

# The Nightingale Program: excellence in palliative care

**Jayne Littledike** and **Alison Davis** describe a palliative model of care, provided by specialist nurses, that offers strategies and advice to support people living with dementia, their families and care providers during all stages of diagnosis

**D**ementia Australia's Nightingale Program, established in 2016, is a unique and innovative nurse-led model of care. It is the only specialist dementia palliative care program in Australia, providing dementia-specific education and clinical support to people living with dementia, their families and carers in South Australia.

The concept for the program was initiated following feedback from Dementia Australia clients, who experienced unmet needs in terms of accessibility and provision of palliative care services. This inequity is also evidenced throughout the literature (Dempsey *et al* 2016; Duane *et al* 2015; Hanson *et al* 2019). The program was developed to improve planning opportunities and early access to a palliative approach to care for people living with dementia, their families and carers.

The Nightingale Program team consists of three Clinical Nurse Consultants and a Consultant Geriatrician. The service provides specialist assessment, education and support within a dementia palliative model of care. To promote an interdisciplinary approach, the nightingale team collaborate with other specialists, primary health care providers, Adelaide palliative care services, aged and community care and other service providers in the sector.

In providing this overview of the Nightingale Program we aim to inspire other clinicians to implement similar approaches and to promote accessibility to palliative services so that all people living with dementia have a voice in their care, can live longer in their own homes and experience dignity at the end of their lives.

## Dementia and palliative care

Dementia is the leading cause of death for females and the second leading cause of death overall in Australia. Furthermore, the Australian Bureau of Statistics (2018) identified that deaths due to dementia



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have increased by 68.6% since 2009. Despite this, many people, including health professionals, do not view dementia as life limiting and therefore do not seek out palliative care services (Hanson *et al* 2019).

Additionally, there is a lack of clinicians with expertise in both palliative and dementia care, which results in significant missed opportunities to identify the end-of-life stage, to work through future planning and to discuss the complexity of symptoms experienced in dementia.

Other factors affecting palliative outcomes for people living with dementia include a lack of documented future care directives, increased hospital admissions characterised by protracted length of stay, leading to a significantly higher risk of death, falls, delirium, and a likely loss of function, as well as premature entry to residential aged care (Hansen *et al* 2019).

The majority of people living with dementia have at least one carer and this person is often a spouse or family member. Carers of people living with dementia experience higher rates of physical, psychological and economic stress and higher rates of depression when

compared to other carer groups (Brodaty *et al* 2003). In addition to these challenges, family carers often face ethical dilemmas as the person living with dementia is reliant on them as their substitute decision maker and advocate.

## Palliative care

The World Health Organisation (2018) defines palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through treatment to prevent and relieve symptoms, to minimise physical, psychosocial and spiritual stress. Palliative dementia care goes beyond a biomedical approach and addresses the many cognitive, psychological and functional progressive changes experienced throughout the stages of dementia.

Too often, people living with dementia receive inadequate or inappropriate end-of-life care (Dempsey *et al* 2015). Given the lack of understanding of the progression of dementia, it is not surprising that clinicians are often unable to anticipate the needs and complications that arise

during the end stages, including recognising the key indicators that indicate that the terminal stage is near and when to refer to palliative care services. (Dempsey *et al* 2015). People living in the advanced stages of dementia are at risk of multiple complications including recurrent infections, dual incontinence, dysphagia, pain, myoclonic jerks (quick, involuntary muscle jerks) and seizures. Additionally, it is estimated that approximately 90% of people living with dementia have multiple comorbidities such as heart and respiratory disease and diabetes (Moss *et al* 2002; Mitchell *et al* 2007 cited in Dempsey *et al* 2015).

### The Nightingale Program

The Nightingale Program recognises the importance of the wellbeing and personhood of people with dementia within a model of palliative care. The service provides specialist nursing support to people living in the community, residential and acute care settings. There is no fee for this service and no impact on other services that the client may be receiving. A face-to-face service is provided throughout metropolitan South Australia, with phone support offered in regional areas of the state. Goals of the program include ensuring families have ongoing dementia-specific palliative care support, education, advanced planning and practical advice.

