



THE REPUBLIC OF UGANDA  
**Ministry of Health**

# HUMAN-RIGHTS, ETHICAL AND LEGAL ISSUES IN PALLIATIVE CARE: A GUIDE FOR PATIENTS AND THEIR FAMILIES





# Contents

<b>Acknowledgements</b>	<b>2</b>
<b>Foreword</b>	<b>3</b>
<b>Section 1: Introduction</b>	<b>5</b>
<b>Section 2: Some key concepts and definitions</b>	<b>6</b>
2.1 What is palliative care?	6
2.2 What are human rights?	7
2.3 How are palliative care and human rights linked?	7
<b>Section 3: Ethical issues in palliative care</b>	<b>11</b>
Principle 1: Autonomy	11
Principle 2: Beneficence	12
Principle 3: Non-maleficence	12
Principle 4: Justice	12
<b>Section 4: Children’s rights and palliative care</b>	<b>13</b>
<b>Section 5: Women’s rights and palliative care</b>	<b>15</b>
<b>Section 6: The rights of special-needs groups in relation to palliative care</b>	<b>16</b>
<b>Section 7: Legal rights and palliative care</b>	<b>17</b>
7.1 What are legal rights?	17
7.2 What can patients do to protect their rights?	18
7.3 Protecting your property	19
7.4 The effect of not having a valid will	21
7.5 Where can I report an abuse of human rights?	23
Sample cases	23
Definitions	25
Appendix 1: A sample power of attorney	26
Appendix 2: A sample of a simple Will	27
Appendix 3: A sample of a detailed Will	28
Appendix 4: For further information please contact the following organisations	32
Contributors	34

# Acknowledgements

The Ministry of Health Uganda acknowledges the contribution of the Palliative Care Association of Uganda and the African Palliative Care Association (APCA) for their technical support; as well as the contribution of the Uganda Network on Law, Ethics and HIV/AIDS (UGANET) for its support with legal consultancy in developing these guides.

The publication of this guide has been made possible with financial support from the Open Society Initiative for Eastern Africa (OSIEA), Open Society Foundations (OSF) International Palliative Care Initiative (IPCI) and Law and Health Initiative (LHI), organisations that are committed to promoting access to palliative care as a right for everyone who needs it.

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. Quality of life will be determined by the extent to which the patient and his/her family receive ethical care, including support with the legal and human rights needs. Everyone has a right to respect and dignity from those providing care.

The care received must ensure that there is excellent pain and symptom control; psychosocial and spiritual support; informed decision-making and coordinated services across the continuum of care such as communication, information sharing, personal preferences, advanced care planning and bereavement care. Relief from pain is central to palliative care, and is a human right. Dehumanizing, excessive, yet avoidable pain and suffering is a serious breach of fundamental human rights. Every individual is unique, and should have equal access to palliative care without any form of discrimination. All patients should receive quality care regardless of their medical condition, social status, financial status, educational background or where they live.

The Government of Uganda has made efforts in advancing palliative care and making it accessible for all Ugandans. The government therefore requires all health care providers to ensure that patients receive quality palliative care services.

This guide, which the Government has developed in collaboration with its partners, highlights patients' rights in relation to access, humane and ethical care, and the delivery of palliative care. The guide helps patients to understand their rights in relation to the care received and provides insights into the common legal and human rights issues they may encounter, and encourages them to share these with the health care provider for support.

The guide offers a list of contacts for legal, human-rights service providers and organisations in Uganda that can be contacted for further information and assistance. I hope the guide will enable patients to understand their rights and to collaborate with health care providers in ensuring that these rights are met and their legal needs are supported. I highly recommend these guidelines to all those involved in the care of patients.



