

# USING THE UN HUMAN RIGHTS SYSTEM TO ADVOCATE FOR ACCESS TO PALLIATIVE CARE AND PAIN RELIEF



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## ACKNOWLEDGEMENTS

This toolkit was written by Duncan Wilson, supported by Gabriela B. de Luca, both of the Open Society Public Health Program. It draws in part on a report written by Taras Kosmyna and Eugenia Pyntikova while students at Georgetown University Law Center, under the supervision of Fernanda Alonso, Ana Ayala, Tanya Baytor, and Oscar Cabrera of Georgetown's O'Neill Institute for National and Global Health Law. The original report was reviewed by Mary Callaway, Tamar Ezer, Kathleen Foley and Kiera Hepford, all former Open Society Foundations staff, as well as external reviewers Liliana De Lima, Diederik Lohman, and Ryan Quinn.

It was piloted in May 2015, at a gathering of palliative care and human rights practitioners in Nairobi, and incorporates the lessons learned, comments, and suggestions of these practitioners.

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Published By

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New York, New York 10019 USA

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Design and Layout by Ahlgrim Design Group

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# ABBREVIATIONS

## INTERNATIONAL TREATIES

<b>UDHR:</b>	Universal Declaration of Human Rights
<b>CAT:</b>	Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment
<b>CEDAW:</b>	Convention on the Elimination of All Forms of Discrimination against Women
<b>ICCPR:</b>	International Covenant on Civil and Political Rights
<b>ICESCR:</b>	International Covenant on Economic, Social and Cultural Rights
<b>CRC:</b>	Convention on the Rights of the Child
<b>CRPD:</b>	Convention on the Rights of Persons with Disabilities

## TREATY BODIES

<b>CAT:</b>	Committee against Torture
<b>SPT:</b>	Subcommittee on Prevention of Torture
<b>CEDAW:</b>	Committee on the Elimination of Discrimination against Women
<b>CESCR:</b>	Committee on Economic, Social and Cultural Rights
<b>CRC:</b>	Committee on the Rights of the Child
<b>HRC:</b>	Human Rights Committee
<b>CRPD:</b>	Committee on the Rights of Persons with Disabilities

## OTHER

<b>ECOSOC:</b>	Economic and Social Council
<b>NHRI:</b>	National human rights institution
<b>OHCHR:</b>	Office of the High Commissioner for Human Rights
<b>UPR:</b>	Universal Periodic Review
<b>LOIPR:</b>	lists of issues prior to reporting
<b>NGO:</b>	non-governmental organization
<b>CSO:</b>	civil society organization

# EXECUTIVE SUMMARY

This toolkit is intended to serve as a resource for organizations considering advocating for increased access to palliative care and pain relief as a human right within the United Nations human rights system. It clarifies what human rights are and how they are relevant to palliative care, as well as what the UN Human Rights System is. It also presents why and how to engage with the UN human rights system to advocate for increased availability and accessibility of quality palliative care and pain relief.

## WHAT IS PALLIATIVE CARE?

Palliative care seeks to relieve suffering and improve quality of life for those with life-limiting conditions. It is a holistic approach that improves quality of life for patients and their families by addressing the psychosocial, legal, and spiritual problems associated with life-threatening illness. Palliative care has been shown to be highly effective in managing pain and physical symptoms, and can improve adherence to medications. It is a core component of health care and of the human right to the highest attainable standard of health. It is also connected with a range of other rights and is increasingly recognized as a stand-alone right.<sup>1</sup>

## WHAT ARE HUMAN RIGHTS AND HOW ARE THEY RELEVANT TO PALLIATIVE CARE?

Human rights are the basic freedoms and entitlements that we all need in order to live with dignity. They have been secured in international law since the agreement of the Universal Declaration of Human Rights in 1948. Palliative care has been specifically recognized as a component of the right to the highest attainable standard of physical and mental health (the right to health).<sup>2</sup> Similarly, access to pain relief to avoid severe pain and suffering is required under the right to be free from torture and other cruel, inhuman or degrading treatment or punishment.<sup>3</sup>

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1 FXB Center for Health and Human Rights & Open Society Foundations, *Health and Human Rights Resource Guide*, (2013); available at: <https://www.hhrguide.org/>.

2 UN Committee on Economic, Social and Cultural Rights, *General Comment Number 14*, (2000), UN Doc. E/CC.12/2000/4, para. 34; UN Committee on the Rights of the Child, *General Comment Number 15*, (2013), UN Doc. CRC/C/GC/15, para. 25.

3 UN Human Rights Council, "Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak," (2009), UN Doc. A/HRC/10/44, para. 72.

In addition, those who are most often in need of palliative care and pain relief include socially excluded and marginalized groups that often face stigma, and barriers to accessing effective health care, raising concerns related to non-discrimination and equality.<sup>4</sup> Other human rights that are particularly relevant in relation to palliative care include the rights to information, autonomy, independent living, the rights of the child, and, the rights of persons with disabilities, among others.

## WHY ADVOCATE FOR PALLIATIVE CARE AND PAIN RELIEF AS HUMAN RIGHTS?

Invoking the human rights framework when advocating for palliative care and pain relief can add significant value to traditional approaches that emphasize medical, public health, or moral arguments. Human rights emphasize that people are not passive recipients of welfare or services; they are subjects of rights to be treated with dignity. Accordingly, the state has binding legal human rights obligations, according to which it must absolutely ensure that everyone is free from unnecessary suffering. The state must also progressively ensure that adequate preventive, curative, and palliative health care is available, accessible, acceptable, and of sufficient quality to everyone who needs it.<sup>5</sup>

The frame of human rights, with its emphasis on the population as rights holders and the states as duty bearers, challenges traditional power dynamics. It promotes the empowerment of people to know what their rights are and how they can claim them, and affirms their right to effective participation in decisions that affect them. It also emphasizes the accountability of the state to the people for the realization of human rights, by requiring monitoring of progress, access to justice, and remedies for violations.

## WHAT IS THE UN HUMAN RIGHTS SYSTEM?

The UN human rights system comprises a series of international mechanisms to promote and protect human rights. It can be a key avenue to hold the state externally accountable for what it does and does not do to realize rights related to palliative care.

The UN human rights system includes a range of mechanisms, some of which monitor particular international human rights conventions, and others that are set up under the UN Charter with a broader mandate. These are known respectively as “treaty bodies” and “Charter-based mechanisms.”

**Treaty bodies:** created by specific human rights conventions, treaty bodies receive and review reports on a state’s progress in implementing the treaty, issue authoritative interpretations of the nature of the obligations under the treaty (known as “General Comments” or “General Recommendations”), and may also have powers to review individual complaints or to conduct inquiries into situations where grave abuses are suspected. They are composed of independent experts nominated by countries that have voluntarily agreed to be legally bound by the treaty (known as states parties).

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<sup>4</sup> A list and description of certain of these groups is provided in Annex I to this toolkit, along with a survey of illnesses that commonly warrant palliative care and pain relief.

<sup>5</sup> “State” is the legal term for a country. It is not only the government of the country, but all elements of the state: executive (government), judiciary (courts), and legislature (parliament).

The primary way for civil society organizations to engage with treaty bodies is by submitting parallel reports (also known as “shadow reports”) to inform their consideration of states’ periodic reports under the treaty. A parallel report will present information alternative to that in the state report—to either challenge or contextualize how the state itself reports on progress. Parallel reports can suggest areas for the treaty body to focus on in the review, suggest questions and recommendations for the treaty body to consider during the review and when issuing its concluding observations (the recommendations it makes at the end of the review on steps the state should take). The process for drafting and submitting parallel reports is outlined in the body of the toolkit. In addition, a majority of treaty bodies afford the possibility to submit individual communications alleging violation of a convention right, subject to the acceptance by the state in question of the individual communication mechanism. Many also have powers to initiate inquiries into alleged gross violations, and to order interim measures to avoid irreparable harm, pending a full consideration of an alleged violation.

Charter-based mechanisms: these are established under the UN Charter and generally operate within the UN Human Rights Council, an intergovernmental body of 47 states responsible for the promotion and protection of human rights. The primary mechanisms by which civil society can engage in the Human Rights Council are:

(1) **Universal Periodic Review**, under which the UN Human Rights Council comprehensively reviews the human rights record of all UN member states once every four and a half years. Civil society organizations can contribute to the UPR, and those recognized by the UN’s Economic and Social Council to have particular status (known as “ECOSOC status”) can attend the consideration of the state under review at the Human Rights Council.

(2) **Special Procedures**, including special rapporteurs, independent experts, and working groups, which are independent human rights experts who monitor, advise, and publicly report on human rights situations around the world either by country or by thematic issue. Among those most relevant to palliative care are the special rapporteurs on the right to health and on torture, and the Independent Expert on the rights of older persons. Civil society organizations can engage with special procedures by submitting information on individual cases; submitting views or analysis on human rights concerns; supporting country missions; working to raise awareness and follow-up on the work of special rapporteurs; and inviting special procedures to engage with their own work.

There are also a complaints mechanism and an advisory committee within the Human Rights Council that are considered briefly in the body of this toolkit.

## WHY AND HOW SHOULD ADVOCATES ENGAGE WITH THE UN HUMAN RIGHTS SYSTEM?

Engaging with the UN human rights system can serve as a useful tool for promoting palliative care and pain relief. It can provide an important complement to advocacy and engagement at the national level, a forum for accountability, and an opportunity to demonstrate international attention to the state of palliative care as an issue of universal human rights. That a UN body can find that the state has breached its human rights obligations by failing to take appropriate steps to ensure palliative care for all can have a significant mobilizing effect. It can also lend

immense credibility to local activism and advocacy, and provide opportunities for NGOs to connect and forge alliances for a stronger international movement. To make the most of the opportunity presented by the UN human rights system, there are some important steps and strategic considerations to take into account:

- **Identify your state's human rights obligations:** Each state has voluntarily agreed to be bound by a number of international human rights laws, a number of which relate to palliative care. A first step in considering engaging with the UN human rights system is therefore to identify which instruments the state has agreed to be bound by.
- **Identify allies:** A number of national and international organizations may be preparing to engage with the international human rights reviews of the state. Working collaboratively can help in planning, strategizing, and coordinating advocacy and follow-up to the review. Palliative care will only be one of a number of issues raised at the UN human rights system, so working in coalition with a broader range of health and human rights organizations can help to ensure palliative care is considered alongside other issues.
- **Make a plan:** Planning is essential to ensure that engagement with the UN Human rights system leads to improvements on the ground. Organizations will need to develop a calendar to clarify when the state will be reviewed by different international human rights bodies, important deadlines for submission of reports, and opportunities to engage directly with the review process. Planning should include all stages—for the preparation, advocacy, report writing, engagement in the review processes, and also, crucially, the follow-up: what will happen after the UN review to ensure it translates into improved outcomes for people in need of palliative care in your country?
- **Get in early:** The earlier palliative care issues are raised in the process, the more likely they are to feature in the recommendations and follow-up. In each of the processes, opportunities to raise issues in advance of the actual review should be exploited.
- **Write an effective parallel report:** Written reports are an important way for civil society to influence international human rights reviews. They should be concise, well-structured, well-evidenced, up-to-date, follow the relevant guidelines, clearly based on the state's obligations, and include potential questions and recommendations. They do not need to consist of novel material and can be collated from information the organizations have already gathered and published elsewhere, but the parallel report must be related to the state's relevant human rights obligations.
- **Engage in the review directly:** There are opportunities for direct engagement at different points in the various processes of the UN human rights system, and these can include briefing sessions as well as formal statements. Being able to present priority issues related to palliative care, and often being able to engage in dialogue with the human rights body, will help ensure the issues are raised in the review.
- **Plan for follow-up and implementation:** During preparation and throughout the review, civil society organizations should negotiate a process that considers how recommendations from the UN human rights review are implemented at the national, regional, and local levels. They should also develop a plan for monitoring and accountability, considering the use of such tools as rights-based budget analysis, human rights indicators, community monitoring, and different forums for accountability at the local, regional, and national levels.

# 1. PALLIATIVE CARE

Palliative care is an area of health care dedicated to relieving and preventing patient suffering associated with life-limiting illness. It employs a multidisciplinary approach to patient care that is well suited to the holistic treatment of a number of diseases, and its benefits extend beyond individual patients to their families and other loved ones. Far from burdening health care systems, palliative care can be delivered in a cost-effective manner across a variety of settings. Morphine for pain relief is not protected by patent and can cost as little as U.S. \$0.01 per milligram.<sup>6</sup> Uganda, for example, has a model program that has demonstrated the feasibility of effective delivery of palliative care, including oral morphine, in a resource-poor setting.

The **World Health Organization** (WHO) has defined palliative care as “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.”<sup>7</sup>

The WHO also recognizes the many dimensions of palliative care—namely that it:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor to 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 family members cope during the patient’s illness and in their own bereavement;

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<sup>6</sup> Kathleen M. Foley, et al., “Pain Control for People with Cancer and AIDS”, in *Disease Control Priorities in Developing Countries*, 2nd ed., ed. Jamison et al. (Washington, D.C.: The World Bank, 2006). Available at: <http://www.ncbi.nlm.nih.gov/books/NBK11800/>.

<sup>7</sup> See World Health Organization, “WHO Definition of Palliative Care,” available at: <http://www.who.int/cancer/palliative/definition/en/>.

- uses a team approach to address the needs of patients and their families, including bereavement counseling if indicated;
- enhances 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 or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications; and
- encompasses psychosocial support, including legal services to address legal issues impacting health, such as the disposition of property, planning for children, accessing social benefits, and discrimination.

The WHO has also defined the contours of palliative care for children with life-limiting illness. The principles listed below apply to palliative care for children as well as to other pediatric chronic disorders:

- Palliative care for children is the active total care of the child's body, mind, and spirit; it also involves giving support to the family.
- It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care for children requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- Palliative care for children can be provided in tertiary care facilities, in community health centers, and even in children's homes.

## A SUCCESSFUL MODEL

The Ugandan Ministry of Health has prioritized policy change to enable access to palliative care. For example, Ugandan nurses who go through a nine-month palliative care course are allowed to prescribe opiates. Palliative care was included as part of the National Health Strategic Plan in 2004, with the goal of improving training and access to pain medication. The success story of Uganda, described by Dr. Mwangi-Powell from the African Palliative Care Association (APCA), is "a story which shows how people's society, the hospice movement, the government, [and] advocates came together and they said we can do something about this. But I think most important thing is a good political will. When there's no political will things become very difficult." She noted that the support available in Uganda is the reason why her organization the (APCA) is based there, adding, "[W]e want to preach, we want to say it can happen somewhere, because it has happened in the country where we are based...It's not a mission impossible. It's possible...."

\*Open Society Foundations, "Access to Palliative Care: a Neglected Component of the Right to Health, A Report on the UN Human Rights Council Side Event, Geneva, June 2011", p. 15, available at: <https://www.opensocietyfoundations.org/sites/default/files/access-palliative-care-20130311.pdf>.

Furthermore, the WHO provides 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 the highest attainable standard of health. The WHO Essential Medicines List currently includes 20 palliative care medications for adults and 13 medications for children.<sup>8</sup>

In May 2014, the World Health Assembly (WHA) passed its first palliative care resolution, representing a significant milestone in the global recognition of palliative care as a human right and a state obligation. The resolution emphasizes that access to palliative care and pain relief is an element of the right to health, and calls on member states to integrate palliative care into healthcare systems, and improve funding, training, and availability of pain relief. It requires partnerships between government and civil society, including patient organizations, and monitoring. It also calls on the WHO to include palliative care in global health strategies, develop guidance, provide technical assistance, and monitor progress.

Despite such broad recognition of palliative care, as of January 2014, only 10 percent of people who needed palliative care were currently receiving it. An estimated 20 million patients need palliative care at the end of life; this number rises to at least 40 million if all those that could benefit from palliative care at an earlier stage of their illness are included.<sup>9</sup>

**MORE INFO:** Further information is available on the website of the [Worldwide Hospice Palliative Care Association](#).

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<sup>8</sup> See World Health Organization, "WHO Model Lists of Essential Medicines", available at: <http://www.who.int/medicines/publications/essentialmedicines/en/>.

<sup>9</sup> See World Health Organization, "First ever global atlas identifies unmet need for palliative care," (January 28, 2014), available at: <http://www.who.int/mediacentre/news/releases/2014/palliative-care-20140128/en/>.

## 2. PALLIATIVE CARE AND HUMAN RIGHTS

This chapter outlines the connections between palliative care, pain relief, and human rights, including the emerging right to palliative care. It aims to equip advocates with arguments to use when engaging with the human rights mechanisms discussed later in this toolkit.

