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# Palliative Care and Human Rights: *A Resource Guide*

"You must matter because you are you, and you matter until the last moment of your life. We will do all we can, not only to help you die peacefully, but also to live until you die."

*Dame Cicely Saunders,*
*founder of the modern Hospice movement*

www.equalpartners.info

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Palliative Care and Human Rights – A Resource Guide



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Cover photograph courtesy of Open Society Institute.

**Open Society Institute**
400 West 59th Street, New York, NY 10019 USA
Website: www.soros.org

**Equitas – International Centre for Human Rights Education**
1425, René-Lévesque Blvd. West, Suite 407
Montréal, Québec, Canada H3G 1T7
Website: www.equitas.org

# Contents

# Acknowledgements

This Guide to Palliative Care and Human Rights is a modified excerpt of *Health and Human Rights: A Resource Guide,* edited and compiled by Jonathan Cohen, Project Director of the Open Society Institute Law and Health Initiative, Tamar Ezer, Program Officer in the Law and Health Initiative, Paul McAdams, Senior Education Specialist at Equitas – International Centre for Human Rights Education, and Minda Miloff, consultant to Equitas.

*Health and Human Rights: A Resource Guide* was prepared for *Equal Partners: Health and Human Rights*, a global seminar for Open Society Institute and Soros Foundation staff held in Cape Town, South Africa from June 3-8, 2007.

The following people drafted, contributed, or commented on materials for this excerpt:

Magda Adamowicz, Volha Baraulia, Frank Brennan, Robert Burt, Iain Byrne, Mary Callaway, Kath Defilippi, Kathleen M. Foley, Dmytro Groysman, Kiera Hepford, Liz Gwyther, Karyn Kaplan, Jane Li, Emma Lozman, Sue Nieuwmeyer, Judith W. Overall.

The Guide's translation project was managed by Volha Baraulia, and the Guide was formatted by Emma Lozman and other production assistance was provided by Paola Deles and Anna Vinnik. In addition, staff of the Open Society Institute Public Health Program and Human Rights and Governance Grants Program provided valuable comments on the Guide.

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# INTRODUCTION

## About this Guide

*Now we have the responsibility to move forward by recognizing that true interdependence and real interconnectedness requires that we – from health and from human rights – advance together: equal partners in the belief that the world can change.*

Jonathan Mann (1947-1998)

### Purpose and organization

This Guide was prepared as a user-friendly, multi-purpose resource that can be used on a regular basis on the job. To ensure easy and widespread access to the Guide, a web-friendly version is available at www.equalpartners.info. On this website, you will also find translations of the guide into several other languages. It is divided into two parts: an introduction to **health and human rights in general** and a section specifically focused on **palliative care and human rights**.

### How to use and modify the Guide

The Guide is a practical **reference tool** for you to use in your day-to-day work. You can also **add** new materials as you see fit, **take notes** in the margins, and **print** specific sections for use in training.

### Putting the Guide into action

This Guide is a **starting point** for a wide range of health and human rights programming. The Guide will provide you with ideas, information, and resources to develop programs.

| You can use the Guide to: | How |
|---|---|
| **Collaborate with colleagues on strategy development** | There are many opportunities for Law Program and Public Health Coordinators to collaborate on health and human rights work. The Guide provides examples of projects that can be adapted at the country or regional level, as well as extensive information on developing claims before regional and international bodies. The annual strategy process is a good time to consult the Guide for ideas on how law and health staff can collaborate. |
| **Develop regional or thematic courses and trainings** | The Guide contains the information and resources needed to develop a course or training seminar. While it does not contain actual curricula or training materials, an experienced educator can use the information in the Guide to develop a course or seminar. |

**Continued**

| You can use the Guide to: | How |
|---|---|
| **Identify human rights claims** | The Guide contains real-life examples of human rights abuses, as well as legal standards and precedents that can be used to seek redress for these abuses. The introduction to health and human rights briefly describes the main regional and international human rights mechanisms with which you can lodge complaints. There is great potential for using regional and international mechanisms to advance health-related claims, and this is an excellent area of collaboration for law program and public health staff. |
| **Adapt the project examples in your country** | The Guide contains examples of effective health and human rights projects from around the world. Each project example summarizes the work accomplished and includes contact information for the implementing organization. You can adapt these project examples to any country or region. You can also share the project examples with your NGO partners to encourage them to take on more work on health and human rights. |
| **Conduct further research** | If you are conducting research on health and human rights—for example, writing an article or news item, preparing a conference presentation, or developing a Request for Proposals (RFP)—you can consult the Guide for a list of articles, books, websites, and other resources. While not comprehensive, the resource list was prepared by experts in the field and contains their recommendations of the most useful resources. |
| **Educate other funders** | While this Guide is initially directed at OSI (Open Society Institute) and the SFN (Soros Foundations Network), it can also be used by other funders who are interested in health and human rights. The Guide (or sections of it) can be translated into local languages and adapted to local contexts. Parts of it can be expanded, abbreviated, or modified depending on the purpose and audience. |

# PART I: HEALTH AND HUMAN RIGHTS
# Using human rights mechanisms



## *Treaties and enforcement mechanisms*

One of the main ways to advocate for health and human rights is to lodge complaints or file reports with regional or international human rights mechanisms. These mechanisms were established to enforce governments' compliance with the regional and international human rights treaties they have ratified. These treaties make up the so-called "hard law" of international human rights, while the interpretations of the treaty mechanisms make up "soft law" that is not directly binding on governments. There are two main types of enforcement mechanisms:

- **Courts**, which act in a judicial capacity and issue rulings that are binding on governments in the traditional sense;

- **Committees**, which examine reports submitted by governments on their compliance with human rights treaties, and in some cases examine individual complaints of human rights violations.

The main treaties and corresponding enforcement mechanisms discussed in this Guide are shown on the following page.

## *Using the mechanisms*

One of the greatest advantages of regional and international human rights mechanisms is that they allow individuals and NGOs to lodge complaints or file reports of human rights abuses.

The best way to learn about how to use a particular mechanism is to visit its website or contact its Secretariat. The contact information for each enforcement mechanism discussed in the Guide, as well as some introductory information about its mandate and procedures is provided on the next pages.

Advocacy using these regional and international mechanisms go hand-in-hand with country advocacy as regional and international recommendations mean little without enforcement at the national level. Additionally, domestic remedies generally have to be exhausted (including the raising of regional and international claims) before complaints can be taken to regional or international bodies.

### Treaties and corresponding enforcement mechanisms

| Treaty | Enforcement Mechanism |
|---|---|
| International Covenant on Civil and Political Rights (**ICCPR**) | Human Rights Committee (**HRC**) |
| International Covenant on Economic, Social, and Cultural Rights (**ICESCR**) | Committee on Economic, Social and Cultural Rights (**CESCR**) |
| International Convention on the Elimination of all forms of Racial Discrimination (**ICERD**) | Committee on the Elimination of Racial Discrimination (**CERD**) |
| Convention concerning Indigenous and Tribal Peoples in Independent Countries (**ILO Convention**) | International Labour Organization (**ILO**) |
| Convention on the Elimination of All Forms of Discrimination Against Women (**CEDAW**) | Committee on the Elimination of All Forms of Discrimination Against Women (**CEDAW Committee**) |
| Convention on the Rights of the Child (**CRC**) | Committee on the Rights of the Child (**CRC Committee**) |
| African Charter on Human and People's Rights (**ACHPR**) & Protocols | African Commission on Human and People's Rights (**ACHPR Commission**) |
| [European] Convention for the Protection of Human Rights and Fundamental Freedoms (**ECHR**) | European Court of Human Rights (**ECtHR**) (with Committee of Ministers) |
| European Social Charter (**ESC**) | European Committee of Social Rights (**ECSR**) (with Governmental Committee and Committee of Ministers) |
| Framework Convention for the Protection of National Minorities (**FCNM**) | Committee of Ministers of the Council of Europe & Advisory Committee (**AC**) |

**Note:** The above is only a fraction of the treaties and enforcement mechanisms that can be used to advocate for health and human rights. Some of the resources listed at the end of this Introduction contain more detailed information about the regional and international human rights systems.

## Human Rights Committee

### Mandate

The Human Rights Committee (HRC) oversees government compliance with the International Covenant on Civil and Political Rights (ICCPR). The HRC has two mandates: to monitor country progress on the ICCPR by examining periodic reports submitted by governments; and to examine individual complaints of human rights violations under the Optional Protocol to the ICCPR.

### Civil society participation

NGOs can submit "shadow reports" to the HRC on any aspect of a government's compliance with the ICCPR. Shadow reports should be submitted through the HRC Secretariat based at the Office of the High Commissioner for Human Rights (OHCHR) in Geneva, which also keeps a calendar of when governments come before the Committee. The HRC meets three times a year. Individuals and NGOs can also submit complaints to the HRC under the Optional Protocol.

**Contact**
Patrice Gillibert
HRC Secretary, UNOG-OHCHR, CH 1211 Geneva 10, Switzerland
Tel: +41 22 917 9249
Fax: +41 22 917 9006
Email: pgillibert@ohchr.org
Web: www.unhchr.ch/html/menu2/6/hrc.htm

## Committee on Economic, Social, and Cultural Rights

### Mandate

The Committee on Economic, Social, and Cultural Rights (CESCR) oversees government compliance with the International Covenant on Economic, Social, and Cultural Rights (ICESCR). The CESCR monitors country progress on the ICESCR by examining periodic reports submitted by governments.

### Civil society participation

NGOs can submit "shadow reports" to the CESCR on any aspect of a government's compliance with the ICESCR. Shadow reports should be submitted through the CESCR Secretariat based at the Office of the High Commissioner for Human Rights (OHCHR) in Geneva, which also keeps a calendar of when governments come before the Committee. The CESCR meets twice a year.

**Contact**
Wan-Hea Lee
CESCR Secretary, Office 1-025, Palais Wilson, Palais des Nations, 8-14 Avenue de la Paix, 1211 Geneva 10
Tel: +41 22 917 9321
Fax: +41 22 917 9046
Email: wlee@ohchr.org
Web: www.unhchr.ch/html/menu2/6/cescr.htm

## Committee on the Elimination of Racial Discrimination

### Mandate

The Committee on the Elimination of Racial Discrimination (CERD) is the body of independent experts that monitors implementation of the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD) by states. It monitors country progress on ICERD by examining periodic reports submitted by governments. The Committee then addresses its concerns and recommendations to the country in the form of "concluding observations." Besides commenting on country reports, CERD monitors state compliance through an early-warning procedure and the examination of inter-state complaints and individual complaints.