**Hon, Dr. Ondoa D. J. Christine**  
**Minister for Health**

# Section 1: Introduction

*“I want to live and die in dignity ... I want to be listened to,  
I want to leave my children with security ... What can I do?”*  
(A patient in Nsambya Home Care, November 2011)<sup>1</sup>

Care is about the patient. The best interests of the individual should be paramount. This means that the patient’s best interests are the primary consideration in all decision making about them. It also means that, as a patient, you are entitled to care based on good ethics; you have a right to receive adequate pain relief and symptom management, and should be treated with dignity and respect.

Facing a life-threatening illness i.e. a disease with no cure is a difficult issue. It nevertheless requires each patient and their care providers to positively address the challenges that come with it.

A health care worker will ensure that the care given observes four very important ethical principles,<sup>2</sup> upholds the human rights of yourself and your family, and ensures support in meeting your legal needs.

As a patient (adult or child) you ought to be involved in your own care, understand all aspects of the care you are receiving, have information that is required to make informed decisions, know your rights in relation to your care, and receive adequate support from your health care provider in relation to other personal needs (such as legal, psychological and spiritual needs).

Children have the right and ability to comprehend and understand health information when given to them in ethical, appropriate means. Together, the health care provider, the patient and their family members who are providing additional care make a great team in the patient’s overall care plan and therefore together can produce the desired outcomes of palliative care: **a life of quality, and dignity in death.**

This booklet covers key issues that you might need to understand about ethical care, human rights and legal aspects. It aims to help people with serious illness as they face these issues, and give them guidance on how they can find solutions.

---

1 UGANET–APCA Consultancy Report, 2012

2 **Autonomy** – Acknowledges patients’ rights to self-determination, without prejudice. **Beneficence** – The production of benefit, doing good, always acting in the best interests of the patient. **Non-maleficence** – Acting so as not to be malicious nor do harm. **Justice** – Fairness in the application of care. See Section 3 below for more details.

# Section 2: Some key concepts and definitions

## 2.1 What is palliative care?

Palliative care is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness. Improvement comes through the prevention and relief of suffering by means of early identification, and then assessment and treatment of pain and other problems – physical, psychosocial and spiritual.<sup>3</sup>

The purpose of palliative care is to:

- Provide relief from pain and other distressing symptoms
- Affirm life and regard dying as a normal process
- Integrate the psychological and spiritual aspects of patient care
- Offer a support system to help patients live as actively as possible until death
- Offer a support system that helps the family cope during the patient's illness and in their own bereavement.

This means that:

- You are a unique individual and you ought to be treated with sensitivity and care
- Your beliefs should be respected at all times
- You should receive the appropriate care
- Your consent should be sought before any treatment is given or withdrawn.

### 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.
- 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.

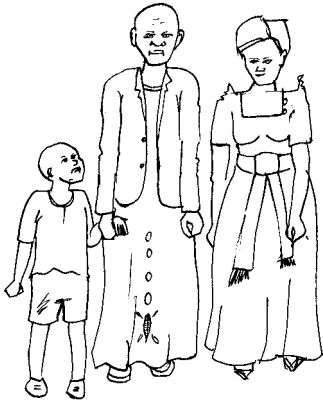
---

3 World Health Organization (modified definition).



## 2.2 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 inbuilt and they belong 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

## 2.3 How are palliative care and human rights linked?

As a patient, if you understand your human rights you will be able to: identify violations of palliative care rights such as your right to access good care and adequate medication; you can advocate for the provision of palliative care and use the law to ensure you get these rights, and you should be able to complain

to human rights bodies about a lack of compliance to human rights agreements.<sup>4</sup> Both palliative care and human rights are based on principles of human respect, dignity, non-discrimination and universality. This is why we say that palliative care is about human rights.

The 1995 Constitution of Uganda, chapter 4 has restated the particular fundamental rights and freedoms of each individual, and these rights and freedoms are important in palliative care. The provisions in the Ugandan Constitution affirm the dignity, equality and autonomy of each human being. These are important rights if a person is vulnerable because of pain or confusion, which is why they are important in palliative care.

There are seven special aspects in the Constitution of Uganda that link human rights with palliative care. These are highlighted in the following sections.

