



Dementia overview

Tirohanga whānui o te mate wareware

The information in this guide is accurate to the best of our knowledge as of June 2023.

Definition

Dementia is an umbrella term used to describe the impaired ability to think that is different from a usual consequence of ageing (Alzheimers New Zealand nd; Vuong et al 2019). It results in both cognitive and functional limitations. Dementia affects memory, orientation, comprehension and calculation. It compromises a person's judgement, as well as their ability to understand written and verbal language and to communicate. These limitations eventually result in a lack of mental capacity.

Key points

- Dementia is a progressive terminal illness (Mitchell et al 2009).
- The experience of dementia is different for everyone. Progression is variable and what a person can do changes day to day (Alzheimers New Zealand nd).
- Both the person living with dementia and their loved ones go through numerous losses related to the disease process. It is important to consider the person and their **whānau**/family when providing care.
- To meet goals of care, the care team, whānau/family need to regularly review the progression of dementia (Mitchell et al 2009; Murray et al 2005).

Why this is important

People living with dementia experience a broad range of symptoms related to their disease. Understanding the disease process can help the health team adapt their approach to best support the person and their whānau/family.

Implications for **kaumātua***

Research on dementia in **Māori** is very limited. However, the evidence available indicates that dementia presents up to 10 years earlier in Māori compared with New Zealand Europeans and that Māori have an increased risk of dementia because they have a higher prevalence of modifiable risk factors (Cullum et al 2020).

Māori may interpret **mate wareware** (dementia) in a way that is different from a western medical view. Whānau/family may interpret the causes 'within historical, cultural and

* **Kaumātua** are individuals and their connection with culture varies. This guide provides a starting point for a conversation about some key cultural concepts with **kaumātua** and their whānau/family. It is not an exhaustive list; nor does it apply to every person who identifies as Māori. It remains important to avoid assuming all concepts apply to everyone and to allow care to be person and whānau/family led.

social contexts rather than as physical illness or disease' (Dudley et al 2019). In some instances, they may interpret it as part of a spiritual journey on which kaumātua are preparing to join their **tīpuna** (ancestors) and a normal part of growing old rather than a disease or illness (Dudley et al 2019). It is important to consider and support these viewpoints when providing holistic care.

Research (Dudley et al 2019) found factors that can have a positive impact on those with mate wareware are:

- using **te reo Māori** (which may have been the first language of the kaumātua but they were suppressed from using it as a child)
- participating in cultural activities and events that are seen as **rongoā** (medicine) to slow or prevent progression of the disease
- maintaining kaumātua independence and involving them in activities for as long as possible.

While kaumātua with dementia may live in aged residential care, it is still important to give their whānau/family all of the information, knowledge and resources they need to best support their ongoing involvement in the care of their loved ones.

Assessment

Diagnosis

Diagnosis is based on a comprehensive clinical assessment by a general practitioner, nurse practitioner, geriatrician or old-age psychiatrist. To have a diagnosis of dementia, the person must have a history of significant cognitive decline (attention, planning, inhibition, learning, memory, language, visual perception, spatial skills or social skills) that interferes with independence in everyday activities (Hugo and Ganguli 2014).

Common observable deficits include:

- attention – finding it difficult to focus in environments that contain multiple stimuli (eg, TV, radio and conversation)
- executive function – being unable to perform previously familiar tasks, needing help with day-to-day decisions, loss of initiative and poor judgement
- learning and memory – struggling to recall, being repetitive in conversation and behaviour, needing reminders to complete task (eg, eating) and being confused about time and place
- language expression and comprehension – using terms such as 'that thing' and 'you know what I mean', and sometimes failing to recall names of close friends and family
- social skills – being insensitive to social standards with little insight and so becoming socially withdrawn or isolated
- motor and visual function – losing ability to use tools, write or do other previously familiar activities (eg, knitting) and getting lost.

