

## Mainstreaming Palliative Care for an Age-Friendly Society Minutes

**PACE Mid-term Policy Conference**  
July 2016

*Document prepared by AGE Platform Europe*

**Venue:** Brussels Office of the Council of Europe  
**Date:** 15 June 2016 13:30 – 18:00 (Brussels time)  
**Organiser:** AGE Platform Europe  
**Participants:** See annex 1

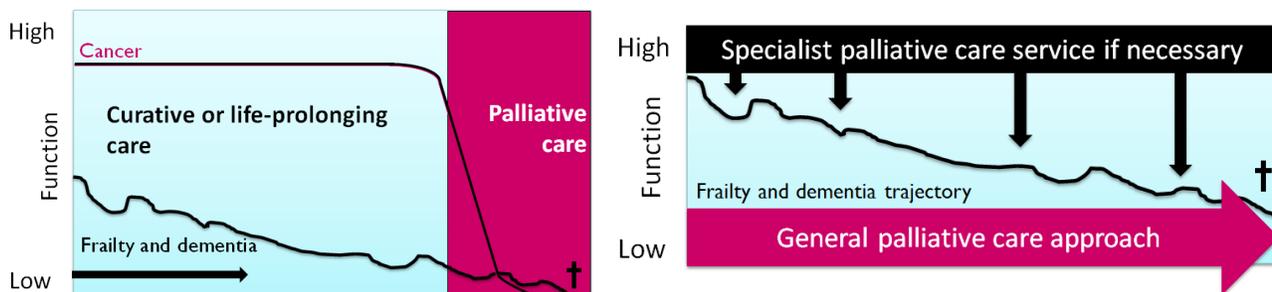
### 1. Introductory speeches

By Humbert de Biolley, Deputy Head of the Brussels Office of the Council of Europe (CoE).

- European instruments and a charter exist to protect civil, political, social and economic rights of older people, such as the European Court of Human Rights, and the European Social Charter. However, none of these are addressing palliative care directly.
- A [recommendation](#) on the organization of palliative care was adopted in 2003. The CoE secretariat will launch a discussion next year on its implementation in Member States.

By Lieve Van den Block, professor at the Free University of Brussels (VUB) and coordinator of PACE.

- Societies are ageing rapidly, and illness and dying trajectories are changing fundamentally: multiple comorbidities are prevalent, there is a lack of shared decision-making or pro-active care planning. 25-40% of 80+ are frail (leading cause of death in community-dwelling of older people) and 1/3 of 85+ live with dementia.
- In this scenario, high-quality palliative care for older people is a huge public health and clinical challenge that needs to be addressed urgently.
- Palliative care should not be terminal care only (see old model on the left) but integrated early into disease management alongside life-prolonging treatments (see new model on the right). The goal of person-centered and family-focused palliative care is to improve the quality of life of patients and families facing a life-threatening illness; this needs to be done through early identification and impeccable assessment and treatment of physical, psychosocial and spiritual problems.



*Source: Lieve Van den Block's presentation during the conference*

## 2. Part I: Palliative care in Europe: state of play, benefits and drivers of diversity

- Moderator: Luc Deliens
- Speakers: Paul Vanden Berghe (EAPC); Iva Holmerova (Chair of the CZ Alzheimer Society); Katherine Froggatt (Lancaster University); Lara Pivodic (VUB)
- Objective: highlight the benefits of palliative care, focusing on how it can improve the lives of older people with life-threatening conditions
- Main messages:
  - o Palliative care is still often restricted to end-of-life cases, usually to patients with cancer;
  - o Basic and specialized palliative care are integral part of health care and should be provided alongside curative treatment;
  - o The provision of palliative care should adopt an interdisciplinary approach, involving all stakeholders (practitioners, nurses, carers, informal carers, patients...);
  - o “Responsive care”: children of relatives resorting to palliative care now will be more responsive in the future and won’t assimilate palliative care to something negative;
  - o Recognise Alzheimer’s disease as a major public health challenge (see [Paris Declaration 2006](#)) as people with dementia have the right to timely diagnosis, and thus have access to quality care, including palliative care (see [Glasgow Declaration](#));
  - o Notable benefits (see enclosed PPT)
  - o Clear diversity in policy and practice in the delivery of palliative care and the quality of dying across Europe
  - o Palliative care should be a top priority on the political agenda
- Comments:
  - o Related to Study 1 – macro level: Some countries might not explicitly integrate palliative care in their legislative framework, even though being a priority at a lower level (ex. Sweden). Would the ranking of study 1 be biased? It was decided that PACE researcher will only take account of explicit mentions of palliative care in national legislation;
  - o How could palliative care be improved in Central and Eastern Europe? Currently, older people are taken care of by their relatives at home. However, the situation will change with mobility and a change in lifestyle and family structures. It is necessary to convince policy and decision makers that the shift will happen and improvements need to happen.

