



The International Longevity Center Global Alliance, Ltd. is a non-governmental organization in consultative status with the Economic and Social Council since 2012.

**International Longevity Centre Global Alliance input on the normative content of:
The right of older persons to Care and Support, Long-Term and Palliative Care
10th Working Session of the Open-ended Working Group on Ageing, April 2019**

Understanding of the right

The provision should include a definition of long-term care and of palliative care. There are wide ranging misconceptions about what long-term and palliative care are, an underestimation of the urgent need for appropriate services and assumptions about the adequacy of existing care options. These misconceptions hinder progress and are real barriers in the development of adequate, quality care services.

1. Affirmation of the Right to care and support

Older persons have the right to quality integrated and holistic care and support including long-term and palliative care that is available, acceptable, accessible, timely and affordable, with full respect to the needs, preferences and autonomy of the older persons without discrimination of any kind.

2. Scope of the right

2.1 The right applies to care, long-term care and support services, in all public and private settings including at: home, community based, primary care, residential institutions, hospitals, day-care centres, hospices, prisons or any other setting.

2.2. Long-term care, including palliative care, applies at any time of a life-limiting condition or loss of intrinsic capacity and it is not limited to pain relief, a specific disease or end of life care

2.3. The right of older persons to care and support services is independent from the income or financial capability of their family members.

2.4. The right to long term and palliative care applies to holistic, integrated care for the physical and mental integrity, social and spiritual needs of older persons at any age with full respect to their privacy and dignity.

3. States Obligations

Member States shall take appropriate and effective measures to:

3.1. Ensure quality care and support services are available, acceptable, accessible and affordable for older persons based on human rights principles.

3.2. Integrate Long-term and Palliative Care into the public health and social care system and the universal health coverage.

3.3. Enable timely access to information about available options of long-term and palliative care support and services

3.4. Ensure older persons participate in the planning of their care, are able to express their free, prior and on-going informed consent to their overall health, social and palliative care

services that are adapted to their needs and preferences and are able to opt out of a specific care service at any time.

3.5. Ensure research, design, delivery and monitoring of care services, including assistive technologies and robotics are carried out with the participation of older persons and in full compliance with international ethical and data protection standards.

3.6. Ensure the adequate training of health, social and spiritual care providers, family members and volunteers in the care and support of older persons, including long-term and holistic palliative care.

3.7. Enable access to essential technologies and medicines, including internationally controlled essential medicines, for the treatment of moderate to severe pain.

3.8. Review national legislation and administrative procedures and guarantee adequate availability of those medicines for legitimate medical purposes.

3.9. Prevent the cruel, inhuman and degrading treatment of older persons, including as a result of the failure to provide adequate care and adequately treat pain, discomfort and other symptoms.

3.10. Facilitate the preparation of advanced directives, living wills or any legally binding document through which older persons may wish to indicate their preferences on all their long-term and palliative care options from diagnosis to end of life care.

3.11. Provide timely information of any changes in the national legislation that may impact the advanced directives and enable a periodic revision of the personal directives.

3.12. Ensure older persons have access to long-term and palliative care in a setting that is consistent with their needs, will and preferences, including at home and long-term care settings.

3.13. Enable supported decision-making where necessary, whilst retaining the legal capacity of the older person.

3.14. Ensure older persons have access to a range of supports to exercise legal capacity, including the appointment of one or more trusted persons to assist them to make decisions based on their instructions, will and preferences.

3.15. Ensure those close to the older person, including family members, are able to receive support and access a range of services including on administrative procedures and bereavement.

3.16. Remove regulatory, educational, and attitudinal obstacles that restrict availability to essential long-term and palliative care medications and technologies.

3.17. Put in place measures to safeguard against the misuse of narcotic and psychotropic drugs and other medications and any other abusive practices.

3.18. Regulate and monitor the compliance of all care providers with professional obligations and standards.

Annex

Normative basis and selected references related to the right to long-term care and palliative care in some international and regional frameworks

International Covenant on Political and Civil Rights ICCPR, 1996

Art. 7. No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation.

International Covenant on Economic, Social and Cultural Rights (ICESCR), 1966

Art. 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.

Convention on the Rights of Persons with Disabilities (CRPD), 2006

Article.10: Right to Life, art. 19: Right to live independently and being included in the community, art. 22: Respect for privacy, art. 25: Health.

Madrid International Plan of Action on Ageing, 2002

Issue 2: Universal and equal access to health-care services

World Health Assembly Resolutions

WHA69.3: Global strategy and action plan on ageing and health 2016–2020: towards a world in which everyone can live a long and healthy life, 2016

WHA69.24: Strengthening integrated, people-centred health services

WHA67.19: Strengthening of palliative care as a component of comprehensive care throughout the life course

Reports

Reports of Independent Expert on the enjoyment of all human rights by older persons:

A/HRC/30/43: Autonomy and Care of Older Persons, 2015

A/HRC/33/44: Comprehensive Report, 2016

A/HRC/36/48: Robots and rights: the impact of automation on the human rights of older persons, 2017

A/HRC/39/50: Social exclusion: concepts, manifestations and the impact on the human rights of older persons, 2018

WHO World Report on Ageing and Health, 2015

Regional frameworks/instruments

Inter-American convention on protecting the human rights of older persons, 2015

Art. 6 (life and dignity), art.11 (consent), art.12 (LTC), art.19 (right to health)

Protocol to the African Charter on Human and Peoples' Rights on the Rights of Older

Persons in Africa, art 11 (residential care), 2016

Council of Europe

Recommendation CM/Rec (2014) 2 on the promotion of human rights of older persons
Recommendation [Rec\(2003\)24](#) of the Committee of Ministers to member states on the organisation of palliative care