### Civil society participation

NGOs can submit "shadow reports" to the CERD on any aspect of a government's compliance with the ICERD. Shadow reports should be submitted through the CERD Secretariat based at the Office of the High Commissioner for Human Rights (OHCHR) in Geneva, which also keeps a calendar of when governments come before the committee. CERD meets twice a year.

**Contact**
Nathalie Prouvez
Secretary of the Committee on the Elimination of Racial Discrimination
Treaties and Commission Branch
Office of the High Commissioner for Human Rights
Palais Wilson - 52, rue des Pâquis, CH-1201 Geneva, Switzerland
Mailing address: UNOG-OHCHR, CH-1211 Geneva 10, Switzerland
Tel: +41.22.917.93.09,
Fax: +41.22.917.90.22
Email: nprouvez@ohchr.org
Web: www2.ohchr.org/english/bodies/cerd/index.htm

## International Labour Organization

### Mandate

The International Labour Organization (ILO), located within the United Nations, is primarily concerned with respect for human rights in the field of labour. In 1989, they adopted the Convention concerning Indigenous and Tribal Peoples in Independent Countries. States must provide periodic reports on their compliance with the Convention to the ILO and to national employers and workers associations. National employers and workers associations may submit comments on these reports to the ILO. The ILO Committee of Experts (CE) evaluates the reports and may send "Direct Requests" to governments for additional information. The CE then publishes its "Observations" in a report, presented at the International Labour Conference. On the basis of this report, the Conference Committee on the Application of Standards may decide to more carefully analyze certain individual cases and publishes its conclusions. Additionally, an association of workers or employers may submit a representation to the ILO alleging that a member state has failed to comply with the Convention and a member state may file a complaint against another.

### Civil society participation

The Convention encourages governments to consult indigenous peoples in preparing their reports. Indigenous peoples may also affiliate with a worker association or form their own worker association in order to more directly communicate with ILO. The CE meets in November and December of each year, and the International Labour Conference is in June.

**Contact**
Office Relations Branch
4, rue des Morilons
CH-1211, Geneva 22, Switzerland
Tel. +41.22.799.7732
Fax: +41.22.799.8944
Email: RELOFF@ilo.org
Web: www.ilo.org/public/english/index.htm

## *Committee on the Elimination of All Forms of Discrimination Against Women*

### Mandate

The Committee on the Elimination of All Forms of Discrimination Against Women (CEDAW Committee) oversees government compliance with the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW). The CEDAW Committee has three mandates: to monitor country progress on CEDAW by examining periodic reports submitted by governments; to examine individual complaints of violations of women's rights under the Optional Protocol to CEDAW; and to conduct missions to state parties in the context of concerns about systematic or grave violations of treaty rights.

### Civil society participation

NGOs can submit "shadow reports" to the CEDAW Committee on any aspect of a government's compliance with CEDAW. Shadow reports should be submitted through the Division for the Advancement of Women in New York, which also keeps a calendar of when governments come before the Committee. The CEDAW Committee meets twice a year. Individuals and NGOs can also submit complaints to the Committee under the Optional Protocol, or encourage the Committee to undertake country missions as part of its inquiry procedure.

**Contact**
Tsu-Wei Chang, Coordination and Outreach Unit, Division for the Advancement of Women, Department of Economic and Social Affairs,
Two UN Plaza,
Room DC2 12th Floor,
New York, NY, 10017
Tel: +1 (212) 963-8070, Fax: +1 (212) 963-3463
Email: changt@un.org
Web: http://www.un.org/womenwatch/daw/cedaw/cedaw38/NGOnote.pdf

## Committee on the Rights of the Child

### Mandate

The Committee on the Rights of the Child (CRC Committee) oversees government compliance with the Convention on the Rights of the Child (CRC). It monitors country progress on the CRC by examining periodic reports submitted by governments.

### Civil society participation

NGOs can submit "shadow reports" to the CRC Committee on any aspect of a government's compliance with the Convention. Shadow reports should be submitted through the CRC Secretariat based at the Office of the High Commissioner for Human Rights (OHCHR) in Geneva, which also keeps a calendar of when governments come before the CRC Committee. It meets three times a year.

**Contact**
Maja Andrijasevic-Boko
CRC Secretary
8-14 Avenue de la Paix, CH 1211 Geneva 10, Switzerland,
Tel: +41 22 917 9000
Fax: +41 22 917 9022
Email: mandrijasevic@ohchr.org
Web: www2.ohchr.org/english/bodies/crc/index.htm

## African Commission on Human and People's Rights

### Mandate

The African Commission on Human and People's Rights, a body of the Organization of African Unity (OAU), has a broad mandate to protect and promote human rights in Africa, as well as to interpret the provisions of the African [Banjul] Charter on Human and People's Rights. The Commission monitors country progress on the Convention by: examining periodic reports submitted by governments; examining complaints of violations of the Convention's provisions brought by individuals, NGOs, and governments; and undertaking a range of promotional activities related to human rights in Africa.

### Civil society participation

Individuals or organizations may submit complaints to the Commission, provided all local remedies have been exhausted and other admissibility criteria have been met. (The requirement of exhausting domestic remedies may be waived if it is obvious to the Commission that this procedure has been unduly prolonged.) Individual or organizational complaints are only considered by the Commission at the request of a majority of its members. Detailed information about the submission procedure can be found on the Commissions website: www.achpr.org/english/information_sheets/ACHPR%20inf.%20sheet%20no.3.doc .

NGOs with observer status with the Commission may attend the Commission's public sittings.

**Additional treaties**: Additional important treaties overseen by the African Commission on Human and People's Rights include the African Charter on the Rights and Welfare of the Child, OAU Doc. CAB/LEG/24.9/49 (1990) and the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa, Adopted by the 2nd Ordinary Session of the Assembly of the Union, Maputo, CAB/LEG/66.6 (Sept. 13, 2000), reprinted in 1 Afr. Hum. Rts. L.J. 40.

**Note on the African Human Rights Court**: To complement the mandate of the African Commission, the African Charter on Human and People's Rights contains a Protocol calling for the establishment of an African Court on Human and People's Rights. As of April 2007, judges for the African Court had been sworn in, however the Court was not yet operational. Once operational, the Court will have jurisdiction over the African Charter and its Protocols and any other "relevant human rights instrument" ratified by the concerned parties. The Court will accept complaints from the Commission, States Parties, and African Intergovernmental Organizations.

**Contact**
African Commission on Human and People's Rights,
48 Kairaba Avenue, P.O. Box 673 Banjul, The Gambia
Tel: +220 4392 962, 4372 070, 4377 721-23
Fax: +220 4390 764
Email: achpr@achpr.org
Web: www.achpr.org

## *European Court of Human Rights*

- **Mandate**

The European Court of Human Rights (ECtHR), a body of the Council of Europe (COE), enforces the provisions of the [European] Convention for the Protection of Human Rights and Fundamental Freedoms. The ECtHR adjudicates both disputes between states and complaints of individual human rights violations. The Committee of Ministers of the Council of Europe is responsible for monitoring the implementation of judgments made by the ECtHR. (See note on Committee of Ministers below.)

- **Civil society participation**

Any individual or government can lodge a complaint directly with the ECtHR alleging a violation of one of the rights guaranteed under the Convention, provided they have exercised all other options available to them domestically. An application form may be obtained from the ECtHR website (www.echr.coe.int/echr/).

The Council of Europe has established a legal aid scheme for complainants who cannot afford legal representation. NGOs can file briefs on particular cases either at the invitation of the President of the Court, or as "Amici Curia" (Friends of the Court) if they can show that they have an interest in the case or special knowledge of the subject matter, and that their intervention would serve the administration of justice. Hearings of the ECtHR are generally public.

**Contact**
European Court of Human Rights,
Council of Europe, 67075 Strasbourg-Cedex, France,
Tel: +33 3 88 41 20 18
Fax: + 33 3 88 41 27 30
Web: www.echr.coe.int

## European Committee of Social Rights

### Mandate

The European Committee of Social Rights (ECSR), also a body of the Council of Europe (COE), conducts regular legal assessments of government compliance with provisions of the European Social Charter. These assessments are based on reports submitted by governments at regular two-to-four-year intervals known as "supervision cycles." The Governmental Committee and the Committee of Ministers of the Council of Europe also evaluate government reports under the ECSR. (See note on Committee of Ministers below.)

### Civil society participation

Reports submitted by governments under the European Social Charter are public and may be commented upon by individuals or NGOs. International NGOs with consultative status with the COE, as well as national NGOs authorized by their government, may also submit "collective complaints" to the COE alleging violations of the Charter.

**Contact**
Web: www.humanrights.coe.int/cseweb/GB/index.htm

## Advisory Committee

### Mandate

The Advisory Committee (AC) assists the Committee of Ministers in monitoring compliance with the Framework Convention for the Protection of National Minorities (FCNM). It monitors country progress on the FCNM by examining periodic reports submitted by governments. Besides examining these reports, the AC may hold meetings with governments and request additional information from other sources. The AC then prepares an opinion, which is submitted to the Committee of Ministers. Based on this opinion, the Committee of Ministers issues conclusions concerning the adequacy of measures taken by each state party. The AC may be involved by the Committee of Ministers in the monitoring of the follow-up to the conclusions and recommendations.

### Civil society participation

NGOs can submit "shadow reports" to the AC on any aspect of a government's compliance with the FCNM. Shadow reports should be submitted through the FCNM Secretariat.

**Contact**
Directorate General of Human Rights (DGII)
Secretariat of the Framework Convention for the Protection of National Minorities
F – 67075 STRASBOURG CEDEX
France
Tel: +33/(0)3.90.21.44.33
Fax: +33/(0)3.90.21.49.18
Email: minorities.fcnm@coe.int
Web: www.coe.int/minorities

## UN Charter bodies

In addition to the treaty bodies listed above, there are a number of bodies created under the Charter of the United Nations for the protection and promotion of human rights.

The principal charter body is the Human Rights Council (HRC), which replaced the Commission on Human Rights (CHR) in 2006. The HRC is a subsidiary organ of the UN General Assembly with a mandate "to address situations of violations of human rights, including gross and systematic violations."

