

# Rapid Review of Models of Palliative Care for People with Advanced Dementia

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Report

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## Related publication

This report is an expanded version of the following publication: Lewis, S., Triandafilidis, Z., Curryer, C., Jeong, S. Y.-S., Goodwin, N., Carr, S., & Davis, D. (2023). Models of care for people with dementia approaching end of life: A rapid review. *Palliative Medicine*, 37(7), 915-930.

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## Acknowledgement of Country

The Central Coast Research Institute (CCRI) acknowledges the traditional custodians of the land, the Darkinjung people, on whose land the Institute is situated and we welcome all who visit this place.

We acknowledge the traditional owners of lands on which we meet and conduct our research and pay our respects to their Elders past, present and emerging and to their culture, heritage and spirituality.



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## Key messages

- People with advanced dementia experience a range of symptoms that may cause distress and impact their quality of life, but many people with advanced dementia do not receive palliative care.
- This review informs development of an end-of-life care pathway for optimal care of Central Coast residents with advanced dementia, and their carers.
- A rapid review methodology was used to answer the question of what national and international models of end-of-life care exist for people with advanced dementia and their carers.
- This rapid review found that the core components of a best practice model of integrated palliative care for people with advanced dementia are well known.
- A small number of models were described in detail in the published and grey literature, and few have been rigorously evaluated.
- Those seeking to implement a new model of integrated care for people with advanced dementia can be guided by existing models which may be adapted for their specific context.
- Sustainability of a model of care will depend on adapting best practice principles to existing resourcing and context, without compromising quality and safety of care.

# Executive summary

## Background

The Central Coast is located in New South Wales (NSW), Australia. Nearly 350,000 residents reside on the Central Coast (Australian Bureau of Statistics, 2022). Population projections estimate numbers will rise to over 375,000 persons by 2031, with the most rapid growth in persons aged 70 years and over (Central Coast Local Health District, 2021). Population ageing is expected to drive increased demand for aged, dementia-specific, and palliative care services on the Central Coast.

In the 2021 Census, 1.1% of Central Coast adult residents reported that they have dementia as a long-term health condition, (compared to 0.8% of the NSW population) (Australian Bureau of Statistics, 2022). People with dementia have different care and support needs at their end of life compared to people with other life-limiting illnesses and are seen less frequently by palliative care services (Parker et al., 2017). A rapid review of published and grey literature was undertaken to inform development of a local dementia-specific model of palliative care by identifying and summarising existing best-practice models of care for people with advanced dementia.

## Methods

Ten databases were searched for articles published between January 2000 and April 2022. Inclusion criteria were: all care settings; AND the model focuses on people with end-stage or advanced dementia; AND contained multiple components. A rigorous process of screening at both title/abstract and full text level was undertaken by the research team which comprised clinicians with expertise in palliative and end-of-life care, occupational therapy, a senior health librarian, and experienced nursing and social science researchers. All project team members participated in screening, reviewing, and extracting data, and writing this report.

The European Association for Palliative Care's framework of domains of care that should be addressed in any model of optimal palliative care for people with dementia (van der Steen et al., 2014) was adapted for this review. The resulting nine domains of care were used to map the included models of care against known best practice.

## Results

Nineteen articles or reports, describing twelve dementia-specific models of end-of-life care in a range of care settings were identified for inclusion in the review. A mini casebook of narrative summaries of the models is provided in Appendix C and elements of each of the models are extracted and presented in table format in the report.

There is strong evidence that the principles of best practice palliative care for people with advanced dementia are well known, but limited examples of translation of this knowledge into integrated models of care. The key issues that emerged from the findings were: referral pathways and timing of admission to care, integration of care, sustainability and evaluation. All included models had elements of care integration (such as a care coordination role, interdisciplinary collaboration and person-centred care); but the level of integration varied considerably.

All of the models of care demonstrated elements of at least six out of nine of the domains of best practice care, although in some cases the supporting evidence was minimal. Key components of the models of care identified included family care, grief and support; integrative, coordinated, and multi- or interdisciplinary care; education (patient, family and carers); comfort measures and optimal treatment of symptoms; and prognostication and recognition that the person with dementia is

nearing their end of life. The domain for which there was the least demonstrated evidence was ethical and practical issues, followed by psychosocial and spiritual support and person-centred care.

### What this review adds

In addition to the included models of care, this report provides the following further resources that may be useful in the development of context-specific models of care for people with advanced dementia:

- a summary of the views of people with dementia, their carers and families, and healthcare professionals about which aspects of care are important for ensuring a good end-of-life experience;
- selected practical examples of how the domains of care were demonstrated in the included models of care;
- a brief summary of relevant models of care that were under development at the time of review; and
- a summary of aspects of the care coordination role (category of healthcare professional, role title and main duties, position description if available) which was a feature of seven of the included models of care.

### Recommendations

#### Recommendation 1: Practice

Dementia-specific models of end-of-life care should be commissioned, developed and trialled to meet the needs of growing numbers of people with dementia and their families and carers. These models should include the recognised domains of best practice palliative care for people with dementia.

#### Recommendation 2: Policy

Policy makers and health service managers should support ongoing investment in long-term planning and evaluation of such models of care.

#### Recommendation 3: Future research

High-quality research including evaluation, particularly economic evaluation, of models of end-of-life care for people with dementia, is needed.

### Conclusion

This review adds to the growing body of literature on end-of-life care for people with dementia by identifying and examining models of care implemented in a range of real-world settings. We sought examples of how the substantial body of evidence on the optimal components of a model of care for this vulnerable population group had been translated into practice and, ideally, evaluated and embedded in health and social care delivery. While a comprehensive, fully integrated, appropriately funded and sustainable model of care was not found, each of the included models offers valuable evidence to assist clinicians and healthcare managers to develop and implement best-practice, context-responsive models of end-of-life care for people with dementia.

## Background

The Central Coast is located in New South Wales (NSW), Australia. Nearly 350,000 residents reside on the Central Coast (Australian Bureau of Statistics, 2022). Population projections estimate numbers will rise to over 375,000 persons by 2031, with the most rapid growth in persons aged 70 years and over (45% increase for persons aged 70-84 years, 38% increase for persons 85+) (Central Coast Local Health District, 2021). Population ageing is expected to drive increased demand for aged, dementia-specific, and palliative care services on the Central Coast.

In 2016-2020, dementia was the leading cause of death for residents of the Central Coast (1,721 deaths 2016-2020 combined) (Australian Institute of Health and Welfare, 2022b). In fact, in 2020 dementia was the second leading cause of death for males in Australia (6.2% of all deaths), and the leading cause of death for females (12% of all deaths) (Australian Institute of Health and Welfare, 2022a). In the 2021 Census, 1.1% of Central Coast adult residents reported that they have dementia as a long-term health condition, (compared to 0.8% of the NSW population) (Australian Bureau of Statistics, 2022).

People with dementia in their last year of life are seen less frequently by palliative care services than people with other terminal illnesses (Parker et al., 2017). It is estimated that as few as 2.4% of people with dementia are using a specialist palliative care service in Australia compared to 75.4% of people with cancer (Parker et al., 2017).

In 2019 the Central Coast Local Health District (CCLHD) was awarded an Australian Government Medical Research Future Fund (MRFF) Rapid Applied Research Translation program grant through NSW Regional Health Partners to address two key aims:

1. to support the development of a long-term strategy for the implementation of palliative care and end-of-life care to the benefit of the Central Coast community; and
2. to enable growth in research and research capacity in CCLHD by giving clinicians and managers the ability to increase their research knowledge and develop clinical research skills.

The first phase of the project comprised a series of workshops designed to bring together key stakeholders to identify existing issues and gaps in services and establish a long-term vision for palliative care and end-of-life care on the Central Coast. From these workshops, clinicians and academics worked together to identify opportunities for priority-led research and mentorship, and three projects were commissioned.

This Rapid Review provides up-to-date evidence about models of end-of-life care, which inform the other two projects. Those projects seek to improve the end-of-life care experience for people with dementia and their carers (Project A), and the experience of Central Coast residents and carers who access emergency care towards the end of life (Project B). The combined findings from all three projects will enable evidence-informed recommendations for the development of a locally-responsive, end-of-life model of care (Triandafilidis et al., 2024).



## Aims and objective of the review

The aims of this rapid review are: to establish from published research what best practice care of people with advanced dementia comprises; and to identify and appraise, using a best practice care framework, existing national and international end-of-life care models for people with advanced dementia and their carers. The objective is to provide evidence from peer-reviewed research and grey literature (published between January 2000 and April 2022) to inform the future development of an end-of-life care pathway for optimal care of Central Coast residents with dementia, and their carers. A secondary objective was to support clinicians and managers to build knowledge and skills in relation to reviewing literature and deriving recommendations for evidence-based practice.

## Dementia and end of life

Dementia describes a collection of symptoms caused by disorders of the brain that lead to a person experiencing progressive functional decline. There are over 100 diseases that can cause dementia, with the most common being Alzheimer's disease, vascular dementia, and dementia with Lewy bodies (Dementia Australia, 2022). The progressive brain degeneration experienced by people with dementia is life-limiting and impacts substantially on their quality of life, and that of their family and carers.

The personal, social, health and economic burden of dementia in Australia is considerable (Australian Institute of Health and Welfare, 2021).

### Dementia Burden of Disease in Australia (AIHW, 2021)

- leading cause of burden of disease in women and 6<sup>th</sup> highest cause in men in 2018;
- main reason for 23,200 hospitalisations in 2018-2019, with estimated cost of hospital care directly attributed to dementia being \$383 million;
- between 386,200 and 472,000 Australians living with dementia in 2021, with this number predicted to reach over 849,300 by 2058;
- between 134,900 and 337,200 friends and family (75% of whom are women) support people with dementia.

Dementia symptoms can occur over many years as the disease trajectory is prolonged, fluctuating and unpredictable compared to other life-limiting illnesses (Brennan et al, 2023; Eisenmann et al., 2020; Hanson et al., 2019; van der Steen et al., 2014). Symptoms of dementia include a progressive decline in multiple areas of memory, communication, cognitive reasoning and decision making. This decline is accompanied by behavioural and psychological symptoms of dementia (BPSD), such as depression, aggression, agitation, disturbed sleep patterns, restlessness, and hyperactivity (Hanson et al., 2019; Ishimaru et al., 2021; Kim et al., 2021). Persons with dementia also experience a progressive loss of functional capacity in activities of daily living (ADLs) as dementia advances, such as eating, toileting

and dressing, and instrumental activities of daily living (IADLs) such as managing medications, managing finances, socialising, and mobilising outside the home (Hanson et al., 2019; Kim et al., 2021).

As symptoms worsen, the person with dementia requires increasing amounts of assistance and support. This is often provided by family or friends, referred to in Australia as carers (in contrast to paid carers or healthcare workers). Carers may help their friend or family member with dementia by administering medications, undertaking personal care, doing housework, and providing comfort and emotional support (Broady et al., 2018), and are at risk of significant stress due to the demands of caring for someone with dementia. While there is no cure for dementia, there are many opportunities for both informal carers (with appropriate training and support) and paid caregivers to explore and respond to symptoms in order to maximise quality of life until the end of life (Bamford et al., 2018; Browne et al., 2021).

Despite being a leading cause of death for people in Australia (Australian Institute of Health and Welfare, 2022a), dementia is often not recognised as a terminal illness by healthcare professionals, people with dementia and their families (Hanson et al., 2019). The course of the disease can be unpredictable; progression from mild to severe dementia can be rapid or slow; and recognition that someone has entered a palliative or end-of-life phase is difficult (Browne et al., 2021; Moon et al., 2021). As the disease progresses, people with dementia experience reduced capacity for decision making and verbal communication. They are at risk of poor symptom control, increased hospitalisations (Leniz et al., 2019) and medical interventions which may be ineffective or even harmful when they are nearing end of life, and palliation is the key goal.

Advocacy group Dementia Australia has identified inconsistent, fragmented and inequitable palliative care services for people with dementia, compounded by a lack of widely accepted standards of care and clear care pathways. Too often, people with dementia experience disruptive and often avoidable transfers between home, residential aged care and acute hospital care. 'Dying well' is an aspiration rather than reality for many people with dementia at the end-of-life (Dementia Australia, 2019). Similarly, the Australian Royal Commission on Aged-Care Quality and Safety (2021) highlighted four areas of immediate concern, two of which were dementia care and palliative care (Brennan et al, 2023).

#### [Australian Royal Commission on Aged Care Quality and Safety Report 2021](#)

*Residential aged care is often a person's final place of residence before they die. Palliative care and end-of-life care, like dementia care, should be considered core business for aged care providers... However, throughout our enquiry we heard examples where the care of people in the last weeks or days of life was severely lacking and fell well short of community expectations... The most common areas of substandard complex care we heard about involve dementia and challenging behaviours, mental health and palliative care (The Report, quoted in Brennan et al, 2023).*

Many acute care, residential aged care and community services for people with dementia lack specialised knowledge of palliative care (Annear, 2020; De Witt Jansen et al., 2017; Yang et al., 2022). Conversely, palliative care services have traditionally been aimed at people with life-limiting illnesses such as cancer, and may not provide services appropriate to the needs of people with advanced dementia (Hospice UK, 2015; Walsh et al., 2021).

Dementia Australia recommends and advocates for comprehensive models of dementia palliative care across all settings – home, community, residential aged care, hospice and hospital. These would be achieved via a series of recommended practice changes including: dementia-specific palliative care health workforce training, advance care planning delivered at the right time in the disease trajectory, flexible funding models, improved access to services, improved coordination of services around the needs of the person with dementia, and appropriate support for carers (Dementia Australia, 2019).

## The need for dementia-specific end-of-life care models

### A model of care

- is a multidimensional concept which describes the delivery of timely, responsive, evidence-based healthcare services for population groups;
- is developed in consultation with all stakeholders including care providers, patients, carers and organisations involved in patient care and service delivery;
- includes referral pathways describing how a patient might access and travel through care services;
- is based on core principles such as person-centred care, integrated care; and
- includes components such as patient and carer education, workforce training, specialist care service, case-management or nurse-specialist coordination of services and support (Agency for Clinical Innovation, 2013; Davidson et al, 2006).

### Palliative models of care

- are specific to people with life-limiting conditions such as cancer, dementia, heart disease and neurodegenerative diseases;
- prioritise symptom management, care planning and coordination, and quality of life;
- are delivered across a range of settings including hospice, acute care, community, residential aged care, telehealth or home-based care (Beasley et al., 2019; PalliAGED. Palliative Care Aged Care Evidence, 2021).

The care needs of patients with dementia who are nearing end of life differ from patients with other life limiting illnesses such as cancer or heart failure (Bamford et al., 2018). It is important therefore, when designing dementia-specific end-of-life models of care to consider how these needs might differ and incorporate, as much as possible, those elements most desired by people with dementia and their carers.

