



20th April 2018

Questions on long-term and palliative care

AGE Platform Europe input

This short answer is submitted in reply to the call of the Chair of the Open-Ended Working Group on Ageing (OEWG) to NGOs. 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 and desk research using sources referenced in this document.

Separate answers covering normative elements on freedom from violence, abuse and neglect and equality and non-discrimination, as well as questions on autonomy & independence are also submitted.

Further resources:

- [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

- In the European Union (EU), there is no common legally binding definition of long-term care (LTC); however, there are EU policies that contain definitions, such as an EU report³ that defines it as a range of services encompassing care for both self-care⁴ and for activities related to independent living⁵. Such definition focuses on social care and overlooks the support that older people with care needs might need to effectively live independently and autonomously, including through participation in the cultural, economic and social life. It also ignores the support oriented towards enabling rehabilitation and prevention.
- The European Pillar of Social Rights includes a right to affordable and quality LTC, especially home care and community care; however, this is a non-binding instrument.
- 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 a non-binding instrument.
- ILO recommendation R202 lays down principles for universal access to social protection that should apply also to developing access to LTC⁶; however, references to such instrument are scarce across Europe.

Questions 2 & 4

- Lack of access, unaffordability and low quality are issues consistently reported across European Union countries.
- An estimated 30% of older persons lack access to LTC in the region⁷, with substantial gaps in access in all countries⁸ for all levels of care and support needs. Moreover, some services have discriminatory practices in admission driven by the search of profitability.
- Affordability issues are due to the relatively weak social protection for LTC in the EU (1.7% of GDP on average), which is most often a highly means-tested safety net and not a universal entitlement. When social protection is available, hours of care covered are often insufficient⁹.
- Because of the scarcity of resources, difficult working conditions and care services that overlook the dignity of care recipients, quality is a concern, with cases of violence, abuse and neglect reported across the spectrum of care services¹⁰. Reforms aiming to contain costs have aggravated the situation¹¹.

³ [Adequate social protection for LTC needs in an ageing society. Report prepared jointly by the Social Protection Committee and the European Commission](#), 2014

⁴ Self-care or Activities of Daily Living in the report include "bathing, dressing, eating, getting in and out of bed or a chair, moving around, using the toilet, and controlling bladder and bowel functions".

⁵ Activities related to independent living or Instrumental Activities of Daily Living include "preparing meals, managing money, shopping for groceries or personal items, performing light or heavy housework, and using a telephone".

⁶ Scheil-Adlung, X.: "[LTC protection for older persons: A review of coverage deficits in 46 countries](#)", *Extension of Social Security*, Working Paper No. 50, International Labor Organization, 2015

⁷ Idem

⁸ [Adequate social protection for LTC needs in an ageing society](#). For instance, 20.6% of those between 65 and 74, and 32.6% of those over 75 report limitations in daily activities in Sweden, but only 16.3% of those over 65 receive LTC. This gap is bigger in most countries, up to 73.4%-88.9% of older persons reporting limitations in Slovakia, where only 3.2% of them are receiving care.

⁹ [This joint European Commission-OECD report](#) analyses social protection for LTC in several EU countries and shows gaps in protection.

¹⁰ WHO: [European Report on preventing elder maltreatment](#), 2011

¹¹ These include, for instance, the underfunding of the law of personal autonomy in Spain; the abolition of the LTC insurance in the Netherlands; the reform of social care in the United Kingdom that has put a reportedly unsustainable financial burden on local authorities; the closing of residential care in Portugal or Belgium without home or community-based alternatives.

- Relatives and other informal carers (friends, neighbours), mostly women, remain the main providers of care (around 80%)¹²; in most countries they are legally responsible for providing and/or covering the costs of care that the older person her/himself cannot afford.
- As a consequence, the ability of older persons to live autonomously and independently, as well as free from violence, abuse and neglect, is seriously at risk.

Question 3

- EU countries fund their LTC systems in different ways (tax-based or social insurance)¹³, but none offers full protection for care and support needs. An explicit legal entitlement to LTC will ensure sufficient and sustainable funding for support and avoid reported impacts of cost-containment measures in access to care.
- Training care professionals and offering them proper working conditions are needed to ensure the quality of services, the elimination of restrictive practices (allowed in many EU countries) and the physical integrity of older persons in need of care and support.

Question 5

- There is no binding legislation Europe-wide defining palliative care. 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.

Questions 6 & 7

- According to WHO, older people suffer unnecessarily due to lack of access to palliative care. There is evidence that people over 85 are less likely to access palliative care than younger individuals, and older persons living with dementia are particularly at risk of lacking access¹⁴.
- Discriminatory treatment is driven by the persistence of misconceptions, both in society and among care professionals, about the holistic meaning of palliative care, which is wrongly associated only with end-of-life situations or to specific illnesses, such as cancer. Older persons with chronic conditions that may ultimately lead to death are therefore particularly affected. Other factors of discrimination include lacking a proper diagnosis¹⁵.

Question 8

- Across Europe, there is unequal integration of palliative care into health and LTC policies for older people or ageing strategies, with some countries having developed their legislations in this area and others having taken irregular or no action¹⁶.
- As stated in the Council of Europe CM(2014)2 recommendation, integration and coordination of care services is an essential condition to ensure access to quality palliative care.

¹² [Data provided by Eurocarers](#), European network of informal carers.

¹³ See [paper on funding of LTC](#) published in the framework of a peer review between EU countries on this matter.

¹⁴ World Health Organization: [Better palliative care for older people](#), 2004

¹⁵ Lloyd, A. et al.: *Why do older people get less palliative care than younger people?*, European Journal of Palliative Care, 2016

¹⁶ A mapping of countries' action on access to palliative care for older people living in LTC facilities is available [here](#).

Guaranteeing a right to person-centered, quality LTC and a right to palliative care are intimately intertwined, as palliative care addresses physical, spiritual and psycho-social needs; holistic palliative care is therefore an intrinsic element of good LTC for people with a life-threatening condition.

- Given such relationship, lack of access to LTC has a negative impact on access to quality palliative care and to older people's ability to make choices about the conditions and place of dying¹⁷.

Question 9

- There are innovative practices seeking to improve LTC, which include initiatives that focus on empowering older persons with care and support needs to regain autonomy¹⁸, or health and social care providers working towards integrating their services¹⁹.
- Practices for the integration of holistic palliative care into LTC include the "Six Steps to Success" programme in the United Kingdom, which educates professionals to deliver palliative care in care homes. Such programme is being tested across six European countries²⁰.
- Other initiatives include voluntary European frameworks developed by civil society organisations on the dignity of older persons in need of care and the quality of care services, which aim at influencing policymaking and practice in line with a rights-based approach²¹.

¹⁷ World Health Organization: [Better palliative care for older people](#), 2004

¹⁸ More information on this initiative, put in place in Fredericia (Denmark), is available [here](#).

¹⁹ Some of such integrated care initiatives are available in the [website of the SUSTAIN project](#).

²⁰ For more information, consult the [website of the PACE project](#).

²¹ Both the European Charter of the rights and responsibilities of older persons in need of care and assistance and the European Quality Framework for LTC services are available [here](#).