Legal Aspects of Palliative Care

Hospice Palliative Care Association of South Africa

Hospice Palliative Care Association of South Africa
no end to caring

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The HPCA thanks patients, staff and others connected with hospice who kindly provided permission to use their photographs on the cover of this book.

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Unfortunately, in end-of-life care, we do not have a vocal constituency:

The dead are no longer here to speak,

the dying often cannot speak,

and the bereaved are often too overcome by their loss to speak.

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

Foreword

Life-limiting illness can mean pain and difficulty in a time of bewilderment. It can also bring practical problems, some with legal overtones. These can increase stress for patients and families, and make coping harder.

This excellent manual, produced by careful and caring experts across the field of palliative care, brings together up-to-date approaches, and sets them in a helpful framework for dealing effectively with the legal issues that will almost certainly arise.

The idea for the manual came from a project the Open Society Institute of New York funded. The idea was to strengthen legal advice offered to hospice patients. When students and staff from the law faculties at the Universities of Cape Town and the Witwatersrand worked with hospice staff to explain legal resources available to hospice patients, the need for the manual became obvious.

The manual gives hospice staff information about legal assistance for their patients – and it directs them how to find it. On the flip side, it also provides information for legal practitioners to enhance their understanding of palliative care and to extend their services to this vulnerable group.

The manual unites experts in two fields. It brings together writers working in palliative care and in human rights advocacy in South Africa. They have produced a practical reference guide for use in palliative care services and legal practice. The manual contributes to developing legal and ethical expertise in palliative care to guide hospice personnel as well as lawyers. So it will be a resource for both healthcare workers and for human rights advocates and legal practitioners.

To start, the authors identified key legal issues by getting input from hospice personnel and legal practitioners who know something about the challenges facing patients or clients living with life-limiting illness. So the manual is practical – it is directed to the legal aspects of palliative care those working in the field have singled out.

To ensure inclusion of both the palliative care and legal perspective, most chapters were written collaboratively across the two fields.

The manual starts with a chapter explaining the ethos behind palliative care. Then it looks at palliative care from a rights perspective. An examination of the ethical issues in palliative care follows. Then come chapters covering topics such as the legal requirements for palliative care organisations to be recognised under South African law, the challenges in accessing care and medication, poverty and financial issues, debt, the rights of the child, palliative care for the older person, refugees and other vulnerable groups. A chapter is devoted to the role and status of community caregivers in South Africa. The penultimate chapter explains estate planning and the legal formalities when someone dies, while the closing chapter covers dying from the palliative care perspective.

In total, the manual encompasses a wealth of expertise and experience. It provides a unique document that expands the realms of both disciplines.

It is a pleasure to be associated with this manual, and to commend it not just to lawyers, rights advocates and palliative care workers, but to all whose lives will be touched by life-limiting illness – which means every one of us.

Edwin Cameron
Constitutional Court
May 2009

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How to use this manual – Overview

Welcome to Legal Aspects of Palliative Care in South Africa

Palliative care is essentially a response to patients and family members facing the diagnosis of life-threatening illness. Hospice patients face many problems, some of which require legal interventions. These legal issues can increase emotional stress in patients and families and impact on the way they cope with the illness

It is our sincere hope that you and your colleagues will find this manual useful as you integrate the principles and framework articulated in this handbook into the practice of high-quality palliative care and legal services.

Why have this manual – the legal aspects of Palliative Care?

Hospice personnel recognise the distress that legal issues may create for their patients and patients' families. In caring for vulnerable populations, we have also become aware of the impact of human rights violations on health. The palliative care approach uses an interdisciplinary team in the care of patients and family members, this is also important in accessing justice for patients and families in poor communities. Hospice staff are aware their patients are often victims of human rights abuses such as discrimination, sexual and domestic violence, disinheritance and economic disempowerment – which are drivers for instance, of the HIV/AIDS epidemic. Discrimination faced by People Living with HIV and AIDS might mean they face stigma relating to employment, housing, and education. In addition they may face challenges accessing palliative care, pain relief medication and accessing health care in general. Lawyers and paralegal personnel can play a crucial role working at the intersection of law and health, combining legal skills with an understanding of health issues and the challenges facing underserved and marginalised groups.[1] A book that collects together and articulates many of the struggles faced by the dying patient and their family, particularly for those living in poor communities, offers guidance to hospice and legal personnel and will help practitioners in both disciplines better meet the needs of their patients and clients.

Acknowledging that the legal aspects of Palliative Care is a new approach

The hospice approach aims to provide holistic or total care with personnel from different fields pooling their skills in the interdisciplinary team to ensure positive outcomes for patients. Hospice staff need to be able to identify certain problems as legal problems and thus require legal awareness raising or even legal assistance. This manual aims to assist staff to broaden understanding of legal issues and in turn to improve the identification and referral of problems for legal assistance. Legal practitioners can develop an understanding of the impact of life-limiting illness on the lives of their clients and of the context leading to legal problems and this manual aims to highlight such problems and offers guidance and where possible, practical solutions.

Who is this guide for?

Palliative Care practitioners whether clinical, psycho-social, managerial; staff or volunteers; and the legal community working with palliative care patients, families and hospice staff.

What can be found in this guide?

The first three chapters discuss theory – palliative care, human rights and ethics and the following chapters are practically oriented to assist with legal issues encountered in palliative care. What each chapter contains:

Chapter 1 – Introduction to Palliative Care
The first chapter covers the ethos and philosophy of palliative care, including definitions of palliative care for adults and for children, the traditional and modern view of palliative care in the continuum of care for both the developed and developing world and finally barriers to palliative care.

Chapter 2 – Introduction to Human Rights and Palliative Care
The second chapter sets up the claim that palliative care is a human right and goes on to look closely at the history of human rights development and international and local human rights covenants in order to advance and develop the provision of palliative care.

Chapter 3 – Ethical issues
This chapter explains that clinical decision-making in palliative care is guided by the bio-ethical principles of beneficence and non-maleficience, autonomy and

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[1] Tamar Ezer, personal communication December 2008

justice and that these principles assist the palliative care practitioner to assess issues that are often very emotive and to use such framework to guide the patient, family members and care team to a practical decision which is open to review as the patient's condition or wishes change.

Chapter 4 – NPO Sector

This chapter guides the reader through the legal requirements that all palliative care organisations need to meet in order to be recognised and registered as Non-Profit Organisations in terms of South African law.

Chapter 5 – Access to Care

This chapter argues that South Africa's Constitution gives everyone the right of access to health care services and asks whether this means that all South Africans have the right to the provision of good health care at the end of life? It articulates what this right means for palliative care patients and clarifies the role of government to facilitate individuals realising this right, the responsibility of healthcare workers to provide adequate care and the healthcare sector to ensure adequate training and cover the challenges and barriers to accessing palliative care and accessing pain relief medication.

Chapter 6 – Poverty, financial issues and social development

This chapter identifies the impact of poverty on the daily lives of palliative care patients and their families and looks at the human rights and human dignity of those who are disadvantaged in terms of the South African Constitution. The problems inherent in applying for a Birth Certificate when no proof of birth is available are addressed, as well as current resources in terms of social grants, and documentation needed to apply for them and strategies for social development are discussed.

Chapter 7 – Debt in the context of the Palliative Care patient

Hospices provide quality palliative care free of charge, assist patients in accessing social grants and may offer programmes that promote economic empowerment. However, many people helped by hospice have very low income and feel they have no choice but to borrow money or buy on credit, and for them debt is a daily reality. This chapter explores debt transactions (credit agreements) which come at a great price, too often forgotten by the unwary consumer.

Chapter 8 – Legal rights of Children and Young People in Palliative Care

A life-limiting illness such as cancer, AIDS or muscular dystrophy increases the vulnerability of children and changes the capacities and dependency of that child. Palliative care services, that reach children in their homes, through day care programmes and in residential care facilities, have the potential to improve the quality of life of these children and those around them with skilled and compassionate interventions. This chapter describes legal rights of children and young persons including their right to palliative care.

Chapter 9 – Palliative Care for Older Persons

The effect of the AIDS pandemic is such that the burden of care of orphans falls on older people and older people, because they are reaching the end of their lives and are perceived to be of less value to society, are one of the most neglected groups in South Africa in terms of rights and care. There is not sufficient acknowledgement of this phenomenon, not sufficient attention to developing the capacity of older persons and supporting their efforts. This chapter discusses current pressures on older persons in South Africa and argues that there has not yet been universal recognition that the future of South Africa is in the hands of older people and consequently much more emphasis needs to be put on the needs of the older person.

Chapter 10 – Refugees and other vulnerable groups

This chapter specifically addresses some of the barriers facing refugees, asylum seekers and migrants, sex workers, drug users, prisoners and gay men in accessing various forms of health care. Some of these groups have previously been stereotyped as being 'high risk groups' for HIV transmission and infection. Another group of people who are being stigmatised and marginalised are those with multi drug-resistant or extensively drug-resistant TB. It is such prejudice, along with other issues, that we need to tackle in order to ensure equitable access to health care in compliance with existing South African law.

Chapter 11 – Community Caregivers

This chapter explores the role and status of community caregivers within palliative care and more broadly within community-based organisations and the wider health sector. Within a palliative care context, community caregivers form part of an interdisciplinary team whose focus is on providing holistic home-based care in line with the World Health Organisation (WHO) definition of palliative care. The Integrated Community Home Care Model, promoted by the Hospice Palliative Care Association, regards community carers as a key resource within the community.

Chapter 12 – Dying and the Law

This chapter looks at what preparations should be in place when faced with death and argues that everyone needs to think of how to prepare for such an eventuality at a time when we are well and our minds are still clear. This chapter covers Dying testate (with a will) and dying without a will (intestate succession), customary law, taking care of the children, the legal process after someone dies, what should happen when someone dies at home, preparations for funerals.

Chapter 13 – Death and Dying

This chapter will discuss the type of legal issues which commonly occur in the palliative care situation, communication with the terminally ill and bereaved family, and the implications of cultural and spiritual diversity with regard to illness and funerals. The importance of thorough debriefing of both palliative care and legal people is addressed.

Finding your way around the chapters

Every chapter will include the following:

- A terminology box on the opening pages explaining any difficult/technical terms used in the chapter.
- Most chapters include boxed case studies which explain by the use of individual stories, a problem the author wishes to illustrate. Case studies help the reader to compare the given scenario with a particular problem they may be faced with.
- Key points in summary at the end of the chapter.
- Throughout the chapters there will be notes on resources (where to go for additional support/information) and where space is limited, the reader is invited to refer to the end of the book where further information on resources is collected into appendices, listed by chapter reference.
- Each chapter has a reference list or bibliography as end notes for the chapter.

Online availibility

Electronic versions of this manual are available as individual chapters in PDF format on the HPCA website and our funders' websites:

- www.hospicepalliativecaresa.co.za/legal resources
- www.soros.org/initiatives/health/focus/law
- www.soros.org/initiatives/health/focus/ipci/about
- www.osf.org.za/home

Should you have any comments, suggestions or feedback about this book, kindly contact nicola@hpca.co.za. It may not be possible to respond to each email individually, but your feedback helps us gauge interest levels and may inform any future editions of the manual.

Nicky GunnClark
HPCA
June 2009

Introduction to Palliative Care

Liz Gwyther and Jonathan Cohen

1

Introduction

The essence of palliative care is the relief of suffering.
—Derek Doyle

Advocates for both palliative care and human rights are increasingly recognising the link between these two powerful disciplines rooted in respect for human dignity.

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

Palliative care:

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

(WHO August 2002)

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

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

WHO definition of Palliative Care for children

Palliative care for children represents a special, albeit closely related field to adult palliative care. The WHO definition of palliative care, appropriate for children and their families, is as follows (the principles apply to other paediatric chronic disorders):

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

Terms you will read in this chapter:

Advocate: to speak on behalf of another person or group

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

Dichotomy: separation between two different approaches

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

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

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

Palliative care can best be understood in its fundamental sense as a response to suffering – the suffering of patient and family members when faced with the diagnosis of life-threatening illness. Inasmuch as both are concerned with the alleviation of human suffering, palliative care has much in common with the modern human rights movement. Derek Doyle expresses suffering as the distress associated with events that threaten the intactness or wholeness of the person and describes the appropriate response to suffering as multidisciplinary palliative care, as described in the table below.

Cause of patient suffering	Palliative Care response
Pain	Treatment of pain
+ other physical symptoms	& other physical symptoms
+ psychological problems	& psychological problems
+ social difficulties	& social difficulties
+ cultural issues	& cultural issues
+ spiritual concerns	& spiritual concerns
= Total suffering	= Multidisciplinary palliative care

Continuum of care

1. Traditional view of Palliative Care

The traditional view of palliative care developed in the 1960s, with disease-oriented treatment such as chemotherapy or radiotherapy for oncology patients (who were then told 'there is nothing more we can do' before being referred to a palliative care service), has been challenged. Disease-oriented care and palliative care are not 'an either-or' option but a 'both-and' option.
The separation of the two led to patients experiencing a sense of abandonment by their doctors and a sense of failure on the part of the doctors. The 'false dichotomy' between disease-modifying treatments for HIV/AIDS or cancer and palliative care must be overcome. In the HIV setting, even patients near death from AIDS may recover and lead functional lives with ARV therapy. Further, uncomfortable symptoms in AIDS patients are sometimes best treated with ARV therapy or aggressive treatment of opportunistic infections, while pain and symptom control may improve adherence to ARV therapy and quality of life **(see Diagram 1 overleaf)**.

2. Palliative Care in the developed world

In the developed world, supportive and palliative care is (ideally) offered to patients alongside disease-oriented and life-prolonging care. Care is holistic and patient and family-centred. This results in better patient care, better bereavement outcomes and a more satisfactory professional experience. All clinicians are trained in palliative care and can provide this care to patients at the same time as providing disease-oriented care. So the oncologist will prescribe pain medication as well as chemotherapy. The HIV clinician will manage the pain of oesophageal candidiasis as well as prescribing fluconazole as antifungal treatment **(see Diagram 2 overleaf)**.

3. Palliative Care in the developing world

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

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

The diagram also illustrates that disease-oriented care (chemotherapy, radiotherapy, antiretrovirals) is often not available to many people at the time of diagnosis because of limited resources and results in discrimination against the poorer members of society. This discrimination in provision of health resources requires urgent attention and efforts to scale-up palliative care must be linked to or accompanied by efforts to simultaneously pilot and scale-up comprehensive HIV/AIDS care, including ARV therapy or cancer control programmes **(see Diagram 3 below)**.

Diagram 1

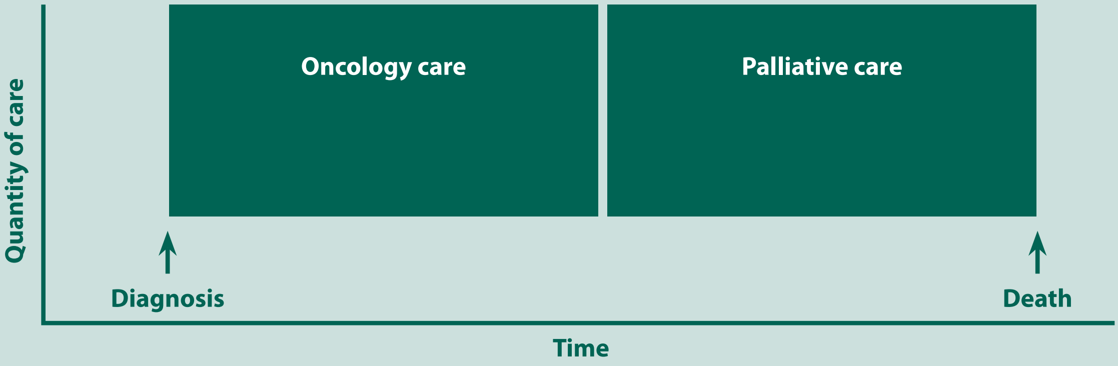


Diagram 2

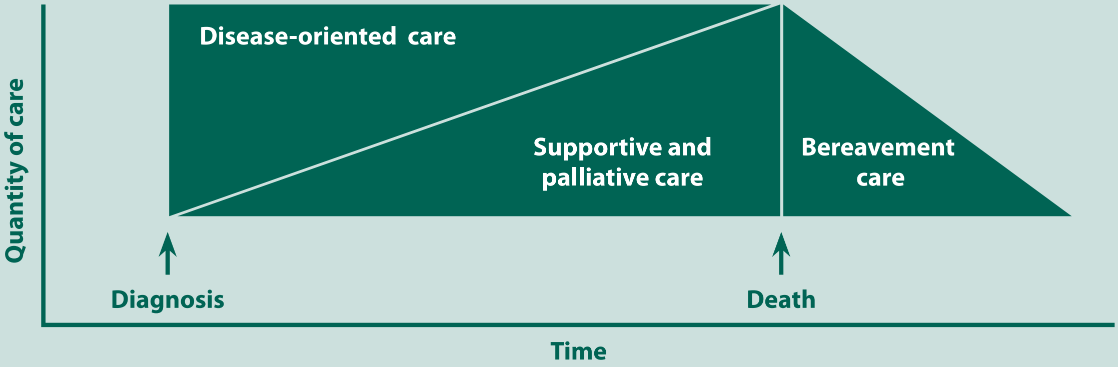
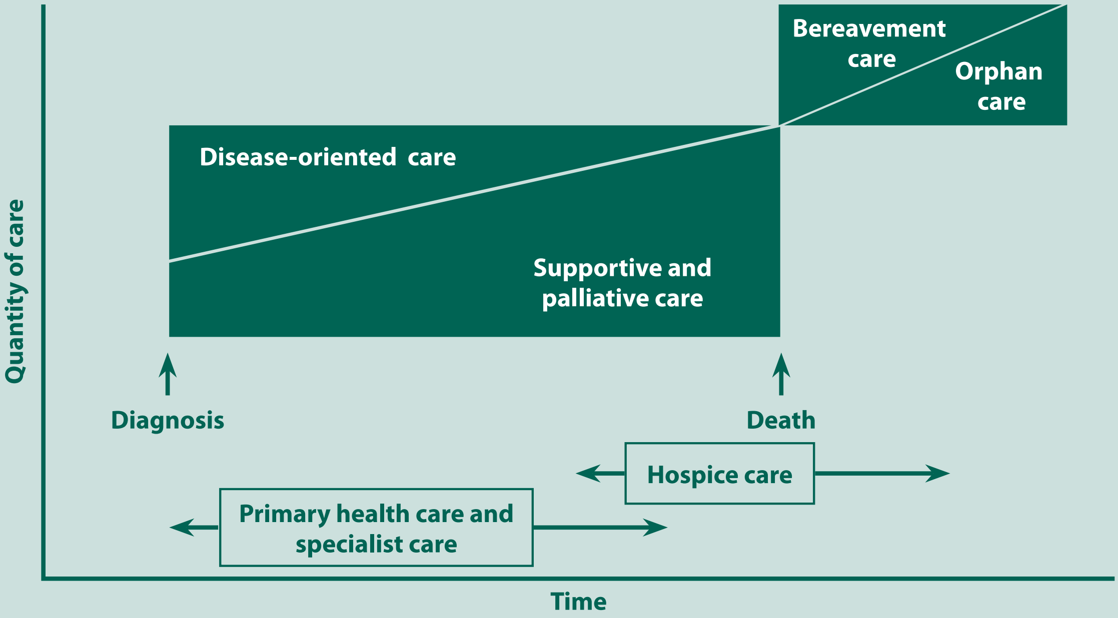


Diagram 3



Barriers to Palliative Care

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

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

Social factors that are barriers to palliative care include discrimination against minorities and disempowered groups such as refugees, prisoners and homeless people. There may also be language barriers in accessing palliative care. Hospices may not be established in rural communities. Access to palliative care may equally be denied to wealthy patients whose doctors choose to continue active treatment even when futile.

There are other access factors that are barriers to the provision of palliative care, such as transport costs to health care facilities for seriously ill patients, the fact that there are no government subsidies for palliative care and no physician reimbursement for palliative care. There may be inefficient procurement processes in remote clinics/hospitals and some palliative care drugs not held at Community Health Centres in spite of their being on the Essential Drug Lists.

These barriers need to be addressed if all patients requiring palliative care are to access that care. This requires education of health care workers and policy makers; raising awareness of the benefits of palliative care within communities; and addressing patient and family concerns. The outcome of accessible palliative care is better quality of life for patients, compassionate support for patients and families and the development of caring communities.

Place of care

In South Africa, palliative care has traditionally been provided by hospices. This has lead many people to view palliative care as *end of life* care. Hospice care and terminal care are important aspects of palliative care but palliative care starts from the moment of diagnosis of a life-threatening illness. Palliative care can be delivered in the most appropriate setting for the individual patient and his/her family as is specifically described in the definition of palliative care for children. The majority of patients are cared for in their own homes, but palliative care can also be carried out in hospitals, clinics, the frail care setting, hospice in-patient units and prisons (if the prisoner is not released home for terminal care). Patients do not need to travel to a facility to access palliative care. Palliative care staff take the care to the patient. Palliative care can be delivered as in-patient care, out-patient care and home care. Continuity of care depends on good communication between health care workers in the different settings and on co-ordination of care, usually by the patient's home care nurse.

The WHO public health model for the implementation of Palliative Care

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

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

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

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Introduction to Human Rights and Palliative Care

Liz Gwyther, Jonathan Cohen and Tamar Ezer

Human Rights and Palliative Care

What are human rights?

Failure to provide adequate pain relief may constitute negligence

Other International Human Rights Conventions

The South African Constitution

Conclusion

2

Human Rights and Palliative Care

> *All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.*
>
> —Article 1, UDHR

Both palliative care and human rights are based on principles of the dignity of the individual and the principles of universality and non-discrimination. To palliative care personnel, this creates a self-evident premise that palliative care is a human right.[1]

However, we need to look closely at the history of human rights development and the human rights covenants that have been established in order to pursue this claim.

What are Human Rights?

The term 'Human Rights' refers to the rights and freedoms to which all humans are inherently entitled.

The Universal Declaration of Human Rights[2] (UDHR) was adopted by the United Nations General Assembly in 1948 and the UDHR together with two binding treaties, the International Covenant on Civil and Political Rights[3] (ICCPR) and the International Covenant on Economic, Social and Cultural Rights[4] (ICESCR) make up the International Bill of Rights.

While the UDHR is a resolution of the UN General Assembly, the ICCPR and ICESCR are legally binding treaties that have been ratified by nearly every nation on earth. Their provisions are reflected in many national constitutions and are enforceable at the national level through litigation and at the regional international level through a variety of treaty monitoring mechanisms, complaints procedures, and courts.[5]

In addition to the ICCPR and ICESCR, specialised treaties (such as the Convention on the Rights of the Child and the Convention on the Elimination of All Forms of Discrimination Against Women) and regional treaties (such as the African Charter on Human and People's Rights and the European Convention for the Protection of Human Rights and Fundamental Freedoms) contain provisions and procedures that further strengthen the right to palliative care.

The value of understanding human rights and human rights instruments is that they can be used for the following purposes, among others:

1. to document violations of palliative care rights such as access to care/access to medication
2. to advocate for the provision of palliative care
3. to use legal recourse to ensure realisation of these rights. The chapter on access to care describes legal cases from South Africa using rights-based law.
4. to complain to national or international human rights bodies about lack of compliance to human rights agreements.

Terms you will read in this chapter:

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

Covenant: an agreement that is binding on all parties

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

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

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

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

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

inter alia: Latin phrase meaning 'among other things'

Lack of compliance: not ready to agree to/put into action

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

Plaintiff: a person who accuses someone else of wrong doing in a civil court document

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

Preamble: that which comes before/introduces/leads up to a report, speech or formal Ratified: confirmed/agreement to a treaty negotiated by someone else

Universality: affecting/relating to everyone in the world

The right to the highest attainable standard of health

Article 25.1 of the Universal Declaration of Human Rights states:

> *Everyone has the right to a standard of living adequate for the health of himself and his family, including food, clothing, housing and medical care and necessary social services.*[6]

The ICESCR Article 12.1 asserts that:

> *The State Parties to the present Covenant recognise the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.*[7]

The ICESCR recognises that, in resource-constrained settings, these rights may not be immediately attainable but State Parties that are signatories of the ICESCR commit to progressive realisation of the right to health over a period of time and to reporting on the steps taken to reach this goal. The Committee on Economic Social and Cultural Rights (CESCR), which is the UN body responsible for overseeing government compliance with the ICESCR, also recognises that the right to health is dependent upon a number of other social, economic and cultural rights:

> *Such as food and nutrition, housing, access to safe and potable water and adequate sanitation, safe and healthy working conditions, and a healthy environment.*

While this raises the challenge of how to prioritise a population's socio-economic needs in working towards the realisation of the rights articulated in the ICESCR, it affirms that rights are interdependent and should not be pitted against one another. The Committee on Economic, Social and Cultural Rights indicated that access to 'essential drugs, as defined by the WHO Action Programme on Drugs' is part of the minimum core content of the right to health. When we review the WHO Essential Drug List it is evident that fourteen palliative care medications are currently on this list.

General Comment No. 14 issued by the CESCR asserts that:

> *In particular, States are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons, including prisoners or detainees, minorities, asylum seekers and illegal immigrants, to preventive, curative and* ***palliative health services;***[8]

General Comment No. 14 further describes, (in the section on older persons):

> *attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity.*

Thus palliative care is already articulated as part of the rights guaranteed by the International Bill of Rights. Some countries have taken this further and included references to palliative care as a human right in official documents. In 2000, a Standing Committee of the Canadian Senate proclaimed that end of life care was a right of every citizen.[9] In 2003, the European Committee of Ministers adopted a Recommendation which stated, in part, 'palliative care is… an inalienable element of a citizen's right to health care.'[10]

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

> *States should… take measures necessary to ensure for all persons, on a sustained and equal basis, the availability and accessibility of quality goods, services, and information for HIV prevention, treatment, and care and support… including preventive, curative and palliative care of HIV and related opportunistic infections and conditions.*[11]

The South African Department of Health's Patients' Right Charter[12] describes access to healthcare as follows:

> *Everyone has the right of access to health care services that include:*
> *iii. provision for special needs in the case of… patients in pain, persons living with HIV or AIDS patients;*
> *v. palliative care that is affordable and effective in cases of incurable or terminal illness.*

In discussing States Parties' Obligations, General Comment No. 14 discusses the fact that as with all human rights, the right to health imposes three levels of obligations on State parties: The obligation to respect, protect and fulfil the right to health.

Respect the right to health

- *Refraining from denying or limiting equal access for all persons;*
- *abstaining from enforcing discriminatory practices as a State policy;*
- *abstaining from imposing discriminatory practices relating to women's health status and needs.*

Protect the right to health

- *To adopt legislation… ensuring equal access to health care and health related services provided by third parties;*
- *to ensure that medical practitioners and other health care professionals meet appropriate standards of education, skill and ethical codes of conduct;*
- *to take measures to protect all vulnerable or marginalised groups of society in particular women, children, adolescents and older persons, in the light of gender-based expressions of violence.*

Fulfil the right to health

> *To give sufficient recognition to the right to health in the national political and legal systems.*

In considering these obligations with regard to palliative care, there is an opportunity for palliative care professionals to engage with government to ensure a national policy for palliative care, education in palliative care for all health care professionals and provision of palliative care in the public health system alongside the NGO sector programmes. In this way, we can ensure that all those with life-threatening or life-limiting illness who require palliative care will have access to this service.

The right to be free from cruel, inhuman and degrading treatment

In addition to the right to health, the Universal Declaration of Human Rights in Article 5 states in part 'no one shall be subject… to cruel, inhuman or degrading treatment'. This statement is typically applied to the treatment of prisoners but has been used to encompass patients' rights to pain relief and in legal cases, claiming negligence in the failure to relieve patients' pain adequately.

Failure to provide adequate pain relief may constitute negligence

An unreasonable failure to provide adequate pain relief may constitute negligence. Breaches in reasonable pain care may be: an unreasonable failure to take an adequate pain history; an unreasonable failure to adequately treat the pain or in the context of uncontrolled pain, an unreasonable failure to secure expert consultation. Negligence cases against health professionals and hospitals, based on these principles, have resulted in multimillion dollar judgments[13] as the following cases illustrate.

The South Australia Supreme Court case of *Giurelli vs Girgis 1980*[14] decided that there had been an unreasonable failure to take an adequate pain history **(see the case study on the facing page)**.

The judge in the North Carolina case of *Estate of Henry James vs Hillhaven Corporation 1991*[15] decided that there had been an unreasonable failure to adequately treat the pain. This was the first negligence lawsuit where a health care provider was held liable for failure to treat pain appropriately. The jury awarded $15 million in damages to the family of Henry James, whose dying days were made intolerable by the decision of a nurse and her employer, a nursing home, to withhold or reduce pain medication ordered by the patient's physician. The lawsuit focused on health care providers' responsibilities to ensure the proper administration of pain medications in appropriate doses[16] **(see the case study on the facing page)**.

Other International Human Rights Conventions

As noted above, in addition to the Universal Bill of Rights, other important international and regional conventions exist and are referred to in this manual. These include:
- Convention Relating to the Status of Refugees, 1954[17]
- Convention on the Elimination of All Forms of Racial Discrimination, 1969[18]
- Convention on the Elimination of All Forms of Discrimination Against Women, 1981[19]
- Convention on the Rights of the Child, 1990[20]
- The African Charter on Human and Peoples' Rights, 1986[21]
- African Charter on the Rights and Welfare of the Child, 2000.[22]

The South African Constitution[23]

The right to non-discrimination and equality is a foundational principle under both the South African Constitution and international law. Under the South African Constitution, 'everyone is equal before the law and has the right to equal protection and benefit of the law.' This echoes the ICCPR, 'all persons are equal before the law and are entitled without any discrimination to the equal protection of the law.' This fundamental principle is further highlighted in the preambles to international human rights conventions.[7] The CESCR has explained how this right to equality applies to the delivery of health services.

Health facilities, goods, and services have to be accessible to everyone without discrimination – ‘especially to the most vulnerable and marginalised sections of the population.’[13] The Committee has urged particular attention to the needs of ‘ethnic minorities and indigenous populations, women, children, adolescents, older persons, persons with disabilities and persons with HIV/AIDS.’ Moreover, health facilities, goods, and services ‘must be affordable for all,’ and ‘poorer households should not be disproportionately burdened with health expenses.’

CASE STUDY: THE FACTS IN *GIURELLI VS GIRGIS*

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

White J held that the surgeon was liable, because he had failed to take into account the possibility that the fracture was not uniting satisfactorily and had dismissed the plaintiff's complaints without making any proper investigation. The plaintiff was not believed or given sufficient time or opportunity to describe his symptoms, or the defendant did not ask sufficient questions. He had allowed only five (5) to ten (10) minutes for consultations, but "pressure of time did not justify the risks of not listening and inquiring."

CASE STUDY: ESTATE OF *HENRY JAMES VS HILLHAVEN CORPORATION*

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

Conclusion

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

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

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

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Ethical Issues

Nico Nortjé, Liz Gwyther, Anita Kleinschmidt and Tamar Ezer

Introduction

Patient autonomy

Conclusion

3

Introduction

> *A doctor has neither the duty nor the right to prescribe a lingering death.*
>
> —Prof. Robert Twycross

Bio-ethics, also known as medical ethics, is the study and employment of moral principles, duties and rights in the broad fields of medical conduct, applications and research. The term 'ethics' is used in three different but related ways, signifying (1) a general pattern or 'way of life,' (2) a set of rules of conduct or 'moral code,' and (3) inquiry *about* ways of life and rules of conduct.

Individuals working in the field of medicine are faced daily with moral dilemmas and difficult decision-making, such as when life begins and when life ends; the withholding or withdrawal of treatment; the allocation of scarce medical resources; and the accessibility of resources. Practical decision-making is often influenced by family and community (including other health care professionals') beliefs about what is right and wrong.

In the case study below, some of the many ethical questions raised are: Was their right to refuse treatment as their child's proxy more valid than the child's right to live? Should we consider quality of life when making decisions to treat or not? Who should the decision-makers be?

The case outraged many, and officials in the administration of President Ronald Reagan rushed to pass legislation preventing future similar scenarios. The American Paediatric Association and other organisations went to court and overturned the legislation. The US Department of Health and Human Services then drafted guidelines which said that it was not necessary to give futile treatment to terminally ill infants.

Many of the contemporary debates in bio-ethics are the direct result of advancement in scientific and medical knowledge and technology. With these new advances the human race is not only morally challenged as to the basic nature of life and death but also about the power the social structure can assert over those in need who do not have

CASE STUDY: AN ETHICAL CONUNDRUM

An ethical conundrum for example is the decision of when, and if, it is ethically permissible to withhold treatment from a child. This issue came into public focus with the case of 'Baby Doe' in the USA in 1982. The newborn infant was diagnosed with Down's Syndrome, a chromosomal disorder that causes moderate to severe developmental disabilities. The baby also had oesophageal atresia, the separation of the oesophagus from the stomach. The obstetrician who delivered the baby told the parents that their child would have only a 50 percent chance to survive surgery for his atresia of the oesophagus, and that even if surgery were successful, their child would remain severely retarded and would face a lifetime of medical treatment, disability, and dependency. The parents consequently refused to consent to the surgery and the baby died after six days.

Terms you will read in this chapter:

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

Conundrum: something that is puzzling or confusing

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

Euthanasia: the active killing of someone in a painless manner

Fraudulent (Will): not honest, true or fair and intended to deceive people

Ineluctable obligation: inescapable obligation – it must be done

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

Not fundamentally immoral: not essentially, completely wrong, right down at the very root of the matter

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

Prevail: to prove to be stronger and more effective

Proxy: somebody authorised to act for another person

Vegetative state: a wakeful but unconscious/unaware state usually due to brain damage the means to pay for it. There is often no clear-cut right or wrong answer, particularly when we also consider diversity in cultural traditions in South Africa.

Clinical decision-making in hospices and palliative care has relied on bio-ethical principles as a guide. These principles – beneficence, non-maleficence, autonomy and justice - assist the palliative care practitioner to assess issues that are often very emotive and to use a framework to guide the patient, family members and care team to a practical decision which is open to review as the patient's condition or wishes change.

These principles were initially described by two US authors Beauchamp and Childress[1] to assist clinical decision-making in medicine. We recognise the US emphasis on the individual (autonomy) compared to an African emphasis on community so that principles of beneficence and distributive justice may have more weight in the South African setting.

Patient autonomy

Autonomy is the ability to make decisions for oneself on the basis of deliberation.[2] No-one has the right to infringe upon another person's autonomy or coerce them into making decisions. The basis for this is the established right of privacy and the right to refuse treatment. Personal autonomy is a minimum self-rule that is free from both controlling interference by others and from limitations, such as inadequate understanding that prevent meaningful choices.

Informed consent

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

The right to information is enshrined in both the South African Constitution and international and regional human rights conventions. Under the South Africa Constitution, 'Everyone has the right of access to- (a) any information held by the state; and (b) any information that is held by another person and that is required for the exercise of protection of any rights.'[3]

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

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

In many settings, medical care has been implemented through a paternalistic approach where the doctor decided the treatment without providing adequate information and without discussion with the patient. Legally and ethically, the patient may even make decisions contrary to the advice of a medical practitioner, with possible detrimental effects,

CASE STUDY: INFORMED CONSENT

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

as long as that patient has been informed properly beforehand. It is clear that the information given to the patient should be accurate and understandable to that patient. When patients lack the capacity to make a decision, a designated proxy decision-maker should be consulted. The proxy assists in the decision-making process based upon the patient's previously expressed wishes and known values (also referred to as the Living Will or Advance Directive). A proxy might be guided by these documents but is under no legal obligation to follow it to the letter if he or she thinks the requested action is not to the benefit of the person). If there is no recognised person to act as proxy, decisions should be made in the best interests of the patient, considering the patient's personal values to the extent that they are known and in accordance with societal norms and values. Medical personnel should always support patient self-determination by discussions with proxies, providing guidance and referral to other resources such as the Living Will or Advance Directive and identifying and addressing problems in the decision-making process. Within our African context it is important to remember that support of autonomy also includes recognition that some cultures place less weight on individualism and choose to defer to family or community values in decision-making.

The fact that social norms assign primary responsibility for care to women and decision-making to men, means that gender affects decision-making as women may not have autonomy in decision making. In particular in the circumstances of communal decision-making, women's opinions may be discounted, over-ruled or not even asked for.

Respect for human dignity, described in the HPCA of South Africa's Code of Ethics[4], requires the recognition of patient rights. Patients have the moral and legal right to determine what will be done with their own person; to be given accurate, complete, and understandable information in a manner that facilitates an informed decision; to be assisted with weighing the benefits, burdens, and available options in their treatment, including the choice of no treatment; to accept, refuse, or terminate treatment without undue influence, duress, coercion, deceit, or penalty; and to be given necessary support throughout the decision-making and treatment process. This includes the opportunity to discuss and make decisions with family, significant others, knowledgeable personnel and other health professionals.

Confidentiality

All medical personnel have a duty to maintain confidentiality of all patient information. Trust between patient and medical personnel can be destroyed by unnecessary access to patient information or by the inappropriate disclosure of patient information. The rights, well-being, and safety of patients should be the primary factors in arriving at professional judgments concerning the sharing of confidential information received from or about patients, whether oral, written or electronic. Relevant data should be shared only with those members of the medical team who have a need to know. Information pertinent to patients' treatment and welfare is disclosed only to those directly involved with their care. However, duties of confidentiality are not absolute and may need to be modified to protect the patient and other innocent parties. The right to privacy is enshrined in the South African Constitution: 'Everyone has the right to privacy, which includes the right not to have-*(d)* the privacy of their communications infringed.'[5]

Beneficence and non-maleficence: Balance the benefits and risks

The principles of beneficence providing benefit to the patient, and non-maleficence ('first do no harm') are often considered together. According to the guidelines presented by the MRC[6], beneficence refers to the practise where individuals are treated in an ethical manner not only by respecting their decisions and protecting them from harm, but also by making efforts to secure their wellbeing.

The moral obligation of beneficence is paramount to ethics where actions are weighed for their possible good against the costs and possible harms. The MRC[5] points out that a difficult ethical problem remains when applying the principle of beneficence. Some treatment presents more than minimal risk without immediate prospect of direct benefit to the individual. Therefore all risks and benefits should be carefully assessed by analysing all relevant information, a practical balance of the principles of beneficence and non-maleficence.

The SA Medical Research Council (MRC) has issued a position statement regarding detention of XDR-TB patients. It includes the statement that:

> *Prevention of XDR-TB through improved TB control must be the first priority. Nevertheless, the Department of Health is also legally required to address XDR-TB appropriately in the interest of protecting public health, while operating within the context of the Bill of Rights enshrined in the Constitution, thereby promoting, respecting and protecting individual rights.*
>
> *Enforced hospitalisation/quarantine of patients with XDR-TB is only justifiable as a last resort; after all reasonable voluntary measures to isolate individual patients have failed.*

This situation highlights the dilemma of protecting the individual patient's rights (beneficence for patient) and protecting people who may become infected by the untreated XDR-TB patient[7] (non-maleficence with regard to the community).

Futile Treatment

If a patient's condition continues to deteriorate and treatment is ineffective, it may be that life-prolonging treatment is no longer appropriate[4]. This requires careful assessment and evaluation and a review of the goals of care in discussion with the care team including patient and family members. Futile treatments are those that are assessed as bound to fail, those that may not restore a patient to independence or at least to an acceptable quality of life, or treatments that may simply be prolonging the dying phase. It is unethical to subject patients to futile treatments. The challenge comes when clinicians are uncertain or disagree whether the treatment is effective or futile.

Living Wills

Some people draw up a document stating who may make decisions about their treatment on their behalf if they become unconscious, and when treatment should be stopped. Some insert this information into their will. An example of the wording in a Living Will:

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

Living Wills have been the subject of ongoing debate in South Africa for many years. Health workers were unsure of the legality of these documents. The National Health Act at s.7 (1)(e) clears up the debate by stating that a health service may not be provided to a patient without informed consent unless a delay in treatment might result in the patient's death and the patient has not 'expressly, impliedly, or by conduct refused that service.' The Living Will, which sets out a refusal of certain procedures in writing, is a clear example of a patient's express refusal of treatment which may save his life but not restore the quality of life which he considers necessary for a meaningful existence. Some people object to Living Wills because of a concern that the patient may have changed his mind, but not changed the Will. There are also concerns raised that family members could draw up a fraudulent Living Will. The response to these objections is that if the doctor does not believe that the patient is terminally ill or in a persistent vegetative state, for example, the Living Will shall not be relevant. The decision whether to use a Living Will always follow a medical diagnosis, which minimizes the two concerns above.

Withholding and withdrawing treatment

Consideration of withholding or withdrawing treatment as a sound clinical decision developed as a consequence of the availability of advanced medical technology and the resultant ability to prolong life that in some cases leads to prolonging the dying process. This prolongation of life may occur without allowing for patient perspectives such as quality of life, being close to family members at a critical stage of life, and the implications of provision of end-of-life care in the alien environment of the hospital or intensive care unit[8].

The key is to be able to identify when active treatment will improve quality of life and prolong life, in contrast to when active care and medical technology will not positively influence the course of the illness but merely prolong the

CASE STUDY: *CLARKE VS HURST* 1992(4) SA 630 D

Dr Clarke suffered a heart attack, and while resuscitation eventually restored his heartbeat, he had severe brain damage. After he had been in a persistent vegetative state for four years, his wife applied to the court for permission to take treatment decisions on his behalf, in order to halt the artificial feeding which was keeping him alive. Dr Clarke had made a Living Will before he had the heart attack.

The court said that the doctors should 'give effect to his wishes as expressed when he was in good health', but should also look at his quality of life. The court found that Dr Clarke experienced no quality of life after the brain damage. Furthermore, the court also took into consideration that Dr Clarke expressly stated in his Living Will, before he became ill, that he would not want to be kept alive in a persistent vegetative state. Taken together, these two factors led to the judgment allowing his wife to refuse artificial feeding on his behalf.

dying process. Twycross makes the statement that a doctor has neither the right nor the duty to prescribe a lingering death.[9] Benatar et al. of the University of Cape Town Bioethics Centre wrote a comprehensive and considered statement on withholding and withdrawal of life-sustaining therapy, providing clear guidelines and recommendations and making the unequivocal statement that withholding or withdrawing treatment 'is regarded as distinct from participating in assisted suicide or active euthanasia neither of which is supported by this statement' [10].

