

# Transforming advanced dementia: the Palliare Best Practice Statement, an interprofessional learning framework and tool for improvement

by Debbie Tolson (FRCN 2011)



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**D**ementia is an umbrella term, used to describe progressive, terminal illnesses such as Alzheimer's disease that disrupt brain health. As the condition progresses from the mild through to the advanced, then terminal stage, the needs of the individual change, increasing in both intensity and complexity. Textbooks often refer to mild, moderate and severe dementia jumping quickly from the middle stages of illness to end of life. However, for many people, there is a stage inbetween when they are living with advanced dementia. This period may involve months or years of life with advanced illness.

Although the term 'advanced dementia' is used in practice and by family carers, there is no definitive definition. I coined the term 'Palliare', derived from Latin, meaning to cloak in support, to begin a new positive practice narrative for dementia specific palliation. I wanted to find a new single term, meaningful in different languages, to describe and distinguish dementia specific palliation from palliative care related to other conditions. Palliare and the Palliare projects are about advanced dementia care.

The Palliare Best Practice Statement offers a framework for practitioners to improve advanced dementia care in practice.

## Improving advanced dementia care an interprofessional learning framework

### Abstract

The original Palliare Project was completed by a collaboration of seven European countries. The featured publication (Tolson et al 2017) – an editorial – compresses the findings of 11 work streams into a highlight article and overviews the Palliare Best Practice Statement (BPS), which sets out the components of best practice. The BPS recognises the complexity of advanced dementia care, values interdisciplinary contribution and embraces the centrality of family caring and rights-based approaches. It offers a refreshing and positive perspective focused on living the best life possible with advanced dementia, acknowledging that there is for many, a lot of living with advanced dementia to be done before end of life care is required.

The six elements of best practice are accessibly presented in the BPS in terms of 'what' is required, the underpinning evidence and the 'how' to demonstrate delivery of practice at its best. Offering the BPS as an interdisciplinary learning framework, as done in Tolson et al (2017), provides a structured way for educators to optimise care through Palliare education, and for managers and service providers to understand what practitioners need to know to provide good quality advanced dementia care. The editorial challenges the status quo, introduces a new positive Palliare narrative and a tool whereby evidence informed, advanced dementia care can be described and delivered. Rather than passive acceptance of what is, this editorial calls for improvement actions to achieve in practice what should be.

### Citation

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### Link

[www.jamda.com/article/S1525-8610\(17\)30185-8/fulltext](http://www.jamda.com/article/S1525-8610(17)30185-8/fulltext)

## Introduction and background

In 2013, I moved to a new role as the inaugural Director of the Alzheimer Scotland Centre for Policy and Practice at the University of the West of Scotland (UWS). Having come from a previously purely academic role, I was excited by the opportunity to set up the new centre in partnership with Scotland's leading dementia charity. This I felt, was bringing me closer to my nursing practice roots. At that time, I was frustrated that so much of our service response and policy rhetoric about dementia reflected a social model. I felt this was wrong. After all, neuroprogressive illnesses such as Alzheimer's disease, cause dementia. For me, there has never been any doubt that living with dementia is an illness experience and I find the lack of awareness about the complexity of advance dementia care perplexing (Brown and Tolson 2020, Brown et al 2020).

Setting up the new centre gave me a blank canvas to start new programmes of work and challenge the status quo. With the support of UWS nursing colleagues and policy colleagues from Alzheimer Scotland, the ideas for the Palliare Project began to take shape. A funding opportunity presented itself, namely the Erasmus+ K2 Strategic Partnership Fund and, although not focused on nursing or healthcare, we crafted a project to fit the agenda for modernising the approach to practice-based learning within universities in response to a societal problem. And at that time, what bigger societal problem was there than dementia and the development needs of the European workforce?

With the 'bravado of the new in post' and the backing of my 'you can do it colleagues' I contacted and managed to assemble a team of inspiring leading nurses, doctors and other health and social care professionals from across seven countries. Ideas flowed and together we shaped what was to become the Palliare Project and some now refer to as the Palliare movement. The first Palliare Project objective focused on understanding and describing best practice for advanced dementia care during the extended palliative care phase. This we investigated by a combination of an interrogative literature review, policy analysis, in-depth case studies, educational gap analysis and a pedagogical review.

