardless of their social status, education, physical or mental health, etc. Unfortunately, there are groups in most communities that are more marginalised or disadvantaged because of their social status.⁶ These groups require special consideration as palliative-care patients because they often do not receive full recognition in planning and in care.

The Constitution of Uganda provides special recognition for the vulnerable and marginalised as protected groups.⁷ These groups are often poor and can easily be discriminated against, which means that their social, legal or human-rights needs may be greater compared to the general population. Remember, therefore, that while all people have the same legal and human rights, vulnerable and marginalised groups may need extra support to make sure that their human and legal rights are respected.

Some of the groups who may need additional support include: children (especially those whose parents are also ill); the elderly (especially those who do not have adequate family support); persons with disabilities; homeless people; refugees and internally displaced people; and prisoners.

6 APCA standards: Care for Special Needs Populations.

7 Articles 35 and 36 of the Constitution of Uganda

Partnership between institutions of special-needs populations and palliative-care services is essential in meeting the needs of patients and their families if they do have special needs.



Section 3: The legal framework for human rights in palliative care



Many other right-to-health issues need urgent attention, such as palliative care ... Every year millions suffer horrific, avoidable pain ... Palliative care needs greater attention.”

(Statement made to the UN Human Rights Council by the Special Rapporteur on the Right to Health, 2008)

“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.”

(Guideline No.6 on HIV and Human Rights)

3.1 International human-rights instruments

There are four aspects that need to be mentioned as having an international dimension:

- Under Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR) and Article 7 of the International Covenant on Civil and Political Rights, all countries that have signed up to those covenants are obliged to take steps to ensure that patients have access to palliative care and pain treatment.
- According to the UN Committee on Economic, Social and Cultural Rights (CESCR): “States are under the obligation to respect the right to health by ... refraining from denying or limiting equal access for all persons ... to preventive, curative and palliative health services.”⁸
- Access to essential drugs, as defined by the WHO Action Programme on Essential Drugs, is part of the minimum core content of the right to the highest attainable standard of health.⁹ Fourteen palliative-care medications are currently on the WHO Essential Drug List.
- The UN Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment has stated that “the *de facto* denial of access to pain relief, if it causes severe pain and suffering, constitutes cruel, inhuman or degrading treatment or punishment”.¹⁰

3.2 Human rights enshrined in the Constitution of Uganda

There are eight aspects of human rights enshrined in the Constitution of Uganda (CoU), highlighted as follows.

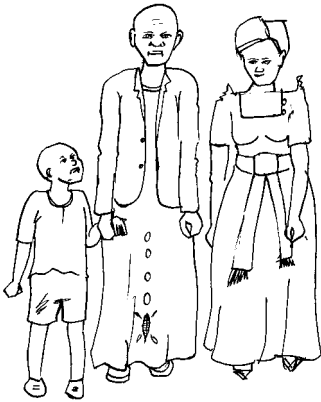
8 9 CESCR General Comment 14, paragraph. 34.

9 10 CESCR General Comment 14, paragraph. 12.

10 Human Rights Council, Report of the Special Rapporteur on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment, Manfred Nowak, A/HRC/10/44, 14 January 2009.

Accessed on 4 August 2009 at <http://daccessdds.un.org/doc/UNDOC/GEN/G09/103/12/PDF/G0910312.pdf?OpenElement> (see paragraph. 72).

3.2.1 Equality, human dignity and freedom from discrimination (CoU Articles 20 and 21)



Every person has an inherent right to equal respect and humane treatment. The autonomy of each individual is emphasised, along with an acknowledgement that every person is of value. All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.

This means that while providing care, a health care worker should do the following:

- Treat each patient humanely, recognising their worth
- Give patients priority and provide quality care not as though doing them a favour but as fulfilling a recognised responsibility
- Communicate effectively and honestly, applying emotional detachment that affirms the patient's dignity
- Support the patient as they make informed decisions, seeking their consent/assent at all times
- Before undertaking medical procedures, explain to the patient what the procedure entails
- Listen to the patient, their fears and concerns when they demand to know any information associated with their illness
- Do not discriminate against a patient because of their vulnerable state or symptom gravity (e.g. confusion, fatigue, bad smell from wounds).

