

# **New Zealand Framework for Dementia Care**

# Acknowledgements

We would like to acknowledge the significant time and effort contributed by the sector advisory group in developing this New Zealand framework for dementia care (the framework). The group comprised representatives from each district health board, the National Dementia Cooperative and primary health care services.

We would also like to thank the following organisations for their support:

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Alzheimers Auckland	New Zealand Association of Occupational Therapists (NZAOT)
Alzheimers New Zealand	Nikau House and wellness service
The University of Auckland	Nutrition Matters
Auckland University of Technology (AUT)	Relaxed Therapy
Bupa Care Services New Zealand	The Royal New Zealand College of General Practitioners
The University of Canterbury	Ryman Healthcare Ltd
Dementia Care NZ	The Selwyn Foundation
District health boards (DHBs)	Te Hopai Trust
Healthcare of New Zealand	Waitemata PHO.
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Katikati Medical Centre	

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# Foreword

New Zealand has a growing number of older people. For most, their older years will be active years, with many working longer and remaining involved in their local communities. However, an increasing number of older people will also have health problems that require support.

Dementia is a key example. As our ageing population grows, there will also be an increase in the number of people with dementia. In 2011, just over 48,000 New Zealanders had dementia. By 2026, it is estimated that over 78,000 New Zealanders will have dementia.<sup>1</sup> This is an increase of over 60 percent.

More people with dementia will lead to an increase in costs. It is estimated that in 2011 the total financial cost of dementia in New Zealand was \$954.8 million. This figure includes the costs of residential care, pharmaceuticals, and general practitioner visits, as well as productivity loss and the loss of healthy years of life. As the population with dementia grows, the financial and social costs will too. So we need to be prepared.

The Government is determined to make a difference in the lives of people with dementia, their families, whānau, friends and communities. Action today will improve the wellbeing of our older people now, and prepare us for the future.

In 2012 the Government provided \$2.5 million a year to district health boards (DHBs) to develop dementia care pathways to better support people with dementia and maximise their independence and wellbeing. The Ministry of Health has led a national project in partnership with DHBs, non-governmental organisations, people with dementia, and other groups across the country to create a national framework to guide the development of these pathways.

The framework aims to provide the person with dementia with the services they need, from diagnosis to the end of life stage. The framework encourages different health and social services to work together to provide people with integrated care. It emphasises services that take into account a person's wishes, cultural preferences and lifestyle. It also encourages health professionals to diagnose dementia earlier to ensure people can get the help they need as soon as possible.

We encourage DHBs to involve all stakeholders in the development of their dementia care pathways. It is vital that those whose lives are most affected by the journey of this disease are involved.

We thank everyone who has been involved in the development of the framework, particularly people with dementia and their carers who so willingly provided comment and input to the fabric of the framework.

Hon Tony Ryall  
Minister of Health

Hon Jo Goodhew  
Associate Minister of Health



Hon Tony Ryall



Hon Jo Goodhew

<sup>1</sup> Alzheimers New Zealand's *Dementia Economic Impact Report 2012*

### **Socialising in the community**

The Group (run by Alzheimers Whanganui) meets the social needs of people with dementia living in the community through everyday activities, while also giving their carers some time out.

The Group is finding that being out and about, using community organisations such as the museum and indoor bowling clubs, means that they are breaking down the stigmas associated with dementia as people see the person and not their disability.

This photo shows two members of The Group on one of their regular outings. The ladies have no family nearby and loved the opportunity to hear and share the excitement of the young girl's story about her birthday.



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### **Walking group**

Alzheimers Auckland had a group of people with dementia express an interest in walking at the Botanic Gardens, mostly because they could take their dogs and enjoy the great café. Now the group meets every week and everyone enjoys the time they get to socialise together.



# Introduction

## Why the framework was developed

New Zealand has an ageing population and an increasing number of people with dementia. In 2011, there were an estimated 48,182 New Zealanders with dementia, an increase of 18 percent since 2008. By 2026, this number is estimated to have increased to over 78,250 (Alzheimers New Zealand 2012). The Ministry of Health (the Ministry), together with the health and social support sector, recognises that dementia care needs to be improved nationwide in a way that maximises the independence and wellbeing of the person with dementia and their family and whānau while ensuring safety and affordability of services. To this end, the Ministry has developed a national framework for dementia care.

## Issues associated with dementia

This framework seeks to address a number of issues currently associated with dementia.

There is generally a negative social stigma associated with dementia. Many people are afraid of being diagnosed with dementia because they believe that nothing can be done to help them once they have been diagnosed (Alzheimer's Disease International 2012). Some health practitioners are reluctant to make a diagnosis as they feel they do not have the training to provide a diagnosis and/or are unaware of the information and support services available to increase a person's wellbeing after diagnosis (Ahmed et al 2010; Aminzadeh et al 2012). The framework aims to improve the information available, dispel the myths about dementia and ensure that the health and social support sectors, people with dementia and their families and whānau are adequately educated about the realities of dementia and the types of support available to maximise independence and wellbeing.

Many people with dementia currently receive a diagnosis from a secondary health service at a more advanced stage in their illness. A later diagnosis means that the person with dementia often misses the opportunity to identify and communicate what is important to them because they may be no longer able to communicate their wishes and preferences. A late diagnosis can also increase stress on the person and their family and whānau because they have not had access to the education and support services that can help them minimise or avoid symptoms of dementia (Aminzadeh et al 2012). This can create challenges such as depression, anxiety, behavioural and psychological symptoms and carer stress. The framework aims to encourage awareness of dementia and reduce the stigma attached to it. It encourages people to seek an earlier diagnosis to give them the opportunity to maximise their wellbeing and identify their wishes for the future by developing an advance care plan and appointing an enduring power of attorney.

Currently, a specialist service usually diagnoses a person with dementia. However, the increasing number of people with dementia is likely to add pressure to these specialist services. Primary health care services need to be better able to provide earlier diagnosis and appropriate care and support for people with dementia and their families and whānau. Primary health care practitioners need better knowledge, support and tools to have the confidence to make earlier diagnoses in the community setting (Aminzadeh et al 2012). An early diagnosis by a primary health care practitioner will free up specialist services to respond to episodic events and provide support and advice to the primary health care services in complex cases.

People who are diagnosed with dementia often experience an uncoordinated and/or duplicated response to their care and support needs. This can cause confusion and stress for both the person with dementia and their family and whānau. Care and support services need to be better integrated and easier to navigate through.

In the past, people living with dementia have been treated with only a medical model of care, which does not maximise the person's wellbeing and independence. Overseas, models of care have moved towards a more integrated approach that includes both health and social aspects of care. In New Zealand, although we have started moving in this direction, we still have a long way to go. Support services need to take into account the spiritual, family and whānau, cultural, economic, social and occupational needs as well as the health needs of the person with dementia to maximise the person's independence and wellbeing.

A further factor driving the development of this framework is the belief that dementia is an older person's condition and, on the whole, dementia services have been developed to support older people. However, dementia affects a variety of people, including younger people, people with Down syndrome and people with alcohol and/or drug addictions. Appropriate information, education, sector knowledge and services need to be developed with these groups in mind.

Dementia care must also consider the needs of Māori and other ethnicities. There is a myth that only a small number of Māori develop dementia because Māori life expectancy is shorter than that of New Zealand Europeans. However, in 2011, of the estimated 48,182 New Zealanders with dementia, 1970 (4 percent) were Māori, and by 2026, the number of Māori with dementia is expected to have increased to 4493 (5 percent of the estimated 78,267 people with dementia) (Alzheimers New Zealand 2012). Māori also have a higher rate of risk factors for dementia when conditions such as depression, head trauma, and substance abuse disorders are considered (Ministry of Health 2011b). The health and social support sectors need to work in partnership with Māori to develop health and social supports that appropriately reflect the cultural needs of Māori with dementia.

It was anticipated that there would be a strong Māori involvement in the development of this framework. However, despite every effort, this was not achieved. The dementia care workforce does not have strong Māori representation amongst clinicians, and this issue needs to be addressed by focusing on increasing the number of Māori working in dementia services. To ensure an authentic and prominent Māori voice is included in the development of dementia care pathways it is hoped that DHBs will work with Māori in their communities to ensure they are developing services that will be used and valued by Māori.

In 2011, 1838 (3.7 percent) of the estimated 48,182 people with dementia were Asian and 930 (1.9 percent) were Pacific peoples. By 2026, the share of European/other people with dementia is expected to drop and those of all other ethnicities are expected to increase. Of the estimated 78,267 people with dementia in New Zealand, 6568 (8.4 percent) are expected to be Asian and 2051 (2.6 percent) are expected to be Pacific peoples (Alzheimers New Zealand 2012). There are many cultural reasons that may prevent families and whānau from seeking support for family members with dementia. For example, some non-European ethnicities attribute the symptoms of dementia to the 'normal' ageing process. Some ethnicities, particularly migrant families, may not completely understand dementia and see it as a mental health diagnosis, which can carry a great deal of shame and prevent families from seeking intervention and treatment for the person with dementia. In some cultures, it is important for elders to be looked after by their own family or whānau. Such cultural factors may delay families and whānau seeking support, leading to a lack of understanding of the difficulties faced by the person with dementia and increased stress for both the carers and the person with dementia.



There can also be issues with language and communication. Effective communication is critical for all people with dementia as they experience a gradual deterioration in their ability to organise and express their thoughts. Communication issues can be even more significant for people from culturally and linguistically diverse backgrounds who may not be able to communicate with service providers in their preferred language.

