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### **Palliative and end of life care for people with advanced dementia**

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## Paper five: Palliative and end of life care in advanced dementia

### Abstract

Despite growing understanding in recent years of the biological, psychological, social, environmental and spiritual aspects of dementia, people with advanced dementia continue to experience inequalities in accessing health care capable of improving their lives. The complexities of advanced dementia challenge professional competence and demand the highest level of skilled, compassionate care. In this article we consider the status and direction of palliative care as it applies to people with dementia and explore contemporary issues regarding advanced dementia and end of life, with a focus on guidance for practitioners and support for best practice.

### Early thinking and thinking early

Palliative care developed as a specific area of expertise over many years of supporting people with a life limiting cancer diagnosis (Henderson and Sharp 2019). Dementia and other chronic conditions are also life limiting and a palliative care approach offers a focus on quality of life, maintaining function and maximising comfort (van der Steen et al., 2014). In advanced dementia, there is some evidence that a focus on fundamentals of care and giving comfort can also prepare families for the end of life and increase satisfaction with care (van Soest-Poortvliet et al, 2015). The value of such an approach to the lives of people with dementia is acknowledged in recent policy and practice guidance documents (see Fig 1). Yet a recent literature review indicates that people with dementia are less likely to receive palliative care than others with different life limiting illnesses, and that family members can be ill informed about what to expect in advanced dementia (Broady et al 2018). Jones et al (2016) suggest widespread acceptance and adoption of a palliative approach in dementia care has some way to go before the intent of policy and practice frameworks are fully realised.

The physical and psychological symptoms experienced in advanced dementia have been outlined by the World Health Organisation (2012) and Reisberg et. al. (1982), both providing a picture of substantial and complex health needs (Alzheimer Scotland 2015). The term ‘advanced dementia’ itself has lacked clarity, an issue recently addressed by Scotland’s Fair Dementia Care Commission (2019). This Commission recognises that people can experience dementia-specific, extended palliative care needs over months or years and provide a definition of advanced dementia which draws on the European Palliare Project (Holmerova, et al 2016), views of health care practitioners and family carers:

*‘Advanced dementia is associated with the later stages of illness when the complexity and*

*severity of dementia-related changes in the brain lead to recognisable symptoms associated with dependency and an escalation of health care needs and risks. Addressing advanced dementia-related health needs requires expert health care, nursing and palliative care assessments, together with insights provided by family carers and others, particularly when the person has difficulty communicating their own needs and emotions. Advanced dementia involves living, sometimes for years, with advanced illness and the advanced dementia continuum includes the terminal stages of death and dying. The experience of advanced dementia is unique to the individual and dependent on the aetiology of the underlying illness, comorbidities and other factors relating to health, personality, biography and socio-economics'*

Alzheimer Scotland, Fair Dementia Care Commission Report 2019, pgs. 14-15.

Despite the complex physical and psychological needs consistently identified in advanced dementia, the Fair Dementia Care Report (2019) highlights existing inequalities in access to health care which is free at the point of delivery for people with advanced dementia. A detailed perspective on what constitutes optimal palliative care for older people with dementia is provided by van der Steen et al (2014) in a Delphi study which ranks most highly: the best possible treatment of symptoms and comfort; person-centred care by practitioners; communication, and family care and involvement.

When the care approach adopted in dementia is palliative, due consideration is required to the timing, focus and pace of conversations with the person with dementia and their family (Kydd and Sharp 2016). Adopting the approach early necessitates both sensitivity and clarity in communications given the frequent confusion between the terms 'palliative care' and 'end of life care' (Social Care Institute for Excellence, 2014), these being connected but not synonymous. 'Palliative care' is defined as holistic, life-affirming care provided to people with life limiting conditions; 'end of life care' is that provided to people approaching the end of their lives – that is, those thought likely to die within one year, or where death is imminent (Leadership Alliance for the Care of Dying People 2014; Marie Curie 2018). A qualitative study of the views of people with dementia and carers about end of life indicates the potential for both to be unclear about the palliative nature of dementia (Poole et al., 2018). The term 'palliative care', if not fully understood, may alarm people who associate the term with imminent end of life and undermine the sense of hope so important to recovery of self-esteem and purpose following a diagnosis of dementia (Sharp, 2017).