Previous research has shown that a palliative approach to end-of-life care for people with dementia can provide benefits including better control of symptoms such as pain and agitation, focus on provision of comfort care, avoidance of overly aggressive treatment, continuity of care and decreasing distress of families through open discussion of end-of-life issues and shared decision-making (Hines et al., 2011; Senderovich & Retnasothie, 2020; van der Steen et al., 2014). **However, few models of end-of-life care have been specifically designed for people with dementia** (Bamford et al., 2018).

While NSW Health's *End-of-life and Palliative Care Framework 2019-2024* recognises the importance of person-centred, individualised patient care (NSW Health, 2019), the Framework does not

specifically address the needs of people with dementia. Prognostication of end of life for people with dementia is difficult (Browne et al., 2021) and often complicated by complex multimorbidity. People with dementia can potentially fall between service gaps due to practitioner bias (Erel et al., 2022), organisational factors such as lack of time (Courtright et al., 2020), patients not meeting care criteria (Mataqi & Aslanpour, 2020), or families rejecting a terminal prognosis (Courtright et al., 2020). **Therefore, people with dementia may not be offered palliative care services or may experience limited access to specialist services and support.**

If a person with dementia is able to access established palliative care, it may not be well aligned with their needs. Palliative carers and clinicians may not have dementia-specific training nor experience in caring for a person with dementia (Hospice UK, 2015), and palliative care tools used for symptom assessment may not be appropriate for a person with dementia who cannot communicate (Ding et al., 2020). Established palliative care settings such as hospices might not have policies or resources in place to support a person with dementia who is displaying unpredictable or agitated behaviours (Hospice UK, 2015). A Hospice UK Survey found that while almost 90% of hospices were providing care for patients with dementia, most were not confident about their ability or capacity to meet the needs of patients with dementia (Hospice UK, 2015). People with dementia have been found to experience less optimal care and symptom management compared to patients who have been diagnosed with cancer (Bamford et al., 2018; Teggi, 2018). **Hence, people with dementia have been described as the ‘disadvantaged dying’** (Davies et al., 2017; Teggi, 2018).

Given the documented issues surrounding end-of-life care for people with dementia, there is a clear need for dementia-specific end-of-life care models to be developed. These models of care need to be more responsive to the needs of local populations, people with dementia, and their carers. This rapid review seeks to fill this need, and additionally inform the development of a Central Coast model of dementia-specific end-of-life care.

### **‘Best practice’ in supporting people with dementia at the end of life: the perspective of people with dementia and their carers**

One of the aims of this rapid review was to establish what best practice care of people with advanced dementia comprises. If markers of quality care are known, it is possible to compare and contrast the design, features, implementation and outcomes of the different models of care identified by the review.

Various studies have explored the views of people with dementia, their carers and families, and healthcare professionals about which aspects of care are important for ensuring a good end-of-life experience (Armstrong et al., 2019; Nishimura et al., 2020; Sellars et al., 2019). Aspects of good end-of-life care include: having timely planning discussions; recognising end of life; having care staff who are skilled, respectful, kind and compassionate; having care that is individualised to the person with dementia’s needs; and attending to spiritual and cultural needs and preferences.

Examples of good end-of-life care, according to service users and providers, are shown below in Table 1. Ideally, dementia-specific end-of-life models of care would include these elements.

## Examples of good end-of-life care, as defined by persons with dementia, their carers, and healthcare professionals

### Timely planning discussions

- Planning for end-of-life takes place while the person with dementia is still able to participate in decision-making (Bamford et al., 2021; Jones et al., 2019).
- Advance Care Planning (ACP) involves the person with dementia, family /caregiver, and health professionals involved in the person's care, and is appropriately documented and shared (Bamford et al., 2021; Jones et al., 2019).
- Effective communication is achieved between family and healthcare teams, carers are well-informed about options for end-of-life care (eg. Hospice) what to expect when the person is dying (Armstrong et al., 2019; Sellars et al., 2019).
- Advanced care planning attends to people's uncertainty regarding prognosis of end-of-life, and lack of confidence in healthcare settings (Sellars et al., 2019).

### Recognising end-of-life; prognostication and comfort care

- Recognition that end-of-life is near is timely and prompts updated discussions and documentation (e.g., hospitalisation, resuscitation) (Bamford et al., 2021).
- Philosophies of palliative and dementia care are combined (Fox et al., 2019).
- Comfort care is provided to minimise distress, manage pain and other symptoms (Bamford et al., 2021; Nishimura et al., 2020).
- Medications are reviewed for appropriateness (Bamford et al., 2021).
- Artificial, life-prolonging or aggressive treatments, and hospitalisations, are avoided (Bamford et al., 2021; Nishimura et al., 2020).
- Preferences for end-of-life are supported (e.g. preferred place of care and death) (Nishimura et al., 2020).
- Family are present at time of death (Lawrence et al., 2011); and death occurs in the person with dementia's usual (or preferred) place of care (Bamford et al., 2021).

### Coordination and continuity of care

- Care coordination and continuity of care ensures the person with dementia's needs are met. This includes out of hours and crisis support (Bamford et al., 2021).
- Effective relationships with primary care (GP services) are established and maintained. This may include having a named liaison person within the GP practice and limiting the numbers of GPs with whom residential aged care residents are registered (Bamford et al., 2021).
- A multidisciplinary team is involved in care; care is integrated, effective coordination occurs *within* as well as between services (Bamford et al., 2021; Kupeli et al., 2016).
- Continuity of care includes care after death; family members are supported by healthcare workers involved in the care of the person with dementia; and grief support for carers is provided (Bamford et al., 2021).

### Practical, emotional and instrumental support

- Carers providing care for a person with dementia in their own home have timely access to equipment (e.g., pressure-relieving/water mattress) and practical support (e.g., district nursing) (Bamford et al., 2021).
- The person with dementia could maintain pleasures in life, was not left alone for long periods of time, had good relationships with friends and family, and was emotionally supported (not anxious or fearful) (Nishimura et al., 2020).
- Preferences regarding place of care are supported and enabled (Poole et al., 2018).
- Persons with dementia feel 'at home' in their environment; the care environment is calming, safe, and enables privacy and social connection (Fleming et al., 2015).
- Hospitalisation and/or entry into residential care is delayed, preferences re place of care supported (Sellars et al., 2019).

**Care is person-centred, holistic and timely**

- Care is person-centred, tailored to the individual's needs (Davies et al., 2017; Fox et al., 2019; Lawrence et al., 2011; Pennbrant et al., 2020).
- Care is holistic (attending to physical, psychological, social, emotional and cultural needs) rather than task-focused (Fleming et al., 2015; Fox et al., 2019; Lawrence et al., 2011).
- Multisensory interventions (e.g. touch, sight, smell, taste) create meaningful, person-centred interactions between staff and the person they are caring for (Bunn et al., 2018; Stacpoole et al., 2016).
- Staff are attentive and respectful, provide an element of normality (being part of, engaged in daily life and routines) (Davies et al., 2017).
- Staff value, dignify, and recognise the 'person within' (Davies et al., 2017; Nishimura et al., 2020).
- The person's biography (life story, cultural background) is known (Simard & Volicer, 2010; Stacpoole et al., 2016).
- Life satisfaction, i.e., the person is satisfied with duration of life and the support they received from others (Nishimura et al., 2020).
- Persons with dementia and their carers remain connected and engaged (social, sensory, spiritual) (Sellars et al., 2019).

**Psychosocial and spiritual care**

- Care meets the psychosocial and spiritual needs of the person with dementia and their family (e.g. cultural or religious preferences) (Bamford et al., 2021; Kupeli et al., 2016).
- Psychosocial and spiritual care, and relationships with family carers are prioritised (Fox et al., 2019).
- The person with dementia is able to die with dignity and respect, staff respect patient and family views regarding death (Armstrong et al., 2019).
- Family involvement is facilitated and emotional support is provided (Bamford et al., 2021).
- A peaceful, safe, home-like environment is created, (access to plants, light, fresh air; soft lighting, flowers, photographs, music) (Bamford et al., 2021; Fleming et al., 2015).

**Staff optimisation and recognition**

- Staff should be valued and recognised; leadership and specialised training opportunities are offered (Bamford et al., 2021).
- Timely emotional and peer support is offered to staff who are feeling vulnerable (for example following the death of someone they have cared for) (Bamford et al., 2021).
- Post-death meetings are held to encourage staff reflection and promote positive coping, learning from experience (Bamford et al., 2021).
- Ongoing learning is valued and embedded into care practices - staff are skilled and knowledgeable about dementia care (Bamford et al 2021)
- Staff have the necessary skills to meet the specific needs of people with dementia at the end of life (Ding et al., 2020; Pennbrant et al., 2020).
- Staff are active in educating others, raising awareness among GPs and service providers to remove stigma and improve care experience (Bamford et al., 2021).

**Patient-staff relationships**

- Staff are well-resourced; able to work flexibly when needs arise, and have detailed knowledge about the persons they are caring for (Bamford et al., 2021; Pennbrant et al., 2020).
- Staff are kind, compassionate, and caring, willing to 'go the extra mile' such as staying longer after a shift to care for a dying patient (Bamford et al., 2021; Davies et al., 2017).
- Staff value, dignify, and recognise the 'person within', and are attentive and respectful (Davies et al., 2017; Sellars et al., 2019).
- Care is person-centred, individualised and tailored to the person with dementia's needs (Davies et al., 2017; Sellars et al., 2019).
- Personhood is maintained e.g., person is free from physical restraints, treated as an adult, able to maintain their identity (Nishimura et al., 2020).

### Table 1. Examples of good end-of-life care, as defined by persons with dementia, their carers, and healthcare professionals

These examples identifying what high quality end-of-life care looks like for people with dementia and their carers highlight the importance of keeping the person with dementia at the centre of any model of care, surrounded by supportive staff, family and carers.

### Core components of a model of palliative care for people with advanced dementia

In 2018 Palliative Care Australia (PCA) and Dementia Australia (DA) issued a joint policy statement, updated in 2023 (Dementia Australia & Palliative Care Australia, 2023) recommending the following components of palliative care be provided to people with advanced dementia:

- early involvement of the person with dementia, their family and carer(s) in decision making about goals of care, documented in an advance care plan;
- a flexible model of specialist palliative care which can be delivered in a range of settings including home, hospice, residential aged care and acute care, and is easily accessible to ensure continuity and integration of care;
- compulsory training in dementia and palliative care for all health and care professionals providing care to people with dementia, with particular emphasis on assessment and management of symptoms including pain, distress and behavioural symptoms;
- improved access to support and respite for families and carers;
- advance care plans linked to My Health Records; and
- national, consistent advance care planning legislation.

With the exception of the last component (legislation) these are present (and expanded upon) in the European Association for Palliative Care's (EAPC) 11 domains of care that should be addressed in any model of optimal palliative care for people with dementia (van der Steen et al., 2014). The EAPC domains are widely accepted (Amador et al., 2019; Kochovska et al., 2020), therefore this review draws on this framework, albeit with some variations.

We adapted the EAPC framework in the following ways:

- the first domain, which considers the appropriateness of palliative care for advanced dementia, was removed because models of end-of-life care for people with dementia are based on the premise that advanced dementia requires palliative care;
- domains 2 and 3 (relating to person-centred care, shared decision-making, setting care goals with the person with dementia and their family, and advance care planning) were combined into a single domain as these often overlap in practice;
- domains 6 and 7 (relating to avoiding burdensome treatment and optimising treatment to provide comfort), were combined into one domain; and
- domain 10 (relating to education of the healthcare team) was expanded to include other workforce issues such as communication, collaboration and barriers to integration.

This resulted in a dementia-specific end-of-life model of palliative care framework consisting of nine domains, each describing best-practice elements of end-of-life care. The nine-domain framework is



summarised in Figure 1 below and was used for mapping the models of care included in the review (see Table 5).



Figure 1. Essential components (domains) of a model of palliative care for people with dementia.

#### Dementia-Specific End-of-life Model of Care Framework: 9 Domains

**Domain 1:** person-centred care, communication and shared decision-making regarding care goals and advance care planning;

**Domain 2:** family care and support, communication and involvement in care planning; uncertainty, grief and bereavement;

**Domain 3:** continuity, coordination and integration of care;

**Domain 4:** interdisciplinary communication and collaboration, organisational and workforce issues including education, barriers to integrated care;

**Domain 5:** education of the person with dementia, family and carers;

**Domain 6:** optimal treatment of symptoms (e.g., pain, challenging behaviour) and providing comfort; avoidance of overly aggressive, burdensome or futile treatment (e.g., nutrition/feeding decisions); quality of life;

**Domain 7:** prognostication and timely recognition of dying; preferred place of death;

**Domain 8:** psychosocial and spiritual support; and

**Domain 9:** social, legal, ethical, financial, practical (e.g., transport, equipment) issues.

## Methods

### Methodology: rapid review

Evidence of models of palliative and/or end-of-life care for people with advanced dementia was sought using a rapid review methodology (Tricco et al., 2017). Rapid review methods are useful for rapidly scoping the state of current evidence and practice within health and social care contexts, are time sensitive, and can provide explanations for what works and why (Thomas et al., 2013). The resulting knowledge can then be translated into policy and practice.

This multidisciplinary project included clinicians with expertise in palliative and end-of-life care, occupational therapy (dementia and behavioral and psychological symptoms of dementia), a senior health librarian, and experienced nursing and social science researchers. All project team members participated in screening, reviewing and extracting data, and writing this report.

### Key questions and definitions

The key questions underpinning this review were:

1. What national and international models of end-of-life care for people with dementia and their carers are described in published research and grey literature?
2. Which features of these models could be used as the basis for a similar model of care for Central Coast people with dementia in their final year of life?

The review questions were translated to the Population, Concept and Context mnemonic as follows:

Population	Adults with a diagnosis of dementia in the advanced stage
Concept	Best practice models of care; optimal outcomes for people with dementia and families/carers; service utilisation and cost-effectiveness
Context	All care settings including home, community, residential aged care, hospice and acute care

The terms end-of-life care and palliative care are often used interchangeably but are distinct concepts. Therefore, we adopted the definitions provided by Palliative Care Australia and the Australian Commission on Safety and Quality in Health Care, and used both terms in our search strategy.

Palliative care	End-of-life care
"Palliative care is person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary goal is to optimise the quality of life" (Palliative Care Australia, n.d.).	"End-of-life care refers to that period when a patient with a life-limiting illness is nearing death. Death may occur within days or a longer period, not exceeding 12 months" (Palliative Care Australia, n.d.; Rawlings et al., 2021).

## Search strategy

A six-step search strategy was used.

