



5th February 2019

Questions on the normative framework of long-term and palliative care

AGE Platform Europe's input

This short answer is submitted in reply to the call of the Chair of the Open-Ended Working Group on Ageing (OEWG). AGE Platform Europe (AGE) has ECOSOC status and is accredited to the OEWG since 2012.

As the largest European network of self-advocacy organisations of older people, our position aims to reflect the situation at EU level and to provide a comparative overview of the EU Member States on behalf of the 40 million older citizens represented by our members. Our contribution is based on written answers received from organisations of older people in several EU Member States, oral debate in the frame of our Council of Administration where representatives from 24 countries¹ and 6 European organisations/federations² sit as well as reflections shared during an expert seminar on the human rights of older persons co-organised by AGE in 2018, webinars organised with AGE members and desk research using sources referenced in this document.

Separate answers covering normative elements on autonomy and independence, as well as questions on social protection and social security, and education, lifelong learning, training and capacity building, are also submitted.

Further resources:

- [AGE Platform Europe's submission on questions on long-term and palliative care, 9th session of the Open-Ended Working Group on Ageing, 2018](#)
- [On quality long-term care and fight against elder abuse](#)
- [Older persons' self-advocacy handbook](#)
- [Toolkit on the dignity and wellbeing of older persons in need of care](#)

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¹ All EU countries with the exception of Croatia, Latvia, Luxembourg and Slovakia

² FIAPA, ESU, NOPO, EURAG, EDE, OWN Europe



Question 1: What are the legal provisions in your country that recognizes the right to long-term and palliative care? Do they have a constitutional, legislative or executive foundation?

1.1 Long-term care

- In Europe, several policies refer to a right to long-term care (LTC); the European Pillar of Social Rights³ includes a *right to long-term care*, affordable and of good quality, especially home care and in the community; however, this is a non-binding instrument⁴.
- Situations across European states vary widely. Some recognise the right and most have legislations enshrining the right to support schemes for care needs, but these have often been reversed⁵. Some EU countries have enforced legislation to shift to relatives the responsibility to deliver care to older people or cover for the costs associated to it⁶. Moreover, in some countries there is no recognition of a right to long-term care or universally accessible entitlements⁷.

1.2 Palliative care

- There is no legislation Europe-wide recognising the right to palliative care; there are non-binding regional instruments that recognise the need for states to guarantee older people's access to palliative care⁸.
- At the national level, situations vary widely, with several EU countries having legislations that recognize a right to palliative care; however, the scope of the right varies widely⁹.

Question 2: What are the key normative elements of the rights to long-term and palliative care? Please provide references to existing laws and standards where applicable.

2.1 Long-term care

[See detailed normative elements \(affirmation of the right, scope, and state obligations\) in ANNEX](#)

³ This is a non-binding European Union policy, which was proclaimed by all EU states in 2017. More information: https://ec.europa.eu/commission/priorities/deeper-and-fairer-economic-and-monetary-union/european-pillar-social-rights/european-pillar-social-rights-20-principles_en

⁴ On top of this, Council of Europe CM(2014)2 recommendation calls on member states to ensure older people's access to quality, affordable and coordinated care, with a stress on community care, but this is also a non-binding instrument.

⁵ This has often been the case because of cost-containment measures. For a European and country-by-country overview of long-term care schemes across Europe: Spasova, S., Baeten, R., Coster, S., Ghailani, D., Peña-Casas, R. and Vanhercke, B. (2018). *Challenges in long-term care in Europe. A study of national policies*, European Social Policy Network (ESPN), Brussels: European Commission.

⁶ Idem

⁷ In many countries, for instance in Greece, government only guarantees highly means-tested support.

⁸ The non-binding Council of Europe CM(2014)2 recommendation calls on member states to guarantee access to palliative care to all those in need to ensure well-being, regardless of the living arrangement, in a supportive environment and through training of professionals. Recommendation (2003)24 addresses specifically palliative care, and calls on timely and universal access, whenever and as long as needed, with no discrimination based on illness or any other grounds.

⁹ A mapping of legislation and policies on long-term care and palliative care in the context of long-term care facilities is available in: Froggatt, K., Edwards, M., Morbey, H. and Payne, S. (2016). *Mapping palliative care systems in long-term care facilities in Europe*, EAPC Taskforce Report, PACE EU project, Lancaster: Lancaster University.