It is important to stress palliative care does not mean doing *less* but often *more*, with an emphasis on social, psychological and spiritual aspects of care (Murray, et al., 2017). It is perhaps more helpful to think about a continuum of care, which needs to be flexible and adaptive to the many changes across the often-lengthy trajectory

of dementia. The European White Paper on Dementia and Palliative Care (EAPC) (van der Steen et al., 2014) proposes that goals of care in early dementia should prioritise maintenance of function and as the illness progresses to more advanced states, maximising comfort becomes the priority.

Considering possible futures, making decisions, expressing and recording wishes, requires mental capacity and verbal abilities and family are often expected to step in and make some difficult decisions. Although mental capacity may be lost at an early stage, even before diagnosis, adopting a palliative approach early, before advanced dementia is reached, allows optimal opportunity for engagement about personal wishes and involvement in future care and care decisions. Although challenging, experienced and knowledgeable practitioners will have early conversations with the person and family members during diagnosis, and as dementia progresses, to support both understanding and action planning for the advanced condition and end of life. The following models indicate some of the ways in which such early conversations are supported, appreciating there are others, and that post-diagnostic support to people with dementia and their families is provided by a range of practitioners across the UK.

The Alzheimer Scotland five pillar model of post-diagnostic support (2011) arose from the recommendations of a local pilot project in the West of Scotland which achieved better outcomes by working proactively in partnership with people with dementia and their families from an early point following diagnosis. The model balances support which is focused on living well and self-reliance with preparation for inevitable changes, decision-making and care. This model frames the Scottish Government commitment that every person diagnosed with dementia in Scotland has a right to a minimum period of one year's post diagnostic support, delivered by a named and experienced Link Worker (NHS ISD Scotland 2010). Areas of practical support within the Alzheimer Scotland (2011) model promote current well-being, symptom control, peer support, planning for future decision-making and future care. Another example of a professional role fulfilling a positive, enabling function and future focused support is that of the Admiral Nurse. These are qualified nurses who, alongside other health and social care professionals, work with the person with dementia, their family and carers to maintain and develop skills, develop coping strategies and sustain personal relationships (Dementia UK 2017). Evans et al (2018), in exploring the role of the Admiral Nurse, recognise the valuable part they play in supporting people with dementia, their family and carers with planning for the end of the person's life and supporting their wishes.

Regardless of the model of care delivery, much more needs to be done before every person with dementia experiences timely support across the continuum of their illness and the skills required of professionals to provide such support needs to be better understood. Continuity of support relationships are important in building trust,

essential to enabling the undeniable challenge of difficult conversations around the future to take place. They remain important across the trajectory of dementia and the knowledge and skills of family, established support staff and other personal support networks, may need to be frequently revisited and enabled. The Advanced Dementia Practice Model (Alzheimer Scotland, 2015) reinforces the importance of access to the highest quality palliative care skills and support for the continuity of care from family and carers who know the person best. Continuity of care and safeguarding personal connections requires a focus on what is important to the person and those who are most significant in that person's life. The perspective of people with dementia, families and professionals about what is essential to good end of life care do not always converge, so an approach that supports co-operation and discussion is essential (Poole et al., 2018).

It is important to anticipate and plan for situations where it may be difficult for those affected to articulate needs, preferences, and what is important to them. Advanced Care Planning (ACP) involves capturing conversations between people, their families and carers around future wishes and priorities; the purpose being to support those with chronic and serious illnesses to live and die in a place, and manner of their choosing (Rietiens et al 2017). Having conversations where end of life wishes are discussed does not appear to happen routinely in many families (Poole et al., 2018). The language around advance planning, such as: advance statement, advance directive, living will and anticipatory care plan, differs in meaning and content across the UK, and importantly, also in legal status. A summary of these differences can be seen in Fig 2. Regardless of how an advance plan is created, it is important that wishes are discussed with family and any legally appointed persons. GP's can ensure details are held electronically to be shared with other professionals. There are different approaches in different parts of the UK to ensuring decisions such as those surrounding Cardio Pulmonary Resuscitation are adhered to. Such documents need to be readily accessible to emergency service staff, such as paramedics, in acute situations. In the absence of evidence of wishes, acute care staff may be obliged to follow procedures which could mean unwanted clinical interventions are pursued in advanced dementia or at the end of a person's life.