- 1) An initial scoping search was run in the PubMed database, resulting in a test set of 20 citations to articles assessed by the review team members as relevant to the topic;
- 2) the PubMed unique identifiers (PMIDs) of these citations were entered into the PubMed PubReminer open source data mining tool (<https://hgserver2.amc.nl/cgi-bin/miner/miner2.cgi>) and a frequency table of Medical Subject Headings (MeSH) used to index the articles in the set was produced;
- 3) the frequency table informed development of a logic grid of MeSH terms and keywords relevant to the concepts of advanced dementia, palliative care and models of care;
- 4) MeSH terms and keywords were then used separately and in combination with Boolean operators (OR, AND) to search the Medline (Ovid) database (search strategy supplied in Appendix A);
- 5) the search strategy was then adapted for the following databases: Embase (Ovid), CINAHL (EBSCO), PsycINFO (Ovid), ProQuest, Informit Collection, Joanna Briggs Institute, The Cochrane Library, The Campbell Collaboration and Google Scholar. Searches were run in April 2021, and updated in November 2021 and April 2022; and finally
- 6) citation tracking (backwards by checking reference lists and forwards via Google Scholar) was undertaken. Relevant grey literature resources such as reports were identified via Google advanced search, and searches of key websites and journals were undertaken (listed in Appendix B).

## Screening process

Retrieved references underwent up to three stages of screening using title and abstract:

- 1) initial screening was performed by a single reviewer (SL);
- 2) a smaller number of articles (n=264) were then reviewed by two independent team members (SL, NG, SC, SJ, DD, CC) for full-text retrieval; and
- 3) any disagreements were resolved via further screening by a third reviewer (ZT) or, in a few cases, the review team.

Articles and other resources retrieved in full text were divided between members of the project team for assessment. Each article was read and assessed by one reviewer. Where a clear decision could not be made about whether to include or exclude the article, the decision was made in discussion with the review team and decided by majority vote. Additional relevant articles were identified during full text review and retrieved in full text for assessment.

## Inclusion criteria

Resources were included in the review if they met the following inclusion criteria:

1. dementia is the primary diagnosis of the patient group and the main focus of the article; AND
2. the article focuses on the last year of life or advanced/palliative phase of the disease (i.e., “advanced dementia”, “severe dementia”, “late-stage dementia” or “end-stage dementia”, and/or the person is assessed as meeting level 6/7 of the Global Deterioration Scale, and/or the person with dementia is nearing end of life); AND
3. any setting for delivery of a model of care, including acute care, community care, residential aged care, hospice, or home were considered; AND

4. the article describes an intervention, variously described as a model of care, model, program, care pathway, care plan or framework, which was informed by a palliative approach to care; AND
5. the model of care, framework or program describes a patient pathway which includes multiple components including patient care, care coordination, education, and delivery of services; AND
6. articles are written in English: AND
7. articles are published no earlier than 2000.

### Exclusion criteria

Resources were excluded where:

1. dementia was not the primary diagnosis or focus (e.g., dementia mentioned as part of a spectrum of multi-morbidity); OR
2. the article was not specific to end-of-life or severe, end-stage or advanced dementia; OR
3. the article did not describe an intervention or model consisting of multiple components which was informed by a palliative approach to care; OR
4. the article did not provide sufficient information to determine if it was a model of care or single episode of an intervention; OR
5. the full-text of the article was not publically available or able to be accessed via university or other library repositories; OR
6. the article was a systematic, narrative, realist or other type of literature review.

### Data extraction and analysis

Data extraction and analysis took place in three stages. First, data from included studies were extracted by all authors in a template developed by the review team (see Appendix 3). Then three reviewers (SL, ZT and CC) summarised in table format data including citation details, context (country, delivery setting), intervention and funding details, and whether any evaluation had been reported.

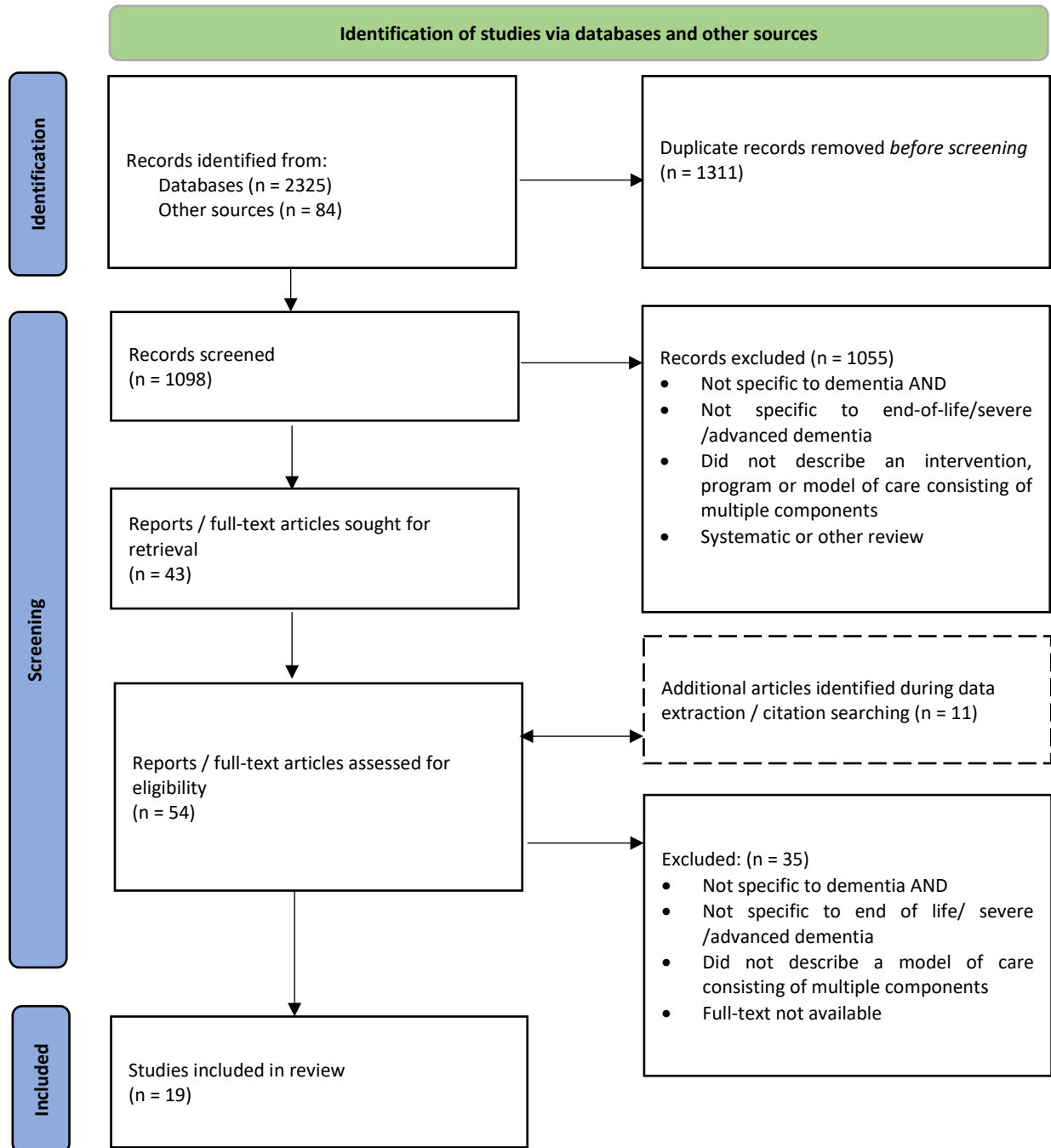
Next the nine domains of the adapted EAPC framework for optimal palliative care for people with dementia was used as a best practice guide against which the included models of care were mapped.

Finally, the extracted data were presented in a narrative summary which highlights four main issues critical for rapid translation of findings from the review to inform development of a local model of care.

## Results

A total of 2409 references were identified through database searches and additional searching. After duplicates were removed, 1098 references underwent initial title and abstract screening by one reviewer, after which 734 references were excluded as not relevant. The remaining 364 references were reviewed by two independent reviewers, with further articles excluded where these did not meet inclusion criteria or were found to be literature, rapid or systematic reviews. Where reviewers' decisions did not agree, these articles were flagged and then independently reviewed by another member of the team. This resulted in 43 references being selected for further screening and review.

The full text of articles were then retrieved and articles randomly divided between team members, who completed a screening template with questions such as "is a model of care described?" and whether the article should be included in the review (yes/no, include reasons). Where there was insufficient information to make a decision, authors were contacted for further information, and/or articles underwent additional rounds of screening until team consensus was reached. This resulted in fifteen articles being selected for inclusion. During full text review an additional eleven references were identified via reference lists/citations for retrieval and review. Of these, seven articles were excluded. This resulted in nineteen studies for inclusion in the review (see Figure 2).



**Figure 2. PRISMA diagram**

*Adapted From:* Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: 10.1136/bmj.n71

## Models of Care

Nineteen studies, describing 12 models of care, were identified. These models are presented in detail in this report.

Model of Care (reference number)	Citations (author, date)
Aliviado <sup>(1)</sup>	Lin et al., 2020
Alzheimer's Disease and Related Dementia Palliative Care Program <sup>(2)</sup>	Hanson LC, et al., 2019
Challenge Pathway <sup>(3)</sup>	Harrop et al., 2018
Collaborative Model for End Stage Dementia <sup>(4)</sup>	Lindsay et al., 2010
Compassion Intervention <sup>(5)</sup>	Elliott et al., 2014; Jones et al., 2012; Jones et al., 2017; Moore et al., 2017
Model of Multidisciplinary Palliative Care <sup>(6)</sup>	Abbey et al., 2008
Nightingale Program <sup>(7)</sup>	Littledike & Davis, 2020
Oxleas Advanced Dementia Service <sup>(8)</sup>	Sonola et al., 2013
Palliative Care in Dementia Project <sup>(9)</sup>	Scott & Pace, 2009
PEACE <sup>(10)</sup>	Diwan et al., 2004; Shega et al., 2003; Shega et al., 2010
Programme Dignity <sup>(11)</sup>	Hum et al., 2018; Hum et al., 2020; Pereira et al., 2020
SEED Programme <sup>(12)</sup>	Robinson et al., 2020

Delivery settings for the models of care included the following:

- residential aged care (n=5; Aliviado, ADRD-PC Program, Compassion Intervention, MMPC, Nightingale Program and PEACE);
- hospice (including hospice in the home) (n=5; Challenge Pathway, Aliviado, Palliative Care in Dementia Project, PEACE, Oxleas Advanced Dementia Service);
- community and home-based care (n=9; Programme Dignity, ADRD-PC Program, Nightingale Program, PEACE, Challenge Pathway, Palliative Care in Dementia Project, Oxleas Advanced Dementia Service, Collaborative Model for End Stage Dementia, SEED Programme);
- primary care clinics (n=2; PEACE, SEED Programme); and
- hospital (acute care) (n=4; Programme Dignity, ADRD-PC Program, Nightingale Program, PEACE).

Four models of care were located in England (Compassion Intervention, Oxleas, Palliative Care in Dementia Project, SEED Programme), three in both Australia (Collaborative Model for End Stage Dementia, MMPC, Nightingale Program) and the United States (Aliviado, ADRD-PC, PEACE), and one each in Singapore (Programme Dignity), and Wales (Challenge Pathway). Table 2 summarises the key

components of the included models of care. A brief summary of each model of care, plus related references, is provided in Appendix 3.

The study designs used to test or evaluate the models varied and included a randomised controlled trial (SEED Programme), a pilot trial (ADRD-PC Program), feasibility studies (Compassion Intervention, PEACE, Aliviado, SEED Programme), impact and process evaluations (Challenge Pathway, Oxleas, SEED Programme), and a prospective cohort study (Programme Dignity). Qualitative, quantitative and mixed methods were used (e.g., surveys, interviews, patient chart/ medical record audits, field notes, ethnographic observations, case study). Some models of care were described in a single paper; other studies provided detailed descriptions and evaluations of care models in two or more papers and reports, implementation manuals, and/or online websites. Two models had not been systematically or formally evaluated (Nightingale Program, Collaborative Model for End Stage Dementia). Table 3 summarises the evaluation of each model of care (where evaluation was carried out).

Table 4 summarises the results of mapping the included models of care to the nine-domain framework of essential components of dementia-specific palliative care (adapted from the EAPC 11-domain framework (J. van der Steen et al., 2014). Key components of the models of care identified included family care, grief and support (D2); integrative, coordinated, and multi- or interdisciplinary care (D3 and D4); education (patient, family and carers) (D5); comfort measures and optimal treatment of symptoms (D6); and prognostication and recognition that the person with dementia is nearing their end of life (D7). The domain for which there was the least demonstrated evidence was ethical and practical issues (D9), followed by psychosocial and spiritual support (D8) and person-centred care (D1). For some models of care, the supporting evidence for each domain was minimal or difficult to identify. The Supporting Excellence in End-of-Life Care in Dementia (SEED) Programme (Robinson et al., 2020) provided the most comprehensive reporting for any model of care.

Practical examples of how each of the domains of care was demonstrated in the included models were limited for the following reasons:

- lack of detail in the reporting of some models of care, for example the Challenge Pathway (Harrop et al, 2018) and the Collaborative Model for End-Stage Dementia (Lindsay, 2010);
- resources were not freely available, for example the Aliviado Dementia Care resources which are behind a paywall; or
- resources no longer exist, for example the Massive Open Online Course (MOOC) developed for carers of people with advanced dementia as part of the SEED Programme (Robinson et al, 2020).

However, we have selected practical examples of how the domains of care were demonstrated, which may be useful to readers seeking to develop a locally-responsive model of care for people with advanced dementia (see Table 5).



Table 2: Summary of included models of care (n =12)

Model of Care	Author (Year)/Country	Setting	Referral pathway	Key components	Healthcare professionals	Funding
1. Aliviado Dementia Care	Lin et al. (2020)/US; Jones et al. (2021)/US	Home hospice program delivered in suburban area	PWD were identified from hospice medical records.	<ul style="list-style-type: none"> <li>• Dementia care training for HCP</li> <li>• A toolbox consisting of assessment instruments, symptom management algorithms, care plans, and carer education sheets</li> <li>• Clinical workflow changes to integrate toolbox materials into hospices' electronic health records</li> <li>• Mentorship through the Aliviado technical support centre</li> </ul>	<ul style="list-style-type: none"> <li>• Nurses</li> <li>• Social workers</li> <li>• Chaplains</li> <li>• Ordering providers (physicians, nurse practitioners, physicians assistants)</li> <li>• Home health aides</li> </ul>	Pilot funded by the National Institute on Aging at the National Institutes of Health.
2. Alzheimer's Disease and Related Dementias Palliative Care (ADRD-PC) program	Hanson et al. (2019)/US	Hospital, home, RAC	PWD were aged 65 years or older, identified during hospital admission with acute illness, diagnosis of dementia Stage 5-7 on the Global Deterioration Scale (GDS), and had an identified family decision-maker	<p>The following support is provided while hospitalised and two weeks post discharge:</p> <ul style="list-style-type: none"> <li>• PC consultation</li> <li>• Phone support</li> <li>• Informational booklet for families</li> <li>• Individualised recommendations for PC domains</li> <li>• Assistance with completing a Medical Orders for Scope of Treatment (MOST) order set, the North Carolina version of</li> </ul>	<ul style="list-style-type: none"> <li>• Primary care physicians and nurse practitioners</li> </ul>	Pilot funded by the National Institute on Aging (NIA) and National Palliative Care Research Center. Trial funded by \$4.1 million dollar grant from the NIA.

