



**UWS** UNIVERSITY OF THE  
WEST of SCOTLAND

# DEMENTIA PALLIARE BEST PRACTICE STATEMENT

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This Best Practice Statement was developed as part of the Dementia Palliare: Interprofessional experiential learning solutions: equipping the qualified dementia workforce to champion evidence informed improvement to advanced dementia care and family caring project.

This project was led by the University of the West of Scotland in collaboration with Charles University, Prague; the Faculty of Healthcare Jesenice, Slovenia; Linnaeus University, Sweden; Turku University of Applied Sciences, Finland; Oporto Nursing School, Portugal and the University of Alicante, Spain. The project was funded by the European Union Erasmus+ programme between 2014-2016.

## INTRODUCTION

*Dementia Palliare* is a new positive practice approach to supporting people with advanced dementia who are not yet requiring end of life care, but who have limited opportunities for self-realisation and are increasingly reliant on the support of others for their health and wellbeing. Dementia Palliare recognises the increasing complexity of physical healthcare needs which must be addressed in tandem with psychosocial and spiritual needs. Dementia Palliare recognises the essential contribution of the living environment and family caring to the wellbeing of the person with advanced dementia. In other words Palliare, which means to cloak in support, draws on a biopsychosocial – spiritual model of dementia care that places the person and caring relationships at the centre of healthcare practice. Dementia Palliare is a best practice approach to delivering advanced dementia care with dignity and compassion led by professionals with appropriate specialist knowledge and competencies, and whenever possible in partnership with the individual, their family and friends.

*Dementia Palliare* requires professional commitment to an interdisciplinary approach that is responsive to the range of support needs experienced and expressed by the individual and family, in tandem with needs that are identified or anticipated by expert health and social care professionals. Dementia Palliare embraces, as required, medical, nursing, psychological and other professionals allied to health, as well as social care interventions designed to promote well-being and reduce the negative impacts of dementia symptoms in order that the person lives the best life possible. Dementia Palliare strategies should consider physical, psychological, social, spiritual and existential needs, especially those aspects that may be amenable to change such as coping strategies, physical activity, social environment and quality of interactions to maximise the quality of life of people with advanced dementia and their family so that they are enabled to live the best life possible.

*The Dementia Palliare project* aims to strengthen interprofessional collaboration in dementia care; this will be facilitated through a virtual international Community of Practice (CoP) [www.dementia.uws.ac.uk](http://www.dementia.uws.ac.uk). This learning environment brings together people who have an interest in advanced dementia care to share and learn from one another to champion evidence informed improvements in advanced dementia care and family caring. The CoP is the first step towards the establishment of a sustainable collaborative virtual European Dementia Academy.

This Best Practice Statement has been informed by a literature review on advanced dementia care and family caring, a review of current dementia policies and in-depth case studies on the experience of advanced dementia care and family caring, all carried out as part of the Dementia Palliare project. It has also drawn on other relevant materials and evidence listed in the appendices. All of this work will inform the development of four interprofessional accredited learning modules focusing on providing advanced dementia care and on equipping the qualified dementia workforce (personnel) to champion improvement in advanced dementia care.

*Scotland in a European context* - The Charter of Rights for People with Dementia and their Carers in Scotland ([www.dementiarights.org/charter-of-rights/](http://www.dementiarights.org/charter-of-rights/)) has informed both the National Dementia Standards of Care for Dementia (Scottish Government, 2011) and Promoting Excellence: A framework for all health and social services staff working with people with dementia, their families and carers (Scottish Government, 2011). The framework details the knowledge and skills all health and social care staff should aspire to achieve in relation to their role in supporting people with dementia their families and friends. Alzheimer Scotland has developed 5 and 8 pillar models of care for earlier periods of the person's dementia care needs. In 2015, they developed an advanced dementia model for providing specialist support for people with advanced dementia and at the end of their life. It is a system model to shape care and calls for the role of Dementia Practice Coordinator to be embedded in the Scottish health and social care system; it is designed to drive forward the commitments in the upcoming third Scottish dementia strategy to support people with advanced dementia and those who are at the end of their life. Both the Advanced Dementia Model and the Best Practice Statement have shared principles and values. However while the advanced model was developed for a Scottish care system the Dementia Palliare Best Practice Statement is designed for the European workforce (personnel), many of whom, unlike Scotland do not have workforce development plans in place. It offers a positive practice approach for supporting people with advanced dementia but who are not yet requiring end of life care. It is designed for a qualified workforce to use whatever the policy context, national or local system or setting they work in. It is not a standard or a guideline, it is a learning resource that can be used alongside other educational frameworks, action plans etc. by the qualified dementia workforce to champion evidence informed improvements to advanced dementia care and family caring.