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

Double Effect

The doctrine of double effect originated in the thirteenth century philosophy of St. Thomas Aquinas. St. Thomas Aquinas observes that 'nothing hinders one act from having two effects, only one of which is intended, while the other is beside the intention.'

Beauchamp and Childress[1] identify four conditions which usually apply to the principle of double effect:

1. The act itself must not be fundamentally immoral, but must be a good or neutral act;
2. Only the good effect (patient comfort) must be anticipated, not the bad effect, even though it is foreseen;
3. The negative effect must not be the means of the good effect; and
4. The good effect must prevail over the bad that is permitted. In modern palliative care practice, trained clinicians balance the good effect and minimise the unwanted effect of treatment to maximise comfort for the patient and minimise the risk to the patient.

Justice

Justice is described as fairness. Essentially justice is about treating people equally in relation to criteria acknowledged to be morally relevant – such as treating people equally in relation to their needs, rights, ability to benefit, or autonomous desire.[11]

Justice may be further described as distributive justice (fair distribution of resources), right-based justice (equal access to health care), and legal justice according to the laws of the land.

Discrimination in access to health care and in health insurance, combined with dramatic increases in the costs of health care and the allocation of scares resources, have fuelled debates about what social justice requires.[1] Problems of distributive justice arise in resource-poor settings and this highlights the concern about an unfair distribution of burdens, which includes inequitable access to therapies (due to geographical, financial or even political reasons) and the prioritizing of allocation scarce resources **(see case study below).**

In South Africa, there is a dual health care system where private health care is provided to those who have the ability to pay either directly or indirectly through insurance. However, should one not have the means to pay one is

CASE STUDY: *TAC VS MINISTER OF HEALTH* (NEVIRAPINE)

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

forced to go without and might even become part of a 'vulnerable' community. This merits the inclusion of the debate surrounding the existence or absence of a moral responsibility to protect the vulnerable of society – and to give them access to the benefits of therapies even though they cannot afford to pay for it. This is further covered in the access to care chapter.

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

Legal and Palliative Care aspects of the Euthanasia debate

Death is usually considered a tragedy but there are circumstances where patients, family members, the health worker and/or society regard death as something desirable for the patient.

Society may identify death as a desirable outcome when the patient has no hope of recovery and is experiencing terrible pain, or because the patient has a terminal illness and although the pain is under control, the patient feels that their continued existence is undignified or meaningless. Palliative care developed as a response to the experience of suffering in the widest sense of the term – physical, psychosocial and existential suffering. Whereas palliative care may not be able to alleviate all suffering completely, pain control can be achieved through accurate assessment and management of a patient's pain.

In South Africa, euthanasia, or the deliberate, direct act of killing a patient is illegal. The act of euthanasia is not the same as withholding or withdrawing treatment following due consideration of the patient's condition, the likely benefit and effectiveness of treatment in the face of the progressive illness. In these cases, the underlying disease or trauma takes its course and leads to the patient's death, not a direct act by the health worker.

Concerns are raised in society that continuing futile treatment may result in the dying process being extended over a longer period of time. Palliative care ensures that care is not withdrawn although a particular treatment may be considered futile and therefore withdrawn. The patient still receives care and medication to optimise comfort.

In the cases which have come before our courts, the courts have found that acts which have the express intention of hastening a patient's death, even when the patient was dying, fall within the criminal law definition of murder.

An additional concern from the lay public and some health workers is that strong pain medication may depress respiration and hasten death. Clinicians trained in pain management recognise that this is, in fact, not a valid perception as pain medication used appropriately does not depress respiration and will not hasten death. Without this insight, the courts nevertheless stipulate that this medication can be prescribed, as the direct intention is not to kill the patient, but to relieve pain.

Assisted suicide takes place when the health worker or family member helps the patient to end his/her life. This is not euthanasia because the patient carries out the act which leads to death himself. This is illegal in South Africa, but allowed in certain other countries such as the Netherlands and the state of Oregon in the USA. South African courts have regarded the act of suicide assistance as setting in motion the train of events leading to death and fulfilling the definition of murder in our law, i.e. the intentional killing of another human being.

Palliative care workers recognise a request for euthanasia as a cry for help that demonstrates a sense of hopelessness and results in part from a gap in care. It is important to discuss issues that may have led to this request with sensitivity, to acknowledge the person's concerns, to explain unrealistic fears, discuss realistic fears and what can be done to manage these issues. It is also important to explore the patient's perception regarding when s/he would choose to die. Frequently the patient doesn't want euthanasia immediately but at a time in the future. The issue is more one of having control or autonomy over dying than a wish to end life today. If the doctor or nurse can have an open, compassionate discussion with the patient regarding the care available and goals of care, the patient is may be reassured. The euthanasia discussion is complex with both the pro and anti camps convinced of their convictions and since there is no simplistic response, we anticipate that this debate will continue for many years to come.

Conclusion

The aim of palliative treatment is to obtain symptom control and a high quality of life even if life expectancy may be relatively short and the patient's health may be poor. In essence, palliative care is an affirmation of life, even in the face of impending death. There is thus a shift of goals from the cure and prolongation of life to the alleviation of psychological and spiritual suffering, the relief of pain and other symptoms, and the enhancement of the meaning and quality of the patient's remaining life.[12] Palliative care therefore utilises every relevant component of modern medicine to achieve maximal comfort, to alleviate fear and anxiety, to establish security and trust, and to encourage patient autonomy.[13]

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

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The NPO Sector

Elizabeth Scrimgeour and Charlene May

Introduction

The Non-Profit Organisations Act, 71 of 1997

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4

Introduction

The information in this chapter pertains to current legislation including the South African Companies Act 1973. We are aware that a new Companies Bill is intended to replace the Companies Act in 2010 and an update of the Non-Profit Organisation Act is expected in late 2009 as the Department of Social Development, in consultation with its partners in local government, NGOs and civil society has identified gaps in the current legislation. This chapter will be updated accordingly. ***Further information on how to find out the current status of South African legislation can be found in the Resources Section at the end of this book, along with information on how to access other publications by South African legal experts.***

How does NPO registration influence the NPO management? What are the 'pitfalls' around NPO registration and what measures can be taken to prevent these?

This chapter aims to highlight the Memorandum of Association and management pitfalls that palliative care organisations may be exposed to and guides you through the legal requirements that all palliative organisations need to meet in order to be recognised and registered as a Non-Profit Organisation in terms of South African law.

What are NPOs?

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

Why is it helpful for an NPO to have a legal structure?

- A legal structure provides a framework and rules and therefore gives clarity on:
- The responsibilities, obligations and rights of the individual members.
- It helps your organisation to be more accountable to the community you serve.
- It enhances the credibility of your organisation to potential donors.

Do we have to register our NPO?

It depends on the type of legal structure that you choose for your NPO. You may choose a structure for which registration is not required, but others may require mandatory registration.

Regardless of which structure you choose, all NPOs may choose to register with the Department of Social Development (DOSD) as a NPO. The DOSD will usually require you to be registered prior to considering an application for funding.

Types of legal structures

The three main types of Non-Profit Organisations are:
- Voluntary Associations
- Trusts
- Section 21 Companies

Terms you will read in this chapter:

Altruistic: unselfish concern for welfare of others

Ancillary objective: extra, less important aim

Annexed: attached/added to something larger

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

Corps: group of people who work together

Liability: legal responsibility for costs or debts

Mandatory requirements: official or compulsory requirements

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

Organogram: an organisation's chart of human resources

Philanthropic: devoted to helping other people

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

Quorum: minimum number of committee members to conduct business

The Non-Profit Organisations Act, 71 of 1997

The Non-Profit Organisations Act 71 of 1997 came into effect on 1 September 1998. The Act aims to create an enabling environment for NPOs as well as to set standards of good governance, accountability and transparency within the NPO sector. An update of this Act is expected in late 2009.

The Act further creates a voluntary registration mechanism and serves to define what a Non-Profit Organisation is.

> *A trust, company or other association of persons:*
> *A trust, company or other association of persons:*
> *(a) established for a public purpose; and*
> *(b) the income and property of which are not distributed to its members or office bearers except as reasonable compensation for services rendered; Section 1(x)*

The Act makes use of existing legal structures and adds certain basic requirements in order for these entities to be registered as Non-Profit Organisations with the NPO Directorate of the Department of Social Development.

Requirements for registration

In order for the NPO to be registered there are certain requirements that must be met with regard to its founding documents. Without these clauses the NPO will not be registered. The mandatory requirements are laid out in Section 12(2) (d) of the Act:

(2) Unless the laws in terms of which a Non-Profit Organisation is established or incorporated makes provision for the matters in this sub-section, the constitution of a non-profit organisation that intends to register must:

- *(a) state the organisation's name;*
- *(b) state the organisation's main and ancillary objectives;*
- *(c) state that the organisation's income and property are not distributable to its members or office bearers, except as reasonable compensation for services rendered;*
- *(d) make provision for the organisation to be a body corporate and to have an identity and existence distinct from its members or office-bearers;*
- *(e) make provision for the organisation's continued existence notwithstanding changes in the composition of its membership or office-bearers;*
- *(f) ensure that the members or office bearers have no rights in the property or other assets of the organisation solely by virtue of them being members or office-bearers;*
- *(g) specify the powers of the organisation;*
- *(h) specify the organisational structures and mechanism for its governance;*
- *(i) set out the rules for convening and conducting meetings, including quorums required for and the minutes to be kept of those meetings;*
- *(j) determine the manner in which decisions are to be made;*
- *(k) provide that the organisation's financial transactions must be conducted by means of a banking account;*
- *(l) determine a date for the end of the organisation's financial year;*
- *(m) set out procedure for changing the constitution;*
- *(n) set out procedure by which the organisation may be wound up or dissolved;*
- *(o) provide that, when the organisation is being wound up or dissolved, any asset remaining after all its liabilities have been met, must be transferred to another non-profit organisation having similar objectives.*

The implications of registration as a NPO

As soon as the NPO is registered its details are placed on a database of registered NPOs in the country. A certificate of registration will be issued within two months after the application has been received and will serve as proof of the NPO's registered status as well as proof that the NPO is a body corporate, which means that it will have an existence separate from that of its members. It will be able to enter into agreements in its own name, without the members incurring personal liability.

A NPO remains registered until the Directorate deregisters the NPO either for contravention of the regulations or on request of the NPO. In the event of non-compliance by a registered NPO the Directorate will give notice to the NPO in writing, requesting the NPO to comply. In the event that criminal activity is suspected the Directorate may choose to both deregister the NPO as well as report it to the South African Police Service.

Duties and obligations of a registered NPO

As soon as the NPO is registered and the certificate issued, the NPO needs to comply with certain requirements in terms of the NPO Act.

> *Section 16(3)*
> *Reflect its registered status and registration number on all its documents*

Section 17(1)(a) and (3)
Keep and preserve accounting records and supporting documentation for the prescribed period

Section 17(1)(b)
Within six months of the end of its financial year, draw up financial statements which include a statement of income and expenditure and a balance sheet

Section 17(2)
Arrange for an accounting officer to compile a written report within two months after drawing up its financial statements confirming that the financial statements are consistent with the accounting records; the accounting policies are appropriate and applied, and that the organisation has complied with the financial reporting requirements of the Act.

Section 18 (a)
Submit to the Directorate a narrative report in the prescribed form together with its financial statements and the accounting officer's report within nine months of the end of the financial year

Section 18 (1)(b-e)
Submit to the Directorate the contact detail of its office bearers, even if they were reappointed within one month of their appointment; the NPO's physical address for service of documents and notice of any change of address one month before it takes effect, any other prescribed/ information reasonable required by the Directorate for the purposes of ascertaining whether the NPO is complying with the material provisions of its constitution and the Act.

Legal structures used by NPOs

Which structure is appropriate?

When deciding to register a Non-profit Organisation it is assumed that you have made the decision not to establish an entity which will make a profit, and which profit will be distributed amongst its members. However, as discussed above, there is more to NPOs than merely registering a Non-Profit Organisation. You need to establish which structure is suitable to the needs of the NPO.

Each entity therefore needs to be evaluated based upon the size, the capacity and complexity of the NPO that you wish to establish. Other factors that may influence the decision on the suitable structure are funding requirements and the tax implications.

Example:
The formal establishment and continued regulatory requirements of the current Section 21 Company structure are more complex than the requirements for the establishment of a Trust, or a Voluntary Association. The most common structure for small, newly established NPOs is a Voluntary Association, while trusts and Section 21 Companies are appropriate for larger, well established NPOs with large budgets, complex programmes and a large staff contingent and is the structure recommended for member hospices by the Hospice Palliative Care Association of South Africa. The Hospice Palliative Care Association recommends a Section 21 Company as this structure has more guarantees for accountability.

Voluntary Associations

A Voluntary Association is created when three or more people decide to form an organisation in order to reach shared non-profit objectives. Voluntary Associations are governed by common law, which requires that the Association's objectives are lawful and not primarily for gain or profit for its members.

Voluntary Associations are suitable entities for small community based organisations, which do not require management of large amounts of money and intricate financial policies, or ownership of land or valuable assets or property in order to reach its objectives.

A Voluntary Association will have a Constitution as its founding document, and the Constitution will regulate the governance of the Association. The Constitution will appoint a group of people and bestow management or executive powers on them to make decisions on behalf of the Association and to manage its affairs.

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

RESOURCES:

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

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

Trusts

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

A Trust is governed by a Board of Trustees, whose powers are normally widespread to enable them to achieve the stated objectives of the Trust. Trustees are expected in terms of the legislation to exercise their duties with care, diligence and skill, which can be reasonably expected of a person who manages the affairs of others. Trustees should therefore be aware of conflict of interest, where their personal interest and that of the Trust is not the same. Trustees can receive reasonable remuneration for the work done, as long as this is not expressly prohibited by the Trust Deed.

In order to establish a Trust you will be required to have an attorney draft your Trust Deed and file the original copy thereof with the Master of the High Court. The Master will register the Trust and will issue Letters of Authority to the trustees formally appointing them to act on behalf of the Trust.

The Master may request that the Trustees provide security for the proper performance of their duties. This can be arranged through an insurance company. If you want to do away with the request for security a clause exempting the Trustees from furnishing security must be included in your Trust Deed document. In this case the Master will require the appointment of an auditor.

Section 21 Companies

The Companies Act 61 of 1973 allows for the Incorporation of an association incorporated not for gain in terms of Section 21. Section 21 Companies therefore resemble business orientated (for profit) companies in their legal structure, but they do not have a share capital and cannot distribute shares or pay dividends to their members. They are instead limited by guarantee, which means that if the company fails; its members undertake to pay stated amounts to their creditors.

A company has a two tiered governance structure consisting of members and directors. The members are able to express their wishes and exercise their powers in general meetings. They appoint and remove directors, amend the founding documents when necessary and decide on disposing of assets. The directors, on the other hand, have broad executive responsibilities. They are required to appoint auditors and convene the annual general meeting of the company.

A Section 21 Company, like all companies, must register with the Registrar of Companies in terms of the Act. Before the company can be registered, however, the name needs to be approved by the Registrar. A company, unlike a Voluntary Association, may not operate until such time as they have been registered with the Registrar.

The founding documents of the Section 21 Company are the Memorandum and Articles of Association. The memorandum sets out the purpose of the NPO; the Articles of Association regulate how it operates. Because the provisions of the Companies Act are detailed, companies are subject to substantial public disclosure obligations and statutory control. It is therefore required that an Attorney draft your founding documents for the Section 21 Company and advise you on these complex requirements. Further the annual reporting requirements for companies are extensive, and it is therefore not the recommended entity for a small community-based organisation. A Section 21 Company does however have considerable freedom of their internal management and the operation and running of day to day affairs. The Section 21 Company has a significantly improved risk profile compared to Voluntary Associations and Trusts due to the requirements for accountability, disclosure and independent audit.

Good governance

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

Certain legal obligations are applicable to all NPO governing bodies:
- Act in good faith and in the best interest of the NPO;
- Do not allow personal interest to conflict with the interest of the NPO;
- Do not act beyond the powers of the NPO/Governing Board or the limitations placed on such powers in terms of the founding document;
- Exercise the degree of skill that may be reasonably expected from such a person of his/ her knowledge. It is however important to note that members are not required to have exceptional intelligence and will not be liable for errors of judgment;

- Apply his/her mind to decisions and exercise an independent discretion, and
- Give intermittent, not continuous attention to the affairs of the NPO.

Legal obligations of Voluntary Associations

Voluntary Associations do not have a specific Act which sets out the legal obligations of members of Governing Bodies. The legal obligations are to a large extent contained within the Constitution of the Association. The Common law provides further principles applicable to Voluntary Associations.

The following are just some of the key legal obligations, which apply to members of Voluntary Association Governing Bodies:

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

Legal obligations of Trustees

The Trust as a legal structure is regulated by the Trust Property Control Act 57 of 1988 together with common law.

Legal obligations in terms of the Trust Deed

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

Legal obligations in relation to Trustees

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

Please note that the above is not a closed list of legal obligations, which is why it is important that Trustees familiarise themselves with the relevant legislation.

Legal obligations of Directors and Members of Section 21 Companies

As previously stated Section 21 Companies are governed by certain provisions of the Companies Act of 1973, as amended. Section 21 Companies must therefore comply with the provisions as set out for Public Companies unless otherwise indicated by the Act. NPOs are advised to seek legal assistance when registering Section 21 Companies as well as when dealing with the duties and obligations, which can be quite onerous. The following are just some of the duties and obligations.

Duties and obligations in relation to the Memorandum and Articles of Association

- The company must send to every member at his/her request and on payment of the prescribed fee, a copy of its memorandum and articles, or shall, if so requested, afford to a member or his duly authorised agent adequate facilities for making a copy of such memorandum and articles (these copies must include all the amendments made thereto),

- The company must on written request from the Registrar, submit a copy of its amended memorandum after it has taken a special resolution altering the memorandum.

Legal obligations in relation to the Register of Members

- Every company must keep a register of its members in one of the official languages of the Republic, and shall enter therein:
  - The name and address of the members;
  - The date on which his/her name was entered onto the register as a member, and
  - The date on which he/she ceased to be a member.

Legal obligations in relation to the Special Resolutions

- Any special resolutions to be adopted by a company must comply with the requirements as provided for in Section 199 of the Act, and
- The company must within one month from the passing of a special resolution lodge copies of the resolution and a copy of the notice convening the meeting concerned with the Registrar who shall, subject to the provisions of the Act, and upon payment of the prescribed fee, register such resolution;
- A copy of every special resolution must be embodied in or annexed to every copy of the articles issued after the registration of the resolution.

Can board members indemnify themselves in their constitution?

Yes, indeed. Board members can add a clause that outlines that the Company or Voluntary Association will indemnify them in the event of a third party claim. The Company or Voluntary Association will need to apply for indemnity insurance.

A clause of indemnification can be added into a constitution, but that does not stop someone from citing board members in their personal capacity. The organisation must then indemnify board members and support their defense that the organisation should be cited as a party as it is a body corporate (juristic person). Also, as a body corporate, the Voluntary Association has liability in the sense that it can sue and be sued in its own name. It is important to note that a board member can not be indemnified in the event where they have acted either fraudulently/negligently. A person cannot operate unlawfully and then rely on indemnification as a protection mechanism. In essence, the protection is **only** enjoyed if the person acts in good faith.

What is good faith?

"Good faith" constitutes actions which need to be interpreted in context. If the organisation has no funds, but still enters credit agreements, board members can still be held liable because they have an obligation to know and understand the financial position of the organisation. Good faith applies to intention, but actions can be seen as negligent in respect of fiduciary duties.

Gender considerations

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

Hospices are charity organisations which often started with a strong volunteer corps. Hospice directors often still view professional staff in a volunteer or honorary capacity so that staff salaries are often not market related. Hospices can also be preferred places of employment for women as they can negotiate flexible working hours to be able to take children to school, or job sharing so that they can work half days to suit their family responsibilities. It is clear that these family-care tasks are gendered in our current society.

Women take advantage of policies regarding maternity leave. If there are no policies to engage replacement staff, the burden of work is then taken up by the staff in the job.

RESOURCE:

The Legal Resources Centre Information Series No. 6: Legal Obligations of Members of Non-Profit Organisation Governing Bodies is a handy booklet which outlines the duties and obligations of Board Members. This booklet can be downloaded free of charge from the LRC website at www.lrc.co.za

The table below provides a quick summary and comparison of each of the three legal structures: Voluntary Association, Trust and Section 21 Company.
Which type of structure is best for your NPO?

	Voluntary Association (VA)	Trust	Section 21 Company
Advantages and disadvantages	• Simpler process to suit simpler, smaller organisations. • No registration required. Only contract. Voluntary registration of name. • VAs have all the powers of Section 21 Companies and Trusts. • Protects its members. The members of an Association are not liable for the debts of the Association when the organisation cannot pay its debts.	• Greater degree of credibility with funders. • Very structured and high level of accountability to the Master of the High Court. • Complex reporting process and audited financial statements are required. • Where it is not registered as a NPO with the Directorate, trustees can incur personal liability.	• Greater degree of credibility with funders. • Very structured and high level of accountability to the community. • Freedom of internal management and day-to-day running. • Complex requirements for establishing a Section 21. • Complex annual reporting requirements once established. • Separate Legal Entity registered in terms of the Companies Act, with statutory control by the Company Registrar. • Significantly improved risk profile compared to VAs and Trusts, due to the requirements for accountability, disclosure and an independent audit. • Directors are held accountable for their actions and the company has recourse in terms of Company Law against Directors who fail in their duty of care.
Legal requirements	• No registration required. - Voluntary registration of name (in terms of Section 7 (2) of the Heraldry Act, 1962). • A Voluntary Association is founded on a contractual basis. Any three or more people wishing to form the Association have to agree on the objectives and character of the Association for it to be incorporated under Common Law. • A constitution needs to be drawn up to govern how the organisation will function. If you wish to register as an NPO make sure your constitution meets the requirements for registration. • A group of people with executive powers must be appointed.	• A formal arrangement, in a written document (Trust Deed), between an owner of funds/property and a group of people (trustees) who apply the assets for the benefit of other people (beneficiaries). • An attorney must draw up the Trust Deed. The deed must be lodged with the Master of the High Court. • The trustees must make themselves aware of all their responsibilities (set out in 'Legal Obligations of Trustees in this document').	• Registration with the Companies and Intellectual Property Office (CIPRO). In order to do so the following is required. • A company name. • At least three directors, who sign consent to act as directors and thereby accept the obligations, responsibilities and rights of the appointment. • An independent auditor. • A memorandum and articles of association.
Applicable legislation	• Largely governed by its own constitution. • Falls under Common Law.	• Trust Property Control Act 57 of 1988. • Common Law.	• Companies Act of 1973 with amendments.
Where to go	• Any lawyer or if you do not have access you can approach the • Legal Resources Centre: A non-profit that helps NPOs (www.lrc.co.za).	• Any lawyer or if you do not have access you can approach the Legal Resources Centre: A non-profit that helps NPOs. • The Trust must be registered with the Master of the High Court in whose area of jurisdiction the greatest portion of the Trust assets is situated. • See www.doj.gov.za/master/m main.htm for your nearest office.	• Any lawyer or if you do not have access you can approach the Legal Resources Centre: A non-profit that helps NPOs. • The Section 21 Company must be registered with CIPRO. Forms can be obtained from their website www.cipro.co.za
Forms to fill in		• Acceptance of Trusteeship, to be completed by each Trustee. • Bond of security by the trustees, if required by the Master – Form J344 (not available online). • All the requirements in Form JM21. • An undertaking by an auditor, if applicable – see paragraph 5.2 of Form JM21.	• CM 5: Application for reservation of name. • CM 22: Notice of registered office and postal address. • CM 27: Consent to be appointed as a director. • CM 29: Registration of Directors, Auditors and Officers. • CM 31: Consent to act as an Auditor. • Power of Attorney: Authorisation to sign on behalf of members/directors. • The following documents will make up the Memorandum and Articles of Association: CM3, CM4, CM4B, CM44, CM44B, CM44C Company adopting Table B. • Purpose: Certificate of Incorporation and Memorandum of Association and articles of association in terms of the Companies Act.

New tax laws for NPOs

South African Law recognises two principal benefits for NPOs in relation to our tax laws:

Income Tax Exemption

In terms of our previous laws, certain NPOs such as religious, charitable and educational institutions of a public character and any fund with the sole object of which is to provide funds for any religious, charitable or educational institution contemplated as stated above, were exempt from the payment of income tax.

The new law creates a PBO or Public Benefit Organisation. This stems from the Income Tax Act Section 10 (1)(cN) and is dealt with through the South African Revenue Service, separate from the NPO Act. A PBO is therefore not a legal entity, but a structure with a certain type of accreditation from SARS.

Basically, PBO status is an additional accreditation that first allows the organisation to be exempt from paying certain taxes, as well as being declared a Public Benefit Organisation. This allows for the organisation to issue invoices to donors where through they can claim a tax break. A PBO can be a Voluntary Association, a Section 21 Company or a Trust.

Due to the nature of the work done, hospices should qualify for PBO status in terms of the Ninth Schedule to the Act. All NPOs can and should apply to be PBOs because of the tax benefit this confers. However, NPOs need to be a legal entity before they can apply for PBO status.

Public Benefit Organisation (PBO)

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

- Which is a Section 21 Company, Trust or Association; and
- The sole object/s of which are to carry on one or more of the Public Benefit Activities (PBAs) subject to certain trading restrictions and in a manner where:
  - Such activities are carried out in a non-profit manner and with altruistic and philanthropic intent;
  - The economic self interest of any fiduciary or employee of the organisation, is not indirectly or directly promoted, except by way of reasonable remuneration payable to that fiduciary or employee; and
  - At least 85 per cent of such activities (measured in time or cost), are carried out for the benefit of persons in the Republic, unless the Minister directs otherwise, but if donations are received from persons outside of South Africa, such donations may be used for the benefit of people outside of South Africa; and
- Which complies with one of the following requirements:
  - Each activity should be for the benefit of or be widely accessible to the public at large, including any sector thereof;
  - Each activity should be for the benefit of or readily accessible to the poor and the needy; or
  - The organisation is at least 85 per cent funded by donations, grants from any organ of state or any foreign grants.

Public Benefit Activity (PBA)

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

Part I lists 63 activities (since coming into the operation of the Revenue Laws Amendment Act 45 of 2003, which extended the list of activities by adding in the activities by adding the activity providing for the 'promotion of free speech and access to media') under the following 11 headings, being:

- Welfare and humanitarian activities
- Health care
- Land and housing
- Education and development
- Religion, belief or philosophy
- Cultural activities
- Conservation, environmental and animal welfare
- Research and consumer rights
- Sports
- Providing assets or other resources
- General

NPOs would have to carefully consider the list in order to determine whether the activities of their organisation match the list. If the NPOs activities fall within the definition of a PBO and their activities can be matched to Part I of the Ninth Schedule the NPO will be registered as an approved PBO and exempt from income tax. There are, however, further requirements in terms of Section 30 (3) of the Act that the NPO will need to meet in order to qualify such as:

- Any conditions prescribed by the regulator; and
- Submissions of a copy of the founding document which provides for the following:
  - Three unconnected persons must accept positions of fiduciary responsibility and no single person should directly or indirectly control the decision making power of the organisation;

- It is required to utilise its funds solely for its primary purpose;
- Surplus funds may only be invested in certain prescribed investments;
- Investments (other than business undertaking and trading activities) acquired by way of donations, bequests or inheritance may be retained in the form so acquired e.g. a donation in the form of a building may be retained and the organisation would not be required to sell the building;
- On dissolution, it must transfer its assets to a similar approved PBO, an institution established by law as defined, or a department of state as defined;
- It may not trade except under certain circumstances set out in the Act;
- It is prohibited from accepting certain donations which are revocable or conditional under certain circumstances;
- It must furnish SARS with copies of any amendments to its founding documents;
- It must not be party to a tax avoidance scheme;
- Remuneration to employees, office bearers, members or other person must not be excessive and no person should benefit from the organisation in a manner that is inconsistent with the Act;
- It must conform to certain reporting standards;
- Where the PBO provides funds to non-approved PBOs, it must take reasonable steps to ensure that the funds are used for the purpose for which they have been provided;
- It must be registered in terms of Section 13(5) of the Non-profit Organisations Act, unless exempt there from; and
- Not use its resources to directly or indirectly support, advance or oppose any political party.

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

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

Donor deductions

Part II of the Ninth Schedule of the Income Tax Act makes provision for PBOs which conduct Public Benefit Activities to qualify for donor deductible status.

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

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

NPOs applying in terms of the new tax laws

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

Step 1. In consultation check:
  a) Part I of the Ninth Schedule and any gazetted schedules, if any, to ascertain whether the activities of your NPO are listed on it, for income tax exemption and
  b) Part II of the Ninth Schedule and any gazetted schedules, if listed on it, for donor deductible status.

Step 2. If the activities of your NPO are listed on the relevant schedule, then check that the founding document of your NPO complies with the provisions of the NPO Act as well as the new tax law. If not, the document needs to be amended accordingly.

Step 3. Ensure that your NPO is registered with the Directorate of Non-profit Organisations in terms of the Act.

Step 4. Complete the application form (Form EI 1), which is available at your nearest SARS office or the SARS website: http://www.sars.gov.za/ You are required to submit the application along with a copy of the organisation's founding document as well as other certain information.

Step 5. If you have not amended or cannot amend the founding document so that it complies with the provisions of the new tax law, then in addition to the application form, complete and submit the SARS Letter of Undertaking (Form EI 2) which is available from your nearest SARS office or the website.

Guide to problem solving within the Palliative Care sector

When establishing an NPO, it is essential to word the founding document in such a way that the rules around the Governance of the Hospice are in place and have been discussed. The relationship between the Operational Management Team and the Board of Directors of an NPO is historically difficult to manage. To optimise the efficacy of the NPO, it is important to establish the roles and responsibilities of the Board of Directors and Management committee (staff) when establishing the organisation.

The focus of the Board of Directors is on strategy and includes financial oversight, sustainability, good governance. Management and personnel (staff and volunteers) focus on operational matters which include the day-to-day interaction with patients, guided by community needs and medical and psychosocial support.

A significant amount of time and energy can be wasted on managing this relationship and therefore it is important to be aware of possible pitfalls and how to avoid them. This will ensure optimal functioning of the Hospice and best possible care for patients and family members. The following are possible management pitfalls and suggested ways to help avoid conflict.

Management pitfalls	Management suggestions
1. The overlapping of the Board of Directors (BoD) and Management Committee functions and responsibility: • This could result in the Manager and management committee having many bosses with individual ideas. • The Directors may experience a lack of control, information and relevant knowledge, which would assist with making fair decisions. • The role of the Directors, Manager or Heads of Departments could be undermined if lines of communication and responsibility are not clear. The one party experiences the other as interfering in their business.	• Clear negotiated guidelines on roles and responsibilities need to be documented as part of policies. • Clear lines of communication need to be identified in line with the Organogram. • The executive function and operational management should be separate, clearly defined and documented with effective communication. • The Manager appoints the members of and chairs the Management Committee meetings. The composition of the Management Committee should include heads of departments and or relevant volunteers/ community members who will ensure that the strategic plan of the Hospice is managed on a day-to-day basis. • The BoD approves a budget and the Manager and Management Committee allocate the funds accordingly. • The performance appraisals of both the Manager and Management Committee are measured against the strategic plan criteria. • The role and responsibility of Board Sub-committees and Management Committee need to be clarified. • Legal, signed and dated minutes of all meetings are to be kept.
2. The Board of Directors may lose touch with changing demands and needs of the organisation. • This may result in a conflict of interests, mistrust and lack of mutual respect, frustration and an inability to adequately perform tasks as requested by the BoD. • Fundraising and funding opportunities may be missed, if the Hospice is not prepared to adapt to changing trends and embrace funding opportunities, which could bring about change. • Job satisfaction of staff may be negatively impacted as frustration levels build over the lack of responsiveness to community needs.	• It is essential to ensure that Directors are suitable and fully representative of the community. They should be passionate and informed about the service delivery. • Ensure that there are management committee members with full Board membership e.g. the Manager and maybe another head of department. • Directors need job descriptions, orientation and regular evaluation. • Senior managers should attend Board meetings as ex-officio members. This encourages transparency and communication. • A Hospice sub-committee should be established with the function of recruiting and approving Directors.
3. A sense of complacency may develop amongst certain Directors if there is lack of involvement and motivation, i.e. they have become an institution on the Board. • Directors may be continually unopposed and re-elected to fill a vacancy because of reluctance to offend a volunteer. • Often only Directors are members of Hospice, which sustains the re-election pattern. • The Directors may not familiarise themselves with the changing environment and needs of the organisation. • These Directors may discourage growth and adaptation to changing needs to limit potential risk and disruption to the organisation.	• Members need to be empowered to fulfil their role and responsibility in the selection of Directors. • Hospice Articles of Association should clearly define terms of office, election and re-election processes. • The election of new Directors could be staggered to retain continuity of expertise. • Directors should be required to attend official events and should a Director fail to attend three Board meetings without apology, the Director should be asked to resign.

Management pitfalls	Management suggestions
4. The Board of Directors may be hesitant to respond to the changing community needs e.g. Hospices have changed from being 'white' organisations looking after patients who have cancer to organisations looking after AIDS patients, including community HBC workers, managing anti-retrovirals, to managing potential orphans and vulnerable children.	• To encourage the awareness of the latest community sentiments it is essential that there is community and management committee representation on the Board. • Directors have a responsibility to maintain awareness of current trends. Management reports to the board should include current issues. Directors are encouraged to attend sector meetings, e.g. regional hospice meetings, conferences. • Good communication between HPCA and the Hospice BoD around the changing environment and prediction of trends will provide the necessary information. • Empowerment of the Board / Hospice sub-committees for making strategic decisions that guide policy in line with the mission, vision and WHO palliative care definition, is important for being current and relevant in service delivery.
5. The possible 'take over' of Hospice resources and mission by the community could be a real threat if not managed proactively e.g. • A renegade group could hijack the Hospice for their own needs • The emphasis of the Main Business could be diluted to benefit a small group interests such as job creation, housing etc.	• A selection committee must approve and approach potential new Hospice members. • The Main and Ancillary Business stated in the Articles of Association needs to be concise and tight within the parameters of palliative care. • The Articles of Association must meet the requirements of the companies act with regard to quorum requirements for special resolutions.
6. Loss of focus on the core business, the mission and vision of the Hospice could be the result of poor communication between the manager and the Board. This may result in not enough attention being paid to the core function at Board level. Sustainability needs and anxiety may overshadow service delivery requirements.	• Yearly strategic planning should be done and an operational management programme made and managed by management committee and supervised by the BoD. • The mission, vision and strategic objectives of the organisation must guide decisions. • Decisions must be made in committee and not by individuals.
7. Adjusting to and managing the changing goals and demands of affiliated Bodies like HPCA and DoH due to changing funder requirements and community needs e.g. management of orphans and vulnerable children, mentorship, training, generic HBC, accreditation, the expanded scope of palliative care and paediatric palliative care.	• The Hospice Board and management should remain knowledgeable with regard to the changing environments, current community needs and health care trends. This will assist Board and management in deliberating the scope of involvement and the impact on the Hospice. • Major policy changes need to be discussed at a strategic meeting consisting of Directors, management committee, key volunteers and interested parties as decided by the Board/management sub-committees.
8. Approval of writing and implementation of policies and procedures may result in uncertainly.	• The Board of Directors should authorise management committee to develop operational policies and procedures. • The Board of Directors must oversee the Financial and Governance policies and have the responsibility to ratify policies and procedures developed by the management committee. • Human resource policies are guided by Labour Law.
9. Directors acting outside of their scope of practice	• The scope of practice of Directors must be documented and circulated. • Board orientation in the function of the Board and the Directors' responsibilities as well as the function of Hospice, is essential. • The Board of Directors needs to establish clear guidelines for disciplinary procedures of Directors. • The Manager needs to establish a forum where grievances can be discussed.
10. Service delivery may be compromised because of funding constraints or restraints placed by Directors on staff. If funding dries up, appropriateness of service needs to be questioned.	• The financial committee and the fundraising committee need to work closely together guided by the strategic plan, mission and vision of the Hospice. • It is essential that the Manager and Department Heads remain in touch with latest trends to ensure the sustainability of the Hospice. Therefore they should be involved with HPCA, other NPOs, CBOs and the DoH. • Networking ensures that the responsibility of care is not only Hospices' responsibility.

Conclusion

This chapter describes the various NPO structures and the legal requirements for each.

Bibliography

These resources will provide you with more information on the laws that govern Non-Profit Organisations.

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Relevant Legislation

The Companies Act No. 61 of 1973
The Income Tax Act No. 58 of 1962
The Non-profit Organisation Act No. 71 of 1997
The Trust Property Control Act No. 57 of 1998

Access to Care

Sarah Sephton and Zodwa Sithole

5

Legal and Human Rights Arguments for Access to Care

The UN Universal Declaration of Human Rights conceptualises human rights as based on inherent human dignity.[1] Death is inevitable. The provision of good health care at the time of death is less so. Throughout the world there are wide disparities in the capacity, resources, and infrastructure devoted to the care of people who are dying.[2]

The Constitution of the Republic of South Africa gives every person the right of access to health care services. Does this mean that all South Africans have the right to the provision of good health care at the end of life?

Every person in South Africa has a constitutional right to access health care services, a right detailed further in the National Health Act of 2003 which aims to promote the health of the inhabitants of the Republic so that every person shall be enabled to attain and maintain a state of complete physical, mental and social well-being.

In order to fulfil this right the necessary conditions for people to access health care must be created by providing positive assistance to patients, health care benefits and health care services. Government has an obligation to promote health by providing hospitals, clinics, medicines and staff to provide this care to all people in South Africa.

What does this Right really mean?

It is argued that in order to fulfil this right the following essential elements need to be fulfilled.

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

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

If a hospital refuses to treat a patient, they have recourse to the Department of Health or the Public Protector. The High Court can review and set aside the decision of the hospital to refuse to treat the patient.

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

All patients have the right to be treated with respect. The Health Professions Council of South Africa (HPCSA) guidelines say that health care workers must not treat patients who are living with HIV differently to other patients. This applies to people with all illnesses including MDR or XDR TB (Multi resistant/extreme drug resistant tuberculosis.) There are guidelines to promote occupational

Terms you will read in this chapter:

Delirium: extreme restlessness, confusion caused by fever etc.

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

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

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

Ineluctable obligation: inescapable obligation – it must be done

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

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

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

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

Tertiary health care: care at a specialist hospital health and safety for health care workers who care for patients with infectious conditions.[3]

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

South Africa has two types of Health Care Service

1. The Private Health Care System where the individual carries the responsibility of health care with assistance from various medical schemes.
2. The State Health Care System: whereby the state provides health care for those unable to afford adequate medical cover. There is a scarcity of resources. This has seen a shift in focus from tertiary health care to primary health care, rationalisation of the academic institutions as well as reallocation of human resources to peripheral clinics.

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

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

In April 2006, the Department of Health published a human resource plan in an attempt to overcome this crisis. However, this plan is weak and lacks concrete targets and proposals to address either the short or long term crisis of human resources. It is likely that it will be subject to severe criticism, and possibly even constitutional challenge, in coming years.

The Government needs to strive to improve the state health care system, which is currently inadequate, and to eradicate gross inequities in service provision and ensure greater access to health care for the poorest people in our country.

A clear example of Government's failure is the Human Rights working group in the Eastern Cape calling on the National Executive to intervene in the problems facing the Eastern Cape Health Department in terms of Section 100 of the Constitution. There are systemic problems, which must be resolved in order to ensure an adequate standard of public health care for the people of the province. Failure to do so can only result in the perpetuation of inadequate public health services in the Eastern Cape. Public Service Accountability Monitor (PSAM) has documented financial mismanagement, staff shortages, poor strategic planning and lack of transparency and accountability that have impacted on service delivery.

> *According to the Department's Draft Human Resources Plan (DHRP) 2007/08 – 2010/11, there is a 34 per cent overall vacancy rate in the Clinical Branch. The DHRP recorded a 61 per cent vacancy rate for medical specialists, 54 per cent vacancy rate for medical officers, 28 per cent vacancy rate for all categories of nursing staff (professional nurses, staff nurses and nursing assistants), 50 per cent vacancy for pharmacists, 55 per cent vacancy rate for dentists, 65 per cent vacancy rate for physiotherapists and a 48 per cent vacancy rate for emergency medical officers. With regard to emergency medical services, section 27 (3) of the Constitution states that 'no one may be refused emergency medical treatment.' In the Eastern Cape, however, only 44 per cent of the population has access to emergency services (RAS, p. 19).*[4]

Despite our Constitution, Health Act and the International Covenant on Economics, Social and Cultural Rights (ICESCR), it is widely accepted by our Courts that there is not an absolute right to most of the socio-economic rights contained in our Constitution, but that there must be a progressive realisation of this right as resources become available.

The rights described in ICESCR are termed aspirational rights. This means that there is no express right to care, but that Government must strive to gradually increase the right to health services in a manner which will uphold and develop the rights enshrined in the Constitution[2] and that the Government agrees to core obligations towards the realisation of these rights. The provision of palliative care is one part of a continuum of health care for all persons. Therefore, an argument can be made that a right to palliative care can be implied from the overall international human right to health. General Comment 14, from the Committee for ICESCR, documents palliative care as a human right.

Access to palliative care is impacted by the lack of palliative care training for all health care professionals, and the current lack of integration of palliative care into the formal health care sector. In 2007 South African hospices cared for approximately 14 per cent of patients requiring palliative care. What was the experience for the patients who died without this care?

Barriers to access to Palliative Care

Understanding and awareness of Palliative Care

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

This might be due to misconceptions about hospice or to the lack of information relating to services offered by palliative care organisations. To overcome these challenges, more information materials need to be developed and more work needs to be done with the general media. The availability of this information must be found in all health facilities so as to assist patients, their families and carers and health personnel. More palliative care campaigns are needed to provide the necessary information and to influence attitudes.

The structural arrangement of a health care system can also contribute to problems concerning palliative care and its administration. Many primary health clinics do not have staff trained in palliative care. This is often the case with private and public hospitals as well. The lack of staff suitably trained in palliative care and designated palliative care beds or wards contribute to patient distress.