Human rights are the basic freedoms and entitlements that we all need in order to live with dignity. They have been secured in international law since the agreement of the Universal Declaration of Human Rights in 1948. This was followed by a range of international and regional human rights treaties that are legally binding on those states that have voluntarily agreed to them. Among the key United Nations human rights treaties that are most relevant to palliative care are the following:

- International Covenant on Economic, Social and Cultural Rights (ICESCR)
- International Covenant on Civil and Political Rights (ICCPR)
- Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)
- Convention on the Rights of the Child (CRC)
- Convention on the Rights of Persons with Disabilities (CRPD)<sup>10</sup>
- Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT)

Palliative care is relevant to a wide range of human rights guaranteed in a number of these treaties. In particular, it has been specifically recognized as a component of the human right to the highest attainable standard of physical and mental health (the right to health).<sup>11</sup> Similarly, access to pain relief to avoid severe pain and suffering is required under the right to be free from torture and other cruel, inhuman or degrading treatment or punishment.<sup>12</sup>

Since the establishment of the World Health Organization in 1948, health has been understood as a human right. As the WHO Constitution states:

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<sup>10</sup> Additional UN human rights conventions include the International Convention on the Elimination of Racial Discrimination, the Convention on the Protection of the Rights of All Migrant Workers and Members of their Families, and the Convention on Enforced Disappearances.

<sup>11</sup> UN Committee on Economic, Social and Cultural Rights, (2000), UN Doc. E/CC.12/2000/4, para. 34; UN Committee on the Rights of the Child, (2013), UN Doc. CRC/C/GC/15, para. 25.

<sup>12</sup> UN Human Rights Council, (2009), UN Doc. A/HRC/10/44, para. 72.

***“Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.***

***The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.”<sup>13</sup>***

The right to the highest attainable standard of health was also later included in the Universal Declaration of Human Rights (adopted in 1948) and in several international conventions including the International Covenant on Economic, Social and Cultural Rights (adopted in 1966); the Convention on the Rights of the Child (adopted in 1989); and the Convention on the Rights of Persons with Disabilities (adopted in 2006). Each state decides which of these international laws it agrees to be legally bound by a process known as ratification or accession. At the time of writing, 162 states have ratified the International Covenant on Economic, Social and Cultural Rights; 151 the Convention on the Rights of Persons with Disabilities; and every state in the world has ratified the Convention on the Rights of the Child, with the exception of Somalia, South Sudan, and the United States.

**MORE INFO:** Up-to-date ratification information can be [found here](#).

The content of the right to health has been clarified in authoritative interpretations (known as general comments or general recommendations) issued by the treaty bodies. For example, in 2000 the UN Committee on Economic, Social and Cultural Rights in its General Comment Number 14 clarified that the right to health is an inclusive right that extends to timely and appropriate “preventative, curative and palliative health services,”<sup>14</sup> as well as to the underlying determinants of health and the participation of people at all levels of health-related decision making. All aspects of the right to health should be progressively available, accessible, acceptable, and of appropriate quality.<sup>15</sup>

The UN Committee on the Rights of the Child also adopted a general comment on the right to health in 2013, which contains references to palliative care.<sup>16</sup> As the committee on the Rights of the Child says: “Children are entitled to quality health services, including prevention, promotion, treatment, rehabilitation and palliative care services. At the primary level, these services must be available in sufficient quantity and quality, functional, within the physical and financial reach of all sections of the child population, and acceptable to all.” Importantly, when addressing issues related to autonomy and decision making for children’s palliative care, the general principles of the Convention on the Rights of the Child (CRC) are extremely relevant, particularly those enshrined in Articles 3 and 12 of the CRC. Article 3 refers to the child’s best interest as the determining factor in all actions dealing with the child, taking precedence over the interests of the adults concerned (e.g. parents, teachers, or guardians). Article 12 refers to the child’s right to express an opinion and to have that opinion taken into account in any matter affecting him or her. In 2010, the Committee on the Elimination of Discrimination

<sup>13</sup> World Health Organization, “Constitution of the World Health Organization,” (1946), available at: <http://apps.who.int/gb/bd/PDF/bd47/EN/constitution-en.pdf?ua=1>.

<sup>14</sup> UN Committee on Economic, Social and Cultural Rights, General Comment Number 14, (2000), UN Doc. E/CC.12/2000/4, para. 34.

<sup>15</sup> Ibid, paras. 11 and 12.

<sup>16</sup> UN Committee on the Rights of the Child, General Comment Number 15, (2013), UN Doc. CRC/C/GC/15.

**THE UN COMMITTEE ON ECONOMIC, SOCIAL AND CULTURAL RIGHTS (CESCR)** is charged with monitoring the implementation of the International Covenant on Economic, Social and Cultural Rights (ICESCR). In its General Comment 14, the CESCR elaborated on the content of the right to health set forth in Article 12 of the ICESCR, finding that it includes “attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity.”<sup>17</sup>

The CESCR has further asserted that, “states Parties 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.”

The CESCR developed a typology of member states’ obligations based on four interrelated elements that are essential to the full enjoyment of the right to health: availability, accessibility, acceptability, and quality. Each of these has relevance to palliative care, as the table below illustrates.

ELEMENT	COMPONENTS	PALLIATIVE CARE OBLIGATIONS
AVAILABILITY	Functioning facilities	Operation of palliative care and hospice facilities.
	Sufficient goods, services, and programs	Adequate hospice services, pain management programs, and staff.
	Trained and appropriately compensated medical and care personnel	Specialists and general practitioners, e.g. physicians, nurses, support staff as well as carers trained in palliative care, counseling, and mobility support.
	Essential medicines	Adequate quantities of essential medicines used in pain management, including opioids such as morphine; refer to the WHO Essential Medicines List. <sup>18</sup>
ACCESSIBILITY	Non-discrimination	Palliative care products, medicines, and services must be accessible to all, especially the most vulnerable and marginalized. These groups include people living with HIV, older persons, children, people living in poverty, and those with developmental disabilities.

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<sup>17</sup> See UN CESCR, General Comment No. 14, id., note 4.

<sup>18</sup> WHO Model Lists of Essential Medicines (for adults and children) include a wide range of relevant essential medicines in section 2, “Medicines for Pain and Palliative Care.”

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ELEMENT	COMPONENTS	PALLIATIVE CARE OBLIGATIONS
ACCESSIBILITY	Non-discrimination	<p><b>Note:</b> The CESCR observes that the Covenant prohibits both direct and indirect discrimination. The prohibition of indirect discrimination would for example extend to situations where women are required to be accompanied by men in order to access care, or where patients are made subject to literacy requirements before receiving care.</p> <p><b>Note:</b> The ICESCR lists prohibited grounds, including “race, color, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.” The CESCR has clarified these grounds, including examples of “other status,” which it considers to include age, health status (including HIV or mental health status), disability, marital and family status, sexual orientation and gender identity, place of residence (whether rural or urban, formal or informal, displaced or nomadic), economic and social situation (including those living in poverty).<sup>19</sup></p>
	Physical access	Hospice care centers and palliative care services must be within safe physical reach. Facilities should be accessible to persons with disabilities.
	Economic access (affordability)	Health care need not be free, but must be affordable for all.
	Access to information	Persons in need of palliative care and their families should be able to access information about palliative care options in a form and a language they can understand. Examples of inappropriate barriers include fees associated with seeking information, or literacy requirements unlikely to be met in the affected community or that are simply inconsiderate of illiterate or low-literacy beneficiaries.
ACCEPTABILITY	Respect for medical ethics	Medical ethics are typically addressed in national codes of medical conduct. These standards must be respected in palliative care delivery. Core values underlying medical ethics include autonomy and informed consent on the part of patients, and beneficence and non-maleficence on the part of providers.

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<sup>19</sup> UN CESCR, General Comment number 20, (2009), UN Doc. E/C.12/GC/20.

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ELEMENT	COMPONENTS	PALLIATIVE CARE OBLIGATIONS
ACCEPTABILITY	Culturally appropriate	Palliative care and hospice services extending beyond the provision of medication should account for the social context in which they are delivered. They should seek to preserve the patient's dignity and connection to their community. Particular attention should be devoted to prevailing gender roles and traditions concerning family structures and the dying process, including the cultural rights and practices of minorities and indigenous peoples.
	Respect for patient confidentiality	While respecting cultural rights and practices, any interference with patients' privacy should be limited as much as possible.
	Skilled medical personnel	The requirement that personnel be suitably skilled is not limited to physicians. It extends also to nurses, counselors, and all other professionals implicated in palliative care or hospice services.
	Essential medicines	The palliative care system should include a mechanism for ensuring that appropriate medications are prescribed. The WHO Model List of Essential Medicines includes a chapter on Pain and Palliative Care. <sup>20</sup>
	Equipment	Much of the equipment required in palliative care is mobility-related, whether it is for personal use (e.g. canes) or institutional use (e.g. lifting hoists). The institution providing care should seek to ensure that this equipment is in keeping with modern standards, in good repair, and appropriate for patient needs.
	Sanitation	Sanitation is an essential component of quality medical service that assures patient dignity. Concerns about sanitation are particularly important for patients with restricted mobility or communicative capacity.

against Women (CEDAW) also addressed access to palliative care and pain relief in its General Recommendation No. 27. The committee recommended specifically that states parties adopt a comprehensive health care policy aimed at protecting the health needs of older women, "including care that allows for independent living and palliative care."<sup>21</sup>

Palliative care also engages a range of other human rights, not only the right to health. The UN special rapporteur on torture and other cruel, inhuman or degrading treatment or punishment considers that "the failure to ensure access to controlled medicines for the relief of pain and suffering threatens fundamental rights to health and to protection against cruel, inhuman or

<sup>20</sup> WHO Model Lists of Essential Medicines, available at: <http://www.who.int/medicines/publications/essentialmedicines/en/>.

<sup>21</sup> See CEDAW General Recommendation No. 27, on older women and the protection of their human rights, CEDAW/C/2010/47/GC.1, October 19, 2010, available at: <http://www2.ohchr.org/english/bodies/cedaw/docs/CEDAW-C-2010-47-GC1.pdf>.

degrading treatment.”<sup>22</sup> This engages the prohibition of torture and other cruel, inhuman or degrading treatment in Article 7 of the International Covenant on Civil and Political Rights as well as the UN Convention against Torture.

Other human rights, that are particularly engaged in relation to palliative care include rights to information, autonomy, independent living, the rights of the child, and the rights of persons with disabilities, among others.

The UN Committee on the Rights of Persons with Disabilities, in particular, has expressed that the individual autonomy and capacity of persons with disabilities to make decisions must be respected at all times.<sup>23</sup> It is critical to presume that all persons with disabilities have legal standing and legal agency simply by virtue of being human. Accordingly, states have a positive obligation to provide persons with disabilities access to support in the exercise of their legal capacity, replacing substitute decision-making regimes by supported decision-making.<sup>24</sup>

## EUROPEAN STANDARDS ON AUTONOMY AND DECISION-MAKING

The European Court of Human Rights has recognized that autonomy and decision making are an integral part of the right to respect for private and family life. The court has found that there is a positive obligation on the state to protect individuals from interference with their legal capacity from others and has affirmed that people have the right to make decisions concerning their own health even if such decisions may result in death: “The freedom to accept or refuse specific medical treatment, or to select an alternative form of treatment, is vital to the principles of self-determination and personal autonomy (...) for this freedom to be meaningful, patients must have the right to make choices that accord with their own views and values, regardless of how irrational, unwise or imprudent such choices may appear to others.”

European Court of Human Rights, *Case of Jehovah’s Witnesses of Moscow and Others v. Russia*, Application no. 302/02, August 2010.

<sup>22</sup> See United Nations Human Rights Council, “Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez,” A/HRC/22/53, (February 11, 2013), available at: [http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53\\_English.pdf](http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf).

<sup>23</sup> UN Committee on the Rights of Persons with Disabilities, General Comment Number 1 (2014), UN Doc. CRPD/C/GC/1.

<sup>24</sup> *Ibid.*

### 3. THE UNITED NATIONS HUMAN RIGHTS SYSTEM

The UN human rights system includes a range of mechanisms, some of which were created under particular international human rights conventions and others under the UN Charter itself. The first type of these mechanisms, known as “treaty bodies,” was established by specific international human rights treaties with a mandate to monitor compliance with that treaty. The latter, known as “charter-based” bodies, are not limited to considering compliance with a specific human rights treaty. This toolkit outlines how civil society can engage each of these human rights mechanisms to advance the right to palliative care and pain relief.

**Treaty bodies:** Created by specific human rights conventions, treaty bodies receive and review reports on a state’s progress in implementing the treaty, and issue authoritative interpretations of the nature of the obligations under the treaty (the general comments or general recommendations). Many also have powers to review individual complaints or to conduct inquiries into situations where grave abuses are suspected. They are composed of unpaid, independent experts nominated by states that are party to the treaty, to serve in an independent and impartial capacity.

**MORE INFO:** Watch this short video, “What is a human rights treaty body?”, by the [UN Office of the High Commissioner for Human Rights](#).

The primary way NGOs, and other parts of civil society, engage with treaty bodies is by submitting parallel reports (also known as “shadow reports”) to inform their consideration of states’ periodic reports under the treaty. A parallel report will present alternative information to that in the state report—to either challenge or contextualize how the state itself reports on progress. Parallel reports can suggest areas for the treaty body to focus the review, as well as questions and recommendations for the treaty body to consider during the review and when issuing its concluding observations (the recommendations it makes at the end of the review on steps the state should take). The process for drafting and submitting parallel reports is outlined in the body of the toolkit.

## A BRIEF LOOK INTO THE UNITED NATIONS

The United Nations is an intergovernmental organization created in 1945 to promote peace and security, economic and social development, and human rights. It has grown from 51 member states at its founding to 193 member states at present.

The United Nations is headquartered in New York City, with further main offices in Geneva, Nairobi, and Vienna. Its principal organs include:

- the General Assembly, which serves as its main deliberative assembly;
- the Security Council, which determines resolutions concerning international peace and security;
- the Economic and Social Council (“ECOSOC”), which promotes international economic and social cooperation and development;
- the Secretariat, which provides studies, information, and facilities needed by the United Nations; and
- the International Court of Justice, which serves as its primary judicial organ.

The United Nations system also comprises a number of “specialized agencies,” including the World Bank Group and the World Health Organization, as well as programs and funds such as the UN Children’s Fund (UNICEF) and the UN Office on Drugs and Crime (UNODC), and other “entities,” such as the Joint UN Program on HIV/AIDS (UNAIDS), and UN Women.

Civil society organizations may participate in UN activities related to human rights by applying for ECOSOC consultative status. Information on this process is available [here](#). Those organizations that do not have ECOSOC status can still submit information (including parallel reports) to the UN treaty bodies and special procedures, and may form alliances with organizations that do have ECOSOC status for the purposes of representation in meetings.

Among the UN treaty bodies that are most relevant to palliative care are:

- Committee on Economic, Social and Cultural Rights (which monitors the ICESCR)
- Human Rights Committee (which monitors the ICCPR)
- Committee on the Elimination of Discrimination against Women (which monitors CEDAW)
- Committee on the Rights of the Child (which monitors the CRC)
- Committee on the Rights of Persons with Disabilities (which monitors the CRPD)
- Committee Against Torture (CAT)

**Charter-based (Human Rights Council) mechanism:** these are established under the UN Charter and generally operate within the UN Human Rights Council, an intergovernmental body of 47 states responsible for the promotion and protection of human rights. The primary mechanisms through which civil society can engage with the Human Rights Council are:

- (1) **Universal Periodic Review**, under which the Human Rights Council comprehensively reviews the human rights record of all UN member states once every four years. Civil

society organizations can contribute written information for consideration during the UPR, and those recognized by the UN's Economic and Social Council to have particular status (known as "ECOSOC status") can attend the review sessions at the Human Rights Council;

(2) **Special Procedures**, including special rapporteurs, independent experts, and working groups, which are independent human rights experts who monitor, advise, and publicly report on human rights situations around the world either by country or by thematic issue. Among those most relevant to palliative care are the special rapporteurs on the right to health and on torture. Civil society organizations can engage with special procedures by submitting information on individual cases; submitting views or analysis on human rights concerns; supporting country missions; working to raise awareness and follow-up the work of special rapporteurs; and inviting special procedures to engage with their own work.

There are also a complaints mechanism and an advisory committee within the Human Rights Council that are considered briefly in the body of this toolkit.

The following chapters of this toolkit will outline the steps for effective advocacy using these United Nations human rights mechanisms.

**MORE INFO:** The UN Office of the High Commissioner for Human Rights acts as secretariat to the UN human rights system. Its [website](#) is an essential resource for those engaging with any part of that system.

## 4. WHY AND HOW TO ENGAGE WITH THE UN HUMAN RIGHTS SYSTEM

Engaging with the UN human rights system can serve as a useful tool for promoting palliative care and pain relief. It can provide an important complement to advocacy and engagement at the national level as a forum for accountability and an opportunity to demonstrate international attention to palliative care as an issue of universal human rights.

