

# Introduction to Human Rights and Palliative Care

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**Human Rights and Palliative Care**

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# 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.<sup>1</sup>

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<sup>2</sup> (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<sup>3</sup> (ICCPR) and the International Covenant on Economic, Social and Cultural Rights<sup>4</sup> (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.<sup>5</sup>

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.*<sup>6</sup>

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.*<sup>7</sup>

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;*<sup>8</sup>

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.<sup>9</sup> 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.'<sup>10</sup>

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.*<sup>11</sup>

The South African Department of Health's Patients' Right Charter<sup>12</sup> 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<sup>13</sup> as the following cases illustrate.

The South Australia Supreme Court case of *Giurelli vs Girgis 1980*<sup>14</sup> 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*<sup>15</sup> 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<sup>16</sup> (**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<sup>17</sup>
- Convention on the Elimination of All Forms of Racial Discrimination, 1969<sup>18</sup>
- Convention on the Elimination of All Forms of Discrimination Against Women, 1981<sup>19</sup>
- Convention on the Rights of the Child, 1990<sup>20</sup>
- The African Charter on Human and Peoples' Rights, 1986<sup>21</sup>
- African Charter on the Rights and Welfare of the Child, 2000.<sup>22</sup>

## The South African Constitution<sup>23</sup>

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.<sup>7</sup> 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.’<sup>13</sup> 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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