3.2.2 Right to life, and protection from inhuman, cruel and degrading treatment (CoU Articles 22 and 24)

Every human being has an inherent right to life, which also means that every life should be protected from harm, pain, psychosocial distress and degrading treatment. In palliative care, this means that failure to treat physical, spiritual and psychosocial pain is a violation of a patient's human right.

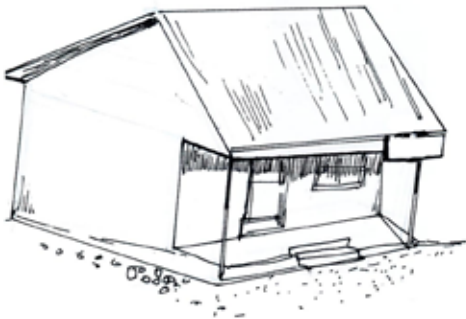
A health worker needs to take an adequate pain history, make an assessment of the current level of pain, and treat it. Excessive pain experienced by the patient is not acceptable.

3.2.3 Right to health (ICESCR Article 12)

Under Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR), every person has a right to a high standard of health so that any person with a life-threatening illness has a right to access treatment, including pain relief and medication.

Article 45 of the Constitution of Uganda recognises that some human rights are not specifically mentioned in the constitution but they are nevertheless important human rights within the full force of law. In terms of palliative care, this means that access to pain-relieving medicines (such as morphine and other opioids) and other essential medicines is a fundamental right. It also means that the state has an obligation to ensure nationwide affordability, availability and fair distribution of essential medicines for pain control.

3.2.4 Property ownership and usage (CoU Article 26; also Succession Act)



Every person has a right to own property and use it (within the law) as they decide. Every person has rights to bequeath (give out) or inherit property. Critical ill health is not a ground for depriving anyone of their rightful property and inheritance, or their freedom to decide and determine how to give/distribute their property as they so wish.

In palliative care this means that a health care worker should:

- Take an interest in assessing the level of security and legal needs of the patient
- Offer advice on practical steps that a patient could take to safeguard their property
- Refer patients or their families to institutions that can provide them with further support.

3.2.5 Right to privacy and confidentiality (CoU Article 27)

A patient's health record is private. No one – not even a person's employer or doctor – can force that person to have their blood tested or to have their results disclosed to anyone without their consent.

In palliative care, this means that a health care worker will not disclose a patient's medical status (e.g. their HIV status) to a third party other than to another member

of the multidisciplinary team and even so it should be on a legitimate ‘need to know’ basis.



3.2.6 Access to justice (CoU Article 28)

Every person is entitled to equality before the law. This means that all persons have a right to equal legal protection, equal access to justice and a fair hearing. No person shall be subjected to differential treatment because of a health condition. In palliative care, this means that each patient has a right to access legal assistance, fair treatment and quality health care services.

3.2.7 Right to information and informed consent (CoU Article 41)

Every patient has a right to access all the files and forms that contain information of their diagnosis and a verbal explanation about their condition. Every person also has a right to access their own medical records. Furthermore, a person cannot be coerced to disclose any information about themselves that they are not comfortable disclosing.

In palliative care this means that informed consent should be obtained from each patient before administering treatment. The patient’s preferences and choices should form the basis for any plan of care.

3.2.8 Right to family, social care and support [CoU Article 31, 34]

This Article of the Constitution of Uganda pertains to provision of care, with the patient and family being the centre of that care. No one should have to face their diagnosis, care and treatment, and the possibility of illness and death, alone. While individual patients must be at the centre of the care process, they should also be surrounded by family, friends and the community – whom they need in such circumstances and deserve to have around them for support during their care and treatment processes.

Section 4: Legal issues in palliative care

Health care workers recognise the distress that legal issues may create for their patients and patients' families. As a result, health practitioners and clinical personnel can play a crucial role working at the intersection of law and health, combining legal knowledge with an understanding of health issues and the challenges facing a person with a life-threatening illness.

Health care workers are encouraged to assess the legal needs of their patients and offer the necessary support.

The main legal issues experienced in palliative care include succession planning (particularly will writing and property inheritance), appointing others to act for someone who is incapacitated through illness, following up on social security benefits due, and the custody of children. Some important aspects of these are considered in more detail below.