The second project objective was to use the findings from our first set of activities to develop an innovative approach to interprofessional learning, designed to equip the qualified European dementia workforce to transform

practice and achieve good quality dementia Palliare. To do this, we combined the findings from the research activities listed above, and presented them in the form of a best practice statement (BPS). It would have been naïve to do this in isolation from stakeholders and we used consensus methods to refine the BPS with a range of professional and lay stakeholders helped by Alzheimer organisations from the collaborating countries (Holmerova et al 2016). Activities included a consensus conference held in Prague, online feedback and dialogue events. Once finalised, the BPS was originally written in English and translated into Czech, Spanish, Swedish, Portuguese.

As a team, we published a number of journal articles during the lifetime of the project and following completion of the project, were invited to write an editorial in the Journal of the American Directors Association. This editorial provided an opportunity to present the BPS as an interprofessional learning framework. What we hoped for was this editorial to be seen as a call to action to dementia educators; what we were unsure about was how this would be received, and how, if at all, the BPS would be used directly in practice or its potential for policy influence (Tolson et al 2017).

## Influence and impact

Palliare Project funding supported various dissemination activities including two conferences, one in Prague, Czech Republic, and an end of project conference in Porto, Portugal. In addition, local events were organised to share findings with practitioners and the public in the participating countries. Testimony to wider interest in the work was an invitation to me to give keynote presentations at the Alzheimer Global Summit in Lisbon, in 2017, and at Europe's largest long-term care conference hosted by the Together We Change the World Foundation in Poland in 2019. The project plan also included a commitment to preparing manuscripts for peer review publications. Our publications included an article sharing the literature review (Hanson et al 2016), policy analysis (Tolson et al 2016), educational gap analysis (Hvali -Touzery et al 2018), and user experience case studies (Lilo-Crespo et al 2018). The best practice statement was made available online with English language, Czech, Portuguese, and Spanish versions (Holmerova et al 2016).

An invited editorial in the Journal of the American Medical Directors Association,

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## RESOURCES

Scottish Parliament debate on the Fair Dementia Care Commission Report  
[www.parliament.scot/parliamentarybusiness/report.aspx?r=12155&i=109835](http://www.parliament.scot/parliamentarybusiness/report.aspx?r=12155&i=109835)

Erasmus+ K2 Strategic Partnership Fund  
[www.erasmusplus.org.uk](http://www.erasmusplus.org.uk)

Alzheimer Global Summit, Lisbon, 2017  
[sede.imserso.gob.es/InterPresent2/groups/imserso/documents/binario/folletocumbre.pdf](http://sede.imserso.gob.es/InterPresent2/groups/imserso/documents/binario/folletocumbre.pdf)

Together We Change the World Foundation conference, Poland, 2019  
[mkod2019.syskonf.pl/?lang=en](http://mkod2019.syskonf.pl/?lang=en)

gave us an opportunity to write about the BPS in a peer review journal (Tolson et al 2017).

These dissemination activities were important in sharing our work with different audiences, and in promoting the Palliare BPS as a tool for improving advanced dementia care.

There have been three main ways in which the BPS has demonstrably influenced advanced dementia care through:

- » Impact on the quality of care.
- » Impact on practitioner education.
- » Policy influence.

Some of these impacts and influences were predicted, others unexpected.

**Impact on the quality of care.** We were delighted to learn from the Czech Alzheimer Society that they had used the BPS to develop quality indicators creating new Vážka criteria, a set of quality indicators developed by the Alzheimer Society in the Czech Republic to demonstrate long-term care facilities are delivering best-practice care for people with dementia and advanced dementia, and a quality certification system. To date, some 70 social care facilities in the Czech Republic have achieved certification as compliant with the Vážka criteria, demonstrating improvements aligned with best practice as set out in the Palliare BPS (Mátlová 2019).

In Portugal, the BPS has been used as a benchmarking tool to raise standards of advanced dementia care in a number of services including hospices (de Abreu 2019). Improvements have focused on understanding and managing advanced dementia symptomatology including stress and distress, pain, and promoting comfort through introduction of sensory interventions. In the UK, realisation of practice impact has been slower; the Scottish Alzheimer Scotland Dementia Nurse Consultant Group is reviewing how best to draw on the BPS. Before the recent pandemic lock down, one of the nurse consultants was preparing an improvement programme in acute care and I will watch with interest to see how helpful this is both during, and post-COVID-19.