### **2.3.1 Equality, human dignity and freedom from discrimination**

Articles 20 and 21 of the Ugandan Constitution make it clear that every person has an inherent right to equal respect and humane treatment, emphasising the freedom of action of each individual to participate (or not) in decision making. In addition, nobody should be subjected to inhumane and degrading treatment under any circumstances, including medical situations.

This means that:

- You have a right to be treated humanely and with dignity
- No matter what illness a person has, each individual's life is valuable and of worth
- Every patient must receive quality health care as a right, not as a favour, because it is a duty of health care workers and the government to provide such care
- All communication must be effective and honest, and must affirm a patient's dignity
- Every patient has a right to be involved in their own treatment and receive accurate information about any medical procedures being suggested
- Every patient has a right to receive information about their health condition or any matter related to it in order to make informed decisions
- Even when a patient is vulnerable or has serious symptoms such as confusion, fatigue or bad smells from wounds, they have the right not to be discriminated against.

### **2.3.2 Right to life, protection from inhumane, cruel and degrading treatment**

Ugandan Constitution Articles 22 and 24 affirm that every human being has an inherent right to life. This also means that every life should be protected from harm, pain and degrading treatment.

In terms of palliative care, a patient has a right to:

4 APCA: Assessment of Legal Needs for Patients and Palliative Care Providers, 2010 (modified slightly).

- Treatment for their pain and control of their symptoms – failure to treat pain is a violation of a patient’s human right, and severe pain amounts to torture and cruel treatment
- Have a health worker take an adequate pain history, do an assessment of their current level of pain and treat it; excessive pain is not acceptable
- Access essential medicines that control pain

### **2.3.3 Right to the highest attainable standard of health**

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.

### **2.3.4 Property ownership and usage**

Under Article 26 of the Constitution of Uganda, as well as under the act of the Ugandan Parliament known as the Succession Act, every person has a right to own property and use it (within the law) as they decide. Every person also has rights to bequeath (give out) or inherit property. Critical ill health is not a ground for depriving anyone of their rightful property or inheritance, or their freedom to decide and determine how to distribute their property as they so wish.

Because property rights and property management are a very central issue of concern for palliative care patients and their families, it is important that adequate steps are taken to safeguard property rights. Therefore:

- A patient can seek support and advice from his or her nearest care provider, such as a health care worker
- Health care workers should discuss each patient’s legal and security needs when they are assessing that patient’s needs
- A patient has the right to appoint an attorney to act on their behalf
- Health care workers should be able to advice on practical steps that a patient may take to safeguard their property, such as will making and succession planning (see section 7)
- With the permission of those involved, health care workers can also refer patients or their families to organisations or individuals where they can receive further legal advice and support.

### 2.3.5 Right to privacy and confidentiality

Under Article 27 of the Constitution of Uganda, a patient's health record is private. In particular, no one – not even their employer or doctor – can force a person to have their blood tested or results disclosed to anyone without their consent. In palliative care, this means that as a patient you have the right:

- Not to have your medical status openly disclosed without your agreement. For example, a patient's HIV test result is not to be disclosed to a third party or even to another health professional without the knowledge and consent of the patient, except when there is a legitimate 'need to know' basis.
- To keep private all information shared with your doctor or health care worker.
- To know about, and give consent to, the care being provided.

### 2.3.6 Access to justice

Article 28 of the Ugandan Constitution makes it clear that every person is entitled to equality before the law. This means that everyone has the right to equal legal protection, equal access to justice and a fair hearing. No one should be treated differently because of a health condition or from being bedridden.

In palliative care, this means that each patient has a right to access legal assistance, fair treatment and quality health care services.

### 2.3.7 Right to information and informed consent



In accordance with Article 41 of the Constitution of Uganda, every patient has a right to access all the files and forms that contain information about them – for instance, records about the way their case is being managed. A person also has a right to access their own medical records.