Templates and guidance are now available online to support families and professionals in all aspects and formats of advance planning in the UK. For examples, see advance planning information and downloadable resources available through NHS England Advanced Care Planning for People with Dementia in all Care Settings (2018); Compassion in Dying (2018), MacMillan Cancer Support (2019) and in Scotland, the anticipatory planning toolkit provided by Health Care Improvement Scotland (2017).

### **Palliative and end of life care in advanced dementia**

People with dementia may die as a result of their dementia, other co-existing or emerging conditions, medical complications such as pneumonia or any combination of these. The lack of recognition of dementia as a life limiting illness and stigma associated with the condition have resulted in the end of life challenges faced by people with dementia, their families and carers being poorly addressed (Sampson & Harrison-Dening, 2013).

In the face of often-lengthy periods of frailty and disability in advanced dementia, it can be difficult to determine when end of life is approaching and active planning for this should commence (Chatterjee, 2008). Co-morbidity brings even greater complexity to this situation and death can result from a range of possible illnesses (Subramaniam 2019). A variety of tools are available to assist earlier identification of people nearing the end of their lives which can help to facilitate appropriate care planning and communications. These include tools such as *The Gold Standards Framework Proactive Identification Guidance* (2016) and *The Supportive and Palliative Care Indicators Tool* (SPICT) (University of Edinburgh, 2018). A recent comparator of such predictor tools aids understanding of which tools are best for specific circumstances and patients (Healthcare Improvement Scotland, 2018). There have been calls for a recognised 'Palliare' phase emerging from a study by Hanson et al (2016), describing a long period of advancing dementia, preceding the end of life. It is suggested that identification, assessment, care and support during this 'Palliare' phase could provide for effective end of life care when it is required.

Palliative care and skilled interventions in advanced dementia remain underdeveloped and barriers persist for people with dementia in accessing palliative care (Erel et al., 2017). Ethical challenges and outcome measures to conduct well designed studies with people with advanced dementia influence the paucity of research in this area (Murphy et al., 2016). There are however, a range of guidance documents, standards, indicators and other resources that can support practitioners about palliative care approaches for people living with dementia (See Fig 1 for examples from the UK).

### **Pain and distress in advanced dementia**

End of life care for people with dementia has been described as poorer than that received by age-equivalent peers without cognitive difficulties (Crowther et al., 2013). One of the most significant areas in palliative and end of life care for people with dementia lies in the recognition and response to pain. The impact of pain on people with advanced dementia remains poorly understood, yet untreated pain is clearly important to quality of life, health, well-being and function (Corbett et. al., 2014). The majority of people with dementia are older and evidence suggests pain is common in older people. A review of barriers to pain management in dementia estimates 25-50% of older people living in the

community are affected by pain and as many as 30-49% of nursing home residents (Bruneau 2014). The issue of pain being poorly recognised and managed in people with dementia is not site specific. In a comparison of the treatment of post-operative pain in older patients following hip fracture repair, Morrison and Siu (2000) demonstrated that patients with advanced dementia received one-third of the amount of opioid analgesia provided to patients who had no cognitive impairment. The level of severe pain reported by the patients who did not have dementia in this study suggests that the majority of subjects who had advanced dementia were in severe pain post-operatively (Morrison and Siu 2000). A study of PRN analgesia in an acute care setting determined that in the first three days of admission patients with dementia significantly less PRN prescribed analgesia than patients without a diagnosis of dementia of the same age with similar conditions (Green et al 2015). In a longitudinal study of 230 people with dementia in acute hospital care Sampson et al (2015) found more than a third reported pain during admission and there was a significant association between behavioural scores and pain both at rest and on movement. Further, Sampson et al. (2015) demonstrated that pain was persistent in at least half of patients observed every four days during the study.

Pain may be associated with co-morbidities, common in dementia but often over-shadowed by it. Other conditions and associated symptoms can receive less attention when experienced by people with dementia and the non-verbal expression of pain may be dismissed as part of the dementia symptomatology (Sampson, et al., 2015). When a person with advanced dementia can only express pain nonverbally, assessment and treatment of pain is challenging (Regnard, et al., 2003). Pain responses may be delayed, occur only on movement, or be communicated through diverse responses. Pain is recognised as a complex, contributing factor in distressed behaviour and may be a risk factor for delirium (Feast, 2018).

