

“Will and support for meaning, dignity and respect”

Declaration of the EUROPEAN CONFERENCE ON CARE AND PROTECTION OF SENIOR CITIZENS The Dignity and Hazards in the Elderly

Continuous increases in life expectancy over the last decades strengthen the hopes of most people for fuller use of their potential and for increasing their contribution to close relatives, families, communities and society as a whole.

However, taking advantage of prolonging life in old age usually requires active creation of certain preconditions, active removal of various barriers and obstacles which hinder personal satisfaction and self-fulfillment, and social inclusion, as well as well-being and security.

Until now, increasing life expectancy and the rising proportion of seniors in populations has been a major source of concern rather than grounds for coordinated planning supported by strong political commitment. Although ageing has been recognized as a challenge in relation to pension and health systems, and to labor markets, which are important preconditions for competitiveness and quality of life of current and future generations, it is also necessary to pay greater attention to the aspects of ageing related to human rights, equal access to health, education, housing, social and other services and goods which should be adapted to the needs of frail, disabled or other disadvantaged seniors.

Frail older people with low levels of health potential (with low levels of intertwined hardiness, resilience and adaptability) are especially disadvantaged and at risk. Hazards associated with unadjusted (maladapted) services and practices suitable for younger population are often underestimated as well as the will to find meaning and desire for fulfillment of higher human needs. Among the key values of meaning for frail older people are dignity, respect and self-owning – maintaining uniqueness of personality and real competencies of decision making.

Economical and cultural development in the European Union and in many other countries offers favorable conditions for development and systematic, generally accessible, implementation of “long-term care” (LTC) as qualitatively higher degrees of support and security for frail people at risk or in situation of lost capacities for self-care.

The strength of the concept of long-term care (LTC) lies particularly in coordinated, seamless provision of services and interventions and in breaking down the barriers between various sectors, institutions, competencies, professional boundaries and payment mechanisms. Furthermore it relies on an emphasis on the meaningful of existence of human beings, enabling life in familiar environments while maintaining autonomy and social roles. It also relies on active prevention and on early detection of various forms of mistreatment by ‘caring’ persons (relatives, or professionals), various forms of neglect, abuse or even violence (domestic violence, misuse of restraints etc.).

Dignity, self-esteem and security must not be put at risk even for the most frail seniors and seniors at greatest risk – those who are dying, unconscious, severely disoriented (confused, or those in severe delirium) or suffering from advanced stages of dementia. Even they must not become the objects of cheap provision for basic biological human needs.

Limited public resources require that greater emphasis is placed on the expediency of long-term care (LTC), including active monitoring of care and the use of high technologies. Those, together with active counseling, supervision, and other forms of support for caring families and for professional teams, are the cornerstone to prevent excessive burden, burnout and failure.

The right concept and setting of the system of health services is exceptionally important for the struggle for the quality of life in old age. The level of functional health belongs to the key factors of quality of life. At the same time, non-discriminate support for health, including availability (accessibility and affordability) of health services is a fundamental mark of the equal position of older persons in society. Furthermore, it is necessary to strive for subordination of health care provision to the essential need for meaning of life and not to allow replacement or overlaying of natural social roles in relation to decremental changes and multi-morbidity with the role of „lifelong patient”, subordinated to the powers of health professionals and of regimes of health care. It is thus important to put an emphasis on the key health problems and challenges.

Following on from the French presidency, which focused on Alzheimer disease, neurodegenerative disorders and dementia and other issues related to dignity, the Czech presidency wishes to emphasize the critical importance of the phenomenon of geriatric frailty, i.e. treatable, and thus fully in the competence of health interventions and services, aspects of the decrease in health potential (mutually interrelated hardiness, resilience and adaptability) and frailty-determined multi-causal health problems beyond the limits of the so called “disease-model”.

Very often health problems in old age remain, despite repeated warnings and calls from various geriatric societies (IAGG, EUGMS, SGMEUMS), out of interest of health institutions. The structure of health services, which was developed for the needs of the young populations as well as the structure of education of physicians and other health workers do not very often correspond to those problems.