## THE DEMENTIA PALLIARE TEAM:



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## GENERAL PRINCIPLES OF BEST PRACTICE STATEMENTS

- Best practice statements are intended to guide practice and promote a consistent and cohesive approach to care.
- Best Practice Statements are primarily intended for use by the qualified workforce and the staff who support them; they may contribute to inter-professional collaboration, and be helpful to formal caregivers, family and friends, and all other interested stakeholders or people involved in care and support of the person with dementia.
- Statements are drawn from the best available evidence at the time they are produced, recognising that levels and types of evidence vary; where a statement is developed in the absence of research evidence and is predominantly based on consensus this will be noted.
- Information is gathered from a broad range of sources in order to identify existing or previous initiatives at local and national level, to incorporate work of a qualitative and quantitative nature and to establish consensus.
- Statements are targeted at practitioners, using language that is accessible and meaningful.
- Consultation with relevant organisations and individuals is undertaken prior to development of a best practice statement.
- Best practice statements are not closed documents. They are a base for discussion and further improvements and should be adapted with new knowledge, experience and evidence.
- Responsibility for implementation of statements rests at local level.
- Key sources of evidence and available resources are provided in the Supporting Documentation section in appendices 1, 2 and 3.

## SPECIFIC RESOURCES AND PROCESSES THAT HAVE INFORMED THE DEMENTIA PALLIARE BEST PRACTICE STATEMENT

- This Best Practice Statement is informed by a number of evidence gathering activities undertaken by the Dementia Palliare project team: a literature review, a dementia policy review and 22 in-depth case studies on the experience of people with dementia, their family and friends and professional staff in seven countries and an educational gap analysis. The executive summaries of these reports are available to view at [www.uws.ac.uk/palliareproject/](http://www.uws.ac.uk/palliareproject/)
- Participation of people with dementia and their families and friends was central to the development of this Best Practice Statement. To ensure that essential learning was gained from the range of experience across the seven European countries, consultation and feedback was facilitated through the Alzheimer and/or Dementia organisations in each of the seven European countries and directly through the Dementia Palliare website and via social media.
- The Glasgow Declaration (Appendix 3) was launched on 20 October 2014 at the annual Alzheimer Europe conference and it was supported by delegates from 26 European Alzheimer organisations. Principles of the Declaration are based on a broad consensus across Europe. These principles have been woven into the Best Practice statement.
- The DEEP (Dementia Engagement and Empowerment Project) Guidelines on Language about Dementia <http://dementiavoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf> has also been woven into the Best Practice Statement as the language we use matters, the way we talk about dementia influences how people with dementia are viewed and also how they feel about themselves.
- The White Paper defining optimal Palliative Care in older people with dementia: a Delphi study and recommendations from the European Association of Palliative Care (Appendix 1) has informed the content of Best Practice Statement.

## THE PROCESS OF DEVELOPING THE BEST PRACTICE STATEMENT



## ADVANCED DEMENTIA

Dementia is caused by disease of the brain, usually of a chronic or progressive nature. Its prevalence shows a striking association with age, but dementia is not a normal part of ageing. It occurs in Alzheimer's disease and other neurodegenerations, in cerebrovascular disease, and in other conditions affecting the brain. It causes disturbance of higher cortical functions; memory, thinking, orientation, comprehension, calculation, learning, language and judgement. Dementia is a life limiting condition. The progression of dementia is often separated into mild, moderate and severe corresponding to early, mid and late or advanced stages. In our literature review we found that advanced dementia and the end of life phase tended not to be distinguished from one another and this fails to reflect the uniqueness of the individual experiences and the fluctuations that may occur in the health and well-being of people with advanced dementia. Moreover it does not recognise the potential for interventions that may enhance quality of life in advanced dementia care.

Advanced dementia will be unique to each individual and dependent on factors relating to underlying health, personality, biography and social context, defining the point at which a person has reached advanced dementia is complex. Moreover advanced dementia can last many months or years (up to 10 years) depending on the presence of comorbidities, point of diagnosis and other factors. However as the dementia progresses', living well requires increasing levels of support and care. Loss of autonomy, declining physical health and increasing vulnerability and frailty usually signal progression and an increasing need for an approach that recognises the increasing complexity of healthcare needs. However healthcare needs must be addressed in tandem with other psychosocial and spiritual needs and careful attention must also be paid to the living environment and family caring. Dementia is experienced by the person and their family in different ways and an approach that responds to these experiences and circumstances in a compassionate and evidence informed way is essential to enable the person to live the best life possible for these months or years. In other words a biopsychosocial – spiritual model of dementia care that places the person and caring relationships at the centre of healthcare practice is required. Advanced dementia can last many months or years and in the subsequent end of life stage of the condition, there is an undisputable need for palliative care as set out in the European White Paper (van der Steen, 2014), which defines optimal palliative care in older people with dementia.

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<sup>1</sup> We recognize that the term dementia is not used by all European countries, for example in Finland the term 'memory disorder' is used, they have a National Memory Programme rather than a dementia plan or strategy. However we have used the term dementia as it is most common term used by Dementia and Alzheimer organisations throughout Europe. [www.alzheimer-europe.org/Alzheimer-Europe](http://www.alzheimer-europe.org/Alzheimer-Europe)

## STRUCTURE OF THE DEMENTIA PALLIARE BEST PRACTICE STATEMENT

The statement is divided into six sections covering:

Section 1: Protecting rights, promoting dignity and inclusion

Section 2: Future planning for advanced dementia

Section 3: Managing symptoms and keeping well

Section 4: Living the best life possible

Section 5: Support for family and friends

Section 6: Advancing Dementia Palliare Practice

The sections are designed to provide a logical and clear information flow. Each section contains a table corresponding to the 'what why and how' of best practice. 'What' summarises the content and the role of the professional. 'Why' expands on the reason for the statement. 'How' demonstrates how the statement can be achieved, highlighting the underpinning philosophy of the statement and/or explicit skill requirements to achieve best practice. Key challenges highlight areas that may require specific action or development.