If more staff in these institutions could be trained in palliative care there would be changes in attitudes towards death and dying. Patients would receive better management of their pain and more holistic care. And family members would receive better support and experience better bereavement outcomes.

Place of Care

Barriers to palliative care exist even for patients who have access to the hospice system. Most hospice programs deliver care to persons who are dying in their own homes. This is appropriate for the South African setting and acknowledges patient preference for home care. Admission to an in-patient hospice unit (IPU) is appropriate for symptom control and family respite. However very few in-patient hospices exist and these usually have a limited number of beds because of funding constraints. Patients with symptoms such as dyspnoea and delirium, as well as terminally ill patients requiring intensive nursing, may be disadvantaged in accessing care when the local hospice does not have an IPU. However, hospices do provide other services through their home-based care and day hospice. For many patients these services are usually available only during office hours. When a patient has problems at night, advice can be given over the telephone – if there is one. Travelling at night can be dangerous in certain areas so hospice management have instructed their staff not to do house-visits at night. Hospice day centres operate well since they provide the services of doctors, professional nurses and social workers.

Referrals

Most hospice patients are referred by hospitals, private doctors and other NGOs. Due to funding issues, some organisations may hold on to their patients and not refer them for palliative care, as the drop in the NGO patient numbers could result in a drop in funding. A solution to this issue is training all NGO staff in palliative care.

Lack of Palliative Care education

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

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

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

Shortage of Palliative Care staff

Member hospices within the Hospice Palliative Care Association (HPCA) of South Africa have experienced increasing numbers of patients from 2000 onwards. Professional staffing for South African hospices is a continuing challenge. The recruitment and retention of professional staff requires hospices to compete with public and private sectors with regard to staff salaries. Hospices are funded through donations and have no guaranteed income, which creates challenges to meet professional salaries. Staff shortages may mean that hospices have to limit the number of patients they can care for. With the advent of the HIV pandemic, patient numbers at hospices have increased and hospice services include prevention strategies, treatment support, holistic palliative care, poverty alleviation, food security and care of orphaned and vulnerable children[5].

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

Pain relief

A report for World Hospice and Palliative Care Day 2007, published by Help the Hospices for the Worldwide Palliative Care Alliance, states that access to pain relief is an essential human right.

Research shows that pain can be controlled with careful assessment and management of pain, addressing psycho-social and spiritual factors that impact on the pain experience and using relatively inexpensive oral medications. Pain that is difficult to control, such as neuropathic pain in HIV, can still be improved through the WHO[6] approach to pain management which describes using non-opioid medication for mild pain, weak opioid for moderate pain and strong opioids such as morphine for severe pain.

However there is inadequate access to morphine and other opioids for pain relief in many parts of the world. Many people are being denied adequate pain relief – the majority (but not all) of these people are in developing countries. In South Africa, current legislation restricts opioid prescription to doctors. In the light of shortage of doctors and the need to provide care for seriously ill patients in the home this logistically restricts access to pain medication for these patients. However, the South African Nursing Council and civil society are working on regulations to allow suitably qualified professional nurses to prescribe and administer medication up to Schedule 6, which includes opioids.

The World Health Organisation has recommended that all nations should have a national policy for the implementation of palliative care services, that the care of people with life limiting illnesses should stand equal to all other health issues. In 2002 a group of palliative care educators met in Cape Town and produced the Cape Town Declaration which states that:

> *Palliative care is the right of every adult and child with a life limiting disease; appropriate drugs including strong opioids, should be made accessible to every patient requiring them in every sub-Saharan country and at all levels of care, from hospitals to community clinics and homes.*[7]

Policy change will only occur if governments understand the importance of palliative care and the need to increase access to drugs for palliative care within their countries. Although the South African Government has long recognised the administration of morphine for pain relief as an important aspect of primary health care, terminally ill patients do not have access to pain relief as a right and their ability to get pain relief depends on the accessibility of doctors and pharmacists.

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

Current prescribing legislation constitutes a failure of the South African Government to take steps to progressively realise the right to health care services. It could be considered discriminatory, as the effect of this omission – not legislating for nurses to prescribe the necessary pain medication – is that poor people in rural areas, with limited access to health care services, bear the brunt of it. This leads to unnecessary suffering and painful deaths which is in breach of the constitutional right of human dignity contained in Section 10 of the Constitution.

South African dispensing laws have failed to consider the question of access to medication for home bound patients.

In effect patients who have no access to transport or who are too weak to attend clinics do not have access to pain control medication. Patients desperate for pain control in the last days of life have died in transport attempting to get to the clinic. This certainly amounts to death without dignity.

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

International experience in Uganda[8] has proven that there are benefits in allowing nurses to prescribe morphine which results in better quality of life for the patient and their family members and a peaceful and dignified end to life for those patients who are in fact dying. This benefits not only patients and their families, but also the clinical teams who previously had to witness the intense and unnecessary suffering of patients.

Possible solutions for access to medication

Once the patient is referred to a hospice, they continue to be cared for in partnership with the referring public health facility according to the Integrated Community Health Care (ICHC)[9] model. Ideally, they should continue to access their medication through the referring public health facility. However, the medication prescribed on referral to a hospice will often need to be changed based upon the symptoms. Patients at this stage are often bed bound and will not be able to return to a public health facility for collection of medication. Therefore, the ideal would be a partnership with the hospice whereby:

a. Hospices could order drugs through the district health system if they have a licensed pharmacy.
b. An agreement could be reached between the hospice and the local clinic or district hospital allowing the hospice doctor or professional nurse to prescribe palliative care medicines on the patient's file.
c. Primary health clinics ensure that the essential medicines for palliative care be available for dispensing to hospice patients.

Recommendations/areas of concern

Pack size is understandably limited at a clinic level, but the availability of some bulk items for palliative care patients needs to considered e.g. paracetamol, ibuprofen, sienna and lope amide. The pack sizes for clinic level are specified in the Provincial Code List, not in the primary health care Essential Drug List[10]. There is therefore scope for regional flexibility with respect to pack sizes, which clinics may stock.

Paediatric formulations are useful for the elderly, weak and those with swallowing difficulties, as well as for children. These formulations should be available to conform with a principle of the essential drugs concept, namely that essential drugs should be available at all times, in the proper dosage forms.

The difficulties in achieving access to Palliative Care

Geographic challenges

Geographical barriers to access to care in rural areas are a big problem. The infrastructure is bad e.g. poor road conditions and poor or non-existent public transport. Home-based teams cover large, sparsely populated areas, the conditions become worse if it is raining, the roads become muddy and mushy, the rivers overflow and in some instances poor bridge construction means that the team cannot cross the river and reach the patients.

Some of the areas do not have proper physical addresses, which makes it difficult for the palliative care team to find the patient after he/she has been referred to a hospice. Distance is another issue; the team has to cover a large area, which limits the number of patients who can be seen per day and adds to the cost of care because of transport costs.

Cultural and social challenges

Seriously ill people or their families are often reluctant to contact hospice at an early stage because of the stigma attached to their illness. There may be denial about the illness and difficulty in accepting the severity of the illness until a very late stage.

People may delay contacting hospice because they fear stigmatisation should a hospice vehicle be seen outside a home. Other people may see illness as a business opportunity, taking advantage of vulnerable people by offering assistance in return for financial gain, whereas hospice services are provided free of charge.

Other families prefer to care for their loved ones on their own, which can result in delayed referrals to palliative care. Families may not be aware of the support and information on home-care that is available to assist them.

Many communities associate hospice with death and are reluctant to approach hospice as this means acknowledging that their loved one may be dying.

Different languages used in South Africa present a problem, as communication between care-givers and patients with different languages or from diverse racial groups present barriers to proper care.

Some cultures believe that talking about death invites death in. Other cultures do not openly express grief, which then leads to them not accepting their illness, which in turn leads to a delay in accessing palliative care.[11]

Religious beliefs can also act as a barrier to care, as some people believe in the power of prayer to the exclusion of medical care. Sometimes the delay in bringing the patient to a medical practitioner means that by the time he/she is consulted, it is too late for medical intervention.

Gender considerations

Women have a nurturing role in society and this extends to women being the custodians of the family's health. Men often distance themselves from caring for the very ill as they see it as a woman's task. This puts a burden on the female members of the family.

Women are more accustomed to attending health facilities, and health facilities are open during working hours which favour the people at home. Health care staff, especially in the nursing profession, are more often women and men may be reticent in taking health problems to a female health care provider. Hospices have found good uptake of services when male carers and counsellors are employed and an after-hours VCT and ARV clinic is more accessible to men in the town.

In the HIV setting, women often test at antenatal clinics and their husbands/partners choose not to test. Under these circumstances women are offered ARVs earlier and men often present with more advanced HIV and lower CD4 count at first testing with more severe opportunistic infections. Some male patients do not present for care themselves, but send their wives and then take their wife's medication.

Child-headed households

Child-headed households experience the problem of not knowing whom to approach for assistance if one of the children is not well. Children in child-headed households tend to have many roles, they are expected to care for their siblings, make sure that there is something to eat and have other responsibilities so that the child replaces the parent within the family relationship. The responsibility is an onerous one on a child and is made worse if one of their brothers or sisters is on medication, they may get the dosage incorrect or forget to ensure that medication is taken.

Poor compliance is a big problem in these families. Transport is problematic as the responsible child in many cases needs to ensure that siblings are transported to clinics or hospitals. The lack of transport money or somebody to accompany the child to health facilities is a reality. The guilt associated with caring for a terminally ill family member contributes to the isolation that children experience as heads of households. The fear of being ostracised from your community and peers leave long-lasting emotional scars.

Traditional healers

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

Once it has been established that there is no curative care and the patient is removed from the hospital setting, the traditional healer may be involved as the sole provider of health care and acts as adviser to the patient and the family. In Africa, 80 per cent of people consult traditional healers.[12] Some patients have a mixed belief in both traditional and western medicines. Others opt for only contacting the palliative care team after they have already contacted traditional healers. The HPCA has encouraged a dialogue with traditional healers in order to collaborate and provide the best possible care to patients and families.

There needs to be a move towards the empowerment of traditional healers, informing them of palliative care techniques and practices. This will certainly strengthen the sector as well as increase the quality of care which patients receive from traditional healers. The WHO made this call when in 1978 they declared at Alma Ata, USSR that traditional healers should be recognised and should be part of the primary health team.

According to Mr Tobias Mkhize, Traditional Complementary Healer Support Manager, eThekwini Municipality, who works closely with traditional healers based in KwaZulu-Natal, patients must have the freedom of choice to attend both western and traditional medicine, it is important that the patients are not discouraged from going back to the traditional healers after attending western facilities. In the eThekwini district some of the traditional healers have developed referral forms, which they use when they refer patients for western medicine. According to Mr Mkhize the traditional healers' concern is that nurses and doctors don't take these referral forms seriously; they ignore or don't acknowledge them and patients are not treated.

To improve the access of care, the eThekwini Department of Health (eThekwini District) have developed a pilot project to employ a professional nurse to work with both traditional healers and western medicine teams.

CASE STUDY

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

He was lying on a mattress outside in the sun. He lived with his mother, who was an informal trader – selling sweets outside a local school. She left a cup of water and a plate of porridge covered with a plate in the shack for him. When I arrived it was about 10h00, and the food and water were untouched. He tried to sit-up to greet me, but was groaning with pain and grimacing. I told him to lie down. After a chat, I learned that he had been a long distance driver, and had contracted HIV. He learned of this 11 months before, but had never attended a clinic or hospital.

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

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

I had to travel back to the office to consult a doctor telephonically for a script. The doctor was unavailable. The next day, when I spoke to the doctor he was unwilling to prescribe anything stronger than Brufen without seeing the patient, and was unwilling to travel to the patients' home. I travelled out to the patient again, arming him with a referral letter to the CD Clinic at the government hospital, asking for pain medication – preferably an opiate. I also gave him travel money (from hospice).

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

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

An examination of Case Law dealing with Access to Care

On 11 June 2007 the Department of Health dismissed 41 health care workers in Khayelitsha for participating in the public sector strike. Before the industrial action started on 1 June, Khayelitsha's clinics were already seriously understaffed. The strike exacerbated the staff shortage, but the dismissals made it impossible for at least two of Khayelitsha's three health facilities to offer adequate care. At all times before the dismissals in Khayelitsha, essential services were being provided and workers who participated in industrial action did so peacefully without any destruction to property or endangering patients lives.[13]

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

Following a meeting with some of the remaining health workers at Site B, the Treatment Action Campaign (TAC) together with five patients who use Khayelitsha's health services proceeded with urgent litigation in the Cape High Court to compel Government to restore health services in Khayelitsha, including re-instating the dismissed workers. The first applicant was TAC. The second to sixth applicants were Sizeka Maya, Nomafrica Velem, Neliswa Nkwali, Norute Nobola and Fanelwa Angel Gwashu. They described how they are dependent on Khayelitsha's clinics to treat their and their children's chronic illnesses which include HIV, TB and asthma.

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

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

In the 1998 case of *Soobramoney vs the Minister of Health* (KwaZulu-Natal, 1998(1) SA 765), the Constitutional Court said that the Government was justified in restricting access to kidney dialysis, because of the high cost of this type of care, and the need for the Government to have reasonable plans for spending its health care resources.[14]

In 2002 the now well known Treatment Action Campaign case dealing with the provision of drugs for the prevention of mother-to-child transmission of HIV/AIDS came before the Constitutional Court. TAC launched legal action to demand broader access to Nevirapine in 2001. In December 2001, Judge Botha of the Transvaal High Court *declared that 'a countrywide MTCT programme is an ineluctable obligation of the state'.* The High Court's order instructed the Government to allow Nevirapine to be prescribed where it was 'medically indicated' and where, in the opinion of the doctors acting in consultation with the medical superintendent, there was capacity to do so. The High Court also ordered the Government to develop 'an effective comprehensive national programme to prevent or reduce MTCT' and to return to the court with this programme for further scrutiny before 31 March 2002.[15]

The Minister of Health appealed this ruling directly to the Constitutional Court. Unanimously, the Constitutional Court decided that the Government's policy had not met its constitutional obligations to provide people with access to health care services in a manner that was reasonable and took account of pressing social needs.[16] The Court said that the Government was wrong to restrict access to the antiretroviral medicine, Nevirapine, that is effective in reducing the risk of mother-to-child HIV transmission. It ordered the Government to make the medicine available to pregnant women living with HIV.

Access to treatment for prisoners

Since October 2005 the TAC and the AIDS Law Project (ALP) have assisted HIV positive inmates at Westville Prison in acquiring ARVs that have routinely been refused to them by prison authorities. Situated in KwaZulu-Natal, one of the provinces most severely affected by HIV/AIDS, Westville Prison had steadfastly prevented TAC or other NGOs from conducting treatment workshops, treatment literacy programs, or any form of HIV awareness training. When this case came before Court, Judge Pillay cited various precedents where Government has been forced to uphold the rights of prisoners dating as far back as 1912, and concluded relatively early on that there was no dispute and that these fifteen prisoners as well as any others in similar condition should have been receiving ART. The Government was given leave to appeal this decision but the court ordered the interim operation of the Court order.[17]

On 18 August 2006 the State filed an urgent application before Judge Nicholson for a hearing to appeal this interim execution order. To date the State has not pursued the appeal and the parties have attempted unsuccessfully to resolve the matter without further litigation. The interim order needs to be implemented unless and until such time as it is successfully appealed by the State. South Africa has 237 prisons with twelve to thirteen sites currently accredited to provide ART thus the majority of prisoners in South Africa are not likely to have access to ART in prison.

Summary

Section 27 of the Constitution of the Republic of South Africa gives every person the right of access to health care services. The Health Act aims to promote the health of the inhabitants of the Republic so that every person shall be enabled to attain and maintain a state of complete physical, mental and social well-being.

The South African Patients' Rights Charter states that 'Everyone has the right of access to health care services that include:

> *provision for special needs in the case of ... patients in pain ... palliative care that is affordable and effective in cases of incurable or terminal illness'*

In order to realise these rights there needs to be Government policy regarding palliative care for all persons living with life-threatening illness, training of all health care professionals to provide palliative care and access to essential palliative care medications.

Palliative care should form part of comprehensive health care and should be integrated into the formal as well as informal health care sector.

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Poverty, financial issues and social development

Sarah Sephton and Sue Nieuwmeyer

With special thanks to Jill Knott, Principal Social Worker at Wits Hospice

6

Overview

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

—Ehrenreich, 2007

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

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

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

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

This chapter draws on the experience of hospice social workers in Soweto, Gauteng; South Coast, KwaZulu-Natal; Port Elizabeth, Eastern Cape; and Ladybrand, Free State. The experience of caregivers, members of NGOs and hospice staff – present at discussions and focus groups held by Desia Colgan of Street Law during 2007 – has also been a valuable source of reference.

Terms you will read in this chapter:

Abridged certificate: shortened/reduced certificate

Affidavit: a written statement made on oath before a Commissioner of Oaths e.g. Police

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

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

Beneficiaries: those who benefit with money or property

Entrepreneurial: starting or financing new businesses/enterprises

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

Informal sector: unregulated business

Lapsed policy: a policy which has expired or been stopped

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

Migration: moving from one region or country to another

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

Paralegal: someone with legal training who assists a qualified lawyer

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

Potable water: water suitable for drinking

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

Prohibition of unfair discrimination: the legal banning of unfair treatment

Remunerative work: work that brings in money

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

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

Poverty

At the end of 2007, a short questionnaire was completed by hospice social workers in Soweto (Gauteng), Ladybrand (Free State), South Coast (KwaZulu-Natal) and Port Elizabeth (Eastern Cape). The following tables were compiled from the experience on the ground of these social workers.

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

Other issues of poverty	Impact on daily living
Housing shortage	• Leads to overcrowding in the home • Poor sanitary conditions • Lack of secure shelter for orphaned children and loss of shelter to an adult family member (see chapter on Law of Succession)
Many orphans, especially in deep rural areas	A grandmother over 60 may be feeding several children on her own Old Age Grant. Under 60, she may have little, if any, income.
Crime	Poverty and unemployment both lead to an increase in crime
Debt	See table on needs and social work planning in Section 8: Social Development in palliative care later in this chapter.
Lack of knowledge about available local resources	Inability to source state assistance
Breakdown of extended family who might have helped with finances or care, due to family deaths from AIDS and related family expenses	Lack of a support system for families

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

Human Rights and poverty

Following the Universal Declaration of Human Rights in 1948, the United Nations drafted the International Covenant on Economic, Social and Cultural Rights. Alongside the International Bill of Human Rights, the United Nations have drafted a variety of instruments dealing with the rights of particular vulnerable groups such as women, children and aboriginal peoples.

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

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

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

The South African Constitution is unique in granting civil, political and socio-economic rights, and particularly in granting rights pertaining to the alleviation of poverty in its Bill of Rights. Some of the most important sections for people living in poverty are:

- Section 26 which grants the right to adequate housing
- Section 27(1)(a) which provides the right to access health care services
- Section 27(1)(b) which provides the right to access sufficient food and water
- Section 28(1)(c) which gives special emphasis to children's rights

Section 27(1)(c) grants people the right to social security, including appropriate social assistance if they are unable to support themselves and their dependants. This is a right directly targeted at alleviating poverty.

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

The impact of poverty on people's lives

Poverty intersects with human rights at every possible juncture; both the civil and political and the economic, social and cultural rights of the poor are affected. One of the most basic human rights guaranteed to everyone is the right to life and to physical integrity; however, people living in extreme poverty may lack access to food and adequate shelter, face greater risk of disease, or be forced to accept dangerous working conditions. People living in poverty are often not registered with Home Affairs or do not register their children, and so may experience difficulties in obtaining social grants or registering their children for school. People living in poverty may be excluded from the justice system because they are unable to hire a lawyer to represent them or because they are hindered by illiteracy, lack of self-confidence and mistrust of the system. Those living in poverty are less able to participate in, or influence, political decision-making. The denial of the rights to adequate food, housing, health and education to people living in poverty is clear. Because poverty so disproportionately affects vulnerable groups such as women, children, and particular racial groups, poverty must also be seen as a denial of people's right to equality.

Gender and poverty

The term 'feminization of poverty' refers to an increase in the relative levels of poverty among women and/or female headed households. Social norms and values assign primary responsibility for reproduction and care to women and decision-making to men. The fact that the primary responsibility for care is placed on women means that there is greater variation in work force activity for women as these responsibilities cannot easily be combined with economical activity. In addition, women's income when they work is more likely to be allocated to the welfare of their children. Women face greater difficulty in translating their work into higher incomes. Gender norms and practices tend to exacerbate the effects of poverty so that poor women enter the labour market with lower levels of health, nutrition, education and skills than men.

There is both active discrimination against women and unconscious biases that face women in the workplace. The result is that women are assigned to less well paid jobs than men or are paid less for the same job.

Increased access to paid work does not translate into improved family wellbeing if women's increased workload in the labour market is not accompanied by an increase in men's contribution to unpaid domestic labour. Women often rely on older children to look after younger children at home – usually this responsibility falls to girl children and impacts on their educational prospects and their ability to escape the cycle of poverty.

The difficulties faced by poor women are exacerbated if the man deserts or abandons the family, a strategy often used by poor men to escape contributing to the family income.

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

The AIDS epidemic has affected the income generating and child rearing age group. Sick adults are not able to earn an income and turn to their mothers for care and to assist with care for their children. Grandmothers take on this burden of care without an income to sustain the extended family other than social grants.

Human Rights-based approach to poverty

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

Before 1997 most United Nations development agencies pursued a 'basic needs' approach. They identified basic requirements for beneficiaries and tried to improve services to fulfil these basic needs. In contrast, the United Nations has now adopted a rights-based approach, which translates peoples' needs into rights. Using a human rights-based approach, individuals are active rights holders; governments have duties and obligations to these rights holders. This is an important distinction. A need that is not fulfilled results in deprivation and dissatisfaction. A right that is not fulfilled results in a legal violation that may be addressed in court.

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

Importantly, the Constitutional Court rejected the international law principle that the South African government must meet a 'minimum core' obligation to ensure the satisfaction of minimum essential levels of each right to everyone. Instead, in South Africa, the Constitutional Court will consider whether the government's measure to realise social rights is 'reasonable'. Reasonableness, according to the Court, means at the very least that the basic needs of the 'most vulnerable' must be addressed. Therefore in constitutional cases in South Africa it appears that the needs of those living in extreme poverty will receive priority when the legal content of human rights is considered.

The case of *Khosa and Mahlaule* challenged the constitutionality of some of the provisions of the Social Assistance Act 59 of 1992 for excluding permanent residents from eligibility for social grants. The Court found at that 'in addition to the rights to life and dignity, the social-security scheme put in place by the state to meets its obligations under Section 27 of the Constitution raises the question of the prohibition of unfair discrimination'. The Court held the decision to exclude a particular group must be consistent with the Constitution as a whole and that for such an exclusion to be valid, the government must be able to show that there was a rational connection between the differentiating law and the purpose the government was trying to achieve. This case means that the government cannot arbitrarily discriminate against a particular vulnerable group of people when meeting its obligations under the constitution.

These cases demonstrate the way in which people living in poverty may approach the court for assistance where their human rights have been violated. Where a violation is found, the court has decided that the government is under a clear duty to implement reasonable programmes to address the rights of those in desperate need on an expedited basis.

Barriers to accessing social grants

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

- The birth was never registered
- The Birth Certificate has been lost
- A shack fire destroyed documents
- There was theft of the ID by others

The absence of the correct documentation is a huge problem, especially when trying to register the birth of a child or young person, whose birth was never registered. If the birth occurred in another part of South Africa and the child's parents are deceased, the child cannot go back to the hospital where he or she was born and get copies of the Birth Certificate, as the child is often not sure where he/she was born.

Registration of Births

The following is an extract from a 2007 brochure from the South African Department of Home Affairs.

> *The Births and Deaths Registration Act (51 of 1992) states that the birth of a child must be reported and registered within 30 days of its birth. This will assist Home Affairs to update its records and help create a reliable and accurate Population Register in the country. It will also help the Department of Home Affairs to speedily deliver other services it may have to when the child is older (e.g. Birth Certificate, ID book, Death Certificate etc.). To register a birth, the Bl-24 (notice of birth) form must be completed and submitted to the nearest Home Affairs office. If the applicant is abroad, he or she should submit the application at the nearest South African Mission or Consulate.*

Requirements for Birth Registration

It is important that the notice of birth be given by one of the parents or the legal guardian. If neither of the parents or the guardian is able to do this, a person, requested by the parents or the guardian, may give notice on their behalf. This person must have their written permission.

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

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

Birth notification of an abandoned or orphaned child

When registering a child whose parents and/or relatives cannot be traced, the following steps are taken according to the Department of Home Affairs:

- A notification of birth form (Bl-24) is completed;
- A report from a social worker is needed, as the particulars from the parents are not available;
- Upon the registration of a birth, an abridged certificate is issued free of charge

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

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

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

The hospice social worker, Soweto , reported the following:

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

Helping adults to access Birth Certificates in the Palliative Care situation where there is no proof of notification of a birth

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

- Clinic card – proof that the adult as a baby and small child attended a clinic. Most adults will not have this;
- Baptismal certificate – sometimes available;
- Affidavit by someone who has known the adult for more than ten years – not always possible, especially when people relocate from other areas.

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

CASE STUDY – DIFFICULTIES OBTAINING BIRTH CERTIFICATES AND ID APPLICATIONS

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

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

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

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

I have contacted another branch of Home Affairs and the officials are more accommodating. They have agreed to interview Joe and his aunt Anna in the New Year (2008) It has so far proved very difficult, seemingly impossible, to get Joe an ID document as his birth was never registered.

—Jill Knott, Pricipal Social Worker, Wits Hospice

Application for an Identity Document

The following is paraphrased from a 2007 brochure of the Department of Home Affairs. Providing there is a Birth Certificate and other necessary documentation, this process should be straightforward. The applicant applies at the nearest Department of Home Affairs.

> *An identity document proves that a person is who he/she says he/she is. An ID is needed in order to access housing, education, and health care services, to apply for a driver's license, access job opportunities, register for examinations, enter into business agreements or partnerships or even register for the Unemployment Insurance Fund. Identity documents are also used for voting in national, provincial and local elections.*

Who qualifies to apply for an Identity Document?

Identity documents are issued according to Section 25 of the Identification Act of 1997. This law states that if you are a South African Citizen or permanent residence permit holder, and are 16 years or older, you qualify to apply for an Identity Document.

Anyone, working for the state or a statutory body outside South Africa, or who has been seconded to serve the government of another country, also qualifies to receive an identity document. This extends to that person's spouse and/or children.

To obtain an Identity Document:

- A Bl-9 application form must be completed
- Certified copy of a Birth Certificate; or
- A copy of the TBVC (Transkei, Bophuthatswana, Venda and Ciskei) country identity or travel document; and
- Two recent identical ID sized photographs; and
- The fingerprints need to be taken for recording in the Population Register on the Bl-9 application form. This can only be done by an official of the Department of Home Affairs at a regional or district office or at a South African Foreign Mission abroad;
- If married, the marriage certificate must be submitted;
- Should a woman apply for an Identity Document and resume the use of any of the surnames she was previously known by, documentary proof, e.g. birth certificate or marriage certificate, must be submitted to prove that she is entitled to that surname;
- In the case of re-issues, the ID can be issued to persons whose identity documents are lost, stolen or damaged;
- If divorced, a divorce certificate is needed;
- If widowed, the death certificate of your deceased spouse is needed .

A first application for ID is free of charge, but applicants must bring two ID photographs. A fee of R15 is payable for the re-issue of an identity document.

Waiting period for Identity Documents

The social worker from the Eastern Cape (Port Elizabeth) reported that although the waiting period is supposed to be four months, many patients wait for six to twelve months before receiving their Identity Documents. However, in other areas, waiting time might only be from six weeks to three months.

Unemployment Insurance (UIF)

The Unemployment Insurance Act and Unemployment Insurance Contributions Act apply to employers of workers employed for more than 24 hours a month. When workers are unable to work due to illness, they may claim their unemployment insurance in the form of 'illness benefits'.

How to apply

- The worker or family member collects the prescribed claim form from the nearest office of the Department of Labour and requests the employer to complete it. A doctor must complete the medical section of the form. The client should see that the doctor's name is clearly readable and that the doctor's practice number is on the form, otherwise the claim will be rejected by Pretoria. The claimant must have a bar-coded ID and proof of residence.
- The worker returns the form to the local Department of Labour.

The system of claiming is usually straightforward and payment is over six months for UIF, with the first payment often about six weeks after the employer/medical form has been accepted. Information to all clients should stress the importance of making copies of all completed forms for illness benefits or anything else and that these should be kept in a safe place together with any relevant correspondence.

Social Grants

Current resources in terms of state grants and documentation needed to apply for them are explained as well as people's actual experience in making these applications.

One of the problems when applying for Old Age and Disability Grants is the problem of accessibility to an office of the South African Social Security Agency (SASSA); elderly and sick people often cannot travel to the nearest office, which can be miles away. Family members are not always willing to help in getting the necessary documentation and are often unaware of exactly what is needed and what they need to do or where to go. The queues at the SASSA offices are very long and the officials not always very helpful. Once grants have been authorised, collection from the relevant payout points can also be problematic. A Disability Grant can take up to three months to be authorised and by that time the palliative care applicant may have died of their disease. The above are some of the difficulties experienced by social workers assisting people to apply for grants, Birth Certificates and ID documents.

Social Assistance is an income transfer in the form of grants or financial award provided by government. From 01 April 2006, the responsibility for the management, administration and payment of social assistance grants was transferred to the South African Social Security Agency. SASSA is a section 3A public entity and focused institution responsible to ensure that government pays the right grant, to the right person, at a location which is most convenient to that person.

Most adult patients in palliative care will apply for Disability Grants, although some may have an Old Age Grant. An adult is only allowed to receive one social grant.

Qualifying requirements for grants

Applicant must be a South African citizenship or Permanent Resident for the following grants:

- Old Age; Disability; War Veteran's; Care Dependency (both applicant and child); Child Support (both applicant and child).
- Foster Child Grant: The applicant and child must be resident in South Africa at the time of application.
- Grant-in-Aid: The applicant must be a social grant recipient.

For Asset and Income Table, current amounts of grants in 2008 and 2009, and main offices of SASSA, **see the Resources Section at the end of this book.**

Social Grants

Grant	Requirements	Documents
Old Age	• Resident in SA at application • Over 60 (F); over 65 (M) • Means test, both spouses • Not resident in a State Institution • Not receiving other social grant	• 13 digit bar-coded ID • Marriage Certificate or • Certificate of Divorce or Death Certificate, if applicable • Tax certificate • Bank statements for 3 months • Proof of residence
Disability	• Resident in SA at application • 18–59 (F), 18–64 (M) • Means test, self and spouse • Not in a State Institution • Not in receipt of other social grant	• 13 digit bar-coded ID • Medical Assessment from clinic/hospital doctor • Marriage certificate • Tax certificate (if paying tax) • Bank statements • Proof of residence
War Veteran's	• Over 60 or disabled • Resident in SA at application • From Second World War or Korean War • Means test • Not in a State Institution • Not in receipt of other social grant	• 13 digit bar-coded ID • Proof of war service • Medical Assessment, if disabled • Marriage certificate • Tax certificate • Bank statements • Proof of residence
Grant-in-aid	• For those receiving Old Age, Disability or War Veteran's Grants, who are unable to care for themselves. Must require full-time care (physical or mental).	• Proof of receipt of one of the above grants.

Where to apply for a grant?

- The nearest SASSA Office, which is usually a section of the office of the Department of Social Development
- The applicant has to be seen by an official of SASSA and have finger-prints taken. Officials visit some communities on a regular basis
- Sometimes an official will come to the home of a very ill or disabled patient, but in rural areas it is doubtful if this would happen. Even in urban areas, a patient can wait for weeks before the official visits.

The receipt from the official of SASSA is the proof of application and must be safeguarded. It is issued when all requirements are met for the grant to be received.

- If the application is not approved by the SASSA Office, the person must be informed in writing with reasons.
- There is a right of written appeal to the Minister for Social Development, explaining why the applicant disagrees with the decision to refuse the grant. This appeal must be lodged within 90 days of notification of the outcome of the application.

Problems in sourcing grants for abandoned or orphaned children

- Children under 18 cannot be the grant recipient. A responsible adult has to be found.
- Sometimes grants are abused by the adult and the child does not benefit.

An adult applying for a child grant would need the death certificate of the parents and Birth Certificates of the children.

When children are in the care of someone other than the parent and the parent is still alive, the parent has to make an affidavit stating that she/he has placed the children with the other (family member or friend usually) before a child grant can be accessed.

Child Grants

Name of grant	Requirements	Documents
Child Support Grant	• Applicant must be the primary caregiver of the child/children • Child under 14 years • Means test for applicant & spouse • Not more than 6 children	• Birth Certificate of child • Clinic card • ID of applicant • Letter from school principal for school-going children • Proof of income • Proof of residence • Letter from employer if adult applicant is working
Foster Child (Care)	• An application to place the child in the care of someone other than the parent. Investigation is carried out by a statutory social worker, working within a child & family NGO or in the Dept of Social Development, and an assessment report submitted to the Children's Court. • Allow a minimum of 4 months • A foster child can also receive a care dependency grant, if applicable.	• 13 digit bar-coded ID of applicant • Marriage certificate • Birth certificate of child • Report from school principal • Clinic card
Care Dependency	• Child aged 1 to 18, who is physically or mentally disabled • Applicant, spouse & child means test (except for foster parents) • The child is not permanently cared for in a State Institution	• 13 digit bar-coded ID (applicant) • Birth Certificate (child) • Bank statements (applicant) • Marriage certificate • Proof of residence

Foster Grants (see table: **Child Grants** above)

Unfortunately social workers at child and family organisations and at the Department of Social Development tend to have heavy case loads and there are immense delays in the foster-care process. It is reported from Ladybrand Hospice that clients can wait up to a year for an appointment with the designated social worker from the Department of Social Development for Children's Court Enquiries, whilst in Soweto the period can be two to three years.

Methods of payment of grants

- Cash payments at a specified pay-out centre
- Banks
- Institutions

The recipient may choose to give a Power of Attorney to another person to collect his grant.

Suspension of Grants

The following may result in the suspension of a grant:

- Changes in circumstances
- Outcome of a review
- Failure to co-operate when a grant is reviewed
- Committing a fraudulent activity

The most important document for a Disability Grant (DG) is the medical report. What is written there (100 per cent disability or 75 per cent disability) will determine whether a DG is given only for six months or for longer. A DG granted for six months only will require review and a new medical certificate. People living with HIV have to have a CD 4 count of below 200 and will usually only be given a DG for six months at a time.

An application must be made for restoration of a grant within 90 days of the suspension.

Main reasons for lapsing of grants

- Death
- Admission to a State Institution
- If the grant is not claimed for three consecutive months
- When the period of temporary disability has lapsed
- The grant recipient is absent from the Republic for a continuous period longer than six months.

Reviews

All income must be declared at the time of application. This will form the basis on which SASSA will decide whether a grant must be reviewed. Notification of three months in advance of the date of the review or the date on which the medical certificate is due will be given.

Author's note: *Those who are casual workers working in only some months of the year should be assisted to work out an average monthly income for the year, so that they do not receive less than they should.*

Period Social Relief of Distress

Social Relief of Distress is a temporary provision of assistance intended for persons in such dire material need that they are unable to meet their or their families' most basic needs. In order to qualify for Social Relief of Distress, the applicant must comply with one or more of the following conditions:

- The applicant is awaiting permanent aid;
- The applicant has been found medically unfit to undertake remunerative work for a period of less than six months;
- The breadwinner is deceased and insufficient means are available;
- The applicant has been affected by a disaster, and the specific area has not yet been declared a disaster area;
- The applicant has appealed against the suspension of his or her grant;
- The person is not a member of a household that is already receiving social assistance;
- The person is not receiving assistance from any other organisation.

The SASSA 2007/08 brochure states that Social Relief of Distress is issued monthly or for any other period for a maximum period of three months. Extensions of the period by a further three months may be granted in exceptional cases. Vouchers are issued, no money is given.

Author's note: *In practice, this may be a food parcel from only one shop in the area of the SASSA office and may require transport costs for the applicant. After persistent enquiry by one of the authors at the end of January 2008, a SASSA official of one branch office finally admitted that no social relief was being given since negotiations had broken down with the service provider.*

Transport expenditure may be paid in exceptional cases where:

- the applicant is referred for treatment by a medical officer and no other transport arrangements can be made; and
- the applicant must travel to a specific destination to accept employment where he or she will not be dependent on further State Aid.

Responsibility of the beneficiaries of a grant

It is the responsibility of beneficiaries to keep SASSA informed of changes in their circumstances and means.

For further information on birth certificates, social grants and how to access SASSA **see the Resources Section at the end of this book.**

Social development

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

—NGO participant, Pietermaritzburg

The aim of social development projects is to uplift the community. Effective social development has its roots in the community; ideas and dreams which start there can be fostered and partnered and come to fruition. There needs to be a close working relationship between government, non-government organisations (NGOs) and people in communities in terms of developing skills, resources, and income generating projects in communities, so that community people feel they own the various initiatives.

Social development in Palliative Care

Hospice social workers investigate and identify needs with the client

Where there is no social worker, a home-based caregiver might help with practical matters and together with the client plan to meet these. Conversations between clients and palliative care and legal staff should be on an equal basis, where power is shared and the expertise of the client recognised. There is always a danger of creating added dependency, when the helping person provides solutions, instead of encouraging action and initiative on the part of the client in partnership with the helper. **The table overleaf shows possible needs and planning.**

Patient support groups

Patients often benefit by having their own group, facilitated by a social worker or social auxiliary worker and carers, where they can discuss any concerns they may have. Unfortunately, in deep rural areas, distances and transport difficulties of patients may stand in the way of support groups.

Benefits of a support group to those who attend:

- The group can provide an environment where there is acceptance.
- Friendships can develop. The group can become a community of care.
- People know that everyone in the group is living with the same condition, namely HIV/AIDS – 'we are all in the same boat'.

- There is peer-group exchange of information and personal expertise with regard to diet, medication and other matters. This is often experienced as very supportive.
- Friendships are made and sometimes people who have been rejected by their family, or have no immediate family, grow to experience the group as 'family'.
- Professional information is given and discussion facilitated around healthy eating, treating infections promptly, condom use, sexuality, disclosure, starting a vegetable garden, use of antiretroviral therapy.
- People can be empowered by being encouraged to take responsibility for their own health and in taking an assertive and active role in the decision-making about their treatment.
- Information is given about resources available to people, such as applying for Identity Documents, Disability and other grants.
- Healthy refreshments or a meal may be given.
- Second hand clothing may sometimes be available.
- Activities may be offered which teach skills. Sometimes articles made can be sold for extra income.
- Life skills may be taught, such as conflict resolution, negotiation and other ways of self-empowerment.
- If funding is available, business skills may be taught. Working in the informal sector of the economy or operating a small business can generate the income a family needs to survive.

Needs expressed by patient or family	Social work planning with the client
Financial a) to source income	a) Discussion is held regarding any monies due to the patient: • Unemployment Insurance (UIF) • Pension or grant • Any relevant insurance policies regarding sickness benefits • Maintenance money from father of a child or children • Documentation towards application for a grant is addressed if above monies do not exclude this • Sourcing of interim food parcels for patient and family if necessary and possible
b) to plan debts	b) Informing creditors of current financial situation No rash promises should be made regarding payments at this stage, but an undertaking that the client is doing his/her best to source income to pay.
c) to keep up payments on a funeral policy or attempt to restore a lapsed policy	c) Assist client/family member to talk to funeral policy manager. Talk with other family members to see if they can contribute. See if the client's church can help.
Emotional Fears that neighbours might discover patient has HIV	• Counselling the fears. • Exploring together who the patient has disclosed her health status to and advantages/disadvantages of doing this.
Patient is receiving antiretroviral therapy but has started drinking again	Exploring together what has happened and what the client puts this down to. What are his hopes for himself and his children for the future? How could staying healthy contribute to these?
A child of the patient is addicted to the drug TIK. The patient requests counselling for him	The social worker plans to see the child. Later, a family meeting might be held and referral to a specialised agency dealing with drug addiction, if this is available.
Spiritual The ill person believes he is being punished by God	Counselling conversation and possible referral to spiritual leader of the patient's choice or traditional healer.
Exemption from school fees is needed	The social worker provides a letter to school principal.

CASE STUDY – LEGAL ASSISTANCE

Lydia has only her Disability Grant as income but she owns an RDP (Government Reconstruction and Development Programme) house. She has six adult children and cannot leave the house to only one of them. The hospice social worker arranges for her to see a lawyer. A will is made in which Lydia stipulates that on her death, the house is to be sold and the proceeds divided equally amongst her six children.

Networking

The palliative care social worker, social auxiliary worker or home-based carer, liaises with other organisations in the different communities in which she works in order to source help for clients:

Food parcels: Other organisations may be issuing these and the client can be referred. Churches and individuals in some areas may sponsor food parcels.

Burial: Some churches may subsidise this for their members. See further information in the section on funerals in **Chapter 13, Death and Dying**.

Legal Assistance: Confidentiality of the client always to be respected and referrals made with their consent. Community paralegals can give legal assistance and are often mediators e.g. in disputes between neighbours and others are skilled at pursuing missing birth certificates, ID etc. Some clients may not wish to be helped by someone in their immediate community. Local paralegals have access to lawyers for more complex problems. Such lawyers work at legal clinics at universities, at Justice Centres, at the Legal Resources Centre and private lawyers doing some of their work for free (pro bono). Other organisations such as Black Sash, Lawyers for Human Rights and Pro Bono.Org may also provide legal assistance. If local legal assistance is not immediately obvious, other NGOs, local branches of political parties, trades union will have access to this information.

Summary

In broader terms it should be noted that more educators in schools with expertise in mathematics and science subjects are desperately needed, in order to equip learners to work in technical and industrial sectors of the country. In addition, the apprentice system, equipping school-leavers with a range of artisan skills, needs to be accelerated.

This chapter discusses poverty amongst palliative care patients from the practical experience of social workers in hospices in South Africa. The legal rights of disadvantaged people have been clearly explained and the chapter also gives practical information about documents required to facilitate applications for Birth Certificates, Identity Documents and Social Grants illustrating difficult encounters through a practical case study. The chapter also illustrates some strategies for social development.