Model of Care	Author (Year)/Country	Setting	Referral pathway	Key components	Healthcare professionals	Funding
				<p>Physician Orders for Life Sustaining Treatment (POLST)</p> <ul style="list-style-type: none"> <li>Recommended referrals to post discharge services</li> <li>Transitional care</li> <li>Training session to PC physicians and nurse practitioners</li> </ul>		
3. Challenge Pathway	Harrop et al. (2018)/Wales	Hospice, home, community	Open referral system	<ul style="list-style-type: none"> <li>Specialist care</li> <li>Home-based hospice care</li> <li>Social workers</li> <li>Dementia day programs</li> <li>Peer-support groups</li> <li>Training for health and social care workers, families and volunteers</li> </ul>	<ul style="list-style-type: none"> <li>Nurse Specialist</li> <li>Dementia Support Worker</li> </ul>	Evaluation funded by Aneurin Bevan University Health Board Research and Development Department and South East Wales Academic Health Science Partnership (SEWAHSP). Funding support was also provided via a Marie Curie Cancer Care core/programme grant, Marie Curie Research Centre, Cardiff University
4. Collaborative Model for End Stage Dementia	Lindsay (2010)/Australia	Dementia day therapy unit, home	<ul style="list-style-type: none"> <li>Specialist Geriatricians</li> </ul>	<ul style="list-style-type: none"> <li>Carer education and support</li> <li>Identification of EOL</li> <li>Coordination of support with GPs and PC team</li> <li>Post-bereavement support</li> </ul>	<ul style="list-style-type: none"> <li>Case manager</li> <li>Psychologist</li> <li>Nurse</li> <li>Diversional Therapist</li> </ul>	Program funded by New South Wales Health (Illawarra Shoalhaven Local Health District)

Model of Care	Author (Year)/Country	Setting	Referral pathway	Key components	Healthcare professionals	Funding
5. Compassion Intervention	Jones et al. (2017)/England; Moore et al. (2017)/England	RAC	<ul style="list-style-type: none"> <li>Care home staff are trained to identify eligible residents (a diagnosis of moderately severe dementia in addition to another concern such as persistent distress or another condition)</li> </ul>	<ul style="list-style-type: none"> <li>An interdisciplinary care leader who coordinates care</li> <li>Education, training and support for all involved in caring for the person with dementia, particularly care home staff and carers</li> </ul>	<ul style="list-style-type: none"> <li>The interdisciplinary care leader</li> <li>Clinical Lead Professional responsible for medical care</li> <li>The RAC nurse unit manager</li> <li>Other healthcare staff who deliver direct care to the person with dementia;</li> <li>The wider team providing support as needed</li> </ul>	Program and evaluation funding was provided by Marie Curie Cancer Care (now Marie Curie) through a process administered in partnership with Cancer Research UK.
6. Model of Multidisciplinary Palliative Care (MMPC)	Abbey et al. (2008)/Australia	RAC	<p>Existing residents of RAC identified as follows:</p> <ul style="list-style-type: none"> <li>Diagnosis of dementia</li> <li>Incontinence</li> <li>Functionally non-verbal or making noises indicating distress</li> <li>Reduced interest in food/weight loss</li> <li>Poor skin integrity</li> </ul>	<ul style="list-style-type: none"> <li>Case conferencing</li> <li>Education of RAC staff</li> <li>Involvement and support of carers</li> </ul>	<ul style="list-style-type: none"> <li>RAC staff</li> <li>Volunteer primary care practices</li> </ul>	Trial funded by the Prince Charles Hospital Foundation, Queensland.

Model of Care	Author (Year)/Country	Setting	Referral pathway	Key components	Healthcare professionals	Funding
			<ul style="list-style-type: none"> <li>Poor peripheral circulation</li> <li>Judged by experienced nursing staff as likely to die within 12 months</li> </ul>			
7. The Nightingale Program	Littledike & Davis (2020)/Australia	Home, acute care, RACF	<ul style="list-style-type: none"> <li>Dementia Australia National Helpline</li> <li>Healthcare professionals</li> <li>Primary care providers</li> <li>Carers/family</li> <li>RAC staff</li> <li>Community service providers</li> </ul>	<ul style="list-style-type: none"> <li>Weekly case conference with a Consultant Geriatrician</li> <li>Symptoms and medication management</li> <li>Clinical report is produced and shared with family, GPs, and other specialists and health care providers</li> <li>Use of validated assessment tools</li> <li>Carer education and support</li> </ul>	<ul style="list-style-type: none"> <li>Clinical Nurse Consultants</li> <li>Consultant Geriatrician</li> </ul>	Program funded by the Rosemary Foundation for Memory Support
8. Oxleas Advanced Dementia Service	Sonola et al. (2013)/England	Home	<ul style="list-style-type: none"> <li>Community matrons</li> <li>Consultant psychiatrists</li> <li>Advanced practice nurses</li> <li>GPs</li> <li>District nurses</li> <li>Hospices</li> <li>Mental health wards</li> </ul>	<ul style="list-style-type: none"> <li>Personalised care plans</li> <li>Care coordination</li> <li>Carer support</li> </ul>	<ul style="list-style-type: none"> <li>Consultant geriatric psychiatrist</li> <li>Specialist nurses</li> <li>Specialist social worker</li> </ul>	Funding from clinical commissioning groups (CCGs) and local authorities/councils
9. Palliative Care in Dementia Project	Scott & Pace (2009)/England	Home, RACF	<ul style="list-style-type: none"> <li>GPs</li> <li>RACF nurse/manager</li> <li>Psychiatrists</li> <li>Alzheimer's Society</li> <li>Care manager</li> </ul>	<ul style="list-style-type: none"> <li>Specialist palliative care worker</li> <li>Educational programme for RAC staff</li> <li>Healthcare workers and professionals</li> <li>Referrals to other services</li> </ul>	<ul style="list-style-type: none"> <li>Specialist palliative care nurses</li> </ul>	Program and evaluation funded by the King's Fund, UK

Model of Care	Author (Year)/Country	Setting	Referral pathway	Key components	Healthcare professionals	Funding
			<ul style="list-style-type: none"> <li>Hospital clinician</li> </ul>			
10. PEACE (University of Chicago portion)	Diwan, Hougham, & Sachs (2004)/US; Shega et al. (2003)/US; Shega et al. (2008)/US; Shega et al. (2010)/US	Primary care clinic, hospital, RAC, hospice, home	<ul style="list-style-type: none"> <li>Physicians</li> </ul>	<ul style="list-style-type: none"> <li>Physical and psychological symptom management</li> <li>Advance care planning</li> <li>Education on the disease process</li> <li>Community resources</li> <li>Coordination of care</li> <li>Patient-carer centred care</li> <li>Hospice services</li> </ul>	<ul style="list-style-type: none"> <li>Nurses</li> <li>Social workers</li> <li>Fellowship-trained physicians (geriatrics)</li> <li>Other disciplines as needed, e.g., audiology, neurology</li> </ul>	Program funded by The Robert Wood Johnson Foundation's "Promoting Excellence in End-of-Life Care Initiative."
11. Programme Dignity	Hum et al. (2018)/Singapore; Hum et al. (2020)/Singapore; Pereira et al. (2020)/Singapore	Hospital, home	<ul style="list-style-type: none"> <li>Geriatric and palliative inpatient wards</li> <li>Outpatient clinics</li> </ul>	<ul style="list-style-type: none"> <li>Regular home visits and phone calls from multidisciplinary team</li> <li>Assessment and pharmacological interventions to manage pain and behavioural issues</li> <li>Carer education and support through counselling and referrals to other community services</li> <li>After hours support</li> <li>Direct admission to ward or hospice as required</li> </ul>	<ul style="list-style-type: none"> <li>Doctors</li> <li>Nurses</li> <li>Medical social workers</li> <li>Hospital physicians</li> </ul>	Research funded by the Temasek Foundation Cares CLG. Beyond the research project, program is funded by the Singapore government (40%) and fundraising and donations (60%).
12. SEED Programme	Robinson et al. (2020)/England	Primary care	<ul style="list-style-type: none"> <li>Patients identified from the practice dementia register and screened by a GP</li> </ul>	<ul style="list-style-type: none"> <li>Timely planning discussions</li> <li>Recognising EOL and providing supportive care</li> <li>Co-ordinating care</li> <li>Effective working with primary care</li> </ul>	<ul style="list-style-type: none"> <li>Dementia nurse specialist</li> </ul>	Program and evaluation funding was provided by the Programme Grants for Applied Research programme (National

Model of Care	Author (Year)/Country	Setting	Referral pathway	Key components	Healthcare professionals	Funding
				<ul style="list-style-type: none"> <li>• Managing hospitalisation</li> <li>• Continuing care after death</li> <li>• Valuing staff and ongoing learning.</li> </ul>		Institute for Health Research)

EOL = end of life, GP = General Practitioner, PC = palliative care, RAC = residential aged care (includes nursing homes).

Table 3: Evaluation of models of end-of-life dementia care

Model of Care and study design	Primary outcomes (PO) and secondary outcomes (SO)	Methods	Results
<b>Aliviado Dementia Care</b> Feasibility, applicability, and fidelity pilot	PO: Hospice staff outcomes include dementia knowledge, confidence and attitudes  SO (Person with Dementia): Hospital admissions and entry to nursing home, antipsychotic use, caregiver satisfaction	Pre and post training survey  Informal focus group	N = 72 hospice staff, 11 persons with dementia  Program feasibility (program completion), applicability (indication of implementing changes to practice), and fidelity (completion of assessment instrument or care plan) exceeded pre-established criteria.
<b>Alzheimer's Disease and Related Dementias Palliative Care (ADRD-PC) program</b> Pilot RCT completed Multisite RCT ongoing	PO was hospital or emergency department visits in the 60 days after discharge  SO patient and carer-centred were: <ul style="list-style-type: none"> <li>• Patient comfort</li> <li>• Carer distress</li> <li>• PC domains addressed in the treatment plan</li> <li>• Access to hospice or community-based PC</li> </ul> SO decision-making were: <ul style="list-style-type: none"> <li>• Discussion of prognosis</li> <li>• Discussion of goals of care</li> <li>• Completion of MOST order set</li> <li>• Documented decisions against rehospitalisation or other potentially burdensome treatments</li> </ul>	Carer interviews  Chart and medical record review	N = 62 Persons with dementia and carer dyads <ul style="list-style-type: none"> <li>• The intervention proved feasible</li> <li>• Hospital and emergency department visits did not differ</li> <li>• Intervention patients and families were more likely to: <ul style="list-style-type: none"> <li>○ Have PC domains addressed</li> <li>○ Receive hospice</li> <li>○ Discuss prognosis and goals of care</li> <li>○ Have a MOST at 60-day follow-up</li> <li>○ Make decisions to avoid rehospitalisation.</li> </ul> </li> </ul>
<b>Challenge Pathway</b> Implementation and impact evaluation of service outcomes for the	<ul style="list-style-type: none"> <li>• Number of referrals for patients with dementia</li> <li>• Type of referrals</li> </ul>	Clinical data audit  Interviews with project staff	N = 3 project staff, 15 carers and 20 health care professionals <ul style="list-style-type: none"> <li>• Referrals increased</li> </ul>

Model of Care and study design	Primary outcomes (PO) and secondary outcomes (SO)	Methods	Results
first 16 months of operation	<ul style="list-style-type: none"> <li>Carer knowledge, confidence and service outcomes</li> <li>Healthcare professionals (HCPs) service impact and knowledge</li> </ul>	Surveys with carers and HCPs	<ul style="list-style-type: none"> <li>There were more dementia patients referred for PC than for EOL support</li> <li>Most carers and healthcare professionals rated the service as helpful</li> </ul>
<b>Collaborative Model for End Stage Dementia</b> Case study	NR	NR	<p>N = 1 person with dementia and carer dyad</p> <p>Positive benefits identified</p>
<b>Compassion Intervention</b> Multisite feasibility study	<ul style="list-style-type: none"> <li>Compare the operation of the Intervention in different health and social care settings</li> <li>Estimate the cost of employing an Interdisciplinary Care Leader (ICL)</li> <li>Demonstrate the Intervention caused no physical or psychological harm to Person with dementia or carers</li> </ul>	<p>Interviews with carers and HCPs</p> <p>Field notes</p> <p>Clinical data</p>	<p>N = 9 persons with dementia, 28 HCPs</p> <ul style="list-style-type: none"> <li>The interdisciplinary care leader role was found to be feasible, with reasonable costs</li> <li>The manual was found to be holistic and transferable to other contexts</li> <li>It was not possible to assess whether the intervention led to better outcomes for residents and their families or carers, but it did no harm</li> </ul>
<b>Model of Multidisciplinary Palliative Care (MMPC)</b> Trial in two RAC facilities	NR	<p>Clinical data audit</p> <p>Documentation of program goals and outcomes</p> <p>Ethnographic observation and photography</p> <p>Interviews with HCPs and carers</p> <p>Pre and post surveys with RAC staff</p>	<p>N = 17 persons with dementia; n = 7 bereaved carers; n = 42 (out of 266) who returned post-program questionnaires</p> <ul style="list-style-type: none"> <li>Increased reporting of symptoms for the nine patients who died during the study</li> <li>Multidisciplinary case conferencing was successful in formalising discussion of issues</li> <li>No change in carer scores</li> <li>Most bereaved carers expressed satisfaction with care</li> <li>Staff belief in their ability to improve care increased but confidence decreased</li> </ul>