## HOW CAN THE STATEMENT BE USED?

This Best Practice Statement is intended to serve as a guide to promote a consistent and cohesive approach to advanced dementia care. The primary target audience for this statement are professionals (who are qualified to European Qualification Framework EQF level 6 or above) working with people who have advanced dementia and their family and friends, in any community, health or social care setting. The statement is intended to be challenging and aspirational but realistic and practical, it is intended to:

- stimulate learning and increase awareness among multidisciplinary and Interprofessional teams
- provide a basis for developing and improving care directly and indirectly, including continuing involvement of the person with dementia as the condition advances and his/her family/significant others
- enhance partnerships between, and with, people with dementia, their family and friends
- stimulate ideas and priorities for improvement and research

**Section 1: Protecting rights, promoting dignity and inclusion.**

**Statement: People with advanced dementia have the right to be respected as citizens in their community, and their dignity and that of their family and friends must be respected and promoted**

**Key points:**

1. Professionals ensure that their daily practice and the practice of others is underpinned by adhering to, applying and advocating the principles of values based practice, ethical principles, and international and national human rights acts and legislation.
2. People with advanced dementia must be treated with dignity
3. Dignity is supported at each interaction with the person and their families whilst meeting biological, psychological, spiritual, existential and social needs.

Content and the role of the professional (what)	Reason for statement (why)	How demonstrate statement is being achieved (how)
<p>Professionals have reflected upon their value base and its influence on their contribution to supporting people with dementia, their families and friends.</p>	<p>Stigma, discrimination, sub-optimal care and isolation from society can all be barriers to people with dementia and their families living their lives to full potential and in accordance with their wishes. These barriers can be subtle, pervasive and at times engrained in health and social care practices.</p>	<p>People with dementia, their families and friends are fully informed of their rights under the human rights legislation, national and local protection and support policies regardless of their ethnicity, gender or sexual orientation.</p>
<p>Professionals understand that citizens may not fully understand dementia and this may affect people with dementia, their families and friends seeking support, accessing care services or being involved in the care and support of people with dementia.</p>	<p>A key feature of advanced dementia is increasing dependency and diminishing opportunities for self-realisation. Attention to non-verbal expression to maximise connection and engagement with the person with dementia, and enable expression of preferences is key. As well, having due respect for the personal knowledge and skills of their family carer.</p>	<p>People with dementia, their families and friends have full participation at local, regional and national level in all areas of change and development in health social care.</p>
<p>Professionals are fully aware of human rights legislation; values based practice, The Glasgow Declaration of Rights and the impact of stigma and discrimination on people with dementia, their family carers and professionals working with people with dementia.</p>		<p>People with dementia, their families and friends have the opportunity to contribute to the development or revision of a charter of rights or similar statement for their country.</p>
<p>Professionals ensure that their daily practice and the practice of others, is underpinned by adhering to, applying and advocating the principles of value based practice, ethical practice and human rights legislation. This includes; candour, legality, partnership and compassionate approaches to working with people with dementia, their family and friends.</p>		<p>People with advanced dementia and their families are provided with equal access to information, health and social care which supports their quality of life and dignity; this includes empowering them to access care and support, helping them understand dementia and their rights and supporting them to work in partnership with professionals.</p>
<p>Dignity is supported at each interaction with the person with dementia and their families whilst meeting biological, psychological, spiritual, existential and social needs.</p>		<p>People with advanced dementia, their families and friends, are supported by a specialised, knowledgeable and respectful workforce. (See section 6)</p>

**Key challenges:**

1. Lack of understanding about advanced dementia and the experiences of families among the professional workforce
2. Low professional and social status of dementia care
3. Lack of knowledge and understanding of human rights as they apply to dementia care
4. Ensuring dignity is respected and supported in every task, activity and interaction
5. A lack of National Dementia Plans in many countries [www.alzheimer-europe.org/Policy-in-Practice2/National-Dementia-Plans](http://www.alzheimer-europe.org/Policy-in-Practice2/National-Dementia-Plans)

## Section 2: Future Planning for advanced dementia care

**Statement:** Effective future planning for advanced dementia care is supported by all professionals by engaging in a partnership approach with people with dementia, their families and friends. This should happen from the point of diagnosis to ensure the opportunity is provided to live as well as possible as dementia advances.

### Key points:

1. It is recommended that planning for the future takes place at an early stage so that the person with dementia has sufficient cognitive abilities to articulate goals and desired direction of care. However, diagnosis can happen at different points in the illness, sometimes not at all, future planning will need to reflect the differing circumstances so the person can live the best life possible and prepare for potentially challenging times ahead.
2. Families and friends are likely to need support from professionals to engage in these processes.
3. Transitions experienced by people with dementia and their families are often a time of crisis. Typical transitions include a transition of self upon diagnosis, transition of places including admission to hospital and transition from independence to increasing dependence. Recognition of these transitions should stimulate person centred future planning and increased care and support at the time of transition.