The responsibilities of the Human Rights Council include: the Universal Periodic Review (UPR); the Special Procedures; the Human Rights Council Advisory Committee (formerly the Sub-Commission on the Promotion and Protection of Human Rights); and the Complaints Procedure. These responsibilities are summarized at: http://www.ohchr.org/english/bodies/hrcouncil/docs/FACTSHEET_OUTCOMES_FINAL.pdf

- **Universal Periodic Review (UPR)**

  Beginning in 2008, the HRC will periodically review the human rights obligations and commitments of all countries. All UN Member States will be reviewed for the first time within four years. A working group will meet three times per year for two weeks to carry out the review. The review will take into account a report from the State concerned, as well as recommendations from the Special Procedures (see below) and Treaty Bodies (see above) and information from non-governmental organizations and national human rights institutions.

- **Special Procedures**

  "Special Procedures" is the general term given to individuals (known as "Special Rapporteurs," "Special Representatives," or "Independent Experts") or groups (known as "Working Groups") mandated by the HRC to address specific country situations or thematic issues throughout the world. The HRC currently includes twenty-eight thematic and ten country Special Procedures.

  Activities undertaken by the Special Procedures include responding to individual complaints, conducting studies, providing advice on technical cooperation at the country level, and engaging in general promotional activities. The Special Procedures are considered "the most effective, flexible, and responsive mechanisms within the UN system."[1]

  Special Procedures cited in this Resource Guide include:

  - Working Group on Arbitrary Detention
  - Special Rapporteur on Extrajudicial, Summary or Arbitrary Executions

[1] FACTSHEET: Work and Structure of the Human Rights Council, July 2007.

- Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health
- Special Rapporteur on Violence against Women, its Causes and Consequences

For more information about the Special Procedures, see: http://www.ohchr.org/english/bodies/chr/special/index.htm

- **Human Rights Council Advisory Committee**

  The HRC Advisory Committee functions like a "think tank," providing expertise and advice and conducting substantive research and studies on issues of thematic interest to the HRC at its request. The Committee is made up of eighteen experts serving in their personal capacity for a period of three years.

- **Complaints Procedure**

  This confidential complaints procedure allows individuals or organizations to bring complaints about "gross and reliably attested violations of human rights" to the attention of the HRC. The procedure is intended to be "victims-oriented" and to conduct investigations in a timely manner. Complaints are reviewed by two working groups that meet at least twice a year for five days during each period.

## *Other committees and groups*

- **Committee of Ministers**

  The Committee of Ministers (www.coe.int/cm) is the decision-making body of the Council of Europe, and is comprised of the foreign ministers (or their permanent representatives) of all COE member states.

  In addition to supervising judgments of the ECtHR and evaluating reports under the ECSR (see above), the Committee of Ministers also makes separate Recommendations to member states on matters for which the Committee has agreed to a "common policy"—including matters related to health and human rights.

  Some of these Recommendations are provided by the **Parliamentary Assembly** of the Council of Europe (assembly.coe.int), which is a consultative body composed of representatives of the Parliaments of member states.

- **European Union**

  The European Union ( www.europa.eu/europa.ed.int/eur-lex/) has twenty-seven member states and is a separate system from the Council of Europe (www.coe.int), which has forty-seven member states. Mechanisms for advocating for health and human rights within the European Union (such as

EU Directives and the European Court of Justice) are not discussed in this Guide. It should be noted, however, that all member states of the European Union are bound by the institutions and instruments under the Council of Europe.

### Economic and Social Council (ECOSOC)

The UN Economic and Social Council (ECOSOC) coordinates the work of fourteen UN specialized agencies, functional commissions, and regional commissions working on various international economic, social, cultural, educational, and health matters. ECOSOC holds several short sessions per year as well as an annual substantive session for four weeks every July.

ECOSOC consults regularly with civil society, with close to 3,000 non-governmental organizations enjoying consultative status. ECOSOC-accredited NGOs are permitted to participate, present written contributions, and make statements to the Council and its subsidiary bodies. Information about NGOs with consultative status can be found at: http://www.un.org/esa/coordination/ngo/.

ECOSOC agencies and commissions that may be cited in or relevant to this Resource Guide include:

- Commission on the Status of Women
- Commission on Narcotic Drugs
- Commission on Crime Prevention and Criminal Justice
- Committee on Economic, Social and Cultural Rights
- International Narcotics Control Board

# The Right to the Highest Attainable Standard of Health

## What is the legal basis for the "right to health"?

- The best and most complete statement of the "right to health" can be found in the International Covenant on Economic, Social and Cultural Rights (ICESCR), Article 12. It sets out "the right of everyone to the enjoyment of the **highest attainable standard of physical and mental health**."

- *See also* International Convention on the Elimination of All Forms of Racial Discrimination, article 5(e) (iv); Convention on the Elimination of All Forms of Discrimination, Articles 11(f) and 12; Convention on the Rights of the Child, Article 24.

- The Committee on Economic, Social and Cultural Rights, the UN body monitoring compliance with the ICESCR, has provided detailed guidance on implementing the right to health (General Comment 14).

## What does the right to health mean?

- A right to **health care** that is **available, accessible, acceptable, and quality** and

- A right to the **underlying determinants of health**, including civil and political rights

## What are the components of the right to health care?

- **Availability** of health facilities, goods, and services

- **Accessibility** of health facilities, goods and services; this includes:

  - Non-discrimination
  - Physical accessibility
  - Economic accessibility/affordability
  - Information accessibility

- **Acceptability** of health facilities, goods, and services; they must be:

  - Respectful of medical ethics
  - Culturally appropriate
  - Sensitive to gender and life-cycle requirements

- **Quality** health facilities, goods, and services that are scientifically and medically appropriate

### *How can this right be meaningfully protected if it is dependent on resources?*

- This right contains a **minimum core**, priority obligations, and aspects for **progressive realization to the maximum of available resources**.

- The minimum core includes:

  - Non-discriminatory access to health care.
  - Equitable distribution of health facilities, goods, and services
  - Essential medicines, as defined by the WHO; this encompasses access to palliative care and harm reduction medications.
  - Minimum essential food, potable water, basic shelter, and sanitation.
  - National public health strategies and plans of actions adopted and implemented through a participatory process. National strategies and plans must give particular attention to vulnerable and marginalized groups in both their process and content.

- Priority obligations include:

  - Ensuring reproductive, maternal, and child health care.
  - Providing immunization against major infectious diseases.
  - Taking measures to prevent, treat, and control epidemics.
  - Providing education and information on major health problems.
  - Appropriately training health personnel, including education on health and human rights.

- National public health strategies and plans need to include **benchmarks** to measure progressive realization. There is thus an important **monitoring** role for civil society.

- Courts, tribunals, and health ombudspersons can also play a critical role in ensuring government accountability for the right to health.

# Essential reading

## General resources in health and human rights

Part II of this Guide contains topic-specific resources. The following are general resources on health and human rights, divided into the following categories:

- Conventions: UN
- Conventions: Regional
- Guidelines and interpretations
- Books
- Key articles, reports, and other documents
- Periodicals
- Websites
- Search engines
- Training materials

## Conventions: UN

- International Covenant on Civil and Political Rights.
  Source: www.unhchr.ch/html/menu3/b/a_ccpr.htm
- International Covenant on Economic, Social and Cultural Rights.
  Source: www.unhchr.ch/html/menu3/b/a_cescr.htm
- International Convention on the Elimination of all forms of Racial Discrimination.
  Source: www.ohchr.org/english/law/cerd.htm
- Convention concerning Indigenous and Tribal Peoples in Independent Countries.
  Source: www.unhchr.ch/html/menu3/b/62.htm
- Convention on the Elimination of all Forms of Discrimination Against Women.
  Source: www.ohchr.org/english/law/cedaw.htm

- Convention on the Rights of the Child.
  Source: www.ohchr.org/english/law/crc.htm

- Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment.
  Source: www.ohchr.org/english/law/cat.htm

### Conventions: Regional

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  Source: www.achpr.org/english/_info/charter_en.html

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  Source: www.achpr.org/english/_info/women_en.html

- African Charter on the Rights and Welfare of the Child.
  Source: www.achpr.org/english/_info/child_en.html

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  Source: conventions.coe.int/treaty/en/Treaties/Html/157.htm

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  Source: www1.umn.edu/humanrts/instree/Maastrichtguidelines_.html

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- François Xavier Bagnoud Centre for Health and Human Rights, Harvard School of Public Health
  www.hsph.harvard.edu/fxbcenter/

- Global Lawyers and Physicians
  www.glphr.org

- The International Center for the Legal Protection of Human Rights (monthly report of significant human rights decisions from common law jurisdictions)
  www.interights.org

- International Federation of Health and Human Rights Organizations
  www.ifhhro.org

- International Society for Health and Human Rights
  www.ishhr.org

- International Helsinki Federation for Human Rights (IHF)
  The IHF is a community of 46 human rights NGOs in the OSCE area that co-operate on promoting implementation of human rights and compliance with international human rights standards.
  www.ihf-hr.org/index.php

- Johns Hopkins School of Public Health Center for Public Health and Human Rights
  www.jhsph.edu/humanrights/index.html

- National Economic and Social Rights Initiative
  www.nesri.org

- Physicians for Human Rights
  physiciansforhumanrights.org/

- Science and Human Rights Program of the American Association for the Advancement of Science
  shr.aaas.org

- Special Rapporteur on the Right to the Highest Attainable Standard of Health
  www2.essex.ac.uk/human_rights_centre/rth/rapporteur.shtm or
  www.ohchr.org/english/issues/health/right/

- University of Minnesota Human Rights Library contains a lengthy list of health and human rights websites, though many of these are out of date
  www1.umn.edu/humanrts/links/health.html

- World Health Organization's Health and Human Rights page
  WHO's 25 Questions and Answers on Health and Human Rights is a useful introductory document
  www.who.int/hhr/en/

## Search engines

- The UN Treaty Body Database includes all general comments, concluding observations, reports, and other documents of the UN human rights system, organized by treaty monitoring body and special procedure.
  www.unhchr.ch/tbs/doc.nsf

- The International Human Rights Index also includes the above documents but is searchable by key word, country, and right.
  www.universalhumanrightsindex.org

- The University of Minnesota has an excellent database of international human rights documents and information. It is organized simply and clearly and is generally the easiest way to find documents.
  www1.umn.edu/humanrts/

- Professor Anne Bayefsky's website (York University, Toronto, Canada) includes international human rights documents and jurisprudence that are searchable by country, category of document, and theme or subject matter.
  www.bayefsky.com

- The Global Justice Center maintains a database of domestic and international court decisions that cite to CEDAW or the CEDAW Optional Protocol.
  www.globaljusticecenter.net/casebank

- The European Court of Human Rights maintains a database of decisions.
  cmiskp.echr.coe.int/tkp197/search.asp?skin=hudoc-en

- Health and Human Rights Info, a project of the International Society for Health and Human Rights, is a searchable database of organizations, manuals, training materials, projects and reports, and articles related to several areas of health and human rights.
  www.hhri.org

- The Harvard School of Public Health has produced a searchable database of syllabi from health and human rights courses around the world.
  www.hsph.harvard.edu/pihhr/syllabidatabase.html

## Training materials

- The Human Rights Resource Center, part of the University of Minnesota human rights library, contains a range of interactive training packages on human rights.

www1.umn.edu/humanrts/edumat/

- The website of Equitas contains a collection of education manuals and resources as well as extensive information and links to Equitas projects and partners.
  www.equitas.org

# What are key terms related to health and human rights?

## *Glossary*

The following terms relate both to health and human rights and to human rights in general.



