



# Understanding the role of palliative care for people with advanced dementia

Advanced dementia is a terminal condition for which palliative care is appropriate, however, knowing when to initiate this process can be challenging. Clinical indicators such as recurrent aspiration pneumonia, recurrent fevers and eating difficulties accompanied by significant weight loss, can be useful for predicting life expectancy, although there is often variability. Therefore, focusing on the person’s goals of care and quality of life, rather than life expectancy (i.e. quantity of life) should guide when a palliative approach be considered.

## KEY PRACTICE POINTS:

- Improving quality of life, maintaining function and maximising comfort are key goals throughout the different phases of dementia care, however, the emphasis on particular goals changes over time
- It can be difficult to estimate life expectancy for a person with advanced dementia; recurrent aspiration pneumonia, febrile episodes and eating difficulties accompanied by weight loss > 10% have been identified as predictors of six-month mortality
- Discussions about the role of palliative care in dementia management should occur as part of advance care planning with the patient, and be ongoing with the family/whānau as the person’s cognitive capacity and physical function declines
- Spiritual and cultural practices may help to address the psychosocial needs of people with advanced dementia, e.g. they may still be able to recognise and find comfort in rituals, songs or religious services
- Refer people with advanced dementia who are being cared for at home to the local Needs Assessment Service so that carers can access respite care and other support services

This is the final topic in a series on cognitive impairment and dementia in older people. This article should be read in conjunction with “Symptom management in palliative dementia care” see: [www.bpac.org.nz/2020/palliative2.aspx](http://www.bpac.org.nz/2020/palliative2.aspx)

## Taking a palliative approach to dementia care

Palliative care describes a person and family/whānau-centred approach to providing care for someone with a life-limiting or terminal illness. The primary goal is to help the person live their life as fully and as comfortably as possible until their death, and to support their family through the illness and bereavement.<sup>1</sup> Palliative care does not intend to hasten or postpone death, but rather focuses on improving the person’s quality of life by identifying, assessing and treating symptoms such as distress or pain, and addressing the person’s physical, psychosocial and spiritual needs.<sup>1</sup> Palliative care may be suitable whether death is days, weeks, months or years away, and can occur alongside treatments aimed at prolonging the person’s life.<sup>2</sup>

Palliative care has traditionally been most closely associated with advanced-stage cancer care, however, dementia is also recognised as a terminal condition for which this process is necessary.<sup>1</sup> Knowing when to initiate palliative care in the context of dementia management can be challenging. Factors contributing to the complexity of this decision include that:<sup>3</sup>

- There is usually a long period of time between diagnosis and death (see: “The management focus changes as dementia progresses”)
- The prognosis is often unclear – the rate and pattern of progression vary depending on factors such as the dementia subtype, severity and age at diagnosis, and co-morbidities<sup>1</sup>
- People with advanced dementia cannot express a preference for palliative care due to severe cognitive impairment

### **The management focus changes as dementia progresses**

Improving quality of life, maintaining function and maximising comfort are the goals of care throughout the different phases of dementia, however, the emphasis on particular goals changes over time.<sup>4</sup> In the early stages of dementia, management typically focuses on slowing the rate of symptom onset and progression, helping the person to remain active and independent, and planning for their future care. In the mid-stage, the interventions aimed at slowing symptom progression often become ineffective and the focus of care shifts to managing behavioural and psychological symptoms of dementia (BPSD) and maintaining patient safety. As dementia progresses to the advanced stage, and the person’s health needs become more complex (see below) and their quality of life diminishes, care is increasingly focused on maximising comfort, which can be at the expense of prolonging life.

### **People with advanced dementia have increasingly complex health needs**

In addition to severe memory loss, people with advanced dementia may have pain (due to various underlying causes), significant difficulties with eating and swallowing, limited or no speech or mobility, incontinence and BPSD.<sup>5</sup> At this stage, 24-hour care is required. The setting of this care varies – some people will be cared for at home, some in residential care (i.e. rest homes, long-stay hospitals, dementia units or psychogeriatric units), while others may require specialist palliative care (either hospital-level or hospice). Some of the symptoms of advanced dementia, e.g. swallowing difficulties, incontinence and immobility, make people highly susceptible to additional problems such as infection and malnutrition.<sup>5,6</sup>

The loss of communication abilities makes it challenging for clinicians to assess, diagnose and monitor treatment effects in people with advanced dementia; family/whānau or other carers are relied on to provide this information.