In addition to the above rights, you (as a patient) also have roles and responsibilities that include:

- You need to adhere to the treatment given to you by a health professional
- You have a responsibility to provide feedback and information related to your condition to the health care worker.

## Section 3: Ethical issues in palliative care

*Ethical care is being in accordance with the accepted principles of right and wrong that govern the conduct of a profession*  
*“Ethics apply to all professional care but assume greater importance when caring for people with life-threatening illnesses. Ethical care is human-rights based.”<sup>5</sup>*



There are four main ethical principles in palliative care that health professionals should follow. These are:

### ***Principle 1: Autonomy***

This principle acknowledges **patients' 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 that as a patient:

- You can only be given treatments with your informed consent
- you have the right to be given full information in order to make decisions
- you have the right to decide what treatments you do or do not wish to have
- Health care workers have an obligation to provide honest and complete information when it is requested – which applies not only to medical treatments, but also to matters such as where you are to receive care, and who will provide that care.

### ***Principle 2: Beneficence***

**Beneficence means the production of a benefit, doing good, always acting in the best interest of the patient.** This requires that the health care team prevents or

---

5 African Palliative Care Association: A Handbook of Palliative Care in Africa.

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 while maximising the benefits of treatment.

More specifically:

- Whatever is done or said must be for the patient's good. This 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 cultural well-being and it must be distinguished from paternalism ('doctor knows best').

### ***Principle 3: Non-maleficence***

**Non-maleficence means not being malicious; doing no harm.** It supposes that a person ought not to inflict harm deliberately. Violation of this concept may include offering information in an insensitive way, providing inappropriate treatment for pain or other symptoms, continuing aggressive treatment not suitable to the patient's condition, providing unwanted sedation, or withholding or withdrawing treatment.

This means that:

- Whatever is done or said must not harm you as a patient, either physically or psychologically
- Health care professionals should be honest with you; lying to you 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 they will help the patient with only a small chance of unpleasant adverse effects.

### ***Principle 4: Justice***

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

Unfortunately, observation of health care around the world shows much lack of justice. Many treatments are only available to the rich, to those with influence and power, or to those articulate enough to ask for better treatment. For example, in some countries morphine is available only if the patient can afford it; but according to the principle of justice, all patients should receive the care that they need.

## Section 4: Children's rights and 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 nature of 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 terminal 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 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.



## Section 5: Women's rights and palliative care

Human rights recognise all persons as being equal before the law and all are protected by the law. Indeed, the Constitution of Uganda recognises women and men as equal and enjoying equal rights.<sup>6</sup>

However, as a result of cultural norms, deep-rooted attitudes, and practices that influence ways of life and decision making, women and girls are often not given the same rights and opportunities as men. This makes women vulnerable in terms of their rights and they may need special support and protection to make sure their full rights are respected.

Areas where women's rights especially need to be safeguarded in relation to palliative care patients could include the following:

**Respect for autonomy, privacy and confidentiality.** The need to respect this right is very important for women because, often, they are not decision makers. Women with serious or life-threatening illness should be given the opportunity to get involved in their own treatment and care planning and to make decisions accordingly. Their views must be respected. What a woman shares with a health care worker should not be shared with third parties without her consent as this could hurt her best interests.

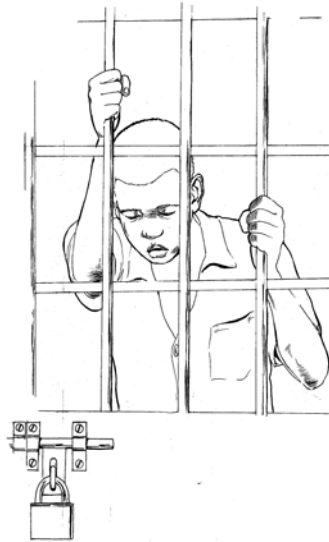
**The domestic setting of care:** It is important to take into account the domestic setting where a woman patient is being cared for. Such settings should be free from violations.