# A

### Acceptability
One of four criteria set out by Committee on Economic, Social, and Cultural Rights by which to evaluate the right to the highest attainable standard of health. Acceptability: means that all health facilities, goods and services must be respectful of medical ethics, culturally appropriate, sensitive to gender and life-cycle requirements, as well as designed to respect confidentiality and improve the health status of those concerned (General Comment 14). *See also* "Adequacy," "Availability," and "Quality."

### Accessibility
One of four criteria set out by Committee on Economic, Social, and Cultural Rights by which to evaluate the right to the highest attainable standard of health health. Accessibility: means that health facilities, goods and services have to be accessible to everyone without discrimination. Accessibility has four overlapping dimensions: non-discrimination, physical accessibility, economic accessibility (affordability), and information accessibility (General Comment 14). *See also* "Acceptability," "Adequacy," and "Quality."

### Accession
Acceptance by a state of the opportunity to become a party to a treaty and be legally bound by it. Unlike ***ratification***, this is a one-step process.

### Actio popularis (public action)
A legal action brought by any member of a community in vindication of a public interest.

### Adoption
Process by which the parties drafting a treaty agree to its text and open the treaty for ***accession*** or ***ratification*** by potential state parties.

### Adoption theory
Theory maintaining that international law becomes an automatic part of domestic law following treaty ***accession*** or ***ratification***, without further ***domestication***.

### Amicus curiae (friend of the court)
A legal document filed with the court by a party not involved in a lawsuit, generally advocating a particular legal position or interpretation.

### Availability
One of four criteria set out by Committee on Economic, Social, and Cultural Rights by which to evaluate the right to the highest attainable standard of health. Availability: means that functioning public health and health care facilities, goods, and services, as well as programmes, have to be available in sufficient quantity. This should include the underlying determinants of health, such as safe drinking water, adequate sanitation facilities, clinics and health-related buildings, trained medical personnel, and essential drugs (General Comment 14). *See also* "Acceptability," "Accessibility," and "Quality."

## B

### Basic needs
Used largely in the development community to refer to basic health services, education, housing, and other goods necessary for a person to live.

## C

### Concluding observations
Recommendations by a treaty's enforcement mechanism on the actions a state should take in ensuring compliance with the treaty's obligations. This generally follows both submission of a state's ***country report*** and a constructive dialogue with state representatives.

### Country report
A state's report to the enforcement mechanism of a particular treaty on the progress it has made in implementing it.

### Customary international law
A source of international law consisting of rules derived form the consistent conduct of states acting out of the belief of a legal obligation. A particular category of customary international law, ***jus cogens***, refers to a principle of international law so fundamental that no state may opt out by treaty or otherwise.

## D

### De facto (in fact, in reality)
Existing in fact.

### De jure (by right, lawful)
A situation or conclusion based on law.

### Dignity
The quality of being worthy, honored, or esteemed. Human rights are based on inherent human dignity and aim to protect and promote it.

### Discrimination

Distinction between persons in similar cases on the basis of race, sex, relation, political opinions, national or social origins, association with a national minority, or personal antipathy (WHO).

### Domestication
Process by which an international treaty is incorporated into domestic legislation.

## E

### Entry into force
Point at which a treaty becomes a legally binding document on all state parties.

### Essential medicines
Medicines that satisfy the priority health-care needs of the population. Essential medicines are intended to be available at all times in adequate amounts, in the appropriate dosage forms, with assured quality, and at a price the individual and the community can afford.

### Exhaustion of domestic remedies
Requirement to seek all available avenues for national redress before submitting a complaint on behalf of a victim to any regional or international tribunal. There are limited exceptions to this requirement if national remedies are unavailable, ineffective (sham proceedings), or unreasonably delayed.

## G

### General comments/recommendations
Interpretive texts issues by a treaty's enforcement mechanism on the content of particular rights. Although these are not legally binding, they are widely regarded as authoritative and have significant legal weight.

## H

### Health
A state of complete physical, mental, and social well-being, not merely the absence of disease or infirmity (WHO).

### Human rights
Universal legal guarantees for all human beings, set out in international standards, protecting human dignity and fundamental freedoms and privileges. Human rights cannot be waived or taken away.

### Human rights covenants/conventions
Treaties which are legally binding on states which ratify them.

### Human rights declarations
Statements of non-binding human rights norms and principles (though they may reflect binding customary international law).

### Human rights indicators
Criteria used to measure compliance with international human rights standards.

## I

### Interdependent/ indivisible
Term used to describe the relationship between civil and political rights and economic and social rights. Interdependence and indivisibility mean that one set of rights does not take precedence over the other, and that guaranteeing each set of rights is contingent upon guaranteeing the other.

### International law
The set of rules and legal instruments regarded and accepted as binding agreements between nations. Sources are: treaties, custom, general principles of law, and judicial decisions and juristic writings (Statute of the International Court of Justice, art. 38(1)(d)).

### Interpretive declaration
Declaration by a state as to its understanding of some matter covered by a treaty. Unlike ***reservations*** (see below), declarations merely clarify a state's position and do not purport to exclude or modify the legal effect of a treaty.

## M

### Maximum available resources
Key provision of ICESCR, Article 2 obliging governments to devote the maximum of available government resources to realizing economic, social and cultural rights.

### Monitoring/ fact finding/ investigation
Terms often used interchangeably, generally intended to mean the tracking and/or gathering of information about government practices and actions related to human rights.

## N

### Negative rights
State obligations to refrain from interfering with a person's attempt to do something.

### Neglected diseases
Diseases affecting almost exclusively poor and powerless people in rural parts of low-income countries that receive less attention and resources.

## P

### Positive rights
State obligations to do something for someone.

### Progressive realization

Requirement that governments move as expeditiously and effectively as possible toward the goal of realizing economic, social and cultural rights, and to ensure there are no regressive developments.

### Protocol
Addition to a treaty that clarifies terms, amends text, or establishes new obligations.

### Public health
What we as a society do collectively to ensure the conditions in which people can be healthy (Institute of Medicine).

## Q

### Quality
One of four criteria set out by Committee on Economic, Social, and Cultural Rights by which to evaluate the right to the highest attainable standard of health. Quality: means that health facilities, goods, and services must be scientifically and medically appropriate and of good quality. This requires skilled medical personnel, scientifically approved and unexpired drugs, and hospital equipment (General Comment 14). *See also* "Acceptability," Accessibility," and "Availability."

## R

### Ratification
Follows ***signature*** and indicates a state's acceptance of a treaty and agreement to be bound by it.

### Reservation
A unilateral statement by a state when signing, ratifying, or acceding to a treaty which purports to exclude or modify the effect of certain treaty provisions. Under the Vienna Convention on the Law of Treaties, a state cannot enter a reservation that is "incompatible with the object and purpose of the treaty."

### Respect, protect, and fulfill
Governments' obligations with respect to rights. ***Respect:*** government must not act directly counter to the human rights standard. ***Protect:*** government must act to stop others from violating the human rights standard. ***Fulfill:*** government has an affirmative duty to take appropriate measures to ensure that the human rights standard is attained.

### Right to health
Right to the enjoyment of a variety of facilities, goods, services, and conditions necessary for the realization of the highest attainable standard of health.

## S

### Self executing treaty
A treaty that does not require implementing legislation for its provisions to have effect in domestic law.

### Shadow report
Independent NGO submission to a treaty enforcement mechanism to help it assess a state's compliance with that treaty.

### Signature
Expression of a state's willingness to continue the treaty-making process and proceed to ratification. Although the provisions of the treaty are not yet legally binding on the states, signature creates an obligation to refrain in good faith from acts that would defeat the object and purpose of the treaty.

### Special procedures
Mechanisms with the Human Rights Council, including special rapporteurs, clarifying communications with countries, and country missions, to address country-specific human rights violations or thematic issues.

### Special rapporteurs
Individuals appointed by the Human Rights Council to investigate human rights violations and present an annual report with recommendations for action. There are both country-specific and thematic special rapporteurs, including one on the right to the highest attainable standard of health.

## T

### Transformation theory
Theory maintaining that international law only becomes part of domestic law after ***domestication*** and the incorporation of treaty provisions into domestic legislation.

### Treaty
A formal agreement entered by two or more nations which is binding upon them.

## U

### Underlying determinants of health
Conditions necessary for good health, including safe and potable water, adequate food, housing, halthy occupational and environmental conditions, health-related education, non-discrimination, etc. This includes both social and economic and civil and political rights.

## W

### Working groups
Small committees appointed by the Human Rights Council on a particular human rights issue. Working groups write governments about urgent cases and help prevent future violations by developing clarifying criteria on what constitutes a violation.

# PART II: PALLIATIVE CARE AND HUMAN RIGHTS

## Overview

This chapter will introduce you to key issues in **palliative care and human rights.**

The chapter is organized into six sections that answer the following questions:

- **How** is palliative care a human rights issue?
- **What** is OSI's work in the area of palliative care and human rights?
- **Which** are the most relevant international and regional human rights standards related to palliative care?
- **What** are some examples of effective human rights programming in the area of palliative care?
- **Where** can I find additional resources on palliative care and human rights?
- **What** are key terms related to palliative care and human rights?