 For information on managing BPSD, see: [www.bpac.org.nz/2020/bpsd.aspx](http://www.bpac.org.nz/2020/bpsd.aspx)

### **Predicting the end of life can be difficult**

The duration of the advanced phase of dementia is variable, but generally lasts one to three years.<sup>7</sup> A person with advanced dementia is said to be approaching their ‘end-of-life’ when they are likely to die within 12 months, however, this can be difficult to estimate.<sup>1,8</sup> Recurrent aspiration pneumonia, febrile episodes and eating difficulties accompanied by weight loss of > 10% over six months have been identified as some indicators of the transition from advanced dementia to the end of life, with each of these complications associated with a six-month mortality of 40–50%.<sup>9,10</sup>

### **Advance care planning establishes the goals of care**

Ideally, discussions about the role of palliative care in advanced dementia will have occurred as part of the advance care planning (ACP) process, and will be ongoing with the family/whānau as the person’s cognitive capacity and physical function declines (see: “Advance care planning for people with dementia”). A health event, e.g. infection or new onset respiratory difficulties, will require decisions to be made about undertaking potentially life-prolonging care, e.g. antibiotic treatment or assisted ventilation, versus a palliative approach that focuses on symptom management and comfort. This is likely to be decided by the person’s proxy decision-maker (enduring power of attorney [EPOA] or welfare guardian – see link below), with clinical advice. ACP that establishes the patient’s preferences and goals of care can help to reduce the burden of decision-making and reduce the likelihood of unwanted interventions at the end of life.<sup>6</sup>

 For further information on appointing and activating an EPOA, see: [www.bpac.org.nz/2020/cognitive.aspx](http://www.bpac.org.nz/2020/cognitive.aspx)

### **Consider the psychological, spiritual and cultural needs of people with advanced dementia**

A “whole person” approach that addresses physical, psychological, spiritual and cultural needs is fundamental to the provision of palliative care. General practitioners are often very aware of these needs due to their long-standing relationship with the patient. It is important that the clinician remains involved where possible to ensure continuity of care, even if the responsibility of care shifts to another primary care provider or to secondary care.

People with advanced dementia often cannot communicate their needs, which can result in behavioural or psychological symptoms. Cultural or spiritual practices may help to address the psychosocial needs of people with advanced dementia as they may still be able to recognise and

## Advance care planning for people with dementia

Key recommendations for advance care planning (ACP) for people with dementia and their family/whānau include:<sup>11</sup>

- Initiate discussions as early as possible following a dementia diagnosis and integrate the care plan into the person's daily care. These discussions are likely to be ongoing over multiple consultations and the person can make changes to their care plan, if they have the mental capacity.
- Try to understand the whole person; explore their life story, values, norms, beliefs and preferences, and their fears and concerns for the future and for the end of life (see: "Consider the psychological, spiritual and cultural needs of people with advanced dementia")
- Evaluate their understanding of their condition and discuss the expected trajectory of dementia (and any other co-morbidities) and possible end-of-life decisions
- Discuss their preferences for care, i.e. where would they like to be and who would they like involved
- Identify a person for EPOA and get this process underway while the person still has capacity
- Judge mental capacity task-specifically, i.e. do they have the capacity to make a certain decision at that particular moment. A toolkit for assessing capacity, designed for health practitioners and social workers, is available from: [www.alisondouglass.co.nz/%20for](http://www.alisondouglass.co.nz/%20for)
- Establish the person's views on life-prolonging interventions, e.g. hospitalisation if they have a medical event, cardiopulmonary resuscitation (CPR), life support (including defibrillation, intubation and ventilation), antibiotics (e.g. oral versus intravenous treatment or no treatment at all). If the patient has strong preferences for specific interventions or treatments, these can be documented in an advance directive (see below).