Content and the role of the professional (what)	Reason for statement (why)	How demonstrate statement is being achieved (how)
<p>Professionals provide the person with dementia a full biopsychosocial assessment of assets, strengths, needs and preferences. This assessment needs to take account of past life experiences that may surface as the dementia progresses (first language, migration, conflict).</p> <p>Whilst in the post diagnostic support phase, professionals engage with the person with dementia and their family to discuss and agree a shared perspective and approach to planning for advanced dementia care. Planning should be considered as a process and not as a one off event, this acknowledges change over time.</p> <p>Professionals develop their skills and knowledge with regards to Advanced planning, legal protections concerned with capacity and Advanced Directives. This should be shared in an appropriate format to support people with dementia and their family to develop and communicate these formal agreements with the family and health and social care team.</p> <p>Professionals explore and support opportunities for independence and social connectedness for the person with dementia and their families. Existing social networks are strengthened where possible.</p> <p>Professionals provide opportunities for peer support and practical education for families and friends. This education focuses upon skills and opportunities for communication, practicalities and person centred strategies to support them manage the complexities of advanced dementia care.</p>	<p>Evidence has shown that planning for advanced dementia is often not undertaken. This results in family members and professionals having to try and agree on what the person with advanced dementia may want during a time of significant transition, fluctuation and challenge.</p> <p>In order to engage in planning and making informed choices, the person with advanced dementia and their family require full and honest information with regards to what kinds of decisions can be made in advance and how these can best be communicated.</p> <p>Professionals can miss, dismiss or avoid these difficult conversations if they have not developed established, trusted relationships or have the required skills and knowledge in order to be able to approach them.</p> <p>Pre-planning can help avoid inappropriate or unwanted interventions and unplanned moves to in-patient care in the last year of life. Pre planning can improve the quality of life and death experienced by the person with dementia and their family carers.</p> <p>Family and friends can feel excluded or disempowered, particularly at times of crisis or transition</p>	<p>Evidence of a national, regional or local policy which supports the development of advanced dementia care planning. This policy should be translated as appropriate to ensure the involvement of family and friends.</p> <p>A record of discussions between the professional, person with dementia and family. Evidence of that everyone involved has access or possesses relevant information and they are supported to contribute to decision making processes as far as possible.</p> <p>A statement of wishes and preferences recorded for the person with dementia with regards to how, when and where they wish to engage in detailed advanced dementia care planning.</p> <p>Once advanced dementia care planning is engaged with, all preferences about where to live and die, preferred activities, what makes an individual happy, how they can be made comfortable should all be discussed openly and recorded fully.</p> <p>All planning should take into account any sensory or intellectual disability and should use resources or aids that are appropriate for the individual to understand.</p>

### Key challenges:

1. The progressive and life-limiting nature of dementia is often not recognised or acknowledged, cultural taboos about discussing death and dying maybe a factor.
2. Continuing management of transitions in care to achieve continuity of advanced dementia care
3. Importance of future planning earlier in the trajectory is often underestimated
4. Insufficient communication with patient, family and friends is common

### Section 3: Managing symptoms and keeping well

**Statement:** The management of symptoms encompasses the biopsychosocial, spiritual and existential needs and preferences of the person with dementia, their family and friends

#### Key points:

1. Advanced dementia care is not synonymous with end of life care.
2. Symptoms maybe physical and relate to support with daily tasks and care, they may also relate to the social, psychological, existential and spiritual needs of the person.
3. Adopting a Dementia Palliare approach to practice will lead to lower use of unnecessary aggressive treatments and increased use of treatments to promote an optimal quality of life and reduce distress.

Content and the role of the professional (what)	Reason for statement (why)	How demonstrate statement is being achieved (how)
Professionals will support implementation of the wishes, needs and aspirations outlined in the persons care plan. Professionals will continue to have direct and open conversations about the potential trajectory of the illness during advanced dementia.	To implement a care plan the professional will need to understand the nature of advanced dementia, have an ability to build trusting relationships in order to have open conversations and support the person, their family and friends to implement the wishes, needs and aspirations of the person.	Trusting relationships between professionals, people with dementia, family and friends are established. All relevant persons (person with dementia, family and friends) understand the potential trajectory of dementia and are supported
Professionals develop skills and networks to enable regular engagement with health, social and non-statutory services and harness the range of expertise that different disciplines can bring to maintain wellbeing for the person with dementia and their families.	Dementia specific skills are necessary for understanding the trajectory, the needs of people with advanced dementia and factors that might improve their quality of life	An evidence based approach, with a focus on promoting optimal quality of life, symptom management and the reduction of pain or distress is agreed with all relevant persons and documented.
Professionals need to develop the knowledge and skills so optimal comfort, safety and well-being is achieved when a person may have complex physical symptoms and co-morbidities.	Despite the prognosis and time-limiting nature of dementia, there are many aspects of care and issues that can improve quality of life, thriving and health of people with dementia	Professionals take an evidence based approach to interventions and treatments. Dieticians and speech therapists can provide advice to promote skilled assistance with eating and drinking. Non-pharmacological interventions can be used to prevent and decrease stress and distress.
Professionals provide education and engage in discussions regarding maintaining and, where possible, improving wellbeing and a healthy lifestyle.		
Professionals are able to discriminate in an evidence informed way between necessary and unnecessary or ineffective aggressive interventions or treatments.	Ineffective or unnecessary over aggressive treatments such as feeding tubes or psychotropic mediation are sometimes used in people with advanced dementia when less aggressive and more effective options are more appropriate.	