## 3. Part II: The perspectives of end-users and health and long-term care practitioners

- Moderator: Liz Lloyd
- Speakers: Marie Lynch (EDPC); Nele van den Noortgate (EUGMS); Jori Horecký (EDE)
- Objective: explain the challenges facing healthcare systems and long term care facilities in intergrating palliative care in everyday practice.
- Main messages:
  - o Still a need to clarify the meanings and differences between “curative care”, “palliative care” and “end-of-life care” to the general public;
  - o LTCFs shouldn’t be affiliated with “the place where people die”;

- LTCFs staff will have to be trained – though it will be tough at the beginning and they will most probably be overburdened;
- We need a “wrap –around approach”;
- Need to consider that some GPs might not feel comfortable talking about palliative care;
- Geriatric Palliative Medicine = the medical care and management of older patients with health related problems and progressive, advanced disease, for which the prognosis is limited and the focus of care is the quality of life;
- Develop palliative care in LTC facilities & geriatric wards and educate Palliative Care home teams in geriatrics
- Ageism in accepting cancer patients in palliative care facilities should be avoided, meaning that palliative care should be accessible to older but also younger cancer patients;
- Main barriers to mainstream palliative care: the physician, attitudes of staff and approaches of personnel, lack of staff and resources, strategies and legislation;
- Comments/discussion:
  - Do patients know when they are provided palliative care?
  - Do caregivers in care homes know when they are giving palliative care?
  - How do we change the perception from terminal care to palliative care?
- Further reading: minutes of the 1<sup>st</sup> PACE User Forum (25 September 2015; see enclosed)

#### **4. Part III: Integrating palliative care in all policy areas that affect older people with a life-threatening condition**

- Moderator: Sheila Payne
- Speakers: Barbro Westerholm (Member of the Swedish Parliament); Antoni Montserrat Moliner (DG Health); Rodd Bond (NetwellCASALA)
- Objective: show how palliative care goes far beyond the end-of-life dimension, how it is linked to a global strategy for the design of age-friendly environments
- Main messages:
  - The European Union can and should play a role in mainstreaming palliative care;
  - The appropriate delivery of quality palliative care relates to the design of age-friendly environments by enabling older people to remain active in society;
  - The built environment where older persons are receiving palliative care has an influence in their experience with palliative care: living conditions and the physical environment are important and should be further included in the discussions;
  - Confusion of “palliative care” and “terminal care” in certain countries;
  - The lack of (skilled) staff is a major problem in most of the countries;
  - Limitation at the EU legislation level: health is a competence of the Member States. However, the Council of Health ministers of the EU will be discussing a proposal for a Recommendation on chronic diseases that will include a chapter on palliative care: this is a possibility for PACE to influence the outcome;
  - No point in separating palliative care discussion from health care issues;

- Age-friendly environments go beyond health care sector, we need to lift the discussion towards a societal discussion, not only in the health care sector;
- Discussion/comments:
  - The terminology “Palliative care” is not accepted worldwide ex. WHO

## 5. Closing Remarks

- Marian Harkin, Member of the European Parliament, delivered the closing remarks of the event. She supported the need to change societal images that relate palliative care exclusively to end of life situations, thereby harming the access to beneficial palliative care at earlier stages. She stressed her commitment to the topic, and explained she will do her best to ensure that the outcomes of PACE are taken into account in the relevant parliamentary work.
- Anne-Sophie Parent, Secretary-General of AGE Platform Europe, stressed the importance of palliative care for older persons and agreed with the need to challenge wrong and narrow societal images – maybe rethinking the term and discussing alternative options such as “supportive care”. She also argued that this specific care needed a better understanding, thus avoiding the confusion and negative connotation linked to it. According to her, palliative care should support the patient alongside curative treatment, making one’s life as meaningful and comfortable as possible until the end.
- Lieve Van den Block closed the conference by explaining that the outcomes will be taken forward notably to shape the policy recommendations of the project. A second meeting of the project User Forum, composed of experts of AGE Platform Europe and Alzheimer Europe, will be organised in the first half of 2017 building on these outcomes and focusing on each policy topic mentioned during the conference. Lieve reminded the importance of education on the meaning of palliative care, a training given to every health and social care providers to deliver appropriate and good care to those diagnosed with a life threatening condition.