Networking to assist clients	
Food parcels	Other organisations may provide these
Subsidised burial	Some churches do this
Encouraging learners to get back to school	Social workers liaise with learners and with schools
Skills training	• Sourcing possible training • Learning bead-work, jewellery or soft-toy making to sell for income • Cooking, waitron skills, household skills • Sponsors for further education and training in building, electrical, plumbing etc. • Consult Sector Education & Training authorities (SETAS – part of the SA Qualifications Authority structure) about possible courses
Encouraging home industries and vegetable gardens to generate income for the family	Look for a donor for seeds, compost and garden implements.
Foster Child Grants	The social worker liaises with a child & family welfare organisation or with the Department of Social Development.
Encourage clients to get involved in community projects	Some patient support groups start a choir or a dance or drama group. They may perform for others in different communities for a fee.
Accessing legal assistance for clients	Legal assistance can be sourced via community paralegals, at legal aid clinics or through pro bono services of private lawyers. Refer to the Resources Section at the end of this book for a list of contact details for legal organisations.

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Managing debt in the context of illness

Jonathan Campbell

Introduction

Credit agreements

Enforcement of debt

What happens to debt upon the death of the debtor?

7

Introduction

> *People become sick because they are poor, they become poorer because they are sick, and they become even more ill as their poverty increases.*
>
> —W.K. Asenso-Okyere, 1994

Palliative care addresses the needs of the whole patient and we are aware of the conundrum that 'the sick become poor and the poor become sick'. In order to fully assist patients and family members, hospices provide quality palliative care free of charge, assist patients in accessing social grants and may offer programmes that promote economic empowerment. However, many people that we help are also worried about the fact that they are in debt. This is a problem that many carers also face in the current economic situation.

Many people today owe money as a result of the purchase of goods or the loan of money, as they do not have sufficient funds to pay for what they need, or think they need. Some people prefer to avoid getting into debt, and try to save money before buying what they want. In this way they avoid paying interest on outstanding debt, but rather earn interest on their savings. But many people with very low income feel that they have no choice but to borrow money or buy on credit, and for them debt is a daily reality. These transactions are called credit agreements which come at a great price, too often forgotten by the unwary consumer.

Credit agreements

The cost of credit

Credit providers (sellers of goods or lenders of money) charge interest on outstanding debt, as well as other fees, the most important of which are initiation and monthly service fees. Although the National Credit Act 34 of 2005 has placed limits on the cost of credit, the total cost is still extremely high and must be carefully calculated. The smaller the credit, the more expensive it is likely to be, and the cost of small loans in particular is exorbitant. The maximum interest rate that money lenders may charge is five per cent per month, but many lenders unlawfully charge interest much higher than this, some as much as 100 per cent per month. **For further information in regard to the cost of credit, see the pamphlet *The Cost of Credit* which is found in the Resources Section at the end of this book.**

Consumer rights and duties

The National Credit Act provides many measures to protect consumers who purchase or borrow on credit, such as the right to pre-agreement disclosure, the right to protection against certain marketing practices, and the right of cooling off. These rights and others are explained briefly in the pamphlet *Consumer Rights and Duties* found in the

Terms you will read in this chapter:

Contempt of court: crime of deliberately failing to appear in court or to respect the authority of a court of law

Credit agreements: agreements by which buyers can take possession of something and pay for it later or over time, usually in monthly instalments

Credit bureaux: offices/departments for keeping records of credit owed by every citizen

Default judgment: judgement taken without opposition by the customer, usually based on the failure of the customer to meet payments

Emoluments attachment order: the legal instruction given to your employer to deduct the money you owe from your salary

Initiation fees: the fees charged for starting/initiating the credit process

Pre-agreement disclosure: sharing of all the facts, interest to be charged and hidden costs with the customer before they sign any credit agreement

Pro rata basis: a debt administrator can pay what you owe to your various creditors according to a fixed proportion e.g. a bigger portion to the one who is owed the most

Service fees: the fees charged for handling the credit process

To attach assets: to seize property or a salary legally for non-payment of debts

Resources Section at the end of this book. Consumers' prospects of obtaining credit are influenced by their credit record, and credit records are kept by certain credit bureaux. **Consumers' rights (regarding information held by credit bureaux) are set out in the pamphlets *Consumer Rights and Duties* and *The Credit Bureaux* in the Resources Section.**

Reckless credit

Before entering into a credit agreement, the credit provider must assess the consumer's (i) understanding of the risks and costs of the proposed credit, (ii) debt repayment history and (iii) financial means, prospects and obligations. A credit agreement is reckless if the credit provider fails to do this, and a court may set aside or suspend all or part of the consumer's rights and obligations (e.g. the consumer might not have to repay the credit provider).

The unlawful use of identity documents, bank cards or PIN numbers

Frequently identity (ID) books or bank cards (credit, debit or ATM cards) are held by credit providers (e.g. money lenders) as security for debt. Money lenders also use these documents to collect on a debt, for example:

- Money lenders control ID documents in order to recover the proceeds of borrowers' social security grants (e.g. old age state pensions).
- Money lenders use bank cards and PIN numbers to withdraw money directly from borrowers' bank accounts (frequently money lenders withdraw far more than they are entitled to, leaving borrowers with little to live on).

These practices are not just unlawful, but are a criminal offence. If consumers who are victims of these practices report them, such money lenders should be arrested, charged and convicted, which could stamp out these widespread unlawful practices. Unfortunately this does not happen frequently enough.

Enforcement of debt

The letter of demand

The collection of debt usually begins with a letter of demand addressed to the debtor (a 'default notice' in the case of credit agreements), requiring payment within a stated time or by a date indicated. It is essential that debtors respond by the due date, either personally or through a legal representative. This response could be payment of the debt or an offer to pay off the debt in specified instalments (unless, of course, the debtor has a defence to the claim). Failure to respond could result in a summons being served on the debtor. This will also lead to an increase in legal costs that can be avoided by proactive behaviour on the part of the debtor.

Summons and judgment

Court action is started by the issue of a summons. A summons is the legal document that initiates legal proceedings in court. It is issued by the court and served on the defendant (the debtor) by the Sheriff of the Court. In the case of credit agreements, summons may not be issued until (i) the debtor has been in default for 20 business days and (ii) 10 business days have passed since the credit provider delivered the default notice (these periods may run concurrently). It is essential that the debtor seeks legal advice when s/he receives summons, or obtains proper assistance from elsewhere. The debtor must respond within five court days (business days) of receipt of the summons by (i) paying the debt, (ii) negotiating payment of the debt in instalments, or (iii) formally defending the action.

Failure to respond will almost certainly result in default judgment being granted against the debtor, without the need for a court hearing, and the debtor will be ordered to pay the judgment costs. For this reason it is essential that the debtor acts immediately on receipt of a summons.

Debt collection

Once judgment is obtained, the judgment creditor has three options to recover the judgment debt:

(a) Attach and sell attachable assets (movable or immovable property) by way of a warrant of execution. This method is preferred if the debtor has attachable assets.

(b) Give notice to the debtor to appear in the debtor's court for a financial enquiry, when the court may order the debtor to pay off the debt in instalments which s/he is able to afford. This method will be used if the debtor has no assets, but has a steady income. (Note that if the debtor fails to appear in court as required, s/he may be arrested for contempt of court).

(c) Obtain an emoluments attachment order in terms of which the employer of the debtor is required by the court to deduct from the debtor's salary a specified amount each month and pay it to the creditor. This method is preferred to (b) above if the debtor is in secure employment.

Administration orders

It is possible for a debtor who has a lot of debt which s/he is struggling to pay off to have him/herself placed under administration by the court. This can also be initiated by a creditor. The debtor is ordered to pay a certain monthly sum to an administrator appointed by the court, who then distributes the proceeds of these payments to all creditors on a pro rata basis. An advantage of this process for the debtor is that no creditor may take independent action against the debtor to enforce the debt. A major disadvantage is that the administrator takes a large fee for the work done, and the debtor is further impoverished as a result. For this reason, administration orders are not recommended.

Debt re-structuring

In any court proceedings involving a credit agreement, a court may declare a consumer to be over-indebted, usually upon the recommendation of an independent debt counsellor. The court can then order that one or more of the debts be re-structured (e.g. by extending the period of time within which the debt must be paid and requiring smaller payments, and/or by postponing the dates of payments). This is a new provision of the National Credit Act which has not been used much yet, and depends to a large extent on the availability of a registered debt counsellor.

What happens to debt upon the death of the debtor?

A person's debt is also known as a 'liability'. Upon death, all assets and liabilities 'vest' in the deceased estate. A new legal entity comes into being (e.g. Estate Late Dhlamini) which owns the assets and is responsible for payment of the liabilities. The Executor or estate representative is responsible for the payment of all debt in/liabilities of the deceased estate from the proceeds of the assets in the estate. Once all liabilities are paid, the balance of the assets is distributed to the heirs in accordance with the will or the laws of intestate succession (if there is no will).

If the liabilities in the estate exceed the assets, then the creditors of the deceased estate will be paid on a pro rata basis, with preference being given to certain creditors (e.g. former employees of the deceased). Note: the heirs of the deceased never become personally responsible for the debts of the deceased (whether or not the assets exceed the liabilities); rather, the deceased estate is responsible for such debts prior to the estate being wound up.

A credit provider may require a consumer to take out **life insurance cover** for the outstanding amount due in terms of the credit agreement. Indeed, it is advisable for consumers to maintain insurance cover in order to protect their heirs. Upon death, the insurer will pay out to the credit provider the outstanding amount due under the credit agreement. Insurance premiums are usually paid monthly together with the monthly instalment in re-payment of the capital and credit costs (interest and fees).

A credit provider may also require a consumer to take out life insurance cover for immovable property (e.g. a house) subject to a mortgage bond, or against loss or damage to any other property which is the subject of the credit agreement (e.g. furniture).

The pamphlet entitled *The Cost of Credit*, as mentioned earlier, is found in the Resources Section at the end of this book.

The Rights of Children and Young People in Palliative Care

Cati Vadwa and Joan Marston

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8

Overview of Palliative Care for children

This chapter describes legal rights of children and young persons including their right to palliative care. Children may be affected either as patients receiving palliative care or as family members of palliative care patients.

Definition

Palliative care for children is the active care of the body, mind and spirit of the child with a life-threatening, chronic, life-limiting illness or severe disability, and includes support for the family into the bereavement period. The aim of palliative care is to improve quality of life and relieve suffering. For children this also includes support of optimal childhood development, formal education, and developmental stimulation to enable the child, at any age, to live the best life possible.

What's different about Palliative Care for children?

Just as adults do, children have the right to palliative care. However, children are not merely little adults, so palliative care for children can not be adult palliative care cut down to size. 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 realisation 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.

A life-limiting illness such as cancer, AIDS or muscular dystrophy increases the vulnerability of children. It also changes the capacities and dependency of that child. Palliative care services, that reach children in their homes, through day care programmes and in residential care facilities, have the potential to improve the quality of life of these children and those around them with skilled and compassionate interventions.

Children's rights and realities as context

A children's rights approach underlies effective paediatric palliative care programming. The essential requirements of childhood are outlined in children's rights: health care and a healthy environment, parental and family care, education, access to information, participation, play, friends, identity, dignity and protection from harm. 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). These rights are set out in international documents such as the United Nations Convention on the Rights of the Child (UNCRC) and the African Union's African Charter on the Rights and Welfare of the Child. South African legal protections are entrenched in the Constitution and laws, especially the Children's Act, and

Terms you will read in this chapter:

Advocacy: active vocal support for those who may not have the ability to represent themselves.

Analgesics/Analgesia: medication that relieves pain

Asylum: protection granted by a government to someone who has fled from another country

Cognitive developmental challenges: challenges to develop thought processes and thus acquire knowledge

Disclosure: information that is revealed which has been secret e.g. HIV status

Exemption: permission not to do what others are required to do e.g. exemption from school fees

Historically unprecedented: this is the first time it has happened (no record in history)

Holistic care: care which takes into account all of the patient's physical, mental and social conditions

Jurisdiction: the authority to enforce laws or pronounce legal judgments in a certain area

Muscular dystrophy: a medical condition with gradual wasting and weakening of the skeletal muscles

Succession: inheritance of position or possessions from deceased parents documents such as the National Strategic Plan on HIV and AIDS and STIs 2007–2011 (NSP).

The guiding principles in realising children's rights are written into South African laws:

- The best interests of the child
- According to need (special provision for special need)
- All rights for all children (equality and non-discrimination)
- Ethical, meaningful child participation in critical areas of their lives including decision-making. The application of these principles in practice, requires adults to be taken into account.
- The whole child
- Each child's individual characteristics (like personality in particular)
- The situation at any point in time *and* their developmental stage
- Uniqueness of each child
- The changing needs, dependencies and abilities of each child

The realities of children's lives in South Africa are that most live in extremely difficult circumstances: in poverty, with many exposed or subjected to violence, abuse, neglect or exploitation; many children living with only one parent or in households headed by a grandparent. On top of this, HIV/AIDS is increasing the scale, scope and interactions of challenges faced by children and their families, communities and service providers. The result is historically unprecedented numbers of children and young adults requiring palliative care, and of children living with someone who is in need of palliative care. Palliative care practitioners need to affirm and build on existing caring resources present in every person, household, family and community. External support can strengthen or undermine the resilience and social and material resources. The approach that is taken in any intervention is key to its long-term success or failure.

Gender issues In children

The rights of all children in South Africa are protected by the Constitution of South Africa, the Children's Act, and various national and international Charters such as the UN Convention on the Rights of the Child (1989). However cultural and social factors may affect the right to gender equality both in the way society perceives the roles of girls and boys; and in the expectations related to the provision of care and support in households where the parent/primary caregiver may be absent, sick or elderly.

The burden of caring for themselves and their siblings, in these households, often falls on the girl child, who then sacrifices her right to education, right to play and right to protection, when carrying out this role.
Government, hospice 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, and be aware that girls are more vulnerable in these situations.

Primary Caregivers of children are usually female and also may be single, and/or elderly, and living in poverty. These factors may prevent their ability to promote gender equality in communities where culturally and socially the male child is seen as more important than the girl child. Male children often grow up without a male role-model or father-figure which may affect their view of gender.

When the parent/primary caregiver dies, palliative care programmes may need to intervene to protect discriminatory inheritance rights of the widow and the female child in personal laws and customary practices. Gender issues need to be considered in providing children with access to sexual and reproductive information, including family planning and contraceptives, the dangers of early pregnancy, the prevention of HIV/AIDS and the prevention and treatment of sexually transmitted infections (STIs) and must take into consideration changing cultural views about children's need for contraception and STI prevention and addressing cultural and other taboos surrounding adolescent sexuality and sexual orientation.

Paediatric Palliative Care in practice

There are new opportunities to ensure that children needing palliative care actually receive it. The National Strategic Plan for HIV and AIDS, and STIs 2007–2011 has paediatric palliative care targets. South African National AIDS Council (SANAC) is responsible for a mid-term review and in the next period there will be opportunity to further strengthen this provision. For ongoing issues related to this, there are structures within the South African National AIDS Council tasked with monitoring and supporting implementation. They can be approached with issues that require attention.

Children as partners in their own care

Effective paediatric palliative care depends upon a multiplicity of partnerships, but most importantly with the child. Building partnerships with children in their own care is vital and too often neglected. When only parents are consulted, important and insightful perspectives of the affected children are missed that could improve care quality. When children are partners in their palliative care, they are:

- Happier
- Feel included and cared for
- Healthier
- Take on appropriate responsibilities
- Talk about their hopes and worries
- Cope better
- Know what to do and what not to do
- Share in their palliative and health care

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.

Co-operation is built on trust. Children must believe that the adult carers have their best interests at heart. They need to trust that carers will provide ongoing and consistent care and protection.

Trust depends also on honesty. While children should never be told a lie – they do not need to be told 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. But whatever they are told it must be the truth, because if they find out that a person has lied to them, they will feel betrayed and will no longer trust that person.

'Disclosure to a child is a process, not an event', is the most often repeated advice provided on disclosure to children. Who decides to tell what, how and when are decisions that the primary caregiver should make with the health care worker. Palliative care providers need to be included in this process.

The Children's Act 38 of 2005 Section 10 provides a legal obligation to ensure Child Participation and states:

Every child that is of such an age, maturity and stage of development as to be able to participate in any matter concerning that child has the right to participate in an appropriate way and views expressed by the child must be given due consideration.

Consent and assent

Children should be offered real choices about their care and treatment where possible and reasonable. For children under 12 years, decisions on treatment rest finally with the parent or guardian and the health-care worker. There are certain choices which adults need to make for the child, according to the child's best interests. If an adult is going to decide, then the child should not be offered the illusion of choice. Palliative care workers can assist primary caregivers to find real choices appropriate to the child. This can be as simple as: 'You can eat now or in 15 minutes.'

But it is better if a child AGREES to the treatment or care – gives *assent*. Then he or she is less anxious and more resilient, even if there has to be a painful procedure.

This assent and co-operation depends on children understanding and accepting their need for health-care and is a major part of their participation in health care. They need to know the facts and to accept them – to assimilate them into their lives and to put them into practice as far as they can. If there is medication to be taken, this is explained to the child in words he or she can understand.

The Children's Act No. 38 of 2005 provides the legal framework for consent in relation to medical treatment and surgical procedures. Specific provisions include conditions under which a child may consent to his or her own medical treatment. The criteria include the child's age ***plus*** their maturity and capacity.

Specific health problems

The most critical childhood illness in South Africa is HIV/AIDS. HIV/AIDS accounts for 40 per cent of deaths in children under five years, but it could be eliminated with improved prevention in adults and effective Prevention of Mother To Child Transmission (PMTCT). Children with HIV/AIDS get sick more quickly than adults do, and the illness progresses more rapidly without treatment. Co-trimoxazole prophylaxis and Highly Active Anti Retroviral Therapy (HAART) are two critical interventions in which palliative care workers could play a role in reducing suffering, disability and death. Children respond well and can adhere to HAART. Children Living with HIV/AIDS who are not on HAART are at high risk of having both physical and cognitive developmental challenges. Once on HAART, these risks drop dramatically. Early detection and treatment of HIV/AIDS in children – with special attention to developmental monitoring, early intervention and support – should be high priorities. Palliative care workers are ideally placed to turn this epidemic around, and consequently reduce their own workload.

Pain and symptom management

Pain and symptom management are essential elements of palliative care. The effectiveness of pain interventions depends on the availability of palliative care drugs and analgesics (including morphine), access to these medications, and health professionals trained and skilled in pain and symptom management. Pain is a common experience in children, however it is often overlooked or ranked low in care priorities.

Minimising or eliminating pain and suffering in children has a positive effect on everyone, including other children in the household and the caregiver. However, the assessment of pain in babies and even in older children can be difficult when they cannot describe their pain, and different skills and tools are required and available. Pain assessment tools must also take into account cultural differences and factors that influence interpretation of the tool. Education and training in paediatric palliative care is scarce and not available in South Africa, except for short, introductory courses. Health practitioners are afraid of prescribing morphine for children and children are left in pain rather than having effective analgesia administered.

What do children say about what hurts? One study reported pain and discomfort as the factors most frequently cited by children as the worst aspects of hospitalisation and the areas most needing improvement. Children said that play activities helped and were valued by children of all ages. Unfortunately, the value of play, both as a right and as distractive therapy, is seldom recognised even though children may continue to play until the day of their death.

In order to hear children's views and experiences, regular opportunities for seeking their unique perspectives should be included in ongoing programmes of quality assessment.

In addition to physically obvious pain, children can experience pain that is:

- Social – being ignored, excluded, discounted, unloved, treated unfairly or badly
- Psychological – fear, anxiety, horror
- Spiritual – humourless, hopeless and without future or possibility of relief, loss of joy, wonder and awe.

Links to other parts of the child's life

Palliative care for children needs to be integrated into other parts of a child's life. For example, basic child health care needs to be provided such as immunisations (unless contra-indicated) and growth monitoring. Care for a child receiving palliative care may need to be co-ordinated with the guidelines on the Integrated Management of Childhood Illness. Children may benefit from attending Early Childhood Development programmes and ordinary schooling with other children, or those who are too frail and need protection may need to have these rights fulfilled by having services provided at home. The principle of a child's best interest guides these difficult decisions, balancing a child's rights to socialise, to education, to inclusion and to health care. Some children may be able to attend school most of the time, but may have multiple or extended periods of absence. Palliative care workers will need to work with other service providers to ensure that a child's right to education is not violated.

Child development: Ages and Stages

As children grow and develop, they pass through many stages, each of which is characterised by windows of opportunity, different capacities and inclinations. These are seen in typical changes – physical abilities; behaviours; ways of communicating, relating; problem-solving; and risk-taking. Children at different stages differ in **what they can and need to do**, as well as in **what care and protection they require.** These developmental phases are commonly called 'Ages & Stages' because developmental phases roughly correspond to age ranges. But ages are only a guideline.

Some important points to note are:

- Girls and boys have the same developmental needs.
- The ***quality*** of childcare is critically important for a child's development. A sensitive-responsive caregiver is one who sees the world from the child's point of view and seeks to meet the child's needs rather than just serving their own. Thus supporting a child's primary caregiver is a critical component of palliative care. This may mean identifying depression or social problems and seeking to link the adult to appropriate services.
- '**Attachments** are the emotional bonds that infants develop with their parents and other key caregivers. These relationships **are crucial for children's well-being and for their emotional and social development**. Attachment is an organising core in development that is always integrated with later experience and never lost.'

Training in palliative care for children will need to include childhood development and assessment and understanding of the different ages and developmental stages of childhood including adolescence. This training also needs to include recognition of possible developmental delays, and information on how to refer and to whom referrals can be made. For example, young children living with HIV/AIDS who are not on HAART are at high risk of having both physical and cognitive developmental challenges. Once on HAART, these risks drop dramatically. Special attention to developmental monitoring, early intervention and support should be high priorities.

Legal tools

The Children's Act **(Act No. 38 of 2005)** and Children's Amendment Act will play a strong role in guiding future policy and practice in paediatric palliative care as there are specific sections on children with chronic illnesses and those with disabilities. The Act:

- changes the age of majority to 18 (effective 1 July 2007);
- changes the minimum age of consent for specified matters to 12 years old, but combines this with an assessment of maturity and capacity;
- These specified matters include consent to medical treatment, surgical operations, access to contraception, HIV testing and disclosure of results;
- Extends the basis for determining the child's ability to consent from age alone, to now including an obligation to make an assessment of the child's maturity and ability to understand the risks and benefits of any treatment or testing;
- Obligates government to ensure appropriate support and special services for children with disabilities and chronic illnesses.

There is specific reference to children with disabilities or with chronic illness in relation to the standard of 'Best interests of the child' in Section 7.

(1) Whenever a provision of this Act requires the best interests of the child standard to be applied, the following factors must be taken into consideration where relevant, namely:
  (i) any disability that a child may have;
  (j) any chronic illness from which a child may suffer;

In addition, Section 11 deals specifically with children with disability or chronic illness.

(1) In any matter concerning a child with a disability, due consideration must be given to:
  (a) providing the child with parental care, family care or special care as and when appropriate;
  (b) making it possible for the child to participate in social, cultural, religious and educational activities, recognising the special needs that the child may have;
  (c) providing the child with conditions that ensure dignity, promote self-reliance and facilitate active participation in the community; and
  (d) providing the child and the child's care-giver with the necessary support services.

(2) In any matter concerning a child with chronic illness due consideration must be given to:
  (a) providing the child with parental care, family care or special care as and when appropriate;
  (b) providing the child with conditions that ensure dignity, promote self-reliance and facilitate active participation in the community; and
  (c) providing the child with the necessary support services.

(3) A child with a disability or chronic illness has the right not to be subjected to medical, social, cultural or religious practices that are detrimental to his or her health, well-being or dignity.

The Children's Act contains provisions for a National Child Protection Register which records reports, convictions and court findings of children in need of care and protection as a result of child abuse and deliberate neglect. In all such instances the register must reflect on whether the child has a disability and/or chronic illness and if so the nature of the disability or chronic illness.

Children in hospice Palliative Care programmes – From rights to wrongs and back again

CASE STUDY – BENNY

Benny was three years old when referred to a hospice programme by a hospital. He was an orphan cared for by his maternal grandmother who was employed as a domestic worker, and living in a shack in an informal settlement area. Admitted to a children's in-patient unit with HIV-related disease, severe malnutrition, hearing loss from frequent and untreated ear infections, unable to speak or to eat solid food, he was also severely developmentally delayed.

Grandmother did not visit the child, despite frequent attempts by the hospice community nurse to get her to do so. She continued to receive the foster care grant. Benny stayed in the in-patient unit for 15 months and developed a strong relationship with a hospice volunteer who was able to get the child to eat solid foods and obey simple instructions, and who expressed a desire to foster Benny. The volunteer also bought all Benny's clothes and toys and took him out for a day each week.

Despite her offer to foster him, the Department of Social Development felt it was in the best interest of the child for him to be returned to the grandmother. The hospice insisted that the grandmother receive training in giving ART before the placement and expressed their concern, both verbally and in writing, to the Director that Benny would again be neglected by his grandmother.

On follow-up of Benny, it was found that his grandmother had left him alone in the shack, had not taken him for his follow-up visit to the ART clinic, and had not been giving Benny his ARVs. This was immediately reported to the Department of Social Development who have been slow to respond. The hospice and the volunteer have made frequent visits to Benny to ensure that he has clothes and food as well as a bed to sleep on and have taken the child for ART follow-up. The hospice continues to report to the Department of Social Development, but does not wish to bring the case to the attention of the media or human rights lawyers as they are dependent on their relationship with the Department.

Protecting children's rights to family care

Hospices are often ideally placed to raise awareness of the needs of children they care for. However, as they have no legal standing to remove children or to place them in foster care, they are dependent on the actions of government services or other authorised organisations such as Child and Family Welfare agencies, who are often themselves dealing with a huge backlog of cases. Once children are placed in in-patient units for holistic care and nutritional therapy, they often improve dramatically, leaving the hospice as physically healthy children without suitable care in the community. Decisions concerning who has guardianship also place hospices in a vulnerable position when acquiring consent for admission to hospice programmes and treatment. This has led to children's in-patient units also registering as Places of Safety or shelters, but does mean that these hospices are carrying out a responsibility other than palliative care.

Children in households headed by vulnerable people

Children with life-limiting conditions often live in households where the primary caregiver is her/himself also vulnerable. Hospices are required to assist in accessing support for children, elderly relatives or sick parents who may be unable to access social support either through lack of knowledge, lack of finances or their own age or health status. Children heading households may not be able to complete their own schooling as they need to find resources to assist them to care for the family, or may need to be at home to care for babies and very young children or sick parents. The children and elderly heading households may also lack the knowledge and skills to provide safe and effective care. Hospices need to provide training, and access special resources for them, such as cots and baby feeds; as well as available social grants.

CASE STUDY – LIZZIE

Lizzie is a bright and happy 8-year-old girl with a chronic, genetic heart condition. As she is an orphan, she stays in a child-headed household with her older siblings (14 and 17) who are very caring, feed and clothe her well, and make sure she attends clinic appointments and that she takes her medication properly. They live in a small house that belonged to their mother, who did not leave a will. The 17-year-old boy does gardening on Saturdays to generate extra income and the 14-year-old girl sees to all the housework and cooking, often missing school to carry out these activities. Due to her condition, Lizzie requires frequent hospitalisation or admission to a hospice in-patient unit which disrupts her schooling, and this has meant that she started school late and has had to repeat Grade one. The school also complains when Lizzie's siblings cannot pay school fees for her or themselves. When her siblings are writing exams, they find having Lizzie at home makes it difficult for them to study properly, and request the hospice to admit her over these periods, which further disrupts her schooling. Her grandmother has now asked for guardianship of Lizzie, but not of the other siblings, as she does not want the responsibility of adolescents. The mother's family also claim that the house in which the children live belongs to them. Lizzie and her siblings would rather stay together in their mother's house with support from the hospice.

Right to education

No child may be denied education on the basis of being unable to pay school fees. Any child living in a child-headed household is exempt from paying school fees. Children who are forced by circumstances to live in child-headed households will need support in ensuring that this right is realised. School fee exemptions must be offered by the school, and the school must assist those requiring such exemptions to apply for them. A child with a chronic condition must be supported by the school so that during any absence, arrangements are made for her to receive any work that she may be missing. The hospice needs to play an active role in ensuring this continuity of education.

Right to inheritance

South African law provides some protection for children's inheritance in a situation in which someone has not left a will. However in practice this law is not protecting all children. A combination of factors dispossess children: lack of awareness of children's rights, complexities and the cost of the legal and court requirements, and sometimes conflict of interest of relatives as legal guardians who may feel entitled to the property. Traditional protection for children's inheritance was by practices that reinforced the acceptance of orphaned children by their father's family, but these practices no longer function. Customary and formal law are in conflict. Case law exists which has resulted in a review of customary law on succession.

Palliative care workers can approach the South African National AIDS Council through its Programme Implementation's Technical Task Team on Human Rights and Access to Justice which has responsibility for monitoring and addressing implementation of the National Strategic Plan on HIV and AIDS and STIs 2007–2011, which has, under Objective 19.4: 'Ensure laws, policies and customs do not discriminate against women and children' and the Intervention: 'Develop and implement guidelines on the impact of HIV on the Master's Office and running of deceased's estates, with focus on women and children.'

Psycho-social care of children and adolescents facing life-limiting illness and death

Children and adolescents within hospice palliative care programmes face loss and death – either their own or that of a family member – or often both. Hospice programmes prepare children and parents for death though activities that promote resilience, such as holding family conferences to plan for the safe care of children once the parent dies; memory approaches such as developing a Memory Box with special items left for the child; Memory books where parents record their family history, family stories and dreams for the child; and Hero books where the child becomes the hero of their own story. Psycho-social and developmental support is provided through one-to-one counselling; support groups, holiday activities and day-care and after school care centres.

A major challenge for hospices is either a lack of social workers in their district or a very high turnover of staff providing psycho-social services who can obtain better

CASE STUDY – CINDY

Cindy is 12 years old and lives with her mother, 15-year-old brother Thomas, and 17-year-old brother Neo who has muscular dystrophy. Her mother has a job and cannot care for Neo who requires full-time care as he is in a wheelchair and cannot feed himself. The children's granny helps when she is not working, but Cindy has to stay away from school to care for Neo at least twice a week and has fallen behind with her schoolwork. She is also frightened that something will happen to Neo when she is alone with him; and gets angry that she cannot spend time with her friends.

salaries and benefits in the formal health and welfare sector. This results in limited bereavement and emotional support for children at a critical time of their lives.

Who cares and at what cost? The burden of caring for sick family members often falls on girls, affecting their access to a good education, denying them time to play and relax, to socialise, and limiting opportunities for employment when they are older. A few Hospices have day-care centres from Monday to Friday but these are usually for pre-school children. There are few facilities for adolescents with life-limiting conditions requiring full-time care.

Promoting children's right to play in Palliative Care

All children have the right to play, every day. It is a basic need of human development and well-being as vital as food, water and rest. It is essential for quality of life. It improves health – both mind and body. Play is children's way of engaging with and making sense of the world around and within themselves. Through play children develop competencies, self-perceptions, social skills and relationships. It is a key to learning life lessons about respect, inclusion, leadership, co-operation and more.

If a child is not playing – check for pain or other problems. Children with life-limiting illness often experience pain, sadness and suffering for short and intense periods. They are often easily distracted by play, music, storytelling and art. Children's palliative care services need to recognise this and integrate these activities into holistic care programmes, including supporting play in the home. Where programmes focus on clinical interventions only, the child's right to play may be compromised.

Protection of children

Child Protection includes protection from abuse, neglect and exploitation, Abuse may include physical, emotional, intellectual, social, and/or sexual harm. Neglect may be deliberate or as a consequence of the ill-health or mental state (such as depression) of a caregiver. Palliative care workers can provide protection in such situations as they can identify and report abuse, neglect and exploitation, as well as support the development of resilience in children through simple interventions, and promote a safe environment. They can raise the awareness of caregivers to minimise avoidable dangers, and to develop children's life skills. Palliative care programmes should include ongoing education on recognising and dealing with abuse. Palliative care workers can strengthen their relationships with child protection workers to improve referrals and support.

Rights for children of refugees and asylum seekers

Not all children in South Africa are South African, however there is a duty to fulfil their human rights, including health care. This has relevance for palliative care provision. A National Department of Health Directive has confirmed the right of refugees and asylum seekers and their children, with or without a permit, to access basic health care and ART on the same basis as South African citizens.

A draft paper by Sharon Pillay, an attorney at Pro Bono.Org, outlines that in February 2007 the United Nations High Commission for Refugees (UNHCR) issued *Guidelines on Policies and Procedures in dealing with Unaccompanied Children Seeking Asylum*. The UNHCR Guidelines states that 'The basic guiding principle in any child care and protection action is the principle of the 'best interests of the child'.

Unaccompanied minors are vulnerable and marginalised and lack the necessary protection and security. They require immediate protection and assistance. Accordingly they will almost always be in need of care and protection.

SA Law relating to foreign unaccompanied minors

Presently, unaccompanied foreign minors are dealt with under the Child Care Act. Section 32 of the Refugees Act 130 of 1998 provides that any child who appears to have a refugee claim and is found to be in need of care as contemplated in the Child Care Act must be brought before the Children's Court which may make an order that the child concerned be assisted in applying for asylum. The Children's Court will make an order providing protection, care and financial assistance through a placement in a foster or children's home which has been approved by the state.

Once the Children's Act comes into operation, unaccompanied minors will be dealt with under Section 150. If it appears that a child who is resident within the jurisdiction of the presiding officer, he or she must designate a social worker to complete an investigation into whether the child is in need of care and protection as contemplated in Section 155(2). The presiding officer can at the same time order that the child be placed in temporary safe care.

In giving effect to South Africa's obligations both nationally and internationally, the 'best interests of the child' principle must be applied as soon as it is ascertained that the child is unaccompanied and should maintain its uniformity throughout the asylum process.

Recent case law regarding foreign children

In *Centre for Child Law vs Minister of Home Affairs*, the rights of unaccompanied foreign children who were detained in South Africa came under scrutiny. The Court held that:

- All unaccompanied foreign children found in need of care should be dealt with in accordance with the provisions of the Child Care Act, which includes asylum seekers and refugee children.
- They must be brought before a Children's Court for an enquiry into their circumstances to be conducted when they are found to be in need of care.
- If it appears at the enquiry that a child has a refugee claim, that child should be assisted to submit an asylum claim in accordance with Section 32 of the Refugees Act.
- The South African government is directly responsible to provide for the socio-economic and educational needs of unaccompanied foreign children in South Africa.
- Unaccompanied foreign children may no longer be detained at the Lindela Repatriation Centre. They must be provided with legal representation at the State's expense.

Things to remember

- Palliative care for children including adolescents may be provided over many years and includes a wide range of conditions often not found in adults.
- Practitioners require special knowledge and skills to care for children of all ages including adolescents.
- A children's rights approach underlies effective paediatric palliative care programming.
- Meaningful applications of children's rights must be based on an understanding of child development that addresses the realities of each unique child.
- Children should be involved as partners in their own palliative care.
- Decisions made for and with children must be in their best interests, where they are not, they must be challenged.
- Life-limiting conditions increase the vulnerability of children.
- Children require psycho-social support but this does not always mean specialist services are required. It is essential to develop children's resilience and strengthen the psycho-social environment and skills of those closest to the children and their families.
- Palliative care providers face many challenges that require training, expanded response and advocacy.
- Children and their caregivers need more information and support in accessing their right to health and social support, including birth registration, education, grants, social and psychological services.

What you can do

- Recognise and relieve pain, discomfort and suffering in children of all ages.
- Eliminate paediatric HIV.
- Ensure early diagnosis and treatment of children for disabilities, and chronic, life-limiting illnesses and conditions .
- Identify children at risk of harm and in need of protection from violence, abuse, neglect, exploitation, poverty, stigma.
- Learn about, use, monitor and support existing legislation and plans such as the NSP.
- Participate in co-ordinating structures such as SANAC and Provincial Advisory Councils on Children.

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Palliative Care for Older Persons

Kathleen Brodrick and Nelia Drenth

9

Introduction

It is important that social policies recognise ageing as an integral part of human life and development. This does not imply that the specific needs of older persons should be denied or ignored.

Older people, because they are reaching the end of their lives and are perceived to be of less value to society, are one of the most neglected groups in South Africa in terms of rights and care. The responsibilities of older women, with regard to caring for others, are increasing when they should be decreasing. The role of the older women is changing from being grandmothers to be cared for to becoming 'mother' again and to care for orphaned and vulnerable children, often without the financial and emotional support they need.

In South Africa, an older person is defined as, in the case of females: a person who is 60 years or older and in males 65 years or older (Older Persons Act 2006). In October 1996, there were approximately 1.94 million people over the age of 65 of whom 61.4 per cent were female, according to the National Strategy on Elder Abuse.

This chapter discusses current pressures on older persons in South Africa. The case study of a grandmother living in a township illustrates how HIV/AIDS, poverty and family pressures affect the way in which she is able to cope with all that she has to each day by virtue of being the head of her household. Her situation is not uncommon, with aspects of her life being shared by many other older people who live in poverty. The current environment in South Africa is overshadowed by the devastating effects that the HIV/AIDS epidemic is having on the lives of families. Coupled with sickness and death of younger people, poverty, crime, elder abuse and lack of education, older people are having to find ways of meeting the challenges that face them every day. The effect of the AIDS pandemic in South Africa is such that the burden of care of orphans falls on older people. There is not sufficient acknowledgement of this phenomenon, not sufficient attention to developing the capacity of older persons and supporting their efforts. Universal recognition that the future of South Africa is in the hands of older people has not taken place and consequently much more emphasis needs to be put on the needs of the older person.

Terms you will read in this chapter:

Anecdotal evidence: based on the account of someone, not on scientific evidence or direct experience

Autonomy: respecting the right for people to make their own personal informed decisions

Disenfranchisement: to deprive a person of the right to vote, but in this chapter, the right to grieve

Collaboration: working together with one or more people to achieve a goal

Cumulative negative effect: the increasing and stronger effect of successive negative occurrences

Custody: the legal right to look after a child

Intra-familial: relationships (or whatever) within the family

Misconception: a mistaken view resulting from a misunderstanding

Phenomenon: something that is out of the ordinary and creates interest and curiosity

Proactive: acting rather than reacting to events – taking the initiative

Stigma: the shame or disgrace attached to an illness or anything which society does not accept

CASE STUDY ILLUSTRATING SOME OF THE DIFFICULTIES FACING OLDER CAREGIVERS

Mrs N grew up in rural Eastern Cape and had three daughters until, in 1970 at age 31, she came to Cape Town when her husband died and she took up domestic work as the main breadwinner. She is now a 69-year-old widow who has had five daughters who all live in Cape Town and she has produced fourteen grandchildren, five of whom have died. She has a five- year-old grandchild with AIDS and there is a newborn baby grandchild with TB and who is HIV positive.

Mrs N's fourth daughter died in 1998 at the age of 21. At that time Mrs N did not know where to turn in her grief and also did not dare to talk to anyone about the 'mysterious illness' that had caused her daughter's death, for fear of what the community might think and might do to her. She became depressed and isolated from her circle of support, her neighbours and fellow church members.

In 2001 Mrs N was introduced to an NGO (Grandmothers Against Poverty and AIDS – GAPA) in Khayelitsha where she met other grandmothers who had lost family members to AIDS. She received education about the disease and learned coping mechanisms. In time she became a peer group leader, counselling and assisting other grandmothers to understand and cope with the results of the AIDS epidemic. Participation in the group meant that she and the group members had an outlet for their grief and at the same time were able to earn extra money by making craft items which they sold.

Mrs N owns a one bedroom home in Khayelitsha where she cares for her youngest daughter P, who at age 26 has end stage AIDS. In 2002 P was diagnosed as being HIV positive when she gave birth to her first son. Mrs N looked after the little boy until its father stepped in. Her daughter embarked on a wild lifestyle, abusing alcohol, running away, being unruly and abusive towards her mother. In the subsequent years P had three more children. P's second son, L (who lives with her now), was born HIV positive, is now five years old, on antiretroviral medication and attends a preschool. Towards the end of every month money runs out and there is no food in the house. In order for L to take his medication for AIDS, a neighbour provides a bowl of porridge for him before he sets off for preschool. Mrs. N's response to the lack of food in the house was to say 'God will provide'. P's third baby died at two months from AIDS complications and the latest baby has yet to be been released from the hospital where it was born with TB and AIDS. Mrs N took her daughter to the clinic where she was offered ARVs but her daughter has not continued with the treatment.

So in all Mrs N cares for her adult daughter who has AIDS, her five-year-old grandson with AIDS and the newborn baby, if it survives, will live with her as well. Mrs N receives a state pension. Two of her daughters occasionally bring her gifts of food, but they too live in a state of poverty.

Mrs N is nursing P as she is desperately ill and close to death. She has tried to get hospice respite care for P, but the nearby NGO only cares for terminally ill children up to the age of 18 years.

In 2007, on the way to her sister's funeral in the Eastern Cape, Mrs N was involved in a bus accident. When she arrived back she was unable to walk. Friends and neighbours, her GAPA friends and daughters, when they could, helped with washing, fetching chronic medication and housework. Mrs N had to give up hosting her weekly group as she was unable to make preparations for the visitors. Today Mrs N walks with difficulty. Mrs N also has cardiac disease and hypertension.

Mrs N, encouraged by her two 'non infected daughters' pays each month for a burial policy for herself, her daughter P and another HIV positive daughter who is not yet sickly. The baby's funeral cost her R2000. It is very important to her that burials are done in the correct manner and she is prepared to do without food in order to pay the premiums. She said that she has to pay 'because our sons and daughters are careless – they don't care'. It would be a 'disgrace in the neighbourhood and rude if there is not a proper funeral'.

Mrs N is worried about the fact that all the cemeteries in Khayelitsha are full and families have to go further and further away from their homes to find a burial plot. She has come to terms with the fact that she will have to be buried in Cape Town, rather than the Eastern Cape because her family will not be able to afford to transport the body 'home'. Nevertheless, all other burial and funeral traditions have to be carried out according to custom.