Model of Care and study design	Primary outcomes (PO) and secondary outcomes (SO)	Methods	Results
<b>The Nightingale Program</b>	NR	NR	NR
<b>Oxleas Advanced Dementia Service</b> Impact evaluation	<ul style="list-style-type: none"> <li>• Cost of hospital admissions avoided</li> <li>• Patient quality of life</li> <li>• Carer stress levels</li> </ul>	<ul style="list-style-type: none"> <li>• Internal audit</li> <li>• Patients and carers questionnaires</li> <li>• Carer focus groups</li> </ul>	<ul style="list-style-type: none"> <li>• QUALID scores improved or remained stable over time for most</li> <li>• RSS scores improved or remained stable for all carers over time.</li> <li>• Carer reports were generally favourable</li> </ul>
<b>Palliative Care in Dementia Project</b> Pilot study and second-stage cohort study	<ul style="list-style-type: none"> <li>• ED admissions</li> <li>• Patient referrals to other agencies or full hospice service</li> <li>• Symptomatology profiling and identification of patients with dementia who need palliative care</li> <li>• Delivery of educational programme (carers/ HCPs/nurses).</li> <li>• Consultation/ discussion held with carers</li> </ul>	Clinical and administrative data	<p>N = 50 persons with dementia</p> <ul style="list-style-type: none"> <li>• GSF criteria are a useful prognostic tool for identifying patients with dementia who require palliative care</li> <li>• Specialist palliative care nurses can, with consultant supervision, provide effective symptom control, care and support and education</li> <li>• Many end-of-life care issues reflect a lack of knowledge, expertise and understanding about disease progression (e.g. dementia) and care of people who are dying</li> <li>• More education is needed</li> </ul>
<b>PEACE (University of Chicago portion)</b> Feasibility single-site pilot	<ul style="list-style-type: none"> <li>• Patients and carers matched with available resources</li> <li>• Better utilisation of community resources</li> <li>• Greater use of hospice services</li> </ul>	<p>Interviews with patients and carers at enrolment and every six months following</p> <p>Carers interviewed after death</p> <p>Patient chart review</p>	<ul style="list-style-type: none"> <li>• N = 150 patients/carer dyads</li> <li>• High satisfaction rates</li> <li>• Patients enrolled in hospice programs were significantly more likely to die in their place of choice</li> <li>• Carers continued to experience significant stress</li> </ul>
<b>Programme Dignity</b> Prospective cohort study	<ul style="list-style-type: none"> <li>• Patients' symptoms and quality of life</li> <li>• Caregiver burden</li> <li>• Other data such as comorbidities</li> </ul>	Chart review	<p>Patient outcomes:</p> <ul style="list-style-type: none"> <li>• A statistically significant improvement was observed in all symptom scores (pain, nutrition and neuropsychiatric symptoms) and in caregiver burden after 12 months.</li> <li>• A statistically significant improvement in quality of life scores was also observed.</li> </ul>

Model of Care and study design	Primary outcomes (PO) and secondary outcomes (SO)	Methods	Results
			<p>Healthcare utilisation:</p> <ul style="list-style-type: none"> <li>• One-year costs were estimated for Programme Dignity on a per patient-month basis retrospectively for the cohort enrolled in the program (n=184) and a control group (n=139).</li> <li>• Other healthcare utilisation costs (ED visits, admissions, LOS) were also calculated.</li> <li>• Full enrolled Programme Dignity patients were less likely to visit ED, be admitted to hospital, and had lower cumulative LOS than partially enrolled or non-enrolled patients.</li> </ul> <p>Cost-effectiveness:</p> <ul style="list-style-type: none"> <li>• Fully enrolled patients had lower costs at 1, 3 and 6 months than partially enrolled or non-enrolled patients (found to be statistically significant).</li> <li>• The cost of informal caregiving was not factored in to the economic analysis.</li> </ul>
<p><b>SEED Programme</b> Multisite feasibility RCT and process evaluation</p>	<ul style="list-style-type: none"> <li>• An appropriate primary outcome measure for the intervention was not identified</li> <li>• Feasibility of recruitment, participant retention, and 12-month follow-up for multi-centre RCT</li> <li>• Feasibility and acceptability, extent to which SEED intervention implemented in practice, and factors influencing intervention implementation (process evaluation)</li> <li>• Feasibility and acceptability of available outcome measures, feasibility of capturing resource use and HR-QoL data for people with dementia and family carers</li> </ul>	<p>Interviews, observations, dementia nurse speciality activity logs</p>	<p>N = 44 persons with dementia</p> <ul style="list-style-type: none"> <li>• All seven components of the intervention were delivered (either at home or in care home); all were found relevant and no additional components were identified</li> <li>• Implementation issues included the qualifications and training needed to perform the Dementia Specialist Nurse role, lack of clarity about focus and content of the SEED intervention, the SEED intervention mostly being seen as complementary to existing services, and the temporary nature of the SEED intervention affecting commitment from participating GP practices</li> </ul>



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ED = Emergency Department (hospital), EOL = end-of-life, ICL = Interdisciplinary Care Leader, GSF = Gold Standards Framework, GP = General Practitioner, HCP = health care professional, HR-QoL = Health Related Quality of Life, LOS = Length of Stay, MOST = Medical Orders for Scope of Treatment, NR = not reported, PC = palliative care, PO = primary outcome, QUALID = Quality of Life in Late-Stage Dementia (Weiner et al 2000), RAC = residential aged care (includes nursing homes), RCT = Randomised Controlled Trial, RSS = Relative Stress Scale (Ulstein et al 2007), SO = secondary outcome

Table 4. Mapping domains of care (9 domains)

Model of Care (context)	D1	D2	D3	D4	D5	D6	D7	D8	D9
Aliviado Dementia Care (US)	X	X	X	X	X	X	X		X
Alzheimer's Disease and Related Dementias Palliative Care (ADRD-PC) program (North Carolina, US)	X	X	X	X	X	X	X	X	X
Challenge Pathway (South Wales, UK)	X	X	X	X	X	X	X	X	X
Collaborative Model for End-Stage Dementia Care (New South Wales, Australia)	X	X	X	X	X	X	X	X	X
Compassion Intervention (North London, UK)	X	X	X	X	X	X	X	X	X
Model of Multidisciplinary Palliative Care (MMPC) for Residents with End-Stage Dementia (Queensland, Australia)	X	X	X	X	X	X	X	X	X
Nightingale Program (South Australia, Australia)	X	X	X	X	X	X	X	X	X
Oxleas Advanced Dementia Service (UK)	X	X	X	X	X	X	X	X	X
Palliative Care in Dementia (UK)		X	X	X		X	X	X	
Palliative Excellence in Alzheimer Care Efforts (PEACE) (Chicago, US)	X	X	X	X	X	X	X	X	X
Programme Dignity (Dignity in Advanced Dementia or DIADEM) (Singapore)		X	X	X	X	X	X		
Supporting Excellence in End-of-life care in Dementia (SEED) programme (UK)	X	X	X	X	X	X	X	X	X

\*Blue shaded cells show where the domain was not met or not reported in the literature; X= yes.

D1 - person-centred care; D2 - family care, grief and support; D3- continuity, coordination and integration of care; D4 – collaboration and communication; D5 - education of the person, family and carers; D6 – symptom and comfort care; D7 – prognostication, dying, death; D8 - psychosocial and spiritual support; D9 – ethical and practical issues

Table 5. Selected practical examples of domains of care demonstrated in the models of care.

Domain	Examples demonstrated in models of care
(D1) Person-centred care including communication and shared decision-making regarding care goals and advance care planning	The Oxleas Advanced Dementia Service (Sonola et al, 2013) has no standardised care package for patients with advanced dementia. Rather, care is tailored to each person based on their primary needs and available services. The care assessment examines the mental, physical and social needs of the person, their personal and social background, and end-of-life and spiritual wishes.
(D2) Family care and support, communication and involvement in care planning; uncertainty, grief and bereavement	The Oxleas Service provides support to families and carers with the goal of enabling them to care for the person with dementia at home, pain-free and comfortable, until the end of life, with bereavement support also provided. Key to carer support is the recognition that they may be experiencing anticipatory grief due to the nature of dementia. Of nine family carers who participated in evaluation, all experienced stable or decreased scores on the Relative Stress Scale between entry into the service and one year, or death of the care recipient (Sonola et al, 2013):
(D3) Continuity, coordination and integration of care	<p>The Compassion Intervention Manual (Jones et al, 2017) provides guidance on the interdisciplinary care leader role including professional background, level of clinical experience, minimum skills and training required, factors determining case load, and range of duties.</p> <p>The SEED Programme dementia nurse specialist role job description is provided in Appendix 3 of the SEED report (Robinson et al, 2020), and the Northumbria Healthcare Trust job description of the same role is provided in supplementary material. Detailed guidance for commissioning good-quality, community-based end-of-life care in dementia is provided in the SEED report (Robinson et al, 2020); although this is UK-specific, general principles are transferable to other contexts.</p>
(D4) Interdisciplinary collaboration and communication, organisational and workforce issues including education of care professionals, barriers to integrated care delivery	<p>The PEACE Program (Diwan et al, 2004; Shega et al, 2003) provides people with advanced dementia and their carers access to a range of healthcare professionals at one clinical site, including physicians (geriatrics, neurology, psychiatry, ophthalmology, dentistry), social worker, clinical nurse specialists, dietitian, audiologist, physical and occupational therapists, as well as some diagnostic tests.</p> <p>Both the SEED Programme (Robinson et al, 2020) and the Model of Multidisciplinary Palliative Care (MMPC) (Abbey et al, 2008) for residents with end-stage dementia, delivered in residential aged care settings, included post-death facilitated reflections (bereaved carer and care home staff – SEED Programme; care home staff only – MMPC). For care home staff, the aim of these reflections was to identify what was done well and what could have been improved in the care of the person who had died.</p>
(D5) Education of the patient, family and carers	The Challenge Pathway (Harrop et al, 2018) provides education to family members and carers (as well as health and social care professionals and volunteers) on dementia, end-of-life care, advance care planning, emotional support, and linking with local services such as the Alzheimer’s Society. Current and former carers (n=15) were surveyed; all but one rated the service extremely or quite helpful; 11 indicated improvements in knowledge, confidence and practical skills. Free text responses emphasised an increase in feelings of improved safety (24-hour telephone support available) and reduced feelings of isolation.

<p>(D6) Symptom and Comfort Care, including optimal treatment of symptoms and providing comfort (eg pain, challenging behaviour); avoidance of overly aggressive, burdensome or futile treatment (e.g. nutrition/ feeding decisions); quality of life</p>	<p>For people with dementia enrolled in the Nightingale Program (Littledike &amp; Davis, 2020), assessment (Functional Assessment Staging Test and Abbey Pain Assessment primarily) is repeated regularly and nursing recommendations for symptom management and co-morbidities are discussed in relation to goals of care and demonstrated for carers. Targeted and, importantly, anticipatory advice, education and support are provided to the person with dementia, their family and carers.</p> <p>A case study included in the description of the Oxleas Service (Sonola et al, 2013) highlights optimal treatment of symptoms for one person with advanced dementia (hydration, nutrition, safe swallowing, incontinence management, prevention of urinary tract infections, pressure area management). The person was enabled to remain at home cared for by their spouse, until they died.</p>
<p>(D7) Prognostication and timely recognition of dying; preferred place of death</p>	<p>In addition to evaluation of Programme Dignity, researchers also developed and validated a prognostic model for 6-month and 1-year mortality in home-dwelling patients with advanced dementia (Hum et al, 2021). The model, Palliative Support DEMentia Model (PaS-DEM), is based on 6 variables including age, dementia etiology, Functional Assessment Staging Test stage, Charlson Comorbidity Index scores, Australian National Sub-Acute and Non-Acute Patient palliative care phase, and 30-day readmission frequency for the prediction of 1-year mortality. The PaS-DEM was found to be useful in identifying people with dementia at high risk of death in the next year.</p>
<p>(D8) Psychosocial &amp; spiritual support</p>	<p>A case study of care provided by the Carunya community dementia care service (Collaborative Model for End-Stage Dementia) (Lindsay et al, 2010) illustrates the importance of the spiritual needs of the person with dementia and their family and carer. In this case, the deep spiritual/emotional connection between the person with dementia, their wife (also their primary carer) and the dairy farm in rural New South Wales where they had lived and worked for over 50 years played a significant role in decision-making regarding end of life care and place of death.</p>
<p>(D9) Ethical, social, legal, financial, practical (e.g. transport, equipment) issues</p>	<p>A case study included in the description of the Oxleas Advanced Dementia Service (Sonola et al, 2013) describes the range of equipment (hospital bed, pressure mattress, sliding sheet, recliner chair with pressure cushion, hoist, incontinence pads) provided to a carer of someone with advanced dementia living at home.</p>

## Referral and admission to care

The included models of care demonstrate a range of referral pathways and assessment for admission to a palliative care service or program (see Table 2 for details). People with dementia were admitted to the models of care based on criteria that were often described in general terms, for example being likely to derive benefit from the intervention. In a few cases criteria were provided in more detail. For example, inclusion in the Model of Multidisciplinary Palliative Care (MMPC) program depended on a number of the following admission criteria: existing resident of a residential aged care facility, diagnosis of dementia, incontinence, functionally non-verbal or making noises indicating distress, reduced interest in food/weight loss, poor skin integrity, poor peripheral circulation, judged by experienced nursing staff as likely to die within twelve months (Abbey et al, 2008). Evaluation of Programme Dignity included development and validation of a prognostic model (the PaS-DEM model) for 6-month and 1-year mortality in people with advanced dementia living at home (Hum et al, 2021). None of the included studies reported any analysis regarding accuracy of prognostication, in other words, whether the study/program participants were appropriately identified for the interventions delivered, and whether they were admitted into the model of care at the appropriate time based on their level of need.

## Integration of Care

Most of the models of care identified in this review demonstrate evidence of patient-centred care (Domain 1) and continuity, coordination and integration of care (Domain 3). Many also incorporated other elements of integrated care such as interdisciplinary collaboration (Domain 4) and involvement of family and carers in care planning and treatment decisions (Domain 2). In this sense, they may all be considered to be aiming for delivery of integrated care. However the extent to which comprehensive and effective integration of services and support around the person with dementia and their family or carer is demonstrated varies. Issues considered in relation to evaluating the degree of care integration provided by the models were: duration of care, location of care, care coordination role, interdisciplinary collaboration and communication, and evidence of person-centred care.

## Duration of care

Duration of care varied from a brief, time-limited intervention such as the ADRD-PC program (specialist inpatient palliative care consultation, information and recommended referrals to post-discharge services, covering the period of hospitalisation and transitional care for two weeks after discharge) (Hanson et al., 2019), to the majority of models in which care was provided to the person with dementia from enrolment in the program to their death. Some models such as the Collaborative Model for End Stage Dementia (Lindsay, 2010) and the SEED Programme (Robinson et al., 2020) also provided post-bereavement support to families and carers.

## Location of care

Several models of care were specific to one care location only. For example, the Compassion Intervention (Elliott et al., 2014; Jones et al., 2012; Jones et al., 2017; Moore et al., 2017) and the MMPC (Abbey et al., 2008) were developed for residential aged care (RAC), with an emphasis on education and training in both dementia care and palliative care for RAC staff. Other models, such as

Aliviado Dementia Care (Lin et al., 2020), the Challenge Pathway (Harrop et al., 2018) and the Oxleas Dementia Service (Sonola et al., 2013), provided hospice-in-the-home care. In contrast, Programme Dignity (Hum et al., 2020; Hum et al., 2018; Pereira et al., 2020) spans a number of locations of care, all of which may be needed during the advanced stage of dementia. In addition to a range of support provided to families caring for someone with dementia at home, the program also provides after hours support and direct admission to acute or hospice care if needed. Importantly, all members of the team have access to patient information in the national medical health records, which are also accessed by hospital and hospice staff if the patient is admitted to either facility.