#### Key challenges:

1. A lack of understanding about advanced dementia, non-pharmacological or medical interventions, and how to take a positive practice approach to advanced dementia care may lead to inappropriate or aggressive treatments
2. Professionals may find it challenging to have open conversations with family and friends about advanced dementia and the trajectory of the illness

## Section 4: Living the best life possible

**Statement: Professionals to take a positive practice approach to providing care which enables the person with advanced dementia and their families to live the best life possible**

### Key points:

1. The adoption of Dementia Palliare approach will enable professionals to use evidence based and creative approaches to communicate and listen, to support people with advanced dementia, their family and friends to express their views and feelings in order to improve their quality of life
2. Professionals need to be educated in approaches that enable people with advanced dementia to express themselves
3. Living the best possible life is defined by the person with dementia, it includes acknowledging the importance of factors such as relationships, sexuality and spirituality
4. Professionals know and respect individual's interests and preferences in all aspects of their life

Content and the role of the professional (what)	Reason for statement (why)	How demonstrate statement is being achieved (how)
<p>Professionals have the skills and knowledge to provide and support others to provide fundamental care needs.</p> <p>These include:</p> <ul style="list-style-type: none"> <li>● identification and management of pain</li> <li>● management of sensory needs</li> <li>● management of movement, walking and attaining physical comfort</li> <li>● skin condition management</li> <li>● continence care</li> <li>● sleep management</li> <li>● nutrition and eating</li> <li>● bathing and washing</li> <li>● oral care</li> </ul> <p>Professionals understand that the experience of stress and distress by people with dementia is complex and multi-faceted. Professionals understand how distress is expressed by the individual.</p> <p>Professionals understand and educate other professionals and carers about the need to investigate all changes in behaviour, for example to identify and treat delirium or depression.</p> <p>Professionals provide a comprehensive assessment and care plan when the person with advanced dementia is experiencing stress and distress.</p>	<p>People with advanced dementia experience an ongoing need for care; this is not the same as end of life care.</p> <p>As the range of physical symptoms increases, it may become more challenging to meet the fundamental care needs of the person, identify and alleviate physical pain and emotional distress.</p> <p>The challenge of diagnostic overshadowing cannot be underestimated. That is, when professionals believe all changes affecting the person are related to dementia, fundamental health needs can easily be missed.</p> <p>The undertaking of a thorough biopsychosocial assessment starting with biological needs first, helps to support professionals to take an investigatory approach to discovering triggers for the person.</p> <p>Evidence suggests that visual and non-verbal approaches are valuable tools for enabling people with limited verbal communication to express themselves, exercise choice and to participate</p>	<p>All fundamental care needs are assessed; advanced dementia care is planned with a person centred approach and in accordance with best evidence and people with dementia and their families.</p> <p>Pain is assessed and managed appropriately and well.</p> <p>Sensory impairments are assessed and managed appropriately (e.g. glasses, hearing aids)</p> <p>Promoting continence through taking a person centred approach to continence care –following the person's toilet pattern whenever possible. Appropriate incontinence management. No indwelling catheters without clear medical indication.</p> <p>Promoting adequate sleep through taking a person centred approach to sleep management – following the person's sleep pattern and using, as far as possible, non-pharmacological measures.</p> <p>A nutritious diet is provided, dietary preferences are recognised, and mealtimes are an enjoyable and sociable part of the day.</p> <p>Skin condition and oral care is assessed and managed appropriately and well</p> <p>Behavioural changes are managed by non-pharmacological approaches. Psychotropic drugs and in particular antipsychotics are used only when medically indicated, where non-pharmacological approaches have no effect and where there is a risk to the person with dementia or to others. This is evidenced by clear assessment and care plans being in place, including regular review of their use, and a consistent approach being implemented by people working with the people with dementia.</p>