Lastly, people with dementia are sometimes treated as if they are unable to communicate or participate in conversations and decisions about their care and support. However, there is strong evidence that an engaging and respectful partnership between the health and social support service providers and the person with dementia and their family and whānau that focuses on clearly informing and encouraging self-determination and involvement in the development and provision of services will improve the experience of care and outcomes and reduce costs by maximising independence and wellbeing (Mental Health Commission 2012).

## **Purpose of the New Zealand Framework for Dementia Care**

The framework was developed using international evidence, good practice resources, expert opinion and conversations with people with dementia and their families and whānau.

It aims to help people with dementia and their families and whānau to maximise their independence and wellbeing by reducing stigmas and providing clear, comprehensive information and an integrated, holistic approach to dementia care and support.

To this end, it provides a guide that district health boards (DHBs) can use as they work with primary, secondary and community health and social support services (including social, information, emergency and housing) to develop clear, consistent, well-resourced and easily accessible dementia care pathways.

The framework promotes national consistency in dementia care while allowing for flexibility to adapt to local priorities and encourage innovation. DHBs are already developing their own service models and pathways for dementia care, and this framework is deliberately non-prescriptive so that the DHBs will be able to use it in different ways to achieve the same ends. The framework lists good practice examples that DHBs and the health sector can refer to, but the list of examples is a guide only and is by no means comprehensive.

Furthermore, the framework highlights some goals that may take time to achieve. It is anticipated that steady progress can be made towards these goals with the ultimate aim of significantly improving dementia health and support services within five years.

In the 2012/13 annual planning process, the Ministry asked DHBs to develop their own dementia care pathways by June 2013. In the 2013/14 year, DHBs are expected to implement their dementia care pathways and develop regional governance groups. The Ministry's annual planning process will monitor the progress of the development and implementation of these pathways. The development and implementation is expected to be undertaken in collaboration with the primary health care and community care sectors and to align with this framework. The framework can also be used to guide workforce training, planning and recruitment and retention.



### **Sharing memories**

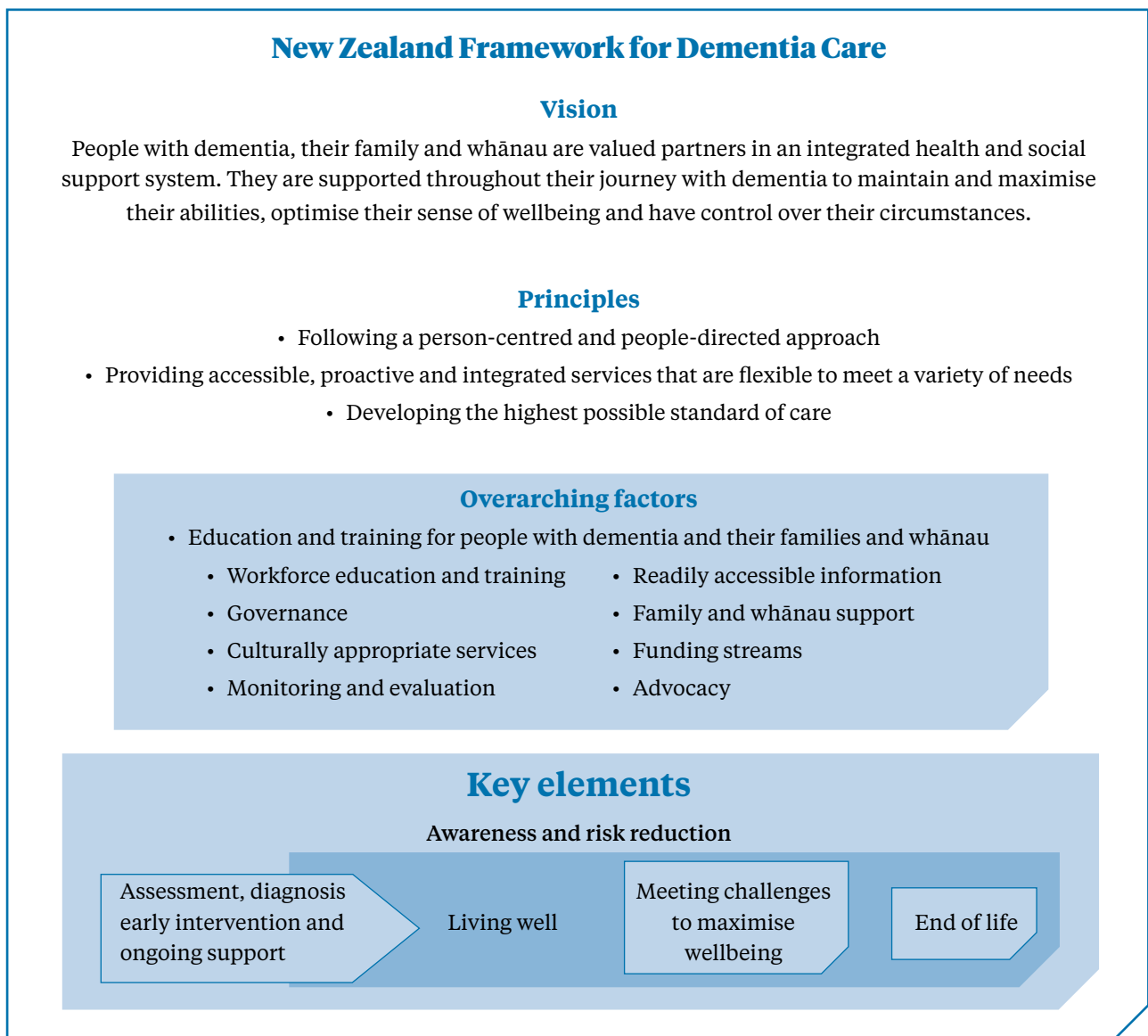
Some activities of The Group, run by Alzheimers Whanganui, spark memories among its members. For example, the man in this photo lived in Holland as a young boy and biked everywhere. His dad had a bicycle repair business, which was run from the shed at home.

By riding the bike many happy memories were triggered, which made this experience very positive for him and other members of The Group listening to him share his story.

# New Zealand Framework for Dementia Care

The framework provides DHBs and the health and social support sectors with a guide for developing their dementia care pathways. The framework has three guiding principles and highlights five key elements for effective dementia care. It also identifies overarching factors that must be considered across all five key elements. The figure below provides an overview of the framework.

**Figure 1: New Zealand framework for dementia care overview**





**Jeff and his best friend Daisy**

Jeff is a member of the Alzheimers Auckland's Botanic Gardens walking group. Jeff and his dog Daisy can normally be found leading the group. Daisy loves attention and helps break the ice among the group members, encouraging them to talk to each other. She also loves sitting on Jeff's lap while the group socialise at the café after their walk.

# Principles of the framework

## Following a person-centred and people-directed approach

Health and social support services ensure that people with dementia and their families and whānau:

- are respected, valued and engaged as partners in care planning and provision of services
- receive clear communications and education that enable them to be engaged at all levels of decision-making, including care planning and provision of services
- are able to self-determine many aspects of their lives
- consent to all decisions about their care and support
- are empowered to participate in decisions and choices that affect them (regardless of their capacity)
- receive care and support services that respond to their social, cultural, spiritual and economic backgrounds; location; symptoms and disease progression needs; preferences and goals even after they have reduced capacity or are legally incapacitated
- have their rights upheld.

## Providing accessible, proactive and integrated services that are flexible to meet a variety of needs

Health and social support services promote earlier recognition of dementia and participation within their communities. They aim to provide a positive experience of care and support by strengthening the culture of partnership and engagement with both the person with dementia and their family and whānau. The services are:

- readily accessible and proactive
- flexible so they can respond to the individual needs of the person with dementia and their family and whānau, including social and economic needs
- supportive of the choices made by the person with dementia and their family and whānau
- provided by appropriately trained staff
- culturally appropriate
- age appropriate
- holistic
- dementia friendly in both their physical environment and service provision.

The services are integrated so that:

- service models are adapted to meet local needs and are supported by local and regional dementia care pathway governance structures
- care planning is consistent, coordinated and flexible across all services (including DHBs, primary and secondary health care, government organisations, non-government organisations and private sector organisations), ensuring seamless continuity of care and support
- interdisciplinary assessment and care planning focuses on functional, psychological and social goals
- gaps in services that cannot be filled locally are met by a sub-regional or regional approach
- the person with dementia's care team is responsible for identifying a suitable navigator<sup>1</sup>.

The services focus on:

- early intervention
- maximising health improvement, maintenance and independence
- supporting people with dementia and their families and whānau to live with a sense of wellbeing
- gaining appropriate consent and making sure that appropriate processes are followed where the person with dementia lacks the capacity to consent (eg, enduring power of attorney, personal order or welfare guardian).

## Developing the highest possible standard of care

Services will be developed with the aim of providing:

- the right services, at the right time and in the right place
- a standard of excellence in dementia care and support that aligns with international trends and standards and uses evidence and best practice models
- a skilled workforce
- continuity of care and support with affordable, efficient and safe services
- national or regional standardisation and consistency of dementia care, with local variations.

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<sup>1</sup> See Key elements: Assessment, diagnosis, early intervention and ongoing support: Early intervention and ongoing support on page 17 for information on the navigator role.

# Overarching factors

The factors outlined below need to be provided across all areas and stages of dementia care.

## Education and training for people with dementia and their families and whānau

Educational and training opportunities for people with dementia and their families and whānau should:

- be developed following the principles set out in *Rauemi Atawhai: A guide to developing health education resources in New Zealand* (Ministry of Health 2012)
- be provided throughout the person's life with dementia
- emphasise the positive aspects of living with dementia
- acknowledge the value of being physically active
- use plain language
- address different learning styles and abilities, including English as a second language
- acknowledge cultural differences and values.