Some models such as the Challenge Pathway (Harrop et al., 2018) and Oxleas Advanced Dementia Service (Sonola et al., 2013) also provided access to 24/7 crisis support for carers supporting a family member with dementia in their home.

### Care coordination role

A common inclusion in the models reviewed was the use of a dedicated Clinical Nurse Consultant, Palliative Care Nurse or Social Work Coordinator, whose role included many or all of the following:

- to identify and enrol people with dementia (and their family and carers) into the service;
- conduct assessments;
- communicate regularly with consultant geriatricians, specialists, general practitioners, allied health and palliative care providers (for example, through weekly case conferences) to ensure continuity of care and assist with care planning;
- provide education to healthcare professionals, people with dementia, their carers and families about dementia and end-of-life issues (for example, stages of dementia disease progression, symptom management/ comfort care, what to expect when death is approaching); and
- provide referrals to outside support such as bereavement counselling for carers.

Table 6 summarises aspects of this role as described in seven of the included models of care. Information includes: the category of healthcare professional in the role, their job title and position description (if provided), the purpose of the role, and key duties.

Table 6: Care coordination role summary

Model of care	Healthcare professional in role	Job title, position description	Care Coordinator – role purpose and key duties
Challenge Pathway	Nurse Specialist  Dementia Support Worker (qualifications not stated).	Two positions - Community Palliative Care Nurse Specialist (Hospice-employed) and Dementia Support Worker (provided by the Alzheimer's Society); no PDs provided.	<ul style="list-style-type: none"> <li>• Regular patient visits and phone calls providing direct patient care, information, advice</li> <li>• Education and training provided to health and social care professionals, volunteers, families, members of the public</li> <li>• Developing relationships with local services</li> </ul>
Collaborative Model for End	Not stated.	Case Manager – no PD provided.	<ul style="list-style-type: none"> <li>• Support and education provided to PwD and their carer</li> </ul>



Stage Dementia			<ul style="list-style-type: none"> <li>• Discussion of EOL issues and planning to enable home as preferred place of death in the single case study presented</li> <li>• Referrals to other healthcare professionals as needed</li> <li>• Liaison with GPs, community palliative care team</li> <li>• Post-bereavement support</li> </ul>
Compassion Intervention	Could be a nurse, social worker or other “profession allied to medicine”. No further detail provided.	Interdisciplinary care leader – no PD provided.	<ul style="list-style-type: none"> <li>• Scope local practice</li> <li>• Identify key personnel to support EOL care for PwD</li> <li>• Assessment of PwD enrolled in the program</li> <li>• Coordinate meetings of core care team (weekly) and wider MDT (monthly)</li> <li>• Training, education, support for health care professionals, family, carers</li> </ul>
The Nightingale Program	Clinical Nurse Consultant	Clinical Nurse Consultant – no PD provided.	<ul style="list-style-type: none"> <li>• Regular holistic patient assessments</li> <li>• Nursing recommendations for symptom control, care plans, demonstrations/education for carers</li> <li>• Weekly case conferences with Consultant Geriatrician resulting in a clinical report shared with family, GP, other healthcare professionals</li> <li>• Liaison with community palliative care team</li> </ul>
Oxleas Advanced Dementia Service	Specialist Nurse (a Community Psychiatric Nurse, Advanced Practice Nurse or Community Matron)	Care Coordinator  No PD provided.	<ul style="list-style-type: none"> <li>• Assessment of PwD and creation of a personalised care plan</li> <li>• Weekly MDT meetings</li> <li>• Ongoing regular visits</li> <li>• Management of discharge from hospital</li> <li>• Liaison with GP, district nursing service, other care providers</li> <li>• Family and carer support, education, training</li> </ul>
PEACE	Clinical Nurse Specialist	Nurse Care Coordinator  No PD provided.	<ul style="list-style-type: none"> <li>• Referral to other healthcare professionals/services available within a single primary care clinic</li> <li>• Review of patient records</li> <li>• Provision of feedback to physicians and families</li> </ul>
SEED Programme	Nurse Specialist (pay band 6)	Dementia Nurse Care Facilitator. PD available in Robinson et al, 2020, Appendix 3. See also Robinson et al, 2020, Supplementary Material 2 (available online at <a href="https://www.journalslibrary.nihr.ac.uk/pgfar/pgfar08080#/bn1">https://www.journalslibrary.nihr.ac.uk/pgfar/pgfar08080#/bn1</a> )	<ul style="list-style-type: none"> <li>• Expert in dementia and/or palliative care</li> <li>• Based in primary care, works with range of community health and social care professionals</li> <li>• Lead facilitator of care/services for people with dementia and their carers</li> <li>• PD lists key duties organised according to the following key components of good EOL care in dementia: timely planning discussions; recognising EOL and</li> </ul>

			providing supportive care; coordinating care; working effectively with primary care; managing hospitalisation; continuing care after death; and valuing staff and ongoing learning.
Additional MoC			
Partnership Model of Hospice Enabled Dementia Care			

### Person-centred care

Person-centred care, defined by the Australian Commission on Quality and Safety in Health Care (2022) as ‘care that is respectful of, and responsive to, the preferences, needs and values of the individual patient’, was implied in all the included models of care. However, the level of evidence varied and clear evidence of person-centred care, including advance care planning, was not identified in either the Palliative Care in Dementia (UK) (Scott & Pace, 2009) model or Programme Dignity (Singapore) (Hum et al., 2020; Hum et al., 2018; Pereira et al., 2020). In many of the models of care, the main mechanisms whereby the person with dementia was included in decisions relating to their care appeared to be advance care planning, (in other words, decisions made according to goals and wishes documented in the past) and interpretation of the person’s wishes by family and carers. The review found scant evidence of supported decision-making for people with advanced dementia. The ‘supportive toolbox’ of “skills, strategies, techniques and resources” required by healthcare professionals to enable people with even advanced dementia to have meaningful involvement in decision-making is an area for further research (Sinclair et al, 2021).

The people with dementia receiving care within each of the included models were generally described in terms of demographic detail and symptom profile. Other information, such as culturally and linguistically diverse backgrounds, Indigenous populations or identification as LGBTIQ+, was not included. Therefore, while this review found some evidence that models of dementia palliative care benefit people with advanced dementia, it is not known whether these models potentially benefit diverse populations of people with dementia.

### Evaluation of Models of Care

Primary and secondary outcomes reported in the included studies targeted patient- and carer-level outcomes (such as symptom control, evidence of advance care planning, documentation of care goals, carer distress/satisfaction/confidence and knowledge, preferred place of death achieved); care provider outcomes (such as increased knowledge and confidence in delivering care, acceptability of changes in practice); and system-level outcomes (such as improved accuracy and completeness of clinical documentation, avoidance of hospital admission, cost of employing a care coordinator, utilisation of community resources). Many of the evaluations were exploratory rather than evaluative,

for example, feasibility studies (Elliott et al, 2014; Shega et al, 2003; Shega & Sachs, 2010; Lin et al, 2022; Robinson et al, 2020).

### Sustainability

A number of the models of care identified in this review were developed, implemented and evaluated as part of a research project. Some, such as the Model of Multidisciplinary Palliative Care (MMPC) (Abbey et al., 2008), the Oxleas Advanced Dementia Service (Sonola et al., 2013), the Compassion Intervention (Jones et al., 2017; Moore et al., 2017) and the Supporting Excellence in End-of-life care in Dementia (SEED) program (Robinson et al., 2020), were not continued once research funding was finished.

For other models of care such as the Challenge Pathway (Harrop et al., 2018) and the Collaborative Model for End Stage Dementia (Lindsay, 2010), it was unclear whether they were still operating. Limited staff capacity and/or changes in health care policy, guidelines and delivery systems (reduced feasibility) may have been factors in the cessation of these programs.

Implementation of three models of care included production of detailed documentation which is freely available. Pro-forma documents such as assessments, work instructions, flowcharts and audit tools, were developed during the trial of the MMPC, and are included as appendices in the final report (Abbey et al., 2008). The SEED Programme report (Robinson et al., 2020) provides a range of useful documents such as a job description for a dementia nurse specialist and an activity checklist for timely end-of-life care planning discussions with people with dementia and their families. Similarly, the Compassion Intervention Manual (Jones et al., 2017) provides detailed guidance on commissioning and implementation of the intervention, although it is unclear whether it has been implemented beyond the initial pilot in two nursing homes in North London between 2014 and 2015. Resources such as these enhance the impact of models of care by facilitating transfer of the model to other locations or settings.

## Discussion

The review identified relatively few models of palliative care for people with advanced dementia, and these varied considerably in setting, scope, degree of integration of services, and evaluation. All models demonstrated at least some evidence of at least six of the nine domains of optimal palliative care. From the narrative summary of the included models, the following four main issues emerged as key to successful translation of the research evidence into a local pilot model of care.

### Referral and admission to care

Despite a range of referral pathways to a palliative care service or program, the included models of care provide limited insights about when, where and how to identify people with advanced dementia who are in need of end-of-life care and to initiate such care. Where the criteria for admission were provided, people with dementia have to demonstrate a significant level of deterioration from multiple and complex symptoms to be offered interventions (Jones et al, 2017). Yet the burden of symptoms is not the whole picture; admission to care should also encompass the psychosocial needs of people with dementia, their families and carers (Browne et al, 2021). Program evaluation of models of care for people with advanced dementia should also include investigation of referral pathways and admission criteria to identify whether these were needs-based and applied consistently. This review also showed that accurate prognostication for people with advanced dementia was not a major element of most of the included models of care. Prognostication tools to accurately identify people in need of end-of-life care, for example, the Supportive Palliative care Indicators Tool (SPICT)<sup>TM</sup> (The University of Edinburgh; Highet et al, 2014), have been developed and implemented successfully. However tools that rely on a chronological disease trajectory are less useful for people with advanced dementia, and recent research has identified lack of consistency in how end of life in dementia is defined, and called for a move beyond prognostication to a needs-based approach (Browne et al, 2021).

### Integrated Care

Traditional models of palliative care are designed to be delivered in the last six months of life. Given the variable disease trajectory of dementia, and the difficulties in prognostication for dementia (Gottesman & Blinderman, 2021; Hum et al., 2021) a longer-term approach to palliative care is needed for people with advanced dementia. A relatively brief, time-limited model of care such as the ADRD-PC program (Hanson et al., 2019) may provide only short-term benefits for people with advanced dementia; this is acknowledged by the authors of the study. Models built around one care delivery location, for example residential aged care (Abbey et al, 2008; Jones et al, 2012; Moore et al, 2017) run the risk of fragmenting care when transitions between care locations are required, for example an acute medical episode requiring hospitalisation.

The models that provided care from the time the person and their family/carer enrolled in the service until their death, and in some cases post-bereavement support, and included a care coordinator role, and were not specific to one care location, were more appropriate for people with advanced dementia. For example, the Nightingale Program based in South Australia (Littledike, 2020), is an integrated model of care (referrals accepted from a range of sources; nursing assessment, care

planning, interdisciplinary collaboration, coordination of services provided by a care coordinator; and support for carers), in which the person with dementia remains until their death, regardless of whether their care setting changes.

### Nightingale Program

A palliative model of care for people with dementia, provided free of charge (funded by Dementia Australia and the Rosemary Foundation) to residents of South Australia:

- nurse-led – 3 specialist Clinical Nurse Consultants and a consultant geriatrician;
- multiple entry points to the program with referrals accepted from the Dementia Australia National Helpline, healthcare professionals, palliative care services, family and friends, residential aged care facilities and community service providers;
- the person remains in the program until their death, regardless of care setting;
- continual nursing assessments with a focus on symptoms and medication management;
- weekly case conference with focus on symptom management, quality of life;
- clinical report shared with family, GPs, specialists, other health care providers;
- validated assessment tools;
- family/carer education and support;
- delivered face to face in metropolitan areas and via telephone in regional areas;
- addressed all nine components of an optimal model of palliative care for people with dementia
- integrated, context-specific, scalable

*'a single and reliable point of contact who has a thorough understanding of the client's needs and is skilled in navigating the [Australian health and aged care] systems' (Littledike & Davis, 2020).*

Best practice models of palliative care should be built around the person with dementia, regardless of their care setting, and how long they need to receive care. Most importantly, while best practice models of care should incorporate all nine domains of palliative care, they should also be flexible enough to take into account the needs of each individual, particularly regarding psychosocial and spiritual support, and needs relating to self-determination, familiarity and safety (Schmidt et al., 2018; Seipp et al., 2021).

The Australian Commission on Quality and Safety in Health Care identifies one of the key dimensions of person-centred care as involvement of carers and family (Australian Commission on Quality and Safety in Health Care, 2022). Therefore, the emotional, psychological, spiritual and practical support needs of family carers should be considered in any model of dementia palliative care. Ideally, families and carers should be meaningfully engaged in shared decision-making processes with healthcare professionals involved in providing care (Gonella et al., 2022).

The quality of end-of-life care and death experience is shaped by the care needs, preferences and experiences of both the person with dementia, and their carer and family (Klapwijk et al., 2021). The needs of family carers and the person with dementia are often interdependent (but not always congruent) (Broady et al., 2018; Huang et al., 2020). For example, interviews with residential aged care staff and review of case notes for people enrolled in the MMPC model of care revealed several instances in which the person with dementia had an advance care directive but their family member was reluctant for it to be followed (Abbey et al., 2008). It is important therefore, that families and carers are appropriately engaged in care planning and considered when developing end-of-life models of care.

In most of the models of care, responsibility for integration and continuity of care, interdisciplinary coordination, and communication with families and carers was the responsibility of a care coordinator. In some models this role also carried responsibility for training of healthcare workers, for example staff of residential aged care facilities, and education for families and carers. This role was generally filled by a senior nurse specialising in either palliative or dementia care or a social worker (see Table 6). This role may also have responsibility for assessment of the person with dementia and development of a personalised care plan in collaboration with healthcare workers, families and carers.

This role is key to delivery of an integrated model of care. The scale of service delivery will determine the number of individuals required in the role and the degree of delegation of components of the role. If the role is not adequately funded and supported, for example, if it is expected to be added on to an existing role, it is likely that the model of care will not be sustained (Abbey et al., 2008).

