

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

Bulgaria

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- 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?

- there are some options for supporting elderly people, who need long term care in Bulgaria, but there is NO definition in Bulgaria for long-term care stated in formally adopted documents, respectively juridical frame, standards etc. Of course, part of these problems is mentioned in different documents, and on governmental, municipality and community level there are different options for help and support. Majority of medical problems and needs for medical care are managed through General practitioners using the options of the annually signed and every year changing agreement between the national health insurance fund and the Bulgarian medical association. Some support is given by the Ministry of Labor and Social Policy, municipalities, Bulgarian Red Cross, NGO etc. But the main part of care for those patients is family responsibility. Another problem is the growing number of single elderly patients needing long-term care. The existing options are: homes for elderly both run by the government (difficult to be admitted there, long period of waiting, available in the big cities and insufficient etc.) and private (too expensive for the majority of those who need care, not appropriate for long-term or chronically ill etc.) and hospices (insufficient, concentrated in or around big cities, quite expensive and working partially with not trained staff, because Long Term And Palliative Care ARE NOT recognized as medical specialty or even as a subspecialty in Bulgaria. Usually the GPs working in the region and have signed agreement with the National Health Insurance Fund are responsible for this homes for elderly or hospices and provide medical care using the existing health care system. The hospices usually do not have medical doctors on constant working positions and rely on GPs or part-time doctors and nurses, also nonmedical staff is working there.

There is a system for people with disabilities – usually they are called “long term patients”, financing some of their needs and the documents could be found on the web-site of the Ministry of Labor and Social Policy.

The most important point is that palliative and supportive care are NOT DEINED AND are EXCLUDED.

Please find here a

[PDF] [Long-term care – the problem of sustainable financing \(Ljubljana, 18 ...](https://ec.europa.eu/social/BlobServlet?docId=13216&langId=en)
ec.europa.eu/social/BlobServlet?docId=13216&langId=en

A report

https://ec.europa.eu/info/sites/info/files/file_import/joint-report_bg_en_2.pdf

is giving also info about the situation, but the faced realities a different. There is also a World Bank report in the field from 2010

<https://openknowledge.worldbank.org/bitstream/handle/10986/27848/584530WP0Box351Final1November212010.pdf?sequence=1&isAllowed=y>

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

- NO regulations are officially approved and adopted concerning older persons in accessing long term care
 - There are no officially approved by the Ministry of health_training programs for acquiring specialty (or subspecialty) in long term and palliative care, there are not enough specialists and trained medical and nonmedical staff respectively, to solve the huge amount of problems of those patients and their families
 - to assess quality of life for those patients and their families in Bulgaria is a great challenge
 - to reveal hidden problems
 - to focus attention on the spiritual needs both for patients, families and carers
 - the place for long-term and palliative care is in primary care/general practice and we need to focus our efforts there – education, facilities etc.
 - Insufficient opportunities through the healthcare system and General practitioners, respectively higher frequency of hospitalization for medical conditions, which could be successfully managed on outpatient basis.
 - Marked negative tendency for reducing the number of GPs and increasing of their age (aging GPs (and healthcare practitioners as a whole))
 - Marked negative tendency for reducing the number of nurses in Bulgaria
 - To reduce out-of-pocket payments for these patients and their families
 - low income for pensioners (low pensions (poverty) and additional payments needed for receiving long term and palliative care
 - lack of understanding of the problem from the authorities and governmental institutions
 - no financial support, even we try hard to find it through national and/or international projects
- FINANCES ARE CRUCIAL FOR ESTABLISHING AND MAINTAINING HIGH QUALITY LONG-TERM AND PALLIATIVE CARE (for education, research, covering medical and nonmedical needs etc)

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

- elaborating and adopting formal juridical documents in the field (not only for people with disabilities) and social contingent (socially vulnerable groups)
 - Adopt proposed by us and improved accordingly to the international standards educational and training programs at all educational levels
 - Sustainable financing of this education
 - Financing research and projects in the field
 - Organizing hospital departments for long term and palliative care, hospices and daily services for those patients (organized years ago and now closed because of financial reasons)
 - Raising the awareness in the society in order to improve the understanding and importance of these problems
 - Raising awareness on the ageism, especially when receiving medical help, incl. emergencies
- Sustainable financing of long-term care and support services

