

Information on the situation at European Union level, provided by the European Commission¹

Guiding Questions: Long-term 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?

Across the EU, LTC (Long Term Care) for older people refers to a range of services and assistance for persons who over an extended period of time are dependent on help with basic activities of daily living (ADLs)¹ and/or instrumental activities of daily living (IADLs)². National definitions, however, vary. In Member States with extensive provision, social protection against LTC risks also increasingly includes measures that help prevent, postpone or mitigate the onset of LTC needs.

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

LTC for older people faces the same challenges³ across the EU Member States – those of universal **access**, high **quality** and long-term **sustainability**. These challenges are growing by the demographic development and by insufficient availability of professional LTC staff.

3) What measures have been taken/are necessary to ensure high-quality and sustainable long-term care systems for older persons, including for example:

- Sufficient availability, accessibility and affordability of services on a non-discriminatory basis?
- High quality of services provided?
- Autonomy and free, prior and informed consent of older persons in relation to their long-term care and support?
- Progressive elimination of all restrictive practices (such as detention, seclusion, chemical and physical restraint) in long-term care?
- Sustainable financing of long-term care and support services?
- Redress and remedy in case of abuse and violations?

Member States are responsible for their LTC policy. The EU promotes cooperation between EU countries in this field - through the **open method of coordination**⁴ and the **European semester**⁵- in particular on closing the gap between the supply and demand for long-term care by exploring how to extend or restore older people's autonomy and capacity to live independently. The EU supports governments in exchanging practices and in applying policy reforms in the fields of health and long-term care.

The EU **Pillar of Social Rights**⁶ has put the right to affordable long-term care services of good quality, in particular home-care and community-based services, firmly into the European social model. As part of the

¹ ADLs: Activities of Daily Living are self-care activities that a person must perform every day such as bathing, dressing, eating, getting in and out of bed or a chair, moving around, using the toilet, and controlling bladder and bowel functions.

² IADLs: Instrumental activities of daily living are activities related to independent living and include preparing meals, managing money, shopping for groceries or personal items, performing light or heavy housework, and using a telephone.

³ COMMISSION STAFF WORKING DOCUMENT on Long-term care in ageing societies - Challenges and policy options, 2013, [file:///C:/Users/eriksdj/Downloads/SWD_Long-term-care_en%20\(2\).pdf](file:///C:/Users/eriksdj/Downloads/SWD_Long-term-care_en%20(2).pdf)

⁴ http://eur-lex.europa.eu/summary/glossary/open_method_coordination.html?locale=en

⁵ https://ec.europa.eu/info/business-economy-euro/economic-and-fiscal-policy-coordination/eu-economic-governance-monitoring-prevention-correction/european-semester_en

⁶ <http://www.consilium.europa.eu/en/press/press-releases/2017/11/17/european-pillar-of-social-rights-proclamation-and-signing/> Signed on 17 November 2017 by the Council of the EU, the European Parliament and the European Commission during the Gothenburg Social Summit for fair jobs and growth.

European Pillar for Social Rights, the '**New Start**' initiative⁷ addresses the work-life balance challenges faced by working parents and carers.

Studies, data and evidence

A 2014 joint Report⁸ by the European Commission and the Social Protection Committee examined LTC challenges across the EU Member States.

The European Commission is working with the OECD on LTC costs⁹ and LTC workforce, and is supporting a number of NGOs and policy networks working on LTC.¹⁰

The European Commission also funds and promotes the SHARE survey of Health and Ageing¹¹. This collects and analyses information on the financial and LTC-need situation of older people.

The **Active Ageing Index** is a joint project of UNECE and the European Commission¹². It is a tool to monitor the status and progress of policies aiming to develop environments that allow older people to live more healthy, active and independent lives. It underlines that being active is not only about work or volunteering. Rather, access to health, living independently within a supportive community, having sufficient financial means, security, education, and more are all aspects of older people's lives that need to be addressed together.

Recognising that active ageing is largely a matter for local policies, the Index is flexible and can adapt to local needs and preferences, and the data availability. While it was started in the EU, it has been successfully applied outside Europe, as international researchers have established the usefulness of its data for policy orientation

4) 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 EU funded EUSTaCEA project (2008-2010) developed a European Charter for the rights and responsibilities of older people in need of care and assistance¹³. The Charter aims to clarify what are the rights of older people in need of care. It includes 10 articles, 9 rights and one article on responsibilities: •Art. 1: Right to dignity, physical and mental well-being, freedom and security; •Art. 2: Right to self-determination; •Art.3: Right to privacy; •Art. 4: Right to high quality and tailored care; •Art. 5: Right to personalized information, advice and consent; •Art. 6: Right to continued communication, participation in society and cultural activity; •Art. 7: Right to freedom of expression and freedom of thought/conscience: beliefs, culture and religion; •Art. 8: Right to palliative care and support, and respect and dignity in dying and in death; •Art. 9: Right to redress; •Art. 10: Your responsibilities.

Based on this Charter there were EU funded follow-up projects resulting in a European Quality Framework for long-term care" and a "European Quality care training package".

In 2013 the EU adopted a Directive to protect and support victims of crime that had to be transposed by national governments by 16 November 2015¹⁴. The Directive aims to **guarantee access to adequate and quality services to all victims**, and support cooperation between different stakeholders, and the development

⁷ <http://ec.europa.eu/social/main.jsp?catId=1311&langId=en>

⁸ Joint EC/SPC Report on Adequate social protection for long-term care needs in an ageing society, 2014, file:///C:/Users/eriksd/Downloads/DGEMPL_LTCReport_Accessible_v3.0.pdf

⁹ Measuring social protection for long-term care, Report after 1st phase, http://www.oecd-ilibrary.org/social-issues-migration-health/measuring-social-protection-for-long-term-care_a411500a-en

¹⁰ For example, the European Social Policy Network (<http://www.esn-eu.org/publications/index.html>), the Eurocarers (<http://www.eurocarers.org>), the AGE Platform (<http://www.age-platform.eu/>)

¹¹ <http://www.share-project.org/>

¹² <https://www.unece.org/population/aai.html>

¹³ www.age-platform.eu/images/stories/22204_AGE_charte_europeenne_EN_v4.pdf

¹⁴ <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2012:315:0057:0073:EN:PDF>

of specialized victims support services. While elder abuse is not explicitly mentioned, the directive includes an article forbidding age discrimination and discrimination based on disability in accessing victim support services.

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

Action in the field of health largely falls on the Member States. The EU has a two-fold role in the field of health. Firstly in the regulation of medicines and healthcare professions, and secondly in the promotion of health and healthy lifestyles. However, formal recognition of long-term care and palliative care professionals is not done at the EU level. There is no legal provision on palliative care in EU law. The Council of Europe has issued in 2003 a Recommendation on the organisation of palliative care¹⁵. Most EU Member States have in the last twenty years introduced legal provisions on palliative care in national law. The guiding questions 6,7,8 can be better answered at the national level.

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

7) To what extent is palliative care available to all older persons on a non-discriminatory basis?

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

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

Recently the EU funded a project on Human Rights for Older People in Long-term care¹⁶, which examined the key trends in the human rights situation relating to LTC in Europe and how to promote a human-rights based approach to long-term care.

ⁱ Individual EU Member States give in their own contributions information on the situation and legislation at the level of their country.

¹⁵ [https://www.coe.int/t/dg3/health/Source/Rec\(2003\)24_en.pdf](https://www.coe.int/t/dg3/health/Source/Rec(2003)24_en.pdf)

¹⁶ <http://www.ennhri.org/Human-Rights-of-Older-Persons-in-Long-Term-Care>