### Sustainability

It is key that a model of care, once developed and, ideally, evaluated, is embedded as core business in order to be sustainable. This review found very limited evidence to identify the conditions needed to support long-term sustainability of any model of end-of-life care for people with dementia, but it can be inferred that adequate, guaranteed ongoing funding of the program and the position of care coordinator as a dedicated role are key. In a resource-constrained environment, some organisations may have to be selective in which components of a model of care could be implemented depending on local context and availability of existing resources. However, there is clear evidence to support what a best practice end-of-life model of care for people with dementia should look like and ideally all domains of care should be addressed in any model. Flexibility and agility to scale up or down as a pragmatic approach to implementing models of care may be needed to improve sustainability while managing deviation from the original design of the model.

From the limited evidence discovered by this review, the conditions needed to support long-term sustainability of any model of care were found to be:

- demonstrated best practice, including alignment with national guidelines and priorities of participating organisations;
- involvement of people with dementia, their families and carers, and health and social care workers who deliver hands-on care, in the development of the model;

- adequate and guaranteed ongoing funding, supported by strong evidence of potential cost savings such as decreased hospitalisations;
- training, support and capacity building of healthcare professionals; and
- collaboration within and across sectors, enabling coordinated care.



Figure 3. Factors for successful and sustained implementation of a model of care.

### Evaluation

The wide range of outcome measures used in evaluating some of the included models of care indicates the difficulties in assessing the effectiveness of complex interventions to improve end-of-life care for people with dementia. Further research is needed to develop methodologies for evaluating the effectiveness of complex models of care in real-world settings, including:

- outcome measures for patients, carers and healthcare professionals that are targeted, easy to deliver and not burdensome; and
- quality indicators that focus on processes, outcomes and structure of care.

Evaluation of models of care should also take into account the costs of caring. Only two of the included models reported any economic evaluation measures, namely the Compassion Intervention which calculated the cost of employing a care coordinator (Elliott et al., 2014; Jones et al., 2012; Jones et al., 2017; Moore et al., 2017) and the Oxleas Advanced Dementia Service which estimated savings due to hospital admissions avoided (Sonola et al., 2013). None of the models evaluated the substantial unpaid care provided by families and carers.

### Translation of evidence into practice

This review provides a first step towards developing a locally responsive, evidence-based, end-of-life model of care for people with dementia on the Central Coast.

Key principles underpinning the CCLHD's Palliative Care service are person-centred care, recognition and support for families and carers, access to skilled providers across all care settings, coordinated, integrative care, and equitable access to quality care (NSW Health, 2019). However, informal observations and feedback from healthcare professionals suggest that, within the CCLHD area, some people with dementia may not be having their needs optimally met; also, that fragmentation of dementia and end-of-life care services may be occurring.

Additional considerations for developing a locally responsive model of care are needed to address the needs of the Central Coast's diverse population. Persons from Aboriginal or Torres Strait Islander backgrounds can experience delayed access to, and commencement of, palliative care (Woods et al., 2018). Existing palliative care services may not be culturally appropriate for persons from an Indigenous or culturally and linguistically diverse (CALD) background. Persons from either of these population groups should have a central role in co-designing the model of care to ensure it meets the needs of their communities.

People from semi-rural areas of the Central Coast may experience difficulties accessing support, with only limited transport options available. A recent systematic review identified a gap in the literature on dementia palliative care in rural areas, and a need for more research on whether technology can be used to mitigate barriers to accessing care (Elliot et al., 2021). Older carers and/or persons at more advanced stages of dementia may also not be able to drive themselves to access appropriate services, and additionally may struggle with access to, and use of, technology.

End-of-life models of care should also respond sensitively to the needs of persons with dementia, their carers and families who identify as LGBT+ (Wakefield et al., 2021). Gender-diverse persons have historically experienced limited access to gender-appropriate services and can delay seeking help due to past experiences of discrimination or due to services not meeting cultural safety needs (Wakefield et al., 2021).

Any local model of care should take these needs into consideration, and plan for how care might be delivered to vulnerable persons with dementia. A co-design approach to developing the Central Coast's model of care will help to ensure it is fit for the local context and meets the needs of all members of the community.

## Limitations

The emphasis of this rapid review was on identifying and synthesising the literature within a given timeframe. More extensive, systematic reviews could potentially identify additional articles or models that we have not included or include those models which were still under development at the time of writing. We have flagged several of models under development in Appendix D. As the emphasis was on rapidly scoping the literature (and not examining specific effects), we have not completed critical appraisals; this is typical of rapid review methodology and in no way reduces the practicality or usefulness of our findings (Tricco et al., 2017).

This review also found that definitions for models of care, and the boundaries between what constitutes a "model" or component are blurred. Hence, some interventions such as Namaste (Stacpoole et al., 2017; Stacpoole et al., 2016) sit within a grey area of practice. The Namaste program is one example of a dementia-specific intervention or philosophy of care designed for people with advanced dementia who can no longer participate in traditional social activities. The focus in Namaste is on creating structured opportunities for staff, the person with dementia, and their families to



engage in meaningful activities and connection to others. This is achieved through multisensory activities such as scenting the room with lavender, gentle face washing and hand massage, and knowing the person with dementia's biography (life story and cultural background) (Simard & Volicer, 2010; Stacpoole et al., 2016). Namaste thus provides a framework for providing person-centred care to people with dementia at the end of life (Bunn et al., 2018). However it does not fit within this report's definition of a model of care, as it needs to be coordinated and implemented into other existing models of care. Namaste does however have many features which make it attractive for clinicians looking to develop or extend existing integrated care models.

There were also difficulties in separating out dementia-specific models of care designed for palliative/end-of-life care from models which included the whole dementia disease trajectory and therefore treated patients whose care needs may not have been as complex nor palliative in focus.

Further, best practice models of dementia-specific end-of-life care were not found for vulnerable populations such as persons from Aboriginal, Torres Strait Islander or Culturally and Linguistically Diverse background, homeless persons, or persons with younger onset dementia. More research and development of models of care targeting vulnerable populations are needed. Notwithstanding the above, this rapid review does provide insights into various models of care that are specific to persons with dementia who are nearing the end of life.

## Conclusion and recommendations

This review adds to the growing body of literature on end-of-life care for people with dementia by identifying and examining models of care implemented in a range of real-world settings. We sought examples of how the substantial body of evidence on the optimal components of a model of care for this vulnerable population group had been translated into practice and, ideally, evaluated and embedded in health and social care delivery. While a comprehensive, fully integrated, appropriately funded and sustainable model of care was not found, each of the included models offers valuable evidence to assist clinicians and healthcare managers to develop and implement best-practice, context-responsive models of end-of-life care for people with dementia.

### Recommendation 1: Practice

Dementia-specific models of end-of-life care should be commissioned, developed and trialled to meet the needs of growing numbers of people with dementia and their families and carers. These models should include the recognised domains of best practice palliative care for people with dementia.

### Recommendation 2: Policy

Policy makers and health service managers should support ongoing investment in long-term planning and evaluation of such models of care.

### Recommendation 3: Future research

High-quality research including evaluation, particularly economic evaluation, of models of end-of-life care for people with dementia, is needed.

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## Appendices

### Appendix A: Search strategy for Medline (Ovid)

1996-current – 30 April 2021; 22 November 2021; 14 April 2022

- 1 exp Dementia/
- 2 "dement\*".ab,ti.
- 3 "alzheimer\*".ab,ti.
- 4 1 or 2 or 3
- 5 Palliative Care/
- 6 Terminal Care/
- 7 Hospice Care/
- 8 exp Advance Care Planning/
- 9 Attitude to Death/
- 10 exp bereavement/
- 11 Hospices/
- 12 exp Life Support Care/
- 13 Terminally Ill/
- 14 death/
- 15 "palliat\*".ab,ti.
- 16 "hospice\*".ab,ti.
- 17 "end-of-life".ab,ti.
- 18 "terminal care".ab,ti.
- 19 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18
- 20 "Delivery of Health Care"/og [Organization & Administration]
- 21 "Delivery of Health Care, Integrated"/
- 22 exp Patient Care Team/
- 23 patient-centered care/ or exp patient navigation/
- 24 "model\* of care ".ab,ti.
- 25 "care path\* ".ab,ti.
- 26 framework\*.ab,ti.
- 27 program\*.ab,ti.
- 28 continuity.ab,ti.
- 29 seamless\*.ab,ti.
- 30 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29
- 31 4 and 19 and 30
- 32 limit 31 to (english language and yr="2000 -Current")

## Appendix B: List of websites and key journals searched

Key websites	Key journals
Alzheimer's Association (US)	Palliative Medicine
Alzheimer's Society (UK)	Journal of Palliative Medicine
Dementia Australia	International Journal of Palliative Nursing
PalliAGED	Dementia
Marie Curie UK	Australian Journal of Dementia Care
CareSearch Palliative Care Knowledge Network	International Journal of Integrated Care
Dementia UK	Journal of Integrated Care
Palliative Care UK	International Journal of Care Coordination
Palliative Care Australia	
Social Care Institute for Excellence	
The King's Fund, UK	
European Association of Palliative Care (EAPC)	
End-of-life Direction for Aged Care (ELDAC)	
DEL-CAP study	

## Appendix C: Brief descriptions of included models of care

### Aliviado Dementia Care

The Aliviado Dementia Care Program comprises two products: Aliviado Dementia Care for Hospice (<https://aliviado.org/products/aliviado-dementia-care-for-hospice>) and Aliviado Dementia Care for Home Health (<https://aliviado.org/products/aliviado-dementia-care-for-home-health>). The target population for both products is organisations providing hospice or in-home care. Access to the Program is via membership.

The program aims to decrease hospital readmissions by providing focussed training on how to best manage dementia symptoms and behaviours. The hospice-specific program includes: dementia care training - 'champion' and 'non-champion' training; Aliviado toolbox (assessment instruments, treatment algorithms, care plan templates, carer education sheets); education and support for caregivers; mentorship through the Aliviado technical support centre; and integration of toolbox materials in electronic health records and/or Intranet (Lin et al., 2020).

During the pilot phase the program was implemented sequentially in two hospices and involved 72 interdisciplinary team members and 11 patients. The program exceeded predetermined feasibility, applicability and fidelity outcome milestones. Challenges identified during the pilot phase included hospice staff turnover, integration of the Aliviado toolbox materials within the electronic health records, and limited research experience and infrastructure in the hospices.

The second phase of evaluation, currently underway, is a randomised controlled trial in 25 hospice agencies. Approximately 750 people with advanced dementia living at home will receive the program, which seeks to address the following outcomes: use of antipsychotic and pain medications before and after Aliviado is implemented; satisfaction among family caregivers; type and hours of hospice care provided to people with dementia; and rates of permanent transfer to residential aged care.

### Alzheimer's Disease and Related Dementias Palliative Care (ADRD-PC) Program

This US-based model of care is based around a palliative care consultation for a patient with advanced dementia, triggered by hospitalisation for acute illness. The in-hospital palliative care consultation addresses the following: stage, prognosis, and trajectory of dementia; assessment and treatment of pain and other physical symptoms; assessment and management of neuropsychiatric symptoms; social support for caregiver stress; spiritual needs assessment; cultural concerns framing care; goals of care decision-making; and key clinical decisions such as feeding options, antibiotic use, and rehospitalisation. Individualised recommendations for ongoing care, and referrals to post-discharge services are provided, and a palliative care nurse practitioner telephones the patient or carer 72 hours and two weeks after discharge.

The program has been evaluated via a pilot randomised controlled trial of 62 patient/family dyads allocated to intervention or control (usual care) groups (Hanson et al., 2019). Hospital admission rates did not differ between the two groups, but intervention patients and families were more likely to: have palliative care domains addressed; receive hospice: discuss prognosis and goals of care; have a MOST (an advance care planning tool) at 60-day follow-up; and make decisions to avoid rehospitalisation. The authors acknowledge that the specialty palliative care provided in this program

should be extended beyond discharge from acute care, and that longer follow-up in a future multi-site randomised controlled trial might elicit additional outcomes not captured in the pilot trial.

### Challenge Pathway

The Challenge Pathway (Project/Service) is a palliative and end-of-life care service for people with dementia living in South Wales (UK). Introduced in March 2014, the Challenge Project was a collaborative venture between the Alzheimer's Society (who provided dementia expertise through a Dementia Support Worker) and 'Hospice of the Valleys' (a charitable hospice, which provided a Community Palliative Care Nurse Specialist and through this, expertise in end-of-life care). The service uses an open-referral system for patients and families, providing access to the following services: specialist care delivered by nurses, with medical support; specialist social workers and welfare rights advisors; physiotherapy and complementary therapy; dementia support workers; community support workers; hospice at home service; respite support; 24-hour telephone support; dementia support groups; peer support groups; advocacy; dementia café; day centre; activity groups; volunteer befrienders; carers' information support program; bereavement support; and chaplaincy.

The Challenge Project was introduced in March 2014. It is unclear if the service is still running. It was evaluated over 16 months between April 2014 and July 2015, via a clinical audit, interviews with project staff, survey of family carers and survey of health professionals (Harrop et al., 2018). While the evaluation found that referrals to hospice palliative care or home-based care increased over the study period, and the program was well-received by carers and health professionals, the authors acknowledge lack of baseline data and low survey response rates impacting on the rigour of the evaluation.

### Collaborative Model for End Stage Dementia

This is a person-centred, collaborative community model of palliative care for persons with end-stage dementia. The model (service) uses a case-management approach and operates from "Carunya", a dementia day therapy unit situated near Wollongong, NSW. The service consists of two elements, the day unit, and the multidisciplinary community dementia care service which includes a case manager, psychologist, nurses, and diversional therapist; these link with local GPs and palliative care teams, provide referrals to specialists (e.g. geriatrician), and arrange residential respite care.

The model has not been formally evaluated and while it appears to be currently operating, there is scant information or literature available (Lindsay, 2010).

### Compassion Intervention

The UK-based Compassion Intervention aims to improve care and outcomes for people with dementia nearing the end of life; was developed based on international best practice, combined with research findings from people with dementia, their families and carers, and healthcare professionals (Jones et al, 2012); and piloted in two nursing homes in North London, UK in 2014-2015 (Elliott et al., 2014; Moore et al., 2017). To date the Compassion Intervention has been implemented only in residential aged care facilities.

The Compassion Intervention consists of the following components: an interdisciplinary care leader (ICL) whose role is to coordinate person-centred care for the person with dementia and their family and carers and facilitate integrated delivery of care across health disciplines and settings; and



education, training and support for all involved in caring for the person with dementia, particularly care home staff and families/carers. The ICL develops a personal care plan for each person with dementia and coordinates delivery of integrated care by a core team (GP, geriatrician or psychiatrist), the RACF nurse unit manager and other healthcare staff who deliver direct care to the person with dementia), and a wider team providing specialist and interdisciplinary support as needed (allied health personnel, social services, etc).

A Compassion Intervention Manual (Jones et al., 2017) provides detailed guidance on commissioning and implementation of the Intervention. A feasibility study was carried out in two RACFs in 2014-2015 (Moore et al., 2017). The study did not demonstrate whether the Intervention can improve outcomes for people with dementia, but encouragingly the ICL role was found to be feasible, with reasonable costs, and the manual, including the template for personal care plans, was found to be holistic and transferable to other contexts.