A UN body may find, for example, that a state has breached its human rights obligations by failing to remove regulatory obstacles that restrict availability to essential pain relief medicines such as morphine. The UN Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment has indicated that such failure may indeed constitute a human rights violation:

“Ensuring the availability and accessibility of medications included in the WHO Model List of Essential Medicines is not just a reasonable step but a legal obligation under the Single Convention on Narcotic Drugs, 1961. When the failure of states to take positive steps, or to refrain from interfering with health-care services, condemns patients to unnecessary suffering from pain, states not only fall foul of the right to health but may also violate an affirmative obligation under the prohibition of torture and ill-treatment. (...) Governments must guarantee essential medicines—which include, among others, opioid analgesics—as part of their minimum core obligations under the right to health, and take measures to protect people under their jurisdiction from inhuman and degrading treatment.”

—UN Special Rapporteur **Juan C. Méndez**

Report of the UN Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez, February 1, 2013, A/HRC/22/53, para. 55-56 and 86, available at: [http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53\\_English.pdf](http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf).

The mere act of considering failure to progressively achieve the full availability, accessibility, acceptability, and quality of palliative care as a human rights concern can have a significant mobilizing effect. It can also lend immense credibility to local activism and advocacy, and provide opportunities for NGOs to connect and forge alliances for a stronger international movement. To make the most of the opportunity, however, there are some important steps and strategic considerations. Among these considerations are:

- 1. Identify your state's obligations:** state obligations under the UN treaties depend on which treaties a state has freely accepted. National civil society organizations should therefore determine the treaties to which their state has voluntarily bound itself. A state accepts its obligations under a specific treaty in a multistep process. Typically, it will first “sign” a treaty, at which point it simply agrees to observe the “object and purpose” of the treaty. It does not assume the full obligations under the treaty until it decides to “ratify” the treaty. Sometimes, however, a state may both sign and ratify a treaty in a single step, known as “accession.” When determining which treaties impose obligations on your state, you should look for those treaties that your state has “ratified” or to which it has “acceded.” Note that some states may ratify a treaty but stipulate “reservations” to specific obligations under it. Upon finding that your state has ratified or acceded to a treaty, do not assume that all its obligations apply—you must check for reservations. Information on ratification and accession is [available here](#).
- 2. Work collaboratively:** A number of national and international health and human rights organizations may be preparing to engage with the international human rights reviews of the state. Working collaboratively can help planning, strategizing, advocating, and follow-up to the review. Treaty bodies and the UN High Commissioner for Human Rights have consistently called for civil society organizations to collaborate in joint submissions.<sup>25</sup> Raising the issue of palliative care within a broader coalition of organizations can also help ensure it is not lost among all the other issues that the human rights body will be considering.
- 3. Plan well:** Important elements of planning include developing a calendar to clarify when the state will be reviewed at different international human rights bodies, important deadlines for submission of reports, and opportunities to engage directly with the review process. Planning should include all stages—for preparation, advocacy, report writing, engagement in the review processes, and, crucially, the follow-up. Palliative care is relevant to rights guaranteed under a number of different treaties, each of which has its own reporting calendar. At any point in time any particular state will be at a different stage in the cycle of reporting under each treaty, and under the overall mechanisms of the UN Human Rights Council, such as the Universal Periodic Review (UPR, see below). Plotting out when the state is due to be reviewed under the various treaties and UPR will help advance planning. A calendar of country reviews by treaty body and under UPR is available on [the website](#) of the UN Office of the High Commissioner for Human Rights.

<sup>25</sup> See for example, United Nations Office of the High Commissioner for Human Rights, *Working with the United Nations Human Rights Programme: a handbook for civil society*, (New York and Geneva, 2008), p 49.

## ILLUSTRATIVE EXAMPLES

REFERENCES FROM THE INTERNATIONAL COVENANT ON ECONOMIC, SOCIAL AND CULTURAL RIGHTS (ICESCR), GENERAL COMMENT 14 FROM THE UN COMMITTEE ON ECONOMIC, SOCIAL AND CULTURAL RIGHTS (CESCR GC 14), THE UN CONVENTION ON THE RIGHTS OF THE CHILD (CRC), AND THE UN PRINCIPLES FOR OLDER PERSONS (UNPOP).

Allocation of resources	The maximum available resources are not allocated to ensuring, at the very least, minimum essential levels of palliative care such as access to essential pain relief medicines.	ICESCR Article 2; CESCR GC 14 para 12
National Health Plan	The state does not have a palliative care program and its National Health Plan does not include the provision of palliative health services.	ICESCR Art. 12; CESCR GC 14 para 12 and 34
Gaps in provision	Palliative care goods and services are only provided in a few selected hospitals or clinics, with no coverage in rural areas.	CESCR GC 14 para 12
Essential medicines	Essential palliative care medicines as defined by the WHO, such as oral morphine, are not available due to regulatory barriers or doctors, nurses or pharmacists being unwilling to prescribe them.	CESCR GC 14 para 12
Access to information	Persons in need of palliative care do not have access to information regarding their right to seek and receive such care, nor how or where they can get it.	CESCR GC 14 para 12
Non-discrimination	The state's health resource allocation is leading to discrimination because investments are disproportionately benefitting people in certain parts of the country or are favoring expensive curative health services that are accessible only to a small, privileged fraction of the population, rather than including palliative health care that would benefit a far larger part of the population.	ICESCR Arts. 2 and 12; CESCR GC 14 para 12, 19 and 30

CONTINUED FROM PREVIOUS PAGE

ILLUSTRATIVE EXAMPLES		REFERENCES FROM THE INTERNATIONAL COVENANT ON ECONOMIC, SOCIAL AND CULTURAL RIGHTS (ICESCR), GENERAL COMMENT 14 FROM THE UN COMMITTEE ON ECONOMIC, SOCIAL AND CULTURAL RIGHTS (CESCR GC 14), THE UN CONVENTION ON THE RIGHTS OF THE CHILD (CRC), AND THE UN PRINCIPLES FOR OLDER PERSONS (UNPOP)
Children	Palliative care goods and services are not adapted to the needs of children who require pain medicines that can be given in appropriate doses for their age and weight.	CESCR GC 14 para 12; CRC Article 24
Older persons	Palliative care is not provided in home-based settings and older persons are thus not able to stay in their own home, and maintain their independence and autonomy, should they require palliative care.	CESCR GC 14 para 12; UNPOP Article 6, 11 and 14
Trained health professionals	Healthcare professionals are not adequately trained to provide effective palliative care to different age groups with different needs.	CESCR GC 14 para 12
Pain treatment	The course of pain treatment does not respect the scientifically and medically appropriate standards, which, according to the “WHO pain ladder,” may require administration of mild opioids (codeine) and strong opioids (such as morphine), until the patient is free of pain.	CESCR GC 14 para 12

**4. Get in early:** The earlier palliative care issues are raised in the process, the more likely they are to feature in the recommendations and follow-up at the end. In each of the processes, opportunities to raise issues in advance of the actual review should be exploited, and the human rights bodies encourage early engagement.<sup>26</sup> The sections below spell out the opportunities under each of the treaty bodies, UPR and other mechanisms. For example, with the treaty bodies, the opportunities for engagement before the review generally include:

<sup>26</sup> See UN Human Rights Committee, “*The relationship of the Human Rights Committee with non-governmental organizations*”, June 4, 2012, UN Doc. CCPR/C/104/3, para 9: “the Committee emphasizes that it is highly desirable to receive input from NGOs at an early stage of the reporting process.”

- a. Engaging with the government when it is preparing the state report, to seek the inclusion of palliative care as an issue within the state report;
- b. Engaging with the treaty body before the review of the state report when it prepares the list of issues around which it will focus the review. This engagement should include the submission of a written report prior to the session where the treaty body will identify the issues on which it will focus the review of the state, and attending pre-sessions or engaging with committee members who are developing the “list of issues.”
- c. Engaging with the state as it develops a written response to the list of issues, at which point there may be a window of opportunity to call for additional steps to be taken in relation to palliative care so that the state can positively respond.

**MORE INFO:** Further information and advice is available in *Working with the United Nations Human Rights Programme: a Handbook for Civil Society, UN Office of the High Commissioner for Human Rights, 2008*

**5. Submit an effective parallel report:** Written reports are an important way for civil society to influence international human rights reviews. Given the volume of information that is submitted during the review by the treaty bodies or the UPR, they should be concise, well-structured, well-evidenced, up-to-date, follow relevant guidelines, be clearly based on the state’s obligations, and include potential questions and recommendations. The report should follow the structure set out in the reporting guidelines<sup>27</sup> that each of the treaty bodies has developed, which guide submissions to the UPR. The report should comment on the treatment of palliative care in the state report (whether the issue is included, whether the description is accurate) and include suggested questions and concluding observations that the committee may consider. Include relevant data, and, where possible, disaggregate this for different populations and different parts of the country. The report must make clear how the information relates to the country’s compliance with the obligations under the relevant treaty. It will be helpful to include the relevant interpretation given to the obligations by the treaty body in a general comment. Parallel reports can be submitted at each stage of the treaty body processes—

## WHAT HAPPENS IF A STATE PARTY DOES NOT PROVIDE A REPORT?

For most treaty bodies, if the state does not provide a report, the committees have had the practice of notifying the state of the date it will review the state’s implementation of the treaty, issuing a list of issues/questions, and proceeding with the review without the state’s presence if necessary. In this case, the committee may develop and transmit provisional concluding observations to the state, which can be made public or not, depending on the treaty body and the state concerned.

<sup>27</sup> These can be found on the web pages for each of the treaty bodies: <http://www.ohchr.org/EN/HRBodies/Pages/HumanRightsBodies.aspx>.

to shape the list of issues, to inform the full review, and in any follow-up procedure (see point 7 below). They can also be submitted at the start of the UPR. The UN secretariat does not translate parallel reports to treaty bodies, so these should be presented in one of the working languages of the committee—generally English, French, or Spanish. Organizations are encouraged to submit reports and summaries in English.



**TIP:** For detailed information on how to structure a parallel report, including templates of model reports, you may refer to the International Service for Human Rights’ [“Simple Guide to the UN Treaty Bodies.”](#) Consider presenting information in innovative ways, in addition to the formal parallel report. For example, in advance of the review of Egypt before the Committee on Economic, Social and Cultural Rights, the International Center for Economic and Social Rights and the Egyptian Center for Economic and Social Rights prepared a short **fact sheet** with a series of diagrams to bring the report to life. The diagrams showed inequities and inadequacies in revenue raising and resource allocation for social rights compared with other countries in the region. The diagrams also show disparities in service provision in different parts of the country.

**6. Engage in the review directly:** There are opportunities for direct engagement at different points in the various processes of the UN human rights system, and these can include briefing sessions as well as formal statements. Being able to present priority issues related to palliative care and engage in dialogue with the human rights body will help ensure the issues are raised in the review. The opportunities for direct engagement with the treaty body processes can be at both the pre-session and the review stages. With respect to UPR, the engagement should be with other states in advance of the review (for example the briefing sessions organized by the NGO UPR-Info) as opportunities to participate directly in the formal sessions are limited to the end. Treaty bodies generally hold, or are willing to accommodate, briefing sessions with civil society organizations in advance of the consideration of the list of issues and of the review of the state report. For these

## PARALLEL REPORTS SHOULD FOLLOW THE SAME STRUCTURE AS THE STATE-SUBMITTED REPORT AND HAVE INFORMATION ON:

1. Whether the state has adopted national frameworks, laws, policies, and strategies, and identified benchmarks.
2. Incorporation and direct applicability of each right of the relevant treaty and examples of implementation based on concrete and reliable information, such as legal cases, national laws and regulations, official statements, surveys and other reports from well-known CSOs, official statistics, newspaper articles, academic research, and testimony of individuals, among others.
3. Structural and other obstacles to realization of rights.
4. Statistical data disaggregated by gender, age, ethnicity, urban/rural areas, and any other relevant criteria, including annual comparative basis over periods of years.

sessions it is preferable to coordinate among civil society organizations, to agree on issues to be raised, and how to structure presentations and divide speaking time, while allowing sufficient space for questions and follow-up from the committee members. There is also opportunity for formal on-the-record statements with some treaty bodies, such as the CEDAW Committee. Additionally, several treaty bodies are eager for lunch briefings with civil society organizations prior to state review. During the review itself, there are unlikely to be opportunities for civil society organizations to speak in the formal “constructive dialogue” between the committee and the state. However, civil society organizations should consider informal follow-up with the country rapporteur during breaks, where that is appropriate.



**TIP:** If direct participation in the review is impossible due to the costs of travel and accommodation, organizations should watch the sessions of all the treaty bodies and the UPR via webcasting. Live and archived webcasts of the treaty body sessions [can be accessed here](#) and those of the Human Rights Council [here](#).

**7. Plan for follow-up and implementation:** Follow-up and implementation are both undoubtedly the most important and most often overlooked aspects of engagement with the UN human rights system. Without appropriate attention to follow-up and implementation from the earliest stage, engagement with the UN human rights system is unlikely to deliver its full potential in terms of improvements in the realization of human rights. Civil society organizations can significantly contribute to follow-up by publicizing the UN recommendations, engaging and influencing relevant state actors, monitoring and reporting on implementation, and building and maintaining coalitions with groups of advocates. Engaging the relevant government actors is key to the successful implementation of UN recommendations. During preparation and throughout the review, civil society organizations should negotiate a process that considers how recommendations from the UN human rights review are implemented at the national, regional, and local levels. They should also consider how implementation will be monitored. Civil society organizations should continue engaging members of the government’s executive, ministerial advisors, and departmental staff throughout the implementation period. This may be by securing state support for the development of a national action plan for the promotion and protection of human rights, or a mechanism whereby civil society and the national human rights institution meet periodically with the various relevant state departments after the review to consider the recommendations and appropriate steps that can be taken to implement them. Importantly, follow-up strategies must also be considered at the international level. Some treaty bodies, such as the Human Rights Committee and the Committee against Torture, also request that states report within a year on steps taken to address priority concerns, but not all concluding observations. The CEDAW Committee, for example, holds a midterm review of progress on priority issues. Within the UPR there is also an optional midterm reporting process. These too can be important opportunities to ensure momentum in implementation. Alternatively, the processes leading to the following state report, or to the Universal Periodic Review, are important opportunities to review progress in addressing recommendations. It is also important to keep in mind that states may be held accountable for the implementation of the same UN recommendation in different UN reviews. For example, if a state does not implement a recommendation made by the CEDAW Committee, the subject matter of that recommendation may be taken before the CESCR Committee, or to the UPR of the country.



**TIP:** In order to ensure that UN reviews lead to improved implementation of human rights in practice, commitments should be secured from the state as to how it will implement the recommendations. NGOs advocating for access to palliative care can bolster the implementation of UN treaty bodies and UPR recommendations in a number of ways. These include:

**Work specific to palliative care:**

- Raising awareness among other palliative care actors of the outcomes of the reviews to strengthen advocacy in the sector for the implementation of relevant recommendations.
- Using outcomes of reviews to trigger and promote national legislative reform and policy change in the field of palliative care, as well as to open dialogue with state bodies with a view to developing national palliative care programs.
- Monitoring the situation of palliative care in the country, including the steps taken locally to implement the review's outcomes.

**Continuing to work as part of a broader coalition of health and human rights organizations:**

- Raising awareness among the general public and civil society about the reviews, the outcomes that the government is required to implement, and how these outcomes can be used to improve the fulfillment of human rights in the country (e.g. organizing thematic discussions, roundtables, seminars, and workshops; translating and publishing outcomes; working with national NGOs and media).
- Engaging with government, health sector bodies, and others to promote a good practice process of implementation of human rights recommendations, potentially including the development of a national action plan for human rights.
- Developing a civil society coalition to monitor implementation of the recommendations, developing indicators and benchmarks, and identifying or developing qualitative or quantitative data sources.
- Preparing parallel reports on progress for the next review.

## ACCOUNTABILITY AND MONITORING APPROACHES

### APPLYING HUMAN RIGHTS INDICATORS TO TRACK PROGRESS

See: *Human Rights Indicators: A Guide to Measurement and Implementation, 2012*

### BUDGET ANALYSIS OF OBLIGATIONS UNDER THE RIGHT TO HEALTH

See: *Dignity Counts: A Guide to Using Budget Analysis to Advance Human Rights, Fundar, the IBP, and IHRIP, 2004*

See: *Democratizing the Budget: FUNDAR's Budget Analysis and Advocacy Initiatives in Mexico, 2006*

See: *International Budget Partnership (IBP) Resources on ESCR Budget Analysis*

### UNDERSTANDING THE NATURE OF OBLIGATIONS OF PROGRESSIVE REALIZATION

See: *The Opera Framework* for monitoring methodology developed by the Center for Economic and Social Rights

### ADDITIONAL APPROACHES

See: *ESCR-Net Monitoring Group Resource Library*

See: *Manual on Human Rights Monitoring, 2011, Chapter 20*

**MORE INFO:** The Human Rights Law Centre and International Service for Human Rights published an extremely helpful guide to implementation of UN human rights recommendations in 2013. It is [available here](#). It recommends considering follow-up from the earliest stages of engagement, including when selecting mechanisms to engage with, drafting complaints, reports, and recommendations, building coalitions, and engaging with all levels and branches of government. Among the follow-up strategies it considers are: publicizing and disseminating UN recommendations; engaging and influencing relevant actors (including government, parliament, the judiciary, and national human rights institutions); monitoring and reporting on implementation; formal UN follow-up procedures; working with international actors; and applying pressure through the UN human rights system.