**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.

---

6 Article 33 of the Constitution of Uganda

## Section 6: The rights of special-needs groups in relation to palliative care



Human rights are inherent; each human being ought to enjoy the same rights despite their social status, education, tribe or other factor. Unfortunately, there are groups in our communities that are often more marginalised or disadvantaged as a result of their social status.<sup>7</sup> They require special considerations 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.<sup>8</sup> These groups are often poor and can easily be discriminated against. This means that their social, legal or human rights needs may be greater compared with the general population, and they might 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 (particularly those who do not have adequate family support); persons with disabilities; homeless people; refugees and internally displaced people; and prisoners.

Partnerships between palliative care service providers and institutions concerned for special-needs groups are essential in meeting the needs of patients and their families if they do have special needs.

7 APCA Standards: Care for Special Needs Populations.

8 Articles 35 and 36 of the Constitution of Uganda

## Section 7: Legal rights and palliative care

### 7.1 What are legal rights?



Legal rights are entitlements a person has by virtue of enacted law, 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 the same way.

The legal rights that are very important in palliative care include the following:

- The right to receive care that meets the appropriate standards of professionalism



- The right to confidentiality of medical records. What a patient tells a health care worker is confidential and should not be shared with anyone outside

the medical profession.

- The right to give informed consent regarding medical treatment. In health care, where procedures can be invasive and cause pain or harm, the issue of consent is important.
- The right to refuse medical treatment. Patients have the right to refuse a treatment or withdraw consent at any time. This right is extended to their kinsmen who have something called ‘power of attorney’.
- The right to have a competent substitute decision-maker in the event of mental incapacity. This is usually done through a power of attorney.
- All rights that give protection to one’s property.
- All rights that safe guard right of one’s loved ones and children, e.g. protection from land grabbing.

## **7.2 What can patients do to protect their rights?**

Patients can do the following things to protect their rights:

**Write a will.** You can get forms for writing a will from legal aid service providers. A will allows you to say what you wish to happen to your property after you die, and it will protect your loved ones. It will enable a smooth transfer of ownership of your property to another person that you will have appointed to take over after you have passed away.

**Seek legal aid services.** Legal aid service providers can assist patients to protect their rights in various ways, and they can also make referrals to different (more specialised) service providers. These services include a provision for free services where appropriate. See the list of useful organisations at the end of this guide.

**Seek counselling services.** Patients and their families can seek counselling services from service providers, including legal counselling on how to protect their rights. See the list of useful organisations at the end of this guide.

**Network with others.** Patients and their families can work together with fellow patients in assisting one another to share their experiences and liaise with their care takers and service providers to ensure that their rights are protected. A collective voice has greater impact.

**Give feedback.** Giving feedback to your service provider enables them to follow up on your concerns so that you obtain the required assistance.

## 7.3 Protecting your property

One concern that patients with life-limiting illnesses and their families often have is how to make sure that their property is left to the person they want it to be left to. Understanding your legal rights can help to make sure your wishes are respected.

### 7.3.1 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 written testament or a will. When a person makes a will, they are called a 'testator'. The written 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 (see section 7.4).

### 7.3.2 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. 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 21<sup>9</sup> 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 by free will without duress or undue influence
- The will must be written in a language the testator understands.

In addition, for a will to be considered valid, it must fulfil certain requirements with regard to content that has been stipulated under the law. These requirements are noted 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 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 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 could be kept with:

- a bank,
- a lawyer,

9            Uganda Succession Act. The law on succession Cap 59 is the applicable law on succession and inheritance.

- a trusted friend or 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, e.g. making sure that your property is equally distributed to all your beneficiaries. If this is not possible, you should mention why some are receiving more than others. Failure to provide this explanation can make the will challengeable in a court of law.

### **7.3.3 Executing a will**

Execution of a will by the executor is performed under the law through what is termed ‘letters of probate’. Letters of probate are documents granted by a court authorising the executor to deal with the estate of a person who has died and has left a will. The person applying for the letters of probate must attach a copy of the will or the original will of the deceased person. An application is made thereafter for a ‘letter of no objection’ from the Office of the Administrator General. Once that letter is issued, the application for a grant of probate is made to a court of law, which then grants it if all the necessary requirements are met.

