

Guiding Questions for the focus areas of the IX Session of the Open-ended Working Group on Ageing:

Long-term care 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?

Long-term care is defined as one or more services provided to maintain the functional abilities of a chronic patient to the maximum possible level of his physical, mental and social well-being, both at home and in a specialized institution. This type of assistance is one of the priorities of the National Strategy on Aging (2016), is also determined by the order of the Ministry of Health (from 01.19.2016 No. 38n) (1). Counseling at home, in district clinics, in hospitals.

1. <https://www.kp.ru/daily/26612/3630248/>

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

- Absence of geriatric doctors, regional leaders of such a service
- Absence of profile geriatric structures (cabinets, departments in hospitals)
- poor treatment, poor awareness of elderly patients (1).

1. <http://www.mgzt.ru/n-4-ot-31-yanvarya-2018-g/geriatriya-territoriya-trevogi-i-zaboty>

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?

In 2014 and 2016, the government reported on the creation of health and social services as close to the place of residence of older people and accessible to all in need (1,2); focus on preventing isolation and violence. Since 2017, the government has been implementing pilot projects (federal funding) for long-term assistance in 5 regions of the country to improve all aspects of this model

(3). As reported by the government (February 2018), an information register of the elderly who need long-term care services will be created (4).

Since 2004, the institution of the foster family for single elderly people has been developing, which is defined by federal legislation and already exists in 30 regions of Russia (5).

Since long-term care is completely new, the quality of services is still low, as is affordability; this applies, for example, to private long-stay homes, some of which have identified retention and other forms of abuse. Such organizations are checked by the prosecutor's office and are closed.

1. <https://www.kommersant.ru/doc/2825749>

2. <https://rg.ru/2014/02/11/sozium.html>

3. <https://vnnews.ru/medicine/61126-novgorodskaya-oblast-stanet-pilotnym-regionom-dlya-vnedreniya-sistemy-dolgovremennogo-ukhoda-za-pozhilymi-lyudmi.html>

4. <http://gubernia.pskovregion.org/news/pskov-stanet-pilotnym-gorodom-po-vnedreniyu-sistemy-dolgovremennogo-uhoda-za-po/>

5. <http://posobie-help.ru/subsidii/semeynye/opredelenije-priemnim-semijam.html>

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?

A law on the licensing of private homes for the elderly is needed, the need for this Law was not spoken by the ombudsman of the Perm region. Only about half of the country's regions have adopted their own Foster Family Laws for the elderly. There is no federal law on such a foster family.

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

The Federal Law of the Russian Federation "On the Fundamentals of Health Care for Citizens in the Russian Federation" (2011) first identified palliative care as a separate species, in 2012 a special order was issued by the Ministry of Health to create a palliative service that determined who receives this assistance, in what forms, and financing and guarantees of state free assistance, a basis for the training of medical specialists was created (1).

1. <http://www.aif.ru/health/life/1157528>

6) What are the specific needs and challenges facing older persons regarding end-of-life

The main problems: the availability of adequate pain relief therapy - there are administrative restrictions for prescribing narcotic drugs; lack of specialists in this field; the lack of institutions for home care and home nursing (1,2). Studies, including, academic, and data are available (3,4).

1. <http://www.aif.ru/health/life/1157528>

2. https://vademec.ru/news/2016/03/04/v_rossii_postepenno_razvivaetsya_palliativnaya_pomoshch_n_eizlechimo_bolnym/
3. http://www.budget-solution.ru/projects/palliative_care_SPb
4. <http://www.dissercat.com/content/nauchnoe-obosnovanie-organizatsionno-funktsionalnoi-modeli-sistemy-palliativnoi-pomoshchi-na>

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

State palliative care is free, but there are only about 100 specialized clinics in the country, and up to 500 (1) are needed; the greatest shortage of palliative care institutions in the country's regions is due to which many oncologists are at home. For some patients there are paid institutions of palliative care, but experts say that 80% of these patients have material problems. 2/3 patients staying at home do not have information about available social services at their place of residence.

1. <https://www.kp.ru/guide/palliativnaja-pomoshch.html>

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

It is reported that up to 40% of patients with palliative care receiving home care need better housing (1); Data from the questionnaires of patients / family members revealed problems in providing care and services: drug shortages in pharmacies, access to pain medicine, distance to pharmacies and clinics, waiting in line, the need for return of ampoules and patches; non-invasive analgesics received only 26% of patients in the country, and 40% of patients with invasive analgesics (3). Defects of care at home lead to an increase in the length of stay in hospitals (2,3).

1. <https://www.kp.ru/guide/palliativnaja-pomoshch.html>
2. <http://www.remedium.ru/health/detail.php?ID=69760>
3. <http://www.mgzt.ru/content/palliativnaya-pomoshch-vremya-reformy>

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

As part of the creation of a national long-term care system, it was reported that a "single information registry of citizens in need of long-term care" (1), the desire to create a maximum range of services at home, excluding inpatient treatment (2).

In Moscow, a pilot project is under way to create a model of outpatient personalized care for older people in need of palliative care (3).

Lessons on respecting the rights of older people:

- Increasing the responsibility of the government to create care systems for the elderly, the development of public awareness systems, the elderly about long-term care problems, including palliative care, the sources of resources for patients and their families; improvement of the quality of life of the population, incl. housing conditions, drug provision, creation of medical and social infrastructures, including training of professionals; support for the activities of social non-governmental organizations;
- increasing the role of civil organizations in long-term care, including palliative: the creation of specialized non-governmental organizations; improved monitoring of the condition of care and rights of elderly patients / clients; partnership with state organizations in these areas.

1. <http://gubernia.pskovregion.org/news/pskov-stanet-pilotnym-gorodom-po-vnedreniyu-sistemy-dolgovremennogo-uhoda-za-po/>
2. <http://smi44.ru/news/society/v-kostromskoy-oblasti-vnedryaetsya-sistema-dolgovremennogo-ukhoda-za-lyudmi-pozhilogo-vozrasta/>
3. <http://www.mgzt.ru/content/palliativnaya-pomoshch-vremya-reformy>