4.1 *Succession planning*

4.1.1 What is 'succession'?

Succession is when one individual inherits the property of another person. In Uganda, there are two types of inheritance: testate succession and intestate succession.

Testate succession occurs where a person dies leaving a testament or a will. When a person makes a will, they are called a 'testator'. The will sets out the wishes of the testator and how they wish their estate to be distributed after their death. A person should be named in the will as the one responsible for implementing the wishes of the testator after their death and that person is known as the 'executor'. After the death of the testator, the executor has a legal duty to ensure the testator's wishes, as expressed in the will, are fulfilled.

Intestate succession occurs when no valid will has been left by the deceased person. In these circumstances, special legal arrangements have to be put in place to deal with the person's estate.

4.1.2 Making a will

As stated above, a will is a document made during a person's lifetime in which that person directs or states how their property and other affairs should be dealt with after their death. Most often Will making is not talked about in our society. It's related to dying and yet it's a concept that everyone despite their health status needs to understand and apply in their lives. It is therefore important to introduce the topic of will making during routine care delivery.

Anybody can make a will, whether they are a man or woman, married, single, widowed or divorced. However, for a person to make a will, they must have what is known as 'legal capacity' to do so. A will reduces conflict in a family when

someone has died e.g. it allows young children to inherit the property of their deceased parents. Someone is considered to have 'legal capacity' if they meet the following conditions:

- They are at least 21¹¹ years old
- They are in their right state of mind (i.e. not mentally unstable and not drunk) at the time of writing the will
- The will has been made under the free will of the testator without duress or undue influence
- The will is written in a language that the testator understands.

In addition, for a will to be considered valid it must fulfil certain requirements with regard to content that have been stipulated under the law. These are listed as follows:

- The particulars of the testator (i.e. names, addresses, marital status, tribe, village) must be included
- The date when the will was made (i.e. day, month, year) must be stated
- Names and address of the executor (the person who will be responsible for making sure that the wishes in the will are carried out) must be given
- A list of the properties that are part of the estate of the deceased person and their location must be made clear
- Names and relationships of all the main beneficiaries of the estate, and other persons given gifts in the will, must be specified
- The names and addresses of the guardians appointed to look after any young children must be stated
- Creditors and whatever is owed should be mentioned
- The will must be signed or thumb-printed by the testator
- The will must be attested to (witnessed) by at least two people in the presence of each other and they must not be beneficiaries to the will. The witnesses must sign or thumb-print their names.

Copies of the will must be kept with someone whom the testator trusts. The will may be kept with:

- A bank
- A lawyer
- A trusted friend/relative
- A religious leader
- An NGO e.g. Uganda Network on Law, Ethics and HIV/AIDS (UGANET).

Challenges in will making

Undue influence or being forced to write a will. You should write a will out of your own wishes and not because someone else is forcing you to do so.

A will needs to be fairly written making sure that your property is equally distributed to all your beneficiaries. If this is not possible, you should mention

11 Uganda succession Act; The law on succession Cap 59 is the applicable law on succession and inheritance

why some are receiving more than others. Failure to provide this explanation can make the will challengeable in a court of law.

4.1.3 Executing a will

It is a requirement of the law that in the execution of a will the executor must ensure that the following people are kept informed

- The testator's wife/wives or husband, as recognised by the law
- Biological children of the testator who are below 21 years of age without consideration of whether they were born within or outside wedlock
- Trustees for the benefit of others, i.e. minor children. Such an arrangement is suitable and properly directed to his/ her young children or persons with disabilities.
- Dependent relatives – these are relatives who were totally or substantially dependent on the testator for survival but not those who occasionally received assistance from them
- Any other persons of their choice and this include individuals of organisations such as churches, and legal entities such as companies, NGOs etc.

4.2 Powers of attorney

4.2.1 What is a 'power of attorney'?

A 'power of attorney' is a legal power used by an individual to appoint someone to make decisions on their behalf. It is a legal document, and the person designated to act is called an 'attorney-in-fact'. The appointment can be effective immediately or can become effective only if the person is no longer able to make decisions on their own.