## **7.4 The effect of not having a valid will**

As stated above, when a person dies without making a will, the inheritance is dealt with as ‘intestate succession’. This can also happen if a will is declared invalid by a court or when the will has been revoked by a later marriage.

### **What happens to my property if I don't have a valid will?**

If you die without making a will and you have property that needs to be distributed (your ‘estate’), then:

- The property in the estate is not necessarily distributed according to your wishes because these have not been written down
- The estate is kept in trust by a personal representative of yours, but that person is appointed by a court of law not by you
- Only beneficiaries recognised by law can inherit your estate.
- You can see that for these reasons alone – and there are others – it is well worth making a will if you have possessions to leave to others when you die.

### **7.4.2 Letters of administration**

In order to deal with your estate after your death when no will has been left, a person has to apply for what's known as ‘letters of administration’. Letters of administration are documents granted by the court authorising a person to

administer the estate of a person who has died without leaving a will. An application for letters of administration is made to a court. The application can be made by any of the following categories of people:

- The wife/wives or husband of the deceased
- Children of the deceased who are of age i.e. above 21 years old
- A close relative of the deceased
- The Administrator General

When applying for letters of administration, the person doing so needs the following documents:

- A death certificate indicating the death of the testator, to be taken to the Administrator General's office
- An introduction letter to the Administrator General from the local councillor of the area on behalf of the person making the application, introducing that person and informing the Administrator General of the death of the person whose estate is to be settled
- An application letter to the Administrator General for a certificate of no objection
- A certificate of no objection gives clearance which enables the person applying to deal with the estate to apply to the court for letters of administration. The Administrator General may summon a family meeting to establish certain facts or in case there is a dispute arising from the estate.

### **7.4.3 Administrator General**

The Administrator General is a public officer responsible for the administration of estates of persons who are deceased without wills. The Administrator General is represented in every district by the Chief Administrative Officer (CAO). The CAO also recommends to the Administrator General persons to be issued with certificates of no objection, holds family meetings and advises families of deceased persons where necessary.

Among other things, in relation to these responsibilities the Administrator General:

- Receives reports of death
- Resolves disputes among the beneficiaries or family members of a deceased person
- Issues certificates of no objection
- Acts as a public trustee, ensuring that the rights of the beneficiaries (especially any children) to inherit property are not violated where there is no will
- May also be granted letters of administration by the court

## **7.5 *Where can I report an abuse of human rights?***

In case a human rights abuse occurs in a community, it is important to know that there are many avenues where someone can obtain support. Some of the offices



where a person can seek assistance in these circumstances are noted as follows:

- The police (for criminal matters – i.e. theft of property, land grabbing, domestic violence, etc.)
- The Family Protection Unit of the police, or the Probation and Welfare Office for the district (for intervention on matters of child neglect, abandonment, etc.)
- Courts of law (in relation to the custody of children, land grabbing, domestic violence, etc.)
- NGOs (who might be able to help with land disputes, child protection, and succession planning)
- The CAO (for succession and inheritance matters)
- A lawyer (for marital disputes, land disputes, succession matters, etc.)
- The Uganda Human Rights Commission (if a complaint needs to be lodged against an individual, an institution or the state).
- Health service providers within the respective institutions where one is seeking services, i.e. a health centre, hospital, clinic, etc.
- You could also engage the established professional bodies that regulate the conduct of professionals

## **Sample cases**

Below are sample cases where individuals or families are facing problems that they need help with. For each example, think about what some of the rights of the patients in these stories are, and how health care workers can support these patients through their difficulties. Answers are provided, but try to think things through yourself first.

**Example 1:** Alice is suffering from lung cancer. Recently, her condition has deteriorated and she cries the whole night complaining of pain. She receives pain killers as part of her treatment, but this usually doesn't help her. She is facing a lot of agony and her attendants only watch her suffer.