## Annexe 1 – List of Participants

Name	Organisation	Position	Country
Baltruks Dorothea	European Social Network	Policy Officer	EU
Bellon stefano	Alta Vita IRA - Padova (Retirement home)	Presidente	IT
Brochier Carine	Institut Européen de Bioéthique	Projects coordinator	EU
Clements Alex	East of England Office Brussels	Assistant European Policy Office	UK
Derks Alvy	N/A	Independent Health, Wellness and Fitness Professional	EEL
Gabrielli Alessia	REGIOEUROPA (Representation of Greek Regional and Local Authorities)	policy assistant	EEL
Galariotis Theodore	Greek Network EIP on AHA	Founding Member	EEL
Garcia Carmen	CEOMA	President	ES
Gayarre Sara	European Patients Forum	Communication Assistant	EU
Gurn Niamh	European Parliament	MEP assistant	EU
Haiges Lea	Landesvertretung Baden-Württemberg	Trainee	DE
Hawlicek Hilde	AGE Platform	Vice-President	AT
Klein Maximilian	Europabüro der bayerischen Kommunen	Deputy Head of Office	DE
Kozłowska Malgorzata	European Commission	Policy officer	EU
Martins Fernando	APRe!	Vice-President	ES
Patrizi Tiziana	Regione Piemonte	EU liaison officer	IT
Petersen Gudula	Grünenthal GmbH	Director Governmental Affairs & Patient Centricity	DE
Pettus Katherine	IAHPC - International Association for Hospice & Palliative Care	Advocacy Officer	International
Ramos-Ascensão José	COMECE	Legal adviser	ES
Ressler Christine	Europabüro der bayerischen Kommunen	Policy assistant	DE
Roux Caroline	VITA International - media	director	BE
Saarto Tiina	Helsinki University Hospital	chief physician - professor of palliative medicine	Fi
Tejedor Jose-Luis	CEOMA - ASPUR (Asociación de Profesores Universitarios Jubilados)		ES
Unger Susanne	Saxony Liaison Office Brussels	Desk Officer	DE
Van De Velde Guy	Flemish administration, politics on elderly people	support of director	BE
Vidal y Plana Ramon-Ricard	FATEC	Vice-president	ES
Williams Althea	Formerly Amnesty International	Free-lance researcher	
Windey Tarsi	independent	senior advisor	BE

## Speakers – Moderators - Organisers

Deliens Luc	Free University of Brussels (VUB)
de Groote Zeger	Free University of Brussels (VUB)
Pivodic Lara	Free University of Brussels (VUB)
Smets Tinne	Free University of Brussels (VUB)
Van den Block Lieve	Free University of Brussels (VUB)
Holmerova Iva	Alzheimer Europe
Challinor Vanessa	Alzheimer Europe
Diaz Ana	Alzheimer Europe
Payne Sheila	Lancaster University
Froggatt Katherine	Lancaster University
Parent Anne-Sophie	AGE Platform Europe
Arrue Astrain Borja	AGE Platform Europe
Tram Nhu	AGE Platform Europe
Lloyd Liz	AGE Platform Europe, University of Bristol
Westerholm Barbro	AGE Platform Europe expert, Member of the Swedish Parliament
Van Den Noortgate Nele	European Union Geriatric Medicine Society (EUGMS)
Bond Rodd	NetwellCASALA
Vanden Berghe Paul	European Association of Palliative Care (EAPC)
Lynch Marie	European Forum for Primary Care (EFPC)
Horecký Jiri	European Association for Directors and Providers of Long-Term Care Services for the Elderly (EDE)
Montserrat Moliner Antoni	European Commission
Harkin Marian	European Parliament