



# Dementia Palliare Project

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Equipping the qualified dementia workforce to champion evidence informed improvements to Advanced Dementia Care & Family Caring through education



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## Palliare Project

### WEBSITE

[www.uws.ac.uk/palliareproject/](http://www.uws.ac.uk/palliareproject/)

### COMMUNITY OF PRACTICE

<http://dementia.uws.ac.uk/>

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## **▣ WHAT IS DEMENTIA PALLIARE?**

Palliare refers to the often extended and prolonged, advanced phase of dementia. The Dementia Palliare project has worked across seven countries between 2014-2016. It supports the qualified dementia workforce to deliver evidence-informed improvements to advanced dementia care and family caring through education.

## **▣ EXECUTIVE SUMMARY**

This project has provided the platform to create a virtual international dementia academy for qualified dementia practitioners.

The academy will host accessible accredited higher education modules in a range of languages that focuses on dementia care. State of the art evidence informed education will equip qualified dementia practitioners to lead reform and champion improvements in dementia care, and enable them to gain further qualifications.

The Academy's interdisciplinary faculty of educators will provide experiential learning experiences on contemporary dementia care in a range of languages thus ensuring its relevance to professionals and care providers. The academy will also host a virtual international Community of Practice which is designed to facilitate the sharing of best practice, provide access to learning resources and support to refresh and upskill practitioners. The experiential learning approach will provide virtual mobility, afford status, and augment practice through the international Community of Practice and bespoke online modules.

## **▣ THE IMPERATIVE FOR ACCESSIBLE AND INNOVATIVE DEMENTIA EDUCATION**

In many parts of the world dementia care and education is impoverished. The global economic and societal impact of dementia is well documented (World Alzheimer Report 2010), there are three interrelated levels of impact namely at the level of the individual, family and friends, and society.

Using the measure of Global Burden of Disease there is evidence that dementia is amongst the top 10 most burdensome conditions affecting people in later life in terms of quality of life, disability and years lived. The World Health Organisation Call to Action includes the establishment of equitable access to comprehensive services, national dementia actions plans and workforce training all of which underpin good quality continuing care and services for people living with dementia. Despite dementia education for care staff and partnership working with families being recognised at strategic and policy level across Europe, the reality is that research and training on advanced dementia is scarce.

The European Parliament (2010) highlighted the need for common guidelines to inform the training of practitioners and others involved in caring for persons with dementia. The G8 Dementia Summit in London encouraged countries to share and build solutions and deliver services across the continuum of care.

The care of older people and the skills of staff who work within them are often undervalued, rather than being seen as a positive career choice that requires a complex skill mix that spans health, social, psychological, spiritual and medical care. Advanced dementia brings with it a loss of autonomy and deteriorating cognitive and physical function. During these many months or years continuous health, social and psychological care is required. People with advanced dementia and their families need to be supported by a qualified and confident care workforce, which is both evidence informed and supported to continually develop their practice.

This is why in September 2014, building on previous work and a genuine commitment to enhancing the status of dementia care and education, this project began to create a range of evidence based, accessible, social, participatory and practice based learning resources to support the care of people with advanced dementia.

## **▣ THE PARTNER COUNTRIES**

Each partner and partner country brings with them unique strengths and different perspectives which will assist in re-framing the European dementia narrative.

Partners were selected to include dementia experts from a range of disciplines with international repute and educators with a track record in the development of innovative experiential learning methods.

## **▣ PALLIARE PROJECT ► FINDINGS**

### **101 ► LITERATURE REVIEW: EXPERIENCE OF ADVANCED DEMENTIA**

The literature review aimed to create a shared understanding of dementia care and family care associated with the extended palliative care. It found that the extended palliative phase was synonymous with end of life care and there were few robust concepts that embraced living the best life possible during this advanced phase. This finding illuminated the need for a new practice approach for advanced dementia care.

### **102 ► DEMENTIA POLICY REVIEW**

A review of dementia related health and social care policy and strategy documents, action plans and workforce development frameworks found all seven countries had some type of national action plan for generic palliative care. The place of palliative care for people with advanced dementia ranged from the family home and hospital to care homes.