## 5. PROMOTING PALLIATIVE CARE AT THE UN HUMAN RIGHTS TREATY BODIES

Each state has ratified (agreed to be legally bound by) a range of international human rights conventions, the majority of which have relevance to palliative care. For each of these treaties, states' parties must submit reports every four to five years on their compliance. These reports are considered by the treaty bodies alongside information from a range of other sources, including civil society organizations and national human rights institutions.

Civil society organizations can make important contributions before, during, and after the review. In order to ensure successful engagement with the process it is important to consider each of these three stages. Before the review, there are opportunities to influence the list of issues that the treaty body will examine in more depth, and during the review there are opportunities to brief the treaty bodies and influence the concluding observations or the recommendations that emerge. After the review, national civil society organizations can play a crucial role in ensuring that recommendations are implemented in practice.

Civil society organizations can influence these processes by submitting parallel reports to inform their consideration of states' periodic reports under the treaty, by attending the reviews, and by convening or engaging with national processes. Parallel reports are a crucial component of any civil society engagement. They present alternative information to that in the state report—to either challenge or contextualize how the state itself reports on progress. Parallel reports can suggest areas for the treaty body to focus the review, suggest questions, and offer recommendations for the treaty body to consider during the review and when issuing its concluding observations (the recommendations it makes to the state at the end of the review).

In April 2014, member states of the UN concluded a two-year process to reform the UN treaty bodies' system with the purpose of increasing its visibility to a wider public, improving the quality and regular submission of state reports, advancing states' implementation of treaty body recommendations, and expanding treaty body membership. As a result of this process, The General Assembly adopted resolution A/RES/68/268, which prescribes measures to

modernize the system, reduce its backlog, and make it more accessible, particularly through harmonizing the ten treaty bodies' working methods. One such measure was to allow for treaty body sessions to be transmitted live via webcast. This ensures that civil society organizations that are not able to send representatives to attend the sessions in person are at least able to observe the proceedings.

**MORE INFO:** Further information and advice is available on [the website](#) of the UN Office of the High Commissioner for Human Rights, particularly under the heading “Treaty Body Strengthening” (see the [Leaflet on Treaty Body Strengthening](#)), and in the 2010 publication by the international non-governmental organization International Service for *Human Rights, Simple Guide to the UN Treaty Bodies*.

## PRIMARY WAYS TO INTERACT WITH UN TREATY BODIES

Civil society organizations can provide input at almost all stages of the work of treaty bodies through:

### WRITTEN SUBMISSIONS FROM CIVIL SOCIETY

Civil society organizations can submit a report to the treaty bodies, usually called a parallel report or shadow report, based on their research and perspective on the national implementation of the relevant treaty. These reports may also contain suggested questions and recommendations that the treaty body members can use in their examination of the state report. For some treaty bodies, civil society organizations may also submit written information to assist the committee in drawing up the list of issues for each state, which can significantly influence the focus of the review.

### ATTENDING THE TREATY BODY SESSIONS AND BRIEFINGS

Generally, representatives of civil society organizations who have previously obtained accreditation from the secretariat of the relevant committee may attend the plenary sessions of the treaty bodies as observers. Despite not being able to formally participate in the dialogue between the treaty body and the concerned state, these representatives may brief committee members, during either formal or informal meetings. Outside of the plenary sessions, civil society organizations may hold meetings with committee members during or prior to the main sessions and interact in the corridors near which the treaty body sessions are held. In some cases, civil society organizations may be able to participate in formal briefings that take place before or during the treaty body sessions. For example, CESCR holds a pre-session briefing that is open to civil society organizations, which can present oral or written submissions. Other treaty bodies allow for civil society representatives to brief committee members orally during their formal sessions or in private sessions with interpretation. Civil society organizations can also request the Office of the High Commissioner for Human Rights to hold “lunchtime” briefings, which committee members are then invited to attend.

## INDIVIDUAL COMMUNICATIONS

In most cases, civil society organizations can submit a complaint on behalf of individual victims or provide assistance to individual victims who wish to submit a complaint against the state to the treaty bodies. In such cases, it is advisable to seek the support of an organization with legal expertise in the international human rights system. The civil society organization may additionally follow-up on the implementation of the committee's decision on the complaint, and in disseminating its content.

**MORE INFO:** Further information and advice is available in the *International Service for Human Rights' Simple Guide to the UN Treaty Bodies*.

## TREATY BY TREATY OVERVIEW

The following pages provide an overview of each of the treaties and treaty bodies, including key provisions of the treaty related to palliative care, opportunities for engagement by civil society, individual complaints procedures, and sources of further information.

### INTERNATIONAL COVENANT ON ECONOMIC, SOCIAL AND CULTURAL RIGHTS (ADOPTED IN 1966 AND HAS 162 STATES PARTIES AT THE TIME OF WRITING)

TREATY BODY	Committee on Economic, Social and Cultural Rights
STATE REPORTING	States parties must report initially within two years of ratification or accession to the covenant and every five years thereafter. A schedule of completed and upcoming sessions is <a href="#">available here</a> .
KEY PROVISIONS RELATED TO PALLIATIVE CARE	<p><b>Key Provisions</b></p> <p><b>Article 2</b> (provision related to general obligations):</p> <ol style="list-style-type: none"> <li>1. Each state Party to the present Covenant undertakes to take steps, individually and through international assistance and co-operation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realization of the rights recognized in the present Covenant by all appropriate means, including particularly the adoption of legislative measures.</li> <li>2. The states Parties to the present Covenant undertake to guarantee that the rights enunciated in the present Covenant will be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.</li> <li>3. Developing countries, with due regard to human rights and their national economy, may determine to what extent they would guarantee the economic rights recognized in the present Covenant to non-nationals.</li> </ol>

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## INTERNATIONAL COVENANT ON ECONOMIC, SOCIAL AND CULTURAL RIGHTS (ADOPTED IN 1966 AND HAS 162 STATES PARTIES AT THE TIME OF WRITING)

### KEY PROVISIONS RELATED TO PALLIATIVE CARE (Continued)

#### Article 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.

See also the Committee on Economic, Social and Cultural Rights' General Comment No. 14 for an authoritative interpretation of this article and an outline of states' obligations.

### HOW CAN CIVIL SOCIETY ORGANIZATIONS ENGAGE IN THE PERIODIC REPORTING PROCESS?

Civil society organizations can engage with the CESCR during the state reporting process in the following ways:

1. Engage in consultation during the development of the state report
2. Submit a parallel report in advance of the preessional meeting on the state under review.
3. Attend the preessional working group and request to host or join a lunchtime briefing with the committee that is likely to take place the day before the preessional consideration of the state.
4. Submit additional written parallel information in response to the list of issues or submit a full parallel report in advance of the review of the state.
5. Attend the review of the state or view the session over webcasting. Request to host or join a lunchtime briefing with the committee that is likely to take place the day before the review of the state.
6. The committee does not have a formal follow-up procedure aside from the following periodic report.

**Deadlines:** For country reviews, one-and-a-half months before the Committee's session. For the list of issues, two months before the preessional working group.

Note: All written information should be submitted in English, French, or Spanish. The UN will not translate parallel reports.

### CAN INDIVIDUAL COMPLAINTS BE BROUGHT?

Yes, complaints can be submitted by individuals whose rights under the ICESCR have been violated, or by civil society organizations, where the state has also ratified an additional international treaty called the Optional Protocol to the ICESCR, and where domestic remedies have been exhausted. The Optional Protocol to the ICESCR was adopted in 2008 (over forty years after the adoption of the ICCPR). At the time of writing, it has 17 states parties.

Ratification information for the ICESCR and the Optional Protocol to the ICESCR is [available here](#).

### FURTHER INFORMATION ON HOW TO ENGAGE

Information for civil society organizations is available on the [CESCR's website](#). Additionally, you may find helpful advice in Amnesty International's 2014 "[Guide to Shadow Reporting on Economic, Social and Cultural Rights](#)."

Information on the Optional Protocol to the ICESCR, and how civil society organizations can use it, has been prepared by leading international NGOs on economic, social, and cultural rights. It is [available here](#).

## INTERNATIONAL COVENANT ON CIVIL AND POLITICAL RIGHTS (ADOPTED IN 1966 AND HAS 168 STATES PARTIES AT THE TIME OF WRITING)

<b>TREATY BODY</b>	<b>Human Rights Committee</b>
<b>STATE REPORTING</b>	States must report initially one year after acceding to the covenant and subsequently upon the committee's request (typically every four years). A schedule of sessions is available at the committee's <a href="#">homepage</a> .
<b>KEY PROVISIONS RELATED TO PALLIATIVE CARE</b>	<p><b>Article 2</b> (provision related to general obligations)</p> <ol style="list-style-type: none"> <li>1. Each state Party to the present Covenant undertakes to respect and to ensure to all individuals within its territory and subject to its jurisdiction the rights recognized in the present Covenant, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.</li> <li>2. Where not already provided for by existing legislative or other measures, each state Party to the present Covenant undertakes to take the necessary steps, in accordance with its constitutional processes and with the provisions of the present Covenant, to adopt such laws or other measures as may be necessary to give effect to the rights recognized in the present Covenant.</li> <li>3. Each state Party to the present Covenant undertakes:             <ol style="list-style-type: none"> <li>(a) To ensure that any person whose rights or freedoms as herein recognized are violated shall have an effective remedy, notwithstanding that the violation has been committed by persons acting in an official capacity;</li> <li>(b) To ensure that any person claiming such a remedy shall have his right thereto determined by competent judicial, administrative or legislative authorities, or by any other competent authority provided for by the legal system of the state, and to develop the possibilities of judicial remedy;</li> <li>(c) To ensure that the competent authorities shall enforce such remedies when granted.</li> </ol> </li> </ol> <p><b>Article 7</b> No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.</p> <p><b>Article 17</b> 1. No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence...</p> <p><b>Article 18</b> 1. Everyone shall have the right to freedom of thought, conscience, and religion...</p> <p><b>Article 23</b> 1. The family is the natural and fundamental group unit of society and is entitled to protection by society and the state...</p>

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## INTERNATIONAL COVENANT ON CIVIL AND POLITICAL RIGHTS (ADOPTED IN 1966 AND HAS 168 STATES PARTIES AT THE TIME OF WRITING)

### KEY PROVISIONS RELATED TO PALLIATIVE CARE (Continued)

#### Article 24

1. Every child shall have, without any discrimination as to race, color, sex, language, religion, national or social origin, property or birth, the right to such measures of protection as are required by his status as a minor, on the part of his family, society and the state...

#### Article 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.

#### Article 27

In those states in which ethnic, religious, or linguistic minorities exist, persons belonging to such minorities shall not be denied the right, in community with the other members of their group, to enjoy their own culture, to profess and practice their own religion, or to use their own language.

### HOW CAN CIVIL SOCIETY ORGANIZATIONS ENGAGE IN THE PERIODIC REPORTING PROCESS?

Civil society organizations can engage with the Human Rights Committee during the state reporting process in the following ways:

1. Engage in consultation during the development of the state report.
2. Submit a parallel report in advance of the preessional meeting on the state under review.
3. Attend the preessional working group and request to host or join a lunchtime briefing with the committee which is likely to take place the day before the preessional consideration of the state.
4. Submit additional written parallel information in response to the list of issues or submit a full parallel report in advance of the review of the state.
5. Attend a formal closed meeting for civil society with the committee in advance of the review.
6. Attend the review of the state as an observer or view the session over webcasting.
7. Where the committee makes recommendations that require states to follow-up within one year, civil society organizations can provide information prior to the one-year follow-up and can attend that session as observers.

**Deadlines:** For country reviews, three weeks before the committee's session. For the lists of issues prior to reporting (LOIPR), ten weeks before the session. For the list of issues, ten weeks before the session.

**Note:** All written information should be submitted in English, French, or Spanish. The UN will not translate parallel reports.

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## INTERNATIONAL COVENANT ON CIVIL AND POLITICAL RIGHTS (ADOPTED IN 1966 AND HAS 168 STATES PARTIES AT THE TIME OF WRITING)

### CAN INDIVIDUAL COMPLAINTS BE BROUGHT?

Yes, complaints can be submitted by individuals whose rights under the ICCPR have been violated where the state has also ratified an additional international treaty called the Optional Protocol to the ICCPR, and where domestic remedies have been exhausted. Civil society organizations can support individuals to make complaints and can submit follow-up information on the implementation of the committee's "views" on the complaint. The Optional Protocol to the ICCPR was adopted at the same time as the ICCPR (in 1966) and at the time of writing has 115 states parties.

Ratification information for the ICCPR and the Optional Protocol to the ICCPR is [available here](#).

### FURTHER INFORMATION ON HOW TO ENGAGE

The Human Rights Committee published an information note in 2012 on "The relationship of the Human Rights Committee with non-governmental organizations" (UN Doc. CCPR/C/104/3). It is available here.

[The Centre for Civil and Political Rights](#) has a range of resources and training on engaging with the Human Rights Committee.

## INTERNATIONAL CONVENTION ON THE ELIMINATION OF ALL FORMS OF DISCRIMINATION AGAINST WOMEN (ADOPTED IN 1979 AND HAS 188 STATES PARTIES AT THE TIME OF WRITING)

TREATY BODY	<b>Committee on Elimination of Discrimination Against Women (CEDAW)</b>
STATE REPORTING	States Parties must report initially within one year of ratification and every four years thereafter. <sup>28</sup>
KEY PROVISIONS RELATED TO PALLIATIVE CARE	<p><b>Articles 2 and 3</b> (provisions related to general obligations)</p> <p><b>Article 2</b> States Parties condemn discrimination against women in all its forms, agree to pursue by all appropriate means and without delay a policy of eliminating discrimination against women and, to this end, undertake:</p> <ul style="list-style-type: none"> <li>(a) To embody the principle of the equality of men and women in their national constitutions or other appropriate legislation if not yet incorporated therein and to ensure, through law and other appropriate means, the practical realization of this principle;</li> <li>(b) To adopt appropriate legislative and other measures, including sanctions where appropriate, prohibiting all discrimination against women;</li> <li>(c) To establish legal protection of the rights of women on an equal basis with men and to ensure through competent national tribunals and other public institutions the effective protection of women against any act of discrimination;</li> <li>(d) To refrain from engaging in any act or practice of discrimination against women and to ensure that public authorities and institutions shall act in conformity with this obligation;</li> <li>(e) To take all appropriate measures to eliminate discrimination against women by any person, organization or enterprise;</li> <li>(f) To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices which constitute discrimination against women;</li> <li>(g) To repeal all national penal provisions which constitute discrimination against women.</li> </ul> <p><b>Article 3</b> states Parties shall take in all fields, in particular in the political, social, economic and cultural fields, all appropriate measures, including legislation, to ensure the full development and advancement of women, for the purpose of guaranteeing them the exercise and enjoyment of human rights and fundamental freedoms on a basis of equality with men.</p>

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<sup>28</sup> See United Nations, Convention on the Elimination of All Forms of Discrimination Against Women. Initial and periodic reporting guidelines are available at: [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=HRI%20GEN%202%20Rev.6&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=HRI%20GEN%202%20Rev.6&Lang=en).

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## INTERNATIONAL CONVENTION ON THE ELIMINATION OF ALL FORMS OF DISCRIMINATION AGAINST WOMEN

(ADOPTED IN 1979 AND HAS 188 STATES PARTIES AT THE TIME OF WRITING)

### KEY PROVISIONS RELATED TO PALLIATIVE CARE (Continued)

#### Article 5

States Parties shall take all appropriate measures:

- (a) To modify the social and cultural patterns of conduct of men and women, with a view to achieving the elimination of prejudices and customary and all other practices which are based on the idea of the inferiority or the superiority of either of the sexes or on stereotyped roles for men and women;

#### Article 12

1. States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning.

#### Article 14

2. States Parties shall take all appropriate measures to eliminate discrimination against women in rural areas in order to ensure, on a basis of equality of men and women, that they participate in and benefit from rural development and, in particular, shall ensure to such women the right:

- (b) To have access to adequate health care facilities, including information, counseling and services in family planning;

#### Article 15

1. States Parties shall accord to women, in civil matters, a legal capacity identical to that of men and the same opportunities to exercise that capacity. In particular, they shall give women equal rights to conclude contracts and to administer property and shall treat them equally in all stages of procedure in courts and tribunals.