As you read through this chapter, consult the **glossary of terms**, found in the last section, *What are key terms related to palliative care and human rights?*

# How is palliative care a human rights issue?

## What is palliative care?

Palliative care is an approach that **improves the quality of life of patients and their families** facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of **pain and other problems, physical, psychosocial and spiritual.**

Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or 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 patients illness and in their own bereavement
- Uses a multidisciplinary team approach to address the needs of patients and their families, including bereavement counseling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy, radiation therapy, HAART, and includes those investigations needed to better understand and manage distressing clinical complications.
  Source: WHO (World Health Organization) 2002 Definition of Palliative Care. Please see **www.who.int/cancer/palliative/definition/en** for a more complete reference.

## What are palliative care rights?

Palliative care embraces human rights that are already recognized in national laws, international human rights documents, and other consensus statements.

Palliative care rights include the **right to**:

- Pain relief
- Symptom control for physical and psychological symptoms
- Essential drugs for palliative care
- Spiritual and bereavement care
- Family-centered care
- Care by trained palliative care professionals
- Receive home-based care when dying and to die at home if desired
- Treatment of disease and to have treatment withheld or withdrawn
- Information about diagnosis, prognosis, and palliative care services
- Name a health care proxy for decision making
- Not be discriminated against in the provision of care because of age, gender, socioeconomic status, geographic location, national status, prognosis, or means of infection.

## Did you know?

- Death statistics
  - Of the 58 million people dying annually, at least 60% will have a prolonged advanced illness and would benefit from palliative care.
  - About 80% of the dying would benefit from palliative care to alleviate pain and suffering in their final days of life. Yet, in countries such as India, only around 1% of them are able to access such care.

- Elderly
  - There are 600 million people 60 years of age or older. By 2025 there will be 1.2 billion, and by 2050 the number will increase to 2 billion.

- Cancer
  - 7 million people die from cancer each year. There are 24.6 million people living with cancer. The incidence of cancer will more than double to an estimated 24 million new cancers per year by 2050.
  - The WHO has demonstrated that up to 90% of cancer patients can receive adequate therapy for their pain with opioid analgesics. Yet, in 2005, 80% of cancer patients did not have access to pain relieving drugs.
  - Despite the WHO stating that palliative care is essential to national cancer control programs, few countries have incorporated it.

- HIV and AIDS
  - In 2005, approximately 2.8 million people died of AIDS. An estimated 39.5 million people worldwide are living with HIV and AIDS. Up to 80% of patients in the advanced stages of AIDS suffer great pain, but very few have access to pain relieving drugs or palliative care services.
  - Pain management and palliative care have been shown to increase drug treatment adherence for both cancer and AIDS therapies.
  - Cancer patients in developing countries have access to opioid analgesics for pain management, but AIDS patients do not.
  - Despite UNAIDS stating that palliative care is essential to national HIV and AIDS plans, few countries have developed palliative care programs.

- Essential drugs
  - Eighteen pain and palliative care professional organizations from all over the world have created a list of essential drugs for palliative care. Fourteen drugs are currently on the WHO Essential Drug List, but few countries have incorporated them into their health care strategies.

- Barriers
  - The International Narcotics Control Board has strongly supported the appropriate use of analgesics for medical use; yet, patients, physicians and policy makers fear addiction and are reluctant to use or prescribe these drugs. Significant regulatory barriers also limit access.

- According to 2004 data published by the International Narcotics Board, 6 nations account for 79% of medical morphine consumption and 120 consumed little or no morphine.
- Despite the existence of a palliative care educational curriculum, little or no training on end of life care palliative care is given to health professionals.

- Caregivers
  - Most of the burden of care at home falls on women and girls. 68% of primary caregivers in South Africa were female; in Uganda 86% were female. Women and girls often give up their jobs or drop out of school to be caregivers.
  - In many countries, after a man's death, wives lose their homes because they have no legal rights to ownership. Children without a birth certificate lose access to the estate and may be unable to attend school because they lack school fees.

## What is OSI's work in the area of palliative care and human rights?

OSI has worked to improve end-of-life care for patients and their families, with a special focus on vulnerable populations, including the elderly, children, and patients with cancer or HIV and AIDS. The main public health network program supporting work in this area is the **International Palliative Care Initiative (IPCI).** Work around the human rights implications of palliative care is still in its infancy with IPCI at the forefront. IPCI, along with OSI's Law and Health Initiative (LAHI), is supporting the development of a background paper and curriculum around palliative care as a human right, outlining the principal human rights norms relevant to palliative care and the legal procedures available to vindicate these rights. Other examples of projects supported by IPCI include:

- **Reports**
  - Brennan, F. Palliative Care as an International Human Right. Journal of Pain and Symptom Management special issue. Volume 33, Number 5, May 2007.

- **Convenings**
  - In October 2006, IPCI and LAHI convened a dialogue between palliative care providers and HIV and AIDS and legal advocates in South Africa to discuss the provision of better services to AIDS patients. A reference group formed to carry this project forward and is pursuing the pilot integration of legal services in a hospice, a joint palliative care/ legal advocates manual, and a potential test case around funeral benefits or disability grants.
  - In 2005, the Worldwide Alliance for Palliative Care convened the Second Global Summit on Hospice and Palliative Care in Seoul, Korea, which released the Korean Declaration on the Right of Palliative Care.
  - In 2006, OSI, with the International Association for Hospice and Palliative Care (IAHPC) and the World Health Organizations (WHO), convened 18 professional organizations to develop an essential medicines list for palliative care.
  - Regional Drug Availability Meetings in Hungary, Uganda, and Ghana have developed country plans to address regulatory barriers to essential pain medications.

- **Trainings**
  - Two -year International Pain Policy Fellowship, training fellows in evaluating regulatory barriers to opioid analgesics in their countries.
  - Two-year Palliative Care in AIDS and Cancer Fellowships, developing palliative care expertise in infectious diseases and in hospitals caring for oncology patients.
  - An annual Salzburg Palliative Care Course (AIDS, Cancer, Nursing).

For more information, visit IPCI's website: www.soros.org/initiatives/health/focus/ipci

# Which are the most relevant international and regional human rights standards related to palliative care?

## Overview

A wide variety of human rights standards at the international, regional, and national levels applies to palliative care. These standards can be used for many purposes:

- **To document** violations of palliative care rights
- **To advocate** for the cessation of these violations
- **To sue** governments for violations of national human rights laws
- **To complain** to regional and international human rights bodies about breaches of human rights agreements.

In the tables on the following pages, **examples** of human rights violations related to palliative care are provided. Relevant human rights **standards** are then cited, along with examples of legal **precedents** and **provisions** from patient right charters and declarations, **interpreting** each standard.

## How to read the tables

As you read through each table, ask yourself the following questions about the **violations**, **standards**, and **precedents and interpretations** that are cited:

| EXAMPLES OF HUMAN RIGHTS VIOLATIONS |
| --- |
| Do any of these violations occur in your country? Are there other violations of this human right that exist in your country? |

| HUMAN RIGHTS STANDARDS | PRECEDENTS AND INTERPRETATIONS |
| --- | --- |
| Are these violations prohibited by the "human rights standards"? Can the standards be interpreted to apply to this violation? | Do any of the "examples of precedents and interpretations" apply to this issue? Can they be interpreted to apply to this issue? |

Remember that human rights law is an evolving field, and that many human rights violations are not directly addressed by existing legal standards and precedents. Through ongoing documentation and advocacy, advocates can build a stronger body of jurisprudence on palliative care and human rights.

## Abbreviations

In the tables, the seven treaties and their corresponding enforcement mechanisms are referred to with the following abbreviations:

| Treaty | Enforcement Mechanism |
|---|---|
| International Covenant on Civil and Political Rights (**ICCPR**) | Human Rights Committee (**HRC**) |
| International Covenant on Economic, Social, and Cultural Rights (**ICESCR**) | Committee on Economic, Social and Cultural Rights (**CESCR**) |
| Convention on the Elimination of All Forms of Discrimination Against Women (**CEDAW**) | Committee on the Elimination of All Forms of Discrimination Against Women (**CEDAW Committee**) |
| Convention on the Rights of the Child (**CRC**) | Committee on the Rights of the Child (**CRC Committee**) |
| African Charter on Human and People's Rights (**ACHPR**) & Protocols | African Commission on Human and People's Rights (**ACHPR Commission**) |
| [European] Convention for the Protection of Human Rights and Fundamental Freedoms (**ECHR**) | European Court of Human Rights (**ECtHR**) |
| European Social Charter (**ESC**) | European Committee of Social Rights (**ECSR**) |

### *Table 1: Palliative care and freedom from cruel, inhuman, and degrading treatment*

| Examples of Human Rights Violations | |
|---|---|
| • National laws restricting opioid availability and access cause cancer and AIDS patients to suffer unnecessary pain.<br>• Fearing prosecution by the state, a doctor refuses to prescribe morphine to relieve a patient's pain.<br>• A country's laws prohibit the prescription of morphine to former drug users. A former drug user is in the advanced stages of AIDS and suffers a great deal. | |
| **Human Rights Standards** | **Precedents and Interpretations** |
| **ICCPR 7** No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation.<br><br>**ACHPR 5** Every individual shall have the right to the respect of the dignity inherent in a human being and to the recognition of his legal status. All forms of exploitation and degradation of man particularly slavery, slave trade, torture, cruel, inhuman or degrading punishment and treatment shall be prohibited.<br><br>**ECHR 3** No one shall be subjected to torture or to inhuman or degrading treatment or punishment.<br><br>***See also:***<br>• Convention Against Torture and Other Forms of Cruel, Inhuman, or Degrading Treatment or Punishment<br>• Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa, art. 4(1) "All forms of exploitation, cruel, inhuman or degrading punishment and treatment shall be prohibited."<br>• European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment | **ECtHR:** finding continued detention of a cancer sufferer where it caused "particularly acute hardship" to constitute cruel, inhuman or degrading treatment [Mouisel v. **France**, 38 EHRR 34, para. 34 (2004)].<br><br>***See also:***<br>• A right to avoid unnecessary pain and suffering is an important part of most patients' rights charters. For instance, the European Charter of Patients' Rights sets out: "Each individual has the right to avoid as much suffering and pain as possible, in each phase of his or her illness. The health services must commit themselves to taking all measures useful to this end, like providing palliative care treatment and simplifying patients' access to them." [art. 11].<br>• The Declaration on the Promotion of Patients' Rights in Europe, promulgated by a WHO European Consultation, similarly asserts: "Patients have the right to relief of their suffering according to the current state of knowledge. . . . Patients have the right to humane terminal care and to die in dignity." [art. 5.10, 5.11]. |