This kind of arrangement helps to identify a person who will legally act in the name of the appointing person, should circumstances arise when the appointing person is incapacitated. But as a safeguard, powers of attorney should be specific as to what property a person is entrusted with, and should have a time limit.

There are two essential elements to a valid power of attorney under the law:

- **Soundness of mind:** the person signing the document must be mentally competent (i.e. understand the content of the document that is being signed and what it does). In addition, he or she must be acting by choice, without undue pressure or coercion from anyone.
- **Witnesses:** The appointing person's signature on a power of attorney must be notarised by a notary public, or at least two adults unrelated

to the appointing person or to each other. These witnesses cannot be named as the attorney-in-fact and they must witness the appointing person sign the power of attorney.

4.2.2 Putting a power of attorney into effect

A long term power of attorney can be drafted so that it becomes effective as soon as the appointing person signs it. Alternatively, that person can specify that it will not become effective unless a doctor certifies that they have become incapacitated (called a ‘springing’ power of attorney). In this circumstance, the person keeps control of their affairs until they are no longer capable of doing so.

4.2.3 Revoking a power of attorney

A person can revoke a power of attorney whenever they want, as long as they are mentally competent. This revocation should be in writing, signed by the appointing person in front of a notary public, and delivered to the attorney-in-fact and any third parties with whom the attorney-in-fact has been in contact with on their behalf (e.g. a bank or employer).

If a person has recorded their power of attorney at a registrar’s office, the person should record the nullification in the same place.

4.3 Custody and guardianship of children

‘Custodian’ means a person in whose care a child is physically placed; ‘guardian’ means a person having parental responsibility for a child. A custodian can be a person, an institution or organisation. So patients who are suffering from life-threatening illness can place their children under the care of a custodian or a guardian.

It is always important to appoint more than one guardian for a child so that the child has someone to take care of him or her in almost all eventualities that can be foreseen.



Section 5: Dealing with common legal needs of patients and their families

There are a number of circumstances when patients of yours, or their family members, might ask you for advice and help in relation to legal or human-rights issues. In this section are some guidelines on the most common of these, most likely to be raised as emerging issues.

5.1 Strengthening legal and human-rights support for your patients

There are a number of things that you can do to strengthen the support that you give to your patients (and their families) in connection with legal and human-rights issues. Below are some examples of ways you can intervene in a patient's situation to provide them support:

- Invite the legal and human-rights organisations listed at the end of this guide to provide you and the rest of your team with basic education on legal and human-rights issues. In this way you can obtain any required clarification from them on issues confronting you that are being raised by patients and families
- Introduce a routine programme where legal practitioners can come to your organisation and provide legal and human-rights support to your patients and families. This can be done on a one-on-one basis in a private room or through group sessions such as during day-care programmes. The listed organisations at the end of this guide are likely to be willing to partner with your organisation in this area. Organisations such as Reach Out Mbuya and Nsambya Home Care have developed such a model and you can learn from them.
- Document legal and human-rights cases and interventions at your facility, in order to support further advocacy to ensure that the legal and human-rights needs of patients and their families are met in their care provision.

5.2 Giving guidance on writing a will

It might well be helpful to bring up this issue as part of your assessment and care even if your patient does not mention it. Below are some steps that you can take:

- Obtain some basic information on writing a will. You can do this by inviting a legal practitioner from one of the organisations listed at the end of this guide to give an educational session on the topic to your team and patients and families where necessary.

- Obtain a format/template for will writing from any of the relevant organisations. Organisations such as Uganda Association of Women Lawyers (FIDA) and UGANET will have this translated into several languages and you can have a copy for each.
- Provide a will-writing format to your patient in their preferred language and invite them for a discussion on any sections they may not have understood as they completed the form.
- Refer the patient to one of the lawyers in the organisations listed at the end of this guide, using a written referral note, if more specialised help is needed.
- Arrange follow-up with both your patient and any lawyer involved, to ensure that adequate support has been given.

Sample cases that require guidance on will making

Example 1: John approaches you and confides in you that he has fathered children by different women but that he is only legally married to one, named Jackie. He wants to make a will so that his children can share the property equally.