Content and the role of the professional (what)	Reason for statement (why)	How demonstrate statement is being achieved (how)
<p>Professionals have the knowledge, skills and behaviour to apply approaches that enable people with advanced dementia express themselves and their views</p> <p>Professionals provide a safe, enabling and secure and dementia friendly environment.</p> <p>Professionals understand that there are a range of non-pharmacological interventions that promote quality of life. Professionals understand how to use these with people who have advanced dementia.</p> <p>Professionals understand the importance of meaningful activities and their role in ensuring the person with advanced dementia is able to participate in activities that are meaningful and enjoyable for them.</p> <p>Professionals understand the importance of 'whole person care', the importance of relationships and having someone understanding to talk to. Professionals work with people with dementia and their families with an approach which maintains and supports personal identity or selfhood and recognises how a person with advanced dementia experiences the world.</p> <p>Professionals understand the support needs of family and friends, and how to give or signpost appropriate interventions.</p>	<p>Being supported to live in a familiar environment, have familiar belongings in an environment suitably adapted contributes to people being able to live the best life possible</p> <p>Being supported to continue to participate in meaningful activities contributes to the people with dementia being able to live the best life possible.</p> <p>Evidence suggests that creating the opportunities for one to one interaction (verbal and nonverbal listening and communicating) in a sensitive manner is the essence of good care</p> <p>Knowing the person, including their expectations and hopes, likes and dislikes, strengths and assets together with an understanding of their family/friends</p> <p>Evidence suggests that family and friends often wish to maintain involvement in the support and care of their loved one before and after they are admitted to residential care. Using this knowledge to plan and provide care can positively influence the person's quality of life</p>	<p>Education of professionals and family and friends in these approaches. Meaningful and individualised activities are incorporated in care plans. Wherever possible they are experienced in collaboration, with the person's family and friends.</p> <p>Methods of communication are shared among all those caring for the person, actively including the family carer/s wherever possible, and are regularly reviewed and documented</p> <p>Professionals understand the principles of a dementia friendly environment and are able to advise other professionals and family members</p> <p>Professionals use tools and techniques to positively influence a person's life through adopting strategies to improve physical activity, social environment and quality of interactions and reduce stress and distress. A friendly and joyful, respectful atmosphere of care is established</p>
<p><b>Key challenges:</b></p> <ol style="list-style-type: none"> <li>1. The adoption of a Dementia Palliare positive practice approach that enables people with dementia and their families to express their views and live the best possible life</li> <li>2. Educating professionals with the knowledge, skills and behaviours to implement tools and techniques to enable the best possible life for people with dementia and their families</li> </ol>		

## Section 5: Support for family and friends

**Statement: The Dementia Palliare approach advocates that family and friends make an important and valued contribution to the lives and well-being of people with advanced dementia in and that the well-being of family and friends is important in its own right**

### Key points:

1. Family and friends are supported to proactively sustain relationships with the person with dementia
2. The expertise of family and friends must be acknowledged and maximised in order to enhance the health, well-being and sense of self of their loved ones and of themselves
3. Family and friends are empowered to engage with professionals, decision making processes and the care of the person with advanced dementia.

Content and the role of the professional (what)	Reason for statement (why)	How demonstrate statement is being achieved (how)
<p>Professionals have the knowledge, skills and networks to enable family and friends to engage with care settings/ services to maintain their own biopsychosocial wellbeing.</p> <p>Professionals provide opportunities for peer support; skills based education and other joint learning opportunities.</p> <p>Professionals encourage a whole family system approach to support and care. This means including both young and old, male and female members of the family in support processes.</p>	<p>Family carers of people with dementia are at increased risk of physical and psychological ill-health.</p> <p>Family carers report increased levels of stress and depression, particularly at times of transition. These experiences not only cause distress but reduce the family's capacity to care in the way they wish to.</p> <p>Co-production and strengths based opportunities to develop long term supportive networks and skills and knowledge have been shown to reduce stress for the family carer and the person with dementia.</p> <p>In Europe, women are often the principal carer for people with dementia; as the daughter, daughter in law or spouse/ partner. This is irrespective of their social standing, other caring responsibilities or employment status. Early discussion can help promote a greater awareness of this gender inequality and, in the long-term, endeavor to attain a fairer distribution of responsibility.</p> <p>To support family and friends who wish to care/to continue caring, to become 'co-experts' as quickly and smoothly as possible so they experience less 'trial and error' learning that increases their stress and impacts negatively on their health and well-being.</p>	<p>An individualised assessment has been offered to the family carers and evidence of this has been recorded.</p> <p>An individualised plan of care has been developed to address the needs and preferences of the family carer separately to the person with dementia. There is evidence that this plan of care is developed and reviewed.</p> <p>There are opportunities, such as groups or safe social spaces for family carers and friends of people with dementia to meet, be provided with support and information.</p>

### Key challenges:

1. To reduce the impact of stress on family and friends and explore ways to empower those who wish to continue caring to be enabled to do so
2. To recognise that experienced family carers often have detailed 'first hand' knowledge and experiences about how best to care for their relative with dementia. It is important that carers who wish to give care are enabled to become 'co-experts' as smoothly and as quickly as possible

## Section 6: Advancing Dementia Palliare Practice

**Statement: Professionals have a key role to play in advancing practice and championing policy and practice reforms in advanced dementia care**

### Key points:

1. Evidence informed Dementia Palliare requires investment in interprofessional education and training.
2. Leadership commitment is essential to champion policy and practice reforms and achieve culture change.
3. Involvement strategies are critical to developing a range of services that are helpful and wanted by individuals and family.
4. Applied research is required to develop interventions with and for people with advanced dementia.