### *Table 2: Palliative care and the right to life*

| Examples of Human Rights Violations | |
|---|---|
| • Unable to obtain pain medication, an AIDS patient is unable to adhere to required treatment and continue taking antiretrovirals. As a result, the patient does not have much time to live. | |
| **Human Rights Standards** | **Precedents and Interpretations** |
| **ICCPR 6(1)** Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.<br><br>**ACHPR 4** Human beings are inviolable. Every human being shall be entitled to respect for his life and the integrity of his person. No one may be arbitrarily deprived of this right.<br><br>**ECHR 2(1)** Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law. | **HRC:** explaining that the right to life "should not be interpreted narrowly" or "in a restrictive manner," and its protection "requires that States adopt positive measures . . . to increase life expectancy." [HRC GC 6, paras 1, 5]. |

### *Table 3: Palliative care and the right to the highest attainable standard of health*

| Examples of Human Rights Violations | |
|---|---|
| • A country does not provide for training in palliative care to its medical personnel. As a result, end of life patients do not receive adequate pain relief and physical, psychosocial, and spiritual, care.<br>• A state provides funding only for hospitals and not for hospices and home-based care facilities. As a result, patients must either forgo treatment or remain far from their homes and families. | |
| **Human Rights Standards** | **Precedents and Interpretations** |
| **ICESCR 12(1)** The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.<br><br>**12(2)** The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for: . . .<br><br>**(c)** The prevention, treatment and control of epidemic, endemic, occupational and other diseases;<br><br>**(d)** The creation of conditions which would assure to all medical service and medical attention in the event of sickness.<br><br>**CRC 24(1)** States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health.<br><br>**ACHPR 16(1)** Every individual shall have the right to enjoy the best attainable state of physical and mental health.<br><br>**16(2)** States Parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick.<br><br>**ESC 11** – The right to protection of health<br><br>With a view to ensuring the effective exercise of the right to protection of health, the Contracting Parties undertake, either directly or in co-operation with public or private organisations, to take appropriate measures designed . . . **(2)** to provide advisory and educational facilities for the promotion of health . . .<br><br>***See also:***<br>• African Charter on the Rights and Welfare of the Child, art. 14 (child's right to the highest attainable standard of health). | **CESCR**: affirming the importance of "attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity." [CESCR GC 14, para. 25].<br><br>**CESCR**: indicating that access to "essential drugs, as defined by the WHO Action Programme on Essential Drugs" is part of the minimum core content of the right to health. Fourteen palliative care medications are currently on the WHO Essential Drug List. [CESCR GC 14, para. 12].<br><br>**CESCR**: "States are under the obligation to *respect* the right to health by . . . refraining from denying or limiting equal access for all persons . . . to preventive, curative and palliative health services." [CESCR GC 14, para. 34].<br><br>***See also:***<br>• Under the Declaration on the Promotion of Patients' Rights in Europe, promulgated by a WHO European Consultation, "Patients have the right to enjoy support from family, relatives and friends during the course of care and treatment and to receive spiritual support and guidance at all times." [art. 5.9]. |

### *Table 4: Palliative care and the right to information*

| Examples of Human Rights Violations | |
|---|---|
| • People are denied information about hospice and palliative care services.<br>• People are denied information about pain management.<br>• People are denied information about their diagnosis and prognosis. | |
| **Human Rights Standards** | **Precedents and Interpretations** |
| **ICCPR 19(2)** Everyone shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of his choice.<br><br>**ACHPR 9 (1)** Every individual shall have the right to receive information.<br><br>**ECHR 10 (1)** Everyone has the right to freedom of expression. This right shall include freedom to hold opinions and to receive and impart information and ideas without interference by public authority and regardless of frontiers. This article shall not prevent States from requiring the licensing of broadcasting, television or cinema enterprises.<br>(2) Every individual shall have the right to express and disseminate his opinions within the law.<br><br>***See also:***<br>• European Convention on Human Rights and Biomedicine, art 10(2): "Everyone has the right to know any information collected about his or her health." | **CESCR:** health care accessibility "includes the right to seek, receive and impart information and ideas concerning health issues." [CESCR GC 14, para 12].<br><br>***See also:***<br>• Under the European Charter of Patients' Rights, "Every individual has the right of access to all kinds of information regarding their state of health and health services and how to use them, and all that scientific research and technological innovation makes available." [art. 3].<br>• The Declaration on the Promotion of Patients' Rights in Europe emphasizes, "Patients have the right to be fully informed about their health status, including the medical facts about their conditions; about the proposed medical procedures, together with potential risks and benefits of each procedure; about alternatives to the proposed procedures, including the effect of non-treatment; and about the diagnosis, prognosis, and progress of treatment." Moreover, "[p]atients have the right to choose who, if any one, should be informed on their behalf." [art. 2.2, 2.6]. |

### *Table 5: Palliative care and the right to non-discrimination and equality*

| Examples of Human Rights Violations | |
|---|---|
| • A country decides that it is not worth investing precious resources in providing care for the elderly.<br>• Former drug users are denied access to opioid-based pain medication.<br>• A state provides only limited health services to non-citizens and refugees, denying them access to palliative care. | |
| **Human Rights Standards** | **Precedents and Interpretations** |
| **ICCPR 26** All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.<br><br>**ICESCR 2(2)** The States Parties to the present Covenant undertake to guarantee the rights enunciated in the present Covenant shall be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, birth or other status.<br><br>**ACHPR 2** Every individual shall be entitled to the enjoyment of the rights and freedoms recognized and guaranteed in the present Charter without distinction of any kind such as race, ethnic group, colour, sex, language, religion, political or any other opinion, national and social origin, fortune, birth or other status.<br><br>***See also:***<br>• International Convention on the Elimination of All Forms of Racial Discrimination, art. 5(e)(iv)<br>• Convention relating to the Status of Refugees<br>• European Convention on Human Rights and Biomedicine, art 3 (equitable access to health care)<br>• European Convention on Citizenship and the Convention Relating to the Status of Stateless Persons | **CESCR**: "[T]he range of matters" for which discrimination on the basis of age is acceptable "is very limited." In fact, States parties "are obliged to pay particular attention to promoting and protecting the economic, social and cultural rights of older persons." [CESCR GC 6, paras 12,13].<br><br>**CESCR:** emphasizing the need "to eliminate any discriminatory legislation and the need to ensure the relevant budget support" for the elderly. [CESCR GC 6, para. 18].<br><br>**CESCR:** upholding "the right of elderly persons to the enjoyment of a satisfactory standard of physical and mental health" and urging of "a comprehensive view, ranging from prevention and rehabilitation to the care of the terminally ill." [CESCR GC 6, para. 34].<br><br>**CESCR:** recommending that **Bulgaria** "take affirmative action for the well-being of older people," in light of their increasing number. [ICESCR, E/2000/22 (1999) 46, para. 238}.<br><br>**CESCR:** noting "with satisfaction" **Finland's** inclusion of age as a prohibited ground of discrimination in its constitution. [CESCR, E/2001/22 (2000) 73, para. 433].<br><br>**CERD:** calling upon states to protect the adequate standard of health of non-citizens and refugees by ensuring their equal access to palliative health services. [CERD/C/NOR/CO/18 (CERD, 2006), para. 21; CERD/C/BWA/CO/16 (CERD, 2006), para. 19]. |

# What are some examples of effective human rights programming in the area of palliative care?

## Introduction

In this section, you are presented with four **examples** of effective activities in the area of palliative care and human rights. These are:

1. Petitioning the State Human Rights Commission for access to palliative care in **India**
2. Litigation to ensure access to morphine in **India**
3. Regulatory reform in **Romania**
4. Integration of patients' rights standards in hospice accreditation in **South Africa**

## Rights-based programming

As you review each activity, ask yourself whether it incorporates the **five elements** of "rights-based" programming:

- **Participation**
  Does the activity include participation by affected communities, civil society, marginalized groups, and others? Is it situated in close proximity to its intended beneficiaries?

- **Accountability**
  Does the activity identify both the *entitlements of claim-holders* and the *obligations of duty-holders*? Does it create mechanisms of accountability for violations of rights?

- **Non-discrimination**
  Does the activity identify who is most vulnerable, and how? Does it pay particular attention to the needs of vulnerable groups such as women, minorities, indigenous peoples, and prisoners?

- **Empowerment**
  Does the activity give its beneficiaries the power, capability, capacity, and access to bring about a change in their own lives? Does it place them at the center of the process rather than treating them as objects of charity?

- **Linkage to rights**
  Does the activity define its objectives in terms of legally enforceable rights, with links to international, regional, and national laws? Does it address the full range of civil, political, economic, social, and cultural rights?

Finally, ask yourself whether the activity might be replicated in your country:

- Does such a project **already exist** in your country?
- If not, should it be **created**? If so, does it need to be **expanded**?
- What **steps** need to be taken to replicate this project?
- What **barriers** need to be overcome to ensure its successful replication?

## Example 1: Petitioning the state human rights commission for access to palliative care in India

A cancer patient and the director of the Institute of Palliative Medicine petitioned the State Human Rights Commission to secure the training of palliative care professionals and the provision of palliative care in government hospitals.

### Project type
Human Rights Commission Petition

### Health and human rights issue
In India, training in palliative care was not included in the education of medical staff, and patients in certain districts could not obtain needed care and pain relief medication.

### Actions taken
A cancer patient and the director of the Institute of Palliative Medicine, of the Kozhikode Government Medical College, petitioned the State Human Rights Commission for the provision of palliative care in government hospitals.

### Results
In 2006, the Commission directed the government to:

- Take steps to include palliative medicine in the curriculum of nursing and undergraduate medical students
- Give training in palliative care to medical staff in government and private hospitals
- Set up a pain and palliative-care hospital in every district.
- Provide enough medicines for relieving pain.

The Commission ordered an action-taken report from the government within 30 days.

**Contact**
Pain and Palliative Care Society,
Medical College (PO),
Calicut 673008, Kerala, INDIA
Email: pain@vsnl.com
Web: www.painandpalliativecare.org/index.htm

## Example 2: Litigation to ensure access to morphine in India

In 1988, a doctor took legal action to secure access to morphine for cancer patients in India.