Palliative Care and the Aged

Significant linkages exist between palliative care and geriatrics, for example, frailty syndrome, elderly cancer, neurodegenerative disorders, end-stage organ failure, elderly with chronic pain, and the bereaved elderly. As Lo and Woo noted:

> *Both palliative care and geriatrics focus on patient-centred holistic care, emphasizing quality of life, adding life to days when days can no longer be added to life. Both specialities take a patient-centred rather than an organ-based approach, carefully considering the benefits and burdens of intervention and treatment in advanced disease and age … Both geriatricians and palliative-care physicians attend to families' needs, e.g. ameliorating bereavement and stress associated with caregiving for the demented and the terminally ill … Older people are [also] more likely to face bereavement, for which counseling and support should be available.*

Indeed, using Dame Saunders' concept, the potential components of 'total pain' experienced by the aged are shown in Table 1.

Moreover, there is a growing recognition of the need to establish closer links between palliative care and the aged globally. Indeed, the theme for the 2007 World Hospice and Palliative Care was *Across the Ages: From children to older persons*, emphasizing that people of all ages need access to hospice and palliative care, either as patients, as family members, or as informal carers of people facing progressive, life-limiting illness.

Table 1: Potential components of total pain in elders (different components may overlap)

Physical Pain	Psychological Pain	Social Pain	Spiritual/existential Pain
Pain from cancer	Worry	Poor living conditions	Indignity
Pain from metastases	Anxiety	Financial Hardship	Meaning of suffering
Pain from treatment	Fear	Inadequate communication	Meaning of life
Pain from joints	Negativity	Inadequate information	Purpose of life
Pain from trauma	Low self-esteem	Loneliness	Value of life
Pain from wound	Despair	Isolation	Sanctity of life
Pain from sores	Depression	Neglect	
Pain from immobility	Demoralisation	Abuse	
Pain from poor oral/dental hygiene	Derealisation	Burden on family/carers	
		Family disharmony	
		Discharge placement	

Grandmothers and the AIDS epidemic

The impact of the AIDS epidemic extends well beyond persons with HIV or AIDS. Most adults who die of AIDS have parents who survive them who are affected in several ways by the illness and the death. Since adults with AIDS are typically in their twenties and thirties, their parents tend to be in their fifties, sixties and seventies, and they constitute a substantial population of older persons who are directly impacted by the epidemic. AIDS is referred to as 'the grandmothers' disease', because elderly women so often assume the role of caregivers, tending for their dying son or daughter, and then the children left behind.

The 4th *Report on the Global AIDS epidemic*, published by the Joint United Nations Programme on HIV/AIDS (UNAIDS, 2004), states that the worst orphan crisis is in Sub-Saharan Africa, where 12 million children have lost one or both parents. It is estimated that this number may climb to more than 18 million by 2010. The death of the parents adds an immense burden predominantly on the shoulders of the grandmothers, as they become the primary caregivers, often without financial and emotional resources. In addition, the grandmother often has to take care of the children from more than one household, when more than one of her own children die of AIDS-related illnesses. The grandmother thus has to cope with her own multiple losses, as well as caring for grieving, and often infected, children. She has to prepare herself emotionally for grieving over these grandchildren eventually as well. She finds herself in a constant grieving environment.

Research into the plight of grandmother-headed households living on the Cape Flats in 2000 showed that grandmothers were ill equipped to deal with the effects of the AIDS epidemic. Grandmothers found that they were faced with the deaths of their children and grandchildren after a relatively short period of progressive weakening, weight loss and being bedridden. Their normal channels of support such as neighbours, other family members and communities closed as everyone feared the possible consequences and stigma of being associated with the disease, the origin of which is clouded by misconceptions in many communities.

Grandmothers in the study reported that they were becoming poorer because of the additional costs of caring for a sick person, their pensions being now the only income for their households and their responsibilities for caring for grandchildren being now full time. Furthermore, the grandmothers did not have any knowledge of HIV/AIDS and were powerless to begin to know how to care for their sick children and grandchildren.

Older people are considered to be the 'keepers of the culture' and because of the huge expense of a culturally correct funeral, household income dropped considerably as grandmothers borrowed money from neighbours and friends to pay for the funerals of their children and grandchildren.

Grandchildren still at school relied on their grandparents' income to keep them at school after the death of their parents. Although there might be relief in some schools from paying fees, the children still need uniforms, pens, pencils, files, glue etc. and still have to pay for outings or they are excluded. Children, below school going age, have to remain in grandmother's care everyday as there is no money to pay for crèche or preschool fees. Grandmothers found that they have no time for themselves, having to line up at hospitals and clinics from the very early hours of the morning with small children while they waited for their medication or doctor visits. No provision is made for the children or the older people at the hospitals.

The stress of loss of children to HIV/AIDS, lack of money, their own chronic illnesses, presence of small children all day and night, lack of understanding about the illness and lack of neighbourly support diminished the older people's sense of worth resulting in widespread depression and thoughts of suicide.

The challenges that grandparents, and specifically grandmothers, face in fostering their grandchildren, are summarised as follows:

- Financial implications;
- Emotional strains resulting from negative community reactions towards the fostered grandchildren, or worries about the cost of childcare;
- Physical strain and exhaustion resulting from taking care of infants and younger children, as well as from additional work required to cover the escalating cost incurred for taking care of the grandchildren;
- Reduced participation in social activities due to the fear of the community of including the infected children. Intra-familial relations may become strained in the event of conflict over custody or if the grandparents judge other family members to be negligent about sharing responsibility.

The grandmother's own health status must be added to this list of challenges with which she is confronted.

Rights of older caregivers

The Older Persons Bill 2006 and the Constitution of South Africa are some of the guidelines regarding the rights of older persons. The National Action Plan (NAP) is a national initiative, whereby the South African Government responded to the call for a detailed policy and legislative programme to realise the fundamental rights and freedoms enshrined in the Constitution. The NAP affirms that no one shall be unfairly discriminated against on the basis of age. The NAP also refers to the right of access to justice, and as a result, the Department of Justice ensures that courts are made more accessible for older people. The older persons are also protected under the Right of Access to Health Care Services. The NAP encourages the following to be addressed on provincial level:

- Providing adequate state funding
- Establishing homes and frail care centres
- Providing funding for home-based care
- Improving the quality of care in homes and frail care centres.

South Africa is a member of the United Nations and has adopted the UN principles for older persons. The authors have added some suggestions on how palliative care may be able to contribute to these principles.

Independence

- Older persons should have access to adequate food, water, shelter, clothing and health care through the provision of income, family support and community support and self-help. (Palliative caregivers assist by identifying the needs of the elderly and provide resources to a certain extent and within the means of the relevant Hospice.)
- Older persons should have the opportunity to work or have access to other income-generating opportunities.
- Older persons should be able to participate in determining when, and at what pace, withdrawal from the labour force takes place. (Older persons in the employ of Palliative Care organisations should be included in this decision-making process.)
- Older persons should have access to appropriate educational and training programmes. (Palliative care training programmes are a means of empowering the healthy elderly to become involved in care-giving in the community and to advocate for palliative care amongst all population groups.)
- Older persons should be able to live in environments that are safe and adaptable to personal preferences and changing capacities.
- Older persons should be able to reside at home for as long as possible. (The wish of the dying older person to die at home should be respected by palliative caregivers.)

Participation

- Older persons should remain integrated in society, participate actively in the formulation and implementation of policies that directly affect their well-being and share their knowledge and skills with younger generations.
- Older persons should be able to seek and develop opportunities for service as volunteers in positions appropriate to their interest and capabilities.
- Older persons should be able to form movements or associations of older persons.

Care

- Older persons should benefit from family and community care and protection in accordance with each society's system of cultural values.
- Older persons should have access to health care to help them to maintain or regain an optimum level of physical, mental and emotional well-being and to prevent or delay the onset of illness.
- Older persons should have access to social and legal services to enhance their autonomy, protection and care.
- Older persons should be able to utilise an appropriate level of institutional care providing protection, rehabilitation and social and mental stimulation in a humane and secure environment.
- Older persons should be able to enjoy human rights and fundamental freedoms when residing in any shelter, care or treatment facility. These should include full respect for their dignity, beliefs, needs, privacy and the right to make decisions about their care and the quality of their lives.

Self-fulfilment

- Older persons should be able to pursue opportunities for the full development of their potential, even when they have been diagnosed with a terminal illness.
- Older persons should have access to the educational, spiritual, and recreational resources of society.

Dignity

- Older persons should be able to live in dignity and security and be free of exploitation and physical and mental abuse.
- Older persons should be treated fairly regardless of age, gender, racial or ethnic background, disability or other status, and be valued independently of their economic contribution.

All of the above-mentioned principles should be addressed and adhered to through policy implementation in palliative care.

There are no specific rights, recognised in the Older Persons Bill 2006, for older persons who find themselves in a care-giving role. However, in order to afford older persons the right to remain in their communities for as long as possible, which is a clearly stated right, they should have access to support programmes. If they become frail while in a care-giving role, then provision should be made for home-based care.

Alpaslan & Mabutho (2005), identified the following challenges experienced by grandmothers taking care of AIDS orphans. All of these challenges affect the rights of the elderly:
- Limited and/or lack of income prevents grandmother caregivers from providing orphans' basic needs;
- Elderly grandmother caregivers experience difficulties with Government Aid;
- Elderly grandmother caregivers are the only ones left to be economically active, but their own health problems challenge and prevent them from earning a decent income;
- Elderly grandmothers face the challenge of no support from the children's fathers and the extended family;
- Elderly grandmother caregivers face the challenge that the AIDS orphans in their care do not accept their authority.

It is common to discover that older people in South Africa suffer from low self esteem and consequently feel that they are unable to think of solutions to problems concerning life choices. Often they are not proactive in seeking help outside their communities. The reason for this may be that they have spent most of their lives living under the apartheid system, when their movements, their educational opportunities, their access to health facilities and work opportunities were all controlled by the state. This system continuously eroded their sense of self esteem, creativity and problem solving ability. Older people, when exposed to education on human rights, are required by human rights workshop facilitators to take a hard look at their lives. This reflection leads to the recognition that they have been disadvantaged. Furthermore, they realise that this previously enforced environment fostered feelings of lack of self worth and helplessness. Once older persons recognise that they need not remain quiet or compliant, a large obstacle to their taking charge of their lives and demanding their human rights disappears.

Elder abuse

Elder abuse is a growing phenomenon worldwide and is emerging as a growing social problem. The responsibility for dealing with elder abuse shifted from the Department of Social Development (South Africa) and has become the responsibility of the community and other non-governmental sectors. The Department of Health took the lead and formed a committee for the Development of Elder Abuse Strategy in 1998. This was in collaboration with key departments and NGOs. The Department of Social Development, in the Older Persons Bill 2006, focused on the protection of older persons in the community and in residential facilities in Chapter 5 of the Act.

Older persons who are in need of care and protection are defined as follows:
- Have their income, assets or old age grant taken against their wishes or who suffer any other economic abuse.
- Have been removed from their property against their wishes or who have been unlawfully evicted from any property.
- Have been neglected or abandoned without any visible means of support.
- Live or work on the streets or beg for a living.
- Abuse a substance or are addicted to it and are without any support or treatment for such substance abuse or addiction.
- Live in circumstances likely to cause, or to be conducive to, seduction, abduction or sexual exploitation.
- Live in circumstances which may harm them physically or mentally.
- Are in a state of physical, mental or social neglect.

Data on elder abuse and neglect in South Africa are not collected systematically. An opinion poll done by the National Department of Health reported that there is a widespread awareness of abuse of older persons in South Africa. Concealment of abuse occurs due to the stigma attached to it and fear of victimisation. There is therefore a lack of accurate and current figures for the abuse and neglect of the elderly, and more specifically, elderly females, in South Africa.

The profile of older persons who are likely to be abused and neglected is summarised by the *National Strategy on Elder Abuse* as follows:
Older persons who:
- Are dependent on one person for all or part of their care.
- Exhibit difficult or inappropriate behaviour, confusion or memory loss as a result of previous mental or psychological disturbances or due to more recent conditions such as impairment through some kind of illness

- Have communication problems
- Have longstanding negative personality traits
- Have feelings of low self-esteem
- Have a background of conflict and tension
- Have limited social contact and networks

The above-mentioned profile is of vital importance in the palliative care environment, as it assists in identification of the vulnerable elderly and in the approach towards care. Abuse of older persons must be brought to the attention of the Director General of the Department of Social Development. At a local level, abuse should be reported to a social worker or a police official. However it is the responsibility of all people to report cases of abuse.

Abuse of children by older persons

There is anecdotal evidence that the Child Care Grant given by the Department of Social Development is often used by the mothers of the children for their own use. In some cases children are left with grandparents, without the intended financial grant being given to the grandparent for the child's upkeep. In other cases, when a grandmother has managed to secure a grant for the upkeep of a child, the mother of the child has kidnapped him/her from the grandmother's care so that the grant can be paid to her. Many grandmothers, once the parents of a child have died, apply to foster the orphan which entitles them to a substantial foster care grant. Rarely is the money used solely for the child. It is used for the purchase of food for the whole household.

Palliative Care for older persons

Many areas of palliative care for the elderly are yet to be explored, such as their attitudes toward their own death; their reactions to the death of others; the meaning and impact of multiple deaths; and the bereavement coping styles of older persons.

It is difficult to predict the timing or quality of life at the end of life for people with chronic or terminal illness. Moss, Moss and Hansson state that the terminal decline in cancer tends to be relatively predictable, but fewer than one fourth of older persons die of cancer. Most people die from other chronic diseases which are not as predictable. The nearing death of an older person is often viewed as a normal process of life. Emotions attached to this process are overlooked, thus leading to disenfranchisement or little social permission to grieve the death of an older person. This in itself attacks the right of the older person to die with dignity as well as the rights of the loved ones to grieve the death of the deceased.

The death of an elderly parent is seen as an expected psychosocial loss and is influenced by the following domains:

- Anticipation that the parent will predecease the child;
- Disenfranchisement – where there is little social permission for family members to grieve the loss of an elderly parent;
- The circumstances of the death – indicating sudden death, prolonged illness, or a violent death;
- Social construction of the loss; and
- Maintaining the tie with the deceased

Old age is a time of multiple and sequential losses, thus exposing the elderly to the risk of bereavement overload and a cumulative negative effect. It is a regular occurrence that people view older person's normal responses to bereavement, such as fatigue, social withdrawal, and confusion, as problems of old age. Loss of siblings spouses, parents and grandchildren have specific meaning for older persons and should certainly be addressed in bereavement programmes.

Available support structures for older people

Since 2001 – when a pilot project by the Albertina and Walter Sisulu Institute of Ageing in Africa at the University of Cape Town and a group of NGOs was run in Khayelitsha to educate grandmothers about HIV/AIDS and coping skills – worldwide interest was awakened to the potential capacity of grandmothers to successfully step into the role of carers, mothers to orphans and educators of their communities. It was found that grandmothers, when taught in their own language, benefited greatly from educational workshops on a number of related subjects. The subjects were, HIV/AIDS knowledge, home nursing, food gardening, human rights, bereavement and very basic business skills. Furthermore, the formation of psychosocial groups where grieving grandmothers were counselled by their peers was very successful in curing depression and lessening stress levels. The manufacture of handicraft by the groups not only attracted grandmothers to the groups, but contributed to their self esteem and the household income.

The acknowledgement of the important role that grandmothers have to play in the maintenance of family structures and their capability to run households has been made worldwide. In South Africa, many organisations make provision for the education and support of their older population. In the Free State, the ACVV has organised grandmothers' groups, Age in Action, in all provinces, to promote the training of older people about HIV/AIDS. In all provinces NGOs are including older people in their training programmes. Examples are: GAPA, Ikamvalabantu in the Western Cape, and Muthandane Society for the Aged in KwaZulu-Natal.

A telephonic help-line for older people who are being abused is manned by counsellors from the organisation, Halt Elder Abuse (HEAL). The line can also be used by the general public to report cases of abuse. The number to dial is 0800 003 081.

Gender considerations

Most older people and most of their carers are women. Women are perceived as nurturers and carers and in the event of an older man becoming ill, his wife will care for him at home. Caring is not seen as a male role and men do not perceive themselves as having the skills for nursing. If the wife becomes ill, the husband may feel inadequate in the caring role. Often this means that women are admitted to a care home or to hospital rather than being cared for at home. As well as the distress of moving from her own home, this has implications for the cost of care.

In general, women have a longer life expectancy and there are more elderly widows than widowers. It is also true that men more commonly remarry when their spouse dies than do women. This reinforces the fact that more older women are on their own than older men. In relationships where there was inequality or sharp division of roles such as the man paying the accounts, the woman on her own may not have the skills to take on these tasks. Similarly, the man may not have learned how to cook and finds himself without the skills to produce a meal.

As described earlier in this chapter, the effects of the AIDS epidemic has impacted heavily on the elderly. Grandparents often have the distress of caring for their adult children who are sick and may be dying as well as caring for their grandchildren who are orphaned. This is usually the grandmother.

Conclusion

The worldwide role of older persons, as a source of accumulated knowledge and guardians of moral values, takes on new dimensions in South Africa. Grandparents do not have the luxury of watching their children rearing their grandchildren, visiting them occasionally, helping out where needed and offering guidance or insights about family history. The time has come when older people have to take on the total responsibility of young families because their children have died from AIDS related diseases. At the same time grandparents are themselves becoming frail due to age-related disease. The challenges for grandparents in coping with all that comes their way, cannot be met without the assistance of all agencies that interact with older people. These agencies need to offer insight and information into human rights, education about HIV/AIDS, education about age-related diseases and psycho-social support for older people. The state-run agencies must provide basic necessities of living such as housing, water, health and protection against abuse.

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Refugees and other potentially vulnerable groups

Duncan Breen and Liz Gwyther

With special thanks to Eric Harper of Sweat, Lukas Muntingh of CSPRI, Joanna Vearey of Forced Migration Studies Programme and Grant Jardine of Cape Town Drug Counselling Centre

10

Introduction

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

As service providers, we are in a unique position to contribute to the future of the country by ensuring the successful realisation of these rights in our respective fields. In some cases, particular population groups may face greater barriers to realising their rights and by being aware of such barriers we can tackle them as they arise.

This chapter specifically addresses some of the barriers facing refugees, asylum seekers and migrants, sex workers, drug users, prisoners and gay men in accessing various forms of health care. Some of these groups have previously been stereotyped as being 'high risk groups' for HIV transmission and infection. It is such prejudice, along with other issues, that we need to tackle in order to ensure equitable access to health care in compliance with existing South African law. Another group of people who are being stigmatised and marginalised are those with multi drug-resistant or extensively drug-resistant TB.

Many health care workers may initially feel uncomfortable assisting some of the categories of people described in this chapter. These are categories of people who may experience prejudice on a number of fronts and it would not be uncommon for some health care workers to share such prejudices. These may face severe challenges to their human rights regarding access to health care as well as other issues. This chapter aims to help health care workers negotiate some of the difficulties of working with such challenges. In the case of those in prison, it is also important to note that they will be entirely dependent on prison officials to provide access to health care and hence can be additionally vulnerable for this reason.

The palliative care approach sees each person as unique with their own needs and their own stories. Palliative care encourages an empathetic, non-judgmental approach to patient and family members. Palliative care practitioners assist patients to become active members of the care team and to make informed decisions about their health care as best fits their own context and need.

Assisting potentially marginalised groups

Accessing health care can prove a major challenge for potentially marginalised groups. In some cases, these challenges will relate to accessing services once a person arrives at a health care institution. For those in prison, being able to access a health care institution in the first place can be a major challenge. This section will explore how health care workers' attitudes can affect how potentially marginalised groups may access services at health care institutions.

When a patient such as a drug user, sex worker or refugee arrives at a health care institution seeking assistance, some health care workers may be too quick to identify with what they **think** are the real needs of the patient, based on their beliefs about the patient. This may prevent the health care worker from actually hearing what it is that the patient is requesting. For example, a health care worker may believe

Terms you will read in this chapter:

Asylum Seeker: someone who has fled from political oppression in their own country and is seeking protection in another country

Disempowering: to have power or influence taken away from you

Incarceration: putting somebody in prison or a place of confinement

Marginalised groups: groups which are kept away/excluded from the centre of influence, power or acceptance

Migrants: people who move from one place to another, often for employment or economic improvement

Post-exposure prophylaxis (PEP): a short, intense course of antiretroviral treatment to prevent potential infection following exposure to a risk of HIV infection e.g. after a sexual assault , needle-stick injury

Xenophobia: an intense fear or dislike of foreign people, their customs and culture that a sex worker should leave sex work, because **the health care worker thinks it is best for the sex worker**. In this way, the health care worker would be disempowering the sex worker by making decisions for him or her and risks alienating him or her from accessing further treatment. The process of administering health care should be seen as a partnership between the patient and the health care worker, where both are able to provide input on the course of treatment to be followed. If intervention into a patient's situation is appropriate, the health care worker should contact an organisation that has experience and expertise in dealing with some of these issues and they can provide advice or assistance where necessary.

In this way, no health care worker is dealing with such difficult issues in isolation. If a health care worker is presented with a patient and does not know the best advice to offer, such partnerships can be valuable in then being able to provide a higher quality of service to the patient.

A list of service providers is available in the Resources Section at the end of this book.

At the same time, given the stresses health care workers face on a daily basis, having such a supportive network can reduce the feeling for a health care worker that it is solely up to him or her to 'solve' a patient's problems. By working in such partnerships, such stresses can be alleviated and health care workers can avoid 'burning out'.

The next section of this chapter will focus on working with people who may be more vulnerable and in need of additional assistance to access quality health care.

Refugees, asylum seekers and migrants

The Law

In South Africa, refugee status and the rights this provides are governed by the 1998 Refugees Act. Although this is a very progressive piece of legislation, there are still many challenges in implementing all the measures it provides for. The Department of Home Affairs (DHA) determines who qualifies for refugee status and issues and renews the documents that refugees are provided with. It is well documented that the DHA has experienced many challenges in issuing documents to South African citizens and those applying for refugee status face even more extensive delays.

In terms of the Refugees Act, to be granted refugee status is to be given the right to remain in the country and to have the protection of the South African government. Refugee status also provides for most of the rights granted to South African citizens such as the right to work, study, access health care and have freedom of movement in accordance with the Bill of Rights. The key right refugees are not granted is the right to vote and refugees are not entitled to receive a social grant until they have received permanent residence status.

The Refugees Act provides refugee status for someone who can demonstrate 'a well founded fear of persecution' in his or her own country and could not rely on the protection of his/her own government. This persecution is usually due to factors such as race, ethnicity, nationality, religion, political opinion or membership of a particular social group such as homosexuals (or in some cases, women). A person can also be granted refugee status if there is war or a similar generalised threat affecting the whole or the specific part of the country where they were based. A person with refugee status will be issued with a Section 24 permit and can apply for a refugee ID.

A person who has applied for refugee status, but has not yet had his or her application finalised, is called an 'asylum seeker'. Although the law states that the process of applying for refugee status should be a rapid one, in practice it takes a long time. Many people wait for a number of years before being told whether their applications have been approved or rejected. In the meantime, asylum seekers are allowed to work and study as well as access health care. Asylum seekers will be issued with a 'Section 22 permit'.

Whilst both refugee and asylum seekers' documents have expiry dates, the recent expiration of such a document should not be reason to deny a refugee or asylum seeker access to the services to which they are legally entitled. Refugees and asylum seekers are required to renew their documents at the Refugee Reception Offices run by the DHA. However, the challenges faced by DHA mean that no one is guaranteed access to a Refugee Reception Office on any given day and therefore it is likely that documents may expire before the bearer is given the chance to renew them. Because of these challenges, many foreign nationals in South Africa remain without documents, or are in possession of expired documentation. Because a person does not have valid documents to be in South Africa does not mean that he or she is not deserving of refugee status. Many are forced to become self-reliant, but service providers can assist them by helping to ensure their access to the services they provide.

Health Care

The Law

Basic Health Care

The South African Constitution guarantees 'access to health care for all' and everyone within the country is assured access to life-saving health care. In the context of HIV, this guarantee should extend to HIV services, including antiretroviral therapy (ART).

According to Section 27 (g) of the 1998 Refugees Act, a refugee is 'entitled to the same basic health services and basic primary education that the inhabitants of the Republic receive from time to time.'[1] For asylum seekers the situation was less clear until the National Department of Health (NDOH) issued a directive in 2007. Importantly, this directive clarifies that refugees and asylum seekers – with or without a permit – shall be exempt from paying for ART services, irrespective of the site or level of institution in which these services are rendered. The recent HIV & AIDS and STI Strategic Plan for South Africa, 2007–2011[2] specifically includes refugees and the National Department of Health (NDOH) has also clarified that patients do not need to be in possession of a South African identity book in order to access ART.[3] Without support from all public health practitioners, the intentions of the recent Directive, and supporting guidelines, may not be met.

According to the directive from the NDOH, undocumented migrants should have the same access to basic health care as refugees and asylum seekers given the state's decision not to discriminate on the basis of documentation. This is a welcome move that allows all people in South Africa to be included in prevention and treatment services.

Children who have arrived in South Africa without their parents are known as 'unaccompanied minors' and face additional risks without the care of a guardian. In terms of the law, unaccompanied minors may apply for refugee status as an adult may. In the same way then, the provisions for refugees and asylum seekers also apply to unaccompanied children. It is therefore evident that South African legislation and subsequent policies and directives have become more inclusive and that it is safe to conclude that no person who finds him/herself in the jurisdiction of the Republic is excluded from access to healthcare.

Gender issues

In addition to the significant losses experienced by refugees (loss of country, home, possessions) women are vulnerable to sexual exploitation and loss of dignity as described in this very moving account by Alice (not her real name) in a national newspaper in 2008:

Story

'It's either you have sex with me or you get deported.' Living a life like this is far away from the hopes I had growing up in Zimbabwe, dreaming of becoming a doctor. My dreams were shattered when my father passed away before I even finished school. Partly out of desperation, I fell in love with an old businessman in our village. I thought I loved him. He promised to take care of my mother and me, and to pay for my school fees. He took advantage of me, impregnated me and dumped me. I dropped out of school. Since I had no qualifications, my only choice was to find a job as a maid so that I could fend for my old mother and my unborn child. Under all this pressure, I gave birth to an immature baby at six months. I had to stay in hospital until he was old enough to get out. My stepsister down here in South Africa felt sorry for me and asked me to come and look for something here, since there are few opportunities in Zimbabwe. I entered the country illegally, and stayed at home, afraid of being deported. I respected my sister's husband. He looked like a good, caring husband and father, until all hell broke loose. It started one day when I was coming out of the bathroom. I got inside the house to realise he was back from work earlier than usual. I had only a towel around me. As I took my clothes so that I could go and dress in the bathroom, he moved faster towards the door and locked it from the inside. He became aggressive – I could not take his hands off me. He pushed me on the bed. He touched me everywhere, kissed me and forced me to have sex. This happened for almost three weeks and I suffered in silence. One day I related the whole story of her abusive husband to my sister. Instead of comforting me, she became angry and even accused me of seducing her husband. She told me I was loose and that is why I had a child at home out of wedlock. She threw me out of the house and this is how I ended up on the streets. I am asking for help. I would like to enrol and train so that I get a certificate, I want to be able to stand on my own feet, spread my wings and fly higher.

This story is part of the I Stories series produced by Gender Links Opinion and Commentary Service for the 16 Days of Activism on Gender Violence.

Ingrid Palmary at the Forced Migration Studies Programme at Wits University comments:

Alice's story echoes the experiences of many women who travel far from home to seek opportunities and livelihoods they cannot find in their home country. Both women and men who migrate face a number of challenges, but the nature of these challenges and their impact is very different. Problems often begin for women as soon as they decide to leave their country. The border post is one of the most dangerous places in a woman's journey. Syndicates of smugglers based at the borders are responsible for widespread violence against women.

Moreover, added to the risks of sexually transmitted diseases and unwanted pregnancy, survivors of these attacks often face social stigma and exclusion, rather than support. The stigma attached to victims of sexual violence is what makes it a particularly effective way to harm women. This is one reason why during times of conflict, including the xenophobic attacks of May 2008, rape is such a common and effective weapon used against foreign women.

Once a woman crosses the border, she faces a number of challenges. Overall, women, who bear the primary responsibility for the care of children, find migration with children extremely difficult and more expensive than migrating alone. On arrival in South Africa, they have greater difficulty in finding work given their childcare responsibilities. They may even have greater difficulties finding low-cost accommodation that will accept children. Research also shows women who migrate with their children tend to earn less than those who do not. As with all poor women, they also face difficulty in finding safe and affordable childcare for their children while at work.

Like men, many women arriving in South Africa find themselves unable to get the documents needed to legalise their stay in the country. However, the effects can be much more serious for women than for men, as lack of documentation makes women particularly vulnerable to violence. Undocumented women migrants who suffer from domestic violence, or any other form of gender-based violence so widespread in South Africa, are unlikely to report to the police or make use of other social services. Research by the Forced Migration Studies Programme shows that xenophobia and discrimination from service providers acts as a significant barrier to getting services for women who were in abusive relationships. In addition, abusive men use women's migrant status to justify their abuse, and their inability to go to the police was a reason for their ongoing abuse. In her story, Alice recounts how she was first afraid to tell of being raped by the brother-in-law in her home, and later how she endured abuse because she had no money and nowhere to go. Fear of repercussions means these women are not only unable to seek justice, but also do not get access to psychological and health support, such as post-exposure prophylaxis for HIV.

– Ingrid Palmary is a senior researcher with the Forced Migration Studies Programme at Wits University.

Specialised care

Access to ART

Refugees are often incorrectly stereotyped as 'disease carriers', particularly in relation to HIV. In fact refugees often move from countries in conflict with relatively low rates of HIV to more stable countries with higher rates of HIV.

The memo circulated by the NDOH in the first quarter of 2007[4] provides important clarification that not being in possession of a South African identity booklet should not prevent an individual from accessing ART, providing that all other conditions are met. This has positive implications for both non-citizens and citizens without identity booklets who are in need of ART.

The recent (September 2007) Directive goes further and indicates that refugees and asylum seekers – with or without a permit – shall be exempt from paying for ART services, irrespective of the site of level of institution where these services are rendered.[5]

HIV is a public health issue and ensuring the free provision of ART to all individuals within South Africa who are in need of treatment, will have a public health benefit, particularly from an infectious disease control perspective. Whilst the numbers of non-citizens within South Africa are small, they are significant. It is important to ensure that individuals are able to access treatment early, as the burden upon the health system will be greater for untreated, sick individuals, as well as increasing the burden within society as communities will have to care for the sick and dying.[6]

Fees

Health care

The NDOH directive BI 4/29 REFUG/ASYL 8 2007 announced that refugees and asylum seekers 'with or without a permit that do access public health care shall be assessed according to the current means test.'[7] Refugees and asylum seekers therefore fall into the same categories as South Africans in terms of paying fees according to their income. This means that those without income will pay minimal fees whilst only those with a high level of income will be classified as 'Private Patients' and pay the maximum fees.

Because the NDOH directive does not discriminate against asylum seekers who have not yet been issued with documentation, the same means test applied to South Africans will determine the fees they pay.
In terms of the 1998 Refugees Act, refugees and asylum seekers should not be classified as 'foreigners' and asked to pay the R1 800 deposit required of other non-nationals. Because the NDOH does not discriminate between asylum seekers with or without documentation, if a person is unable to provide identification documents they must then be charged in terms of the same means test structure as South African citizens.

In practice

In practice foreign nationals experience a number of barriers to accessing the health care to which they are entitled under South African law. For example, public hearings held by the South African Human Rights Commission in June 2007 on the issue of access to health care, revealed that refugees are denied access to services due to inconsistent application of the relevant policies and laws.[8] Some hospitals have indicated to service providers that whilst they recognise the requirements of the NDOH directive to provide health care to those without documents, they do not intend to comply with the directive given the limited budget with which their institution is provided.

In addition, a number of research reports have found that barriers to general health care for refugees and asylum seekers came in the form of:

- **Lack of documentation** issued by the Department of Home Affairs due to the large queues and limited services being provided by the Refugee Reception offices.
- Unaccompanied minors facing further obstacles due to the additional challenges they face in accessing documentation from the DHA.
- Undocumented nationals facing additional obstacles due to their constant vulnerability to arrest and deportation whatever their circumstances. They may be unwilling to present themselves at hospitals or clinics for fear of being reported to police and deported.
- **Xenophobia** from health care staff. Frontline staff (clerks and nurses) were described as being the most likely to refuse services to refugees and asylum seekers. Treatment was more likely to be provided once contact had been made with a doctor. In addition, it was suggested that xenophobia was heightened towards refugees with disabilities.[9]
- Confusion by health care service providers over the rights of different categories of foreign nationals. Many service providers are unaware of the legal status of refugee documents and asylum seeker permits and are fearful of getting into trouble for assisting someone with such documents.
- Confusion over the fees to be paid by the different categories of foreign nationals. Until the NDOH directive, it was generally unclear as to how asylum seekers were to be charged.[10]
- Poverty, as some refugees and asylum seekers were not employed and thus perceived financial barriers to

accessing health care. Uncertainty about fee structures by health care staff contributed to this as some foreign nationals were charged higher fees than they should have been in terms of the law.
- Language issues as translators were often not available to assist foreign nationals in explaining their illness to health care service providers.[11]

Barriers to accessing ART

- It is often the internal policy of health care institutions that creates the barrier to ART for non-citizens, where institutions WRONGLY demand an ID booklet, individuals – citizens or otherwise – without an ID booklet are refused treatment, and referred out of the public sector and into the NGO sector. This not only increases the burden on a resource limited (and externally funded) NGO sector, but prevents the public health system from fulfilling their obligations to provide healthcare to all.[12]
- A previous lack of clarification from the NDOH regarding the rights of asylum seekers to access ARTs. The new policy directive issued by NDOH will go a long way towards tackling this issue but there will still be challenges in ensuring there is widespread awareness of this new measure.
- A fear of approaching the police regarding post-exposure prophylaxis (PEP). A number of foreign nationals have reported negative experiences in dealing with the various South African police services. Many foreign nationals also appear unaware that they can present themselves at a public hospital for this service (PEP) and health care providers are obliged to keep clinical information confidential.
- The challenges of providing information to non-national populations in an accessible and appropriate way. Refugee and migrant populations live in many different areas and it is difficult to communicate with all. Many non-nationals are therefore not aware of initiatives such as the prevention of mother to child transmission of HIV (PMTCT).
- Stigma in non-national communities around HIV. Such stigma challenges common support structures such as ‘treatment buddies’ or support groups. Instead it was been found that foreign nationals often prefer to be

CASE STUDY: ACCESS TO ANTIRETROVIRAL THERAPY

Jean* arrived in South Africa in 1998. He left the Democratic Republic of Congo (DRC) in order to escape violence and conflict. He travelled to Johannesburg where he applied for, and received refugee status. Although he did have refugee papers, these were stolen in 2001. He has applied for a replacement but is still waiting and currently has no documentation. Jean has been working informally since his arrival, he currently mends shoes. He lives in the inner-city and shares a flat with other people he met there who came from the DRC. Jean had a South African girlfriend for several years, but she has now left Johannesburg; he does not know where she is.

In 2006, Jean started to become unwell, and developed a bad cough. When he was too sick to work, he went to the local government clinic. He was diagnosed with TB and started on treatment. He was advised to test for HIV, which he did at the clinic. He found out that he was HIV positive and was referred to the closest ART rollout site. There, they tested his CD4 count and found that it was 194. The counsellor explained that he must finish his TB treatment before he could commence ART. However, once Jean had completed his TB medication, he was then told that he could not receive ART because he did not have a green South African identity booklet. He explained that his refugee booklet had been stolen but the counsellor said that he needed a green South African identity booklet. At this point, although feeling better, Jean was still very weak; he was still unable to work and his friends were no longer able to support him.

The counsellor at the ART site referred Jean across the city to an NGO site that provides ART. They did not ask him for any documentation. They checked his CD4 count and found it was 120. He received adherence counselling and then started ART. Jean has been receiving ART at this site since 2006 and is currently well. Jean has to travel far to the NGO site to receive his medication and to have his CD4 count monitored and the taxi fare is expensive. He is eligible to receive ART at his local government ART rollout site (that is in walking distance) but unfortunately, the right to access ART is not being upheld.

– Jean is a refugee and has the right to access ART. The September 2007 Directive confirms that refugees and asylum seekers – *with or without a permit* – are entitled to free ART.

** Not his real name*

part of such support structures located outside of the communities where they live.

In South African hospices, palliative care is provided regardless of citizenship and is free of charge so that refugees can access palliative care if they are in an area that has a service. In addition, a number of South African hospices are ARV treatment sites (funded by the US government through Catholic Relief Services which promotes access to ART for refugees). Tapologo Hospice in Rustenburg North West Province is one of these sites that provide a comprehensive treatment and palliative care service, including care for orphans and vulnerable children.

Addressing the challenges as Health Care Practitioners

- Know the rights of refugees, asylum seekers and migrants and inform your colleagues of these.
- Challenge prejudice against foreign nationals where you see it. Remember that the law is on your side and it is the duty of each and every health care practitioner to provide fair health care access in terms of the law.
- Maintain communication with civil society service providers who can offer advice and assistance if specific challenges emerge. Key organisations such as Lawyers for Human Rights (Johannesburg, Pretoria and Durban), Wits Law Clinic (Gauteng), UCT Law Clinic (Cape Town) and the Legal Resources Centre (Cape Town, Grahamstown, Durban and Johannesburg) can provide clarity on any legal concerns regarding non-national access to health care.
- Where the policy of the health care institution where you work prevents refugees, asylum seekers or migrants from accessing health care, you can challenge this policy or else refer to the legal service providers listed in the Resources Section at the end of this book for advice on the issue. If necessary, this could then be an issue that they then address with the institution.
- Create a relationship between your organisation and an organisation offering translation services. Local migrant and refugee service providers may be able to assist you in this regard.

Other potentially vulnerable groups

Although there is likely to be less confusion around the rights of South African citizens to health care access, there are potential barriers that affect a number of categories of citizens. These barriers relate largely to issues of stigma and prejudice. By being aware of these issues, we as service providers can tackle such challenges to ensure the services we provide are accessible to all.

Sex workers[13]

Sex workers face a number of potential barriers to health care. Due to their employment choice, sex workers are among the most marginalised and stigmatised in our society. This is a crucial issue that requires a lot of self awareness from health care workers. It requires that a health care worker does not judge the patient based on his or her own values. Many sex workers say their work is their way to achieve financial security and independence. In terms of prejudice, many service providers do not treat and approach sex workers in the same way they deal with other clients. A number of sex workers have spoken of feeling judged and being lectured to by service providers who have effectively ignored the reasons why the sex worker came for a service. It is vital that you support such people by ensuring they have access to health care services. Service providers need to be approachable and friendly to all people from all walks of life. Despite sex work being seen as a criminal activity, the Constitution protects the rights of all within South Africa and therefore the right of all to seek medical care.

Suggestions for service providers

- Treat people humanely regardless of what work they do and try to reserve your comments and opinions as these may hurt the patient and cause him or her to become more reluctant to seek out health care assistance in the future.
- Regardless of the work that people do, resist the urge to tell others either about their health status unless they have given you permission to do so. Treat them with the respect and confidentiality that you would give to any other patient.
- Avoid talking to sex workers in a manner that may interpreted as 'preaching' with regards to their choice of employment. In the same way you would not tell a teacher or a nurse to change their job do not tell sex workers to change their jobs, unless they have asked you for advice or to tell them of other work opportunities. Whilst you may feel that you are trying to help, in fact the patient is likely to feel judged, humiliated and not heard.
- Challenge prejudice where you see it. In the same way that not everyone in South Africa is HIV positive or taking drugs, not all sex workers are HIV positive and take drugs.
- Listen to what the patient is asking as he or she may be asking about other things that are not related to the work that he or she does.
- Organisations should consider undergoing stigma training workshops for working with marginalised people.
- Sex workers may approach health care workers for

multiple needs. In such cases, health care workers can play a key role by contacting, or referring patients to, organisations that are better equipped to provide for specialised needs. You might not be able to assist with all needs, but you can refer people to others who can assist. For this reason it is useful to be familiar with the various services provided by other organisations and to network with them.

- The majority of people know what they need, but might not know how to ask for it or how to get what they want and need. Bear in mind that some may have experienced gross human rights violations and repeated abuse without adequate support and as a result they can end up overwhelmed and unable to articulate what the problem is. Try to be patient and give the patient time and space to think through what they need, even if at times these needs are contradictory. All of us from time to time want conflicting things.
- Try to find staff members who speak the main languages of the patient as the patient can then be more articulate. This is not to say that one should assume that the person does not speak English but rather that people can be given the option to either speak in English or their mother tongue.

Prisoners

The Law

International norms and standards provide that prisoners must have access to the same quality and range of health care services as the general public receives from the National Health Service.[14] In this way, incarceration should not impact on a person's ability to access health care. Section 12 of the Correctional Services Act and the accompanying Regulations provide specific requirements regarding health care for prisoners.

Section 35(2)(e) of the Bill of Rights provides for the rights of prisoners to have 'adequate medical treatment' whilst Section 35(2)(f) provides for a detainee to be visited by his or her chosen medical practitioner. If the state is unable to provide a particular treatment, it needs to demonstrate that it cannot afford this treatment or that such treatment would place an unwarranted burden on the state.[15] Furthermore, Section 11 of the Bill of Rights provides for the right to life. The high numbers of natural and unnatural deaths in prisons illustrate that this right is violated to a significant degree.[16]

Health care for prisoners in South Africa is regulated by the Department of Correctional Services (DCS) rather than the NDOH. This can pose challenges in ensuring a consistent standard of health care is available to all South Africans across the country. In June 2006, the Durban High Court ordered the DCS to provide ART to prisoners in Westville Prison in accordance with public sector policy.[17] Prior to this ART was being denied to prisoners. Whilst the state has been criticised for the slow speed at which it has sought to rectify this, the DCS has managed to increase the number of sites where ART is available.

Medical Parole

Section 79 of the Correctional Services Act provides for a prisoner to be placed under correctional supervision or on parole if they are diagnosed by a medical practitioner as being in the final phases of a terminal illness. This is to allow for a prisoner to die a 'consolatory and dignified death'.[18] Medical parole has long been a contentious issue and the Correctional Services Act Amendment Bill being reviewed at the time of writing proposes changes to the current legislation on medical parole.