Example 2: Jane's husband died without leaving a will and now she needs to access his account in a certain bank in order to pay for her medical bills.

5.3 *Other useful examples*

Below are some other useful examples of what you might encounter in your health care work with regard to legal and human-rights issues.

Example 3: Your patient and their family are having property-related challenges and require your help. You should:

- Obtain specific information on the nature of the challenges involved
- Provide basic support such as conducting family meetings and providing mediation if this can solve the problem.
- With the parties' consent and as necessary, refer the case to a human-rights or legal organisation for more specialised support.
- Undertake follow-up to ensure sufficient support is provided.

Example 4: Your patient needs legal representation in court. You should:

- Try to understand the court case from the patients or family's perspective
- Reassure the patient of the availability of free legal services through networking organisations if the patient is worried about the costs of being involved in a court case

- Make a referral to one of the legal and human-rights organisations, as necessary
- Undertake follow-up with the patient to ensure sufficient support is being obtained.

Example 5: A patient's family would like information and guidance on what to do with regard to the will of their recently deceased loved one.

As stated above, what needs to be done by the family can take two forms, depending on whether their loved one has left a will or not (see previous section on intestate and testate succession). In this example, a will has been written, but you will need some basic education on the two processes so that you can guide any family member appropriately. You can also access basic training from any of the organisations listed at the end of this guide.

The processes relating to executing a will almost certainly require support from a lawyer. Explain this to the family and refer them to one of the organisations listed at the end of the guide.

In addition, follow-up with both the family and the lawyer to ensure that support has been provided. You can encourage all parties to update you on progress.

Example 6: Your patient's 10 year old daughter has been sexually abused and your patient requires your guidance on what to do. You should report the case to police, who will take the statement. The daughter will also undergo a medical examination to look for evidence of sexual abuse. If there appears to be a case, the case file will be transferred to the state attorney.

While this process is going on, you and/or the family should get assistance from any of the organisations listed at the end of this guide or from a lawyer on how to proceed with the case.

Example 7: A lady had been undergoing home-based care for two years. She was HIV positive and had developed cancer of the eye. She didn't have much family support apart from her two young sons, and the only property she had to her name was the house she lived in with her children. She later died.

A much larger family group was available to bury her, but they were never present as she suffered with the cancer. Her ex-partner/father of the children returned a week after her death and sold off their home. The children are now homeless a mere two months after the death of their mother, and they have no money to go to school.

In this case, some simple steps would have helped to address this unfortunate situation before it occurred:

- The patient should have discussed the vulnerable state of the domestic setting with her doctor or health care worker while she was still alive. In turn, the health care worker – on noticing that she had sole care of her sons – should have probed for more details.

- The patient could have entrusted the land agreements or land title of her house to a trusted friend, with copies given to the local council committee, a spiritual leader or group, or a health care provider.
- The patient could have obtained a referral to a relevant organisation for legal support.
- The patient could have written a will, giving her house to her sons alone.

5.4 Failure to undertake your responsibilities as a palliative care provider

Individuals have a right to seek legal intervention if their rights are violated even if their doing so is not common practice in Uganda as a result of ignorance among patients and their families. Violations of the rights of patients usually occur as a result of health care workers failing to observe the ethical principles set out earlier in this guide.

Hence, problems may arise including:

- Withholding important information
- Not respecting a patient's right to decision making
- Breaches of confidentiality, without prior discussion with the patient
- Failure to give the patient necessary treatment, such as pain medications
- Compromising a patient's and family's dignity, e.g. shouting at them, carelessly exposing their bodies etc.

Such failures can cause considerable disquiet, harm and even legal ramifications for those of your patients who are affected. Your aim should therefore always be to attain the highest standards of ethical care and concern for your patients as you practice palliative and other care among them.

Definitions

Attorney-in-fact: Someone specially named by another through a written “power of Attorney” to act for that person in the conduct of the appointer’s business.

Power of Attorney: A written document in which one person (principal) appoints another person to act as an agent on his or her behalf.

Disquiet: Absence of peace or rest

Executor: A person appointed to administer the estate of a person who has died leaving a will which nominates that person.

Humane: Being compassionate, sympathetic and kind towards people.

