

Legal Aspects of Palliative Care

Hospice Palliative Care Association of South Africa



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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-maleficence, autonomy and

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 availability

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](http://www.hospicepalliativecaresa.co.za/legal%20resources)
- 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

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