An in-depth understanding of the person and their previous management of pain is essential. Recording a pain history is important as this knowledge can become lost when the person with dementia can no longer describe their pain, or management of it. The situation is even more problematic if there are no family members or friends available, or they have no clear understanding of how the person managed their pain. The challenge for staff lies in working out if there is pain, what type of pain it is and how severe it is. Interpreting the presence of either acute or chronic pain in people with dementia requires knowledge of the different clinical entities of these types of pain and specific approaches to managing different types of pain.

A helpful question to ask is, 'If the person I am caring for was not experiencing cognitive difficulties, would I consider pain to be a concern?'

See Fig 3 for other important aspects to consider and steps to take when assessing pain in a person with dementia. Reducing pain is associated with a reduction in symptoms of depression, regardless of the degree of cognitive impairment present (Erdal, 2017). Failure to address pain has been described as an infringement of human rights (Brennan et al 2016). A comprehensive review of the evidence identifies that research is seriously lacking and deeply concerning about pain assessment and management in advanced dementia, particularly at the end of life (Husebo et al., 2016).

### **Pain tools**

Pain assessment tools based on observation of behaviour and responses are widely available and useful for assessing pain in the person with advanced dementia. Such tools complement but do not replace other aspects of assessment as described in Fig 2. Some limitations of such tools include:

- No specific behaviour solely indicates pain and there is a risk of over or under diagnosis of pain when there are other possible causes, e.g. boredom or depression.
- Each person's expression of pain will be different and important responses can be overlooked or misinterpreted.
- No single tool will work for everyone and should only form part of the assessment process.
- Acute pain may be more obvious and chronic pain may go unnoticed.

While these tools contribute to pain recognition in people with advanced dementia, lack of education about using appropriate tools can contribute to poor assessment outcomes. A useful review of behaviour based pain tools is available from the City of Hope Palliative Care and Pain Center (2018). Examples of those most widely used are:

- The Abbey Pain Scale (Abbey et al., 2004)
- The DISDAT Disability Distress Assessment Tool (Regnard et al., 2007)
- PAINAD pain tool (Warden et al., 2003)

- Doloplus 2 pain tool (Pautex et al., 2007)
- Mobilization-Observation-Behaviour-Intensity-Dementia-2' (MOBID-2) (Husebo, 2017).

For those people with most advanced dementia the PAINAD and Doloplus 2 are recommended by Schofield (2018). A tool using observation and movement for pain not experienced at rest, is the '*Mobilization-Observation-Behaviour-Intensity-Dementia-2'* (MOBID-2) (Husebo, 2017).

### **Management of pain in advanced dementia**

While accurate frequent pain assessment is a key step in managing pain, other helpful points include:

- Consider cause of pain
- Consider discomfort as well as pain – e.g. positioning and possible joint and pressure discomfort
- Encourage slow and careful movements when providing care
- Consider least restrictive clothing
- Ensure good nutrition, hydration and sleep
- Monitor for signs of delirium
- Consider alternatives to medication – e.g. massage, heat, cold, positioning, movement
- Ensure prescribed medication is given - regular rather than PRN medication
- Seek expert support from palliative care teams
- Consider alternative modes of administration
- Manage side effects of medication

### **Other sources of distress**

The impact of illness, delirium and personal care activities ([cross ref to article xx?](#)) are also relevant to palliative and end of life care for the person with advanced dementia. Part of planning ahead earlier in dementia should be a discussion about how these could be addressed. Eating and drinking is a core aspect of quality of life and as end of life approaches, ability may decline. Loss of appetite and swallowing difficulties in the advanced stages of the illness can be distressing for family and carers as well as the person with dementia. There are strong social and emotional associations with the nurturing aspects of

taking food and drink. For family and carers of someone with advanced dementia this may be one of the last areas where they feel they can offer support as needs become more complex.

It is important to consider potentially reversible conditions, as difficulties with food and fluids do not always signify the end of life, for example, pain in the mouth or sensory changes. Artificial feeding is contra-indicated in advanced dementia (National Institute for Health and Care Excellence (NICE), 2018) and offers little or no benefit over the use of careful hand-feeding support (Sampson, Candy and Jones, 2009).