 Training material and an ACP manual for health professionals are available from: [www.hqsc.govt.nz/our-programmes/advance-care-planning/projects/staff-information/](http://www.hqsc.govt.nz/our-programmes/advance-care-planning/projects/staff-information/)

"Kia korero | Let's talk advance care planning" is a campaign encouraging people to plan for their future healthcare. Resources for patients, including a guide for creating an advanced care plan, are available from: [www.hqsc.govt.nz/our-programmes/advance-care-planning/kia-korero-lets-talk-advance-care-planning/](http://www.hqsc.govt.nz/our-programmes/advance-care-planning/kia-korero-lets-talk-advance-care-planning/)

A guide to assist ACP with Māori patients and their whānau has been developed by Northland DHB: "He Waka Kakarauri: A model for engaging Māori in Advance Care Planning (ACP)

conversations", available from: [www.northlanddhb.org.nz/our-services/a-z/he-waka-kakarauri/?url=/Services/AZ/M%C4%81oriinAdvanceCarePlanningACPconversations.aspx](http://www.northlanddhb.org.nz/our-services/a-z/he-waka-kakarauri/?url=/Services/AZ/M%C4%81oriinAdvanceCarePlanningACPconversations.aspx)

### Advance directives

Advance directives are instructions that consent to, or refuse, specified medical treatments or procedures, e.g. antibiotic treatment for infections such as pneumonia, in the future when the person is no longer competent (sometimes referred to as a "living will"). Advance directives are the best way for a person to express these wishes as there are limitations to the ability of an EPOA to refuse or consent to treatments on their behalf.<sup>2</sup> These are often difficult conversations to have, particularly as a person in the early stages of dementia may find it challenging to consider their future health needs. However, exploring their preferences while they still have capacity is essential to help the clinician and the person's EPOA make future health decisions.

 Patient information about advance directives is available from: [www.hdc.org.nz/your-rights/about-the-code/advance-directives-enduring-powers-of-attorney/](http://www.hdc.org.nz/your-rights/about-the-code/advance-directives-enduring-powers-of-attorney/)

 A brief advance directive template is available from: [www.healthnavigator.org.nz/media/2061/advance-directive-revised-april-2017-v12.pdf](http://www.healthnavigator.org.nz/media/2061/advance-directive-revised-april-2017-v12.pdf)

### What if a patient or their family raises the topic of euthanasia?

Under current New Zealand law, people cannot request euthanasia or assisted dying\* at any stage of their care. Later this year (2020), New Zealanders will vote on the End of Life Choice Bill. If introduced, the legislation will allow people to access assisted dying if they meet specific criteria, including that they must "suffer from a terminal illness that is likely to end the person's life within six months" and be "competent to make an informed decision about assisted dying". Based on these criteria, people with dementia would most likely be excluded from accessing assisted dying. Although dementia is a terminal illness, it is not likely to end the person's life within six months. At the stage where dementia is so advanced that it is likely to be terminal within six months, the person would no longer be competent to make an informed decision. The Bill excludes people from making the decision in advance and from having an EPOA make the decision on their behalf.

It is important to address any fears or concerns that may have prompted the patient or their family to initiate this discussion. Ensure that people understand the palliative care options available and encourage the use of ACP to explore and express their preferences and goals for care.

\* Euthanasia – healthcare professional administers terminal treatment; assisted dying – self-administered terminal treatment

find comfort in things that are culturally or spiritually significant to them, despite having severe cognitive impairment.<sup>4</sup> Cultural and spiritual practices may also hold significance for the family/whānau (see: “Māori end of life care customs”).

Definitions and experiences of spirituality differ between people and cultures. Broadly, spirituality may be considered to encompass a person’s beliefs and values, sense of meaning or purpose in life, connectedness, identity and awareness, and for some, faith and religion.<sup>12</sup> For example, spiritual expression may be found in nature, relationships, services, practices, rituals, music or art.<sup>12</sup> These preferences should be explored as part of advance care planning with the patient and their family/whānau.

