

G.16 Palliative care

G.16.1 Palliative care

- What models of palliative care are effective for people with dementia

G.16.1.1 Qualitative evidence

Carer identified issues

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
Bereaved carer – meeting physical care needs							
Lawrence (2011)	Structured interviews	Ensuring adequate food and fluid intake, hygiene, toileting, dressing.	Serious ¹	High	High	High	Moderate
Bereaved carer – going beyond task-focused care							
Crowther (2013), Lawrence (2011), Moore 2017	Structured interviews, Unstructured interviews	End-of-life care was evaluated positively if it was felt that the professionals cared about their dying relative.	Serious ¹	High	High	High	Moderate
Crowther (2013), Treloar (2009)	Unstructured interviews, Mixed methodology	Getting to know individual's interests, sensitivities and preferences (including food preferences).	Serious ¹	High	High	High	Moderate
Bereaved carer –planning							
Dening (2012), Lawrence (2011)	Structured interviews	Advance directives and advance statements.	Serious ¹	High	High	High	Moderate
Lawrence (2011)	Structured interviews	Discussing treatment planning with families and the wider care team.	Serious ¹	High	High	High	Moderate

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
Lawrence (2011)	Structured interviews	Enabling family members to be present at the time of death.	Serious ¹	High	High	High	Moderate
Dening (2012)	Semi-structured interviews, focus groups	Family carers described how little happened routinely; they had to initiate and then “push” for services to be provided, these were unpredictable and fragmented	Serious ¹	High	High	High	Moderate
Bereaved carer – impact of hospitalisation							
Dening (2012), Treloar (2009)	Semi-structured interviews, focus groups	Not liking the hospital environment.	Serious ¹	High	High	High	Moderate
Crowther (2013)	Unstructured interviews	Dying on an open ward rather than finding a side room in a hospital.	Serious ¹	High	High	High	Moderate
Dening (2012)	Semi-structured interviews, focus groups	Carers described how acute hospital staff struggled to provide basic care. Carers perceived a lack of understanding, little compassion and low staffing levels	Serious ¹	High	High	High	Moderate
Bereaved carer - Knowing the person well and having a sense of their personal and social identity was said to enable carers and health-care professionals to make better informed best interests decisions on behalf of a person with dementia							
1 Lamahewa (2017)	Focus groups and semi-structured interviews	This was thought to be particularly pertinent at the end of life, when the person with dementia may not always be able to verbally express themselves.	Not serious	High	High	High	High
Bereaved carer – Knowledge of dementia provides insight for decision making							
1 Lamahewa (2017)	Focus groups and semi-	A sense of preparedness, understanding and insight into the impact of dementia on the end of life seemed likely to have resulted in a greater level of acceptance amongst some carers, which was said to have a	Not serious	High	High	High	High

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
	structured interviews	powerful influence on decision making between families and practitioners.					
Current carer - Lack of familiarity of the person with dementia by health-care providers inadvertently leads to disease labelling							
1 Lamahewa (2017)	Focus groups and semi-structured interviews	Lack of familiarity of the person with dementia by health-care providers inadvertently leads to disease labelling, whereby the individuality and identity of the person is lost and they are defined by their disease. This was considered to be particularly relevant when a person with dementia is admitted to hospital where staff have no information about them.	Not serious	High	High	High	High
Current carer - When healthcare professionals do not communicate with carers because of poor communication or lack of time to involve the family, this can complicate decision making							
1 Lamahewa (2017)	Focus groups and semi-structured interviews	When healthcare professionals do not communicate with carers because of poor communication or lack of time to involve the family, this can complicate decision making	Not serious	High	High	High	High
Current carer - Family carers reported often having to retell the same narrative to different health-care professionals							
1 Lamahewa (2017)	Focus groups and semi-structured interviews	There was a sense of frustration due to the lack of continuity in some settings, even within the same care setting	Not serious	High	High	High	High
Current carer – Carers sometimes have doubts making decisions, particularly if there was not an up-to-date living will							
1 Lamahewa (2017)	Focus groups and semi-structured interviews	Often decisions were based on the family member's insight about/or knowledge of the values or preferences of the person with dementia. However, they expressed feelings of uncertainty in how to best meet the needs of their relative. Further complications resulted if formal discussion had not taken place or if legal arrangements were not in place	Not serious	High	High	High	High
Carer - Carers often held strong views regarding the perceived quality of care							