Frailty and its clinical consequences are thus becoming a source of misunderstanding, unnecessary suffering, discrimination, neglect, preventable disability, avoidable social exclusion, unnecessarily bad prognosis of various diseases and accidents. These are generally severe health challenges for the dignity and security of old people, which are the touchstone of quality of health and social care.

The Prague conference builds on previous EU presidencies, conferences, recommendations and both political and expert documents of European meetings and negotiations, including

- Meeting and recommendations of the conference „*The fight against Alzheimer’s and related diseases*“ held during French presidency of the EU in October 2008 in Paris
- Meeting and recommendations of the conference “*Intergenerational Solidarity for Cohesive and Sustainable Societies*” held during Slovenian presidency of the EU in

- April 2008 in Brdo, which focuses inter alia on long-term care in intergenerational perspective
- *“European silver paper on the future of health promotion and preventive actions, basic research, and clinical aspects of age-related disease”* adopted at the conference held during French presidency in September 2008 in Wroclaw, Poland, and supported by EUGMS, IAGG-ER, EAGP, ISG and ISSAM.
 - Discussion paper of the European Commission *„What can the European Union do to protect dignity in old age and prevent elder abuse“* a following conference on elder abuse held in March 2008 in Brussels
 - *“Healthy ageing: keystone for a sustainable Europe – EU health policy in the context of demographic change”* (2007, discussion paper)
 - Communication of the EC *„Demographic future of Europe - from challenge to opportunity”* (COM(2006) 571 final)
 - A position paper *„Ageing and Health in Europe – Challenges, opportunities and the role of Specialist Health Care for Older People“* for the UNECE Ministerial Conference on Ageing (Berlin, 2002) from the EUGMS and the SGMEUMS
 - Meeting and recommendations of the conference *„eHealth 2009“* held during Czech presidency of the EU in February 2009 in Prague
 - *Madrid International Plan of Action on Ageing (MIPAA)* adopted by the Second World Assembly on Ageing, held in Madrid in 2002
 - *The United nations Principles for older people* adopted by the General Assembly of United nations in 1991
 - *European charter for family carers* supported by the Confederation of Family Organisations in the European Union (COFACE) in 2009

With respect to the challenges and opportunities and in order to support dignified, active and healthy ageing of European citizens, the Prague conference and participating international seniors’ organizations turn to responsible bodies, institutions, academia, public and other relevant stakeholders and call for the adoption and the implementation of the following recommendations.

We address particularly:

A) European Commission and national governments

1) Changes in approach to the old age:

- a) Please strive to ensure that demographic development and arrival of the longevity society are not perceived one-sidedly from the perspective of demographic alarmism or the demographic ‘timebomb’, which is based on the fear of lack of resources for social security and health systems, but are also seen as an opportunity and the chance to change our approach to life in old age.
- b) Encourage open discussions about convention on rights, responsibility, and participation of older people in society
- c) Consider the effect, which may be brought by purposeful, single-minded inclusion and integration of issues related to old age and ageing into government and parliamentary structures, and modulate any division of competencies so that they respond to demographic changes in society and the urgent need to solve them

- d) Consider the establishment of an EU gerontological institution or program aimed at monitoring, education and other roles or tasks related to adjusting policies and services to the needs of ageing populations
- e) Pay attention to arguments that there is continuum of “Elder Dignity, Abuse and Neglect” (EDAN) and that mistreatment of old people, including neglect, abuse or even violence, are not usually isolated phenomena, but the consequence of insufficient respect for/towards older generations, their unclear social role and lack (absence) of flexible support systems for older people with disabilities and for caring families
- f) Include issues related to EDAN and adult protection services in the OMC and strengthen cooperation and exchange of good practice and experience within the EU, including in the area of research
- g) Ask the European Commission to adopt positive strategies on active, healthy and dignified ageing in the EU, which will understand ageing as an opportunity and will formulate concrete recommendations to adjust individual policies, services and goods such as housing, health, education and other services and opportunities and not only focus on the fiscal implications of demographic development, or on prolonging working life
- h) Continue to remove discriminatory age barriers and to strengthen protection against (age) discrimination in various areas of life

2) Respect to cultural and religious heterogeneity

- a) Acknowledge and take into account the cultural and religious diversity (heterogeneity) of today’s Europe; recognize the sense of being uprooted experienced by ethnic and religious minorities; promote respect of the variety of experiences in old age and rights (rightful claims) arising