 For information on managing BPSD, see: [www.bpac.org.nz/2020/bpsd.aspx](http://www.bpac.org.nz/2020/bpsd.aspx)

## Supporting carers of people with advanced dementia

Caring for a person with dementia at home can place significant stress and strain on the caregiver and their family. The protracted trajectory of decline with dementia, compared with other terminal conditions, e.g. most cancers, creates a scenario of prolonged caregiver requirements that are difficult to sustain. As dementia progresses and the person becomes increasingly dependent, the caregiver may feel restricted, isolated, lonely and exhausted, particularly if they are an older person with their own health problems.<sup>15</sup> There is often a sense of loss for the person they knew and their life together, and they may also feel resentful for the loss of their independent life.<sup>15</sup>

### Māori end of life care customs

Many whānau maintain their mātauranga Māori (knowledge), tikanga (customs), and kawa (protocols) for end of life care.<sup>13</sup>

Care customs may include:<sup>13</sup>

- Using te reo Māori (Māori language)
- Incorporating rongoā (traditional healing), including mirimiri (massage)
- Observing tapu (protocols and practices that govern things restricted, profane) and noa (protocols and practices that return a state of tapu back to its ordinary state, safe), e.g. not using a pillow intended for the head (considered as tapu, sacred) for any other purpose
- Karakia (incantations, prayers, chants)
- Waiata (songs, singing)
- The presence of kaumātua (older Māori) who oversee and provide cultural guidance and support
- Kai (food) and related tikanga; see: [www.bpac.org.nz/BPJ/2008/August/tikanga.aspx](http://www.bpac.org.nz/BPJ/2008/August/tikanga.aspx)
- Taking care of personal taonga (treasured objects)
- Correct handling of the body after death, e.g. whānau remaining with the body until they are buried

Key findings from a 2018 qualitative pilot study, ‘Pae Herenga’, investigating Māori whānau end of life care customs include that:<sup>14</sup>

- There is a high level of customary caregiving knowledge among older carers and greater collective support for this group; younger carers had strong cultural care values but less customary care knowledge and support
- Care customs were handed down by observing the practices and processes of kaumātua or chosen and prepared for a specific care role by kaumātua
- Whānau who had received cultural mentoring from their tūpuna (grandparents) and who had a high proficiency in te reo Māori, tikanga and kawa had more extensive cultural care practices
- Māori whānau were heterogeneous; care customs can vary between iwi (tribe) and whānau

Māori whānau often want to care for their relations who are terminally ill or have high needs, although the setting of this care may vary (home, hospital or hospice setting).<sup>13</sup> Understanding the needs of the patient and their whānau, supporting their cultural care customs, and helping them to understand and navigate the health care system are important factors in providing effective and culturally appropriate palliative care for Māori.

### Ensure caregivers know how to access respite care

Support for caregivers is essential to help them maintain their wellbeing and can help the person with dementia to remain at home for longer. Respite care is any support or service that helps those caring for a person with dementia, or other chronic health condition, to have a break. It can be informal, e.g. asking family or friends, or formal, e.g. employing a support worker, arranging for the person with dementia to go to a day programme or into overnight care. Ensure that caregivers of people with dementia are aware that respite care is available and refer them to the local Needs Assessment Co-ordination Service to access funded respite care. Alzheimers New Zealand or Dementia New Zealand can also help people to access these supports. People may also choose to employ a support worker privately; voluntary support services may also be available.

 For information on which respite care services are available locally, see: [www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/respites/respites-supports-and-services](http://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/respites/respites-supports-and-services)

 Information for people providing care in the community is available from: [www.carers.net.nz](http://www.carers.net.nz) and [www.msd.govt.nz/documents/what-we-can-do/community/carers/a-guide-for-carers-july-2019.pdf](http://www.msd.govt.nz/documents/what-we-can-do/community/carers/a-guide-for-carers-july-2019.pdf)

### Making the transition from home to residential care

For many people with dementia, a palliative approach will most likely be provided in a residential care setting. However, hospice services are also available to these patients and referral should be considered if their level of need exceeds the resources of the primary palliative care provider (see link below for the full criteria and “Consider referral to specialist palliative care”).

 The full referral criteria for adult palliative care services are available here: [www.health.govt.nz/system/files/documents/publications/referral-criteria-for-adult-palliative-care-services-in-new-zealand.pdf](http://www.health.govt.nz/system/files/documents/publications/referral-criteria-for-adult-palliative-care-services-in-new-zealand.pdf)

### The decision is often challenging for family/whānau or other carers

Triggers for discussions and decisions about transitioning the person from home to residential care may include that:<sup>15</sup>

- The carer cannot provide the level of care needed by the person with dementia
- The carer is unable to cope with the pressure and intensity of providing 24-hour care or needs to prioritise their own health or quality of life
- The home is no longer safe for the person with dementia

These discussions may be initiated by the carer, by other family/whānau members or by a healthcare professional. The decision can be challenging for the carer, who may feel a sense of guilt or inadequacy, and can cause conflict within families, e.g. if there are differing views about who should provide care and where. The local Alzheimers New Zealand or Dementia New Zealand branch can provide support to help family/whānau navigate these complex issues.