In this case:

- Severe debilitating pain is dehumanising. It is Alice's right to receive effective pain medicine.
- The health care worker needs to do a pain assessment and manage it effectively.
- It is torture for Alice's family to see her groaning helplessly, and no health care worker should allow this to happen.

**Example 2:** John's illness had advanced significantly. The pain was too much and in most cases he would cry out for help, sometimes becoming violent. The medical workers would then tie his arms to the bed with ropes. He never liked this and he asked them not to do it, but they said, "There is nothing else we can do! You are violent, and we have to tie you up for our own and your protection!"

In this case:

- Failure to treat the pain resulted in violent action, so dealing with the violence could have been avoided altogether if the health care workers had dealt with the pain.
- Tying a human being to a bed when effective treatment exists to calm such a patient is very dehumanising, very cruel and amounts to torture.
- It's very frustrating and painful for the family to have to see their loved one in this state.

**Example 3:** 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 in which she lived with them. She later died.

Members of her extended family were available to bury her, but they were never present while she was suffering with the cancer. Her ex-partner/father of the children returned a week after her death and sold off her 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 her vulnerable domestic state 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 to her house to a trusted friend, with copies given to the local council committee, 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, bequeathing her house to her sons alone.

# Definitions

**Administrator General:** A person appointed by the government to handle the estate of someone who died without a will, with a will with no nominated executor, or the executor named in the will has died, has been removed from the case, or does not desire to serve.

**Attorney:** 1. A person appointed to act for another in business or legal matters.  
2. A lawyer.

**Attorney-in-fact:** someone specifically named by another through a written “power of attorney” to act for that person in the conduct of the appointer’s business

**Chief Administrative Officer:** someone at the district level who acts on behalf of Administrator General.

**Duress:** Unlawful pressure exerted upon a person to coerce/force that person to perform an act that he or she ordinarily would not perform.

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

**Guardian:** A person who has been appointed by a judge to take care of a minor child or incompetent adult personally and/or manage that person’s affairs.

**Humane:** This is compassion and tenderness for people especially for the suffering or distressed:

**Inherent:** Existing in someone or something as a permanent and inseparable element.

**Legal capacity:** This determines whether a person may make legally binding document like a will or engages into any contract.

**Power of attorney:** A written document and legally bidding document in which one person (the principal) appoints another person to act as an agent on his or her behalf.

**Ratify:** Accepting and giving legal force to an obligation.

**Testator:** A testator is a person who makes a valid will.

**A will:** The document through which a deceased person disposes of his property

**Tribunal:** A committee or board appointed to give a ruling in a particular matter.

**Vulnerable:** Capable of being physically or emotionally wounded or hurt

**Incapacitated:** Deprived of strength or power; “lying ill and helpless”

**Revoke:** To cancel by recalling, withdrawing, or reversing

# 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 matter 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), of .....Makindye, 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 by .....on 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.....of .....today the .....day of .....20.....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.

Birth Particulars:

Father’s name: .....

Mother’s Name: .....

My tribe: .....

My totem: .....

My religion: .....

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

Marital Status

I am .....single/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:

.....  
.....

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)

On .....date at .....

On .....date at .....

On .....date at .....

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

I divorced/ separated from .....who 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		

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

NAMES	ADDRESS
1.	
2.	
3.	

9. Heir /heirss

I appoint .....to be my heir/heirss

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.		

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.		

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.