#### Article 16

1. States Parties shall take all appropriate measures to eliminate discrimination against women in all matters relating to marriage and family relations and in particular shall ensure, on a basis of equality of men and women:

- (h) The same rights for both spouses in respect of the ownership, acquisition, management, administration, enjoyment and disposition of property, whether free of charge or for a valuable consideration.

### HOW CAN CIVIL SOCIETY ORGANIZATIONS ENGAGE IN THE PERIODIC REPORTING PROCESS?

Civil society organizations can engage with CEDAW during the state reporting process in the following ways:

1. Engage in consultation during the development of the state report.
2. Submit a parallel report in advance of the preessional working group on the state under review.
3. Attend the preessional working group and make oral presentations and answer questions on the information it has provided to help the committee define the list of issues and questions, composed of approximately 30 questions for the state to respond to ahead of the review.

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## INTERNATIONAL CONVENTION ON THE ELIMINATION OF ALL FORMS OF DISCRIMINATION AGAINST WOMEN

(ADOPTED IN 1979 AND HAS 188 STATES PARTIES AT THE TIME OF WRITING)

### HOW CAN CIVIL SOCIETY ORGANIZATIONS ENGAGE IN THE PERIODIC REPORTING PROCESS?

(Continued)

4. Submit additional written parallel information in response to the list of issues or submit a full parallel report in advance of the review of the state.
5. Attend an informal meeting for civil society with the committee in advance of the review.
6. Consider making use of informal opportunities for lunchtime briefings with committee members or side events on palliative care during the review. Organizations may find it helpful to contact International Women's Rights Action Watch Asia Pacific (IWRAP-AP) [to advise on this](#). They have extensive experience of coordinating civil society engagement with CEDAW.
7. Attend the review of the state as an observer or view the session over webcasting. There is also the opportunity for a formal on the record civil society statement.
8. Where the committee makes recommendations that require states to follow-up within one or two years, civil society organizations can provide information prior to the one-year follow-up and can attend that session as observers.

**Deadlines:** For country reviews, two weeks before the committee's session. For the list of issues, five weeks prior to the pre-session working group.

**Note:** All written information should be submitted in English, French, or Spanish. The UN will not translate parallel reports.

### CAN INDIVIDUAL COMPLAINTS BE BROUGHT?

Yes, complaints can be submitted by individuals whose rights under CEDAW have been violated where the state has also ratified an additional international treaty called the Optional Protocol to CEDAW, and where domestic remedies have been exhausted. Civil society organizations can support individuals to make complaints and can submit follow-up information on the implementation of the Committee's "views" on the complaint. The Optional Protocol to CEDAW was adopted in 1999 (some twenty years after the adoption of CEDAW) and at the time of writing has 105 states parties.

Ratification information for CEDAW and the Optional Protocol to CEDAW is [available here](#).

### FURTHER INFORMATION ON HOW TO ENGAGE

CEDAW published an information note in 2010 on its relationship with non-governmental organizations. It is [available here](#).

The NGO International Women's Rights Action Watch-Asia Pacific has produced a series of guides for civil society organizations on engagement with CEDAW. These can be [accessed here](#).

**CONVENTION ON THE RIGHTS OF THE CHILD**

(ADOPTED IN 1989 AND HAS 193 STATES PARTIES AT THE TIME OF WRITING)

**TREATY BODY****Committee on the Rights of the Child****STATE REPORTING**

States Parties must report initially within two years of ratification and submit progress reports every five years thereafter.

**KEY PROVISIONS RELATED TO PALLIATIVE CARE****Articles 2 and 4** (provisions related to general obligations)**Article 2**

1. States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.
2. States Parties shall take all appropriate measures to ensure that the child is protected against all forms of discrimination or punishment on the basis of the status, activities, expressed opinions, or beliefs of the child's parents, legal guardians, or family members.

**Article 3**

1. In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.
2. States Parties undertake to ensure the child such protection and care as is necessary for his or her well-being, taking into account the rights and duties of his or her parents, legal guardians, or other individuals legally responsible for him or her, and, to this end, shall take all appropriate legislative and administrative measures.
3. States Parties shall ensure that the institutions, services and facilities responsible for the care or protection of children shall conform with the standards established by competent authorities, particularly in the areas of safety, health, in the number and suitability of their staff, as well as competent supervision.

**Article 4**

States Parties shall undertake all appropriate legislative, administrative, and other measures for the implementation of the rights recognized in the present Convention. With regard to economic, social and cultural rights, states Parties shall undertake such measures to the maximum extent of their available resources and, where needed, within the framework of international co-operation.

[The CRC also contains a series of general principles which are of overarching importance and are relevant to all other rights]

**Article 5**

States Parties shall respect the responsibilities, rights and duties of parents or, where applicable, the members of the extended family or community as provided for by local custom, legal guardians or other persons legally responsible for the child, to provide, in a manner consistent with the evolving capacities of the child, appropriate direction and guidance in the exercise by the child of the rights recognized in the present Convention.

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## CONVENTION ON THE RIGHTS OF THE CHILD (ADOPTED IN 1989 AND HAS 193 STATES PARTIES AT THE TIME OF WRITING)

### KEY PROVISIONS RELATED TO PALLIATIVE CARE (Continued)

#### Article 6

1. States Parties recognize that every child has the inherent right to life.
2. States Parties shall ensure to the maximum extent possible the survival and development of the child.

[in addition, the following provisions are of particular relevance to palliative care]

#### Article 23

1. States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions that ensure dignity, promote self-reliance and facilitate the child's active participation in the community.

#### Article 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. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.
2. States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures:
  - (a) To diminish infant and child mortality;
  - (b) To ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care;
3. States Parties undertake to promote and encourage international co-operation with a view to achieving progressively the full realization of the right recognized in the present article. In this regard, particular account shall be taken of the needs of developing countries.

Note: See also the Committee on the Rights of the Child, [General Comment No. 15](#) on the right of the child to the enjoyment of the highest attainable standard of health, for an authoritative interpretation of this article and an outline of states' obligations.

#### Article 30

In those states in which ethnic, religious, or linguistic minorities or persons of indigenous origin exist, a child belonging to such a minority or who is indigenous shall not be denied the right, in community with other members of his or her group, to enjoy his or her own culture, to profess and practice his or her own religion, or to use his or her own language.

#### Article 31

1. States Parties recognize the right of the child to rest and leisure, to engage in play and recreational activities appropriate to the age of the child and to participate freely in cultural life and the arts.
2. States Parties shall respect and promote the right of the child to participate fully in cultural and artistic life and shall encourage the provision of appropriate and equal opportunities for cultural, artistic, recreational and leisure activity.

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## CONVENTION ON THE RIGHTS OF THE CHILD (ADOPTED IN 1989 AND HAS 193 STATES PARTIES AT THE TIME OF WRITING)

### KEY PROVISIONS RELATED TO PALLIATIVE CARE

#### Article 37

States Parties shall ensure that:

- (a) No child shall be subjected to torture or other cruel, inhuman or degrading treatment or punishment...

### HOW CAN CIVIL SOCIETY ORGANIZATIONS ENGAGE IN THE PERIODIC REPORTING PROCESS?

Civil society organizations can engage with the CRC during the state reporting process in the following ways:

1. Engage in consultation during the development of the state report.
2. Submit a parallel report in advance of the preessional working group on the state under review.
3. Issue a request to attend the preessional working group (in the cover letter that accompanies the parallel report) to make oral presentations and answer questions on the information provided to help the committee define the list of issues for the state to respond to ahead of the review.
4. Submit additional written parallel information in response to the list of issues in advance of the review of the state.
5. Attend the review of the state as an observer or view the session over webcasting. Consider making use of informal opportunities to update committee members on any relevant developments following the preession during the review. The committee does not meet formally with NGOs during the review of the state report.
6. The committee does not have a formal follow-up procedure, however, national civil society organizations can follow-up on the concluding observations of the committee by, for example, promoting participatory processes of follow-up by government, data collection, and considering informal visits of committee members.

**Deadlines:** For country reviews, three months before the relevant preessional working group. For the list of issues: three months before the relevant preessional working group.

**Note:** All written information should be submitted in English, French, or Spanish. The UN will not translate parallel reports.

### CAN INDIVIDUAL COMPLAINTS BE BROUGHT?

Yes, individual complaints can be submitted by and on behalf of children whose rights under CRC have been violated where the state has also ratified an additional international treaty called the Third Optional Protocol to the CRC, and where domestic remedies have been exhausted. Civil society organizations can support children to make complaints and can submit follow-up information on the implementation of the committee's "views" on the complaint. The Third Optional Protocol to the CRC was adopted in 2011 (some twenty two years after the adoption of the CRC) and at the time of writing has 14 states parties.

Ratification information for the CRC and the Third Optional Protocol to the CRC is [available here](#).

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## CONVENTION ON THE RIGHTS OF THE CHILD (ADOPTED IN 1989 AND HAS 193 STATES PARTIES AT THE TIME OF WRITING)

### FURTHER INFORMATION ON HOW TO ENGAGE

The CRC has issued an information note on the involvement of partners (including non-governmental organizations) in the presessional working group. This document is [available here](#).

[Child Rights Connect](#) (formerly the NGO Group for the Convention on the Rights of the Child) supports civil society organization engagement with the CRC and has a range of useful information on its website including a guide to engaging with the state reporting process. Child Rights Connect produces a guide for civil society on how to develop, submit and follow-up on a parallel report to the CRC—[The Reporting Cycle of the Committee on the Rights of the Child: A Guide for NGOs and NHRIs](#). It is now in its fourth edition and is recommended by the OHCHR and the CRC itself. Additionally, Child Rights International Network (CRIN) has a resource page on engaging with UN treaty bodies with [helpful information and links](#).

## CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (ADOPTED IN 2006 AND HAS 151 STATES PARTIES AT THE TIME OF WRITING)

TREATY BODY	<b>Committee on the Rights of Persons with Disabilities</b>
STATE REPORTING	States Parties must report initially within two years of ratification and submit progress reports every four years thereafter.
KEY PROVISIONS RELATED TO PALLIATIVE CARE	<p><b>Article 3 - General Principles</b></p> <p>(a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons.</p> <p><b>Article 4 - General Obligations</b></p> <ol style="list-style-type: none"> <li>1. States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. To this end, States Parties undertake: <ul style="list-style-type: none"> <li>(a) To adopt all appropriate legislative, administrative, and other measures for the implementation of the rights recognized in the present Convention;</li> <li>(i) To promote the training of professionals and staff working with persons with disabilities in the rights recognized in this Convention so as to better provide the assistance and services guaranteed by those rights.</li> </ul> </li> <li>2. With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law.</li> <li>3. In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, states Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.</li> </ol> <p><b>Article 9 - Accessibility</b></p> <ol style="list-style-type: none"> <li>1. To enable persons with disabilities to live independently and participate fully in all aspects of life, states Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas...</li> </ol> <p><b>Article 10 - Right to life</b></p> <p>States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.</p>

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## CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (ADOPTED IN 2006 AND HAS 151 STATES PARTIES AT THE TIME OF WRITING)

### KEY PROVISIONS RELATED TO PALLIATIVE CARE (Continued)

#### **Article 19** - Living independently and being included in the community

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- (b) Persons with disabilities have access to a range of in-home, residential, and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

#### **Article 25** - Right to health

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender sensitive, including health-related rehabilitation. In particular, states Parties shall:

- (a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programs as provided to other persons, including in the area of sexual and reproductive health and population-based public health programs;
- (b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
- (c) Provide these health services as close as possible to people's own communities, including in rural areas;
- (d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy, and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;
- (e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
- (f) Prevent discriminatory denial of health care, health services, or food and fluids on the basis of disability.

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## CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (ADOPTED IN 2006 AND HAS 151 STATES PARTIES AT THE TIME OF WRITING)

### KEY PROVISIONS RELATED TO PALLIATIVE CARE (Continued)

#### Article 25 - Right to health

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender sensitive, including health-related rehabilitation. In particular, states Parties shall:

- (a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programs as provided to other persons, including in the area of sexual and reproductive health and population-based public health programs;
- (b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
- (c) Provide these health services as close as possible to people's own communities, including in rural areas;
- (d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy, and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;
- (e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
- (f) Prevent discriminatory denial of health care, health services, or food and fluids on the basis of disability.

#### Article 31 - Statistics and data collection

1. States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention. The process of collecting and maintaining this information shall:
  - (a) Comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities;
  - (b) Comply with internationally accepted norms to protect human rights, fundamental freedoms, and ethical principles in the collection and use of statistics.
2. The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of states Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.

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## CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (ADOPTED IN 2006 AND HAS 151 STATES PARTIES AT THE TIME OF WRITING)

### KEY PROVISIONS RELATED TO PALLIATIVE CARE (Continued)

3. States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.

#### Article 32 - International cooperation

1. States Parties recognize the importance of international cooperation and its promotion, in support of national efforts for the realization of the purpose and objectives of the present Convention, and will undertake appropriate and effective measures in this regard, between and among states and, as appropriate, in partnership with relevant international and regional organizations and civil society, in particular organizations of persons with disabilities. Such measures could include, inter alia:
  - (a) Ensuring that international cooperation, including international development programmes, is inclusive of and accessible to persons with disabilities;
  - (b) Facilitating and supporting capacity-building, including through the exchange and sharing of information, experiences, training programmes and best practices;
  - (c) Facilitating cooperation in research and access to scientific and technical knowledge;
  - (d) Providing, as appropriate, technical and economic assistance, including by facilitating access to and sharing of accessible and assistive technologies, and through the transfer of technologies.
2. The provisions of this article are without prejudice to the obligations of each state Party to fulfill its obligations under the present Convention.

#### Article 33 - National implementation and monitoring

1. States Parties, in accordance with their system of organization, shall designate one or more focal points within government for matters relating to the implementation of the present Convention, and shall give due consideration to the establishment or designation of a coordination mechanism within government to facilitate related action in different sectors and at different levels.
2. States Parties shall, in accordance with their legal and administrative systems, maintain, strengthen, designate, or establish within the state Party, a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the present Convention. When designating or establishing such a mechanism, states Parties shall take into account the principles relating to the status and functioning of national institutions for protection and promotion of human rights.
3. Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.

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## CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (ADOPTED IN 2006 AND HAS 151 STATES PARTIES AT THE TIME OF WRITING)

### HOW CAN CIVIL SOCIETY ORGANIZATIONS ENGAGE IN THE PERIODIC REPORTING PROCESS?

Civil society organizations can engage with the CRPD during the state reporting process in the following ways:

1. Engage in consultation during the development of the state report.
2. Submit a parallel report in advance of the preessional working group on the state under review.
3. Attend the civil society briefing session ahead of the preessional working group to make oral presentations and answer questions on the information provided to help the committee define the list of issues for the state to respond to ahead of the review. The preessional working group session where the committee adopts the list of issues is closed.
4. Submit additional written parallel information in response to the list of issues in advance of the review of the state.
5. Attend the review of the state as an observer or view the session over webcasting. Consider making use of informal opportunities to update committee members on any relevant developments following the preession during the review. Make a timely request to attend the briefing session on the state under review to make oral presentations and answer questions on the information provided to help the committee frame questions and consider concluding observations.
6. Where the committee makes relevant recommendations that require states to follow-up within one year, civil society organizations can provide information to the committee rapporteur on progress in implementing those recommendations.

**Deadlines:** For country reviews, one month before the committee's session. For the list of issues: one month before the session.

**Note:** All written information should be submitted in English, French, or Spanish. The UN will not translate parallel reports.

### CAN INDIVIDUAL COMPLAINTS BE BROUGHT

Yes, complaints can be submitted by individuals whose rights under the CRPD have been violated where the state has also ratified an additional international treaty called the Optional Protocol to the CRPD, and where domestic remedies have been exhausted. Civil society organizations can support individuals to make complaints and can submit follow-up information on the implementation of the committee's "views" on the complaint. The Optional Protocol to the CRPD was adopted at the same time as the CRPD and at the time of writing has 85 states parties.

Ratification information for the CRPD and the Optional Protocol to the CRPD is [available here](#).

### FURTHER INFORMATION ON HOW TO ENGAGE

The UN Office of the High Commissioner for Human Rights has produced [guidance on monitoring](#) the CRPD.

The International Disability Alliance has produced [guidance and delivers training on how to engage with the CRPD](#).

## CONVENTION AGAINST TORTURE AND OTHER CRUEL, INHUMAN OR DEGRADING TREATMENT OR PUNISHMENT

(ADOPTED IN 1984 AND HAS 162 STATES PARTIES AT TIME OF WRITING)

### TREATY BODY

### Committee Against Torture

### STATE REPORTING

States must report initially one year after acceding to the covenant and subsequently upon the committee's request (typically every four years). A schedule of sessions is available at the committee's [homepage](#).

