



Dementia Palliare:

Equipping the registered dementia workforce to support advanced dementia care and family caring

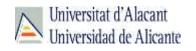
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Presentation

- What is Palliare?
- Why advanced dementia?
- Overview of work to date
- Future plans
- Join our virtual Community of Practice







Background to Dementia Palliare

- 'To cloak'
- Palliative care derived from Palliare
- 7 countries
- 11 work streams (intellectual outputs) over two years
- Palliare is the extended palliative phase of dementia

 advanced but not end stage and increasingly reliant on others





Advanced dementia

- 36 million people globally live with dementia. By 2040 to increase to over 80 million
- Estimated cost of dementia in Europe is €160.3 billion (€22,194 per person with dementia)
- Progressive condition requiring increased support to live well

- Middle/late stages see extended, intensive palliative care phase (Palliare)
- Palliare stage often lasts longer than early stages
- Variations across Europe in opportunity to improve the extended palliative phase of dementia care
- Palliare Project aims to tackle stereotyping of dementia care as low skilled.





Work streams across 7 countries

- 1. Literature review
- 2. Policy review
- 3. Case studies
- 4. Educational gap analysis
- 5. Best Practice Statement on advanced dementia

- 6. Experiential learning framework
- **7**. Virtual community of practice
- 8. Education modules
- 9. Facilitator manual
- **10**. Training learning facilitators
- **11**. Sustainability plan





Work completed to date, 2014-2015

- Literature review on experience of advanced dementia
- Comparative analysis of national dementia plans
- In-depth case studies of experiences of advanced dementia in range of care settings
- Educational gap analysis
- Working towards consensus on European Best Practice Statement on advanced dementia
- Review of experiential and online learning
- Design of virtual Community of Practice and associated social media
- Mid-point conference, Prague, July 2015





Future plans, 2015-2016

- Populate virtual Community of Practice and support use across Europe and beyond
- Design three education modules on advanced dementia – one undergraduate and two postgraduate
- Agree and share European Best Practice Statement on advanced dementia
- Develop a business model for creation of a European Dementia Academy
- End of project conference, Porto, September 2016





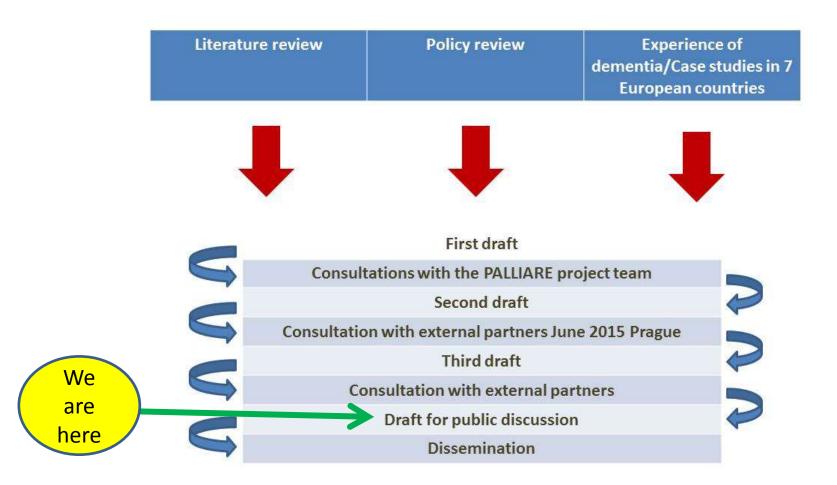
Development of European Best Practice Statement







Development of European Best Practice Statement







European Best Practice Statement

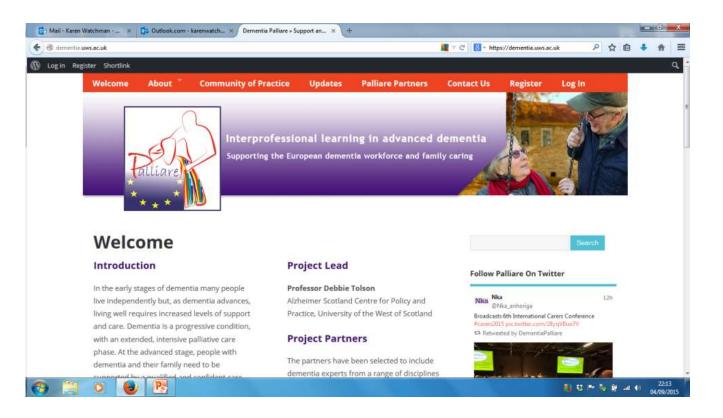
The statement is divided into six sections covering:

- Section 1: Protecting rights, dignity and inclusion
- Section 2: Future planning for Dementia Palliare
- Section 3: Managing symptoms and keeping well in Dementia Palliare
- Section 4: Living the best life possible
- Section 5: Support for family and friends
- Section 6: Advancing Dementia Palliare practice
 Your feedback is welcome too...





Virtual Community of Practice



http://dementia.uws.ac.uk





Virtual Community of Practice

- Informal, self-organised network with specific focus
- Evidence base for eLearning modules and Community of Practice
- Mediating artefacts social media etc
- Identify opportunities and barriers to inclusion
- Please join us and share with families and colleagues

http://dementia.uws.ac.uk









Palliare Partners



Scotland: Professor Debbie Tolson (Erasmus+ Project Lead) Anna Waugh, Dr Rhoda MacRae, Dr Karen Watchman, Margaret Brown, Dr Barbara Sharp, Professor Graham Jackson, Leslie Hamilton



Sweden: Professor Elizabeth Hanson, Dr Asa Sandvide



Portugal: Professor Dr Wilson de Abreu



Slovenia: Professor Brigita Skela Slavic, Dr Simona Hvalic Touzery, Katja Pesjak



Finland: Kimmo Polvivaara, Pirkko Routasalo, Anne Merta



Spain: Professor Dr Manuel Lillo Crespo, Maria Josefa Cabanero Martinez, Miriam Sanchez-SanSegundo, Mcristina Sierras



Czech Republic: Professor Iva Holmerova, Radka Reprkova









Thank you

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