3) Long-term care

- a) Give more attention to discussion on the adoption of European-wide principles and standards of LTC and to the European concept of geriatrics/gerontology and comprehensive rehabilitation
- b) Participate in the creation of the European concept and standard nomenclature of LTC which will enable continuity of support and care as well as an exchange of intelligent and comprehensible experiences, and examples of good practice while emphasizing an enabling community model of LTC, independent living, and “ageing-in-place/home/community”
- c) Support the development and use of ICT in LTC based on the results of the conference on „E-health“, which was held during the Czech presidency of the EU
- d) Minimize the impact of the global crisis on the financing of health, social and other services, which are precondition of dignified life in old age
- e) Support in the maximum feasible way the de-institutionalization of social and health care services

4) Community life

- a) Recognize and appreciate the meaning of community living of older persons in home environment by creation of permanent appropriate conditions for its development
- b) Appreciate the potential of older persons for economic and social development including the importance of community care and support for local employment and including the importance of older people for re-vitalization of small rural settlements

- c) Open ESF and other financial instruments in the EU to the needs of ageing populations, not only to the working population and labor markets

5) Education and research

- a) Effective political decision making must be based on evidence. Support purposeful and efficient (policy/practice-oriented) research into all areas of life in old age and ageing so that the extent and quality of research projects correspond to the significance of changes in today's society
- b) Recognize the importance of the incorporation of the needs/demands of seniors and longevity society into all levels of educational systems and support the development of education in gerontology and geriatrics

6) Public opinion

- a) Support targeted and efficient measures, especially through the media, aimed at changing the views of society on the role of older generations within society and about life in old age

B) Local and regional authorities and their bodies:

1) Changes in approach to the old age:

- a) Be sensitive to dignity of and hazards for frail seniors as well as to the potential of healthy and active fit seniors.
- b) Do not forget that many lonely old people have no other advocate, help nor anyone to rely on other than their neighbors and their community (municipality) and that caring families need your support as well.

2) Examples of good governance and practices

- a) Exploit to the maximum limit the possibilities of the information global society – chances to share your experiences, examples of good practice within the whole EU as well as all other developed countries
- b) Appreciate the meaning of the urban environment supporting inclusion, health, security, and the adjustment of local transport, housing and other services (policies), and join the age-friendly cities movement (network), implement the principles and recommendations of the WHO Age-friendly cities project

3) Right for lifelong home, support of life in community, long-term care

- a) Respect the right for life time homes, support for ageing in community (in place) and for appropriate social services.
- b) Support the inclusion of seniors into community life, increasing their productivity and self-fulfillment.
- c) Create conditions for the development of comprehensive systems of integrated community support services allowing for independent meaningful life for your frail fellow citizens – including security of contact, early intervention in case of emergencies and senior-friendly provision of quality services
- d) Strive to map and address gaps (“white places” and “no-man’s land”) in the services systems and negative competence conflicts on the edge (margins) of responsibilities of different government departments, ministries and other public administration bodies.
- e) Accept the creation of conditions for comprehensive coordinated LTC, including screening and monitoring (dispensarization) of frail seniors at risk and detecting the

signs of elder abuse, as part of the responsibility of local government and administrative systems.

- f) Take into account the diverse experiences of ageing in urban and rural environments and be sensitive to the problem of real or symbolic displacement of seniors trapped within modern urban processes such as suburbanization and gentrification.

C) The universities, academia:

- a) Pay full and thorough attention to the development of education and research for ageing and ageing and longevity societies, to develop understanding of life in old age, of support of frail older people, and understanding of life in its wholeness without scientific reductionism.
- b) Help to debunk groundless and one-sided demographic alarmism, which severely strengthens prejudice and stereotypes as well as age discrimination
- c) Struggle to ensure that educational curricula aim not only at scientific knowledge and professional skills in specific disciplines, but also to general awareness that dignity, autonomy, and respect are indispensable for meaningful life for all human beings, including frail older people and that even highly developed services must serve to support sensitively, not to be superior to them, or to exclude them.
- d) Strive to ensure that the aim of research is foremost life in old age and factors influencing its quality, not older people as research objects.
- e) Strive for lively connection between research and practice so that research and development respond to the needs of practice and their outcomes are appropriate for practice and are applicable;
- f) Introduce a specific view of ageing into the arena of science, research and education, especially where it hasn't been explicitly present up until now, but especially where such a perspective may extend knowledge and contribute to improvement of the quality of life of seniors and their position in society (e.g. business/ trade, law, architecture, art).