## Workforce education and training

Educational and training opportunities for the health and social support services workforce for dementia care should:

- be based on best practice
- focus on the meaning of a people-centred and people-directed approach (Mental Health Commission 2012)
- include input from people with dementia and their families and whānau
- include experiential learning
- address different learning styles and abilities, including English as a second language
- recognise the different needs of cultural diversity and cultural groups and finds ways to address those needs
- respond to the needs of people with co-existing conditions and/or impairments
- be supported by the health and social support service providers.

## Readily accessible information

Resources should:

- be developed following the guidelines set out in *Rauemi Atawhai: A guide to developing health education resources in New Zealand* (Ministry of Health 2012)
- be developed through national and regional collaboration
- use plain English
- be available in different languages
- accommodate physical impairments (eg, poor eyesight, hearing loss)
- be easily accessed and be provided in more than one medium wherever possible
- be reviewed and updated regularly.

## Governance

DHBs should develop regional and local governance groups to:

- help implement their dementia care pathways in line with the framework
- ensure that a wide range of expertise (eg, secondary care, primary health care, allied health, community services, volunteer services, family and whānau) is involved in developing dementia care pathways and services at the local and regional level
- ensure that new models of care, good practice examples and research are shared locally, regionally and nationally
- develop measureable outcomes of the pathways' effectiveness
- identify and facilitate national and regional collaboration opportunities
- develop regional approaches for complex cases (eg, alcohol or drug addiction related dementia, people with Down syndrome, young onset dementia and tertiary services).

## Family and whānau support

Support for families and whānau should:

- be easy to access and navigate, well-coordinated, proactive and responsive to the needs of the family and whānau
- be available in a range of forms (eg, support groups, respite care, resources, education, home and community support services, grief support)
- involve appropriately skilled staff, with help available to care for and support people with dementia
- encourage participation at all points of service provision (eg, assessment process, home and community support services, residential care and end-of-life care)
- encourage self-management of stress, with education on stress release and coping strategies, and access to support if required.

## Culturally appropriate services

Health and social support services should:

- understand the different cultural representations and perceptions of dementia
- provide people with dementia and their families and whānau with information in their preferred language
- use professional interpreting services that are familiar with health care settings, especially for assessing and diagnosing dementia and developing and reviewing care plans
- ensure that cultural diversity is addressed across all health and social support services, including health and personal care and food preparation
- ensure that people with dementia and their families and whānau have access to culturally appropriate emotional and spiritual support
- ensure that staff have received training in cultural awareness and appropriate communication techniques
- ensure that there is no stereotyping or assumptions made of the person's cultural beliefs, preferences or values.



## Funding streams

A dementia care pathway should ensure that:

- any funding barriers to accessing services are reduced as much as possible
- funding issues do not delay the provision of care and support.

## Monitoring and evaluation

Monitoring and evaluation should:

- include measureable outcomes
- identify gaps and ensure improvements in dementia care and support
- include national and international benchmarking
- evaluate outcomes from the perspective of people with dementia and their families and whānau.

## Advocacy

Health and social support services should ensure that:

- the person with dementia and their family and whānau are supported to self-advocate
- where self-advocacy is not possible, the appropriate support services are made available to help with advocacy (eg, family, Alzheimers New Zealand, Age Concern New Zealand, Health and Disability Commissioner, Supporting Families in Mental Illness New Zealand)
- relevant colleges and professional bodies will advocate for their members by providing advice and expertise to government and within the wider health sector.



### **George is using his gardening skills**

A lifelong gardener, George now enjoys participating in a weekly gardening group that is facilitated by Alzheimers Auckland. George also likes being useful and the gardening group provides him with a sense of purpose, particularly as the gardens are within a school.

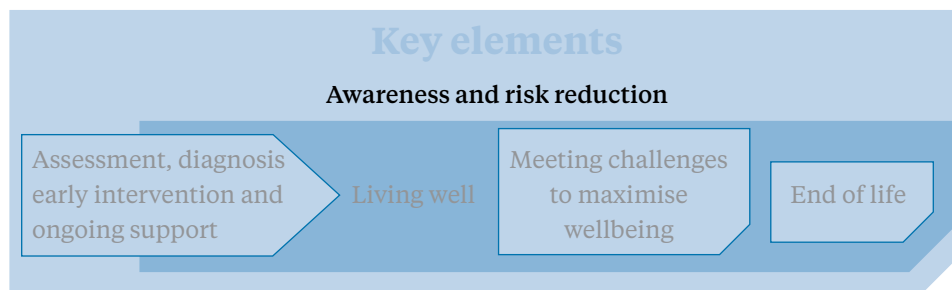
# Key elements

## Awareness and risk reduction

### Aim

The aim is to use both local and national efforts to make New Zealanders more aware of the importance of living a healthy and

active lifestyle, which may reduce the risk of developing dementia. Greater awareness will also increase the social acceptance, inclusion and wellbeing of those living with dementia.



### Good practice points

#### Locally and regionally:

- encourage people to live healthy physically active lifestyles as this may reduce the risk of dementia (**Good practice example:** [Ministry of health physical activity resources](#))
- improve public awareness and self-identification and emphasise risk reduction strategies through local awareness campaigns and national websites providing details of available support services (**Good practice example:** [Alzheimers New Zealand 'We can help' campaign](#)) as well as community education sessions through schools and community groups such as Grey Power; Rotary; Probus South Pacific; Māori, Pacific Island and migrant community groups; and church groups (**Good practice example:** Age Concern education to schools)
- provide sector education and support to improve awareness and recognition of dementia (**Good practice examples:** [Alzheimers Australia Diagnosing dementia, 10 early signs and symptoms of Alzheimer's](#), [NHS Choices: Symptoms of dementia](#)) and to improve awareness of the importance of an assessment to rule out reversible causes, as well as details on how to access support services
- provide education to primary health care services on the importance of risk reduction strategies (**Good practice example:** [Alzheimers Auckland educating primary health organisations \(PHOs\) on dementia and support services, Waitemata PHO pilot](#))
- encourage cooperation between agencies to improve the health and wellbeing of the local population, including people with dementia, particularly addressing social inclusiveness and public transport issues (**Good practice examples:** [Healthy Christchurch](#), [Christchurch City Council's Ageing Together Policy](#), [Age-Friendly Tauranga](#))
- maximise media opportunities (eg, local public health campaigns, local good news stories, sector publications such as *INsite* magazine)
- encourage every adult to plan for their future by developing an advance care plan and choosing an enduring power of attorney
- dispel the myths and assumptions of dementia by promoting accurate information and raising awareness of positive aspects of living with dementia as a chronic condition.

## Nationally:

- engage with national public health campaigns to add the message ‘What is good for the heart is good for the brain’ (eg, Heart Foundation, Quitline, Health Promotion Agency (HPA), Mental Health Foundation of New Zealand)
- recommend that education on dementia be included in applicable national training programmes for health practitioners (eg, nurses, doctors, allied health professionals) and the unregulated workforce (eg, home and community support workers)
- maximise media opportunities (eg, television programmes, radio interviews)
- educate people to plan for the future by developing an advance care plan and choosing an enduring power of attorney.

## Useful websites, resources and good practice example links

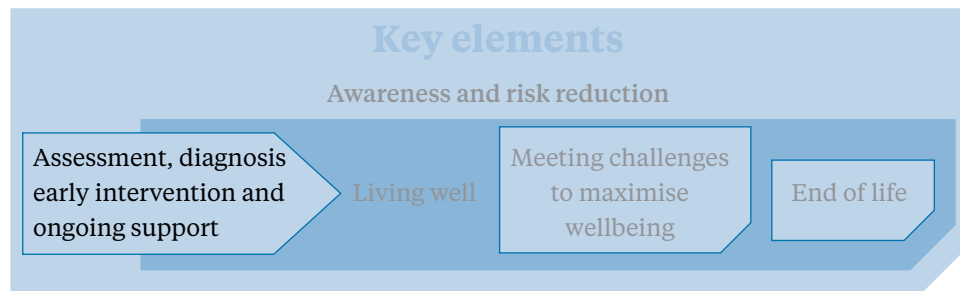
- 10 early signs and symptoms of Alzheimer’s: [www.alz.org/alzheimers\\_disease\\_10\\_signs\\_of\\_alzheimers.asp](http://www.alz.org/alzheimers_disease_10_signs_of_alzheimers.asp)
- Advance care planning: [www.advancecareplanning.org.nz](http://www.advancecareplanning.org.nz)
- Age Concern: [www.ageconcern.org.nz](http://www.ageconcern.org.nz)
- Age-Friendly Tauranga: [www.tauranga.govt.nz/council-documents-reports/councils-strategies-plans-reports/strategies/age-friendly-city-strategy.aspx](http://www.tauranga.govt.nz/council-documents-reports/councils-strategies-plans-reports/strategies/age-friendly-city-strategy.aspx)
- Alzheimers Australia Diagnosing dementia: <http://volunteerawards.health.govt.nz/home>
- Alzheimers New Zealand: [www.alzheimers.org.nz](http://www.alzheimers.org.nz)
- Bupa Care Services New Zealand: [www.bupa.co.nz/Dementia.aspx](http://www.bupa.co.nz/Dementia.aspx)
- Christchurch City Council’s Ageing Together Policy: [www.ccc.govt.nz/thecouncil/policiesreportsstrategies/policies/groups/community/ageingtogether.aspx](http://www.ccc.govt.nz/thecouncil/policiesreportsstrategies/policies/groups/community/ageingtogether.aspx)
- Healthy Christchurch: [www.healthychristchurch.org.nz/](http://www.healthychristchurch.org.nz/)
- Ministry of Health physical activity resources: [www.health.govt.nz/your-health/healthy-living/food-and-physical-activity/physical-activity](http://www.health.govt.nz/your-health/healthy-living/food-and-physical-activity/physical-activity)
- NHS Choices: Symptoms of dementia: [www.nhs.uk/Conditions/dementia-guide/Pages/symptoms-of-dementia.aspx](http://www.nhs.uk/Conditions/dementia-guide/Pages/symptoms-of-dementia.aspx)
- ‘We Can Help’ campaign: [www.wecanhelp.org.nz](http://www.wecanhelp.org.nz)

# Assessment, diagnosis, early intervention and ongoing support

## Assessment

### Aim

The aim is to empower anyone who recognises changes in their own or someone else's memory or cognitive abilities to seek an assessment and have timely access to an assessment.