### KEY PROVISIONS RELATED TO PALLIATIVE CARE

#### Article 1

1. For the purposes of this Convention, the term "torture" means any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person for such purposes as obtaining from him or a third person information or a confession, punishing him for an act he or a third person has committed or is suspected of having committed, or intimidating or coercing him or a third person, or for any reason based on discrimination of any kind, when such pain or suffering is inflicted by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity. It does not include pain or suffering arising only from, inherent in, or incidental to lawful sanctions.

#### Article 2

1. Each state Party shall take effective legislative, administrative, judicial, or other measures to prevent acts of torture in any territory under its jurisdiction.
2. No exceptional circumstances whatsoever, whether a state of war or a threat of war, internal political instability or any other public emergency, may be invoked as a justification of torture.

#### Article 10

1. Each state Party shall ensure that education and information regarding the prohibition against torture are fully included in the training of law enforcement personnel, civil or military, medical personnel, public officials and other persons who may be involved in the custody, interrogation, or treatment of any individual subjected to any form of arrest, detention, or imprisonment.
2. Each state Party shall include this prohibition in the rules or instructions issued in regard to the duties and functions of any such person.

#### Article 16

1. Each state Party shall undertake to prevent in any territory under its jurisdiction other acts of cruel, inhuman or degrading treatment or punishment which do not amount to torture as defined in article 1, when such acts are committed by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity. In particular, the obligations contained in articles 10, 11, 12, and 13 shall apply with the substitution for references to torture of references to other forms of cruel, inhuman or degrading treatment or punishment.

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## CONVENTION AGAINST TORTURE AND OTHER CRUEL, INHUMAN OR DEGRADING TREATMENT OR PUNISHMENT

### KEY PROVISIONS RELATED TO PALLIATIVE CARE (Continued)

2. The provisions of this Convention are without prejudice to the provisions of any other international instrument or national law that prohibits cruel, inhuman or degrading treatment or punishment or that relates to extradition or expulsion.

### HOW CAN CIVIL SOCIETY ORGANIZATIONS ENGAGE IN THE PERIODIC REPORTING PROCESS?

Civil society organizations can engage with the Committee Against Torture during the state reporting process in the following ways:

1. Engage in consultation during the development of the state report.
2. Submit a parallel report in advance of the presessional meeting on the state under review.
3. Attend the presessional working group and request to host or join a lunchtime briefing with the committee that is likely to take place the day before the presessional consideration of the state.
4. Submit additional written parallel information in response to the list of issues and the list of issues prior to reporting or submit a full parallel report in advance of the review of the state.
5. Attend a formal closed meeting for civil society with the committee in advance of the review. Private NGO oral briefing of the committee during its formal session on the day before the state report is considered is available only for NGOs that have submitted written information.
6. Attend the review of the state as an observer or view the session over webcasting.
7. Where the committee makes recommendations that require states to follow-up within one year, civil society organizations can provide written information prior to the one-year follow-up and can attend that session as observers.

**Deadlines:** For country reviews, two weeks before the committee's session. For the LOIPR, ten weeks before the session. For the list of issues, ten weeks before the session.

**Note:** All written information should be submitted in English, French, or Spanish. The UN will not translate parallel reports.

### CAN INDIVIDUAL COMPLAINTS BE BROUGHT?

Yes, complaints can be submitted by individuals whose rights under the CAT have been violated where the state has made the necessary declaration under article 22 of the convention, and where domestic remedies have been exhausted. Civil society organizations can support individuals to make complaints and can submit follow-up information on the implementation of the committee's "views" on the complaint.

Ratification information for the CAT and declarations under article 22 are [available here](#).

### FURTHER INFORMATION ON HOW TO ENGAGE

The International Rehabilitation Council for Torture Victims published a useful practical guide for civil society organizations in 2013 on "Engaging with State Reviews in the UN Committee Against Torture." It is [available here](#). The Association for the Prevention of Torture (APT) has likewise produced a guide on alternative reporting to the CAT.

The Open Society Foundations' Public Health Program also produced a publication in 2012 entitled "Twenty Mechanisms to Address Torture in Health Care," of which chapter 7 is dedicated to engaging with the CAT. It is [available here](#).

## 6. PROMOTING PALLIATIVE CARE AT THE UN HUMAN RIGHTS COUNCIL

The primary mechanisms through which civil society can engage with the Human Rights Council are:

**(1) Universal Periodic Review (UPR)**, under which the Human Rights Council comprehensively reviews the human rights record of all UN member states once every four years. Civil society organizations can contribute information for consideration during the UPR, and those recognized by the UN's Economic and Social Council to have particular status (known as "ECOSOC status") can attend the consideration of the state under review at the Human Rights Council;

**(2) Special Procedures** including the special rapporteurs, independent experts, and working groups, which are independent human rights experts who monitor, advise, and publicly report on human rights situations around the world, either by country or by thematic issue. Among those most relevant to palliative care are the special rapporteurs on the right to health and on torture. Civil society organizations can engage with special procedures by submitting information on individual cases; submitting views or analyses on human rights concerns; supporting country missions; working to raise awareness and follow-up on the work of special rapporteurs; and inviting special procedures to engage with their own work.

There are a complaints mechanism and an advisory committee, and more specific mechanisms including the Expert Mechanism on the Rights of Indigenous Peoples and the Forum on Minority Issues.

### UNIVERSAL PERIODIC REVIEW

The Universal Periodic Review (UPR) was established at the time of the creation of the UN Human Rights Council in 2006 to provide a periodic peer review of the realization of human rights in all UN member states. Under the UPR each state is reviewed every four and a half years with respect to its compliance with the UN Charter, the Universal Declaration of Human Rights, all human rights treaties that it has ratified, and international humanitarian law (the law of armed conflict).

The process concludes with an "outcome document" outlining all recommendations made and indicating whether the state under review has accepted each of the recommendations. As a peer review process between states, the UPR has strengths and weaknesses. A clear strength is that the UPR provides an opportunity to consider the state of palliative care in all UN member states, based on the place of the right to health in the Universal Declaration of

## A BRIEF LOOK INTO THE HUMAN RIGHTS COUNCIL

The Human Rights Council is an intergovernmental body within the United Nations system. It comprises 47 member states, which are elected by members of the United Nations General Assembly through direct and secret ballot.

Membership in the Human Rights Council is based on equitable geographic distribution across African states (13 seats), Asia-Pacific states (13 seats), Latin American and Caribbean states (8 seats), Western European and other states (7 seats), and Eastern European states (6 seats). Members serve for a period of three years and are not eligible for immediate reelection after serving two consecutive terms.

The Human Rights Council holds a minimum of three regular sessions per year. These take place in March (4 weeks), June (3 weeks), and September (3 weeks). If one-third of member states so request, the Human Rights Council can also hold special sessions to address specific human rights violations and emergencies.

### The main goals of the Human Rights Council include:

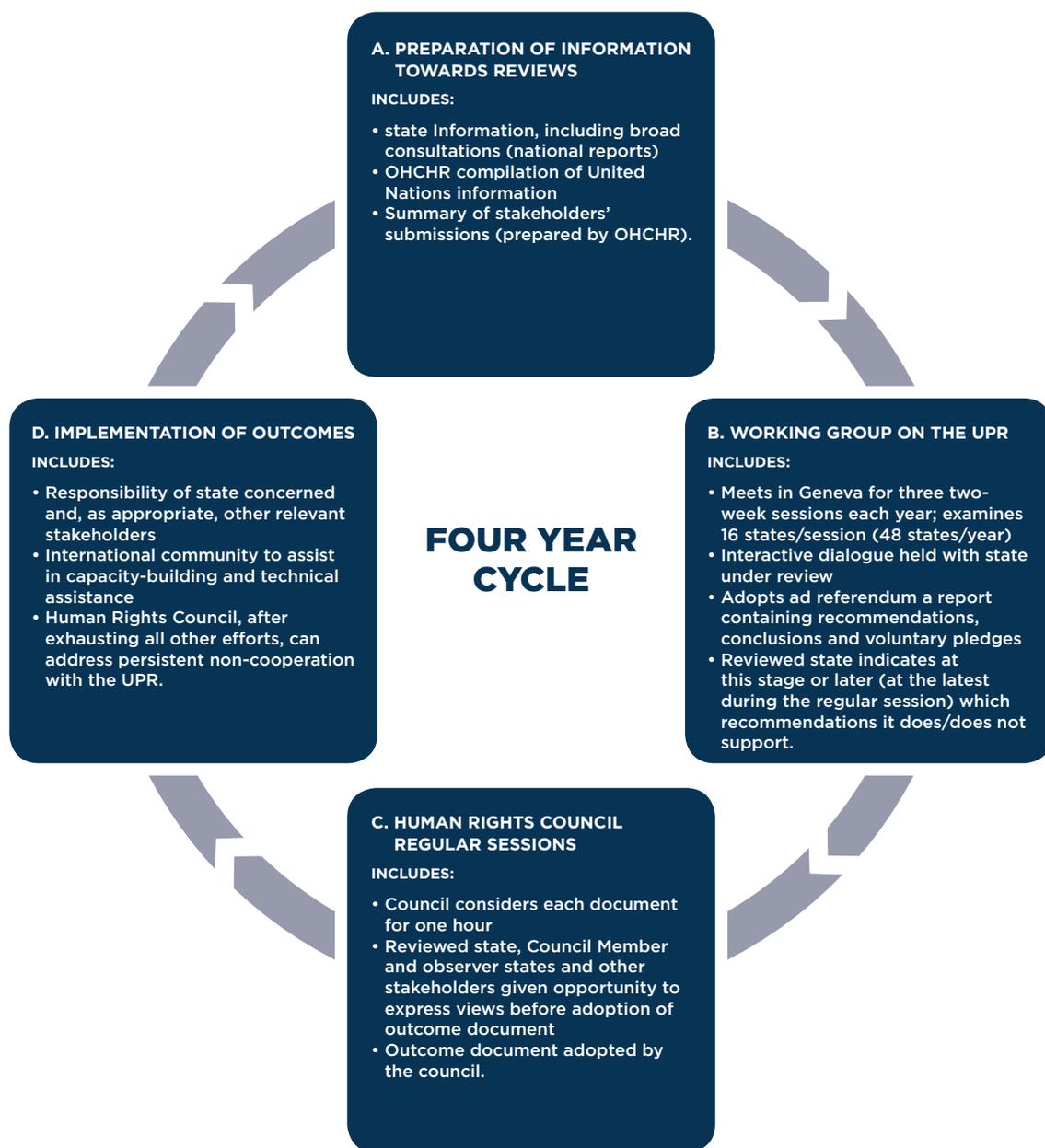
- promoting universal respect for the protection of all human rights and fundamental freedoms for all in a fair and equal manner, without distinction of any kind;
- addressing situations of human rights violations, including gross and systemic violations, and issuing recommendations; and
- promoting the effective coordination and mainstreaming of human rights within the United Nations system.

Human Rights, and irrespective of which human rights treaties the state has ratified. However, the breadth of issues to be reviewed is potentially vast and the issues raised are dependent on those that are considered most important to other member states (often for their own geopolitical reasons). The recommendations that emerge are not legally binding, yet a recent evaluation found that 48 percent had resulted in some measures of implementation after only two and a half years.<sup>29</sup> As with the treaty body processes, the earlier the engagement by civil society organizations, the greater the possibility of ensuring a useful outcome to advance palliative care.

The process consists of four steps and there are opportunities for civil society organizations to influence each of them:

- (1) Preparation for review;
- (2) Review of information by the UPR Working Group;
- (3) Adoption by the Human Rights Council of the outcome document; and
- (4) Follow-up on and implementation of the UPR.

<sup>29</sup> UPR Info, "Beyond Promises: the impact of the UPR on the ground", (Geneva, 2014), available at: [https://www.upr-info.org/sites/default/files/general-document/pdf/2014\\_beyond\\_promises.pdf](https://www.upr-info.org/sites/default/files/general-document/pdf/2014_beyond_promises.pdf).



Source: UN Office of the High Commissioner for Human Rights<sup>30</sup>

<sup>30</sup> UN Office of the High Commissioner for Human Rights, *Working with the United Nations Human Rights Programme: a handbook for civil society*, (New York and Geneva, 2008), p 146.

## 1. PREPARATION FOR REVIEW

To influence the outcomes of the UPR, civil society organizations need to influence the documents that form the basis of the review and influence other member states that will ask questions and make recommendations.

### DOCUMENTS THAT FORM THE BASIS FOR UPR

The UPR is based on the following three documents:

- 1. The state report:** This can be influenced by engaging with consultations during the preparation of the state report on the issues to be presented. As states are encouraged to consult widely in preparing this report, NGOs can take this opportunity to
  - coordinate a national campaign to promote palliative care and bring related issues to the attention of the general public and the media; and
  - promote and participate in broad consultations with the national government in order to alert it to any palliative care concerns, as well as measures that could be taken to address them.

*“States are encouraged to prepare the information through a broad consultation process at the national level with all relevant stakeholders.”*

UN HUMAN RIGHTS COUNCIL RESOLUTION A/HRC/RES/5/1

- 2. A compilation of views of UN treaty bodies, special procedures, and UN agencies:** a ten-page report prepared by the OHCHR on “information contained in the reports of treaty bodies, special procedures, including observations and comments by the state concerned, and other relevant official United Nations documents.”<sup>31</sup> This is not amenable to influence by civil society organizations.
- 3. A compilation of “additional, credible and reliable information provided by other relevant stakeholders”**<sup>32</sup> a ten-page summary prepared by the OHCHR of all information sent by “NGOs, national human rights institutions, human rights defenders, academic institutions and research institutes, regional organizations, as well as civil society representatives” on the human rights situation of the country under review (including information highlighted in parallel reports).<sup>33</sup> This can be influenced by submitting a parallel report in advance. There are strict time limits imposed by the UN on the submission of parallel reports to the UPR, usually around six to eight months before the UPR begins. There are also strict word limits.<sup>34</sup> This is to enable the UN Office of the High Commissioner for Human Rights, which acts as secretariat to the UPR, to collect and compile all civil society organization submissions into one combined report that is then translated into all UN languages. To ensure palliative care issues are raised during the Human Rights Council’s review of a particular state, NGOs advocating for palliative care should cooperate with the national government and

<sup>31</sup> UN Human Rights Council Resolution A/HRC/RES/5/1.

<sup>32</sup> Ibid.

<sup>33</sup> UN Office of the High Commissioner for Human Rights, “Universal Periodic Review: information and guidelines for relevant stakeholders’ written submissions,” available at: <http://www.ohchr.org/Documents/HRBodies/UPR/TechnicalGuideEN.pdf>.

<sup>34</sup> Submissions by individual stakeholders are limited to 2,815 words, excluding annexes, while submissions made by a coalition of NGOs (i.e., two NGOs or more) are limited to 5,630 words. Consult the OHCHR Technical Guidelines for further information: United Nations Office of the High Commissioner for Human Rights, “Technical guidelines for the submission of stakeholders’ information to OHCHR”, available at: <http://www.ohchr.org/Documents/HRBodies/UPR/TechnicalGuideEN.pdf>.

submit a report to the Office of the High Commissioner for Human Rights for inclusion in its document on “other relevant stakeholders to the UPR,” which is submitted to the UPR Working Group.

**MORE INFO:** The UN Office of the High Commissioner for Human Rights has issued clear guidance on the content and form of parallel reports to the UPR: [“Universal Periodic Review: information and guidelines for relevant stakeholders’ written submissions.”](#)

## ENGAGING WITH OTHER MEMBER STATES

Given the great number of civil society submissions, not all issues can be included in OHCHR summaries. For this reason, civil society organizations advocating for access to palliative care must ensure these issues are brought to the attention of the UPR Working Group members so that they may be raised during the interactive dialogue. This can be done by engaging with member states in advance of the review, providing background briefings to them on palliative care, and recommending questions that they may raise. This will be much more effective when done in advance of the meeting, and more effective still where it can be followed up at both the national level and in Geneva, as states’ representatives will generally take instructions from their capitals on issues to raise and recommendations to make, and capitals will often rely on embassies in the state under review to advise on priority issues.

Either separately or as part of a broader civil society coalition, advocates may wish to write to member states in advance of the UPR. This should be short, containing a small number of priority issues, questions, and potential recommendations in a one or two page letter, so that delegates can easily incorporate them into their statements. This letter could be sent to:

- (1) Embassies or consulates of United Nations member states located in the country under review. This approach is useful because many United Nations missions in Geneva call their embassies in the country under review to get a better sense of the human rights violations and other critical issues they should raise; and
- (2) Permanent missions of states before the UN in Geneva.

As some states tend to focus consistently on certain issues, advocates should identify those states specifically concerned with palliative care and encourage them to raise issues and make recommendations on the subject. For example, Uruguay has recently demonstrated a particular interest in palliative care. Listed below are specific rights relevant to palliative care and the countries that tend to ask questions or make recommendations related to those rights.



