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?

   The Fundamental Law of Hungary states that, by means of separate measures, Hungary shall protect families, children, women, *the elderly* and persons living with disabilities. (Article XV, Paragraph (5))
   Act III of 1993 on Social Governance and Social Benefits contains rules relative to the social care system and determines the frameworks of providing care for the elderly as well. Within the frameworks of long-term care, the elderly may receive care, first and foremost, in residential institutions; in addition, they may also receive in-home support, as well as early-warning-enabled home assistance. Persons living in their own homes, who, due to their age, are in need of social or mental support and partially capable of taking care of themselves, may also receive day care.
   Residential institutions and retirement homes are institutions that provide nursing and care to people over the statutory retirement age who are in need of care specified by the law but do not require regular in-patient care. These institutions may be maintained by the state, the churches, or non-state/non-profit actors.

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

   In our activities, we have to deal mainly with problems related to residential homes for the elderly. As far as availability is concerned, one of the main problems is the length of the waiting lists; waiting time may range from a couple of months to one and a half years – six months in average.
   Another difficulty is that only persons with needs for care specified by the law may be admitted to such homes for the elderly. As a result, the elderly persons admitted are usually in a rather poor physical, health condition and, quite often, in a bad mental state; providing care to these people places a heavy and growing professional and financial burden on the already underfunded social sector. The system of providing residential care is going through a transformation: in addition to the traditional homes for the elderly, new professional care centers are emerging, catering to those who need nursing but do not require in-patient care or permanent medical supervision. We do not have any practical experience yet relative to the operation of these centers.

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

   Among the recent governmental measures, we should point out the revision of the concept of "need for care", and the development of certain services' infrastructure using funds received from the EU (e.g., renovation of residential home units, expansion of support services and home assistance). We also have to note, however, that these changes have not yielded any substantial result; the measures taken by the government even have a particularly negative impact on the "group composition" of those taken care of in homes for the elderly as far as their needs for care and health conditions are concerned. We provide herein some examples of the measures required, recommended in order to remedy this situation.

- Sufficient availability, accessibility and affordability of services on a non-discriminatory basis?

It is necessary to increase capacities and expand the service network.

- High quality of services provided?

Eliminating the shortage of professional staff and, to this end, increasing the social and material recognition of this sector's workers, providing real career opportunities in elderly care (social work).

- Autonomy and free, prior and informed consent of older persons in relation to their long-term care and support?

Wider dissemination of knowledge, raising legal awareness, and the fundamental rethinking of the institution of caretaking would be important.

- Progressive elimination of all restrictive practices (such as detention, seclusion, chemical and physical restraint) in long-term care?

To this end, addressing existing infrastructural deficiencies and (both material and personnel) needs would be instrumental.

- Sustainable financing of long-term care and support services?

The restructuring of budgetary sources should be considered in the interest of sustainable financing.

- Redress and remedy in case of abuse and violations?

In this field, the establishment of the Integrated Legal Protection Service and the operation of its patients' rights representative network was a significant and successful measure; however, to increase efficiency, additional educational and legal awareness-raising activities are needed.

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?

Right to receive information, right of self-determination, and, in general, right to human dignity.

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

Within the frameworks of hospice care, palliative care (terminal palliative care) includes all types of supportive treatments aimed at reducing the pain and other symptoms of terminally ill patients, a manifestation of the ethos of hospice and high-level medical expertise within the healthcare system.

Section 99 of the Healthcare Act – Providing care for the terminally ill

(1) The purpose of taking care of dying patients (hereinafter the "hospice care") is to provide physical and psychological care and nursing to persons suffering from a long-term and terminal illness, improve their quality of life, ease their suffering, and help them to preserve their human dignity until death.
(2) For the purpose stipulated in Subsection (1), patients shall have the right to control their pain, ease their physical and psychological suffering, and to have their relatives or other people emotionally close to them by their side.
(3) If possible, hospice care shall be provided in the patients' homes, with their families present.
(4) Hospice care shall include the provision of assistance to the relatives of the dying patients in nursing the terminally ill, and the provision of psychological care to them during the periods of illness and mourning.

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

Comprehensive study:
http://csot.semmelweis.hu/download/tovabbkepzes/palliativ/Hegedus.A.hazai.hospice.es.palliativ.ellatas.pdf

Situation, possibilities and difficulties of hospice and palliative care in Hungary
Hospice-palliative care has been present in Hungary for more than 20 years but physicians know very little about it. The objective of the study is to give detailed practical information about the possibilities and the reasonability of hospice care and the process of how to have access to it. The authors, using the database of the Hungarian Hospice Palliative Association, review and analyze the most recent national data on hospice-palliative care. In addition, legal, financial and educational issues of hospice-palliative care are also discussed. They point out that, at present, there are 90 active hospice providers in Hungary providing care for more than 8,000 terminally ill cancer patients. According to WHO recommendations, much more service providers, institutional care providers and more beds would be needed. Development is hindered by issues of approach and attitude as well: patients are admitted into hospice care too late, and there is a serious lack of information on ordering hospice care. Hospice care is still often confused with chronic or nursing care. The possibility to get a license in palliative care and the compulsory, 40-hour palliative training for resident physicians may improve this situation. The authors conclude that a broad dissemination of data may help to overcome misbeliefs concerning hospice and raise awareness concerning death and dying.

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

Based on the study mentioned at Question 6:
General experience shows that the demand is bigger than the available capacities and growing.

The major issues pointed out by hospice-palliative care providers are as follows:
Approach and attitude:
– patients are admitted into hospice care too late,

– lack of information and cooperation (mainly on the general practitioners' part),
– differences in approach,
– indecisiveness as regards ordering hospice care (e.g., terminal stage).

Financial problems:
– financial difficulties, underfunding,
– searching for other resources,
– issues with the National Health Insurance Fund and the county-level health insurance funds.

Miscellaneous, infrastructural problems:
– shortage of physicians and other health professionals (corrective-gymnastic trainers, psychologists),
– infrastructural problems,
– socially disadvantaged families.

The main issues have not changed since 2010. Problems of approach and attitude predominated in 2013 as well: patients are admitted into hospice care too late, lack of information on hospice care (mainly on the general practitioners' part). In addition, problems related to ordering hospice care, e.g., underfunding and shortage of professionals also played a major part.

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

In Hungary, hospice-palliative care is provided in the following forms:
Based on the statistical survey conducted by the Hungarian Hospice Palliative Association (MHPE) in 2013, 83 healthcare institutions and home services conducted hospice-palliative activities financed by the National Health Insurance Fund:

– 14 hospice units in in-patient institutions (200 beds);
– 64 groups providing in-home hospice care; – 4 mobile hospice teams (hospital support groups);
– 3 palliative out-patient clinics (http://www.hospice.hu/hospice-ok/).

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

We should mention as a good example the INDA program (Inter-professional Dementia Framework Program) conducted in the Gizella Assisted Living Center in Biatorbágy (a private institution maintained by the civil organization Boldog Gizella Foundation) – www.inda.info.hu