### Project type
Litigation

### Health and human rights issue
In 1985, the Narcotic Drugs and Psychotropic Substances Act instituted strict controls on the distribution of morphine in India. This had tremendous impact on the use of morphine for medical purposes. Supplies of medical morphine dwindled from over 750 kilograms per year in 1985 to only 56 kilograms in 1996. Thus, while India was the major exporter of opium to the world, patients with severe pain did not have access to morphine. Moreover, a whole generation of doctors graduated without experience in its use and unaware of its potential in treating patients.

### Actions taken
- Dr. Ravindra Ghooi filed a public interest litigation in the Delhi High Court on behalf of cancer patients in the country, requesting the rationalization of procedures for the supply of morphine for medical purposes.

- Dr. Ghooi filed suit after the death of his mother. His mother had breast cancer, but due to a previous history of diabetes and a stroke, she was not a candidate for aggressive cancer therapy. Nonetheless, she suffered from significant pain. Her physicians were not able to obtain even 1 mg of morphine for her treatment. Dr. Ghooi himself went through an enormous amount of bureaucratic red tape and spent his time and money meeting with government officials, but was ultimately unsuccessful.

### Results
- In 1998, the High Court affirmed, "It is a right of patients to receive any medication they need, particularly morphine."

- The Court then directed the state government to speedily attend to morphine requests and to pending hospital applications for morphine licenses. It further encouraged patients to approach the court if unsatisfied.

- This court case worked in tandem with other advocacy efforts to increase access to palliative care medications. In 1993, the Pain and Palliative Care Society formed to develop community-based palliative care provision in India, and over the next seven years, the Society helped established twenty outreach palliative care programs throughout Kerala. By 2002, eight of the twenty-eight states in India amended their rules governing access to morphine.

**Contact**
All India Lawyer's Forum for Civil Liberties (AILFCL)
Ch.No.444, Western Wing,
Tis Hazari Court, Delhi-110 054

## Example 3: Regulatory reform in Romania

Incorporating patients' rights arguments and international standards in their advocacy, a Romanian team convinced regulators of the need to reform opioid control policies to enable the provision of palliative care.

### Project type
Law reform

### Health and human rights issue
Romania's drug-control policies were more than 35 years old and imposed an antiquated regulatory system on pain medication based on inpatient, post-surgical management of acute pain. This restricted prescription authority, making access to opioid treatment difficult for patients with severe chronic pain due to cancer or AIDS.

### Actions taken
- In 2002, a Romanian team composed of health care professionals working on cancer, HIV AND AIDS, pain, and palliative care and representatives from narcotic authorities and the ministries of health, social welfare, and insurance attended an IPCI workshop on ensuring the availability of opioid analgesics for palliative care.
- The Romanian team returned home and advocated for the creation of a national commission to reform Romania's opioid control policies.
- To convince regulators that a change in opioid law was needed, one argument the team used was to point to Romania's patient rights law, which stated, "The patient has the right to palliative care in order to die in dignity." (24/2003, Cap VI, art. 31).
- The Ministry of Health agreed to the formation of a Palliative Care Commission (PCC) to study the matter.
- Finding that Romania's opioid control policies fell short of WHO guidelines, the PCC invited the Pain & Policy Studies Group from the University of Wisconsin to collaborate in the preparation of recommendations.

### Results
- Based on the resulting report, the Ministry of Health drafted legislation to replace the old narcotics law. Parliament passed this into law in 2005. The Pain and Policy Studies Group then worked with the Ministry of Health on implementing regulations.
- Under the new law, special authorization is no longer necessary to prescribe opioids for outpatients, non-specialists can prescribe after receiving certified training, and there is no dosage limitation.
- Romania is currently conducting a country-wide effort to educate healthcare professionals in the use of opioid analgesics.

**Contact**
Dr. Daniela Mosoiu
Hospice Casa Sperantei
Email: mosoiudaniela@xnet.ro

David Joranson and Karen Ryan
Pain & Policies Study Group
University of Wisconsin
Email: kmryan2@facstaff.wisc.edu,
Web: www.painpolicy.wisc.edu

## Example 4: Integration of patients' rights standards in hospice accreditation in South Africa

The Hospice and Palliative Care Association of South Africa (HPCA) developed palliative care standards for the accreditation of hospices in South Africa, incorporating key protections for patient rights.

### Project type
Development of patient care standards

### Health and human rights
Founded in 1988, the Hospice and Palliative Care Association of South Africa (HPCA) is a professional membership organization for hospice and palliative care organizations. One of its core missions is to ensure professional palliative care services and to guarantee a high standard of care to patients and their families. HPCA thus wished to develop accrediting standards and procedures for hospices in South Africa. Patient rights are central to HPCA's philosophy—providers view themselves as advocates for their patients—and would thus have to figure prominently in criteria developed.

### Actions taken
- In 1994, a HPCA Standards Committee was created to work with the Council for Health Services Accreditation of South Africa (Cohsasa), the accrediting body for facilities in compliance with health professional standards, to formulate comprehensive palliative care standards for hospices.
- The Committee developed standards covering 13 key areas with patient rights as one of them. Patient rights language is further embedded throughout.
- A chapter on patient rights addresses processes to: identify, protect, and promote patient rights; inform patients of their rights; include the patient and the patient's family, when appropriate, in decisions about the patient's care; obtain informed consent; educate staff about patients' rights; and guide the organization's ethical framework.

### Results
- In 2005, the HPCA/Cohsasa standards for hospice accreditation were published and recognised by the International Society for Quality in Health Care Incorporated (ISQua).
- Eleven South African hospices were granted full Cohsasa accreditation in 2006, and another 26 should be fully accredited in 2007.

**Contact**
HPCA (Hospice Palliative Care Association of South Africa),
P.O. Box 38785, Pinelands 7430,
South Africa
Email: HPCA@IAFRICA.COM
Web: www.hospicepalliativecaresa.co.za/

Cohsasa (Council for Health Services Accreditation of South African)
P.O. Box 676, Howard Place 7450,
South Africa
Email: info@cohsasa.co.za
Web: www.cohsasa.co.za/

# Where can I find additional resources on palliative care and human rights?



## Resources

To further your understanding on the topic of palliative care and human rights, a list of commonly used resources has been compiled and organized into the following categories:

- Declarations and resolutions: UN
- Declarations and resolutions: non-UN
- Position statements
- Books
- Reports, key articles, and other documents
- Websites
- Training opportunities and key conferences

## Declarations and resolutions: UN

- Resolution adopted by the UN General Assembly, 26th special session, Agenda item 8, S-26-2. Declaration of Commitment on HIV/AIDS. 2001.
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- The Care of the Dying Patients. Position Statement. American Geriatrics Society, 2002.
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- Ferrell B, Coyle N (eds) *Oxford Textbook of Palliative Nursing*, 3rd edition, 2006.
- Goldman A, Hain R, Liben R (eds) *Oxford Textbook of Palliative Care for Children,* 2006.
- Gwyther L, Merriman A, Mpanga Sebuyira L, Shietinger H: *A Clinical Guide to Supportive and Palliative Care for HIV/AIDS in Sub-Saharan Africa,* 2006. Source: www.apca.co.ug/publications/ClinicalGuide/index.htm
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- European Association for Palliative Care
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## *Training opportunities and key conferences*

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- Diploma in Palliative Care, Coventry University, UK
  Email: hssgen@coventry.ac.uk

- Diploma in Palliative Care Course, University of Gloucestershire, School of Health & Social Sciences, Francis Close Hall, Swindon Road, Cheltenham, UK
  Email: shss@glos.ac.uk

- Diploma in Supportive and Palliative Care,
  Sheffield Hallam University, Sheffield, UK
  Email: admissions@shu.ac.uk
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- Distance Learning Course in Symptom Control, Beth Israel Medical Center, Department of Pain Medicine and Palliative Care
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  Source: www.eperc.mcw.edu

- End of Life Nursing Education Consortium (ELNEC) Core Syllabus
  Source: www.aacn.nche.edu/elnec/index.htm

- Fellowship in Palliative Medicine
  Contact Prof. Reena George (palcare@cmcvellore.ac.in)

- Finding our Way: Living with dying in America
  Source: itrs.scu.edu/fow/pages/FOWCOURSEINDEX.html

- Free online course for nurses and carers
  Source: www.cancernursing.org

- Guide I: Become and Effective Online Educator in Palliative Care
  University of Calgary in partnership with IAHPC
  Email: palacios@ucalgary.ca

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  Email: hargreaves@lancaster.ac.uk
  Source: www.eolc-observatory.net

- Introduction to Palliative Care Nursing Course
  Source: www.CancerNursing.org

- Master of Science in Palliative Care
  Graduate Certificate in Health (Palliative Care)
  Graduate Certificate in Pediatric Palliative Care
  Graduate Diploma in Palliative Care
  Master of Palliative Care
  Graduate Certificate in Palliative Care in Aged Care
  Graduate Diploma in Palliative Care in Aged Care and
  Master of Palliative Care in Aged Care
  Flinders University, Adelaide, Australia
  Source: www.flinders.edu.au

- Master of Science in Palliative Care
  King's College London
  Department of Palliative Care and Policy
  Email: jonathan.s.koffman@kcl.ac.uk
  Source: www.kcl.ac.uk/palliative

- MPhil in Palliative Medicine, University of Cape Town
  Source: www.uct.ac.za/students/degrees/health/postgraduate/

- MSc Diploma and Certificate in Palliative Medicine, Kings College London
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  Universite Laval, McGill University, University of Ottawa, Canadian Institutes of Health Research, National Cancer Institute of Canada
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- University of Washington, Seattle, Center for Palliative Care Education
  Source: depts.washington.edu/pallcare/training/index.shtml

# What are key terms related to palliative care and human rights?

## Glossary

A variety of terms is used in palliative care and human rights work.

# A

### Acute pain
Pain that has a known cause and occurs for a limited time. It usually responds to analgesic medications and treatment of the cause of the pain.

### Addiction
A commonly-used term describing a pattern of drug use that indicates physical or mental dependence. It is not a diagnostic term and no longer used by the World Health Organization (WHO).

### Advance medical directives
Used to give other people, including health care providers, information about a patient's own wishes for medical care. Advance directives are important in the event patients are not physically or mentally able to speak for themselves and make their wishes known. The most common types of advance directives are the living will and the durable power of attorney for health care. A Do Not Resuscitate (DNR) is also a form of an Advance Medical Directive.