- A right to care and support should aim to ensure older persons' enjoyment of the right to choose where and with whom they live on an equal basis with others¹⁰, and to full participation in the community. It should ensure that older persons access the care and support they need to achieve the highest attainable standard of physical and mental health¹¹.
- The use of "care and support" is preferred over "care" or "long-term care", as the latter tend to be associated with paternalistic and infantilizing approaches¹².
- This right should apply to all settings¹³. Its realization involves several state obligations (see ANNEX)¹⁴.

2.2 Palliative care

[See detailed normative elements \(affirmation of the right, scope, and state obligations\) in ANNEX](#)

- A right to palliative care should aim to ensure timely access to holistic palliative care that addresses all needs of older persons with a life-threatening condition –psycho-social, spiritual, existential, pain relief. It should aim to remove any barriers or discrimination based on illness, age or any other circumstances¹⁵.
- The right to palliative care should apply to all settings and be compatible with the right to care and support, for palliative care is an integral element of the continuum of care to which all older persons should have access¹⁶. It involves several state obligations (see ANNEX).

Question 3: How should long-term care and palliative care be legally defined?

- Care and support are the full range of services that allow older persons with a loss of physical capacities, health conditions or a disability to maintain or regain the optimum level of physical,

¹⁰ See article 19 of the Convention on the Rights of Persons with Disabilities: "Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement".

¹¹ Article 12 of the International Covenant on Economic, Social and Cultural Rights states that "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 Thematic study of UN Special Rapporteur on the right to health of older persons: <https://undocs.org/a/hrc/18/37>

¹² United Nations Office of the High Commissioner for Human Rights (Europe Regional Office) and AGE Platform Europe (2018). *The Human Rights of Older Persons in Europe. Seminar report*, Brussels: United Nations Office of the High Commissioner for Human Rights (Europe Regional Office) <https://europe.ohchr.org/Documents/Publications/OlderPersonsInEurope.pdf>

¹³ Article 19 of the Convention on the Rights of Persons with Disabilities states that "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".

¹⁴ See the full list of state obligations in ANNEX. References that elaborate on obligations of states include the Annual Report of the Independent Expert on the enjoyment of all human rights by older persons, Rosa Kornfeld-Matte, 13 August 2015, pages 19-21 https://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session30/Documents/A_HRC_30_43_ENG.docx

¹⁵ Denial of access to pain relief might be considered a violation of human rights according to the Special Rapporteurs on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak and Juan E. Méndez, 2008 and 2013 respectively.

¹⁶ United Nations Office of the High Commissioner for Human Rights (Europe Regional Office) and AGE Platform Europe (2018). *The Human Rights of Older Persons in Europe. Seminar report*, Brussels: United Nations Office of the High Commissioner for Human Rights (Europe Regional Office) <https://europe.ohchr.org/Documents/Publications/OlderPersonsInEurope.pdf>

mental and emotional wellbeing and to prevent or delay the onset of disease¹⁷, and which lead to their liberation and full participation by preserving their autonomy and their independence¹⁸.

- Palliative care is care and support (including advance care planning) that improves the quality of life of older persons who are confronted with life-threatening conditions and increases their comfort and wellbeing by addressing their physical, psycho-social, existential and spiritual needs¹⁹.

Question 4: What are the policies and programmes adopted by your country to guarantee older person's enjoyment of their right to long-term and palliative care? & Question 6: Which are the measures adopted to ensure equitable access by older persons to the enjoyment of the right to long-term and palliative care, paying special attention to those who are vulnerable or in vulnerable situation?

4.1 Long-term care

- There are no specific policies or programmes of the European Union on long-term care for older people, but the EU has funded relevant projects²⁰.
- Initiatives in EU countries have included the creation of financial allowances for older people with care needs, refunds for mobility aids and housing adaptations, or initiatives that focus on empowering older persons with care and support needs to regain autonomy²¹, among others²².

4.2 Palliative care

- There are no specific policies or programmes of the European Union on palliative care for older people, but the EU has funded research²³.
- EU states have different levels of involvement in this area; most of them have national plans to improve access to palliative care; however, older people are not always a specific target of such programmes and the integration of palliative care in policies for older people and their care and support needs seems to be insufficient.