D) Health institutions and systems:

- a) Be aware that the decline of health potential (hardiness, resilience, and adaptability) in old age bring with themselves specific health problems.
- b) Geriatrization of medicine requires more than increasing capacities in reaction to the higher prevalence of age-related diseases, more than partial modification of diagnostic and treatment procedures including their availability without any age-discrimination. What is the issue is deeper transformation, the evolution of medical thinking, education as well as development of the structure of provided health services.
- c) Association of health problems, disability and health-related quality of life with concrete diseases decreases in old age. Mere interest in diagnosis and treatment of diseases often becomes inefficient, many times even harmful. It does not correspond to the variety of biological and also non-biological factors or to strong inter-individual variability of health and treatment priorities in frail and multi-morbid patients. It

therefore must be complemented with qualified interest in other causal and clinical factors including functional difficulties which are multi-causally determined.

- d) Clinical aspects of geriatric frailty and multicausal geriatric syndromes (the geriatric giants) become priorities of geriatric medicine over the disease-model.
- e) It is essential to sensitively subordinate medical decision making and diagnostic, treatment, nursing and other medical stereotypes to existential aspects, including quality of life, autonomy, and improving the social roles of frail older people.
- f) We urgently draw attention to the fact that the health problems of frail older people are often not accurately recognized and acknowledged by doctors and other health workers and thus not dealt with appropriately. Frail geriatric patients are still frequently perceived as an unpopular burden. They are marginalized, because the structure of health services and disciplines created for the needs of the younger population does not reflect their problems, demands and needs. They often find themselves in „no-man’s land“between the interests and competencies of traditional medical specialties.
- g) Such misunderstanding is especially dangerous in the initial phases of ill-health and functional decompensation of frail older people, because of the risk of delay. Qualified geriatricians and implementation of the discipline of geriatrics thus should not be identified only with long-term or post-acute care but should also be available in the acute phases of disease and during hospitalization, if acute care of other specialty is not necessary. It is an analogous requirement and necessity to the previous establishment of pediatric medicine.
- h) We call attention to the persistent risk of geriatric hospitalism, the iatrogenic harm of old person including humiliation of dignity, mistreatment of delirium, inducement of immobility or inadequate use of restraints in hospitals and nursing homes.
- i) We draw attention to hazards in diagnostic interventions, which are motivated not by the benefit of patient, but the purposeless quest for hypothetical disease. We call attention to hazardous indigested polypragmasia and its role in the causation of multi-causal geriatric syndromes as well as to insufficient use of non-pharmacological interventions such as physiotherapy, ergotherapy, psychotherapy, home care and social interventions.
- j) We require that clinical decision making in geriatric patients is strictly based upon individual goals and aspirations, on identification and intervention (of) all treatable biological as well as other factors, rather than on diagnosis, treatment and prevention of individual diseases.
- k) We call attention to the need for sufficient capacity of qualified comprehensive mobile palliative care support to enable dignified deaths for older people in their familiar environments.

E) Seniors:

- a) Cultivate and express (your desire, will, need for) the meaning of life and your unique individuality, strive for personal development, productivity, self-realization, and social participation in every age and notwithstanding possible disabilities and handicaps
- b) Do not give up under manifestations of worsening of functioning and health-related quality of life with advancing age – ask for qualified geriatric assessment and intervention for your health difficulties and ask for qualified geriatric medicine.

- c) Ask your local authorities for comprehensive services and support of long-term care in your community.
- d) Do not reconcile yourself to manifestations of age discrimination, lack of respect for your dignity, or signs of mistreatment, abuse, neglect, or even domestic or institutional violence. Participate actively in solving the phenomenon of EDAN (Elder Dignity Abuse and Neglect) - „be the change, you wish to see in your life and neighborhood.“