A timely assessment is important as it can lead to an earlier diagnosis of dementia, opening the door to information and support that maximises the person's ability to live well with dementia. It provides the person with dementia and their family and whānau with better awareness and understanding of what they are living with, which can have a positive effect on the person's wellbeing. An assessment is also important as it can rule out the possibility of delirium and other conditions that are potentially reversible.

## Good practice points

### Any person:

- who has concerns about their memory or cognition, regardless of their age, is respected and their concerns are investigated through an assessment process
- with known risk factors<sup>2</sup> (eg, Down syndrome, history of delirium, alcohol or drug dependency, significant head injury, late onset depression or anxiety) is offered routine monitoring by their primary care health team and is offered an assessment if dementia is suspected
- being assessed for dementia:
  - receives an explanation of the assessment process, including how long it will take
  - is provided with all the information they need at any given time while they await the outcome of the assessment process.

### The health services:

- ensure that health practitioners and support workers in the community understand the point of access for a cognitive assessment and:
  - for uncomplicated dementia, in most cases, assessment will be undertaken by the person's primary health care team with access to support and referrals if the person has questions about diagnosis or needs assistance in managing complications
  - referral to a specialist should be considered if the following features are present:
    - young onset (eg, under the age of 65)
    - rapid rate of progression

<sup>2</sup> Māori have higher rates of risk factors for dementia, including depression, head trauma and substance abuse disorders (Ministry of Health 2011b).

- atypical presentation (eg, depression; anxiety; neuropsychiatric features; major language, visual or other ‘asymmetrical’ features where memory disturbance is not the primary presenting)
- a high score on clinical cognitive assessment despite corroborated functional and cognitive deficits
- associated movement disorder
- cardiovascular disease
- clinical hypothyroidism
- history of head injury or stroke
- history of sexually transmitted infection (STI) or HIV
- a strong family history especially of non-Alzheimer’s type dementia, for example, front-temporal type
- a complex medical background
- English as a second language, complicating the assessment and initial management planning
- other behavioural and psychological symptoms associated with dementia
- for complicated dementia, such as suspected young onset dementia, people with Down syndrome or cases of questionable dementia, assessment will be undertaken by a specialist team within the secondary health care setting
- for atypical dementias, secondary health care services will have access to a DHB or regional specialist tertiary team
- for complicated and atypical cases, a multidisciplinary approach may be helpful for differential diagnosis
- ensure that primary health care teams, health practitioners and support workers understand the importance of early diagnosis and offer to undertake or refer for assessment opportunistically if there is a trigger that suggests cognitive impairment might be a problem (eg, episodes of delirium, missing appointments, falls, not collecting medication, cardiovascular or cerebrovascular events, known risk factors, family/friend concerns, malnutrition, dehydration or weight loss)
- ensure that the health practitioners undertaking assessments have:
  - skills and knowledge in cognitive assessment and knowledge of dementia
  - access to specialist resources to help make a diagnosis if clinically indicated (eg, CT scans<sup>3</sup>, neuropsychological assessment by a registered neuropsychologist or clinical psychologist or functional assessment by a registered occupational therapist)
  - access to ongoing support from specialists
  - the knowledge to recognise the difference between delirium and dementia, to ensure that any underlying causes of delirium are identified and treated early
  - awareness of the importance of an early diagnosis
  - education to break down the stigma-driven views of diagnosing dementia (eg, a sense of clinical futility)
- ensure that, before the assessment process, the health practitioner gains consent from the person to:
  - undertake the assessment
  - inform the person of the diagnosis
  - include the person’s family and whānau in the process
- develop a standardised assessment process that is culturally sensitive, comprehensive and follows

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3 CT scans are recommended to rule out unexpected lesions that may be treatable, such as some tumours, fresh subdural haematomas, patchy demyelination consistent with low vitamin B<sub>12</sub>, marked lacunar states implying current unmanaged embolic disease and severe normal pressure hydrocephalus (NPH).

the NICE clinical guideline 42, using a validated assessment tool (**Good practice examples:** Taranaki DHB Uncomplicated Dementia Care referral pathway, Canterbury DHB Cognitive Impairment Pathway, Bay of Plenty DHB's Bay Navigator, [Midland Health Network localised Map of Medicine](#)) that includes:

- taking the person's history and any collateral history from family and whānau, including sequence and progression of presenting symptoms
- giving due consideration to social circumstances, including functional assessment of activities of daily living and psychosocial aspects of health
- assessing a cause of cognitive impairment (eg, alcohol and drug toxicity, depression, anxiety)
- making a physical examination and assessment for malnutrition risk using a validated screening tool (**Good practice examples:** [MNA® – Mini Nutritional Assessment](#) (formerly known as the MNA-short form), BAPEN's [MUST: Malnutrition Universal Screening Tool](#), [SCREEN](#))
- taking blood tests as clinically indicated (eg, renal, liver and thyroid function, electrolytes, calcium, random glucose, complete blood count, serum vitamin B<sub>12</sub>, folate levels, iron and ferritin)
- providing a clinical cognitive assessment using a validated tool (**Good practice examples:** the Montreal Cognitive Assessment, MoCA; the General Practitioner assessment of Cognition, [GPCOG](#); [ACE-III](#)<sup>4</sup> and the [DSQIID](#) for people with Down syndrome)
- conducting a CT scan
- reviewing medications to identify and minimise use of medicines (including over the counter products) that are no longer required or may adversely affect cognitive functioning
- assessing for comorbidities, psychological wellbeing, eyesight and hearing.

## Useful websites, resources and good practice example links

- ACE-III: [www.neura.edu.au/frontier/research/test-downloads](http://www.neura.edu.au/frontier/research/test-downloads)
- BAPEN's MUST Malnutrition Universal Screening Tool: [www.bapen.org.uk/pdfs/must/must\\_explan.pdf](http://www.bapen.org.uk/pdfs/must/must_explan.pdf)
- DSQIID: [www.knowledge.scot.nhs.uk/media/CLT/ResourceUploads/4011797/DSQIID\\_questionnaire\\_221%2002%202007.pdf](http://www.knowledge.scot.nhs.uk/media/CLT/ResourceUploads/4011797/DSQIID_questionnaire_221%2002%202007.pdf)
- The General Practitioner assessment of Cognition, GPCOG: [www.gpcog.com.au](http://www.gpcog.com.au)
- Midland Health Network localised Map of Medicine: [www.mapofmedicine.com](http://www.mapofmedicine.com)
- MNA® – Mini Nutritional Assessment (formerly known as the MNA-short form): [www.mna-elderly.com](http://www.mna-elderly.com)
- National Collaborating Centre for Mental Health. 2011. NICE clinical guideline 42 (amended March 2011). *Dementia: Supporting people with dementia and their carers in health and social care*. London: National Institute for Health and Clinical Evidence and Social Care Institute for Excellence: [www.nice.org.uk/CG042](http://www.nice.org.uk/CG042)
- The Montreal Cognitive Assessment, MoCA: [www.mocatest.org](http://www.mocatest.org)
- SCREEN: [www.drheatherkeller.com/index.php/screen/](http://www.drheatherkeller.com/index.php/screen/)

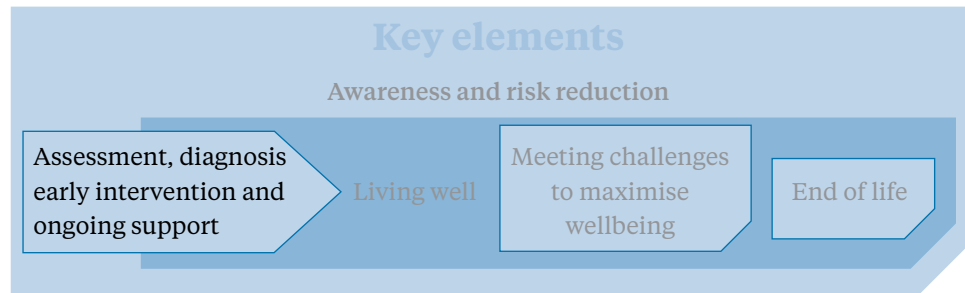
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4 A New Zealand version of the ACE-III is being developed but is not yet available. Once it is available, it would be the preferred version for use.