Question 5: What are the best practices and main challenges in adopting and implementing a normative framework to implement these rights?

¹⁷ See definition of care in the Annual Report of the Independent Expert on the enjoyment of all human rights by older persons, Rosa Kornfeld-Matte, 13 August 2015, page 13: "Care aims at maintaining or regaining the optimum level of physical, mental and emotional wellbeing and to prevent or delay the onset of disease."

¹⁸ United Nations Human Rights Office of the High Commissioner (Europe Regional Office) and AGE Platform Europe: *The Human Rights of Older Persons in Europe. Seminar report*, 2018: <https://europe.ohchr.org/Documents/Publications/OlderPersonsInEurope.pdf>

¹⁹ See definition of palliative care of the World Health Organization (WHO): <https://www.who.int/cancer/palliative/definition/en/>

²⁰ These included the European Charter of rights and responsibilities of older people in need of long-term care and assistance, and the European Quality Framework for long-term care services, www.age-platform.eu/qualitycare; a project on [Human Rights in long-term care](#); and also projects on integrated health and social care, for instance [SUSTAIN](#).

²¹ More information on this initiative, put in place in Fredericia (Denmark), is available [here](#).

²² For a European and country-by-country overview: Spasova, S., Baeten, R., Coster, S., Ghailani, D., Peña-Casas, R. and Vanhercke, B. (2018).

²³ See, for instance, the PACE (Palliative Care for Older People in care and nursing homes in Europe) EU-funded project has implemented a programme in the care homes of 6 European Union countries to improve the delivery of holistic palliative care; outcomes show better quality of dying as a result of the intervention. More information: www.eupace.eu

5.1 Long-term care

Challenges include lack of access, especially in rural and remote areas; lack of affordability, partly due to weak social protection²⁴; underfunding of services and difficult working conditions (including prevalence of abusive situations²⁵); the prevalence practices of forced institutionalization, without written consent; the lack of consultation of older people in designing care and support policies and legislation; the diversity of services involved and the lack of coordination and integration amongst them.

5.2 Palliative care

Misconceptions make palliative care too often accessible only at the very end stages of life, or only to those living with specific illnesses; a lack of cooperation between care providers reduces access to integrated palliative care and the respect of end-of-life wishes; the lack of access to palliative care outside the hospital setting, which has an impact on the inclusion of older people in the community.

Question 7: Does the design and implementation of normative and political framework related to long-term and palliative care include an effective and meaningful participation of older persons?

- Both for long-term care and palliative care, participatory practices in designing services are scarcely reported. Some countries do include the obligation to consult formally older people regarding policies that affect them, including care and support and palliative care.²⁶
- Whereas consultations are often meaningful and do take older persons' views into account, it is reported that in many occasions such consultations do not deliver outcomes or are merely consultative.

Question 8: What judicial and non-judicial mechanisms are in place for older persons to complain and seek redress for denial of their right to long-term and palliative care

- National legislations do generally provide for the possibility for complains through their national human rights institutions. Mechanisms specific to the context of care and support include mechanisms for the prevention of abuse and maltreatment in care, and the obligation for services to have complain mechanisms; whereas these seem to apply more frequently to residential settings, there are cases where home care providers are also required to have complain systems²⁷.
- However, there are frequent reports that such mechanisms are most often unknown, and that older persons may experience a variety of barriers in filing complains²⁸.

²⁴ Muir, T: "Measuring social protection for long-term care", *OECD Health Working Papers*, No. 93, OECD Publishing, 2017

²⁵ European Network of National Human Rights Institutions (ENNHRI): "*We have the same rights*". *The Human Rights of Older Persons in Long-term Care in Europe*, 2017

²⁶ In Belgium, for instance, the Flemish region approved a decree that requires the formal consultation of older people regarding policy measures that target, through the Vlaamse Ouderenraad (member of AGE Platform Europe) as an independent representative body. The Vlaamse Ouderenraad was closely involved in recent policy reforms on long-term and palliative care, both through formal consultation and in informal preparatory policy meetings. In Slovenia, the Federation of Pensioners' Associations (member of AGE Platform Europe) was included in the process of designing the national long-term care act.