Content and the role of the professional (what)	Reason for statement (why)	How demonstrate statement is being achieved (how)
Professionals to lead practice reforms and model evidence informed Dementia Palliare practice. Professionals to demonstrate a critical awareness of policy, legislation and rights relating to people with dementia and their family and friends and have the ability to apply this knowledge to advance practice, develop involvement strategies and champion change	Various care practices are recommended by different bodies. Therefore critical appraisal of these recommendations is necessary to ensure practice is based on best evidence and is appropriate for the individual in their particular settings and circumstances.  A variety of legislation, Action Plans, Strategies and Guidelines refer to dementia care and critical reflection on how they apply in different nation states, care settings and individuals is necessary.	Document that evidence informed Dementia Palliare practice approaches are taken.  Model best practice and lead practice reforms within own sphere of influence  Document that the appropriate legislation, Action Plans, Strategies, Guidelines etc. are implemented in Dementia Palliare care.
Professionals to proactively lead interprofessional and collaborative working to support transitions, continuity and co-ordination of care	Interprofessional collaboration and working and positive relations with people with dementia, their family and friends are a necessary condition for Dementia Palliare.	Document interprofessional collaborative approach to care that supports transitions, continuity and coordination of care. Have the knowledge to advise of other services across sectors that can support people with dementia, their families and friends.
Professionals to proactively lead on effective partnership working and positive relationships with family and friends	Family and friends are experts in the care of their family member.	Document how people with dementia family and friends are involved and supported in their role and relationships with the person with advanced dementia.
Professionals are able to critically appraise research, undertake small scale research or tests of change and understand how this can be meaningful applied in a practice setting	Research informed practice has the potential to improve advanced dementia care and family caring	Evidence continuous professional development and evidence informed practice
Professionals participate in continuous professional development activities (self directed learning, training, membership of or affiliations with dementia learning communities, universities, health institutions or carer groups) so their knowledge and understanding of advanced dementia is refreshed		

### Key challenges:

1. A variety of different legal political and professional documents refer to dementia care
2. An Increasing amount of advice and recommendations are made about the care of people with dementia, not all of these are evidenced informed, critical appraisal is necessary.
3. Care for people with advanced dementia is often fragmented, families are often not involved, intra professional communication is insufficient and many professionals are not fully aware of all the services that are available to support people with dementia and their families

## APPENDIX 1: WHITE PAPER DEFINING OPTIMAL PALLIATIVE CARE IN OLDER PEOPLE WITH DEMENTIA: A DELPHI STUDY AND RECOMMENDATIONS FROM THE EUROPEAN ASSOCIATION FOR PALLIATIVE CARE

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**Palliative Medicine, 2014, Vol. 28(3) 197–209 DOI: 10.1177/0269216313493685**

**Background:** Dementia is a life-limiting disease without curative treatments. Patients and families may need palliative care specific to dementia.

**Aim:** To define optimal palliative care in dementia.

**Methods:** Five-round Delphi study. Based on literature, a core group of 12 experts from 6 countries drafted a set of core domains with salient recommendations for each domain. We invited 89 experts from 27 countries to evaluate these in a two-round online survey with feedback. Consensus was determined according to predefined criteria. The fourth round involved decisions by the core team, and the fifth involved input from the European Association for Palliative Care.

**Results:** A total of 64 (72%) experts from 23 countries evaluated a set of 11 domains and 57 recommendations. There was immediate and full consensus on the following eight domains, including the recommendations: person-centred care, communication and shared decision-making; optimal treatment of symptoms and providing comfort (these two identified as central to care and research); setting care goals and advance planning; continuity of care; psychosocial and spiritual support; family care and involvement; education of the health care team; and societal and ethical issues. After revision, full consensus was additionally reached for prognostication and timely recognition of dying. Recommendations on nutrition and dehydration (avoiding overly aggressive, burdensome or futile treatment) and on dementia stages in relation to care goals (applicability of palliative care) achieved moderate consensus.

**Conclusion:** We have provided the first definition of palliative care in dementia based on evidence and consensus, a framework to provide guidance for clinical practice, policy and research.

## APPENDIX 2: CONTRIBUTING EVIDENCE AND REFERENCES

Alzheimer Scotland, Advanced dementia model of care  
[www.alzscot.org/campaigning/advanced\\_dementia\\_model](http://www.alzscot.org/campaigning/advanced_dementia_model)

Alzheimer Scotland, Eight pillar model of care  
[www.alzscot.org/campaigning/eight\\_pillars\\_model\\_of\\_community\\_support](http://www.alzscot.org/campaigning/eight_pillars_model_of_community_support)

Alzheimer Scotland, Five pillar model of care  
[www.alzscot.org/campaigning/five\\_pillars](http://www.alzscot.org/campaigning/five_pillars)

An integrative literature review on the experience of advanced dementia  
[www.uws.ac.uk/palliareproject/](http://www.uws.ac.uk/palliareproject/)

National Dementia Standards of Care for Dementia, The Scottish Government, 2011  
[www.gov.scot/Publications/2011/05/31085414/0](http://www.gov.scot/Publications/2011/05/31085414/0)

Promoting Excellence: A framework for all health and social services staff working with people with dementia, their families and carers, The Scottish Government, 2011  
[www.gov.scot/resource/doc/350174/0117211.pdf](http://www.gov.scot/resource/doc/350174/0117211.pdf).