# Diagnosis

## Aim

**Services aim to provide earlier diagnosis for people with dementia. An earlier diagnosis will allow the person and their family and whānau to plan for the future and to access health and social support services that will provide them with information to promote self-management and rehabilitation, thus ensuring that they are able to live with a sense of wellbeing for as long as possible.**



## Good practice points

### The person with dementia:

#### When the person:

- is found to have mild cognitive impairment (MCI), they:
  - receive education and information on:
    - living a healthy lifestyle to maintain or improve their cognitive functions, including information on the benefits of certain types of physical activity such as tai chi, gardening and walking
    - changes, signs and symptoms to look out for
    - coping strategies at home
  - are made aware that they can request a reassessment of their cognitive abilities if they experience further changes, signs or symptoms
  - have their cardiovascular risk factors reassessed and receive optimal treatment
- has an underlying cause of depression and/or anxiety for their MCI or dementia, they will:
  - receive adequate treatment for the underlying cause (eg, education, intervention, referral to specialist support services)
  - receive a reassessment of their cognitive functions once they have received adequate treatment
- has an underlying cause of alcohol or drug dependency for their dementia, they will:
  - receive adequate treatment for their addiction that enhances their wellbeing and restores their capacity so that they can engage with health and social support services for their dementia (eg, education, intervention, referral to specialist support services)
  - receive a reassessment of their cognitive functions once they have received adequate treatment for their addiction
  - be given a clear pathway for ongoing care and support with addiction and dementia support services collaborating in their care
- receives a diagnosis of dementia, they will:
  - be encouraged to have their family and whānau with them for support
  - receive follow-up sessions with the health practitioner who made the diagnosis
  - receive news of the diagnosis in a quiet environment without distractions
  - be given enough time to process the diagnosis and to ask further questions
  - receive an explanation of what a diagnosis of dementia means and its implications (eg, the possibility of not being able to drive, access to support services, ongoing assessments, opportunity for treatment)



- receive an acknowledgement that dementia is a progressive chronic condition, however, people retain skills and abilities for an undetermined time
- be provided with information and a suggested plan of self-management and preparation for managing their chronic condition.

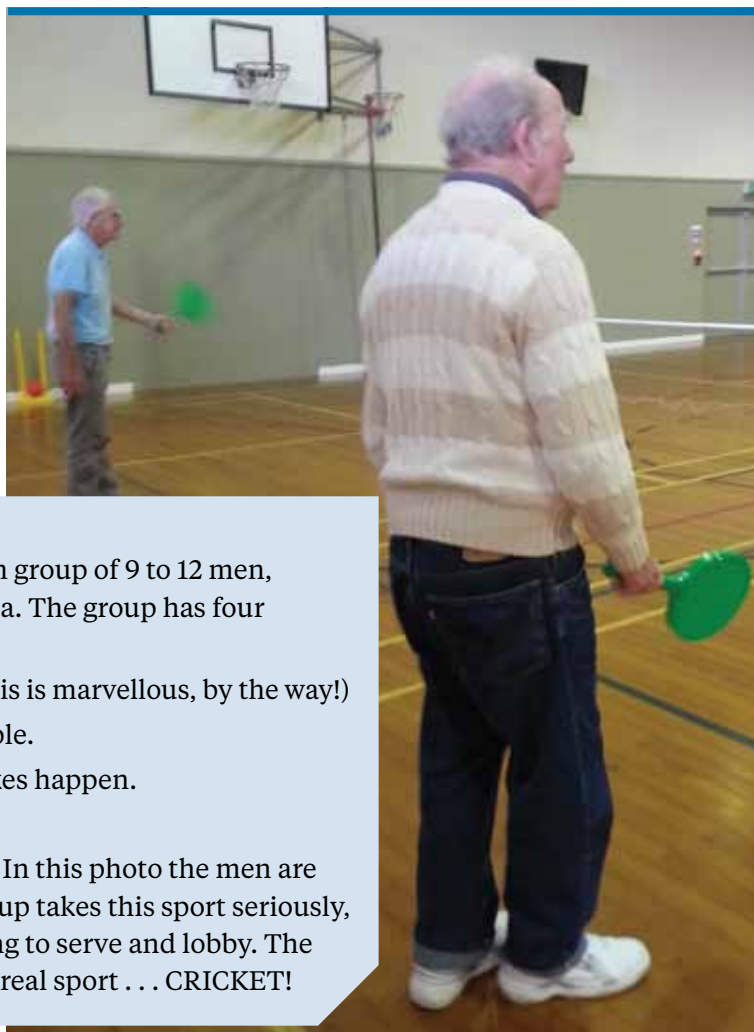
### **The health services:**

- provide a diagnosis of dementia, including subtype, that follows the NICE guidelines
- when giving a diagnosis of dementia, ensure that the person remains at the centre of all conversations and is included in all decision-making, regardless of their perceived capacity
- carry out all sessions at a pace that suits the person with dementia and their family and whānau
  - start ongoing discussions with the person with dementia and their family and whānau about:
    - acknowledging that dementia is a progressive chronic condition
    - the appointment of an enduring power of attorney
    - development of an advance care plan, which is a living document and can be amended at any time (**Good practice example:** The Ministry of Health publication: [Advance Care Planning: A guide for the New Zealand health care workforce](#))
    - future transport options, in particular, driving ([New Zealand Transport Agency: Medical aspects of fitness to drive](#))
    - access to health and social support services
    - the balance of risk/autonomous behaviour
    - carer stress
- prescribe treatments for dementia, if appropriate, that are regularly reviewed and time limited (**Good practice examples:** [cholinesterase inhibitors](#))
- ensure cardiovascular disease (CVD) risk factors are reassessed and treatment is improved as good CVD risk factor management may benefit all people with dementia
- review the use of prescribed medications for pre-existing conditions (eg, antipsychotics, benzodiazepines, hypnotics) as their use may further affect cognitive functions, driving ability or CVD risk
- ensure delivery of medication is organised in a way that makes it easier to take (eg, daily doses versus multiple doses per day, blister packaging)
- encourage the person with dementia to maintain their usual lifestyle and social connections
- provide information about living a healthy lifestyle through nutrition and physical activity (**Good practice examples:** [Canterbury HealthInfo™: Older Person's Health](#), [Ministry of Health food and nutrition guidelines](#), [Ministry of Health guidelines on physical activity for older people](#))
- ensure that the person with dementia and their family and whānau receive a resource pack that can be easily replaced if they misplace it and that includes information about:
  - living with dementia
  - treatment
  - support group information (eg, information about nationwide Alzheimer's support groups)
  - enduring power of attorney
  - advance care planning
  - drafting up a will
  - needs assessment and service coordination
  - home and community support services
  - carer support subsidies and respite care services
  - Work and Income entitlements

- driving with dementia
- physical activity and food information  
(**Good practice example:** Ministry of Health physical activity and food resources).

## Useful websites, resources and good practice example links

- Advance Care Planning: [www.advancecareplanning.org.nz](http://www.advancecareplanning.org.nz)
- Canterbury HealthInfo™: Older Person's Health: [www.healthinfo.org.nz/](http://www.healthinfo.org.nz/)
- Cholinesterase inhibitors: [www.rnzcgp.org.nz/assets/documents/Publications/Archive-NZFP/Aug-2005-NZFP-Vol-32-No-4/TuckerAug05.pdf](http://www.rnzcgp.org.nz/assets/documents/Publications/Archive-NZFP/Aug-2005-NZFP-Vol-32-No-4/TuckerAug05.pdf)
- Cognitive stimulation therapy: [www.cstdementia.com/](http://www.cstdementia.com/)
- Enduring power of attorney: [www.ageconcern.org.nz/money/planning/enduring-power-attorney](http://www.ageconcern.org.nz/money/planning/enduring-power-attorney)
- Ministry of Health publication: *Advance Care Planning: A guide for the New Zealand health care workforce*: [www.health.govt.nz/publication/advance-care-planning-guide-new-zealand-health-care-workforce](http://www.health.govt.nz/publication/advance-care-planning-guide-new-zealand-health-care-workforce)
- Ministry of Health food and nutrition guidelines: [www.health.govt.nz/our-work/preventative-health-wellness/nutrition/food-and-nutrition-guidelines](http://www.health.govt.nz/our-work/preventative-health-wellness/nutrition/food-and-nutrition-guidelines)
- Ministry of Health guidelines on physical activity for older people: [www.health.govt.nz/publication/guidelines-physical-activity-older-people-aged-65-years-and-over](http://www.health.govt.nz/publication/guidelines-physical-activity-older-people-aged-65-years-and-over)
- Ministry of Health physical activity and food resources: [www.health.govt.nz/your-health/healthy-living/food-and-physical-activity](http://www.health.govt.nz/your-health/healthy-living/food-and-physical-activity)
- National Collaborating Centre for Mental Health. 2011. NICE clinical guideline 42 (amended March 2011). *Dementia: Supporting people with dementia and their carers in health and social care*. London: National Institute for Health and Clinical Evidence and Social Care Institute for Excellence: [www.nice.org.uk/CG042](http://www.nice.org.uk/CG042)
- New Zealand Transport Agency dementia driving factsheet: [www.nzta.govt.nz/resources/factsheets/23/](http://www.nzta.govt.nz/resources/factsheets/23/)
- New Zealand Transport Agency: *Medical Aspects of Fitness to Drive*: [www.nzta.govt.nz/resources/medical-aspects/2.html#28](http://www.nzta.govt.nz/resources/medical-aspects/2.html#28)



### Men's gym group

Alzheimers Auckland runs a weekly gym group of 9 to 12 men, all of whom have a diagnosis of dementia. The group has four common themes.

- No wives allowed. (The wives think this is marvellous, by the way!)
- It's great to be with like-minded people.
- It's okay to have a laugh when mistakes happen.
- Cricket is serious business!