**TIP:** The NGO UPR Info has a lot of information on its website ([www.upr-info.org](http://www.upr-info.org)) including databases of recommendations that give an indication of which states routinely make relevant recommendations. These include:

- **Palliative care:** Uruguay
- **Right to health:** Bangladesh, Canada, Cuba, Luxembourg, Malaysia, New Zealand, South Africa, and Venezuela
- **Children’s rights:** Argentina, Brazil, the Czech Republic, Italy, Mexico, the Netherlands, Sweden, and the United Kingdom
- **Freedom from torture:** Canada, the Czech Republic, Denmark, Mexico, and Sweden
- **Women’s rights:** Algeria, Australia, Slovenia, Switzerland, and the United Kingdom

An important opportunity to meet with and engage other member states comes in preessional briefing meetings organized by the Geneva based NGO UPR Info. These briefings are held approximately one month before the UPR Working Group session and are an excellent opportunity to brief a number of member states, identify those with an interest in palliative care, and arrange follow-up meetings as necessary.

**MORE INFO** on the preessional briefing meetings for member states organized by UPR Info is [available here](#).

## 2. REVIEW OF INFORMATION BY THE UPR WORKING GROUP

The UPR review process is undertaken by a “working group” that consists of all 47 members of the Human Rights Council, plus any other UN member state that wishes to take part in the review. It is based on an interactive dialogue between the state under review and other states, chaired by the President of the Human Rights Council and facilitated by a troika (three states elected before each session to facilitate the UPR). The working group session includes:

**(1) A presentation by the state under review.** The state under review presents its national report, addressing questions and issues that other states have previously submitted in writing to the working group. Information highlighted in parallel reports submitted by NGOs can help inform the questions posed to a member state at this stage of the review.

**(2) Interactive dialogue.** The member state under review engages in dialogue with other states, which can ask questions, make recommendations, and offer technical assistance. Because the report stemming from the working group’s review can contain only points raised in the review process, it is critical that palliative care issues be raised at this stage of the review.

**(3) Concluding remarks.** The member state under review makes its concluding remarks, in which it may make observations on other states’ recommendations. Alternatively, it may opt to make these observations in writing and convey them at any time between the working group session and the Human Rights Council plenary.

The UPR review lasts three and a half hours for each state under review. This review results in a report prepared by the troika, with the involvement of the state under review and the UN Office of the High Commissioner for Human Rights as secretariat. This report contains a summary of the interactive dialogue, the member state's responses to questions and recommendations, and a full list of recommendations made by other states. It is adopted during a half-hour working group session a few days following the review.<sup>35</sup> While the role of the troika in preparing the report of the working group may seem crucial, in practice this has generally proven to be merely a formal role in facilitating the review. However, this is a matter of convention rather than procedure, and organizations may wish to consider engagement with the troika after reviewing its membership for a given session.

The working group session is an important opportunity to draw attention to the international human rights review of the state. There may be opportunities for civil society organizations to get national press and media attention to the issues that they are raising during the UPR at this stage, whether or not those issues are eventually highlighted during the review by member states.

Civil society organizations with consultative status with the UN Economic and Social Council ("ECOSOC status") may attend the sessions of the UPR Working Group, but they may not actively intervene in the discussions.

Only those stakeholders enjoying consultative status with the ECOSOC may attend sessions of the UPR working group and the Human Rights Council session that adopts the outcome document (generally around six months later). Civil society organizations without consultative status may wish to approach others who do have such status to forge alliances and perhaps join delegations.

Civil society organizations can hope to influence UPR outcomes by submitting a parallel report and influencing recommendations made by other states, as well as by seeking acceptance by the state under review of appropriate recommendations, or seeking to persuade the state under review to make additional "voluntary commitments" to advance palliative care. Although NGOs are given the floor before the adoption of the outcome document during the Human Rights Council's plenary session, this comes only at the very end of the process. While it can be useful to gain visibility of the topic it is highly unlikely to influence significantly the outcome document.

### 3. ADOPTION OF THE UPR OUTCOME DOCUMENT

After each interactive dialogue, the UPR Working Group prepares a summary report listing the issues raised and recommendations made during the exchange. This "outcome report" also covers any voluntary commitments made by the member state under review. As this report can contain only those points raised during the review, it is critical that palliative care issues be brought up earlier in the dialogue.

<sup>35</sup> See UPR Info, an international NGO dedicated to the UPR process, for more information, available at: <http://www.upr-info.org/en/upr-process/foundation>.

The UPR Working Group adopts its outcome report no sooner than 48 hours following the review, at which point the state under review can choose to accept some recommendations. There are then two weeks during which states can make editorial changes to elements of the report that reflect their input. At that point, the report is submitted to the Human Rights Council for formal adoption during its next session, generally several months later.

This gap between the working group and the formal adoption of the outcome document by the Human Rights Council is an important opportunity for palliative care advocates to meet with the state under review to encourage it to make commitments to advance palliative care.

During the Human Rights Council session that adopts the outcome report, the state under review, other member states, the national human rights institution, and civil society organizations with ECOSOC status each have an opportunity to present before the outcome report is formally adopted. The session lasts an hour and speaking time is divided as follows:

- State under review (20 minutes in total, to be divided as it sees fit between introductory comments, responses to questions, and concluding remarks);
- National human rights institution (2 minutes, immediately following the introductory remarks by the state under review);
- Other member states (20 minutes in total, to be divided equally between the number of states wishing to speak);
- Civil society organizations with ECOSOC status (18 minutes in total).

During its remarks, the state under review generally:

- presents its views on the conclusions and recommendations in the outcome document;
- replies to questions or issues that were not sufficiently addressed during the interactive dialogue; and
- may make voluntary pledges and commitments.

Given the limited time allocated for civil society statements, organizations are encouraged to coordinate their statements. These statements may highlight anything, including issues that were not raised or adequately addressed in the interactive dialogue or the outcome document. As with the working group session, this meeting is webcast, and available live and shortly afterwards on the UN website. This webcast may be useful for advocacy and can be embedded into your organization's website.

Written submissions may also be submitted at this stage, and it is recommended to ensure the oral intervention is submitted as a written document, which then becomes an official UPR document.<sup>36</sup>

The adoption of the outcome report represents a further opportunity to draw attention to the international human rights review of the state, highlighting issues raised and recommendations made that are relevant to palliative care. Even where palliative care is not outlined in the formal

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<sup>36</sup> United Nations Office of the High Commissioner for Human Rights, "Human Rights Council—Guidelines to submitting NGO written statements on-line," available at: [http://www.ohchr.org/Documents/HRBodies/HRCouncil/PracticalGuideSubmissionNGO\\_ws.pdf](http://www.ohchr.org/Documents/HRBodies/HRCouncil/PracticalGuideSubmissionNGO_ws.pdf).

outcome document, civil society organizations can choose to draw attention to this issue in their own interventions, and seek voluntary commitments from the state under review.

**PRACTICE EXAMPLE:** In 2012, during India’s second Universal Periodic Review, Session 13, Uruguay raised the issue of access to palliative care, and the following recommendation was adopted as a result: “Establish measures at the national and state level to remove obstacles in terms of access by the population to pain palliative medicines.”<sup>37</sup> Although India’s response to this recommendation is currently listed as pending, the inclusion of palliative care in the report is an important achievement in itself.

## 4. FOLLOW-UP ON AND IMPLEMENTATION OF THE UPR

As with the treaty body reviews, in order to ensure UPR leads to improved implementation of human rights in practice, commitments should be secured from the state under review as to how it will implement the recommendations. The UN Office of the High Commissioner for Human Rights recommends that states develop national action plans for the promotion and protection of human rights as a basis for implementing recommendations from UPR and other human rights reviews. These should be evidence-based, developed in a participatory manner (including the active involvement of civil society), and independently monitored in practice. Within the UPR process, there also are mechanisms for follow-up, with optional midterm reporting after two years, and an expectation that subsequent reviews will consider how previous recommendations have been implemented, as well as how more recent developments affect implementation.

### SPECIAL RAPPORTEURS

Special rapporteurs are one of a series of UN “special procedures,” a variety of independent, unpaid experts that also include independent experts and working groups. This section of the toolkit provides guidance to help NGOs advocating for access to palliative care engage with special rapporteurs.

Special rapporteurs are appointed by the UN Human Rights Council to report and advise on thematic or country-specific human rights issues. They serve for terms of three years with the possibility of extension for a second and final term of three years. Special rapporteurs undertake country visits, act on individual cases of alleged human rights violations, conduct thematic studies, engage in advocacy and raise public awareness, and report annually to the Human Rights Council and—in many cases—to the United Nations General Assembly. The Human Rights Council in 2011 reaffirmed that states have an obligation to cooperate with special rapporteurs (and other special procedures).

Special rapporteur mandates are either by “country” (i.e., reporting on the human rights situation of a specific state), or “theme” (i.e., reporting on a specific human rights issue worldwide). At the time of writing, there are 14 country and 39 thematic special rapporteurs. Up-to-date information on all UN special rapporteurs is [available here](#).

<sup>37</sup> See UPR Info, “Recommendations & Pledges: India, Second Review, Session 13,” (September 24, 2012), available at: [http://www.upr-info.org/sites/default/files/document/india/session\\_13\\_-\\_may\\_2012/recommendationstoindia2012.pdf](http://www.upr-info.org/sites/default/files/document/india/session_13_-_may_2012/recommendationstoindia2012.pdf).

Certain current special rapporteurs hold mandates that are particularly relevant to palliative care. These include:

- the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (“Special Rapporteur on the right to health”); and
- the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment (“Special Rapporteur on torture”).

Both have played an important role in enhancing global recognition of the right to palliative care and pain relief.

## UN SPECIAL RAPPORTEURS AND PALLIATIVE CARE

UN special rapporteurs have increasingly recognized the connections between palliative care and human rights. Speaking in 2008, at the end of his tenure as the first UN Special Rapporteur on the right to health, Paul Hunt noted that, “many other right-to-health issues need urgent attention, such as palliative care. [...] Every year millions suffer horrific, avoidable pain. [...] Palliative care needs greater attention.”

Since then, the Special Rapporteurs on the right to health and on torture have both emphasized issues related to palliative care and pain relief in their reports. For example, in his 2011 report to the Human Rights Council focusing on the right to health of older persons, Anand Grover devoted a section to palliative care. In that report he affirmed that:

*state parties to the International Covenant on Economic, Social and Cultural Rights are required, as a core obligation under the Covenant, to ensure provision of essential drugs as defined under the WHO Action Programme on Essential Drugs. Despite this and the fact that oral morphine and other narcotic preparations are inexpensive and should not be difficult to obtain, the availability of such medications used in palliative care is often limited. That is due to a number of factors, such as restrictive drug regulations, failure to implement a properly functioning supply and distribution system, and inadequate health-care system capacity. Particularly concerning is the complex international narcotic control framework that severely inhibits access to medicines regulated under the framework. Even when such medications are available, there often remains a lack of understanding of palliative care and the use of narcotics in pain relief amongst medical practitioners. More comprehensive training on palliative care and the use of narcotic drugs is needed.*

*...Palliative care requires important funding and mobilization of numerous actors and stakeholders within the medical sector, and it is absolutely crucial in order to prolong the lives of older persons affected by life-threatening diseases and to ensure their death in dignity.”<sup>38</sup>*

<sup>38</sup> UN Human Rights Council, “Thematic study on the realization of the right to health of older persons by the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Anand Grover”, July 4, 2011, available at: [http://hrbaportal.org/wp-content/files/A-HRC-18-37\\_en.pdf](http://hrbaportal.org/wp-content/files/A-HRC-18-37_en.pdf).

Among other things, the Special Rapporteur recommended:

***“Developing international guidelines and national systems to regulate and monitor hospice-care practices to ensure that the elderly are supported in making informed health-care decisions, and that their human dignity and autonomy are not neglected due to their vulnerability.”***<sup>39</sup>

In his 2009 report focused on healthcare, the UN Special Rapporteur on torture Manfred Nowak, noted that:

***“[t]he de facto denial of access to pain relief, if it causes pain and suffering, constitutes cruel, inhuman or degrading treatment.”***<sup>40</sup>

Consequently, he recommended that:

***“[A]ll measures should be taken to ensure full access [to pain treatment and opioid analgesics] and to overcome current regulatory, educational, and attitudinal obstacles to ensure full access to palliative care.”***<sup>41</sup>

In 2013 his successor, Juan Méndez, commented on the need for palliative care in his report on abuses in health care settings. In the report, the Special Rapporteur emphasized that when states deny access to pain treatment, they “not only fall foul of the right to health but may also violate an affirmative obligation under the prohibition of torture and ill-treatment.”<sup>42</sup> He added that “[e]nsuring the availability and accessibility of medications included in the WHO Model List of Essential Medicines is not just a reasonable step, but a legal obligation under the Single Convention on Narcotic Drugs, 1961. [...] Governments must guarantee essential medicines—which include, among others, opioid analgesics—as part of their minimum core obligations under the right to health, and take measures to protect people under their jurisdiction from inhuman and degrading treatment.”<sup>43</sup> Méndez particularly called on states to:

***“(a) Adopt a human rights-based approach to drug control as a matter of priority to prevent the continuing violations of rights stemming from the current approaches to curtailing supply and demand [...]. Ensure that national drug-control laws recognize the indispensable nature of narcotic and psychotropic drugs for the relief of pain and suffering; review national legislation and administrative procedures to guarantee adequate availability of those medicines for legitimate medical uses;***

<sup>39</sup> Ibid.

<sup>40</sup> UN Human Rights Council, “Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak”, UN Doc. A/HRC/10/44, January 14, 2009.

<sup>41</sup> Ibid.

<sup>42</sup> See UN Human Rights Council, “Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan C. Mendez”, A/HRC/22/53, 1 February 2013, paras. 55, available at [http://www.ohchr.org/Documents/HRBodies/HRCouncil/Regularsession/Session22/A.HRC.22.53\\_English.pdf](http://www.ohchr.org/Documents/HRBodies/HRCouncil/Regularsession/Session22/A.HRC.22.53_English.pdf).

<sup>43</sup> Ibid, paras 55–56.

***(b) Ensure full access to palliative care and overcome current regulatory, educational, and attitudinal obstacles that restrict availability to essential palliative care medications, especially oral morphine. states should devise and implement policies that promote widespread understanding about the therapeutic usefulness of controlled substances and their rational use;***

***(c) Develop and integrate palliative care into the public health system by including it in all national health plans and policies, curricula, and training programmes and developing the necessary standards, guidelines and clinical protocols.*** <sup>44</sup>

In 2008 both rapporteurs issued a joint letter to the Chair of the Commission on Narcotic Drugs (CND). In it, they emphasized that:

***[t]he failure to ensure access to controlled medicines for the relief of pain and suffering threatens fundamental rights to health and to the protection against cruel, inhuman or degrading treatment. International human rights law requires that governments must provide essential medicines—which include, among others, opioid analgesics—as part of their minimum core obligations under the right to health. [...] Lack of access to essential medicines, including for pain relief, is a global human rights issue and must be addressed forcefully.***<sup>45</sup>

They called on the member states of the CND to:

- “Ensure that national drug control laws recognize the indispensable nature of narcotic and psychotropic drugs for the relief of pain and suffering, and guarantee adequate availability of those medicines for legitimate medical uses, including opioid analgesics, and opioids for substance dependence programs.
- Review for that purpose national legislation and administrative procedures relating to controlled medications for provisions that unnecessarily impede their accessibility and availability for medical use, and develop a plan of action to address them while also taking steps to prevent misuse. Health ministries and health care providers shall be closely engaged in this process, and the WHO Access to Controlled Medications Program shall offer technical support.
- Ensure that national competent authorities and health ministries, in consultation with healthcare providers, work to establish healthcare systems that are capable of ensuring wide availability of controlled medicines for medical, veterinary, and scientific use while preventing abuse, dependence, and diversion.
- Ensure appropriate instruction to health professionals on the medical use of all controlled medicines listed on the WHO Model List of Essential Medicines, including the WHO analgesic ladder for cancer pain relief, and on the legal requirements for prescribing and dispensing controlled medicines.
- Allocate sufficient funds and personnel to implement all of the above stated objectives.”<sup>46</sup>

<sup>44</sup> Ibid, para. 86.

<sup>45</sup> See Letter to Commission on Narcotic Drugs from special rapporteurs Manfred Nowak and Anand Grover, December 10, 2008, G/SO 214 (53-21): [http://www.hrw.org/sites/default/files/related\\_material/12.10.2008%20Letter%20to%20CND%20fromSpecial%20Rapporteurs.pdf](http://www.hrw.org/sites/default/files/related_material/12.10.2008%20Letter%20to%20CND%20fromSpecial%20Rapporteurs.pdf).

<sup>46</sup> Ibid.

