

JPND Palliative Care Expert Workshop

25th June, 2014

Sheraton Hotel, Schiphol Airport, Amsterdam



Background

Palliative care has been defined by the WHO as an approach that improves the quality of life of patient and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. This holistic approach to care for people with progressive disorders aimed at optimising the quality of life has tended to be associated with cancer care but is increasingly associated with a range of chronic illnesses. Its role in neurodegenerative disease (ND) care is emerging as a priority amongst patients, practitioners and carers. Palliative / End-of-life care can take place in all stages of ND and in all settings.

There is an urgent need for more knowledge on the most effective ways of taking care of people with ND, especially in end-of-life care. Research can contribute to the development, evaluation and implementation of palliative and end-of-life-care that enhances the quality in the last phase of life.

This June 2014 workshop is an initiative of the [EU Joint Programme - Neurodegenerative Disease Research \(JPND\)](#), the largest global research initiative tackling the challenge of neurodegenerative diseases. The promotion of research into end-of-life and palliative care is a key priority within the JPND Strategic Research Agenda, due primarily to *“the lack of knowledge in this field and growing prevalence of these diseases”*.

The workshop will comprise an invited group of up to 30 leading researchers in the field and knowledgeable representatives of public and patient organisations from across Europe. The objective of the workshop is to share knowledge on JPND, to identify capacity-building and integrative research opportunities, and to recommend future JPND actions and activities. An underlying theme of the workshop will be the aligning of knowledge on these topics from national, regional and EU levels.

As a first step, the workshop will seek to identify research priorities and it is proposed to use the recent [European Association for Palliative Care \(EAPC\) white paper](#) as a foundation for discussion at the workshop. The white paper defines optimal palliative care in older people with dementia, and provides a research agenda with:

- decision making and treating symptoms prioritised by experts
- recommendation of comparative research across Europe’s rich variety of care models, with particular attention to home care and hospital settings
- recommendation of further research into how to give shape to palliative care in dementia across dementia stages

This discussion will be followed by brainstorming sessions aimed at developing a menu of proposed actions for consideration by JPND to implement across the neurodegenerative diseases under its remit*.

* The neurodegenerative diseases that JPND focuses on are: Alzheimer’s disease (AD) and other dementias; Parkinson’s disease (PD) and PD-related disorders; Prion disease; Motor neurone diseases (MND); Huntington’s Disease (HD); Spinocerebellar ataxia (SCA); Spinal muscular atrophy (SMA)

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Programme

9:00-09.30am: Registration and Morning Coffee

09:35am: Welcome

*Marie Claire de Vries, Department of Long-Term Care,
Ministry of Health, Welfare and Sport, The Netherlands*

09:40am: JPND – Tackling the neurodegenerative disease challenge

Mogens Horder, member of JPND Executive and Management Boards
Including: Overview of JPND current activities and future plans

10:00am: Palliative care for patients with progressive neurological diseases

David Oliver, University of Kent, United Kingdom
Including: Overview of consensus paper on available evidence

10:20am: Palliative Care for Neurodegenerative Diseases, in particular Dementia

Jenny van der Steen, VU University Medical Center, The Netherlands
Including: Overview of EAPC White paper

10:40-12:30pm: Sub-group breakouts - [Validating Research Priority Areas](#)

Participants broken up into two subgroups. The same topics/questions will be discussed by each group. Morning session to focus on understanding the research priorities and validating the EAPC agenda.

12:30-1:30pm: Networking Lunch

Chairs and rapporteurs of subgroups to meet

1.30 – 3:00pm: Sub-group breakouts - [Developing Proposed Actions](#)

Same subgroups as morning session. Afternoon session includes identification of five-six priority actions that JPND can initiate.

3:00 – 3:15pm: Afternoon Refreshments

3:15 - 4:15pm: Summary reports from sub-groups' chairs/rapporteurs

Discussion on recommendations, leading to overarching report

4:15 - 4:30pm: Closing Remarks

Mogens Horder, member of JPND Executive and Management Boards