Families involved in decision making around such areas may, no matter how well informed, feel a huge burden and carry sustained concerns such as, 'Was that the right thing to do?' so longer term support may be necessary.

### **Working in supportive partnership with families, friends and carers**

Carers and families of people living with advanced dementia can experience emotional rewards, relationship gains and spiritual growth (Lloyd et al., 2014). Yet caring can also be stressful and as dementia advances the multiple losses can provoke grief responses that can accumulate over time (Sharp 2017). Grief occurs not only in response to, but in anticipation of, multiple losses in different areas of the lives of those affected by dementia over time (Blandin and Pepin 2017). Loss is a fundamental part of the dementia experience and yet one of the most under recognised issues facing people with dementia and their families (Shanagher et al., 2016). The recognition and validation of grief experienced, and bereavement support, are essential to good palliative and end of life care in dementia (van der Steen et al., 2014; Irish Hospice Foundation 2016). Person-centred care needs to encompass supporting and sustaining relationships. Comprehensive guidance on loss and grief in dementia is provided by The Irish Hospice Foundation (Irish Hospice Foundation 2016). This document provides case studies and resources to support practitioners to work with people who are experiencing loss and grief in dementia and outlines key considerations to inform good practice for health and social care professionals.

Working in partnership families, friends and carers should involve:

- Developing good working relationships with family members, friends and carers

- Being aware of the types of losses and the transitions family members, friends and carers experience
- Being sensitive to family and other relationship dynamics which will change over time
- Paying attention to relationships and the context of losses
- Recognising and responding to loss and grief when encountered through -
  - using active listening skills
  - validating and supporting thoughts and emotions
  - encouraging people to think about their support needs
  - signposting to resources of support
  - supporting family members to recognise and respond to changes and plan for the future
- Providing emotional and psychological support

### **Conclusion**

The end of life in advanced dementia is the conclusion of a long journey. Open communication, clear information and a person centred approach as early as possible in the illness can support all those involved to make this period less distressing. Those people who face the end of life with advanced dementia should be offered care in line with best practice in palliative and end of life approaches. This includes continuity of care, skilled communication, family support, shared decision making, and optimal symptom management to achieve comfort, psychosocial and spiritual support, and timely recognition of dying. Palliative and end of life approaches should be supported by a multi-disciplinary and interagency collaboration, including palliative care services.

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Figure 1. Examples of Good Practice Guidelines and Standards on Palliative and End of Life Care relevant to People with Dementia, UK.

National Institute for Care Excellence (NICE) Care of dying adults in the last days of life <https://www.nice.org.uk/guidance/qs144> (2017)

National Institute for Care Excellence (NICE) Guideline [NG97] 1.10 Palliative care in Dementia: assessment, management and support for people living with dementia and their carers, (2018) Pg 30.

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National Institute for Care Excellence (NICE) Guideline [NG108] Decision-making and mental capacity (2018) <https://www.nice.org.uk/guidance/ng108>

National Institute for Care Excellence (NICE): Enteral (tube) feeding for people living with severe dementia (2018)

<https://www.nice.org.uk/guidance/ng97/resources/enteral-tube-feeding-for-people-living-with-severe-dementia-patient-decision-aid-pdf-4852697007>

Scottish Palliative Care Guidelines (2014)

<http://www.palliativecareguidelines.scot.nhs.uk/>

Scottish Government Guidance: Caring for people in the last days and hours of life (2014)

<https://www.gov.scot/publications/caring-people-last-days-hours-life-guidance/>

The Irish Hospice Foundation (2015) Facilitating discussions on future and end of life care with a person with dementia. <https://hospicefoundation.ie/healthcare-programmes/dementia-palliative-care/guidance-documents-dementia/dementia/>