Although long term and palliative care for elderly are essential part of the National health strategy plan 2014-2020 of Ministry of health (1) and is adopted by the National Parliament (2) virtually everything remains on paper and nothing is done in practice

(1) [www.parliament.bg/pub/cw/20140124042637Nacionalna%2520zdravna%2520strategia%25202014-2020%2520\(3\).doc&usg=AOvVaw1ZD8K_Ru-FuIKAP9eZUIJy](http://www.parliament.bg/pub/cw/20140124042637Nacionalna%2520zdravna%2520strategia%25202014-2020%2520(3).doc&usg=AOvVaw1ZD8K_Ru-FuIKAP9eZUIJy)

(2) <http://www.parliament.bg/pub/cw/20151120030041Nzs-2020.pdf>

- Redress and remedy in case of abuse and violations?
 - 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?
 - to be treated with respect, avoiding ageism especially in emergency situations
 - to have more opportunities for dignified life in time of chronic illness and in last days of life
 - to have unrestricted access to complementary medicine facilities, art therapy etc. for improving quality of life
 - 4) In your country/region, how is palliative care defined in legal and policy frameworks?

The right of affordable, quality and unconditional palliative care of every Bulgarian citizen with an incurable disease is defined in Articles 95 and 96 of the National Health Act

https://www.mh.government.bg/media/filer_public/2016/12/08/zakon_za_zdraveto.pdf

In practice National Health Insurance Fund reimburse only **ONE clinical pathway for palliative care for terminal cancer patients** for 20 days for six months, which in practice is discriminating against patients who need palliative care both on diagnosis and on time, as such limitations in the National health act are not foreseen.

- 5) What are the specific needs and challenges facing older persons regarding end-of-life care? Are there studies, data and evidence available?
- 6) To what extent is palliative care available to all older persons on a non-discriminatory basis?

Palliative care is defined by the National Health act only for patients with incurable disease regardless patient's age, but in practice elderly persons suffering for any other incurable life-threatening disease except cancer are discriminated by the National Health Insurance Fund, as palliative care for other diseases are not reimbursed.

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

Providing palliative care is a part of National Standard for Medical Oncology and any hospital that provide medical oncology should also provide palliative care. The existence of palliative care units is mandatory for the issuing of a license for the activities of Comprehensive cancer centers in Bulgaria.

- 8) Are there good practices available in terms of long-term care and palliative care? What are lessons learned from human rights perspectives?
 - A Bulgarian Long term and palliative care society was established, which has held three national conferences with international participation.
 - The society publishes the Folia Palliatica journal.
 - A standard of palliative care has been developed and proposed to the Ministry of Health
 - Education in palliative care for nurses was developed with the help of MATRA foundation from the Netherlands and was implemented in several Nursing colleges in Bulgaria.
 - Several textbooks and guides on palliative care for nurses and doctors have been published. Palliative care is also part of the GP's textbook
 - Palliative care is a mandatory part of annual evidence based guidelines of medical oncology.

In the last years there are NO profound nationwide studies on the needs, services and care provision for elderly who need long term and/or palliative care in Bulgaria. No standards – only a project for palliative care standard, not officially approved and adopted, no accredited programs in the field instead of our efforts and regular proposals to the Ministry of health. I have developed and proposed such a programs for all educational levels /nurses – bachelors, masters – medical students, postgraduate – for MDs incl. GPs, anaesthesiologists, oncologists, paediatricians etc. medical specialists, and PhDs since 2003rd but without success. The only working activity is my CME postgraduate courses in pain management and long term and palliative care 40 hours.

We need to organize a national study to reveal and assess the current situation in Bulgaria focusing on aging and chronically ill population, on the services officially available (their real

contribution to care), to map the Bulgarian territory accordingly to the results, to define patient groups and needs, to propose working decision and documents in the field and to convince our Ministries and to force them to adopt standards, educational programs and ordinances focused on long term and palliative care patients.