### Analgesic medications
Medications used to prevent or treat pain.

# B

### Bereavement
The act of grieving the loss of a significant other.

# C

### Cancer
An abnormal growth of cells which tend to proliferate in an uncontrolled way and, in some cases, to metastasize (spread).

### Caregiver
Any person who provides care for the physical, emotional, or spiritual needs of a family member or friend.

### Chronic pain
Pain that occurs for more than one month after an injury has healed, that occurs repeatedly over months, or is due to a lesion that is not expected to heal.

### Complementary therapies
Approaches to treatment that are outside of mainstream medical practices. Complementary therapy treatments used for pain and/or comfort include: acupuncture, low-level laser therapy, meditation, aroma therapy, Chinese medicine, dance therapy, music therapy, massage, herbal medicine, therapeutic touch, yoga, osteopathy, chiropractic treatments, naturopathy, and homeopathy.

### Community based care
Medical and social service care often provided by volunteer trained members of the community.



# D

### Death
The end of life in a biological organism, marked by the full cessation of its vital functions.

### Do-Not-Resuscitate (DNR) orders
A DNR is a medical directive that gives consent from the patient, his/her advocate or from a Medical Physician that the patient is not to be treated for cardiac or respiratory arrest. This directive is used when treatment of the patient will not be beneficial or successful to the quality or longevity of the patients' life. This is usually the case in the seriously and terminally ill, and/or the frail and elderly. These directives do not mean that comfort measures will be withheld.

### Dignity
The quality of being worthy, honored, or esteemed. Human rights are based on inherent human dignity and aim to protect and promote it.

### Durable power of attorney
A person who is dying may appoint someone else to manage their finances and to make economic decisions on their behalf. This person is referred to as the "agent."

# E

### End-of-life care
Doctors and caregivers provide care to patients approaching the end of life that is focused on comfort, support for the family, and treatment of psychological and spiritual concerns.

### Essential medicines
Medicines that satisfy the priority health-care needs of the population. Essential medicines are intended to be available at all times in adequate amounts, in the appropriate dosage forms, with assured quality, and at a price the individual and the community can afford.

### Ethics
A system of moral principles and rules that are used as standards for professional conduct. Many hospitals and other health care facilities have ethics committees that can help doctors, other healthcare providers, patients, and family members in making difficult decisions regarding medical care. This may vary with religious and cultural backgrounds.

## G

### Grief
The normal process of reacting to a loss. The loss may be physical (such as a death), social (such as divorce), or occupational (such as a job). Emotional reactions of grief can include anger, guilt, anxiety, sadness, and despair. Physical reactions of grief can include sleeping problems, changes in appetite, physical problems, or illness.



## H

### HAART
Highly active anti-retroviral therapy.

### Health care proxy
A written instrument in which an individual legally delegates authority to another person to make certain health related decisions on their behalf.

### Home based care
Medical and social care provided by trained health care professionals or volunteers in a person's home.

### Hospice
A care program that provides a centralized program of palliative and supportive services to dying persons and their families, in the form of physical, psychological, social, and spiritual care; such services are provided by an interdisciplinary team of professionals and volunteers who are available at home and in specialized inpatient settings.

### Hospice care
Care designed to give support to people in the final phase of a terminal illness, and focused on comfort and quality of life, rather than a cure. The goal is to enable patients to be comfortable and free of pain so that they live each day as fully as possible. Aggressive methods of pain control may be used. Hospice programs generally are home-based, but they sometimes provide services away from home -- in freestanding facilities, in nursing homes, or within hospitals. The philosophy of hospice is to treat the whole person by providing support for the patient's emotional, social, and spiritual needs, as well as addressing medical symptoms.

# I

### Informed consent
The process of making decisions about medical care that is based on factual, open and honest communication between the health care provider and the patient and/or the patient's family members.

# L

### Life-limiting illness
An illness with a prognosis of a year or less to live.

### Life-threatening illness
An illness serious enough in which a patient may die.

### Living will
A legal document which outlines the direction of medical care a patient wishes to have or not to have. The living will is used only if the patient becomes unable to make decisions for him/herself, and will be carried out as the patient has directed in the document.

# M

### Medical power of attorney
A document that allows any individual to appoint another person to be their agent and make decisions for them should they become unable to make decisions for themselves.

### Multidisciplinary team
A group of individuals representing different medical disciplines who work together to care for a patient and family.

# N

### Nursing home
A residential facility for persons with chronic illness or disability, particularly older people who have mobility and eating problems. This is also called a convalescent home or long-term care facility.

### Nutrition Hydration
Intravenous (IV) fluid and nutritional supplements given to patients who are unable to eat or drink by mouth, or those who are dehydrated or malnourished.

# O

### Opioid
A type of medication related to opium. Opioids are analgesics used in acute and chronic pain. Opioids include morphine, codeine, and a large number of synthetic (man-made) drugs like methadone and fentanyl.

### Opportunistic infections
Infections caused by organisms that usually do not cause disease in a person with a healthy immune system, but can affect people with a poorly functioning or suppressed immune system.

# P

### Pain
An unpleasant feeling that may or may not be related to an injury, illness, or other bodily trauma. Pain is complex and differs from person to person, as related to the individual's pain threshold.

### Palliative care
An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

### Palliative care for children
Represents a special, albeit closely related field to adult palliative care for children with life threatening or chronic disorders and their families. Includes active total care of the child's body, mind, and spirit; family support; and a multidisciplinary approach that includes the family and makes use of available community resources.

### Palliative care standards
Standards reflecting the level of care a patient and family can expect to receive when dealing with a diagnosis of a life-limiting illness.

### Permanent guardianship of minor children
Offers a parent the option of permanently placing their child (a minor) in the care of another person.

### Power of attorney for personal care
A legal document that specifies one or more individuals a patient would like to make medical decisions on his/her behalf if unable to do so on their own.

### Psychology
Science dealing with phenomena of the mind, the conscious subject, or self.

### Psychosocial care
Care given to meet a constellation of social, mental health, and emotional needs.

## R

### Rehabilitation
Treatment for an injury, illness, or pain with the goal of restoring partial or full function.

## S

### Social work
Work carried out by professionals concerned with social problems, their causes, their solutions, and their human impacts. Social workers work with individuals, families, groups, organizations, and communities, as members of a profession committed to social justice and human rights.

### Spiritual care
Providing the necessary resources to address and support people's values and beliefs, provided these values and beliefs place no individuals at risk. It is based on treating each person with respect and dignity, promoting love, hope, faith, and helping vulnerable people to find the strength to cope at times of life crises when overcome by despair, grief and confusion.

### Suffering
Absence of any power to control or to meaningfully influence a perceived process of one's own disintegration.

### Symptom management
Care given to improve the quality of life of patients who have a serious or life-threatening disease. The goal of symptom management is to prevent or treat as early as possible the symptoms of the disease, side effects caused by treatment of the disease, and psychological, social, and spiritual problems related to the disease or its treatment. Also called palliative care, comfort care, and supportive care.

## T

### Terminal
A progressive disease that is expected to cause death.

### Treatment withholding
When treatment is considered to be ineffective, disproportionate, or of no value to the patient's quality of life, it may be withdrawn or withheld.

### Treatment withdrawal
The ending of treatment that is medically futile in promoting an eventual cure or possible control of the disease.

# W

### Will
A legal document that allows a person to leave any portion of his/her estate and any specific positions to any other person or organization.

### Withholding care
Not offering a specific treatment to a patient.

### Withdrawing care
Withdrawing a treatment that has already started in a patient.

# APPENDIX
# Links

## *Thirteen Health and Human Rights Documents*

- International Covenant on Civil and Political Rights (ICCPR)
  www.equalpartners.info/Appendix/App_01iccpr.html
- Siracusa Principles on the Limitation and Derogation of Provisions in the International Covenant on Civil and Political Rights (Siracusa Principles)
  www.equalpartners.info/Appendix/App_02siracusa.html
- International Covenant on Economic, Social and Cultural Rights (ICESCR)
  www.equalpartners.info/Appendix/App_03icescr.html
- Committee on Economic, Social and Cultural Rights, General Comment 14, The right to the highest attainable standard of health
  www.equalpartners.info/Appendix/App_04EcSocCult.html
- The Maastricht Guidelines on Violations of Economic, Social and Cultural Rights (Maastricht Guidelines)
  www.equalpartners.info/Appendix/App_05Maastricht.html
- International Convention on the Elimination of All Forms of Racial Discrimination (ICERD)
  www.equalpartners.info/Appendix/App_06icerd.html
- Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)
  www.equalpartners.info/Appendix/App_07cedaw.html
- Committee on the Elimination of Discrimination against Women, General Recommendation 24, Women and Health
  www.equalpartners.info/Appendix/App_08ElDisWo.html
- African [Banjul] Charter on Human and Peoples' Rights (ACHPR)
  www.equalpartners.info/Appendix/App_09achpr.html
- Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (Women's Protocol to the African Charter)
  www.equalpartners.info/Appendix/App_10WoProtocol.html
- [European] Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR)
  www.equalpartners.info/Appendix/App_11echr.html
- European Social Charter (ESC)
  www.equalpartners.info/Appendix/App_12esc.html

- Appendix to the European Social Charter
  www.equalpartners.info/Appendix/App_13escapp.html

- European Charter of Patients' Rights
  www.equalpartners.info/Appendix/App_14ecpr.html

# Palliative Care and Human Rights

## A Resource Guide

**A modified excerpt from *Health and Human Rights: A Resource Guide***

***Edited by Jonathan Cohen, Tamar Ezer, Paul McAdams, and Minda Miloff***

**The field of health and human rights brings together two important movements. For public health advocates, human rights provide an essential tool for promoting accountability and addressing the non-medical roots of poor health. For human rights advocates, the protection of public health is a mark of democracy, good governance, and open society. As governments respond to urgent health threats in the 21st century, it is more important than ever for human rights groups to partner with health experts in advocating against abuses and generating pragmatic, rights-based solutions.**

**This Resource Guide provides a practical tool for all staff working at the intersection of health and human rights. It includes fact sheets, program descriptions, jurisprudence, case studies, and glossary definitions regarding palliative care and human rights. It also contains links to thirteen foundational human rights documents containing health-related provisions.**

**Prepared by OSI and Equitas staff together with leading experts in the field, this guide is designed to support health and human rights advocacy, training, education, programming, and grantmaking worldwide.**


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