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
1 Moore (2017)	Interviews	Carers often held strong views regarding the perceived quality of care	Not serious	High	High	High	High
Carer - Carers valued continuity and receiving regular feedback about their relative's health condition and the progression of dementia							
1 Moore (2017)	Interviews	Carers valued continuity and receiving regular feedback about their relative's health condition and the progression of dementia	Not serious	High	High	Moderate ¹	Moderate
Carer – Planning - Being able to monitor services was important and reflected poor levels of trust in service providers							
2 Moore (2017) Dening (2012)	Interviews	The standards of social service staff would drop if they felt they were not being monitored by the family. (Family carers described how little happened routinely; they had to initiate and then “push” for services to be provided, these were unpredictable and fragmented)	Not serious	High	High	High	High
Carer – Carers were rarely informed about the dementia from diagnosis onwards through to the palliative stages							
1 Moore (2017)	Interviews	Carers' capacity to understand the progression of dementia and be involved and informed during advanced dementia relied on information provision throughout the different stages of dementia. At diagnosis, carers were rarely informed about the likely progression of dementia	Not serious	High	High	Moderate ¹	Moderate
Carer - The unpredictable course of dementia made it very challenging for carers to prepare for the end of life							
1 Moore (2017)	Interviews	Some were unsure about the value of early information about advanced stages of disease given the potentially unnecessary anxiety this might create	Not serious	High	High	Moderate ¹	Moderate
Carer – Carers valued timely and sensitive information provided by a knowledgeable professional and that was reinforced in writing							
1 Moore (2017)	Interviews	Some felt that the lack of basic information left them struggling to adapt to changes and feeling ill-prepared for symptoms that they later discovered were common in advanced dementia	Not serious	High	High	Moderate ¹	Moderate
Carer – End of life (EOL) plans were not started early enough							
1 Moore (2017)	Interviews	End of life plans were rarely initiated during the early stages of dementia preventing the person with	Not serious	High	High	Moderate ¹	Moderate

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
		dementia being involved in decision making. Sometimes the person with dementia was never informed of their diagnosis. EOL planning often occurred after admission to a care home or after a critical health event usually involving hospitalisation in the advanced stages of dementia. Carers often appreciated these conversations as they could be involved in care and feel that they had contributed to a plan to promote comfort care at EOL.					
Carer – Some carers were satisfied with EOL care if they felt adequately informed and involved, even when EOL care was not in accordance with advance care plans							
1 Moore (2017)	Interviews	Some carers were satisfied with EOL care if they felt adequately informed and involved, even when EOL care was not in accordance with advance care plans	Not serious	High	High	Moderate ¹	Moderate
Carer – Enabling family members to be present at the time of death							
2 Moore (2017), Lawrence (2011)	Interviews	For most, but not all, being present at EOL was important and some described vigils from hours to weeks, being with the person before they died.	Not serious	High	High	High	High
Carer – Carers often grieve for their relative before the person dies							
1 Moore (2017)	Interviews	Carers described grief as a staged process pre and post death with losses associated with dementia before death.	Not serious	High	High	Moderate ¹	Moderate
Carer – There was evidence of links between satisfaction with EOL care, the carer's capacity to influence the care being provided, and emotional consequences							
1 Moore (2017)	Interviews	Two carers who had not moved their relative from what they perceived as a poor quality care home, reported the lowest satisfaction. This was influenced by their guilt at not having done more to improve EOL care.	Not serious	High	High	Moderate ¹	Moderate
Carer – Participants discussed the failure of services to acknowledge their grief or to provide information about obtaining support							
1 Moore (2017)	Interviews	This was both prior to and after their relative's death.	Not serious	High	High	Moderate ¹	Moderate

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
Carer - Despite high levels of grief, many carers felt they did not need formal support or counselling and did not seek it.							
1 Moore (2017)	Interviews	Instead they described the benefits of their social network including friends, family or faith community. Some carers could not face their grief or the fact that their relative had dementia.	Not serious	High	High	Moderate ¹	Moderate
Carer – Carers who felt well informed about how dementia progressed, were regularly updated on their relative’s health condition and felt involved appeared more satisfied with EOL care.							
1 Moore (2017)	Interviews	Those who failed to influence care that they perceived as poor reported high levels of grief after death and experienced guilt and regret. Admission to a care home was often associated with a loss of control and a need for heightened vigilance	Not serious	High	High	Moderate ¹	Moderate