Bank Accounts

a) I have the following Bank Accounts

Account Number	Bank/Branch	Type of Account

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

My Creditors and Debtors

A

Name and Address of Creditor	Particulars	Amount Owing

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)

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

<b>Institution</b>	<b>Type of services</b>	<b>Location</b>	<b>Contact</b>
Action Group for Health, Human Rights and HIV/AIDS (AGHA)	Policy and human rights	Plot 13 Factory Road, Hancock Road Ntinda PO Box 24667, Kampala	Tel: +256-414-348491
Coalition for Health Promotion and Social Development (HEPS)	Health providers	Plot 351A Namirembe Hill PO Box 2426, Kampala	Tel: +256-414-270970
Centre for Health and Human Rights Development (CEHURD)	Policy and Human Rights	Plot 614 Tufnell Drive, Kamwokya P.O. Box 16617, Wandegaya, Kampala	Tel: +256-414-532283
FIDA - UGANDA	Legal aid services	PO Box 2157 Kampala Plot 11 Kamwokya Street, Kamwokya	Tel: +256-414-530848
Health Rights Action (HAG)	Health providers	Plot 96 Bukoto Street Kamwokya, Kampala PO Box 400081	Tel: +256-414-4382357 and +256-312-282303
Hospice Africa Uganda	Health providers	PO Box 7757 Makindye, Kampala	Tel: +256-414-510089
Kawempe Homecare	Health providers	PO Box 337, Kampala	Tel: +256-414-530414

Mildmay Centre Uganda	Health providers	PO Box 24985 Kampala	Tel: +256-0312-210200
Ministry of Health	Government body	Plot 6 Lourdel road, Nakasero P.O BOX 7272 Kampala, Uganda	Tel: +256-414-340874 Clinical services department
Palliative Care Association of Uganda (PCAU)	Health providers	PO Box 72518 Plot 104 Block 261, Kizungu Lane, Makindye, Kampala	Tel: +256-312-289121
Reach out Mbuya Parish HIV/AIDS Initiative	Health providers	PO Box 7303 Kampala	Tel: +256-414-222630
The Aids Support Organization (TASO)	Health providers	Mulago Hospital Complex PO Box 10443 Kampala	Tel: +256-414-532580/1
Uganda Law Society	Legal aid services	PO Box 426 Kampala Plot 5A Acacia Avenue. Kololo, Kampala	Tel: +256-414-1342424/12
Uganda National Health Consumers and Users	Health providers	Plot 91 Bukoto Street, Kamwokya Kampala PO Box 70095, Kampala	Tel: +256-414-532123
Uganda Network on Law, Ethics and HIV/AIDS (UGANET)	Legal aid services	Ntinda P.O BOX 70269, Plot 194, Old Kiira Road, Ntinda	Tel: +256-414-574553

## Contributors

- Alban Mwikirize, Uganda Network on Law, Ethics & HIV/AIDS (UGANET)
- Angella Asio, Uganda Network on Law, Ethics & HIV/AIDS (UGANET)
- Barbara Bisikwa, Uganda Network on Law, Ethics & HIV/AIDS (UGANET)
- Bernadette Manderu, Hospice Africa Uganda
- Cathy Nyanzi, Uganda Network on Law, Ethics & HIV/AIDS (UGANET)
- 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
- Fatia Kiyange, African Palliative Care Association, Uganda (APCA)
- Grace Munene, African Palliative Care Association, Uganda (APCA)
- Henrieta Kebirungi, Kawempe Home Care, Uganda
- Immaculate Owomugisha, Uganda Network on Law, Ethics & HIV/AIDS (UGANET)
- Ivan Onapito, Mulago Palliative Care Unit, Uganda
- 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
- Rose Kiwanuka, Palliative Care Association of Uganda (PCAU)
- Rose Nabatanzi, Kitovu Mobile AIDS Organisation, Uganda
- Shem Mutala, Rays of Hope Hospice Jinja, Uganda
- Sylvia Nakami, Palliative Care Association of Uganda (PCAU)
- Tamar Ezer, Open Society Foundations-New York

## Editors

- Shelley Enarson, African Palliative Care Association, Uganda (APCA)
- Derek Atkins, Kent, UK

## Translator

- Edward Kalibbala, Makerere University, Uganda





Plot 6 Lourdel Road, Nakasero  
P. O. Box 7272, Kampala, Uganda  
[www.health.go.ug](http://www.health.go.ug)