In practice

The *Judicial Inspectorate of Prisons Annual Report*[19] described health care in most of South Africa's prisons as 'in crisis'. Factors such as a lack of medical staff, overcrowding in prisons, poorly resourced prison hospitals, as well as operational inefficiencies, were some of the items of concern raised. In one prison, an acute shortage of staff was discovered whilst pregnant patients were being kept in the same accommodation space as TB patients and had no access to gynaecological services. In addition only limited screening of newly-admitted prisoners took place and prisoners with infectious diseases were not isolated from the rest of the prison population. The *DCS Annual Report of 2007*[20] reveals a high level of vacancies within the Correctional Services system and this is likely to put further pressure on the ability of the system to meet inmates' needs. The DCS recognised the shortage of skilled staff in the form of professional nurses, medical practitioners, psychologists and pharmacists[21] and the impact this was having on the health care it was able to provide for prisoners. It committed itself to taking steps to rectify this situation. Further major challenges to the health care of inmates are the presence of gangs inside many prisons as well as practices relating to the use of tattooing in prisons. Access to PEP (Post Exposure Prophylaxis) for those who have been sexually assaulted inside prisons can also prove a significant challenge.

Medical Parole in practice

Despite the legal prescriptions, in practice medical parole involves a lengthy and bureaucratic process. In some cases, the condition of prisoners worsens and some die before being released[22]. In *Stanfield vs Minister of Correction Services and Others*[23] the Court judgment declared that 'the overriding impression gained from [the state's] attitude in this regard is that the applicant must lose his dignity before it is recognised and respected'.

It also appears that the Parole Boards have been denying people living with AIDS medical parole due to a fear that those released on medical parole could then access ART and recover to a degree where they could continue to commit crime. A submission by the Civil Society Prison Reform Initiative (CSPRI) to parliament suggested that medical parole be converted to other forms of parole if a person recovered significantly. There is as yet no indication of whether this suggestion has been adopted. As a result, whilst the numbers of people being diagnosed with AIDS in prisons is increasing, the numbers of those released on medical parole is stable or declining.[24]

Additionally, significant delays occur in the process of applying for medical parole. Such delays occur due to:

- Reluctance by family members to accept a terminally ill family member back home.
- The requirement that a prisoner due for release on such grounds be seen by the district surgeon, specialist, social worker and parole board before being released.
- A potential lack of skills on the Parole Board to assess complex medical conditions, resulting in the rejection of applications due to incorrect consideration of the circumstances.[25]

Prison pharmacies

A delegation from the Correctional Services Portfolio Committee visited Pollsmoor Prison in Cape Town and discovered, amongst other concerns, that medicines past their expiry days were being dispensed to prisoners. This is unlikely to be an isolated incident and reflects a further challenge to the provision of 'adequate' health care in prisons. Investigations by the Jali Commission as well as the Special Investigations Unit found major irregularities regarding grey medicine, repackaging of expired medicine and the selling of medicine destined for the prison population to private companies.

Continuation of care after release

It is vital that preparations are made for prisoners undergoing treatment when they are released from prison. Whilst some prisoners may have been able to have good access to treatment whilst inside the prison, their release may pose challenges for the way in which they now have to access care. For those on a course of ART, it is critical that planning is co-ordinated between the DCS and NDOH, as well as the patient's support structures, to ensure the patient is able to maintain access to the course of ART. It appears that currently there is limited support to ensure continuity of care after release and this is a major area that needs to be addressed.[26] Where the prisoner's family is unable to care for the prisoner at home, appropriately qualified and experienced doctors assisting Parole Boards need to be aware of palliative care services and make enquiries to establish what services might be available for such prisoners on release.

Drug Users[27]

Background

Drug addiction has been recognised internationally as a disease that is manageable rather than curable. As a primary and progressive disease, it is the addiction itself that is the key problem rather than its consequences, and it can become worse over time. Key characteristics of the disease can include withdrawal, shame, loss of control, manipulation and lying, and drugs becoming the main focus in the person's life.

Addicts can be ambivalent about their situation with part of them recognising the destructive impact of drugs on their life but with another part attached and attracted to their drugging for different reasons. Service providers can play a useful role by supporting the addict who wants to stop.

A key palliative care perspective is that the drug user in pain requires higher doses of opioid analgesics because of the effect of drug use on speeding up the metabolism of these analgesics. This can result in discrimination as the requirement for higher doses is seen as expression of addiction and manipulation. Also problems occur with previous drug users who have now stopped using and are afraid to take medication for pain control for fear of slipping back into addiction. So both situations are challenging to the palliative care practitioner as the patient still requires and should receive adequate pain management.

Roles to avoid and to be aware of as Service Providers

- The Rescuer; by attempting to 'rescue' an addict to make him or her feel 'safe' and 'loved' can have the effect of sheltering the addict from experiencing the negative effects of his or her actions and thus slowing down the healing process.
- The Persecutor; by punishing the addict by denying him or her services or privileges you do not stop the addictive behaviour, you give the addict a person to blame for his or her behaviour and thus avoid dealing with the problem.
- The Victim; this is a role that can be played by the addict when he or she wants something. Essentially, the addict avoids taking responsibility for the issue and instead shifts the blame for his or her behaviour onto others.

As a service provider, it is important to avoid the roles of the rescuer or persecutor as these roles can reinforce that of the 'victim' and allows the addict to continue his or her behaviour. Instead, service providers could play a supportive rather than rescuing role, and a limiting rather than a persecuting role. In this way they can assist by helping set appropriate boundaries or limits.

Counsellors at the Cape Town Drug Counselling Centre suggest that it is important for service providers NOT to take on cases as individuals, but rather to work as part of a team in dealing with issues of addiction.

Lesbian, Gay, Bisexual and Transgender people[28]

A study conducted by OUT Well-being in 2004 found that many black gay men and black lesbians had been refused access to health care due to their sexual orientation[29]. Although the law is clear, prejudice on the part of service providers can inhibit access to key services. Such prejudice can present in a number of ways. It could be overt in the form of direct refusal of services or it could be less obvious in the form of behaviour that makes the patient uncomfortable, such as insensitive questions and comments or looks from the practitioner or other staff.

Many health care practitioners may have private religious beliefs that conflict with a sexual minority patient's lifestyle. This should not detract from the health care provider's duty to provide equitable services to all patients without discrimination. If a health care service provider is unable to get past his or her own prejudice and is therefore not able to provide services without making the patient feel uncomfortable, then the service provider should refer the patient to another service provider who can. Although in such circumstances a patient may be referred, this does not absolve the physician from becoming aware of the basics of their care. In addition, if no other referral services are available, the provider has a duty of care and should work through their prejudice in order to offer an acceptable service.

Practitioners need to distinguish between people's identities and their behaviour. A person may be gay but that may not impact upon their specific health care needs. If a male patient has sex with men, then it is this behaviour that may be more relevant to preventative measures or treatment being addressed by the health care practitioner.

It is also important that the support staff in a clinic or hospital are given training on sexual minority issues. Such patients are likely to come into contact with receptionists, medical assistants and bookkeepers and it is important that issues of prejudice on the part of these support staff are examined and addressed.

It is possible that many sexual minority patients may be mistrustful of Western medicine. This may be because some patients have had a negative experience with prejudiced physicians. Sexual minority patients may also be suspicious of mental health practitioners. Many people believe in 'curing' people with 'deviant' sexual behaviour and therefore some sexual minority patients may misinterpret referrals to psychologists or counsellors as being for the same purposes. As a practitioner, you may be far more successful if you are able to assure the patient truthfully that you do not consider his or her behaviour or sexual identity a problem.

Conclusion

This chapter has illustrated that there continue to remain significant barriers in South Africa for the provision of equitable access to health care that does not alienate potentially vulnerable minorities. Many of these challenges relate to attitudinal barriers to accessing health care, and for this reason it is vital that staff in all health care institutions are made aware of the effect their attitudes can have on patients. Measures need to be in place to ensure that the prejudice of a heath care practitioner does not result in any person in South Africa being denied their right to access health care. Further challenges involve ensuring that staff are aware of the current legislation with regard to providing health care for foreign nationals with or without documents. Access to health care in prisons remains tenuous, and the reliance of inmates on prison officials for access to health care increases inmates' vulnerability. By addressing the challenges outlined in this chapter, South Africa will be in a better position to ensure that the standard of health care offered in this country is an achievement of which all can be proud.

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Community Caregivers

Sue Cameron, Lindi Coetzee and Nkosazana Ngidi

11

Community Caregivers within the South African Health Care context

Various terms including Community Caregiver (CCG), Community-Based Health Worker, Home-Based Carer, Ancillary Health Care Worker, DOTS Supporter and Onompilo, are used to describe those who work in the community, carry out one or more functions related to health care delivery but usually have no formal, professional health care qualifications. Since the WHO declaration of Alma Ata in 1978 focused attention on Primary Health Care (PHC), CCGs have worked in the community, playing a key role in empowering people with health care knowledge and facilitating access to PHC services. It has taken more than twenty years for CCGs to gain some recognition by the formal health care sector and for standardised training, career pathways and formal support to be considered.

The impact of HIV/AIDS has meant that there has been a dramatic increase in the number of people requiring care and support. With escalating costs of care and hospitals not able to cope with the demand for beds, the aim has been to decentralise care to community level, placing the responsibility, the costs and the burden on Non-Government Organisations (NGOs), Community Based Organisations (CBOs) and family carers. The reality is that many patients who are discharged from hospital do not have family members to care for them within a home setting or, if the primary caregiver has to go to work, the sick person is left alone. Even when family members are available, many do not have the required skills and knowledge and some are simply unwilling to care, perhaps fearing they, themselves, will become infected.

Human rights are normally divided into two groups, namely civil and political rights and then socio-economic and cultural rights. Examples of civil and political rights are the right to life, the right to dignity, freedom of speech, freedom of association and freedom of movement. Examples of socio-economic and cultural rights are the right to have access to sufficient food and water, the right to have access to social security, the right of access to housing and the right to education. The purpose of socio-economic and cultural rights is to ensure that all persons have access to resources and services that are needed. Socio-economic and cultural rights are important for the very poor and vulnerable people in our society. The government provides these rights according to what it can afford. Very often people say that socio-economic and cultural rights are provided within the available resources of the government.

The costs of private doctors, hospitals and medical aids are very expensive and some people cannot afford to pay these costs. Section 27 of the South African Constitution guarantees everyone the right of access to health care services including reproductive health care services. Children are regarded as being vulnerable and every child is given the right to basic health services. This section places a duty on the state to provide children with basic health care. Section 28 also places a constitutional duty on parents, who are financially able, to provide for their children's basic needs. The constitution also provides that no one may be refused emergency medical care. Emergency health care must be distinguished from access to health care

Terms you will read in this chapter:

Crucial prerequisites: essential requirements

Decentralise care: to move care from a health care facility into the homes and community

Disparities in remuneration: a lack of equality in payment for services

Enrolled nursing auxiliary: a person with one year of nursing training who works under the supervision of a professional nurse

Ethical responsibility: responsibility to act in a correct, moral manner

Interdisciplinary team: a team of people with various clinical skills from the hospital, hospice, clinic and community

Primary carers: the main caregivers, usually family or community members

Reciprocal benefits: something that benefits both parties

Reimbursement: to pay someone back for money spent or as compensation

Stipend: money paid in place of a salary for services in the caregiver setting, often below a living wage service which is a socio-economic right. In *Soobramoney vs Minister of Health, KwaZulu-Natal* (1997), the court decided that the Government does not have to provide free health care services to everyone. The court said that if a hospital or clinic has a limited budget, the hospital may prioritise who will receive treatment.

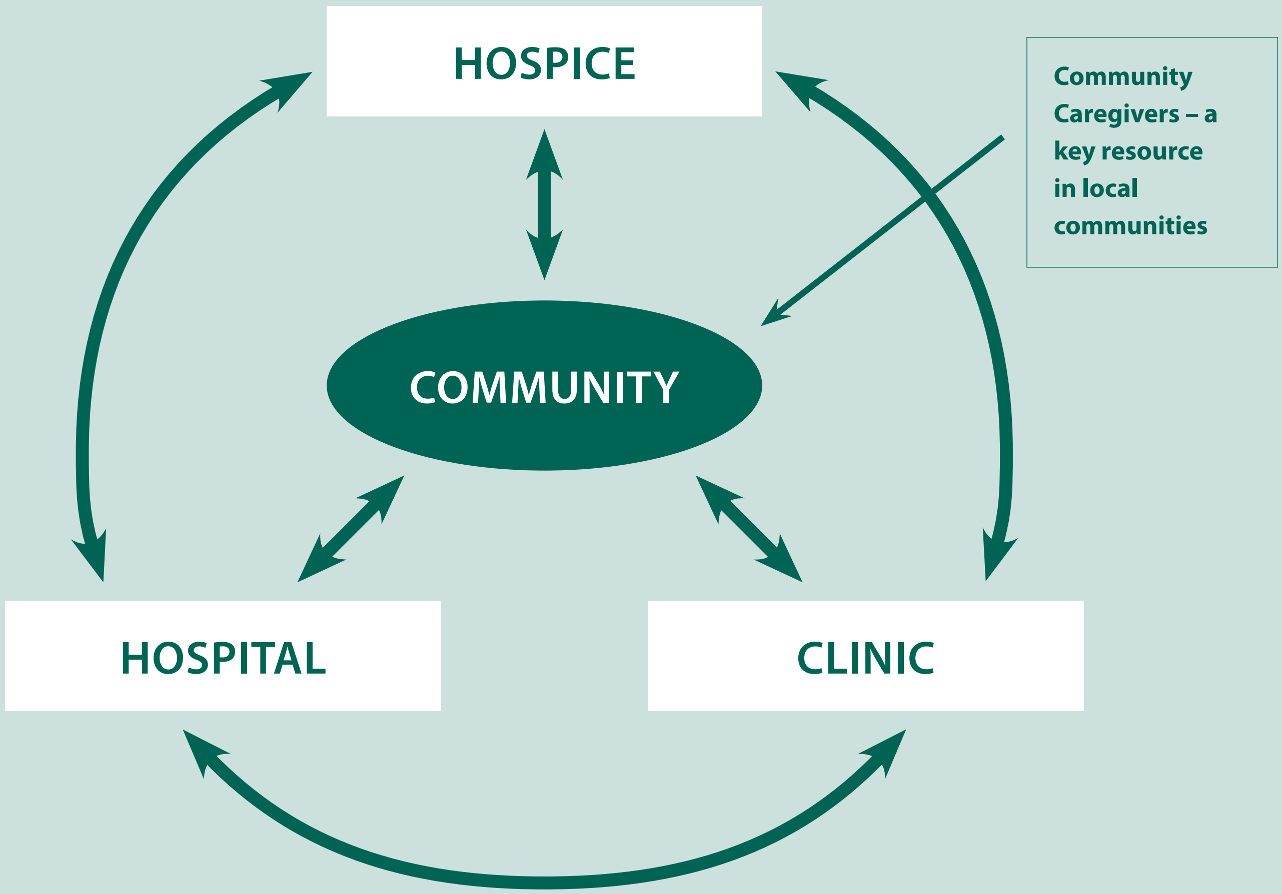
Any decision taken by the hospital or clinic must be reasonable and justifiable in the circumstances. In terms of the court's decision in the *Minister of Health and others vs Treatment Action Campaign* (2002), the Government must aim to have plans in place that will ensure the progressive realisation of the rights of access to health care.

Despite the rights provided for in the Bill of Rights, stigma is still rife within many communities. People living with HIV/AIDS (PLWHA) are often discriminated against and neglected by their families. Many people present late for treatment at PHC clinics, leading to added pressure on home care organisations. In some cases, where sick people are left on their own, CCGs have become the primary carers, assisting with household chores and even spending their own money to provide food or transport to PHC clinics. The effectiveness of shifting the responsibility for the care of PLWHA to home care organisations, staffed by inadequately trained volunteers working without professional supervision or support needs to be questioned.

An additional problem now being faced by many home care organisations is that they are providing care and support not only for an increasing number of orphans but also for children who are HIV positive. Much time is spent in facilitating the placement of children, helping to secure relevant grants and seeking programmes providing paediatric care. In response to this need, HPCA has recently created a paediatric portfolio to focus on the need to provide training for those, including CCGs, providing palliative care for children and to expand existing hospice services to include programmes that will meet the specific needs of children.

Within a palliative care context, CCGs form part of an interdisciplinary team whose focus is on providing holistic home-based care in line with the World Health Organisation (WHO) definition of palliative care. The Integrated Community Home Care Model, promoted by the Hospice Palliative Care Association, regards CCGs as a key resource within the community.

ICHC Model



Care giving activities

CCGs visit homes in the community each day, often walking long distances in the heat or the cold, to assist with:

- Physical care such as bed bathing, mouth care, wound care, cleaning those with frequent bouts of diarrhoea, etc.
- Emotional support
- Training family members how to care for PLWHA
- Securing relevant grants
- Referrals to clinics, hospitals and hospice programmes

When CCGs become well known in their communities, there is a danger that the demands made on them, often after hours, exceed their skills and ability to cope. Their own families begin to suffer and the cost of care becomes too great to sustain.

Although many CBOs claim to provide palliative care, lack of resources within these programmes usually means that care is limited to basic nursing or supportive care. In order to provide palliative care in line with the WHO definition, it is essential that the following are in place:

- CCG training which needs to include home care, palliative care both for adults and children, infection control, psycho-social support as well as record keeping
- Job descriptions, contracts and remuneration
- Adequate equipment and supplies
- Professional supervision
- A referral system which ensures the availability of medication
- Caregiver support and on-going training

Friedman points out that often 'lip service is paid to the importance of community based programmes without a willingness to provide the type of support lent to hospital and clinic based services'. Where CBOs are expected to operate without any of the essentials mentioned above, it is little wonder that only very basic support can be provided.

Although they are collectively responsible for the bulk of the hands-on care provided to people sick with HIV/AIDS by home care programmes in South Africa, lay community caregivers are currently not regulated by any professional council. This means that their work has to take place without the guidelines that a mandatory scope of practice provides. The ethical responsibility of promoting safe practice therefore falls upon the organisation to which they belong. The South African Nursing Council recognises the following categories of nurses:

1. The registered professional nurse who on completion of a minimum of three years training linked to a tertiary education institution is awarded a diploma or degree and is allowed to practice independently within a prescribed scope of practice.
2. The enrolled nurse who on completion of two years of dedicated training works within a scope of practice that allows for only very basic nursing interventions to be provided without supervision by a registered nurse who retains accountability for the activities she has delegated.
3. The enrolled nursing auxiliary who after one year of training is not permitted to provide even basic nursing care without professional supervision.

It is therefore apparent that to safeguard themselves as well as those entrusted to their care, community caregivers should be given adequate training, reimbursement, professional supervision and a proper job description.

Professional supervision

In order for any organisation to claim to provide palliative rather than supportive care, those providing home-based care need to be able to deal with issues of pain and symptom control. While CCGs play a key role in identifying and referring distressing symptoms, pain management is beyond their scope and it is, therefore, essential that CCGs are supervised and supported by professional nurses. The supervision of trained non-professional caregivers by registered nurses has assumed paramount importance in Africa. It is ethically inconceivable to accept that this category of health care worker should be allowed to function independently. It is the professional nurse who is responsible for the first assessment of the patient and for developing the care plan which the CCGs are involved in implementing. She is also responsible for supervising, supporting and teaching the CCGs so that together they provide holistic patient care and family support.

In 2006 HPCA conducted a brief survey exploring challenges and barriers to non supervised care giving by less formally trained palliative care personnel as well supervision and mentorship skills of professional nurses. This was a collaborative venture with Palliative Care International based at Sir Michael Sobell House in Oxford in the United Kingdom.

During interviews with caregivers the areas of concern they raised included:

- Lack of structured and formalised relationship with the primary health clinics and lack of time and commitment to supervision on the part of clinic nurses.
- Lack of medical supplies to use when working with patients.
- Reluctance on the part of nurses to accompany caregivers on home visits.
- Difficulties in report writing.

For the professional nurses the challenges included:

- Limited knowledge of scope of practice and need for referral.
- Difficulties with accountability and monitoring.
- Limited report writing skills.
- Disparities in remuneration between paid caregivers and volunteer caregivers who do the same job.
- Caregivers who are HIV positive themselves are at times not productive, resulting in an uneven distribution of care responsibilities.

When one considers the issue of professional supervision and the benefits it provides for CCGs, it is important to ensure that organisations train and support professional nurses in this role. Many nurses are unfamiliar with the scope of practice of CCGs and they also report that while it is easy to give praise, it is a challenging task to discuss and deal with areas of conflict. Although the National Department of Health recognises that there is a need for some kind of control or supervision of community caregivers, the model of linking them to a clinic does not appear to be working as there are no clear guidelines to direct the process and, in reality, clinic staff members are too busy to take on this supervisory role.

Who pays for care?

While some Community Based Organisations (CBOs) receive funding from the Departments of Health or Social Services at national or provincial level, there remain many informal CBOs providing a range of health care services within their communities without any form of remuneration. Even when care is provided by volunteers, it would be a mistake to regard it as a cheap option. The physical and emotional costs for those, usually women, providing care that is unpaid and under-valued are enormous. Whether it is acceptable to encourage unemployed people in poor communities to work as volunteers remains a contentious issue. As Friedman points out:

> *It is not surprising therefore that worldwide, most schemes which involve voluntarism are situated in predominantly industrialised countries or among upper/middle classes in developing countries, where people can afford to volunteer. Crucial prerequisites to this volunteering are time and money. A secure economic and social life makes voluntarism possible, even attractive… The reverse applies among volunteers from poorer settings where they are driven by the hope that it will lead to paid work or some other benefits … Based on the burden that voluntarism tends to place on the poor, many view the intentional use of this strategy by health services as a form of exploitation.*

Friedman also makes the point that in small rural communities, there might be reciprocal benefits in helping one's neighbour, but within an urban setting, driven by a cash economy, survival depends on some sort of monetary payment. As Margaret Legum, the Chairperson of the SA New Economics Network points out:

> *They [Governments] can intend, and effect, that people are paid closer to what they are worth, rather than what they must take because they have no alternative.*

Organisations providing care to PLWHA and orphans and vulnerable children (OVCs) are unable to charge a fee for service and therefore are reliant on funding from donors, many of whom are reluctant to fund salaries. This point is illustrated by one care provider who recounted that when they included stipends in their proposal, the donor insisted that this budget item be removed or else the funding would not be granted.

At the time of writing, HPCA member hospices either employ CCGs directly or channel government stipends to the CCGs. Remuneration can therefore vary between a stipend of R500 and a salary of approximately R2000 per month. Viewing CCGs as employees means that they then have contracts, job descriptions and are bound by the policies and procedures of the organisation. This is particularly significant when one thinks of areas such as confidentiality, a key concern to PLWHA. An additional advantage is that attrition rates are lower, reducing the need for constant initial training of new CCGs. It is imperative that the CCGs be educated about the patient's right to privacy. Where the CCG works for an organisation and breaches the privacy of a patient during the exercise of her duties, the organisation may be held liable for the damages suffered by the patient. Section 14 of the Constitution provides that everyone has the right to privacy. Legal rules require that doctors, nurses, dentists, psychologists and other health care workers keep patient information confidential. Details about a patient's health status can only be disclosed to someone else, provided the patient has provided his or her informed consent. In a landmark court ruling, *Jansen van Vuuren vs Kruger* (1993), the court ordered a medical doctor to pay damages to a patient where the doctor disclosed a patient's HIV status to another person without the patient's consent. Lay counsellors also have to respect a patient's confidentiality even though they are not registered with a professional body. The common law of South Africa provides that all persons have the right to privacy and this requires all persons to respect the privacy of information belonging to another person.

In South Africa, a patient's information can only be given to another health care worker if:

- The patient consents
- A court orders a health care worker to disclose the HIV status of the patient.
- An act of Parliament requires a healthcare worker to make a disclosure.
- After the death of a person, where the next of kin has given permission.
- A health care worker is allowed to disclose the status to another health care worker if the disclosure is for a legitimate purpose within the ordinary scope of the duties of the health care worker and where the disclosure is in the best interest of the patient.

One area of confusion is that when stipends are paid via hospices, there are conflicting messages from the Department of Health, which insists that the CCGs are volunteers, and the Department of Labour, which maintains that they are employees. The Department of Labour's Expanded Public Works Program is one of the government's short-to-medium term programmes aimed at the provision of additional work opportunities coupled with training. Allowance is made for Expanded Public Works Program projects to pay below the minimum wage as gazetted in the Code of Good practice for employment under the Special Public Works Programme, as this is a form of training on the job. However, there is a concern that the lower rate of pay is applied not only to CCGs in training but also to experienced CCGs who have completed training.

An employee is defined in the Labour Relations Act 66 of 1995 as any person, excluding an independent contractor, who works for another person or for the State and who receives, or is entitled to receive, any remuneration and any other person who in any manner assists in the carrying on or conducting the business of the employer. Persons who do not receive remuneration will be excluded from the definition of employee. However, remuneration includes payment in kind, non-cash payments or benefits given in return for services rendered. Payment in kind would include providing accommodation, food and other supplies. A person working in a charitable institution will only be regarded as a volunteer if such a person does not get paid. In terms of the scenario sketched above, where CCGs are either employed directly by the organisation or receive government stipends which are channelled through the hospice, the relevant individuals will be regarded as employees in terms of the law and will be entitled to the protection afforded by the South African labour legislation.

Issues of gender

Because women's activities are generally invisible in national income accounting systems, there is an assumption among ordinary people as well as policy makers that the supply of women's labour is unconstrained and flexible. It is assumed that women can adjust their time easily and rapidly between market work and household production. Thus, it is often assumed that in response to crises or illnesses, women's labour will be the adjusting variable. When women are the primary carers in the household or work as volunteers in an organisation, the value of the time and effort required to perform this unpaid work is not taken into account in economic terms, despite its key contribution to communities and to the economy.

An evaluation of home-based care in southern Africa found that 91 per cent of caregivers are women. In addition to the burden of care, women have had to forego earning opportunities, resulting in a continued state of poverty within the family. Even when a CCG does receive a salary, it is often the only income supporting the family and is low in comparison to rising costs. In addition, there is often uncertainly about continued funding for CCG stipends or salaries, creating anxiety regarding the lack of job security.

Many young girls are forced to leave school to care for a sick family member, thus forfeiting the chance of an education and future employment prospects. In terms of Section 29 of the Constitution everyone has the right to basic education. Where young children are forced by circumstances to leave school to look after ill family members these learners have no hope of exercising their right to education. In terms of the South African Schools Act 84 of 1996 a child is compelled to attend school from the year in which the child reaches the age of seven to the last school day of the year in which the child reaches the age of 15 or the ninth grade, whichever occurs first. The problem with these rules is that the Department of Education is not monitoring whether the children who are compelled in terms of the law to attend school are in fact in school. If the Department monitored the situation one would have a much clearer understanding of the number of children who are not attending school. One also needs to recognise the impact of placing the emotional burden of care and household duties on children who are too young to assume these responsibilities. Involving more boys and men in care responsibilities would make a significant contribution to changing traditional attitudes towards what are perceived as gendered responsibilities and lessening the burden on girls and women.

Regardless of how well trained CCGs are, it can be awkward for a young black woman to provide care to an older man because of cultural norms and expectations. It is particularly unacceptable for her to suggest to a man that he engage in safe sexual practices. In the rare cases where there is a male caregiver on a hospice team, it is not unusual for him to feel that he should assume seniority and ask his female counterparts to do the more menial tasks simply because of his gender.

Caring for carers

'Who cares for the carers, and why is it taken for granted that women provide, and will continue to provide, care and support to family members and loved ones, with no sense of the cost and value of this work to society and the economy in general?'

There is a crucial need to recognise that CCGs need support to deal with their own emotional needs. The fact that many of those providing care are, themselves, HIV positive, with similar needs to their patients, means that the need for support is even more important.

Dealing with stigma and discrimination, the emotional stress of repeated losses, the physical strain of having to walk long distances to reach patients, the lack of adequate training, protective clothing and gloves all contribute to stress and fatigue.

Caring for caregivers can consist of many interventions to reduce stress, such as providing training so that CCGs feel more confident, providing leisure time, providing reasonable payment so that financial burdens are lessened and by organising debriefing and teambuilding sessions. CCGs could also be empowered by allowing them to participate in the decision making process.

Career pathways

The National Qualifications Framework (NQF) makes provision for various levels of training for Ancillary Health Care workers, including home care, palliative care, caring for people with disabilities as well as health promotion. While Standards have been developed, the process of accrediting training providers and introducing skills programmes has been very slow. It is hoped that when the system is fully functional, there will be career options for those currently working as CCGs.

Summary

Community Caregivers (CCGs) play a vital role in the provision of care to many who would otherwise have little access to any form of assistance. However, this care comes at a cost to the patient, the family, CBOs and CCGs and it is essential that government and donors acknowledge the critical role that caregivers, particularly women, are playing and provide the financial support needed so that palliative care for all who need it becomes a reality.

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Dying and the Law

Desia Colgan

Introduction
Dying testate – with a will
Dying without a will: Intestate succession
Customary law and gender issues
Taking care of the children
The legal process after someone dies
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Introduction

Death is an inevitable fact that we will all face at some time in our lives, be it the death of a loved one or our own eventual passing. What is also inevitable is the grief that we will encounter during such a time. Everyone copes differently, but what is important is the need to protect loved ones from additional administrative and financial problems during such times. Everyone needs to think of how to prepare for such an eventuality and we need to do this when we are well and our minds are still clear. Preparation before death – estate planning – helps with making decisions about:

- what will happen to our money, belongings and the people we love after we die and
- Putting solutions in place so that people have instructions on what to do with our property, our savings and other financial matters such as pension and insurance.

In our law there are two ways of sorting out the property of a person who has died. One is when a person prepares a will before his/her death. This is called testate succession. The other is when a person dies without a will and we call this intestate succession.

Leaving a will is very important if you have property or children. But it is equally important that you take care when writing out your wishes. The law is very careful about wills. You have to put your wishes down in writing and you must use clear language so that any person reading the will can understand it. If certain legal requirements are not met, then the Master of the High Court could reject your will and use the law of intestate succession (explained later) to distribute your possessions. If you write your will properly

Terms you will read in this chapter:

Administration: organising and taking care of paper work and office tasks

Assets: property you own such as your house, your car, your furniture, your books and your money. Your assets can help to pay off any outstanding debts.

Best interests of the child: this means that if there is a conflict between the child's interest and the parents' rights then the child's interest comes first

Burial order: an order that is made once the death has been registered. This allows the person to be buried.

Custody: taking of care of a minor child. Making sure children are fed and clothed.

Customary succession: dying in terms of traditional African law

Death certificate: this is a government form issued by the Department of Home Affairs. A funeral director or undertaker can help you get one.

Death notice: a government form that needs to be filled in by someone who knows the personal details of the deceased and is able to identify the deceased.

Debt: money you owe to someone, referred to as liabilities when dealing with deceased estates

Estate: all the things and the money owned by the person who has died – sometimes referred to as a deceased estate

Executor: an executor is the person who makes sure your property is divided up according to your wishes as set out in the will. See executor's duties

Formalities: set rules that must be followed to make something legal

Freedom of testation: people have the freedom to decide what they want to do with their property after they die

Guardianship: the legal responsibility of a minor child

Heir: a person who inherits

High Court: the supreme guardian of all children

Inheritance: property, belongings or money left to someone by a deceased person

Intend: you mean to do something and you understand what you are doing

Intestate: dying without a will

Marital regime: the type of marriage contract that you have entered into with your spouse (see inset below)

Master of the High Court: the state official tasked with the responsibility of winding up deceased estates. There is a Master's Office in every province

Notary public: an attorney who has been trained to write legal documents and is able to sign and draw up people's contracts, affidavits and property agreements

Spouse: the person to whom the deceased was married. This will be the husband or wife, or partner in a same sex marriage

Testate: dying with a will

Trustee: a person appointed by the High Court to take care of a child's/person's estate

Winding up: closing down a person's estate, a person's property there will be no arguments after your death and members of your family will not need to go to court to sort out any problems that can result from an unclear will.

Many people like to leave a will which states clearly what they would like to happen to their property. The law recognises that people have a right to give their property to anyone they choose. The law refers to this right as a person's `freedom of testation'. These rights of `testation' are not absolute, and there are certain legal provisions that need to be followed and will be applied. For example if a person is married at the time of his/her death, or if there are any children, the law will protect these close family members after a person has died. Although the law protects your immediate dependents, to a certain extent, you can ensure that they are taken care of if you leave them something in your will.

If you die without a will, the executor or the Master of the High Court will not be able to follow your wishes even if you spoke about what you wanted before your death. This means that if your wishes are not written down and certain set formalities are not followed, the law will step in and distribute your property in terms of the Intestate Succession Act.

In this next section we are going to discuss what the law says and what preparations should be in place when faced with death. We will also look at some problem situations and some new changes to the law, particularly the law dealing with customary rights.

Dying testate – with a will

Everyone should have a will so that their loved ones will not have to sort out legal or administrative problems at a time when they are grieving. A will is a document that formally sets out your wishes. In a will you can write:

- who you want to leave your property/money/belongings to
- the amount you wish to leave each person
- and also who will take care of the administration of your estate.

People need a will that has been properly executed. This means that it **must** be in writing and follow the formalities that have been set out in the Wills Act. Wills can give people some peace of mind knowing that their wishes will be followed after they have died. Making a will is an important legal act and that is why certain formalities need to be followed A will can be relatively easy to make and you DO NOT need to go to an attorney or a bank to make your will.

A will must be drawn up before you die. You need to be mentally capable of understanding what you are doing at the time you draw up your will. This means that you are clear headed and can remember what you own and to whom you want to leave your belongings. Everyone over the age of 16 years can prepare a will, as long as they know and understand what they are doing. You also need to make sure that you sign your will **in front of** two witnesses who are over the age of 14 years and who can sign the will as well (see formalities on page 111).

Making a proper will needs careful planning and writing. It does not have to be typed. In a will you can leave anyone your property/belongings. Firstly you need to make sure that the property is yours to give away. You also need to think about any debts you may have. If you have not paid off your debts, the money you owe will be taken out of the estate first and then the remaining amount – if any – will be paid to your heirs.

When preparing a will, matters that need consideration are:

- whether you are married, and if so:
- your marital regime: are you married in community of property; are you married in terms of an anti-nuptial contract or do you have a customary law marriage? (see inset below – what do we mean by marital regime?)
- whether you have children
- who you would trust to take care of the administration of your estate after your death. This person will make sure your property is divided according to your wishes after your death and is called an executor or administrator. Their duties will be discussed a bit later on in this section.

Exercise on trust

Home-based palliative care services support patients and their families in preparing for death. This support is most effective when the patient and family have developed a relationship of trust with their carers as illustrated in the following real life stories:

Story 1

`Hey this one is a big problem you will find that the parents when they passed away they don't even tell the family where the children are supposed to go. They die like that and the children are left in the house like that. And sometimes you find that, most like, the uncles they come to fight for the property. They want to take away the property. Others they want to chase the children away, you find those children living in the street.'

Story 2

`Just from a family point of view they are sitting with a dilemma where the mother is terminally ill and preparing the children will normally happen after the death of the mother. So before the mother dies we test the process to find out what it would be like, because it's very painful on that day. We try to prepare the child in the context of the mother not being around anymore, like we may send the child to the father beforehand, so that the child can gradually get used to the father and the father's home.'

Wills may be very simple or may be very detailed. The detail depends largely on the number of assets that you have. If you have a number of assets and are worried about tax implications (or you plan to set up a trust to take care of your children) then you should seek the assistance of an expert, usually an attorney. If you need help when drawing up your will, there are several places where you could find expert advice. Some experts may charge a fee to draw up your will, some will not. If it's a simple will, an attorney should not charge you much. Banks, legal aid clinics and building societies are also able to help you draw up your will. A bank will want to act as the executor for your estate if you ask them to help draw up your will for you. This is standard practice. They will also keep a copy of the will for safe keeping and you should keep the duplicate copy. After your death, the bank will then become the executor of the estate (discussed later) and will approach the Master's Office. The bank can charge the estate for this function. Be careful of people who offer to help write up your will for free and then suggest you leave them something in your will. Remember that if your will is simple you can draw it up yourself or ask one of your children or friends to help you. You are not obliged to leave them something in your will just because they helped you to draw it up.

You may change your own will at any time before you die. The proper way of doing this will be to state, in a later will, that all previous wills are cancelled or revoked. A testator (the person whose will it is) can destroy his/her will or change it any time before his/her death. The person changing, destroying or making a new will must want to make the change and not be persuaded or forced to do so. He/she should also be mentally alert at the time the changes are being made.

What do we mean by marital regime?

In South African civil law there are three matrimonial property systems/regimes. They are:

- Marriage in community of property, where both parties share a joint estate. This is the system that automatically applies if you do not draw up an ante-nuptial contract.
- Marriage out of community of property, where both parties have separate estates. You have to draw up an ante-nuptial contract before the marriage.
- Marriage out of community of property with accrual. You have to draw up an ante-nuptial contract before the marriage. The difference is that both parties have separate estates but to stop any unfairness they share in the accrual at the end of the marriage. Accrual is the accumulated profits they may make during their marriage.

Note:

1) ***Customary law marriages*** *marriages are recognised in our law. The Recognition of Customary Marriages Act of 1998 gives full legal recognition to customary marriages as long as they are registered at a Magistrates Court. (A customary law marriage is not `the same' as civil law marriages – best not confuse people if you say they are)*
2) ***Same-Sex Unions*** *are now also recognised in our law. The Civil Unions Act No. 17 of 2006 states that a civil union is, `the voluntary union of two persons who are both 18 years of age or older, which is solemnised and registered by way of either a marriage or a civil partnership, in accordance with the procedures prescribed in this Act, to the exclusion, while it lasts, of all others'.*

STORY

Mrs Laher, a car guard, tried for many years to secure maintenance from her husband for herself and her three children. Eventually the court ordered that his furniture be attached and the rental income from one of his properties be paid to Mrs Laher to recoup the maintenance monies he owed. Before this order could be enforced, Mrs Laher's husband died. After his death his family came and took all the furniture out of the house and took over the property so that Mrs.Laher cannot access it.

Solve the problem:

Read the story above and break into groups of three to five. In your groups discuss:

a) Whether Mrs Laher has any legal rights, and;
b) What steps can Mrs Laher follow in order to solve her problem.

Formalities of a valid will as set out in the Wills Act

A will needs the following requirements/formalities:

- it must be in writing
- it must be signed by two witnesses who are of sound mind and over the age of 14 years, who are also not due to inherit anything from the will
- it must be signed by the person who made the will in front of the two witnesses

Drawing up a will

- Give your full name with your identity number and your address.
- Say what your marital status is, and if married, state your marital regime. Give the name and identity number of your spouse.

Are you single, married, divorced or widowed?

- Write down that this is your last will and testament and that you revoke all other wills that you have made before.
- Name someone you trust to take care of administration of your wishes – an executor. You should check with the person first before naming them as your executor in the will. If you do not select someone, or if the Master thinks that they will not be able to do the administration properly, then the Master may select someone for you.
- Make it clear how you want your property to be dealt with. Write down who will inherit each of your possessions. Give details such as their full names, addresses and whether they are male or female, married or unmarried.
- Think of your children. If you have minor children you need to think of someone you trust who can act as their guardian. This person must be able and willing to be their guardian. If it is possible, an expert such as a bank manager, an accountant or a lawyer should be consulted if you have minor children.
- When you are finished, write the date and sign the will, **in full**, in front of the two witnesses – you must sign the will as closely as possible to the last line of writing in the will. This is to stop anyone from adding anything onto your will.

WARNING

A person cannot inherit if s/he signs as a witness. This is to stop people from committing fraud or the court thinking that they may have committed fraud.

- Both witnesses must sign, **in full**, after your signature on the last page. If you have more than one page then you, as the person writing the will, must sign all the pages of your will.

Example of a simple will:

LAST WILL AND TESTAMENT OF Kase Mdu (ID number)
of 25 Malibongwe Drive, Randburg, Johannesburg

1. I hereby cancel all wills made by me before this time,
2. I appoint as executor of my estate my sister, Suni Sunn, of 10 Moss Street, Burgersfort,
3. I leave R5 000.00 to my friend, Sbu Khosa, of 9 First Avenue, Malvern, Johannesburg.
4. I leave my car to my daughter, Akhona Mnisi, of 201 Green Street, Acornhoek, Limpopo Province.
5. I leave the rest of my property to my wife, Agnes Mdu, with whom I have a customary law marriage which 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 Mdu,
6. Should my wife die before me, I would like to appoint my brother, Gideon Mdu, as the guardian of my minor son, Mpho Mdu.
7. I 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 Kase Mdu on this day of 29th October 2006 as the testator of this will in the presence of two witnesses.

Testator. ____________________

Witness 1. ____________________

Witness 2. ____________________

Note: *as long as the heirs are clearly identified, a will remains valid. Even if the date, identity numbers or addresses are left out the will remains valid. The problem is that the Master of the High Court will then have to ask for the addresses of the heirs and if the date is missing it may be difficult to find out when the will was written.*

Dying without a will: Intestate succession

When a person dies without a will, the law of intestate succession sets out the steps that must be followed by the Master when distributing their property and possessions.

The Intestate Succession Act of 1987:

(1) If after the commencement of this Act a person (hereinafter referred to as the 'deceased') dies intestate, either wholly or in part, and –

- *(a) is survived by a spouse but not by a descendant such spouse shall inherit the intestate estate:*
- *(b) is survived by a descendant, but not by a spouse, such descendant shall inherit the intestate estate;*
- *(c) is survived by a spouse as well as a descendant –*
  - *(i) such spouse shall inherit a child's share of the intestate estate or so much of the intestate estate as does not exceed in value the amount fixed … by the Minister of Justice… whichever is the greater; and*
  - *(ii) such descendant shall inherit the residue (if any) of the intestate estate;*
- *(d) is not survived by a spouse or descendant, but is survived –*
  - *(i) by both parents, his parents shall inherit the intestate estate in equal shares; or*
  - *(ii) by one of his parents, his surviving parent shall inherit one half of the intestate estate and the descendants of the deceased parent the other half, and if there are no such descendants… the surviving parent shall inherit the intestate estate; or*
- *(e) is not survived by a spouse or descendant or parent, but is survived –*
  - *(i) by –*
    - *(aa) descendants of his deceased mother who are related to the deceased through her only, …by descendants of his deceased father who are related to the deceased by him only; or*
    - *(bb) descendants of his deceased parents who are related … through both such parents; or*
    - *(cc) any of the descendants mentioned in… (aa) as well as … (bb), the intestate estate shall be divided into two equal shares…*

And so on.