If a move to residential care is being considered, refer the patient to the local Needs Assessment Co-ordination Service who will provide information on the options available, e.g. whether they require care in a dementia unit. When a patient moves to residential care, ensure accurate transfer of their medicines use history if they are also transferring to a different primary care provider, which is often the case.

 Patient information on transitioning to residential care are available from: [www.alzheimers.org.nz/information-and-support/support/transitioning-into-residential-care](http://www.alzheimers.org.nz/information-and-support/support/transitioning-into-residential-care) and [www.health.govt.nz/system/files/documents/publications/long-term-residential-care-for-older-people-feb19.pdf](http://www.health.govt.nz/system/files/documents/publications/long-term-residential-care-for-older-people-feb19.pdf)

### Providing palliative care in the community

The district/community nursing services will work alongside general practice or specialist palliative care services to provide support to people who are receiving palliative care at home and their families/whānau. Other services that may be available include home help, carer support, respite care (see above), equipment for the person's homes, Meals on Wheels. Refer patients to the local care coordination service for assessment. These services may be funded or accessed privately.

Clear communication between the different services involved in providing palliative care in the community is essential. Further information or advice about patient management can be obtained by phone or in writing from a palliative care specialist.

 Patient information about dementia care in the later stages, is available from: [www.alzheimers.org.nz/getattachment/About-Dementia/Booklets-and-fact-sheets/Booklet-6-The-later-stages-and-end-of-life-care.pdf/](http://www.alzheimers.org.nz/getattachment/About-Dementia/Booklets-and-fact-sheets/Booklet-6-The-later-stages-and-end-of-life-care.pdf/)

### Consider referral to specialist palliative care

The following indicators of increasing needs and/or general decline should be considered when deciding if referral of a person with dementia to specialist palliative care is indicated:<sup>16</sup>

- Unable to walk without assistance; and
- Urinary and faecal incontinence; and
- No consistently meaningful conversation; and

- Unable to do Activities of Daily Living (see below)
- Plus any of the following:
  - Weight loss
  - Urinary tract infection
  - Severe pressures sores
  - Recurrent fever
  - Reduced oral intake
  - Coughing and choking on food
  - Aspiration pneumonia

One way to assess a person's ability to carry out activities of daily living is to use the Barthel Scale. Patients who score less than three may meet the criteria for referral to specialist palliative care. The tool is available from NZGP Directory: <https://www.nzgp-webdirectory.co.nz>. Find "Barthel Activities of Daily Living Index" under "Useful forms".

N.B. The referral criteria also include the "surprise question": Would you be surprised if the patient were to die within one year? However, this question has largely been found to be unreliable in terms of sensitivity and specificity for predicting mortality, especially for non-cancer diagnoses.<sup>17</sup>

 Further resources for health professionals about advanced dementia care are available from:

- A podcast from the Goodfellow Unit on the goals of care in end-stage dementia, including a discussion on signs of neglect and abuse, with Dr Michal Boyd: [www.goodfellowunit.org/podcast/goals-care-end-stage-dementia](http://www.goodfellowunit.org/podcast/goals-care-end-stage-dementia)
- An eLearning course from the Goodfellow Unit on palliative care for the non-cancer patient: [www.goodfellowunit.org/courses/palliative-care-non-cancer-patient](http://www.goodfellowunit.org/courses/palliative-care-non-cancer-patient)
- A toolkit for health professionals providing end of life care:\* [www.health.govt.nz/system/files/documents/publications/te-ara-whakapiri-toolkit-apr17.pdf](http://www.health.govt.nz/system/files/documents/publications/te-ara-whakapiri-toolkit-apr17.pdf)

\* The toolkit is under review. A link to the updated resources will be provided once it is available.

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[www.bpac.org.nz/2020/palliative1.aspx](http://www.bpac.org.nz/2020/palliative1.aspx)