**Impact on practitioner education.** The BPS and principles for advanced dementia care have been used to create several master's degree level modules that we offer online and by blended learning as part of the University of West of Scotland MSc in Gerontology (with dementia care). Internationally, the BPS has influenced and changed dementia education in Spain, Portugal, Russia and Brazil (de Abreu 2019),

which now has specific content on advanced dementia. In the Czech Republic, the Institute of Post Graduate Medical Education has changed some of its courses for long-term care practitioners to promote 'Palliare Practice'.

**Policy influence.** When Scotland's third dementia strategy (2017-2020) (Scottish Government 2017) was being prepared, the Palliare Project was in progress. We were delighted that our literature review (Hanson et al 2016) was cited in the new strategy and our call for a positive new practice narrative for advanced dementia embraced.

More recently, the Scottish Fair Dementia Care Commission drew on evidence from the Palliare Project to inform the Fair Dementia Care Commission Report (Alzheimer Scotland 2019). The report called on the Scottish Government to recognise the needs arising from advanced dementia as healthcare needs, promote access to expert nursing and end inequalities that mean that people with advanced dementia pay for care which is free to people with other progressive terminal conditions. The definition of advanced dementia used by the commission draws on the Palliare definition. The Scottish Parliament has debated the Fair Dementia Care Commission Report and the proposed definition of advanced dementia was acknowledged as a strength: '...the Parliament ... believes this to be an important contribution to the understanding of advanced dementia and the care needed by people across Scotland'.

Over 14,000 members of the public have pledged support for the campaign, urging reform to address the inequalities in Scotland that people living with advanced dementia face. Public interest and the interest of Scottish parliamentarians in the call for dementia care that is fair are encouraging. As a nurse, it is affirming that the work I have led has contributed to one of the most significant campaigns and calls for action progressed by Alzheimer Scotland. It is heartening that Palliare findings have contributed evidence and strengthened the call to action. Although we tend to think about the World Health Organization's (WHO) sustainable development goals (SDGs) in relation to countries with less developed health and care systems, it is important as nurses that we raise awareness of inequalities and tackle those that exist in our own countries. I am in no doubt that the Palliare BPS has the potential to support dementia leaders to propel change in policy and practice.

## Current and future relevance

The Palliare BPS is a unique resource in that it does not attempt to be a clinical guideline, nor is it presented as a care standard.

It is a reference resource that seeks to expose the complexity of advanced dementia care, and promote a cohesive approach to best practice and practitioner education through consideration of six domains of practice:

- » 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.

It is a starting point for those interested in promoting positive approaches to evidence-informed, advanced dementia care and the quest for best practice. The SDGs are predicated on ideas about best practice and resonate with the WHO (2017) global action plan for dementia. The Palliare BPS, with its explicit focus on living the best life possible with advanced dementia, aligns with the global development agenda. This is relevant in terms of achieving fair dementia care in Scotland and elsewhere in the UK (Social Market Foundation 2019), and internationally.

One of our recent projects undertaken collaboratively with nurses in southern India highlights the lack of dementia care infrastructure and the vulnerabilities and hardships of people with advanced dementia and their families (Ritchie et al 2020). This preliminary project brings into sharp focus the urgent need for community and practitioner education about advanced dementia and the

BPS is providing a road map for collaborating nurse educators to refresh and strengthen pre-registration nurse curricula. It has also shone a light on desperate acts of care, which include the use of potentially harmful physical restraints by families who feel they have no other way to stop a person with dementia from leaving the safety of the family home. These acts need to be contextualised to be understood in relation to related hardships and poverty linked to shortfalls in the care infrastructure.

The BPS has provided a useful starting point for the team in India to envision what is needed. It is affirming to know that a project undertaken by our nurse-led team in the Alzheimer Scotland Centre for Policy and Practice at UWS has utility here in Scotland, in Europe and beyond. I know that this is a relatively small contribution towards making a better world for people living with dementia; but I am proud of what has been achieved in a relatively short period of time. I am also realistic about the scale of the challenge ahead, particularly given the disruptive impact of the COVID-19 pandemic.

When I began my career as a nurse, I wanted to change the world and soon realised that, if I could use my skills to support an individual to have a better day, I had done a good job. In my role as a professor, I have an appreciation of the different ways that nurses can use their knowledge, skills and leadership resolve to improve practice and influence policy. I am often asked by people I meet what professors of nursing do. For me the answer is simple: we make a difference through practice-based scholarship and projects like Palliare.

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