A simple explanation of the law is set out below:

- If you are married but you have no children then your surviving spouse will inherit everything.
- If you have children but no spouse then your children will inherit equally.
- If you have a spouse and children then the children and your spouse will inherit equally depending on how much money you have left after following a formula set down in law: Remember that children means all children including illegitimate children – children born outside a legal marriage.

Formula: *the surviving spouse will receive the same share of the property as the children or R125 000, whichever is the most, and the children will share the rest.*

Note:** **This means that your wife will get all the money if you have the amount of R125 000 or less.

- If you have no spouse or children the estate will be equally divided between your parents.
- If you have no spouse, no children and no parents your estate will be equally divided between your brothers and sisters.
- If you have no spouse, no children and no brothers and sisters then your estate will be equally divided between the blood relatives who are closest to you.
- If you have no spouse, no children, no brothers, no sisters and no relatives your estate will go to the state.

Exercise

In the following scenarios participants should:

a) Draw a diagram showing the lines of inheritance.

b) Give reasons for their answers below.

Story 1

Mr Sibanda dies without drawing up a will. He left a wife, Mary and three children, Nkhosi, who is five years old, Bernard, who is ten years old and Thandi, who is 19 years old. After all his debts have been paid off his estate adds up to R260 000. How much will Mary, Nkhosi, Bernard and Thandi inherit?

Note: *In this example the marital regime has already been sorted out, the exercise is only looking at the intestate estate.*

Story 2

Kevin forgets to make a will and after his death the Master has to devolve his deceased estate. Kevin never married and he had no children. He did have a brother and a sister, Connie and Brandon, and a half brother Martin, who was his mother's son from a previous marriage. Although his father has passed away, his mother is still alive. Kevin leaves an estate of R700 000. Who will inherit?

Answers:

1) Follow the procedure step by step:
   i) Mr Sibanda has left a wife and three children. In terms of the law the surviving spouse, Mary, will either get an equal share of the property, as a descendant, or R125 000, whichever is the greatest amount.
   ii) If you divide 260 000 by four (wife plus three children) = 65 000. This is an amount that is less than R125 000. Check the law. The wife must get the greater amount.
   iii) The wife Mary will therefore get R125 000. The three children will share the remaining amount in equal shares.
   iv) 260 000 – 125 000 = 135 000 is the remaining amount. This amount must now be divided by three, which equals 45 000.
   v) Each child will receive R45 000.

2) As above, follow a step by step procedure:
   i) Kevin has no spouse and no children but has one surviving parent and descendants of a predeceased parent.
   ii) The surviving parent inherits half of the estate. The estate is divided in half: 700 000 divided by two = 350 000. Kevin's mother inherits R350 000.
   iii) The remaining R 350 000 will be divided amongst the descendants of the predeceased parent. This means that Connie and Brandon will share R350 000 equally and receive R175 000 each.
   iv) Martin is related to Kevin through his mother Mary and will inherit nothing.

Customary law and gender issues

Intestate succession in terms of African Customary Law is based on the principle of primogeniture. Primogeniture means that only a male who is related to the deceased through the male line is entitled to inherit. For example the eldest son of the senior wife or his descendant, if he is dead, usually takes over as the head of the house when the head of the house dies. The formal customary law of succession discriminates against women and children by excluding them from their rightful inheritance. In these cases the right to inherit is an important issue. Often what happens is, that after the death of the adult male, the widow and the children can be thrown out of the family home. That is why it is always advisable for African men to draw up a will to protect their wives and children. Because of the new Constitution and the right to equality, certain changes have started to take place that affect customary law.

Quite frequently we are dealing with single moms who are dying and who are concerned about the future care of their children. Men are less frequently the single parent but have similar concerns for their children's future. The reality of the HIV epidemic in South Africa has resulted in women being abandoned because they have HIV or are very sick with AIDS and this contributes to the breakdown of the family structure.

The Constitutional Court decision of *Bhe and Others vs Magistrate Khayelitsha and Others 2005* (1) SA 580 ruled that certain laws dealing with the administration of black estates are unconstitutional because they discriminate against women. This decision has had a far reaching impact on the future administration of black estates, and new laws related to these changes are being developed and debated.

CASE STUDY

The Bhe case concerned two young girls, aged nine and two. The customary rule of primogeniture that prevents them from inheriting their father's property because of their female gender, was challenged on their behalf.

The girls had been living in Khayelitsha with their parents until their father's death. Even though their parents had been together for twelve years, they were not legally married. After their father had died, the family continued to live on the property until their grandfather told them to leave.

He claimed that under African customary law, the house should now be the property of the eldest male relative of the father's children. This meant that, in terms of the rule of primogeniture, the family house would become his property and he then planned to sell it.

The court decided in favour of the girls and against the grandfather since this was a clear case of African females being discriminated against. The two girls were declared to be the sole heirs of their father's estate and were given the right to inherit equally.

EXAMPLES OF PROBLEMS – CAREGIVERS' STORIES

`Because people do not like to talk about death, especially their own death, their silence causes lots of problems. And there's one big problem… we find that the parents, when they passed away, they don't even tell the family where the children are supposed to go.'

`The stigma of having HIV affects the way people talk to their families and this means that they don't make any plans for when they are not around. The sick person says to us as their caregivers, `Don't tell them (the family) that I am HIV until I die, even if they ask you every day don't tell them anything.'

`How the family are towards the sick person depends on the family and the situation in the house and sometimes there is no one who will help other than the caregiver. The people who stay there may be going to work, others are there but they are scared… we need to educate them. Sometimes the sick people may be left in the shack outside, even if they own the house and that person must stay there until she dies. There's some family they don't have love for these people.'

`People want to grab children when there's a funeral – because there's money attached to a child – and there's no-one to monitor whether the children go to school or not because the social workers does not go out there. NGOs do their best to monitor, but really they cannot help much. It's very complicated that's when you need the legal process to keep an eye on things and make sure the children are being taken care of.'

`The old man never had an ID so when he was killed the mortuary treated his body with no respect and they refused to keep his body at the mortuary. We had to run around and find the chief in his area who would allow the old man to be buried quickly because the mortuary wanted to throw him out. Luckily we found his birth certificate.'

These are all stories from caregivers and the problems they have encountered or have had to sort out.

Taking care of the children

If you decide to draw up a will you need to provide for a legal guardian or even a trustee for minor children. Do not nominate these people without consulting with your family and the people you want to nominate. Explain what you want to do and think about what would be best for the children. Keep your children's birth certificates, medical records, school reports with your will or with all your other documents such as identity documents (IDs), work information and insurance information.

Do not leave your money or property directly to minor children unless you have no-one who can help the children or who you can trust. If you leave these things directly to your minor children, then the state will administer their property through the Guardian's Fund. Each time the children need money a guardian of the children will have to write a letter to the fund motivating why they need the money. This guardian will also have to show proof of the expenses. It can be a very time consuming process.

If you do have some money and you would like to leave it to your minor children, then plan what you would like to do in advance. Go to a lawyer, a bank or a building society and ask them about creating a trust for your minor children.

A trust can provide the following for your children (if there is enough money):
- day to day care of the children
- education needs

The legal process after someone dies

Winding up the estate:

The administration of an estate is a step by step process that needs to be followed. If each step is followed, the estate can be wound up fairly quickly. The estate must be wound up (closed down) by the Master's Office of the High Court in the province where the deceased lived. The steps that need to be taken after a person has died are as follows:
- Report the death to the Master's Office. This needs to be done within 14 days after the person has died. You need to send a death notice to the Master's office. A family member or friend can do this. If the death did not take place at home, then the official from the building where the death occurred can do this.
- A death certificate needs to be issued if the person who signs the death notice was not present at the death or did not identify the body after the death.
- The Master's Office will give the family forms to fill in, to help wind up the estate of the deceased.
- If the estate is worth less than R50 000, a family member or some other representative can wind up the estate on their own.
- If the estate is worth more than R50 000, the Master's Office usually says that an executor must wind up the estate.
- If an executor has not been appointed, the Master will appoint one.

Executor's Duties – if the estate is not complicated or under R50 000, the appointment of an executor is not necessary. An administrator can be appointed by the Master. When a person dies, the property of the deceased person does not go immediately to the heirs. It must first go to the executor or administrator who will then pay off the debts and then divide the rest of the inheritance between the heirs.

Administrator's duties:
For estates that are small and below R50 000 the Master does not appoint an executor. An administrator is appointed instead. The Master will issue `letters of authority' which will give this person the authority to administer the estate – meaning that s/he can collect together all the money owed to the estate and deal with the banking. The procedure is very simple, but the Master will require proof of all assets and debts and how the estate was sorted out. The administrator will have to give the Master proof in the form of receipts, invoices and statements. Once the administrator has supplied the Master with the necessary proof, and the Master is satisfied with the administration, the account will be closed.

The executor's duties are as follows:

- The executor needs to meet with the family to collect relevant documents such as the deceased's identity documents, banking details and any policies that the deceased may have had.
- The executor then reports the estate to the Master with the relevant documents such as the death notice, death certificate (if needed) and the original will, if there is one.
- The Master will then appoint the executor by sending him/her `letters of Executorship'.
- The executor must then arrange for a valuation of the estate.
- The executor puts a notice in the paper and asks all the creditors to come forward. The creditors have 30 days to come forward.
- The executor must open a bank account for the deceased estate and deposit all the money from the estate into this account.

- After that all the deceased person's assets and his/her debts need to be added up.
- The executor contacts the beneficiaries and explains the procedure to them and asks for their opinion on certain matters about the estate.
- The debts are then subtracted from the total amount of the assets. All of the debts are then paid.
- There are also death duties on estates – the executor must pay taxes. If the estate is small there are no costs are they are minimal.
- The executor sends the final account to the Master of the High Court. The account lies at the Master's Office to allow people to inspect it
- If there are no objections to the account and the Master is satisfied, the executor can then pay the heirs their inheritance.
- The executor must then send the Master copies of receipts from the heirs showing that they have received their inheritance.
- The executor is then released from his/her duties by the Master.

If an executor needs help, he can ask for assistance from someone who knows. This could be a lawyer, an accountant or the manager of a banking institution. He can even hire a lawyer to assist with the above duties and responsibilities. This person will usually charge a fee or a percentage of the value of the estate.

When someone dies at home

When someone dies at home, the caregiver or family members need to be careful about taking care of themselves at this time – both emotionally and physically. When someone dies, and there is no doctor or nurse there to help, certain things need to be done or someone trustworthy asked to assist.

- Close the person's eyes and contact someone who can help you – it will be better if that person is your home-based carer, a nurse or a doctor.
- If there is going to be a delay until the doctor or funeral director can get to you, then the body may need cleaning.
- Cover any wounds or sores, taking care to cover your hands with gloves or plastic bags.
- Put a cloth between the legs and up under the buttocks.
- Put clean clothes on the deceased person, if you are able.
- Remove all pillows.
- Straighten the body and limbs (arms and legs).

When the medical practitioner arrives s/he needs to give you the medical certificate of death. This will explain the cause of death. This is not the death certificate. The medical practitioner will hand the documents to next-of-kin or to the funeral undertaker. You need to think about contacting a funeral company at this stage. You will need someone to help you remove the body and prepare it for burial.

The funeral director may need the following documents from you:

- the deceased's ID document or
- an official document that will show the deceased's date and place of birth and place of death
- details of any hazardous work that the deceased was employed to do – if relevant
- details of any funeral policies, burial societies or pre-paid plans
- the medical certificate issued by the medical practitioner.

Funerals and planning

Note: *Where there is no Home Affairs Office in the area the nearest police station will be appropriate.*

The death must be reported to the Registrar of Births and Deaths (Home Affairs) as soon as possible. If the death takes place in the city, the notice of death must be handed to the registrar within 24 hours. If it takes place in the rural areas, it should be handed in within 14 days. After registration of the death the family will receive a death certificate and a burial order. This allows them to proceed with the burial of their family member.

After the necessary documents listed above have been handed in and the funeral director has been instructed as to the family's wishes, he/she will then assist with the number of the decisions to be made.

When someone dies,the family has to make many decisions. Some of these are listed below:

- They will need to decide whether they want to arrange a burial or a cremation, according to their beliefs. If there is a will, sometimes the deceased will give specific instructions about this. For those of the Muslim or Jewish faith, there will be a sense of urgency to arrange the burial.
- Then:
  - Christians will need to consider where the funeral service should be held – in the local church, at a crematorium chapel, even in the home or at the graveside.
  - Muslims will need to gather the mourners for the funeral prayers, traditionally said outside in a courtyard or outside the mosque, before the men only proceed to the graveside. After the burial there will be three days of mourning.
  - Jews will want to accompany the body to the graveside in a procession called the 'levayah' and afterwards organise the 'shivah' or seven days of mourning.

  - African Traditional religions will need to arrange the burial for a time when the family and the community can gather for several days of mourning at the ancestral home of the deceased, if at all possible.
- Who will officiate (run the service or prayers)? This is usually a church minister, the Rabbi or the Imam. Family and friends may also want to say something at the funeral.

Burial

After the registration of death and the issuing of a burial notice, the burial can take place at an approved burial site as it is illegal to bury people on your own property or in an open plot of land. Burials cost money so you need to find out about the costs and select the burial that you can afford. Do not spend money that you do not have.

BE CAREFUL:
Having an expensive funeral is not always advisable. Families need to show their love and respect for the departed but sometimes people take advantage of this wish and it may place an unnecessary burden on the relatives of the deceased.

Pauper's Burial

Some people may be unable to afford to pay for the burial of a loved one. Many people belong to burial societies, or they have an agreement with a funeral parlour. If there is no money for the burial, the family may apply to the municipality for a pauper's funeral. This is a very simple funeral with a simple coffin made of pine and no tombstone is put on the grave.

Final check

It is very difficult to be a careful consumer when you are mourning the loss of a loved one, but there are some matters that people need to be careful of:

- Being persuaded to spend all your money on an expensive coffin or an expensive tombstone
- Spending money on an expensive flower arrangement, or even several flower arrangements
- Spending too much money on refreshments
- Being persuaded to sign a blank form or a form with numbers that have been penciled in
- Not checking up on the hidden costs involved – hidden costs like storage of the body, transport and so on.

What you should do if you are uncertain is:

- Pay for what you can afford – respect or love for the deceased can be shown in many other ways. The words you say at the funeral, the way in which the service is held are all ways of showing respect and love for the person who has died.
- Make careful enquiries about all the costs involved. Do not let people intimidate or confuse you.
- Do not be embarrassed to ask if you are not sure what you are signing.
- Contact the nearest legal aid office, advice office or pro bono office if you have any problems.

The author of this chapter also developed the *Succession Planning Booklet and Facilitation Guide* produced by UNICEF and Department of Social Development in 2009.

Death and Dying

Sue Nieuwmeyer

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Overview

> *The most precious possession any human being has is his spirit – his will to live, his sense of dignity, his personality. We must never lose sight of the person we are treating.*
>
> —Dr Paul Brand

Thinking about death and meeting people who are terminally ill can be challenging and even scary to those who are new to palliative care or who are called upon to provide a legal or financial service to patients and their families. This can include administrative staff who assist newly bereaved family members with account queries and other ancillary staff. It also includes lawyers and law students providing legal services.

Our society as a whole does not prepare us for the trauma of losing a loved one or of contemplating our own deaths. There is an expectation that the bereaved should 'be over it' after a few weeks, when the reality is that grieving will continue for many months and sometimes years.

Support by those more experienced in the field of palliative care and training is required to equip newcomers with knowledge and understanding of the needs of patients and family members at this time in their lives. The main supporters of legal practitioners in the palliative care workplace are social workers. Where there is no employed social worker, the support task would fall on the nursing staff.

One lawyer said at debriefing that she was not prepared for the emotional impact of the situation when she went to draw up a Power of Attorney, given by a patient to a family member. She felt that knowledge about the different diseases, especially cancer and HIV/AIDS, would be useful.

When providing a legal service, preparation is important for the current physical and mental state of the patient and the effect on the family of the illness and anticipated loss.

This chapter will discuss the type of legal issues which commonly occur in the palliative care situation, communication with the terminally ill and bereaved family, and the implications of cultural and spiritual diversity with regard to illness and funerals. The importance of thorough debriefing of both palliative care and legal people is addressed. Cross references to other chapters in the manual will be given when appropriate.

Who is 'the dying patient' in Palliative Care?

- The patient who has been treated actively for cancer and has now reached the stage where the extent of the disease has exhausted curative options. The medical practitioner suggests palliative care with the focus on symptom control and keeping the patient comfortable.
- The patient with late stage illness for whom cure is not possible (and in the case of HIV/AIDS, where antiretroviral treatments have failed).
- The patient living with HIV who is currently seriously ill and beginning antiretroviral therapy. If response to treatment is successful, this patient may eventually move into a status of chronic rather than terminal illness and may no longer need palliative care.

Terms you will read in this chapter:

Debriefing: an interview in which a person discusses a task or event after it has happened

Incontinent: unable to control the bladder or bowels

Letters of Executorship: letters authorising a person to carry out the instructions in the deceased's will

Living Will: a document signed while in good health, which specifies the medical treatment to be undertaken when the patient is no longer able to communicate their wishes – usually includes instruction that they are not to be kept alive artificially by life-support systems

Pauper's Burial: burial of a person without any income or relatives – usually undertaken by the municipality

Power of Attorney: the legal authority to act for another person in legal and business matters

Stokvel: an informal savings society in which members contribute regularly and receive payouts in rotation

Taboo: forbidden to be used, mentioned or approached because of social, cultural beliefs

When should legal aspects be addressed in Palliative Care?

The answer to this is: as early in the disease process as possible. It is not advisable to arrange the drawing up of a will in the last days of a patient's life, when the patient does not have the energy to think through his wishes properly and may at times be confused.

The nursing assessment, when the first contact with the patient is made, or early in the caring relationship, should include a question such as: 'Are your affairs in order, do you have a will?' 'Have you given Power of Attorney to someone?' Where there is a social grant, it is important to ask if the patient has given Power of Attorney to anyone to access the money for him.

These questions should be on the nursing assessment form and ticked off. The replies should be recorded. When assistance is needed, immediate referral to the social worker should be made to access legal assistance as well as social grants.

CASE STUDY

Mr A was a patient in a hospice in-patient unit. He was terminally ill, bedridden and had little energy. His nephew and wife had taken him into their home when it was apparent that he had nowhere else to go. He had been divorced for years and said he had lost contact with his children.

The nephew requested legal assistance so that the patient could draw up a will. Although weak, the patient was mentally lucid. The nephew was present at the bedside with the lawyer during the process of establishing the patient's wishes. The patient had a sum of money in a savings account which he had intended to leave to his children, but now felt he would like to leave to his nephew.

The will was drawn up and duly signed, but the lawyer felt uncomfortable with the conversation which was led by the nephew. The lawyer was also concerned that the will could be contested by the patient's children after his death.

Discussion

The pressure in this situation was that the patient was close to death so there was some urgency when he wanted to make a will. This caused stress to the palliative care staff and to the lawyer.

Should the lawyer have refused to proceed with the will, if he felt uncomfortable with the discussion which took place?

This emphasises the point that, where possible, patients who wish to should be encouraged to make wills earlier on in the disease process. Unfortunately many patients are referred at a late stage of illness. In a case like, this it would be appropriate for the palliative care worker to call the lawyer aside and suggest that he consults the patient and drafts the will without the nephew being present, if the lawyer has not already expressed this to the nephew.

What legal needs may a patient or family member have?

Some common requests for legal assistance by patients and relatives:

- The granting of a General Power of Attorney to another person to manage the person's affairs.
- Power of Attorney is needed so that another person is empowered to collect the patient's social grant.
- The patient wishes to make a will – see chapter on Dying and the Law.
- The patient needs legal protection from other family members who want to evict him from his own house – see case study opposite.
- Guardianship of children – see chapter on the Rights of the Child.
- Advance Directives – see chapter on Ethical Issues.

Legal assistance which might be required after the death of a patient:

- The patient dies early in the month before his social grant has been paid out. The nearest family member wishes to apply for that month's payment to put the money towards funeral costs.
- The brother of the deceased applies for Letters of Executorship and offers the widow an amount of money which she believes is less than she is entitled to in terms of the Will.
- The widow or widower wants the house, which was joint-owned to be put in her/his name. There is no will.
- Minor children are left without guardians – See chapter on the Rights of Children and Young People in Palliative Care.

Problems over house ownership:

CASE STUDY: THE PATIENT COMPLAINED THAT OTHER FAMILY MEMBERS HAD THREATENED TO PUT HIM OUT OF HIS OWN HOUSE

The patient was referred to the hospice social worker, who visited the patient at home. This patient advised the social worker that some of his family members wanted him evicted.

The social worker asked to see the last municipal account and the patient's Identity Document. The account was addressed to the patient and there were no other names on the account.

The social worker asked the patient if he would like her to call round and see all the family together to discuss this matter. The patient was in favour of this.

A family meeting was held and discussion took place about what exactly had been said to the patient about being put out of the house and how this threat had arisen. Family members present were of the opinion that it had been said by one of their number who had been under the influence of alcohol at the time. They said they would not let this happen and that they knew that the house was the property of the patient. The meeting ended amicably and the problem did not recur.

Discussion

If this matter had not been resolved in a satisfactory manner, legal assistance would have been needed.

Powers of Attorney

There are two types:

1. General Power of Attorney (GPA)

- The patient gives another the power to conduct his affairs for practical reasons (illness, disability etc.).
- You can buy a General Power of Attorney form from the CNA or nearest stationery store.
- You may decide to consult a legally qualified person or simply to complete the form yourself.
- The GPA lapses with the death of the patient
- The patient retains overall legal power in any decision-making

2. Special Power of Attorney (SPA)

- Used for specific power rather than general power to conduct affairs of another person
- Banks require an SPA if the financial matters of the account holder are to be handled by another person. Banks have their own forms and will require the following documentation :
  - Identity Document of the account-holder and the recipient of the SPA.
  - Proof of residence: A recent account in the name of the recipient with the current address of the recipient.

Power of Attorney to draw a Social Grant

The Department of Social Development (S.A. Social Security Agency) will issue this to the person who will collect the grant of an ill or disabled client. It is best applied for at the initial application for the grant but may be obtained later as well. Finger prints will be needed.

Communication with the dying patient and family

The following points should be kept in mind:

1. Be prepared for each unique situation

- Both palliative care staff and lawyers or students visiting patients should see that they have basic information about the patient, the illness and the family situation before they set out. They can request a non-confidential summary of the situation from the patient's home care nurse or doctor.
- Be prepared with the usual legal documents/forms required for a dying person and their family.

2. Is an interpreter required?

- The interpreter will preferably be a palliative care staff member or someone the legal person chooses to work with.

3. Is there as much privacy as the patient requires?

- This is difficult to achieve in an open ward or in a small shack with other family members present. The patient is consulted about this. If a patient is mobile, the staff member's car may be used for privacy.

4. Is the patient comfortable?

- Someone in pain will not be able to concentrate on important legal issues or on anything else. It is up to the palliative care professional nurse to help with pain control.

5. Use simple language and check understanding of what is said

- Reflect back the patient's wishes where necessary – to see that both you and the patient are talking about the same thing.

6. Respect cultural and belief systems

- Conversations about death may be taboo for certain patients who see talking about death as 'inviting death in'. For further discussion about culture and beliefs see the section below and refer to the chapter dealing with cultural barriers to access to care.

7. When to refer

- If you are a legal person, you are not expected to answer questions the patient or family ask about his illness or other matters. If you are visiting without a palliative care staff member, tell the patient/family member you will ask the hospice sister to contact them.
- Stick to the legal brief, but show care and compassion.
- If you do not feel comfortable to proceed in terms of legal ethics and boundaries, explain simply to all concerned and withdraw.

How to approach the patient and family

In the palliative care situation, it is the social worker or professional nurse's responsibility to sit down with the lawyer/law student and prepare him/her for the encounter with the patient/family member. The social worker should have the patient's Identity Document in hand or have arranged with the patient that he will bring it in with him.

- Where Power of Attorney is to be given, the Identity Document of the recipient should also be available. Any concerns should be discussed.
- The legal practitioner must be given an outline of the family structure, especially those family members closest to the patient.
- The lawyer prepares him/herself emotionally for the interview.
- The interview with the patient may take place in the community (a very ill or bedfast patient); at the hospice or hospital (in as private a situation as can be arranged).

The appearance of the patient

- Colour may be very pale.
- The patient may be breathless. Listen to him and go at his speed. Allow pauses in the conversation, so that he can recover his breath and have time to think.
- The patient may have rashes, pustules or other disfigurements on his face.
- A patient who is very close to death may not be able to hold a train of thought and may nod off to sleep frequently.
- A patient who has lost the power of speech may be able to write or to use a communication board.
- A very deaf patient may require you to write down questions or comments.
- This may be the patient's first encounter with a legal person and he may feel intimidated. He may be anxious about the importance of what he is about to do in terms of this visit from a lawyer.

It is helpful if the professional person approaches the patient and family showing the following attitudes:

- **Respect** – acknowledging that the patient is the expert on his life.
- **Compassion, caring and commitment** to the needs of the patient.
- **Empathy** – putting oneself in the patient's shoes. Thinking, 'If this were me how would I be feeling? How is this patient probably feeling?'
- **Acceptance** of the patient's looks (he may be disfigured in some way), smell (he may be incontinent) and general appearance and way of talking.
- **Acceptance** of the patient's language, culture and belief systems.
- **Knowledge of one's own inner thoughts**. The lawyer/law student identifies what he/she is thinking whilst talking with the patient/family member and is able to put these thoughts on one side in order to focus on the patient's needs.
- **A tentative approach** – such as 'Am I understanding you correctly? Are we talking about what you want to talk about?'

There is an invitation to share thoughts and feelings:

- 'What did you want to put in your will?'
- 'I want to be sure I understand you. Are you saying … ?'

After a period of silence from the patient, the lawyer might ask: 'I wonder what you are thinking about at the moment?'

Starting off

Don't be intimidated by the illness. Address the patient as you would anyone else.

The lawyer introduces himself:
'Good morning … . My name is … . I am a lawyer. I understand you would like to draw up an Advance Directive ("Living Will" may be the term some people are familiar with)?'

Sit down, if possible, in a position where the patient can see you easily without turning his/her head too much. The light from a window or other should not be shining in his/her eyes.

When the lawyer wishes to explore exactly what the person means, the following might be said:

- Tell me a little more about that.
- Could you help me understand what you mean?
- If I'm hearing you correctly …
- Am I right in thinking … ?
- What has made you think you might need a Living Will?

Ending the conversation

- Summarise what has been decided by the patient and repeat it if necessary.
- Plan to see the patient again as soon as possible for signing of the documents which have been drawn up. Time may be short and terminally ill patients may die at any time.

Debriefing

The lawyer may be faced with an emotional patient, or family members overwhelmed with grief following the death of a loved one. After such an interview, it is important for the lawyer to recognise the emotions which have been transferred from the patient to him/herself. Once identified, he/she realises that these emotions do not belong to him/her and need to be released. This is a vitally important action. Negative emotions (pain, suffering, grief) can be taken up unknowingly from others and stored in the recipient's body to the detriment of the receiver. A sign that this has happened would be when the receiver feels very drained and tired at the end of the day.

This releasing process should be conducted daily by backtracking and remembering who has been seen during the day. Law students and lawyers doing work in palliative care can request time with the social worker, when needed, to help with debriefing.

Other useful practices

- Caring for yourself by eating healthily, exercising and having enough sleep
- Thinking positive thoughts about yourself and rejecting the negative thoughts
- Asking for help when you need it
- Preparing and debriefing properly

Cultural and spiritual diversity and implications for care and funerals

Some understanding of the culture and belief systems of others is helpful, so that people don't talk past each other. (Clues to Culture by Elion and Strieman is recommended for an informative and concise overview of cultural and spiritual diversity in South Africa.) In this chapter we shall outline the practices of the African peoples only.

The African spiritual tradition

- For the African person, belief systems and culture are experienced as being interwoven.
- All of life is seen as inter-connected and all fall under God.
- Those who have gone before, the ancestors or 'living-dead', retain an interest in their families. Since God is a distant divine being, they are the mediators between God and the family. Their function is to see that traditional rules and rituals around life and death are adhered to. Where they are not, a warning may be received from the ancestor in the form of a dream or vision. If the family member does not search his spirit to find out what the problem is or consult a Traditional Healer to help him, he may experience an accident or a breakdown in his health.
- There is continuity between life and death, but the emphasis is on life and health. The healthy African person experiences a balance within himself, between himself and the community, and between himself and the spiritual world.
- There is a strong attachment to the soil and a sense of belonging to the place of birth
- People see themselves through their relationships with others (the community) rather than regarding themselves as separate individuals.
- People are able to be members of other religions whilst at the same time observing the rituals of Traditional African Religion.
- Death is feared, and any discussion or preparation for approaching death is often strongly discouraged. There is a fear that by using the words 'death' and 'dying', death may be invited into the room.
- In palliative care, family members may sometimes require a senior member of the family grouping or clan to be present when decisions have to be made regarding the patient.

However, for many families who come from the Eastern Cape or other rural areas in South Africa and now live in urban areas, it is important to be buried in the place where they were born. Sometimes patients feel that the time has come to return to the place of their birth, and they return of their own accord or with family members.

Bereavement

Registering the death

This is normally done by the funeral undertaker.

The funeral

Financial implications

Where tradition is vitally important, African families are prepared to go heavily into debt in order to satisfy the ancestors and the living family by proceeding with the necessary rituals at the place of birth. There are transport costs for those of the family who will attend the funeral; a beast must be slaughtered (a goat for an ordinary family, an ox for a wealthy family); extra cooking pots bought for the food to be cooked.

CASE STUDY

A Xhosa-speaking man was admitted to a hospice in-patient unit in an urban area. He was terminally ill. The patient's son took responsibility for both his parents. The son requested that staff in the unit should not have any discussions about death and dying with his father or mother. This request was respected and no conversations about death or dying took place except with the son. Conversations focused rather on the comfort of the patient. It was explained to the son that his father was close to passing and he was asked if he wished this to happen at home or elsewhere. The son said he wanted his father to continue to receive care in the hospice. When his father died, the son made all the funeral arrangements.

Saving for the funeral

- African families often pay into a 'stokvel' or a burial group. A stokvel is similar to the English word 'co-operative'. People come together and pay in for various purposes, not necessarily for burial, for instance they may do it during the year to have money at Christmas. African people who move from rural areas into towns, often form a burial group with others from the extended family or clan. The members of the group meet once a month and pay in an arranged amount of money. This money is then used to pay for burials for any member of the group. Funerals of members who die are financed out of this fund. If several members of an extended family die within a short space of time, the fund may be insufficient.
- Borrowing money from a micro-lender or a bank. Large amounts of money are needed and it will take many months to repay the amount with interest.
- Other cultures may take out funeral insurance and pay the premium each month.

The wider significance of the funeral

- As well as the ancestors, the community and neighbours have to be satisfied with the way in which this particular family has completed all necessary rituals after the death of a family member.
- If arrangements are not well made, the entire extended family and clan may be ashamed and may suffer emotionally and spiritually as well as socially.
- Other communities in South Africa would also feel that they had lost face in the eyes of friends, church people and the larger community if they provided a cheap funeral and not much in the way of refreshments to honour their family member who had died.
- The funeral can thus be seen as an investment in the future lives of those left behind, even if they struggle financially to repay loans.

Pauper's Burial

When people have died alone at home, on the street or in a Night Shelter and are apparently without relatives or income, a Pauper's Burial is provided by the health district or large municipality.

If the destitute person dies in the provincial hospital or in an ambulance, then the province and not the municipality has liability to meet the cost. The following steps are taken to access a Pauper's Burial:

- The cemetery department of the municipality (health department of a smaller municipality) is contacted.
- A municipal council member or SAPS member determines whether the person was destitute and will complete the necessary forms.
- The body is collected when authorisation is given by the municipality (Cemetery office) to the funeral undertaker who holds the municipal contract.
- The municipality does not pay storage costs if the body has been removed before this process is complete.

Implications for Palliative Care

Sometimes palliative care staff can see that this situation may arise for a particular patient. However, there are concerns and decisions about this type of burial which should not be taken lightly:

- The patient may have been living on the street, but in fact has savings which he has not disclosed.
- He may have a will, which specifies how he wants his remains to be disposed of, and this is not known to others at that time.
- He may have relatives, but has broken off contact and tells staff that he has no family.
- In an African community, others may be prepared to contribute towards a funeral.
- Months later, a member of a traditional family may arrive and require some soil from the place where the person was buried or the ashes scattered, to take back to the place of birth, so that the proper rituals may be carried out for their relative in order to appease the ancestors.

Property grabbing

Colgan reports that some home-based carers she met in Soweto in 2007 spoke of property being grabbed by adult relatives after the funeral; and that sometimes orphaned children are seen as being a potential source of money through social grants. (See the chapter on Dying and the Law and the chapter on the Rights of Children and Young People in Palliative Care).

Talking with the Bereaved

Palliative care includes practical assistance and counselling to bereaved family members. Research has shown that individual and family breakdown can be prevented at this time if support is available to those who need it. Bereaved family members may need legal assistance. Very often the spouse or partner of the person who died will be the one consulting the legal practitioner, in terms of the will.

- An adult son or daughter may be the main beneficiary of the deceased or they may accompany their parent to give support.
- Parents of a deceased adult child may come forward with problems accessing a life policy made out to them.

It is important to remember that grieving people may be ‘off-balance’ after a death. Judgement and perception may be affected for a while and people say and do things which, a year later, they might regret. The bereaved person is emotionally stressed and is trying to survive; at the same time he or she is called upon to make an extra effort at a time when they feel most vulnerable and exhausted. We know that grieving saps a person’s physical and emotional energy.

The lawyer or care giver can help the person to face the reality of the legal and financial situation in a gentle, patient, calm and compassionate way. He/she can explore with the client whether there is another family member who might be able to assist and support them.

Where possible, in practical terms, clients can be advised not to make over-hasty decisions and to give themselves six to twelve months before making major changes.

The following may occur after a loved one has died:

- The grieving client forgets an appointment or gets the time wrong.
- The client cannot locate documents needed or only brings some of the documents. Many telephone calls may be necessary to some clients before all is in order.
- The client bursts into tears and overwhelms the lawyer with sadness and despair.
- The lawyer worries about something he/she may have said which provoked fresh grief from the client.
- The lawyer thinks the person should have got over their grief by this time.

Applying for the social grant after the death of a patient

If the recipient of a social grant or pension dies before the grant has been paid out for that month, the closest family member may apply to the Department of Social Development (SASSA) for that month’s pay-out. Documentation in support of this application is the following:

- Identity Documents of the deceased and the claimant
- Marriage Certificate or proof of relationship
- Death Certificate
- Funeral account

This money will take about three months to come through.

Why is it advisable to obtain several copies of the Death Certificate?

A certified copy of the Death Certificate will be needed in the following instances:

- For pay-out of any insurance policy ceded to the claimant.
- For the cancelling of debts made by the deceased where there is no liability to pay by family members – such as a son or daughter.

Converting the house into the name of the surviving spouse or partner, when it is joint-owned by the deceased and the partner

The following must first be completed:

- If the person died intestate, a letter of authority is required from the Master of the High Court. This is a completed form from the Master’s office stating when the patient died and that there was no will.
- The municipal account must be fully paid up.

Application can then be made through the municipal housing office.

Summary

- Legal issues should be addressed as early in the illness process as possible.
- The most common legal requests in palliative care before the death of a patient are for powers of attorney, wills, housing issues, guardianship, advance directives.
- After the death of a patient, legal advice may be required for any disputes about the will, house transfer and children's issues.
- The legal person should be prepared by palliative care staff and have sufficient information before seeing a patient or family member.
- Cultural knowledge of diversity and an attitude of respect is required.
- It is essential that both palliative care and legal people debrief properly after distressing encounters in their work.
- Some understanding of the feelings of the bereaved and the importance of the funeral is helpful knowledge.

The provision of legal advice to patients in palliative care and their families empowers individuals and restores hope when hopelessness has made a bid to be in control of the person's life. It is heartening to know that lawyers, university law departments and law students are willing to be of service at a time when families are in crisis.

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Resources

Resources for Chapter 2: Introduction to Human Rights and Palliative Care

Online Resource Guide prepared by the Open Society Institute and Equitas

This resource guide is designed to support health and human rights advocacy, training, education, programming, and grant making worldwide. The Resource Guide includes additional fact sheets, program descriptions, jurisprudence, case studies, bibliographies, and glossary definitions on human rights and patient care, so it may be helpful for readers who are interested in furthering their knowledge in the area.

http://equalpartners.info/Introduction/intro_TOC.html

Resources for Chapter 4: The NPO Sector

How to access information on the current status of South African legislation

The Parliamentary Monitoring Group (PMG) was set up in 1995 as a partnership between the Black Sash, Human Rights Committee and IDASA with the aim of providing a public record of the Parliamentary committee proceedings - the engine room of Parliament. This type of information is needed by civil society to lobby Parliament on pieces of legislation, matters of democratic processes and parliamentary oversight of the executive. Importantly, it provides a window into the performance of each government department and public entity over which each parliamentary committee has oversight. PMG has information regarding the current status of Bills, legislative programmes for each government department, details of parliamentary programmes and public hearings. PMG can also provide early notification of requests for submissions to Parliament.

Further information can be found at:	Space for updated contact details
www.pmg.org.za Tel: 021 465 8885 Fax: 021 465 8887 By mail or in person: 2nd floor, Associated Magazines, 21 St Johns Street, Cape Town 8001	

How to access publications written by South African legal experts

The publishers, Juta, provide without subscription, the Juta Law Catalogue, a list of publications written by legal experts on a variety of legal topics with information on authors and brief content outlines. Information can be found at www.jutalaw.co.za/catalogue

Resources for Chapter 6: Poverty, financial issues and social development

Included here is further information on Birth Certificates, Social Grants and how to access SASSA. To confirm any amendments to this information, kindly check www.sassa.gov.za

Further information regarding Birth Certificates

Births notified within 30 days after birth

Although the Births and Deaths Registration Act (Act 51 of 1992) requires that the birth of a baby must be registered within 30 days after birth, special circumstances may make this impossible. Notices of birth after 30 days are called late registrations and are all free of charge. The only form required in this case is a Notice of Birth form (Bl-24) signed by one of the parents or guardian. Three categories of late registrations are distinguished as follows:

i. Births notified after 30 days, but before one year,
ii. Births notified after one year, but before 15 years and;
iii. Births notified after 15 years.

Birth notified after 30 days, but before one year

- In this case, the parents or guardian have to complete a Bl-24 form. The parents or guardian should also give reasons why the birth was not registered within 30 days as required by the law.
- If the parents are not married and they wish to register the child under the father's surname, the father must acknowledge paternity in the space provided on the Bl-24 form. The father should therefore be present when the birth is registered.
- If the parents are married, the child's birth will be registered on the surname of the father.

Birth notified after one year but less than 15 years of age

The parents or guardian have to complete a Bl-24 form. They also have to give reasons why the birth was not registered within 30 days as required by the law. The supporting documents specified must be handed in at the same time.

Birth notified after 15 years of age

When registering this birth, a Bl-24/15 form is used. This is accompanied by a Bl-9 form (application for an identity document) and the relevant documentation specified. The parents or guardian are also required to give reasons why the birth was not registered within 30 days as required by the law.

Documents needed when a birth is registered after one year

The following documents are required for birth registration of a child not registered within one year of its birth:

- Bl-288 sworn affidavit, and
- Certified copy of the mother's identity documents if parents are not married and the father does not acknowledge paternity. Alternatively, if the biological father acknowledges paternity, certified copies of both parents' identity documents are required. If married to the biological mother, certified copies of both parents' identity documents and their marriage certificate are required, **or**
- Confirmation of the child's personal details as contained in the school register or a school certificate of the first school attended by the child, signed by the Principal. The confirmation should have the principal's personal number on an official letterhead containing the official school date stamp, **or**
- The child's baptismal certificate, if issued within five years of birth, or
- If the parents are not available, an affidavit by a close relative at least 10 years older than the child, who is familiar with the child's birth details and can confirm the child's identity and status, **or**
- Clinic card or school report or any relevant document that may assist in providing the child's identity status, **or**
- A statement from a person who has personal knowledge of the applicant and can attest to the applicant's parentage. This person will also have to accompany the applicant to the Home Affairs office where the applicant and the person will be interviewed separately.

Further information regarding Social Grants

What does inflation mean?

Remember every year because of inflation, the money you receive from a grant will not cover as many of your expenses as it did before. So to keep up with inflation, and ensure people get enough money, the government often increases the amounts payable each year and the income threshold below which you qualify for a grant. So you need to be sure you are looking at up-to-date tables as the government may have adjusted amounts which are not shown on the table you are looking at. The table below shows how between 1 April 2008 and 1 April 2009 the amounts for qualifying income have changed.

Asset and Income Threshold for Social Grants

Asset Threshold	As at 1 April 2008	As at 1 April 2009	As at 1 April 2010
For Older Person, Disability and War Veterans Grant (Child support, Foster Child and Care Dependency Grant – no asset threshold)			
Single person	R338 400	R484 800	
Married person	R676 800	R 969 600	
Income Threshold			
For Older Person, Disability and War Veterans Grant			
Single person	R23 544	R29 112	
Married person	R43 704	R58 224	
Child Support Grant			
Child grants	R9 600 (urban) R13 200 (rural /informal dwelling)	R28 800 (single) R57 600 (married)	
Foster Child Grant:	R15 600	No means test	
Care dependency grant (income of parent)	R48 000	R121 200 (single) R242 400 (married)	
Care-dependency grant (income of child)	R22 560	No means test	

Amount of Grants (paid out to recipient)

Amounts of Grants	As at 1 April 2008	As at 1 April 2009	As at 1 April 2010
Older Person's Grant	R940	R1 010	
Disability Grant	R940	R1 010	
War Veteran's Grant	R940	R1 030	
Grant-in-aid	R210	R240	
Child Support Grant	R210	R240	
Foster Child Grant	R650	R680	
Care-dependency grant	R940	R1 010	
State-aided institution (25%)	R235	R252.50	

Remember that the amount paid out to individual may be less than shown on the above table, due to assessment of other income. Table indicates the maximum payout allowed.