²⁷ As it is the case in Belgium.

²⁸ These include the lack of support to filling complains or abusive situations older people may be experiencing and the asymmetry of power in the context of care.

ANNEX – Normative elements of the rights to long-term and palliative care

1. Long-term care

- **Affirmation of the right:**

Older persons have the right to affordable, accessible, appropriate, integrated, quality, timely, holistic, care and support services which are adapted to their individual needs, promote and protect their well-being and maintain their autonomy, independence and ensure their integration in the community, without discrimination of any kind.

- **Scope of the right:**

This right applies to all settings, public and private, including, but not limited to home, in the community, and in residential settings.

The right to care and support is independent of the income of family members and should be made effective in combination with the right to social security and social protection.

The right to care and support should ensure older persons have choice and control over care and support services which are adapted to their individual needs and preferences; it should be fully compatible with the right to autonomy and independence.

- **State obligations:**

States Parties shall have a duty to take all appropriate measures:

- To ensure free, prior and informed consent of the individual as they access any care and support service.
- To ensure older persons have control over the planning, delivery and monitoring of their care and support and can opt out of the care and support service at any time.
- To ensure the ability of older persons to provide advance directives and guarantee these are respected.
- To ensure community services and facilities for the general population are available and accessible on an equal basis to older persons and are responsive to their needs.
- To ensure adequate funding and social protection to enable the access of older people to quality care and support that is affordable.
- To ensure access and support to participate in the community and in social, cultural, public and political life and educational and training activities on an equal basis with others
- To take measures to ensure that safety in care and support does not collude with the right of older persons to autonomy and to independence.
- To ensure all care and support service providers, including professional and informal providers, receive education, training, supervision and support, including respite, and are subject to laws, policies and procedures to protect older persons from violence, abuse and neglect.
- To include access to assistive technologies and participate in design, development and evaluation of assistive technologies and devices.
- To involve older persons in the research, design, development and monitoring of care and support services, including assistive technologies.
- To ensure quality standards for care and support services are based on human rights principles.
- To ensure public awareness to safeguard the rights of older persons receiving care and support in any setting.
- To ensure older persons have access to information about their health status so their decisions can be free, prior and informed.

- To ensure older persons have access to information about available care and support services, including assistive technologies, so they can effectively use, select and opt out of care and support services.
- To ensure older persons have access to information and training on the use of assistive technologies, including digital and technical skills, so that they can evaluate the risks and benefits of different care and support services and make informed decisions based on this.
- To ensure older persons have access to redress mechanisms for practices that restrict their liberty and autonomy or for issues around pricing, quality, and the protection of human rights in care.

2. Palliative care

- **Affirmation of the right:**
Older persons have the right to timely, quality, accessible and holistic palliative care services, without discrimination of any kind.
- **Scope:**
The right to palliative care applies to all settings, public and private, including, but not limited to home, in the community, and in residential settings.

The right to palliative care applies to the treatment and assessment of pain and of physical, psycho-social and spiritual problems, in the context of a life-threatening condition. It must not be limited to a specific health condition.

The right to palliative care should be made effective including in relation with the right to care and support.

- **State obligations:**
States Parties shall have a duty to take all appropriate measures:
 - To ensure the availability, accessibility, affordability and acceptability of palliative care services in all settings, including at home, in the community and in residential settings, and to respect older persons' wishes and preferences.
 - To ensure minimum standards in the provision of palliative care in care and support services, across all settings, including by facilitating guidance on the implementation of high-quality palliative care.
 - To allocate funding to enable the implementation of evidence-based palliative care across care and support services.
 - To ensure the availability and accessibility of opioids and palliative medicines, and adequate controls and monitoring.
 - To ensure free and informed consent of older people and ensure access to support to make decisions regarding palliative care.
 - To ensure older persons have access to information about palliative care, including challenging stigma and misconceptions, so they can effectively access it.
 - To respect the advance directives and living wills of older people, including regarding palliative and end-of-life care.
 - To ensure all care and support service providers, including professional and informal providers, receive education, training and supervision regarding the delivery of and access of older people to palliative care.
 - To involve older persons in the research, design, development and monitoring of palliative care.