Incapacitated: Where one has no capacity or ability to accomplish anything as a result of being ill or injured

Inherent: Existing as an essential constituent or characteristic or entitlement

Notarised: To certify or attest to a document

Notary public: A public officer constituted by law to serve the public in non-contentious matters usually concerned with estates, deeds, powers-of-attorney, and foreign and international business

Ramification: To have implicating consequences or outgrowths

Ratify: to confirm by expressing consent, approval, or formal sanction.

Testator: A *testator* is a person who has written and executed a last will and testament that is in effect at the time of his/her death.

Vulnerable: Exposed to the possibility of being attacked or harmed, either physically or emotionally

Appendix 1: 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 uganda _____

_____ 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 authorized 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 _____

Appendix 2: A sample of a simple Will

LAST WILL AND TESTAMENT OF (ID number), ofMakindye, Kampala

1. I hereby cancel all wills made by me before this time,
2. I appoint as executor of my estate my sister... of 10 Kawempe, Kampala
3. I leave Five Million shillings to my friend Mr. Mukiibi of Nalaya estates, Kampala.
4. I leave my car to my daughter, Miss Nassuna of Kawempe. Kampala
5. I leave the rest of my property to my wife, Agnes Nazziwa , with whom I have a customary law marriage which marriage is registered in terms of Section 4(1) of Act 120 of 1998, and if she does not survive me, I leave the rest of my estate to my brother, Gideon Mukasa,
6. Should my wife die before me, I would like to appoint my brother, Gideon Mukasa, as the guardian of my minor son, Appolo Kitebi.
7. I direct that my Executor shall have the power to appoint a professional to assist her and shall be exempt from having to furnish security to the Master of the High Court.

Signed byon this day of 29th October 2006 as the testator of this will in the presence of two witnesses.

Testator_____

Witness 1 _____

Witness 2_____

Appendix 3: A sample of a detailed Will

THE LAST WILL AND TESTAMENT OF MR.MADE THIS DAY OF
.....AT.....

1. I.....oftoday theday of20.....Make my Will and revoke all Wills which I made previously. I have made this Will voluntarily while I am of sound mind and nobody or Institution should change my Will.

2. Birth Particulars:

Father's name:

Mother's Name:

My tribe:

My totem:

My religion:

3. I was born onday of(Month)(year) at.....(Village/Town)
.....(Sub-county).....(District)

4. Marital Status

I amsingle/married/widowed/divorced/separated from my spouse(s) whose name is

In case you are married mention your wife (wives) or husband. The names of my spouse(s) are:

a)

b)

c)

5. We got married as follows: (State whether you got married in Church, at the Chief

Administration Officer (CAO's Office), Registrar of Marriages, Births and Deaths, in Mosque or any other authorized place according to Islam, or a place where the Customary Marriage ceremony took place)

i) Ondate at

ii) Ondate at

iii) Ondate at

6. In case you are divorced, separated mention the names of the husband or wife you divorced or separated from.

I divorced/ separated fromwho is no longer my wife/ husband at the time of making this Will.

7. Full names of my children male and female

Name _____ Age _____
Name of father/mother

1		
2		
3		
4		

8. I appoint the following people to be guardians of my young children

NAMES	ADDRESS
1.	
2.	
3.	

9. Heir /heirress

I appointto be my heir/heirress

10. Executor/Executrix

I appoint the following people to be the Executors/ Executrix of my Will

NAME	ADDRESS

11. Property Owned.

I own the following Property:

ITEM	TYPE OF PROPERTY	LOCATION
1.		
2.		
3.		
4.		
5.		

13. I have distributed my property as follows:

Note: The property in your house where you live with your spouse and children should not be distributed.

Names of the person I have given property	My Relationship with that person	Description of the property given
1.		
2.		
3.		
4.		
5.		

14. Property which I have given to my Minor children

You give instructions in the space below to the Executors how they will handle the property which you have given to your children you are below the age of 21 years.

15. Bank Accounts

a) I have the following Bank Accounts

Account Number	Bank/Branch	Type of Account

b) Indicate how you wish to distribute the money on the above accounts.