As information quickly becomes out-of-date, to ensure you access up-to-date information on grants (both the qualifying income and amounts payable) look under Social Grants on the South African Social Security website or dial the SASSA toll free number or a local branch office, both listed opposite.

Contact Details of SASSA offices:

Toll free number: 0800 60 10 11
Website: www.sassa.gov.za

SASSA HEAD OFFICE

SASSA house
501 Prondisa Building
Cnr Beatrix and Pretorius Street
Pretoria

Private Bag X55662
Arcadia
Pretoria
8803

Tel: 012 400 20000 (Switchboard)
Website: www.sassa.gov.za

EASTERN CAPE REGION

Bandile Maqetuka
Acting Regional Executive Manager

1st Floor
Waverly Office Park
3-33 Phillip Frame Road

Private Bag X9001
Chiselhurst
East London
5200
Tel: 043 707 6300
Fax: 043 707 6487

FREE STATE REGION

Gerald Roberts
Acting Regional Executive Manager

African Life Building
75 St. Andrews Street
Bloemfontein

Private Bag X4424
Bloemfontein
9300

Tel: 051 409 0853
Fax: 051 409 0857

GAUTENG REGION

Gerry Rees
Regional Executive Manager

28 Harrison Street
Johannesburg
2000

Private Bag X35
Johannesburg 2000

Tel: 011 241 8300
Fax: 011 241 8301

KWAZULU-NATAL REGION

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Pietermaritzburg
3201

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LIMPOPO

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Fax: 015 291 7996

MPUMULANGA

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Fax: 053 832 5525

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Regional Executive Manager

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Adderley Street
Cape Town
8001

Private Bag 9189
Cape Town
8000

Tel: 021 469 0200
Fax: 021 469 0260

Contact details for legal services organisations

The following list is not comprehensive but is designed to offer pointers on how to find legal services operating in local communities in South Africa.

How do I find legal assistance in my community?

When looking for legal assistance, remember :

- Confidentiality of the client is always to be respected and referrals made with their consent.
- Community paralegals can give legal assistance and are often mediators e.g. in disputes between neighbours whilst others are skilled at pursuing missing birth certificates, ID, or helping with debt problems etc.
- Some clients may not wish to be helped by someone in their immediate community.
- Local paralegals have access to lawyers for more complex problems. Such lawyers work at legal clinics at universities, at Justice Centres, at organizations such as the Legal Resources Centre, Black Sash, Lawyers for Human Rights and Pro Bono.Org. Private lawyers do some of their work for free (pro bono) as part of their commitment to community involvement.
- If local legal assistance is not immediately obvious in your community, other NGOs, local branches of political parties, trades union will have access to this information.
- Legal fees may be charged if the person seeking legal assistance has an income, whilst some lawyers will provide assistance pro bono (for free) to those in need.
- Some of the organisations listed here have contributed to writing this manual and so these organisations are listed in more detail in the List of Organisations Section.

How do I find a paralegal in my community?

Many paralegal advice centres operate within what is known as a cluster which is a referral network of paralegals, university law clinics and government justice centres.

To find a paralegal office near you in the Western Cape you can ring Black Sash (contact details below) or the website for the National Consumer Forum also has a list of paralegal offices in the Western Cape : http://www.ncf.org.za/docs/publications/consumerfair/vol16/part4.pdf

To find a paralegal office near you in the rest of South Africa you can contact NADCAO who may be able to refer you to a local paralegal advice office in your area:

National Alliance for the Development of Community Advice Offices (NADCAO) which is ‘a national alliance for the development of community advice offices and community-based paralegals that aims to facilitate and expand access to social justice by the poor in South Africa through voice and knowledge sharing, support and development, and resource mobilisation.’

NADCAO Secretariat: 12 Plein Street, Cape Town, 8000
Tel: 021 461 7804
Fax: 021 461 8004
www.nadcao.org.za

How do I find a lawyer in my area?

Besides accessing lawyers through paralegals, university law clinics and NGOs you can contact the Law Society of South Africa for access to attorneys via the regional law societies:
http://lssa.questweb.co.za/Index.cfm?fuseaction=home.page&PageID=1791816

Alternatively Lexis-Nexis has launched Law24.com, a comprehensive one-stop website providing extensive yet simple legal information, DIY legal services, expert opinions and free legal advice grouped into various categories: work and employment, money and financial, personal and family, and property and home. Visit www.law24.com

How do I find a university law clinic in my community?

If you want to find a local university law clinic in your area, you can phone your closest university to ask if they have a law clinic or you can contact:

Association of University Legal Aid Institutions (AULAI)
secretary@aulai.org.za
www.aulai.org.za

Four of the well-known university law clinics are listed here but this list is not comprehensive, and you should contact (AULAI) for a law clinic in your area.

University of the Western Cape

UWC Law Clinic
Old Library Building,
University of the Western Cape Campus,
Modderdam Road, Bellville
Tel: 021 959 2756

University of Witwatersrand

Wits Law Clinic
1 Jan Smuts Avenue
Braamfontein
Johannesburg
Tel: 011 717 8562
Fax: 011 339 2640
http://web.wits.ac.za/Academic/CLM/Law/CentresClinicsResearch/WitsLawClinic/contact.htm

University of Cape Town Law Clinic

Fourth floor, Room 4.36
Kramer Law School Building,
Middle Campus, University of Cape Town,
1 Stanley Road, Rondebosch, 7701
Tel: 021 650 3775 or 021 650 3551
Email: uctlawclinic@uct.ac.za
www.uct.ac.za/faculties/law/research/lawclinic/study

Rhodes University Legal Aid Clinic

41 New St, Grahamstown, 6139
PO Box 702, Grahamstown, 6140
Tel: 046 622 9301
Fax: 046 622 9312

What follows is a list of NGOs who assist poor or marginalised groups with legal problems and also includes NGOs with a specific HIV, health and human rights interest.

Legal Resources Centre

South Africa's largest public interest law centre, since 1979, with offices in Cape Town, Johannesburg, Durban and Grahamstown.

The National office
7th Floor Bram Fischer House, 25 Rissik Street, Johannesburg
Tel: 011 836 9831, 838 6601 or 403 0902
Fax: 011 834 4273

Grahamstown Office
116 High Street, Grahamstown
Tel: 046 622 9230

Cape Town Office
3rd Floor, Greenmarket Place, 54 Shortmarket Street, Cape Town 8001
Tel: 021 481 3000

www.lrc.org.za

See further details under List of Contributing Organisations.

Lawyers for Human Rights (LHR)

LHR is an independent human rights organisation with a 30 year track record of human rights activism and public interest litigation in South Africa.
LHR provides free legal services to poor and indigent people from six law clinics around the country located at Durban, Johannesburg, Musina, Pretoria, Stellenbosch and Upington.

Johannesburg: 011 339 1960
Pretoria: 012 320 2943
Durban: 031 301 0351
www.lhr.org.za

Black Sash

Over the past five years, the Black Sash provided free paralegal advice to more than 58 000 people, recovering more than R65m in Social Security Grants and other financial provisions. We provide comprehensive and quality advice in the area of social protection and consumer protection (credit, debt and consumer contracts), labour and citizenship through our regional offices and satellite services.

The Black Sash has a free paralegal advice website which consists of a manual covering various aspects of the law and has recently produced Debt and Credit, an online reference guide for paralegals.

Black Sash National Office
12 Plein Street, Fourth Floor, Cape Town
Tel: 021 461 7804
www.blacksash.org.za

ProBono.org

Pro Bono is the delivery of legal services to the poor, community-based organisations and public interest law institutions in matters in the public interest.

9th Floor Schreiner Chambers, 94 Pritchard Street, Johannesburg
Tel: 011 336 9510
Fax: 011 336 9511
Email: info@probono-org.org
www.probono-org.org

Street Law

Street Law is a prominent democracy, human rights and legal education programme for all South Africans and offers training programs nationally.
See further details under List of Contributing Organisations.

National Street Law office
Tel: 031 260 2769 or Fax 031 260 1540.
Tel: 041 5042077
Email: info@streetlaw.org.za
www.streetlaw.org.za/contact.html

Treatment Action Campaign (TAC)

Campaigning for the rights of people with HIV/AIDS

Their vision is: a unified quality health care system which provides equal access to HIV prevention and treatment services for all people. Their mission is: to ensure that every person living with HIV has access to quality comprehensive prevention and treatment services to live a healthy life

National Office
2nd Floor, Westminster House, 122 Longmarket Street, Cape Town, 8001
Tel: 021 422 1700
Fax: 021 422 1720
www.tac.org.za

AIDS Law Project

The AIDS Law Project (ALP) focuses on removing obstacles that prevent people with HIV/AIDS from having access to adequate health care and treatment in both the private and public sectors, from contesting unfair treatment and discrimination or that deny people with HIV/AIDS access to employment, employee benefits, insurance, education and other services.

Johannesburg Office
Unit 6/002, 6th Floor , Braamfontein Centre
23 Jorissen Street, Braamfontein, 2001
Tel: 011 356 4100
Fax: 011 339 4311 or 011 339 4312
Email: info@alp.org.za

Cape Town Office
122 Longmarket Street, Corner Adderley
Westminister House, 4th Floor, Cape Town
Tel: 021 422 1490
Fax: 021 422 1551

Government – Department of Justice

Justice Centres & The Legal Aid Board Of South Africa – Justice For All

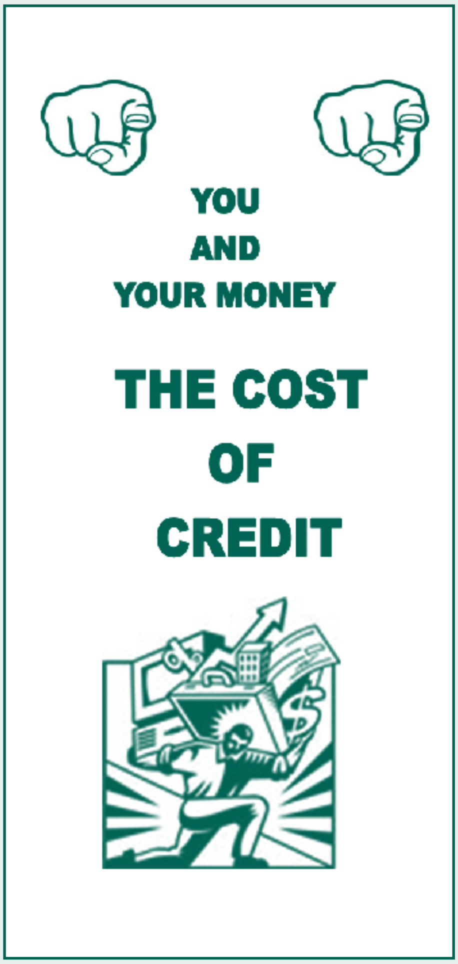
The objective of the Legal Aid Board is to make available legal representation to indigent persons at State expense as contemplated in the Constitution of the Republic of South Africa, which affords every citizen access to justice.

The Legal Aid Board does not offer legal assistance via e-mail, to get legal assistance visit your nearest Justice Centre. To locate your nearest Legal Aid Board Justice Centre call 08610 Legal (53425).

Head office
29 De Beer Street, Braamfontein, Johannesburg
Email: communications2@legal-aid.co.za
www.legal-aid.co.za

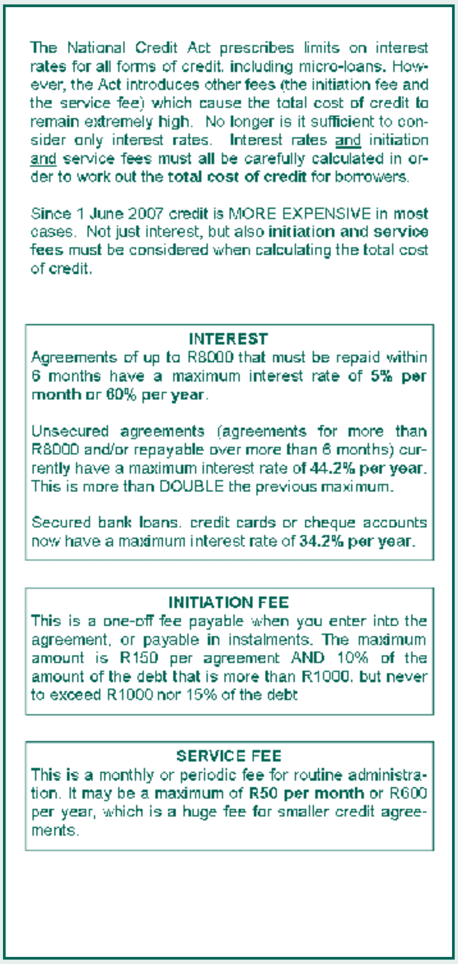
Assistance can be requested from the Legal Aid Officer at a Magistrate’s Court.

Resources for Chapter 7: Managing debt in the context of illness



YOU
AND
YOUR MONEY

THE COST
OF
CREDIT



The National Credit Act prescribes limits on interest rates for all forms of credit, including micro-loans. However, the Act introduces other fees (the initiation fee and the service fee) which cause the total cost of credit to remain extremely high. No longer is it sufficient to consider only interest rates. Interest rates and initiation and service fees must all be carefully calculated in order to work out the **total cost of credit** for borrowers.

Since 1 June 2007 credit is MORE EXPENSIVE in most cases. Not just interest, but also **initiation and service fees** must be considered when calculating the total cost of credit.

INTEREST

Agreements of up to R8000 that must be repaid within 6 months have a maximum interest rate of **5% per month** or **60% per year**.

Unsecured agreements (agreements for more than R8000 and/or repayable over more than 6 months) currently have a maximum interest rate of **44.2% per year**. This is more than DOUBLE the previous maximum.

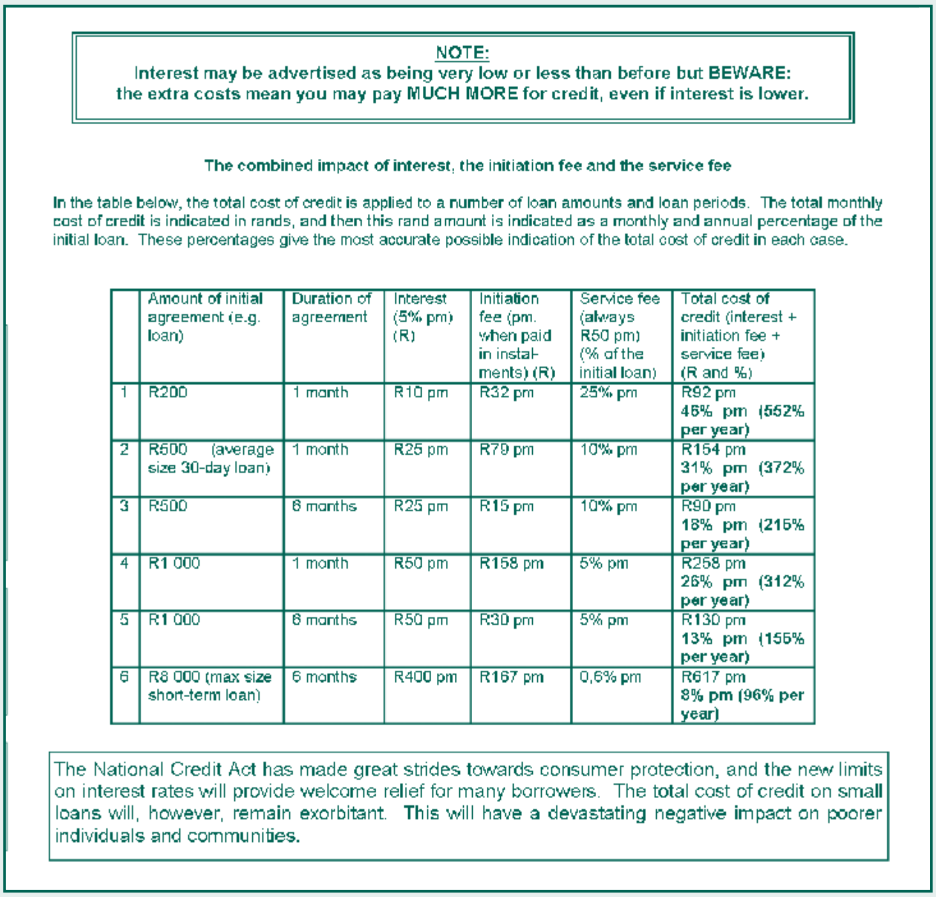
Secured bank loans, credit cards or cheque accounts now have a maximum interest rate of **34.2% per year**.

INITIATION FEE

This is a one-off fee payable when you enter into the agreement, or payable in instalments. The maximum amount is R150 per agreement AND 10% of the amount of the debt that is more than R1000, but never to exceed R1000 nor 15% of the debt

SERVICE FEE

This is a monthly or periodic fee for routine administration. It may be a maximum of **R50 per month** or R600 per year, which is a huge fee for smaller credit agreements.



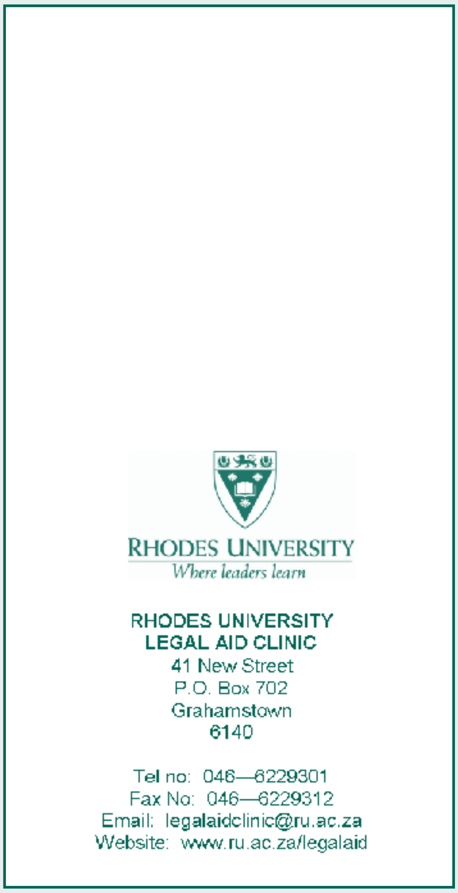
NOTE:
Interest may be advertised as being very low or less than before but BEWARE:
the extra costs mean you may pay MUCH MORE for credit, even if interest is lower.

The combined impact of interest, the initiation fee and the service fee

In the table below, the total cost of credit is applied to a number of loan amounts and loan periods. The total monthly cost of credit is indicated in rands, and then this rand amount is indicated as a monthly and annual percentage of the initial loan. These percentages give the most accurate possible indication of the total cost of credit in each case.

	Amount of initial agreement (e.g. loan)	Duration of agreement	Interest (5% pm) (R)	Initiation fee (pm. when paid in instalments) (R)	Service fee (always R50 pm) (% of the initial loan)	Total cost of credit (interest + initiation fee + service fee) (R and %)
1	R200	1 month	R10 pm	R32 pm	25% pm	R92 pm **46% pm (552% per year)**
2	R500 (average size 30-day loan)	1 month	R25 pm	R79 pm	10% pm	R154 pm **31% pm (372% per year)**
3	R500	6 months	R25 pm	R15 pm	10% pm	R90 pm **18% pm (216% per year)**
4	R1 000	1 month	R50 pm	R158 pm	5% pm	R258 pm **26% pm (312% per year)**
5	R1 000	6 months	R50 pm	R30 pm	5% pm	R130 pm **13% pm (156% per year)**
6	R8 000 (max size short-term loan)	6 months	R400 pm	R167 pm	0,6% pm	R617 pm **8% pm (96% per year)**

The National Credit Act has made great strides towards consumer protection, and the new limits on interest rates will provide welcome relief for many borrowers. The total cost of credit on small loans will, however, remain exorbitant. **This will have a devastating negative impact on poorer individuals and communities.**



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YOU AND YOUR MONEY

Consumer rights & duties

> The last provisions of the National Credit Act of 2006 came into effect on 1June 2007. All consumer credit law is contained within this Act and it applies to all credit agreements and all credit providers.

1. Right to pre-agreement disclosure

- Before entering into a credit agreement the credit providor MUST give you a statement and quotation for FREE.
- At this stage there is NO AGREEMENT: you do not have to sign anything or pay any fee
- The statement and quotation must tell you:
  - the amount of credit providedthe number and amount of instalments payable
  - interest and other fees
  - deposit required
  - credit insurance

You have 5 days to accept or reject the quote. This gives you time to look around for better or cheaper credit.

Only when you accept the quotation is the credit agreement concluded and you are bound by it.
DO NOT PAY ANY FEES BEFORE CONCLUDING YOUR AGREEMENT!

2. Right to apply for credit and non-discrimination

- Every adult can apply for credit, but no-one has the right to be granted credit.
- A credit grantor can refuse to give you credit for **reasonable** business reasons, **but**
  - may not refuse to give you credit because of your race, religion, marital status, ethnic or social origin, gender, sexual orientation, age, disability, culture, language etc.
  - you MAY ask for reasons why you were refused credit. The credit provider should give you these reasons in writing.

3. Right to understandable language

You have the right to be given a quotation and credit agreement in an **official language** you understand, if this is reasonable. If documents don't have a set form they should be in plain language that an average person can understand.

4. Right to information held by credit bureaux

When you apply for credit, the credit provider will check your credit report before deciding whether or not to give you credit.

- You have the right to access information held by credit bureaux about your credit worthiness.
- You can dispute the correctness of this information
- You can have information about rescinded judgments removed from credit bureaux records.
- The credit bureau or NCR MUST investigate and correct any incorrect information FREE of charge.
- A credit provider must advise you before reporting information about you to a credit bureau.

- You have the right to a free credit bureau report once per year during your birthday month.
- After that it will cost R20 per enquiry.

Two IMPORTANT credit bureaux, with contact details, are:
TransUnion ITC: Tel: 086 148 2482; Fax: 011 - 388 9963; Website: www.mycredit.co.za; email: freecreditreport@transmission.co.za.
Experian: Tel: 086 110 5665; Fax: 011 – 707 6700; Website: www.experience.co.za); email: consumer@experian.co.za.

5. Right to protection against marketing practices

The Act contains a number of rules regarding marketing practices:

(a) The advertising and marketing of credit must contain prescribed information on interest and all other charges you will have to pay
(b) Negative option marketing is not permitted (in terms of which an agreement will automatically come into existence unless the consumer declines an offer).
(c) Advertisements must not be misleading, fraudulent or deceptive.
(d) Credit providers may not harass, force or persuade you to apply for credit.
(e) Credit sales at a person's home are strictly prohibited, unless:
  - the sale occurs during a meeting that you pre-arranged for that purpose ; or
  - you are given credit on the sale of goods or services.

(f) A credit provider may require that you have credit life insurance during the time you have a credit agreement with them; but they have a duty to ensure that suitable options for insurance cover are offered to you.

6. Right to confidentiality and privacy

Credit bureaux must protect the confidentiality of consumer credit information that they hold or report on.

Credit providers must give you the option of being excluded from telemarketing campaigns, marketing or customer lists sold or distributed, and mass distribution of e-mail or sms messages.

7. Right of cooling-off

Leases and instalment agreements
You may terminate these agreements (in writing and properly delivered) within five business days of signing them. You must then return the goods you bought. The credit provider must refund the money you paid within seven days of termination, less the following:

(a) reasonable costs of return and repair of damages after sale;
(b) rent for use of the goods, unless they are still in their original packaging; and
(c) compensation for depreciation in value of the goods (by agreement or court order only).

8. Right to early settlement and repayments

You MAY **settle** your debts before they are due, and credit providers must accept early payment. Amounts paid early will be used first for unpaid interest and fees, and second to reduce the principal debt.

In the case of SMALL agreements (less than R15 000) you do not need to give notice to the credit provider if you want to do this. Interest and other fees are payable only until the date of settlement.

i.e. **YOU CANNOT BE PENALISED FOR PAYING EARLY**

In the case of LARGE agreements (eg mortgage bonds) you must give 3 months notice to the credit provider. If you cancel a mortgage bond, you will be liable for the bond cancellation costs.

9. Surrender of goods

You can take the goods you bought on credit back to the credit provider at ANY time (whether you are in default or not). The credit provider must then sell the goods and use the money it gets from the sale to settle your account. If the amount the credit provider receives from selling the goods is less than what you owe, you will have to pay it the amount that is outstanding.

10. Statements of account

Credit providers must give you statements of account, usually once per month (once every two months for instalment sale agreements).

Credit providers must also give you statements of account **on request**, at **no charge**. Consumers may choose how the statement must be delivered:

- orally in person, or by phone; or

in writing (in person, by sms, mail, fax or email – provided the credit provider has these facilities).
Credit providers do not need to give written statements on demand more than once every three months.

11. Duty to report location of goods

In the case of instalment agreements, you get **ownership** ONLY when **all instalments** are paid. Consumer must inform credit provider of changes in :

- business or residential address
- the premises where the goods are kept
- the name and address of any other person who has possession of the goods

If requested, you must also give to the credit provider or Sheriff the address where the goods are kept and the name and address of the landlord of the premises.

12. Duty to pay credit providers

This is the consumer's MOST IMPORTANT duty. It will prevent legal action being taken against you.

Also, maintaining a good credit rating will make it easier for you to get credit in future

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YOU AND YOUR MONEY

THE CREDIT BUREAUX

What can I do if the information on my credit report is incorrect?

The National Credit Act has prescribed a process for managing consumer disputes with the credit bureau. If you believe that the information on your credit report is incorrect, you should do the following:

- Contact the Credit Bureaux and inform them that you wish to register a dispute.
- The Credit Bureaux will investigate the dispute and respond within 20 business days. Credit providers will be notified that there is a dispute on your record but will not be able to view the disputed information during this investigation period.
- Should the information prove to be incorrect or unsubstantiated it will be removed immediately.
- Credit providers will be notified of the correction.

Should you not be satisfied with the resolution of your query you may contact the office of the **Credit Information Ombud** on **0861 66 28 37.**

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Rights regarding information held by Credit Bureaux

Whenever you apply for credit, the credit grantor checks your Credit Report before deciding whether to approve or decline your application.

A Free Credit Report is available once a year, as of 1 September 2006. This gives the Debtor access to all the information that credit grantors can access, including the debtor's paying habits, credit history and any other credit enquiries. Note that this free credit report is only available in the month of the debtor's birthday. You can now check that your personal information, like your ID number, address and employer's details, are correct and up to date. You can also see information relating to how you pay your accounts and how it is represented on your Credit Report.

The two main Credit Bureaux are:

- Trans Union ITC and
- Experian

A. Free Credit Report through TransUnion ITC

There are three main methods:

- Internet – Log into www.mycredit.co.za.
- Email – freecreditreport@transmission.co.za
- Fax – 011 388 9963

A reply to your application will be sent to you within 48 hours.

Should you have already received your Free Credit Report for the year, you can purchase another copy for only R20 from the Personal Credit Products section of this website.

B. Free Credit Report through Experian

To request your free credit report the following procedure must be followed:

- Complete a *Request a free credit report* form which can be downloaded at *www.experian.co.za*.
- Fax it (together with the required documentation) to 011 707 6700
- Or email the above completed report to consumer@experian.co.za.

A reply to your application will be sent to you within 48 hours.

Please note that any further copies of your credit report will be charged at R22.80 (R20 + VAT). For any further queries contact Experian's Consumer Relations desk on 0861 10 56 65.

You are required to provide the following information when making an application with both Credit Bureaux:

- Proof of your full names
- Date of birth
- Identity number (by providing a copy of your national identity document)
- Or, if your identity document is unavailable, a copy of your passport and full birth certificate or a valid driver's licence and other credit-related information

What information is on a credit report?

A credit report includes:

- information about previous credit enquiries.
- account repayments including poor payer information.
- judgments

Resources for Chapter 9: Palliative Care and older persons

A telephonic help-line for older people who are being abused is manned by counsellors from the organisation, Halt Elder Abuse (HEAL). The line can also be used by the general public to report cases of abuse. The number to dial is 0800 003 081.

Resources for Chapter 10: Refugees and other potentially vulnerable groups

Service provider contact list

Refugees, asylum seekers and migrants	Space for updated contact details
Lawyers for Human Rights, Johannesburg: 011 339 1960 Lawyers for Human Rights, Pretoria: 012 320 2943 Lawyers for Human Rights, Durban: 031 301 0351 Wits Law Clinic: 011 717 8562 UCT Law Clinic: 021 650 3775	
Sex workers	
Sex Work Education and Advocacy Task Force (SWEAT): 021 448 7875 Reproductive Health Care Unit, Wits: 011 358 5300	
Drug users	
Cape Town Drug Counselling Centre: 021 447 8026	
Prisoners	
Civil Society Prison Reform Project: 021 797 9491 or 021 959 3283	
Lesbian, gay, bisexual and transgender people	
OUT: 012 344 5108 Triangle Project: 021 448 3812	

Contributing organisations

Centre for the Study of AIDS, University of Pretoria

The Centre for the Study of AIDS (CSA) at the University of Pretoria (UP) was established in 1999 and is a self funded, standalone unit. Using the University of Pretoria as its base, the CSA aims to create new and innovative ways to address HIV and AIDS, human rights and development in Southern Africa. The CSA further promotes a holistic understanding of HIV/AIDS, where it is not simply seen as a bio-medical issue, but is viewed through the lens of social theory, community development and human rights. For more information on CSA projects and publications go to **www.csa.za.org**

Children's Rights Centre

The Children's Rights Centre contributes to the development of a sustainable child-friendly society in South Africa, in which children's rights are fulfilled, protected and promoted. These rights to survival, development, protection and participation have been set out in international conventions and an African charter and the South African Constitution. We support caregivers, service providers, policy makers and others to be effective, caring duty bearers of children's rights. We work with and through our relationships and partnerships with individuals, organisations, networks and other civil society and state structures.

Our office is located in Durban and the scope of our work includes practical training and capacity building, development and distribution of educational, awareness raising and advocacy materials, publications, posters, games and displays including the Children Living Positively series for children living with HIV/AIDS and the adults in their lives. We also host and coordinate networks such as the South African Children's Sector Civil Society HIV/AIDS Network.

Tel: 031 307 6075
Fax: 031 307 6074
Email: info@crc-sa.co.za
www.crc-sa.co.za

Consortium for Refugees and Migrants in South Africa (CoRMSA)

The Consortium for Refugees and Migrants in South Africa (CoRMSA), formerly known as the National Consortium for Refugee Affairs, is a registered Non Profit Organisation tasked with promoting and protecting refugee and migrant rights. It is comprised of a number of member organisations including legal practitioners, research units, and refugee and migrant communities.

The Consortium's mandate involves strengthening the partnerships between refugee and migrant service providers to provide improved co-ordination of activities. This includes developing working relationships with other concerned organisations to provide an effective forum for advocacy and action.

The Consortium liaises with government and other stakeholders to keep them informed of the views of our members. The Consortium also provides a centralised referral system for the media and other practitioners through which it can refer those dealing with specific aspects of the sector to the organisations and individuals most qualified to assist. A full list of CoRMSA members and contact details is available at **www.cormsa.org.za**

Drakenstein Palliative Hospice

Drakenstein Palliative Hospice is situated within the Drakenstein Sub-District, part of the Cape Winelands District, and cares for about 300 sick patients and 130 orphans and vulnerable children per month. We are COHSASA accredited until September 2011.

The hospice started in 1991. Challenges we have faced are the introduction of AIDS patients, training and employing community-based care workers, monitoring anti-retrovirals and adapting our focus to include children and 'living', not only dying, from a life-threatening illness. In response to these changing needs we established Butterfly House, a palliative resource centre in an informal settlement with the aim of providing care for the community, in the community and with the community.

Managing change has been challenging but has resulted in a hospice which is represented by and serves the interest of the Drakenstein community. Networking and forming partnerships has greatly contributed to the success. 'The need is too big to do alone.'

Physical address: Drakenstein Hospice, 109 Breda Street, Paarl
Postal address: PO Box 6130, Main Street, Paarl, 7622
Tel: 021 872 4060
www.drakensteinhospice.org.za
www.butterflyhouse.org.za

Grandmothers Against Poverty and AIDS (GAPA)

GAPA aims to build the capacity of grandmothers to cope better with the challenges when someone in their family dies or is diagnosed with HIV infection. Grandmothers who find they are unable to cope emotionally and practically with sickness and death in their families are invited to attend a workshop series at the GAPA centre. Topics include HIV/AIDS knowledge, human rights, vegetable gardening, drawing up a will, introduction to business skills, bereavement and parenting skills.

Grandmothers are encouraged to join/form support groups where emotional issues are solved and income generating strategies are practiced. GAPA workshops and support groups are all managed and run by grandmothers that have been trained within the organisation. Grandmothers are encouraged to come and learn handicraft skills and to meet other grandmothers. The GAPA team can help other communities outside Cape Town to mobilise their grandmothers into an effective force against the devastating effects of HIV/AIDS on families and communities.

Physical address: J415 Qabaka Cres, Eyethu,
Khayelitsha 7784
Postal address: 15 St George, Campground Rd,
Rosebank 7700
Tel/fax: 021 364 3138
Email: info@gapa.co.za
www.gapa.org.za

Helderberg Hospice

The hospice provides a comprehensive palliative care programme to patients facing life-threatening illness in the communities of the Helderberg.

An inter-disciplinary team includes the patient and family, doctor/s, professional nurses, social workers, carers and volunteers aiming to improve quality of life for the patient as far as is possible. The patient is consulted and their choice respected regarding care, symptoms, medication, and other concerns with most dying patients choosing and being able to die at home. Emotional and spiritual support for both patient and family is given along with help accessing Identity Documents and Social Grants. Many referred people infected with HIV, are encouraged to make a commitment to antiretroviral medication. With daily adherence to medication, the illness may become chronic rather than imminently fatal.

The Interdisciplinary Team visits the patient to provide home-based care or visits the patient in hospital or in Frail Care. Patients can attend the Day hospice to chat and for activities, outings and spiritual input (optional), a ten bed In-Patient Unit for short-stay symptom control and respite care. Patients and families are provided training and education on care including precautions against infection. Staff and trained volunteers offer Bereavement Support after the death of a loved one and the hospice is committed to training and mentoring staff and volunteers for their ongoing development.

Tel: 021 852 4608
Email: info@helderberghospice.org.za

Hospice Palliative Care Association of South Africa

HPCA is an umbrella organisation consisting of 70 member hospices with 24 satellites (branches) and 69 development sites as at December 2008. HPCA supports services in all nine provinces, and aims to develop a hospice in every health sub-district by 2010 in order to achieve its vision: Quality Palliative Care for All.

HPCA's mission statement is to promote quality in life, dignity in death and support in bereavement for all living with a life-threatening illness by supporting member hospices and partner organisations.

HPCA develops capacity in member hospices through support for accreditation of hospices and through its seven HPCA development subcommittees: Advocacy, Education & Research, Finance, M&E, Patient Care, Paediatric Palliative Care Organisational Development.

A number of authors for this manual also head up HPCA portfolios.

Sue Cameron co-chairs the Patient Care Portfolio

The Patient Care Portfolio facilitates the delivery of quality palliative care by member hospices. Key activities include mentorship and accreditation of hospices. There are specific projects undertaken by this group such as collaboration with public health clinics, support of non-hospice NGOs to provide palliative care, VCT project, TB project, gender task team and the update of HPCA clinical guidelines.

Joan Marston leads the Paediatric Palliative Care Portfolio

Paediatric palliative care initiatives encourage member hospices to address needs of children on their Hospice intervention programmes. Portfolio team members campaign locally and abroad to raise awareness of paediatric palliative care needs and services. HPCA also has a growing OVC programme.

Nkosazana Ngidi leads the Education Portfolio

HPCA develops and promotes palliative care education and training programs for both professional and nonprofessional health care practitioners, volunteers and community groups. This group also develops training curriculum on various aspects of palliative care as means of increasing access to knowledge and skills in palliative care thus contributing to improving the quality of life for people with life limiting conditions and their families.

Zodwa Sithole leads the Advocacy Portfolio

HPCA promotes the development of palliative care and the Advocacy group objectives are to increase awareness of and access to palliative care. Key activities are working with the government to develop the required policy to implement palliative care and ensure access to essential palliative care medication and to palliative care training for health care workers. It is important to create awareness of the need and efficacy of palliative care amongst policy makers, patients, communities and health care workers.

Nicky GunnClark is the project co-ordinator: Linking law and hospice care

The HPCA project to link legal and human rights advocates with palliative care practitioners has been supported by the Open Society Institute since its start in 2006. The aim is to improve access to palliative care by reducing the legal barriers to access to palliative care and to train hospice workers in identifying and assisting hospice patients and families with legal problems they may be facing.

www.hospicepalliativecaresa.co.za

Language Inc.

Language Inc., a South African based and owned language supply company, was founded in 2003 and now contracts more than 1,600 people around the world. We focus on translating, editing and proofreading text into and from all major African, Asian and European languages. All South African language translations are completed by Xhosa, Zulu, Setswana, Sesotho, Sepedi, Tshivenda, Siswati, Tsonga, Ndebele or Afrikaans mother tongue speakers. The same standards apply for European and Asian languages. Language Inc., is proud to be a verified BEE company, which achieved a level two status in May 2006.

Postal address: PO Box 7204, Stellenbosch, 7599
Tel: 021 887 2663
Fax: 021 887 2661
www.language-inc.org

Legal Resources Centre

The Legal Resources Centre was established in 1979 at the height of apartheid when legal representation was reserved for those with financial means or power. For the poor and marginalised, state legal aid was inadequate and highly inefficient. Our mission then and now is to use law as an instrument of justice to provide free but effective legal services to the poor and marginalised. The LRC educates on rights and supports policy development and legal reform for the extension, promotion or protection of rights.

The Legal Resources Centre has continued to assist many poor people and has won famous victories on their behalf. The LRC uses legal processes to prevent the infringement of the rights of the poor, particularly by the state; or makes referrals to alternative structures for assistance. The LRC participates in drafting legislation, regulations and even constitutions so that governance measures benefit the poor and vulnerable. In order to adequately represent our clients, the LRC seeks creative and effective solutions by working together with organisations based in client communities and with other NGOs whose activities and research can enrich the content of our cases. The LRC's role is thus found in this interplay between case litigation and law reform and policy development activities.

www.lrc.org.za

Open Society Foundation For South Africa

The OSF-SA is committed to promoting the values, institutions and practices of an open, non-racial and nonsexist, democratic, civil society. It works for a vigorous and autonomous civil society in which the rule of law and divergent opinions are respected.

The Open Society in South Africa is a grant-making organisation, and is a member of the International Soros Foundations Network. The Foundation's strategy is to support and engage in activities that focus on the delivery of a needed service. In doing so it has decided it will:

- act in a limited number of priority areas and with projects which will initiate change and produce demonstrable results within two years
- seek major ventures or fresh ideas that would not see the light of day without the resources and assistance of the Foundation
- seek to act in co-ordination and co-operation with other organisations and funding agencies to ensure that resources are optimally used.

www.osf.org.za/home

Open Society Initiative: International Palliative Care Initiative

The OSI International Palliative Care Initiative has four objectives: to increase public awareness about end-of-life care issues; to provide palliative care education to healthcare professionals and support the integration of palliative care into medical and nursing school curricula; to make essential drugs for pain and symptom management easily available; to integrate palliative care into national healthcare plans, policies, and systems of care.

In 2002, OSI expanded its International Palliative Care Initiative to South Africa with a US$1 million, three-year matching funds initiative. The South Africa initiative acted as a catalyst to advance programs in palliative care education, training, and service delivery, and advocated for their full integration into national HIV/AIDS prevention, care, and treatment programs. Professional and public education is a major focus of these programs, because these efforts will help build a workforce of community health volunteers and professionals who treat and care for patients with HIV/AIDS. Community-based, non-governmental organisations are far ahead of the government in addressing the palliative care needs of dying HIV/AIDS patients and their families, especially at a grassroots level.

www.soros.org/initiatives/health/focus/ipci/about

Open Society Institute Law And Health Initiative (LAHI)

The Law and Health Initiative (LAHI), a division of OSI's Public Health Program, promotes legal action to advance public health goals worldwide. LAHI supports legal assistance, litigation, and law reform efforts on a range of health issues, including patient care, HIV and AIDS, harm reduction, palliative care, sexual health, mental health, and Roma health. LAHI's priorities include integrating legal services into health programs, strengthening human rights protections within health settings, and developing training and education programs in law and health. A special focus is on supporting organisations and advocacy campaigns dedicated to ending human rights abuses linked to the global AIDS epidemic. By bringing together legal, public health, and human rights organisations, LAHI seeks to build a broad movement for law-based approaches to health and for the human rights of society's most marginalised groups. For further information on the Law and Health Initiative, please visit **www.soros.org/initiatives/health/focus/law.**

Rhodes University Legal Aid Clinic

The mission of the Rhodes University Legal Aid Clinic is to promote a culture of human rights as enshrined in our Constitution's Bill of Rights, to provide professional and efficient legal services to indigent and/or vulnerable groups and individuals, to provide legal education and training to law students at Rhodes University, to paralegals and to communities.

The vision of the Rhodes University Legal Aid Clinic is to promote a culture of human rights, to ensure that any indigent person in its sphere of influence will have access to justice and that every Rhodes University student, paralegal and community member who participates in its programmes will receive information, education and training.

Tel: 046 622 9301
Fax: 046 622 9312
Email: legalaidclinic@ru.ac.za
www.ru.ac.za/legalaid

Street law

Launched as an NGO over 18 years ago at the University of Natal, Street Law has grown into a prominent democracy, human rights and legal education programme for all South Africans and now offers training programs nationally. Designed to introduce the law and human rights to people at all levels of education, it makes use of participatory teaching methods that allow learners to interact while they are learning. It provides a practical understanding of the law, the legal system, the Bill of Rights and the Constitution.

In 2006 Street Law was accredited as a service provider to the SAS SETA. Street Law realises that Human Rights and Legal education continues to be a necessary and crucial part of the fight against the spread of the disease and the restoration of dignity and rights to sufferers. The HIV/AIDS, the law and human rights program focuses on educating target groups about basic issues on HIV infections, legal and human rights issues relating to HIV/AIDS, particularly equality and non-discrimination. The program promotes a culture of tolerance and respect for people infected and affected by HIV/AIDS.

www.streetlaw.org.za/contact.html

Notes