The gym group plays a variety of sports. In this photo the men are playing indoor tennis. No one in the group takes this sport seriously, but they do enjoy having a laugh at trying to serve and lobby. The group views tennis as a warm up for the real sport . . . CRICKET!

# Early intervention and ongoing support

## Aim

The aim is to encourage people with a recent diagnosis of dementia to participate in ongoing, culturally appropriate support that is

tailored to meet their needs and maximise their abilities and independence. When and how a person wants to engage with health and social support services is their decision, but the aim is to make the opportunity to engage always available to them and give them and their families and whānau enough information and education to enable them to make appropriate decisions for as long as possible.

The aim is also to help the person with dementia and their family and whānau navigate through the health and social support system. Each person will have someone within their care team allocated the role of navigator. The person undertaking the navigator role will be responsible for providing advice, encouraging self-management, explaining the pathway, coordinating referrals and providing a point of continuity. In most cases the role will be undertaken by a member of the person's primary health care team where most of the population are enrolled for healthcare.

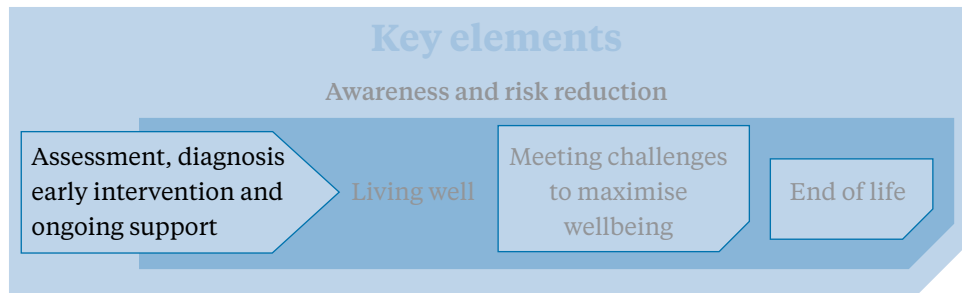
## Good practice points

### The person with dementia:

- has a member of their care team allocated as their navigator (see below)
- receives education and information at a pace and in a format that suits them
- receives a palliative approach to care that recognises that dementia is life limiting
- is assisted to engage with appropriate services
- has their support needs assessed (**Good practice example:** Comprehensive clinical assessment (interRAI))
- if appropriate, following the needs assessment, has their functional abilities assessed using a validated functional assessment tool to identify strengths and weaknesses so that interventions can be put in place to maintain abilities and offset deficits (**Good practice examples:** [Assessment of Motor and Process Skills: AMPS](#), [Allen Cognitive Levels](#)).

### The family and whānau:

- receive education and information at a pace that suits them
- are offered information about broader concepts that could help the person with dementia (eg, the benefits of physical activity for cognitive functions and for preventing/managing comorbidities; nutrition and changes to appetite over time)
- are assisted to connect with dementia support organisations and groups at a pace that suits them with appropriate referrals
- are made aware that dementia is a chronic condition that is life limiting but that there are positive aspects to living with dementia.



## The navigator:

- is a member of the person with dementia's care team (eg, their primary health care team, a multidisciplinary team, a care team related to a comorbidity, or shared across services such as primary health care team with the support of a non-government organisation such as Alzheimers New Zealand)
- works in close collaboration with the primary health care team, if they are not a part of this team, so that other chronic health conditions are covered
- will:
  - be a named first point of contact for the person with dementia and their family and whānau
  - have a good knowledge of dementia
  - have a good knowledge of the health and social support sectors and what services and resources are available
  - be able to help the person with dementia and their family and whānau to navigate the health and social support systems and influence what happens next
  - be available to provide or facilitate the provision of further information, education and support
  - support the person with dementia's decisions and choices
  - ensure that the person with dementia and their family and whānau receive a palliative care approach to maximise their wellbeing
- maintains contact with the person with dementia and their family and whānau after diagnosis for the purpose of follow-up support and:
  - provides or facilitates ongoing information and education to help the person and their family and whānau come to terms with the diagnosis and live well throughout their life with dementia
  - informs the person and their family and whānau of the range and role of health and social support services available, including information about advocacy services, financial assistance, complaints processes and consumer rights
  - discusses care planning and ensures that the person with dementia decides who and what is involved in their care plan and what health and social support services they want to engage with
  - if the person chooses to engage with health and social support services at this time, coordinates contact with those services (eg, Needs Assessment Service Coordination organisation (NASC), multidisciplinary teams, Alzheimers New Zealand, Supporting Families in Mental Illness New Zealand)
  - ensures that the person's family and whānau have the support they need to carry out their role
  - ensures engagement with the primary health care team as a point of continuity
- continues to discuss, educate and encourage the person with dementia to:
  - prepare for the future, for example, choosing an enduring power of attorney, preparing an advance care plan
  - live a healthy lifestyle through good nutrition and physical activity (**Good practice examples:** [Canterbury HealthInfo™: Older Person's Health](#), [Ministry of Health food and nutrition guidelines](#), [Ministry of Health guidelines on physical activity for older people](#))
  - live well by continuing daily activities, keeping socially active and linking with a range of appropriate and adequate care and support services as and when needed
- is supported and informed by other health practitioners and the wider health and social support sectors to carry out their role as navigator and give appropriate and consistent messages
- recognises when specialist knowledge, advice and services are required and coordinates access to them (eg, mental health, gerontology, occupational therapy, dietetic review, speech therapy, specialised equipment, physiotherapy)
- will ensure information and knowledge is transferred appropriately if their role as navigator is shifted to someone else at any stage of the person with dementia's care.

## Useful websites, resources and good practice example links

- Advance Care Planning: [www.advancecareplanning.org.nz](http://www.advancecareplanning.org.nz)
- Allen Cognitive Levels: [www.allen-cognitive-network.org/](http://www.allen-cognitive-network.org/)
- Alzheimers New Zealand: [www.alzheimers.org.nz](http://www.alzheimers.org.nz)
- Assessment of Motor and Process Skills: AMPS: [www.innovativeotsolutions.com/content/amps/](http://www.innovativeotsolutions.com/content/amps/)
- Canterbury HealthInfo™: Older Person's Health: [www.healthinfo.org.nz/](http://www.healthinfo.org.nz/)
- Dementia Care Australia, Symptoms and stages of dementia: [www.dementiacareaustralia.com/index.php?option=com\\_content&task=view&id=119&Itemid=81](http://www.dementiacareaustralia.com/index.php?option=com_content&task=view&id=119&Itemid=81)
- Enduring power of attorney: [www.ageconcern.org.nz/money/planning/enduring-power-attorney](http://www.ageconcern.org.nz/money/planning/enduring-power-attorney)
- Family Court: Information on personal orders, welfare guardians, property rights, property orders and enduring powers of attorney: [www.justice.govt.nz/courts/family-court/what-family-court-does/powers-to-act](http://www.justice.govt.nz/courts/family-court/what-family-court-does/powers-to-act)
- Health and Disability Advocacy: <http://advocacy.hdc.org.nz/>
- Ministry of Health. 2013. *Food and Nutrition Guidelines for Health Older People: A background paper*. Wellington: Ministry of Health: [www.health.govt.nz/publication/food-and-nutrition-guidelines-healthy-older-people-background-paper](http://www.health.govt.nz/publication/food-and-nutrition-guidelines-healthy-older-people-background-paper)
- Ministry of Health. 2013. *Guidelines on Physical Activity for Older People (aged 65 years and over)*. Wellington: Ministry of Health: [www.health.govt.nz/publication/guidelines-physical-activity-older-people-aged-65-years-and-over](http://www.health.govt.nz/publication/guidelines-physical-activity-older-people-aged-65-years-and-over)
- National Collaborating Centre for Mental Health. 2011. NICE clinical guideline 42 (amended March 2011). *Dementia: Supporting people with dementia and their carers in health and social care*. London: National Institute for Health and Clinical Evidence and Social Care Institute for Excellence: [www.nice.org.uk/CG042](http://www.nice.org.uk/CG042)
- Northern Region MHSOP. 2012. *Dementia and Driving Safely: A clinical guideline*. Auckland: Northern Region MHSOP.
- National Dementia Cooperative: <http://ndc.hiirc.org.nz/page/32397/dementia-and-driving-guidelines/?tab=4891&contentType=1585&section=19790>
- Supporting Families in Mental Illness New Zealand: [www.supportingfamiliesnz.org.nz/index.php](http://www.supportingfamiliesnz.org.nz/index.php)
- Work and Income: [www.workandincome.govt.nz/](http://www.workandincome.govt.nz/)

### Gardening group gives carers a break too

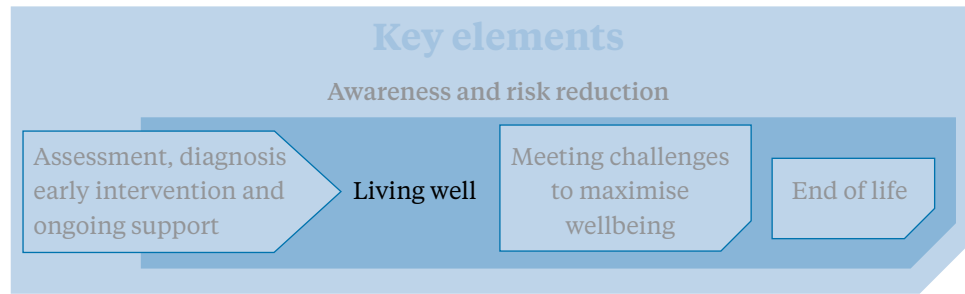
The gardening group (Alzheimers Auckland) isn't just for people with dementia, it also provides a break for their carers. At the start of the group, George's wife worried that he would wander away, or that he wouldn't be able to cope without her. For the first two sessions, she stayed to observe 'just in case' George needed her. As you can see George is pretty happy and hasn't needed his wife while he has been gardening. His wife now goes and has coffee, or does errands, or simply spends a quiet two hours on her own.