16. My Creditors and Debtors

A

Name and Address of Creditor	Particulars	Amount Owing

17. I have shares in the following businesses

Names and Addresses of Business Company/Insurance Policies	Shares in the Business

18. Employment Record

I am self employed/employed by

National Social Security Fund No.....

Provident Fund No.....

19. Burial wishes; I wish to be buried at (Village /Parish/ District)

20. Any other message which I wish to give to my people which I have not talked about above.

.....

Signature/Thumb Mark of the maker of the Will.....

WITNESSES:

FIRST WITNESS:

Full Names...

Physical Address...

Postal Address.....

Occupation:

Signature /Thumb mark.....

SECOND WITNESS:

Full Names:

Physical Address:

Postal Address.....

Occupation:

Signature /Thumb mark.....

Appendix 4: For further information please contact the following organisations

Institution	Type of services	Location	Contact
Association of Women Lawyers in Uganda (FIDA – UGANDA)	Legal aid services	P.O Box 2157 Kampala Plot 11 Kamwokya Street, Kamwokya	Tel: +256-414-530848
International Justice Mission	Legal aid services	Ntinda – Next to Uganda AIDS Commission	Tel:+256-041-4532294
Justice Centre Uganda	Legal aid services	P.O Box 26365 Kampala	Tel: +256-712/701/517449
Ministry of Health	Government body	Plot 6 Lourdel road, Nakasero P.O BOX 7272 Kampala, Uganda	Tel: +256-414-340874 Clinical services department
Uganda Christian Lawyers Fraternity	Legal aid services	Baptist House Bombo Road- Wandegeya. P.O Box 29375, Kampala	Tel: +256-414-534031
Uganda Law Society	Legal aid services	P.O Box 426 Kampala, Uganda Plot 5A Acacia Avenue, Kololo	Tel: +256-414-1342424/12
Uganda Network on Law, Ethics and HIV/AIDS (UGANET)	Legal aid services	P.O Box 70269 Ntinda Plot 194, Old Kiira Road, Ntinda	Tel: +256-414-574553
Palliative Care Association of Uganda	Coordinating body for Palliative Care Services in Uganda	P.O Box 72518 Plot 104 Block 261, Kizungu Lane, Makindye, Kampala	Tel: +256-312-289121

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- Christine Sifuna, Ministry of Health, Uganda
- David Kavuma, Mildmay Uganda
- Dora Musinguzi, Uganda Network on Law, Ethics & HIV/AIDS (UGANET)
- Dr. Faith Mwangi-Powell, African Palliative Care Association, Uganda (APCA)
- Dr. Henry Luzze, Ministry of Health, Uganda
- Dr. Jacinto Amandua, Ministry of Health, Uganda
- Dr. Jack Turyahikayo, Mulago Palliative Care Unit, Uganda
- Dr. Jane Nakawesi, Mildmay Uganda
- Dr. Samuel Guma, Kawempe Home Care, Uganda
- Dr. Stephen Watiti, Mildmay Uganda
- Dr. Yvonne Karamagi, Mildmay Uganda
- Ekyampaire Doreck, Hospice Africa Uganda
- Elisabeth Unterberger, Kawempe Home Care, Uganda
- Esther Apolot, Rays of Hope Hospice Jinja, Uganda
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- Jennifer Achiro, Reach Out Mbuya HIV/AIDS Initiative, Uganda
- John Muyita, Hospice Africa Uganda
- Josephine Bukirwa, Uganda Network on Law, Ethics & HIV/AIDS (UGANET)
- Josephine Kabahweza, Mulago Palliative Care Unit, Uganda
- Josephine Nabitaka, Hospice Africa Uganda
- Joyce Nafuna, Uganda Network on Law, Ethics & HIV/AIDS (UGANET)
- Kiera Hepford, Open Society Foundations-New York
- Mary Callaway, Open Society Foundations-New York
- Olivia Nanseko, Uganda Human Rights Commission
- Olivia Nantale, Mildmay Uganda
- Primah Kwagala, Centre for Health, Human Rights and Development, Uganda
- Prosy Akello, Uganda Network on Law, Ethics & HIV/AIDS (UGANET)
- Rachel Crosby, African Palliative Care Association, Uganda (APCA)
- Resty Ingabire, Nsambya Hospital Home Care, Uganda
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