Dementia types

Common types of dementia (Hugo and Ganguli 2014)

Alzheimer's disease	Symptoms Early stage - memory loss, difficulty finding words, poor judgement; later stages often include behaviours that challenge, irritability, agitation, wandering, gait disturbances, dysphagia, incontinence	Pathology Progressive loss of synapses and neurons, and accumulation of amyloid plaques, and neurofibrillary tangles
Vascular dementia	Symptoms History of stroke or transient ischaemic attacks (TIA), poor attention and executive function, gait disturbance, incontinence, personality changes	Pathology Cerebrovascular disease ('white matter changes'), often a stepwise progression but can be rapid
Mixed dementia	Most commonly, a combination of Alzheimer's disease and vascular dementia	
Fronto-temporal lobe	Symptoms Personality and behaviour change (eg, withdrawal, loss of interest in activities, poor personal hygiene, social disinhibition). Can include a loss of speech and empathy, and rigid behaviours	Pathology Atrophy of the frontal and temporal lobes of the brain. Gradual progression, early-onset dementia
Dementia with Lewy bodies, Parkinson's disease	Symptoms Impaired attention, visuospatial awareness and executive functioning, hallucinations, delusions and depression. Repeated falls and syncope, loss of consciousness (resolves), poor autonomic regulation (vital sign fluctuation, sweating, impaired peristalsis)	Pathology Presence of Lewy bodies in brain, progression is gradual. In dementia with Lewy bodies, cognitive impairment appears before movement disorder

Staging

Global Deterioration Scale/Reisberg Scale (abbreviated) (Dementia Care Central 2020)

Late stages	Signs and symptoms	Duration
Stage 5	<ul style="list-style-type: none"> Major memory deficiencies Needs help with activities of daily living Does not know time, date or location 	1.5 years
Stage 6	<ul style="list-style-type: none"> Cannot carry out activities of daily living without help Forgets names of family and whānau/family members, as well as recent and major life events Difficulty counting down from 10, difficulty speaking Urinary incontinence Personality and emotional changes, delusions, compulsions and anxiety 	2.5 years
Stage 7	<ul style="list-style-type: none"> Cannot speak or communicate Requires help with most activities, loss of motor skills, cannot walk 	1.5 to 2.5 years

Treatment

Supporting someone living with dementia should include meeting their basic needs such as maintaining nutrition and hydration and managing activities of daily living. Engaging the person in meaningful activity and supporting them to maintain as much independence as possible are key to their quality of life. Currently dementia has no cure. However, some medications can slow the progression of the disease.

Reaching a prognosis is particularly difficult, and most tools are no more effective than clinical judgement. However, one study found that pneumonia, febrile episodes and eating problems were common in the last three months of life (Mitchell et al 2009).

Care planning

Person-centred care (Fazio et al 2018)

Person-centred care, a term first used by Kitwood (Kitwood and Bredin 1992; Fazio et al 2018), remains the best-supported and most well-researched approach to care for people with dementia. The following are key themes of this approach.

1. The person living with dementia is more than a diagnosis. Get to know them and support them to uphold their values, beliefs, interests, abilities, likes and dislikes.
2. It is important to see the world from the perspective of the person living with dementia. Recognise and accept their behaviour as a form of communication. Validating their feelings can help the person connect with their reality.
3. Every experience or interaction is an opportunity for meaningful engagement. This should support their interests and preferences, and allow for their choice (eg, of foods, music, clothes, activities). Remember all people with dementia can experience joy, comfort and meaning in life.
4. Build and nurture authentic, caring relationships that demonstrate respect and dignity. Focus on the interaction when completing tasks. Supportive relationships are about 'doing with' rather than 'doing for'.
5. Create a supportive community that allows for comfort and celebrates success and occasions.

Whānau/family care

The person living with dementia may be unable to plan for the future. It is important to ensure whānau/families have an understanding of the clinical progression of dementia so they can help plan for future care needs, including end-of-life care.

Further resources

Dementia STARs education series www.nzdementia.org/Dementia-STARs.

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