# Living well

## Aim

**The aim is for health and social support services to provide integrated and innovative services for people with dementia and their families and whānau so that those people can live in their communities with a sense of purpose and confidence.**



**The person with dementia and their family and whānau will be able to maximise their independence, choices and wellbeing because they are supported by an integrated and innovative health and social support system that is proactive in supporting their needs. The person's navigator will readily assist them with their transition, help them access a range of services and ensure that assessments and care planning are not duplicated.**

**Communities will be educated so that people with dementia are respected and encouraged to participate to the best of their ability in community activities without discrimination or barriers.**

## Good practice points

### The person with dementia:

- receives ongoing care and support with at least quarterly contact with their navigator
- is included in the development of their care plans and any discussions, questions and decisions relating to their health and wellbeing, regardless of their perceived capacity, for as long as they are willing to be included
- is treated with dignity and respect (**Good practice example:** [Maintaining personal identity](#))
- is communicated with using clear and simple language
- should have access to regular health and social reviews by their care team and referrals to the appropriate support services at least once every 12 months to monitor changes in their:
  - physical health
  - support needs
  - psychological health, particularly depression and anxiety
  - functional abilities
  - nutrition, using a validated screening tool (**Good Practice examples:** [MNA® – Mini Nutritional Assessment](#) (formerly known as the MNA-short form), BAPEN's [MUST: Malnutrition Universal Screening Tool](#), [SCREEN](#))
  - communication abilities
  - social connectedness
  - pain (see also Meeting challenges to maximise wellbeing on page 26)
  - medication requirements
- has access to specialised care without prejudice, including but not limited to mental health, gerontology, occupational therapy, dietetic review, speech therapy, specialised equipment, physiotherapy

- is encouraged by services to maintain their skills and abilities through engagement in daily activities, physical exercise and social interaction
- if required, has their decision-making abilities assessed (**Good practice examples:** Counties Manukau DHB's capacity assessment guide for health care professionals, Counties Manukau DHB's capacity assessment guideline), and, if necessary, has their enduring power of attorney for personal care and welfare activated
- has their advance care plans and/or advanced directives respected
- is offered care and support that minimises distress
- is supported to adjust to new environments
- has access to education and peer support groups (**Good practice examples:** [Presbyterian Support Blokes Club \(Waikato\)](#), [Alzheimer's Canterbury Memory Groups](#), [Alzheimer's Hastings Support Groups for People with Dementia](#), [Alzheimer's Napier Memory Cafe](#), [Alzheimer's Tauranga Memory Management Course](#), [Memory Café and Activity Club](#))
- has the opportunity to access social and physical activities that interest them to prevent social isolation, depression or anxiety
- in a crisis situation, receives respite care in an environment that is familiar to them, wherever possible.

### **The family and whānau:**

- know how and when to access assistance
- are included (where appropriate) in the development of the person with dementia's care plans and any discussions, questions and decisions relating to that person's health and wellbeing
- have ready access to information, education and training to assist them with communication and behaviour strategies for people with dementia
- have information to support them to understand and work with the risk/benefit balance of autonomous behaviours, such as the person with dementia being independently mobile in the community, spending time alone at home or preparing food (**Good practice examples:** [When people with dementia walk – what can carers do](#), [The Environment and Dementia](#))
- are encouraged to think about the risk/benefit balance of the person with dementia holding licences for certain recreational activities (eg, gun, skydiving, private pilot, paragliding) and the appropriate time to cancel them
- are encouraged to monitor their own wellbeing through self-assessment and seek support if carer stress is apparent
- have access to a range of dementia respite care services (**Good practice examples:** Taranaki DHB in-home respite, [Canterbury DHB HomeShare respite](#), [Alzheimer's Whanganui: The Group](#), Northland DHB's scheduled residential respite) with the ability to plan respite care in advance.

### **The navigator:**

- works in partnership with the person with dementia and their family and whānau and with the person's care team
- includes the person with dementia in the development of their care plans and any discussions, questions and decisions relating to their health and wellbeing, regardless of that person's perceived capacity, for as long as the person with dementia is willing to be included
- is easily accessible for the person with dementia and their family and whānau when they require support or information
- makes contact with the person with dementia and their family and whānau at least quarterly and is available to those people if they require support or information
- supports the person with dementia and their family and whānau to fill in the *Living Well with Dementia* booklet (see below) with their story

- when appropriate, helps the enduring power of attorney appointee to understand their role, responsibilities and rights
- recognises when specialist knowledge, advice and services are required and coordinates access to them (eg, mental health, occupational therapy, dietetic review, speech therapy, specialised equipment, physiotherapy)
- has core knowledge and competency in reducing or preventing behaviours that challenge (eg, environmental changes, appropriate care management, routines, pain management and fast treatment response for delirium, depression or anxiety)
- ensures a smooth transition across services to avoid duplication of assessments and care planning
- encourages effective communication between services
- is aware of all the health and social support services that the person with dementia is engaged with, including emergency services (eg, ambulance, Police) and has access to care plans, assessments and reports from those services
- encourages the person with dementia and their family and whānau to:
  - access ongoing education, information and advice relevant to their needs
  - maintain skills and abilities by engaging in daily activities
  - explore strategies to live a healthy lifestyle through nutrition, exercise and social activities
  - access appropriate support to:
    - develop communication and behaviour strategies
    - organise and maximise their finances
    - appoint an enduring power of attorney (if they have not already done so)
    - develop and/or update their advance care plan
    - prepare a will (if they have not already done so)
  - connect with local community support networks and occupational activities that suit their individual abilities, skills, interests and values
  - be physically active (especially through activities of daily living)
  - access any health and social support services if and when required
- raises community awareness of dementia
- encourages community services to provide quality services, with appropriately trained staff, who understand the needs of people with dementia, eg, walking groups, swimming pools, gyms, social groups.

### **The Living Well with Dementia booklet:**

- focuses on the person with dementia's needs and preferences and their life to date and can be updated as the person's needs change
- is held by the person with dementia, or their family or whānau, and can be taken to visits at health and social support services (**Good practice examples:** NHS Gloucestershire's *Living Well Handbook*, Midland Region's 'This is Me', Northern Region's 'Living Well with Dementia Plan', Alzheimers New Zealand 'Personal Care' information sheet)
- provides the person with dementia with a place to store contact details and information on the services they access and provides clear and detailed information on the staff (eg, photographs) and their roles within the sector
- is used for coordinating and integrating services and providing details to help make care plans consistent and minimise duplication
- includes:
  - personal details
  - information about the person's clinical details and their care team and services they are accessing



- assessment information and test results that can be shared across services
- person’s support details (eg, the person’s life history, likes and dislikes, cultural needs, daily activities, routines, values, beliefs, leisure interests and hobbies).

### **The health and social support services:**

- ensure that the person with dementia and their family and whānau are treated with dignity and respect and that clear and simple language is used in all discussions with them
- engage with the person’s navigator to help the person live well
- ensure that the family and whānau have the necessary knowledge and resources to care for and support the person with dementia
- support the person with dementia and their family and whānau to understand and work with the risk/benefit balance of the person with dementia continuing with independent behaviours, such as being independently mobile in the community, spending time alone at home or preparing food
- ensure the needs of people with young onset dementia and people with dementia and Down syndrome are considered and met
- include the person with dementia in developing their care plan and in any discussions, questions and decisions relating to that person’s health and wellbeing regardless of their perceived capacity, for as long as that person wishes to be included
- develop care plans that are consistent across services and are integrated, flexible and proactive to meet the person with dementia’s health and social needs and refer to their *Living Well* booklet and advance care plan to incorporate their cultural, spiritual and religious values and preferences
- engage the person with dementia in personalised everyday and social activities that are meaningful to that person (**Good practice examples:** [Activities: living with meaning and purpose](#), [Tailored Activity Program](#), [United States Alzheimer’s Association: Activities](#), *The Best Friends Book of Alzheimer’s Activities* (Bell et al. 2008), *Creating Moments of Joy* (Brackey 2007))
- engage with the family and whānau and provide them with the opportunity to work in partnership with the service provider and participate in the care, support and/or social activities of the person with dementia
- develop an environment that supports people with dementia (**Good practice examples:** [HammondCare Environment and Design](#), [Dementia-friendly environments: a guide for residential care](#))
- ensure that all staff who work with people with dementia receive appropriate training (**Good practice examples:** [Canterbury DHB’s \*Walking in Another’s Shoes\*](#), [Network North E-tool](#), [Health Ed Trust’s ACE Dementia Programme](#), [Careerforce and Alzheimers New Zealand online Level 3 Dementia Unit Standard](#)) including:
  - skilled dementia training that covers: legal and ethical issues, strategies for behaviour and communication, eating and drinking, meaningful activity and other basic care issues
  - enhanced dementia training for senior staff on how to manage care for people with dementia and, where appropriate, end-of-life care
- support the development of dementia champions in specialist roles within their organisation to be the go-to person for training opportunities, advice and support, and to assist the person’s navigator
- ensure that staff are aware of the role, rights and responsibilities of the appointed enduring power of attorney
- ensure there are safe staffing levels.