Fig 2

Type of Advanced plan	Country	Content	Legally binding	Not legally binding
Advance Statement	England and Wales	Any aspect of future health care Personal preferences Beliefs etc.		×
Advance Statement	Scotland	Specific to mental health care and treatment under the Mental Health (care and treatment) Scotland Act 2003 revised 2015.	√ Generally, legally binding	
Advance Decision to refuse treatment	England and Wales and Northern Ireland	Decision to refuse treatment	√ Providing it complies with the Mental Capacity Act is valid applies to the situation in England Wales Under Common law Northern Ireland	
Anticipatory care planning (Anticipatory is a Scottish term)	Scotland	Includes a comprehensive overview of future plans, beliefs and preferences		× Although not legally binding it may be used as evidence in making decisions
Advance directive Scottish term	Scotland	Describes treatments that the person does not want		× May influence decision making but unlike England and Wales <b>not</b> legally binding
Living will	England and Wales	Same as a decision to refuse to treat	√ Legally binding	
Living Will	Scotland	Same as Advance directive		× They may not have any effect but may be persuasive
<p>NB: Different approaches to implementing Not for resuscitation paperwork  <a href="http://www.professionalpalliativehub.com/sites/default/files/MAC14376_lifecoicesNI_E2_lowrespdf_SH_20160607.pdf">http://www.professionalpalliativehub.com/sites/default/files/MAC14376_lifecoicesNI_E2_lowrespdf_SH_20160607.pdf</a></p> <p>British Medical Association, 2007. Advance decisions and proxy decision-making in medical treatment and research: guidance from the BMA's medical ethics department. <i>London: BMA.</i></p> <p><a href="https://compassionindying.org.uk/making-decisions-and-planning-your-care/planning-ahead/advance-care-planning/">https://compassionindying.org.uk/making-decisions-and-planning-your-care/planning-ahead/advance-care-planning/</a></p>				

Figure 3. Assessing pain in the person with advanced dementia

1. Establish the pain history	Both in the short and long term, this may identify chronic and acute pain or other types of pain
2. Ask the person	Do not overlook asking. Allow adequate time to reply and frame the questions in the present tense. Be aware that pain may be described in different ways.
3. Ask someone who knows the person best	They may be able to provide a pain history and identify subtle changes in the person's behaviour.
4. Pain may be expressed through behaviour	Pain should always be the first consideration if there is a change in behaviour. Examples include the person becoming withdrawn, agitated, reluctant for care activities or move around.
5. Observation when working with the person	Assess signs of discomfort or resistance when personal care is given for example when eating (dental pain) moving (osteoarthritic pain) or touching the body (neuropathic pain).
6. Pain <i>may be</i> expressed through facial expression	However, this may not be reliable in the advanced dementia
7. Probability	If the specific disease process the person has is known to be painful – it will be!
8. Use person centred approach to pain management	Consider how the person normally manages their chronic pain. We all use techniques to cope with our aches and pains, this will be no different for people with dementia. It may involve walking about or lying down, using over-the-counter/prescription medication or non-pharmacological treatments for example heat /cold, exercise, acupuncture etc.
10. Consider other types of pain	Acute /chronic physical pain Unresolved emotional problems Social pain (quality of relationships etc.) Spiritual pain (issues such as fears or hopes for the future).

#### Figure 4: Further web sources

The Loss and Grief in Dementia guide (Irish Hospice Foundation 2016) explores ways to support the person with dementia, family members and caregivers experiencing loss during the end of life, dying process and beyond. This provides useful additional resources in the form of factsheets and case studies. The guidance is designed for all staff to be used within their own scope of practice and supports peer learning and practice development. <https://hospicefoundation.ie/>

Good life, Good Death, Good Grief, a broad-based stakeholder group are working to make Scotland a place where there is more openness about death, dying and bereavement. They signpost families, care staff and the public to a range of practical resources and support such as the Scottish Compassionate Communities Network which aims to practically improve people's experiences of deteriorating health, dying, death and bereavement. <https://www.goodlifedeathgrief.org.uk/>

The recent report, '*A Road Less Lonely*' (2018) The report illustrates how a range of organisations across a variety of domains can undertake practical steps to encourage and support open and supportive attitudes to dying, death and bereavement. <https://www.palliativecarescotland.org.uk/content/publications/A-Road-Less-Lonely-WEB.pdf>

Anticipatory Care Planning (2017) ACP matters video. Showing how this approach is changing lives for people living on Scotland. <https://www.nhsinform.scot/care-support-and-rights/palliative-care/planning-for-the-future/make-an-anticipatory-care-plan>