Professional identified issues

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
Professional – meeting physical care needs							
Lawrence (2011)	Structured interviews	Identifying and responding to the physical care needs of the person with dementia.	Serious ¹	High	High	High	Moderate
Lawrence (2011)	Structured interviews	Pain control.	Serious ¹	High	High	High	Moderate
Lawrence (2011)	Structured interviews	Palliative care nurses were considered skilled in identifying and managing pain in patients with complex needs and were also sensitive to nausea and hallucinations in people with dementia at the end of life.	Serious ¹	High	High	High	Moderate
Professional – complex pathways of care							
Dening (2012)	Semi-structured interviews,	People with advanced dementia had complex medical and social needs requiring input from a number of agencies, but the coordination was poor	Serious ¹	High	High	High	Moderate

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
	focus groups						
Dening (2012)	Semi-structured interviews, focus groups	Out of hours staff often felt unsupported and lacking in access to key information	Serious ¹	High	High	High	Moderate
Professional – going beyond task-focused care							
Lawrence (2011)	Structured interviews	Risk of becoming entirely task-focused with little empathy.	Serious ¹	High	High	High	Moderate
Lawrence (2011),	Structured interviews	Getting to know individual's interests, sensitivities and preferences.	Serious ¹	High	High	High	Moderate
Professional – planning							
Lawrence (2011), Grisaffi (2010)	Structured interviews, Semi-structured interviews	People with dementia should be given the opportunity to plan for the future.	Serious ¹	High	High	High	Moderate
Lawrence (2011)	Structured interviews	Whether individuals should be transferred to hospital during the final stages of their life. Hospitalisation was a frequent occurrence despite agreement among care professionals that this was often inappropriate.	Serious ¹	High	High	High	Moderate
Lawrence (2011)	Structured interviews	Palliative care staff noted that professionals across care settings could be reluctant to withdraw active treatment in the absence of explicit planning or a clear consensus among the care team.	Serious ¹	High	High	High	Moderate
Grisaffi (2010)	Semi-structured interviews	Discontinuity of care.	Serious ¹	High	High	Moderate ²	Low
Professional – Flexibility							

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
Davies (2014)	Semi-structured interviews	The growing number of guidelines, standards, rules and regulations placed upon professionals in health and social care makes palliative care standardised leaving no room for flexibility.	Serious ¹	High	High	High	Moderate
Grisaffi (2010)	Semi-structured interviews	GP's prior knowledge of the person with dementia is important in informing decisions. To help the person overcome the communication and capacity issues, relatives and carers are seen as an expert source of information regarding the person's wishes.	Serious ¹	High	High	Moderate ²	Low
Davies (2014)	Semi-structured interviews	NHS Primary Care Trusts have no duty of care for people who are self-funding their care home.	Serious ¹	High	High	High	Moderate
Professional - systemisation							
Davies (2014), Grisaffi (2010)	Semi-structured interviews	Some routines are useful, such as certain meetings, pain assessment, when to stop pursuing certain treatments.	Serious ¹	High	High	High	Moderate
Professional – staff training to reduce the need to call for specialist help.							
Davies (2014)	Semi-structured interviews	Syringe driver training, checks when prescribing.	Serious ¹	High	High	High	Moderate
Dening (2012)	Semi-structured interviews, focus groups	Many, particularly hospice, ambulance staff and district nurses acknowledged they had received little or no training in dementia, in particular concerning communication and managing behavioural problems	Serious ¹	High	High	High	Moderate
Professional - in some cases, the lack of palliative care skills is not seen as a gap to be filled by the generalist, rather the responsibility of a specialist service							
Davies (2014)	Semi-structured interviews	Some district nurses and GPs feel that palliative care should be left to specialists.	Serious ¹	High	High	High	Moderate
Professional – lack of trust, fear of litigation, fear of blame and threats to speciality							

Studies	Study design	Description	Methodologic al limitations	Relevance	Coherence	Adequacy	Confidence
Davies (2014)	Semi-structured interviews	Managing both real and perceived risks can be a difficult challenge	Serious ¹	High	High	High	Moderate
Professional - difficulty in deciding when to start end-of-life care							
Grisaffi (2010)	Semi-structured interviews	The typically slow erratic decline and the indicators for starting the pathway could lead to either a person being on it for a long time or 'yo-yoing' on and off as their state fluctuated.	Serious ¹	High	High	Moderate ²	Low
<ol style="list-style-type: none"> 1. Theme only identified in studies at moderate or high risk of bias 2. Insufficient data to develop a full understanding of the phenomenon of interest 							