### Referrals

Referrals are received through a variety of sources including Dementia Australia's National Dementia Helpline, medical, nursing and allied health professionals, Adelaide palliative care services, family and friends, residential aged care facilities and community service providers. With an emphasis on maintaining a timely response, Nightingale Program clients are clinically triaged and allocated to a nurse according to priority of need. Each nurse manages a case load of 20 to 30 clients which begins with assessment and consultation to ascertain the symptoms of concern, and needs and goals of the clients.

### Assessments

The service is underpinned by continual, multifactorial nursing assessments, which are inclusive of family carer observation and based upon current best practice evidence. The aim of assessment is to help understand the individual's progression and staging of their symptoms, such as pain or depression. A wide range of assessment tools from both the dementia and palliative paradigms are applied.

It is beyond the scope of this overview to



**The Nightingale Program team (from left) Toni Fewster, Jayne Littledike and Alison Davis, all Clinical Nurse Consultants**

describe all of the assessment tools used, however two pivotal assessments frequently used in our clinical reporting are the Functional Assessment Staging Test (FAST) and the Abbey Pain Assessment.

### Identifying stage of dementia

Endsley and Main (2019) identified that determining the prognosis for a person living with dementia and planning future care begins with establishing the current stage of the syndrome. The Nightingale Program assessment process is built around this concept; by identifying the stage of dementia and the person's symptoms we are able to provide targeted and anticipatory advice, education and support. Dementia syndromes (the most common being Alzheimer's disease, vascular dementia, dementia with Lewy body, and frontotemporal dementia) are recognised as having seven distinct stages.

The FAST staging is a validated measure of the course of Alzheimer's disease in the published, scientific literature from a functional perspective (Scalan & Reisberg 1992). Primarily, the Nightingale Program supports people living in the advanced stages of dementia (stages 6 and 7), which can be summarised as progressing from improperly putting on clothing, to a loss of ability to hold up their head independently (Auer & Reisberg 1997; Scalan & Reisberg 1992). Through reflection, we have identified that people at a FAST stage 6 and 7 are the most underserved and most at risk of needing specialist palliative care.

### Pain assessment

Pain is recognised as a common symptom in palliative care, regardless of the diagnosis (Endsley *et al* 2019; Hendricks *et al* 2015). In dementia, pain is often undiagnosed and therefore undertreated, which can affect quality of life, mood, cognition and responses to care (Dempsey *et al* 2016).

The Abbey Pain Scale is an instrument used to score pain symptoms for people who are no longer able to verbalise pain. It

is a movement-based assessment that uses observations of vocalisation, facial grimacing and changes in body language and physiological and physical changes (Abbey *et al* 2004).

In the Nightingale Program, we commonly observe that once pain is managed, symptoms such as agitation, pacing, loss of appetite, impaired sleep and reluctance for care, improve. We acknowledge the subjectivity in pain assessment and our experience is that, through educating carers to recognise the symptoms of pain and identify the triggers, they are empowered to better understand, respond to and manage pain.

### Nursing recommendations

Detailed nursing recommendations are provided to clients to manage the symptoms of dementia and comorbidities, and address the goals of care. These can be provided as a written report or, in many cases, as a demonstration of better approaches to care. Modelling of care is pivotal in providing an individual approach and gives the carer confidence, as they see the immediate benefit.

### Long-term support

The Nightingale Program has the ability to support people, care providers and families over an enduring period of time; this is not afforded to traditional palliative care services which can only support people in the last months of life. Given the complexities of the Australian health and aged care systems, having access to a single and reliable point of contact who has a thorough understanding of the client's needs and is skilled in navigating the systems is essential.

Ongoing support and evaluation is provided to the team at a weekly case conference with a Consultant Geriatrician. New and existing clients are individually presented for discussion regarding symptoms and medication management. A clinical report is developed which details current symptoms and stage of dementia and provides a plan for the pharmacological management of pain, agitation and depression if indicated. This report is shared with family, general practitioners, other treating specialists and health providers in order to optimise symptom control and foster a shared understanding.

### Empowering families and carers

Through a flexible approach, we model best practice care interventions which upskill and empower families and carers. No two people or circumstances are the same; the approach to care needs to be flexible, dynamic and directed by the

# Dying with dignity

**Jayne Littlelike** and **Alison Davis** explain how the Nightingale Program supported Steve, and his wife Vicki, from his initial referral right through to his peaceful and dignified death at home

Steve (pictured at right) began as a client of the Nightingale Program at the beginning of December 2017, at the age of 63. He was a car enthusiast and retired business owner, living with his wife Vicki (pictured with Steve, far right).