It is unknown whether the Compassion Intervention has been implemented elsewhere or further evaluated, therefore its sustainability is unclear.

### MMPC-Queensland

The MMPC is a model of multi-disciplinary palliative care for people with end-stage dementia residing in residential aged care facilities in Queensland, Australia (Abbey, 2008). It was trialled for 10 months in 2004 as part of a research project comprising three phases: Phase 1 – a medical record audit of 25 RACF residents who died in the two facilities during 2004, plus interviews with their carers; Phase 2 – an education program for RACF staff and general practitioners on the main components of palliative care for people with advanced dementia; and Phase 3 – development, trial and evaluation of a model of care based on the Australian government palliative approach guidelines (Commonwealth Department of Health and Ageing, 2006).

Evaluation of the model was comprehensive, and included audits of patient's notes, interviews with bereaved carers and with RACF staff, and pre- and post-education evaluations from RACF staff. Unfortunately, the research team were not able to recruit as many patients as they hoped into the post-implementation phase of the evaluation. There is evidence of a good level of coordination of care facilitated by case conferencing and education of nursing home staff; integration of care is supported by a number of pro-forma documents developed during the trial including the following: Case Conference Nursing Review, Initial Assessment, Fortnightly Assessment (also used to document change in condition), example RACF policy for a palliative care approach, Queensland Health Palliative Care Plan, example work instruction for a palliative care approach, example Palliative Care Procedure Flowchart and Audit Tool.

It does not appear that the MMPC has been implemented in any other RACFs since the research project, and it is not clear whether it has continued in the two RACFs studied.

### Nightingale Program

The Nightingale Program provides “dementia-specific education and clinical support to people living with dementia, their families and carers in South Australia” (Littledike & Davis, 2020). The program is based on a nurse-led model of care and is delivered by three Clinical Nurse Consultants and a Consultant Geriatrician. Sources for referrals include: Dementia Australia National Helpline; health

care professionals; palliative care services; family and friends; residential aged care facilities; and community service providers.

The program primarily provides support to people with advanced dementia, living in a range of contexts including the community, residential aged care and acute care settings. The service provides specialist assessment and education, and support, including: weekly case conference with a Consultant Geriatrician; discussions regarding symptoms and medication management; a regular clinical report shared with family, GPs, and other specialists and health care providers; use of validated tools for patient assessment; and family education and support. The program is delivered face to face in Adelaide, and via telephone in regional areas, with no time limit on the duration of support. As reported in 2020 (Littledike & Davis, 2020) the program had supported over 650 clients, families and carers. No formal evaluation has been carried out.

### Oxleas Advanced Dementia Service

The London-based Oxleas Advanced Dementia Service commenced in 2012. The service targets people with a diagnosis of moderate to severe advanced dementia nearing the end-of-life (stage 6 or 7 of the Global Deterioration Scale for dementia), and who have complex comorbidities (physical/psychological) requiring support to remain living in their home. Care coordination occurs in the home. Most patients are in the last year of life (average age 75 years).

Linkages with primary care and community services are integral to the Oxleas model. The service consists of a consultant geriatric psychiatrist, specialist nurses (variously described as community matron or community psychiatric nurse or advanced practice nurse) and specialist social worker (dementia), who collaborate with GPs, secondary care and social services in providing ongoing and palliative care in the home of the person with dementia. The carer/family are also supported to provide palliative care. The capacity of the service is limited to supporting no more than 25 patients at a time. At the time of publication of the evaluation report (Sonola et al., 2013), the Oxleas service did not have long-term funding and support.

Evaluation of the service identified a number of key components essential to success of the model: support for carers; strong relationships between health services involved in delivering care to the person with dementia; multiple referral pathways to a single entry point and intake form; holistic care assessment and personalised care plans for each patient; a care coordinator assigned to each patient; and rapid access to advice and support, particularly during a crisis.

### Palliative Care in Dementia

The UK-based St Christopher's Hospice provides hospice care to a range of patients including those with advanced dementia. The model of care for these patients consists of a specialist palliative care worker and an educational program for carers/families of people with advanced dementia, healthcare workers and professionals. An evaluation of the service, which examined the experience of the first 50 patients enrolled in the program, was carried out between 2006 and 2008 (Scott & Pace, 2009).

Outcomes for the first 50 patients included ED admissions; source/place, reason and frequency of patient referrals; patient referrals to other agencies or full hospice service (agency type, number); symptomatology profiling and identification of patients with dementia who need palliative care; and delivery of an education program to carers and healthcare professionals. It was unclear how many of the patients received hospice services at home, and how many were admitted to the hospice itself.

The research was more exploratory than evaluative so it was not possible to demonstrate that the program improved end-of-life care outcomes for people with dementia. The report concludes that specialist palliative care nurses can, in partnership with consultant supervision, provide effective symptom control, care and support and education to carers and healthcare professionals.

Since the Palliative Care in Dementia project was reported, St Christopher's has established a new, £6.5 million, state-of-the-art education and awareness centre for clinicians, carers and the community, called the "Centre for Awareness & Response to End of Life" <https://www.stchristophers.org.uk/about-care/>.

### PEACE Program

Collaborators from The University of Chicago (UOC) and the Hospice of Michigan (HOM) developed the Palliative Excellence in Alzheimer Care Efforts (PEACE) Program. The UOC portion of the PEACE program attempts to integrate palliative care into the primary care of patients with dementia at a single clinical site – Windermere Senior Health Centre (Shega et al., 2003). Patient and family members are recruited by direct physician referral or identified through patient registry review. They have access to a range of healthcare professionals at the one site, and two clinical nurse specialists coordinate care, review interview records, provide feedback and follow up with physicians and families. Referral to hospice services occurs in the advanced stage of the disease.

Research assistants interview patients and family members at enrolment and every six months after that (with data used for evaluation and to improve care); families/carers are also interviewed after death of the person with dementia. Family members of non-PEACE patients with dementia who received primary care at the clinic are also interviewed after death and serve as a comparison group. One hundred and fifty patient/caregiver dyads were enrolled in the formal evaluation study. Initial feedback by patients and families suggests high satisfaction rates with the quality of care, adequate pain control, appropriate attention to prior stated wishes and patients dying in desired locations. Patients enrolled in hospice programs were significantly more likely to die in their place of choice and less likely to die in hospitals than non-enrollees. Caregivers continued to experience significant stress. In 2010 it was reported that the PEACE program was transitioning from a research initiative to a fully integrated component of the geriatrics practice (Shega & Sachs, 2010). It is unclear whether the PEACE program is still in operation.

### Programme Dignity (DIADEM study)

Programme Dignity, an interdisciplinary palliative homecare program for patients with advanced dementia, is one of the services delivered by Dover Park Hospice in Singapore.

Integration of care between hospital and home is the responsibility of an interdisciplinary homecare team comprising two hospice physicians, seven nurses and three social workers, with additional support from a geriatrician with palliative experience based at the hospital, all of whom make home visits and regular phone calls. All members of the team have access to patient information in the national medical health records, which are also accessed by hospital and hospice staff if the patient is admitted to either facility. Patients have 24/7 access to the homecare team, with out of hours support available if needed, in addition to regular visits, reviews and support. The homecare team can organise direct admission to either hospice or hospital if this is judged to be necessary. Caregivers are supported through counselling and referrals to community services. Patients are referred directly into

the program from geriatric and palliative inpatient wards, and outpatient clinics, of a tertiary hospital in Singapore.

Programme Dignity was evaluated via the Dignity in Advanced Dementia (DIADDEM) study (Hum et al., 2018). Fifty-three patients were assessed at intake, 5 months and 12 months after enrolment in the program. A statistically significant improvement was observed in all symptom scores (pain, nutrition and neuropsychiatric symptoms) and in caregiver burden after 12 months. A statistically significant improvement in quality of life scores was also observed. Fully enrolled Programme Dignity patients were less likely to visit ED, be admitted to hospital, and had lower cumulative length of hospital stay than partially enrolled or non-enrolled patients. Fully enrolled patients also had lower costs at 1, 3 and 6 months than partially enrolled or non-enrolled patients (found to be statistically significant). The cost of informal caregiving was not factored into the economic analysis. Timing and duration of enrolment in the program was found to be critical in realising cost savings, which has implications for accurate prognostication for advanced dementia.

### SEED Programme

The Supporting Excellence in End-of-Life Care in Dementia (SEED) programme, aims to support delivery of good-quality, community-based care for people with dementia and their families, towards and at the end of life. It comprises six interlinked workstreams which have the goal of scoping, developing, piloting, evaluating (including economic modelling) and commissioning a primary care-based, dementia nurse specialist-led model of care for people with advanced dementia approaching end of life. The SEED model consists of the following components: timely planning discussions, recognising end of life and providing supportive care, co-ordinating care, effective working with primary care, managing hospitalisation, continuing care after death, and valuing staff and ongoing learning. The person with dementia and their family are directly supported by the Dementia Nurse Specialist, care staff, healthcare professionals, GPs and nurses. The Dementia Nurse Specialist is active in linking the person with dementia and their family to other services such as bereavement support and hospice-at-home.

The SEED intervention pilot was evaluated with a cohort of 44 participants and their carers followed for a year (Robinson et al., 2020). All seven components of the intervention were delivered (either at home or in care home); all were found relevant and no additional components were identified. Implementation issues included the qualifications and training needed to perform the Dementia Specialist Nurse role, lack of clarity about focus and content of the SEED intervention, the SEED intervention mostly being seen as complementary to existing services, and the temporary nature of the SEED intervention affecting commitment from participating GP practices. The required level of engagement from GPs and practice staff needs to be explicitly negotiated beforehand to ensure the success of future SEED trials.

The Dementia Nurse Specialist role overlapped some existing services such as Admiral Nurses (mostly viewed as a positive benefit but has cost implications). There was evidence of reflective adaptation of the intervention over time, and some sustainable system-level change such as the annual dementia review template being used in one GP practice and revised end-of-life documentation implemented in some care homes. It is not clear whether the SEED intervention has been sustained in any of the pilot settings or whether it has been implemented elsewhere since the end of the pilot program.

## Appendix D: Models of care currently under development

The following models of care were identified during database searching and full-text screening. These models were not sufficiently advanced in either program implementation (delivery) or publication (at the time of data synthesis and writing) to be included in this report but are noted here for monitoring and future review.

### The Model for Dementia Palliative Care Project (Ireland)

This research project is currently underway in Ireland with the aim of developing a service delivery model to improve the palliative care of people with dementia and their families. Work completed to date includes an interdisciplinary workshop to highlight current gaps in provision of palliative care to people with dementia (Fox et al., 2017), a scoping review to inform development of a model of care for these patients (Fox et al., 2018), and a multi-country survey of key stakeholders to explore what they consider to be important elements of a model of dementia palliative care (Fox et al., 2019; Fox et al., 2020). Progress in the project can be followed on the website (<https://pallcare4dementia.com/the-project/>). The project team has advised that they have drafted a model of care which is not yet publicly available.

### Partnership Model of Hospice Enabled Dementia Care (Ireland)

Northern Ireland Hospice is developing a partnership model of hospice enabled dementia care based on collaborative working across voluntary, charitable and statutory organisations. The model has been evaluated and key recommendations developed. To date these have been reported in a conference abstract (Ballentine, 2018) and a peer-reviewed paper (McLaughlin et al., 2022) which was published after this rapid review was completed. The partnership encompasses a large specialist palliative care hospice, a leading UK dementia charity and community services in palliative and dementia care within a Health Care Trust. Under this model of care, people with dementia are provided with the following: holistic assessment and care, care planning, access to a Dementia-Friendly Day Hospice, creative and complementary therapy programs, and end-of-life support at home, including carer support and pain and symptom management.

Care is provided by a Specialist Palliative Care Dementia Team in partnership with the Dementia charity advocate, Mental Health services, Specialist Community Oncology and Palliative Care Team and primary care services. Healthcare professionals delivering care are provided with specialised education via partnership working, shadowing, study days and access to an online, multidisciplinary course, the European Certificate in Holistic Dementia Care. Informal carers receive support and education from the intervention providers and the Dementia Charity advocate.

The Partnership Model was evaluated using a three-phase formative evaluation. Phase 1 comprised documentary analysis of the medical records of 100 people with dementia referred to the model between May 2016 and December 2017. The main reasons for referral were end-of-life care (41%) or holistic symptom assessment and management (52%). Of the 42 people who died during the evaluation study, preferred place of death was achieved for all 38 who died at home.

Phases 2 and 3 comprised individual semi-structured interviews with carers, focus groups and individual interviews with healthcare professionals and service commissioners. Four issues emerged from thematic analysis of the interview and focus group data: impact of dementia (aggression, pain, carer burden), value of the service (carer support, holistic approach to care), information and learning needs (practical management of the person with dementia, early diagnosis and advance care

planning), and working in partnership (including carers as partners in care, working across teams and organisations).

There was evidence that the Partnership model mapped to all 11 domains of the EAPC domains of best practice for care of people with dementia. Overall, there is preliminary evidence that the Partnership Model achieves positive outcomes for people with dementia, their carers and health professionals involved in their care.

### Empowering Better End-of-life Dementia Care (EMBED-Care)

The Empowering Better End-of-life Dementia Care (EMBED-Care) UK-based project commenced in January 2019 with the aim to “to promote a “step change” in care for people with dementia and their carers to enable delivery of timely person-centred care, to identify unmet needs and improve outcomes, including comfort and QoL, towards end-of-life” (Sampson et al., 2020). It is informed by a body of previous work in dementia and end-of-life care including development of the Integrated Palliative Care Outcome Scale for Dementia (IPOS-Dem) (Ellis-Smith et al., 2018). The project consists of six interconnected work streams, very similar to the SEED program reported in this review (Robinson et al., 2020), to: identify data on current interventions, service use, gaps and inequalities; design the EMBED-Care intervention package; pilot for feasibility and acceptability then proceed to evaluation via a randomised controlled trial. An additional step proposes creating “a network for excellence in dementia palliative care (NEDPC) with UK and international partners, to leverage a sustained step change in care. We will involve people affected by dementia, carers, staff, researchers, third sector, and policymakers to stimulate a public discourse on dying with dementia and provide a platform for workforce development, research, education, implementation, policy, and public engagement” (Sampson et al., 2020).

This body of work is still in progress. In 2021 the researchers presented their findings from an evidence synthesis of 23 systematic reviews which generated a logic model of the Essential Package of Palliative Dementia Care (Evans & Sampson, 2021). More information about the project can be found at the EMBED-Care website: <https://www.ucl.ac.uk/psychiatry/research/marie-curie-palliative-care-research-department/research/centre-dementia-palliative-care> .

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