### **103 ► EXPERIENCE OF DEMENTIA-CASE STUDIES**

Twenty two case studies from seven countries allowed the inclusion and experiences of people with advanced dementia. This identified a number of recurring themes considered to be important for care experiences to be positive: early diagnosis, good coordination between service providers, future planning, support and education for carers and families, thus enabling the person to live the best life possible.

**104 ► BEST PRACTICE STATEMENT ► <http://goo.gl/DTRgHM>**

This important document is designed for the professional European workforce (personnel). This Best Practice Statement offers a new positive practice approach for supporting people with advanced dementia.

It has six sections:

- Protecting rights, promoting dignity and inclusion.
- Future planning for advanced dementia.
- Managing symptoms and keeping well.
- Living the best life possible.
- support for family and friends.
- Advancing Dementia Palliare practice.

**105 ► EDUCATIONAL GAP ANALYSIS**

An educational gap analysis was undertaken to identify the existing education in dementia available to the professional workforce. We found that there is a lack of formal education on dementia. Dementia education is particularly limited in undergraduate programmes.

**106 & 107 ► VIRTUAL COMMUNITY OF PRACTICE ► <http://dementia.uws.ac.uk/>**

We have developed a virtual Community of Practice (CoP) based on the best available evidence on experiential learning. The Community of Practice gives practitioners access to resources and an opportunity to participate in discussion forums in multiple languages. It is a space for those interested in advanced dementia to share and learn from one another.

**108 ► INTERPROFESSIONAL EDUCATION**

Four accredited education modules on advanced dementia care for health and social care professionals across Europe have been developed.

These are:

- Positive practice development in advanced dementia care
- Rights, risks and ethics in advanced dementia care
- Contemporary advanced dementia care
- Achieving change in advanced dementia care

The modules will be delivered online by UWS and partners and be accessible to professionals across the globe. These will enhance the impact of modern universities to provide professional life long learning and their commitment to offer evidence based education that maximises the quality of the student experience.

**109 & 1010 ► TRAINED EXPERIENTIAL LEARNING FACILITATORS**

We have trained an interdisciplinary international team of educators to be experiential learning facilitators. They will continue to moderate the Community of Practice and act as the inaugural faculty for the proposed virtual Dementia Academy.

**1011 - SUSTAINABILITY PLAN**

This brochure forms part of our sustainability plan which seeks to address two opportunities. The first is to support the continuation of the new educational programme. The second is to prepare a viable business model to use the virtual learning environment and community of practice to be the foundation of a virtual European Dementia Academy.



**UWS** UNIVERSITY OF THE  
WEST of SCOTLAND

# DEMENTIA PALLIARE BEST PRACTICE STATEMENT

November 2015





# Palliare Project

## IMPLICATIONS OF FINDINGS AND VISION FOR THE ACADEMY

The Dementia Palliare project has developed innovative learning solutions in an area of dementia care that tends to be overlooked. The project has developed a Best Practice Statement, a virtual Community of Practice and four accredited education modules on advanced dementia care for health and social care professionals across Europe.

The project has the support of and collaborates closely with national dementia organisations in the seven countries and with Alzheimer Europe. Together these collaborations will raise the awareness of advanced dementia care and the need to invest in workforce development to improve the standards of care and champion positive change so the most vulnerable in our society are given opportunities and provided with care that enables them to live the best life possible.

This project provides the platform for a virtual Dementia Academy that is founded upon robust evidence-based innovative learning solutions with a skilled international faculty of facilitators. Our vision is that all dementia care is world leading, based on evidence, provided compassionately, and according to the wishes of the individual.

An international virtual Dementia Academy has the potential to equip qualified dementia practitioners to lead reform and champion best evidence advanced dementia care practice through providing accredited international interdisciplinary dementia education and virtual learning in a range of languages.

MORE INFORMATION

[www.uws.ac.uk/palliareproject/](http://www.uws.ac.uk/palliareproject/)