The case studies of the experience of advanced dementia (person and family perspectives),  
[www.uws.ac.uk/palliareproject/](http://www.uws.ac.uk/palliareproject/)

The Charter of Rights for People with Dementia and their Carers in Scotland  
[www.dementiarights.org/charter-of-rights/](http://www.dementiarights.org/charter-of-rights/)

The Dementia engagement and empowerment project  
<http://dementiavoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf>

The Dementia Policy Review  
[www.uws.ac.uk/palliareproject/](http://www.uws.ac.uk/palliareproject/)

The Educational Gap Analysis  
[www.uws.ac.uk/palliareproject/](http://www.uws.ac.uk/palliareproject/)

## APPENDIX 3: THE GLASGOW DECLARATION

### Introduction

The 24th annual Alzheimer Europe conference (20–22 October 2014) was held in Glasgow, exploring “Dignity and autonomy in dementia”.

Alzheimer Europe (AE) adopted the Glasgow Declaration during its Annual General Meeting on 20 October 2014. The declaration was adopted unanimously by delegates from 26 AE member organisations.

Following the meeting, the declaration was signed by Heike von Lützu-Hohlbein, Chair of Alzheimer Europe and Henry Simmons, Chief Executive of Alzheimer Scotland. They were followed by Alex Neil, Scotland’s Cabinet Secretary for Health and Wellbeing, who became the first European Minister to sign the declaration.

In broad terms, the Glasgow Declaration calls for the creation of a European Dementia Strategy and national strategies in every country in Europe. The signatories also call upon world leaders to recognise dementia as a public health priority and to develop a global action plan on dementia.

[www.alzscot.org/campaigning/international\\_activity](http://www.alzscot.org/campaigning/international_activity)

### The declaration

Glasgow Declaration Alzheimer Europe, its member organisations and the undersigned associations and individuals commit ourselves fully to promoting the rights, dignity and autonomy of people living with dementia. These rights are universal, and guaranteed in the European Convention of Human Rights, the Universal Declaration of Human Rights, the International Covenants on Economic, Social and Cultural Rights and Civil and Political Rights, and the Convention on the Rights of Persons with Disabilities. We affirm that every person living with dementia has:

- The right to a timely diagnosis;
- The right to access quality post diagnostic support;
- The right to person centred, coordinated, quality care throughout their illness;
- The right to equitable access to treatments and therapeutic interventions;
- The right to be respected as an individual in their community.

We welcome the growing recognition of dementia as a public health priority on a national and European level and call upon European governments and institutions to recognise the role that they have in ensuring that these rights of people living with dementia are respected and upheld. In particular, we call upon the European Commission to:

- Develop a European Dementia Strategy;
- Designate a high level EU official to coordinate the activities and research in the field of dementia of existing programmes such as Horizon 2020, the Ambient Assistant Living Programme, the European Innovation Partnership on Active and Healthy Ageing, the Joint Programme on Neurodegenerative diseases research and the Innovative Medicines Initiative;
- Set up a European Expert Group on Dementia comprised of Commission officials, representatives of Member States and civil society to exchange best practices;
- Financially support the activities of Alzheimer Europe and its European Dementia Observatory and European Dementia Ethics Network through its public health programme.

Call upon Members of the European Parliament to:

- Join the European Alzheimer’s Alliance;
- Support the campaign of Alzheimer Europe and its member organisations to make dementia a European priority and create a European Dementia Strategy;
- Make themselves available for people with dementia, carers and representatives of Alzheimer associations from their country.

Call upon national governments to:

- Develop comprehensive national dementia strategies with allocated funding and a clear monitoring and evaluation process;
- Involve people living with dementia and their carers in the development and follow up of these national strategies;
- Support national Alzheimer and dementia associations.

We welcome the international recognition of dementia as global priority and acknowledge the work of Alzheimer's Disease International and the G7 group of countries in driving forward global action on dementia and call upon the international community to:

- Build on the success of European collaboration on dementia and involve European initiatives in the development of a global action plan on dementia,
- Include and consult Alzheimer associations and people with dementia in the decision making process and definition of a global research agenda;
- Adopt a holistic approach to research priorities to include psycho-social, care, socioeconomic and health systems research to ensure that research aims to benefit people living with dementia now, as well as people who will do so in years to come;
- Substantially increase the funding dedicated to all areas of dementia research;
- Promote dementia as a priority in other international bodies including among the G20 group of countries, the Organisation for Economic Co-operation and Development (OECD), the World Health Organisation (WHO) and the United Nations.

## GLOSSARY

Palliare	The root word for palliation in Latin, palliare, means to cloak or shield.
Family and friends	This may not be consistent with the traditional viewpoint of family, they are people who are significant to the person with dementia.
Dementia Palliare	A new positive practice approach to supporting people with advanced dementia but who are not yet requiring end of life care
Workforce	Personnel, staff or labour force
Practitioner	a professional such as a Doctor, nurse, social worker, health worker etc.





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