Steve's care needs were related predominantly to his living with frontotemporal dementia. It affected his ability to communicate, with a loss of verbal language early in his diagnosis. He had poor impulse control. He lost the cognitive ability to process information, to assess his environment or sequence tasks.

Vicki initially sought advice from our service around Steve's increasing sleep disturbance, anxiety, vocalisations and urinary frequency and incontinence. He would become distressed and start to disrobe as he paced, increasing the risk of falls. Vicki had previously attempted toileting schedules and ruled out possible infections, however, at the time of referral, responses were as frequent as every few minutes.

An initial nursing assessment found that Steve had a Functional Assessment Staging Test (FAST) score of 6 (advanced dementia). Following a Nightingale team case conference, which included our consulting geriatrician, a clinical letter with medication recommendations was sent to Steve's GP. A follow-up case conference was also held with the GP to explain the rationale for the changes. Non-pharmacological strategies were also provided and over a relatively short period of time there was notable reduction in Steve's pacing and agitation.

Ongoing support for Steve and Vicki via phone calls and home visits from our team provided ongoing assessment, advice and strategies for the changing symptoms of dementia. This advice covered constipation, probable infections, sleep disturbance, pain, carer fatigue, medication management, changes in swallowing, diet, mobility and other clinical changes including myoclonic jerks and seizures.

Ongoing anticipatory planning from the start ensured that Vicki and Steve were supported in their choices. They were given



information on the progression of the dementia and what type of care, equipment and environmental changes would be necessary to manage Steve's care at home. We also discussed when it was timely to stop prophylactic medications, what 'comfort care' involved and even funeral arrangements and what to do when Steve died at home.

Vicki and Steve were empowered to embrace the moment and took a trip interstate to see family, including a visit to the local pub, just weeks before Steve's death. The photo (above left), taken during that trip, says it all – embrace the good things.

By August 2018, Steve was no longer safe to stand and had progressed to a FAST scale of 7, with changes occurring rapidly: he was sleeping during the day; changes in his swallowing and appetite were noticeable; and he was experiencing more chest infections and urinary tract infections. By September, myoclonic jerks were increasing in frequency and Steve began to have seizures.

By October, he was in the end stages of the disease. Steve had a series of seizures in one day, after which he no longer had a safe swallow. Palliative care services were brought in during Steve's final weeks for a collaborative approach. In those last days we supported Vicki, reassuring her she was capable of the care required and listening to her stories of the man she loved, allowing her to grieve.

On October 31, 2018, Steve died at home, peacefully and with dignity, surrounded by his family, just as he had wished.

person living with dementia and their families, with respect to their goals, personal preferences and religious and spiritual beliefs.

Critical to the program's success is the ability to maximise service opportunities with other stakeholders, through shared care, collaboration and an interdisciplinary approach. Feedback from Nightingale Program clients and families has identified that specialist coordination of support is invaluable.

## Conclusion

We understand the importance of supporting carers and recognise that, without their support and cooperative

approach, our work would not be effective or sustainable. We remain with clients as their needs change, including if there are periods of hospitalisation or admission to residential care. The relationships we build with the person living with dementia and the carers and other stakeholders are vital in promoting ongoing assessment, evaluation and proactive responses that promote living well and dying with choice and dignity. To date, the service has proudly supported over 650 clients, families and carers.

Dementia Australia is keen to explore options for this service to be expanded in South Australia and for the model to be

adopted in other Australian States and Territories.

In the meantime, other services that support people living with dementia can apply the program's principles to their current practice through:

- understanding the person living with dementia
- using dynamic, validated assessment tools
- implementing a planned approach to care – proactive versus reactive
- being flexible – think outside the biomedical model of care
- adopting an interdisciplinary approach
- providing family education and support.

Our vision is a future where every person with a diagnosis of dementia can access the care and support of a nurse with specialist skills in dementia care and palliative care. This person-centred, holistic model of care would be available at a time that still enables choice and proactively supports the person with dementia and their families. ■

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