

**Guiding Questions for the focus areas of the IX Session of the Open-ended Working Group on Ageing:
Long-term care and palliative care**

1) In your country/region, how is long-term care for older persons defined and provided for in legal and policy frameworks? What types of support and services are covered?

The Inter-American Convention on Protecting the Human Rights of Older Persons plainly identifies the conditions required to maintain dignity until death: “States Parties shall take steps to ensure that public and private institutions offer older persons access without discrimination to comprehensive care, including palliative care; avoid isolation; appropriately manage problems related to the fear of death of the terminally ill and pain; and prevent unnecessary suffering, and futile and useless procedures, in accordance with the right of older persons to express their informed consent” (article 6)

Article 19 of the Inter-American Convention establishes the following State obligations regarding palliative care in addition to the guarantees mentioned previously:

- Promote and strengthen research and academic training for specialized health professionals in geriatrics, gerontology, and palliative care.
- Promote the necessary measures to ensure that palliative care services are available and accessible for older persons, as well as to support their families.
- Ensure that medicines recognized as essential by WHO, including controlled medicines needed for palliative care, are available and accessible for older persons.

Moreover, articles 6, 11 and 12 of the Convention call for non-discrimination and equality of access in the provision of palliative care.

2) What are the specific challenges faced by older persons in accessing long-term care?

In Latin America and Caribbean although programmes are being implemented, there is still much to be done. In some countries for example, public health system programmes present major operational deficiencies. The professionals who run them do not always have the right training, medication is misused to keep terminally ill patients sedated, and there is no coordination with curative care. Once older persons are admitted into palliative care programmes, it is immediately assumed that they will not survive for long. Home visits are limited and of poor quality, and not all primary care providers are properly trained. The situation is different in the private sector, where palliative care is of a much higher quality than in the public sector. However, it is costly and thus unaffordable for the most vulnerable segments of the population.

3) What other rights are essential for the enjoyment of the right to long-term care by older persons, or affected by the non-enjoyment of this right?

The ultimate goal of palliative care is not a good death, but a good life until the end. It is for this reason that the Interamerican Convention addresses palliative care so extensively, not only in article 6 on

the right to life and dignity in old age, but in article 12 on the rights of older persons receiving long-term care, article 19 on the right to health and article 11 on the right to give free and informed consent on health matters.

4) In your country/region, how is palliative care defined in legal and policy frameworks?

In the Inter-American Convention on Protecting the Human Rights of Older Persons defines palliative care as “[a]ctive, 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.”

5) What are the specific needs and challenges facing older persons regarding end-of-life care? Are there studies, data and evidence available?

The adoption of the Inter-American Convention on Protecting the Human Rights of Older Persons shows that it is possible and necessary to develop a legally binding multilateral instrument that can ensure full and effective promotion and protection of the rights of older persons.

6) How is palliative care provided, in relation to long-term care as described above and other support services for older persons?

Most countries of the region do not meet the demand for palliative care and fail to recognize it as a discipline or to include it in public or private health-care systems. Fewer still have legislated for it, and funding and continuity have been impaired as a result.

The majority of national palliative care programmes in the region were created in the late 1990s, meaning the approach is fairly recent. There are isolated initiatives resulting from local efforts, but few countries have a national public policy guaranteeing access to palliative care.

In countries that do have national palliative care programmes, they are linked primarily to oncological diseases and can still be difficult to access for non-cancer patients, such as those living with HIV/AIDS or suffering from other chronic or terminal illnesses. The law does not require the provision of palliative care for these patients, and pain management with analgesics depends on whether doctors are authorized to prescribe opioids.

The lack of national policies has led to the emergence of private initiatives to provide care for the terminally ill, but at a very high cost, which debar low-income patients from access. There are also non-profit foundations that provide support and pain relief, although they lack duly accredited personnel. This situation threatens the sustainability of these activities, which are carried out mainly by volunteers and with resources from charitable and non-governmental organizations (NGOs).

7) Are there good practices available in terms of long-term care and palliative care? What are lessons learned from human rights perspectives?

Cuba is one of the countries in the region that stands out in this area. The Pain Management and Palliative Care Programme (PADCP) for cancer patients is part of the free universal national health system. The PADCP includes home care by multidisciplinary teams of doctors, nurses and psychologists. It also covers free hospitalization and medication during treatment. The Ministry of Health has made a proposal to include the palliative care component in primary health care as part of the Family Doctor and Nurse Programme in the interests of ensuring long-term management of disease and helping people cope with bereavement. The overall objective is to enhance the subjective well-being and quality of life of cancer patients requiring palliative care and their families by providing comprehensive care that encompasses physical, social, emotional and spiritual needs, while avoiding ill effects for the medical team. Palliative care training, meanwhile, has been officially accredited since 2010 in the form of a diploma in palliative care for adult patients and a national diploma in cancer management. Faculties of medicine also include palliative care content.

In **Argentina**, palliative care services were first provided by isolated private centres in 1982, before eventually being incorporated into frameworks of health-care regulation in 2000.

Current legislation in Argentina includes the right to comprehensive palliative care as part of treatment, this being enshrined in Law 26742 on patients' rights. In addition to this law, commissions and programmes have been set up within the Ministry of Health and the National Cancer Institute.

In **Costa Rica**, palliative care is covered by the universal social security scheme. Hospitalization, medication and specialist consultations are provided free of charge, and there are NGOs that support the uninsured.

From the legal point of view, although Costa Rica has not legislated for palliative care, the Constitutional Chamber has issued resolutions relating to the rights of terminally ill patients. One of the first and most significant was a 1994 ruling enshrining the right to a dignified and pain-free death.

The issue was institutionalized in 2008 with the creation of the National Council for Palliative Care, comprising representatives from the Ministry of Health, the Costa Rican Social Security Fund (CCSS), the National Centre for Pain Control and Palliative Care, the Costa Rican Palliative Care Federation, the Social Protection Committee (JPS) and some foundations.