With the support of the UN Office of the High Commissioner for Human Rights, special rapporteurs act through several instruments in order to fulfill their mandates. These include:

- sending communications to states to bring alleged violations to their attention (including both individual cases and concerns of a structural nature);
- undertaking country visits (i.e., fact-finding missions);
- submitting annual reports to the Human Rights Council;
- issuing public statements and press releases; and
- other activities, such as conducting thematic studies, convening expert consultations, developing international human rights standards, engaging in advocacy, raising public awareness, and providing advice and support for technical cooperation.

Each of these tools used by special rapporteurs provides opportunities for NGOs advocating for access to palliative care. In particular, the communications and country visit tools open valuable possibilities for NGO participation.

## 1. COMMUNICATIONS

Civil society organizations, and individuals, can write to the relevant UN special rapporteurs alleging that human rights violations have occurred or are ongoing, or that there is a high risk of violations taking place. The special rapporteurs then have the discretion to take up the issue in direct interaction with governments (and in some cases other actors, such as companies or international organizations) and report to the Human Rights Council on the outcomes. Communications can concern a range of matters, not only cases affecting an individual or community, but also any area of law, policy, or practice that threatens the realization of the relevant human rights.

**MORE INFO:** Information on how to submit a communication to a UN Special Rapporteur is [available here](#).

Communications can be a powerful tool through which civil society organizations can engage their governments in dialogue with a UN special procedure on issues related to palliative care and human rights. These communications are submitted to the UN Human Rights Council and can serve as important instruments for domestic advocacy. They may also serve as a means to expose the roles of other actors, such as private companies and bilateral or multilateral donors failing to adequately respect, protect, or fulfill human rights related to palliative care.

However, not all governments respond to special rapporteur communications. For example, as of May 31, 2014, the UN Special Rapporteur on the right to health had sent 344 communications since June 1, 2006 (the time at which statistics began to be collected), and had received responses to 187, or a rate of 54%. With respect to the UN Special Rapporteur on torture, the overall number of communications sent is higher (1,729), but the response rate was equivalent (53%).<sup>47</sup> Full correspondence of communications between special rapporteurs

<sup>47</sup> UN Human Rights Council, *Communications report of Special Procedures: Communications sent, 1 March to 31 May 2014; Replies received, 1 May to 31 July 2014*, UN Doc A/HRC/27/72, August 20, 2014.

and governments is now available in annual reports to the Human Rights Council and may be useful in domestic advocacy, even where the state has not responded.<sup>48</sup>

## 2. COUNTRY VISITS

Special rapporteurs typically undertake two to three country visits each year. They undertake missions by requesting an invitation from the state, although some states have issued standing invitations to special rapporteurs. Although these are formally known as country visits, the Special Rapporteur on the right to health has undertaken missions to a broader range of entities, including the pharmaceutical company GlaxoSmithKline, the World Trade Organization, the World Bank Group, and the International Monetary Fund.

Country visits are used to assess the state of the relevant human rights issues in that country and involve meetings with a wide variety of national and local authorities, public bodies, civil society organizations, representatives of relevant international organizations in the country, as well as individuals and communities. They typically last no more than two weeks and conclude with an initial statement at a press conference, before the formal report to the Human Rights Council is presented several months later.

Country visits by special rapporteurs can be useful opportunities for civil society organizations to gather and present information on palliative care issues that can be brought to the attention of the Human Rights Council. There are several ways in which palliative care advocates can engage in the country visits mechanism to strengthen their own work and that of the special rapporteurs:

- Advocates can encourage special rapporteurs to undertake a country visit by writing to the special rapporteur or their support staff at the OHCHR and explaining why a visit would be useful.
- National organizations can also encourage their governments to issue invitations to special rapporteurs, including a “standing invitation” to all special rapporteurs.
- Once a country visit is planned, civil society organizations can submit information to the special rapporteur to assist with preparation and urge them to look into areas of particular concern during the visit. They may also wish to suggest focus issues and field visits (including, for example, to hospices or hospitals to observe how palliative care is delivered).
- Advocates can publicize the visit of the special rapporteur in advance and convene civil society organization briefing sessions for the special rapporteur during the country visit, to answer questions and help bring palliative care concerns to their attention. Because country visits are often quite short, it is useful to coordinate these meetings among several domestic NGOs to make sure as many groups as possible have a chance to share their experiences.
- Once a country visit has been completed, the special rapporteur will issue a report containing recommendations. Civil society organizations can use this report as an advocacy tool to push for the government’s implementation of key palliative care recommendations.

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<sup>48</sup> See UN OHCHR, “Communications Reports of Special Procedures”, available at: <http://www.ohchr.org/EN/HRBodies/SP/Pages/CommunicationsreportsSP.aspx>.

### 3. ANNUAL REPORT TO THE HUMAN RIGHTS COUNCIL

Special rapporteurs submit annual reports to the Human Rights Council in which they describe their activities undertaken during the past year and sometimes report on specific human rights issues or legal developments they wish to stress. Annual reports also include an overview of the mandate as a whole, as well as recommendations or suggestions for better fulfilling the mandate. Occasionally, the Human Rights Council will request that special rapporteurs report on themes or issues that are of particular interest to the council. In 2010, special rapporteurs submitted 156 reports to the Human Rights Council and 26 reports to the UN General Assembly; these included 58 reports on country visits.

Annual reports by special rapporteurs are public and can therefore serve as an effective tool for follow-up or advocacy in the area of their mandate. These reports represent an excellent opportunity for NGOs to seek widespread support for the palliative care concerns they wish to emphasize.

### 4. PUBLIC STATEMENTS AND PRESS RELEASES

Special rapporteurs occasionally issue public statements or press releases, either individually or jointly, on issues of concern. For example, in 2014 the special rapporteurs on torture and on the right to health, along with the Independent expert on the Enjoyment of all human rights by older persons, issued a joint statement on palliative care of older people.

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#### JOINT STATEMENT BY UN SPECIAL RAPPORTEURS ON THE OCCASION OF WORLD HOSPICE AND PALLIATIVE CARE DAY 2014

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##### **WHO CARES ABOUT THE SUFFERING OF OLDER PERSONS AT THE END OF THEIR LIVES? WE DO—UN RIGHTS EXPERTS**

##### **World Hospice and Palliative Care Day - Saturday 11 October 2014**

GENEVA (11 October 2014) - Unnecessary suffering of older persons for lack of pain medicines and palliative care at the end of their lives violates basic human rights, a group of United Nations independent experts has warned today on the occasion of the World Hospice and Palliative Care Day.

“Palliative care is not only about lifting older persons out of needless pain and distress; it is an imperative to maintain their dignity at the end of their lives,” the human rights experts said, noting that the number of older persons is expected to more than double globally from 841 million people in 2013 to more than 2 billion in 2050.

“States have an obligation to ensure that older persons can enjoy the last years of life without unnecessary suffering, yet only 10 percent of the international demand for palliative care is met,” said the UN Independent Expert on the enjoyment of all human rights by older persons, Rosa Kornfeld-Matte.

Older people have special needs, because their problems are different and often more

CONTINUED FROM PREVIOUS PAGE

complex than those of younger people, she noted. “Paradoxically, older people receive less palliative care than younger people and services focus on certain diseases such as cancer.”

“An urgent and sustainable response is needed to improve palliative care for older people and meet the growing needs of the world’s ageing populations,” Ms. Kornfeld-Matte added.

States also have an obligation to prevent pain and suffering that amounts to cruel, inhuman or degrading treatment, added the UN Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez.

Mr. Méndez urged governments around the world to ensure full access to palliative care of all terminally ill, including older persons, and overcome all obstacles that restrict availability to essential palliative care medications. “states should promote widespread understanding about the therapeutic usefulness of controlled substances and their rational use,” he stated.

“Healthcare systems which ignore the need to have accessible and good quality palliative care will never be able to effectively promote and protect right to health and related human rights of their citizens,” the UN Independent Expert on the right to health, Dainius Puras, said.

“Palliative care is an obligatory integral part of the full realisation of the right of everyone to the highest attainable standard of physical and mental health,” Mr. Puras further stressed. World Hospice and Palliative Care Day is celebrated every year on 11 October. The Day is organized by a committee of the Worldwide Palliative Care Alliance, a network of hospice and palliative care national and regional organizations that support the development of hospice and palliative care worldwide. This year’s theme is ‘Who Cares? We Do!’

The United Nations human rights experts are part of what it is known as the Special Procedures of the Human Rights Council. Special Procedures, the largest body of independent experts in the UN Human Rights, is the general name of the independent fact-finding and monitoring mechanisms of the Human Rights Council that address either specific country situations or thematic issues in all parts of the world.

# 7. OPPORTUNITIES WITHIN THE REGIONAL HUMAN RIGHTS SYSTEMS

## THE INTER-AMERICAN HUMAN RIGHTS SYSTEM

The two main bodies of the Inter-American human rights system are the Inter-American Commission and the Inter-American Court of Human Rights. The commission began operating in 1960, and it is mandated to receive and make recommendations relating to individual complaints, hold thematic hearings on specific areas of concern, and publish studies. It has established several thematic rapporteurships to monitor certain human rights themes and or vulnerable groups in the Americas. The commission can also submit certain complaints to the Inter-American Court of Human Rights, which in turn has been operating since 1979 and has the mandate to decide cases brought against those states that have specifically accepted the court's jurisdiction.

Notably, the Inter-American human rights system is the first regional system to adopt a treaty that explicitly refers to palliative care. The Inter-American Convention on Older Persons, adopted in June 2015, shall enter into force as soon as two states have ratified it and will allow the Inter-American Commission on Human Rights to receive petitions containing complaints of violations of the convention. It requires countries to provide access to palliative care without discrimination, to prevent unnecessary suffering and futile procedures, and to appropriately manage problems related to the fear of death. It also mandates that countries establish procedures to enable older persons to indicate in advance their will and instructions with regard to health care interventions. The convention defines palliative care as: “the active, comprehensive, and interdisciplinary care and treatment of patients whose illness is not responding to curative treatment or who are suffering avoidable pain, in order to improve their quality of life until the last day of their lives. Central to palliative care is control of pain, of other symptoms, and of the social, psychological, and spiritual problems of the older person. It includes the patient, their environment, and their family. It affirms life and considers death a normal process, neither hastening nor delaying it.”<sup>49</sup>

**MORE INFO:** Information on how to engage with the Inter-American human rights system can be found in the 2014 manual by the International Justice Resource Center's 2014 manual [Advocacy Before the Inter-American System](#).

## THE AFRICAN HUMAN RIGHTS SYSTEM

The main bodies of the African human rights system are the African Commission on Human and Peoples' Rights and the African Court on Human and Peoples' Rights. The African Commission

<sup>49</sup> Organization of American States, Inter-American Convention on Protecting the Human Rights of Older Persons, OEA/Ser.P. June 15 to 16, 2015, AG/doc.5493/15 corr. 1, available at: [http://www.oas.org/en/media\\_center/press\\_release.asp?sCodigo=E-198/15](http://www.oas.org/en/media_center/press_release.asp?sCodigo=E-198/15).

was established under the African Charter on Human and Peoples' Rights and became operational in 1986. It reports to the African Union and has jurisdiction over the rights set out in the African Charter. Its duties include examining national reports on the situation of human rights that each state is required to submit every other year, adopting resolutions and declarations, conducting country visits, issuing rulings on individual complaints, and submitting cases to the African Court. The African Commission has also developed a system of special rapporteurs and working groups who monitor and investigate specific questions linked to the commission's work. The African Court on Human and Peoples' Rights was created in 2004 and was later integrated into the African Court of Justice.

As of September 2015, the African human rights system was still in the process of drafting specialized protocols on particular sets of rights, such as a draft African Protocol on Older Persons and a draft African Protocol on Persons with Disabilities. These drafting processes offer time-bound opportunities to influence some of these normative standards by engaging with the NGO coalitions that coordinate civil society input.

**MORE INFO:** Information on how to engage with the African regional system can be found in the 2015 manual published by the Programme on Women's Economic, Social and Cultural Rights, *The African Regional Human Rights System*.

## THE EUROPEAN HUMAN RIGHTS SYSTEM

The European human rights system is the earliest regional human rights system, created by the Council of Europe in 1949. It covers the majority of European countries and oversees treaty bodies as well as promotional activities. The European Court of Human Rights was established under the European Convention for the Protection of Human Rights and Fundamental Freedoms. It monitors compliance with the convention and its protocols by issuing advisory opinions and receiving complaints of individual human rights violations. The Council of Europe's Committee of Ministers is responsible for monitoring the implementation of judgments made by the European Court of Human Rights. It is also the decision-making body of the Council of Europe and is mandated to make recommendations to member states on matters for which there is an agreed "common policy." Another important body of the Council of Europe is the European Committee of Social Rights, which conducts regular reviews of state compliance with the provisions of the (Revised) European Social Charter.

**MORE INFO:** Information on how to engage with the European human rights system can be found in the [series of factsheets](#) from the European Court of Human Rights by theme on its case-law and pending cases, and in the European Court of Human Rights's 2014 publication [Practical Guide on Admissibility Criteria](#).

# ANNEX I: PALLIATIVE CARE NEEDS BY CONDITION AND POPULATION

The health conditions and populations listed below roughly mirror the breakdown of advocacy groups in the field of palliative care, and therefore may be instructive for forming advocacy coalitions in preparation for United Nations intervention.

## PALLIATIVE CARE NEEDS BY CONDITION

CONDITION	PALLIATIVE CARE NEEDS
<b>CANCER</b>	Patients suffering from any form of cancer are vulnerable to pain both from the tumor itself and from its treatment. Treatment-related pain includes pain resulting from chemotherapy, biopsies, blood draws, lumbar punctures, laser treatments, and surgical interventions. <sup>50</sup>
<b>HIV/AIDS</b>	People living with HIV/AIDS require palliative care to help them cope with opportunistic infections arising from their immune system deficiency, as well as with the nausea and discomfort associated with treatment.
<b>NEUROLOGICAL CONDITIONS</b> (E.G., AMYOTROPHIC LATERAL SCLEROSIS ["ALS"], MULTIPLE SCLEROSIS ["MS"], DEMENTIA)	Patients suffering from neurological conditions may suffer from respiratory failure, nutritional failure, pain, spasticity or loss of mobility, and associated depression, anxiety, and other expressions of mental illness. <sup>51</sup>
<b>END-STAGE CARDIAC AND PULMONARY ILLNESS</b>	Pulmonary and cardiac disease can be progressive, chronic, and non-treatable. End-stage illness is typically seen in elderly patients, and it requires pain management and life-sustaining support. <sup>52, 53</sup>

<sup>50</sup> See World Health Organization, "HIV/AIDS Topics: Palliative Care," available at: <http://www.who.int/hiv/topics/palliative/PalliativeCare/en/#>.

<sup>51</sup> Dylan Harris, "Forget Me Not: Palliative Care for People with Dementia," *Postgraduate Medical Journal* 83(980) (June 2007): 362-366, available at: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2600060/>.

<sup>52</sup> K.M. Hill and M.F. Muers, "Palliative Care for Patients with Non-malignant End Stage Respiratory Disease," *Thorax* 55 (2000): 979-981, available at: <http://thorax.bmj.com/content/55/12/979.full.pdf>.

<sup>53</sup> Louise M. E. Gibbs, et al., "Dying from Heart Failure: Lessons from Palliative Care," *British Medical Journal* 317 (1998): 961, available at: <http://www.bmj.com/content/317/7164/961>.

## PALLIATIVE CARE NEEDS BY POPULATION

POPULATION	PALLIATIVE CARE NEEDS
<b>OLDER PERSONS</b>	Older persons are more vulnerable to cancer, neurological illness, and suffering associated with other advanced-stage illnesses. Older persons are also less likely to have disposable income and thus to be able to advocate independently on their own behalf.
<b>NEWBORNS AND INFANTS</b>	Newborns with congenital abnormalities or at the limits of viability require prompt and advanced palliative care. This need is particularly acute for children whose families opt for aggressive treatment and those whose condition causes them great discomfort.
<b>PRISONERS AND DETAINEES</b>	Incarcerated populations rely fully on resource-restricted care provided in closed settings and have limited ability to advocate for additional pain relief. Many inmates spend the majority of their lives in prison, and many acquire terminal conditions over the course of their incarceration. Given many countries' emphasis on the prison system as a punitive mechanism, prisoners and detainees are highly vulnerable to gaps in care coverage.
<b>PERSONS WITH DEVELOPMENTAL DISABILITIES</b>	Many countries' health care systems feature serious gaps in terms of assuring end-of-life care for persons with developmental disabilities. An inability to effectively express one's own interests with respect to end-of-life care can significantly affect the quality of life and duration of survival of a person suffering from late-term illness. <sup>54</sup>

<sup>54</sup> Barbara Goldsmith et al., "Providing End-of-Life Palliative Care for the Developmentally Disabled and Their Families," *Journal of Hospice & Palliative Nursing* 8 (2006): 270-275.

## RESOURCE MATERIALS

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