### **Health, aged residential care, home and community support and respite services should also:**

- ensure key staff have ready access to appropriate advice and support for dementia care (**Good practice examples:** BUPA line, Waitemata DHB residential aged care integration programme)

- make staff retention a priority so that people with dementia, their family and whānau have continuity of care and support
- ensure all assessments are carried out using accredited tools
- prevent unnecessary admission to hospital and/or reduce the length of hospital stay with supported timely discharge (**Good practice examples:** Counties Manukau DHB Community Geriatric Service, Taranaki DHB Intermediate Care model, [Waikato DHB Supported Transfer and Accelerated Rehabilitation Team](#) (START), Canterbury DHB Community Rehabilitation Enablement and Support Team (CREST))
- follow good dementia design principles when developing new facilities or retrofitting old ones (**Good practice examples:** [HammondCare Environment and Design](#), [Dementia-friendly environments: a guide for residential care](#)).

### General hospital settings and those managing acute episodes:

- ensure that their environment supports people with cognitive impairment (**Good practice examples:** [Caring for People with Dementia in Hospital Settings](#), [Dementia-friendly Environments](#))
- ensure that alternative options are explored to guarantee that the person with dementia is cared for in the best place possible, including:
  - intensive home care packages
  - intermediate care
- ensure that all people with dementia are supported appropriately throughout their admission and:
  - are cared for in an environment that is calm, quiet and comfortable
  - have minimal moves and transfers within the hospital
  - are supported by staff with appropriate training (eg, health care assistant) so that their families and whānau feel confident leaving them
- identify a dementia champion within the hospital to:
  - organise training and support for hospital staff
  - provide hospital environment advice (**Good practice examples:** [Dementia Design Audit Tool](#), [The Kings Fund: Developing supportive design for people with dementia](#))

### Christmas celebrations

For each activity The Group (Alzheimers Whanganui) hires vans, picks up people from their homes, and provides an ample morning tea. This photo is of The Group's Christmas party. The Blair family, of Puketea Estate, are very supportive of Alzheimers Whanganui's work and host The Group's Christmas party each year. The staff and volunteers of The Group get into the spirit of the day by dressing up as angels. The Group finishes off their Christmas party singing Christmas carols in the Estate's small chapel, which has an amazing old organ.



- provide advice on strategies for communication and behaviour (**Good practice examples:** Alzheimer’s New Zealand: Communicating with a person who has dementia, [Dementia-friendly environments – Communication strategies](#))
- ensure management of delirium is supported by a delirium support team within the hospital
- ensure that all health practitioners recognise the difference between delirium and dementia and know the correct pathway for assessment and diagnosis if the person does not already have a diagnosis
- identify people at risk of delirium and inform other staff members
- ensure that all health practitioners know how and when to access specialist dementia advice and support
- ensure that at-risk groups are offered screening for cognitive impairment, for example, people over the age of 75 presenting with a fracture, fall, or with a high attendance at emergency department (**Good practice example:** Auckland DHB Better Brain Care Pathway)
- ensure that when positive screening occurs within a hospital, staff facilitate the assessment within the limits of the hospital setting (including assessment for other causes of cognitive decline, for example, undiagnosed stroke) and ensure that the appropriate care team follows up the assessments
- ensure that the person with dementia’s navigator and care team are informed of the person’s presentation to hospital.

## Useful websites, resources and good practice example links

### Dementia resources

- Activities: living with meaning and purpose: [www.health.vic.gov.au/dementia/strategies/activities.htm](http://www.health.vic.gov.au/dementia/strategies/activities.htm)
- Age Concern’s Accredited Visiting Service: [www.ageconcern.org.nz/happiness/keeping-connected/would-you-more-company](http://www.ageconcern.org.nz/happiness/keeping-connected/would-you-more-company)
- Bupa: [www.bupa.co.nz/Dementia.aspx](http://www.bupa.co.nz/Dementia.aspx)
- Caring for People with Dementia in Hospital Settings: <http://hammondcare.myshopify.com/products/caring-for-people-with-dementia-in-hospital-settings>
- Carers New Zealand: [www.carers.net.nz](http://www.carers.net.nz)
- Dementia Design Audit Tool: [www.hammond.com.au/shop/design-for-dementia](http://www.hammond.com.au/shop/design-for-dementia)
- Dementia-friendly environments: activities living with meaning and purpose: [www.health.vic.gov.au/dementia/strategies/activities.htm](http://www.health.vic.gov.au/dementia/strategies/activities.htm)
- Dementia-friendly environments: a guide for residential care: [www.health.vic.gov.au/dementia/index.htm#designing](http://www.health.vic.gov.au/dementia/index.htm#designing)
- Dementia-friendly environments – Communication strategies: [www.health.vic.gov.au/dementia/strategies/communication-strategies.htm](http://www.health.vic.gov.au/dementia/strategies/communication-strategies.htm)
- Eldernet: [www.eldernet.co.nz](http://www.eldernet.co.nz)
- The Environment and Dementia: [www.fightdementia.org.au/understanding-dementia/section-9-the-environment--dementia.aspx](http://www.fightdementia.org.au/understanding-dementia/section-9-the-environment--dementia.aspx)
- HammondCare Environment and Design: [www.hammond.com.au/research/environment](http://www.hammond.com.au/research/environment)
- The Kings Fund: Developing supportive design for people with dementia: [www.kingsfund.org.uk/projects/enhancing-healing-environment/ehe-design-dementia](http://www.kingsfund.org.uk/projects/enhancing-healing-environment/ehe-design-dementia)
- Social Care Institute for Excellence – Dementia gateway: [www.scie.org.uk/publications/dementia/index.asp](http://www.scie.org.uk/publications/dementia/index.asp)
- Victorian Government Health Information: Dementia-friendly environments: Good practice for quality care: An A–Z of strategies, checklists and tools: [www.health.vic.gov.au/dementia/strategies/index.htm](http://www.health.vic.gov.au/dementia/strategies/index.htm)
- SCREEN: [www.drheatherkeller.com/index.php/screen/](http://www.drheatherkeller.com/index.php/screen/)

- Tailored Activity Program: [www.ncbi.nlm.nih.gov/pmc/articles/PMC2682173/](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2682173/)
- United States Alzheimer's Association: Activities: [www.alz.org/care/alzheimers-dementia-activities.asp?gclid=CIqQ6fDNtLUCFQpapQodnjYAbA](http://www.alz.org/care/alzheimers-dementia-activities.asp?gclid=CIqQ6fDNtLUCFQpapQodnjYAbA)
- Waikato DHB Supported Transfer and Accelerated Rehabilitation Team (START): [www.waikatodhb.govt.nz/page/pageid/2145879286/START](http://www.waikatodhb.govt.nz/page/pageid/2145879286/START)

### **Dementia nutrition and physical activity resources**

- BAPEN's MUST: Malnutrition Universal Screening Tool: [www.bapen.org.uk/screening-for-malnutrition/must/must-toolkit/the-must-explanatory-booklet](http://www.bapen.org.uk/screening-for-malnutrition/must/must-toolkit/the-must-explanatory-booklet)
- Caroline Walker Trust: *Eating Well: Supporting older people and older people with dementia: Practical guide*: [www.cwt.org.uk/pdfs/EW-Old-Dementia-Practical-Resource.pdf](http://www.cwt.org.uk/pdfs/EW-Old-Dementia-Practical-Resource.pdf)
- Dr Heather Keller: Nutrition and dementia: [www.drheatherkeller.com/index.php/nutrition-dementia/](http://www.drheatherkeller.com/index.php/nutrition-dementia/)
- MNA® – Mini Nutritional Assessment (formerly known as the MNA-short form): [www.mna-elderly.com/](http://www.mna-elderly.com/)
- United Kingdom Alzheimer's Society: Exercise and physical activity for people with dementia: [www.alzheimers.org.uk/factsheet/529](http://www.alzheimers.org.uk/factsheet/529)

### **Dementia education and training**

- Alzheimers New Zealand: [www.alzheimers.org.nz](http://www.alzheimers.org.nz)
- Careerforce and Alzheimers New Zealand online Level 3 Dementia Unit Standard: [www.careerforce.org.nz/Workplace-Health-and-Disability-Training-dementia26974.html](http://www.careerforce.org.nz/Workplace-Health-and-Disability-Training-dementia26974.html)
- Canterbury DHB's *Walking in Another's Shoes*: [www.bapen.org.uk/screening-for-malnutrition/must/must-toolkit/the-must-explanatory-booklet](http://www.bapen.org.uk/screening-for-malnutrition/must/must-toolkit/the-must-explanatory-booklet)
- Health Ed Trust's ACE Dementia Programme: <http://healthedtrust.org.nz/het-courses/ace-courses-for-caregivers/ace-dementia-programme>
- Network North E-tool: [www.networknorth.org.nz](http://www.networknorth.org.nz)
- Dementia Friendly environments: a guide for residential care: [www.health.vic.gov.au/dementia/index.htm#designing](http://www.health.vic.gov.au/dementia/index.htm#designing)

### **Finances**

- Ministry of Social Development: Entitlements for 65 plus: [www.msd.govt.nz/what-we-can-do/seniorcitizens/entitlements](http://www.msd.govt.nz/what-we-can-do/seniorcitizens/entitlements)
- Sorted: Your independent money guide: Living in retirement: [www.sorted.org.nz/life-events/living-in-retirement](http://www.sorted.org.nz/life-events/living-in-retirement)
- *Maintaining personal identity*: [www.health.vic.gov.au/dementia/changes/personal-identity.htm](http://www.health.vic.gov.au/dementia/changes/personal-identity.htm)

### **Dementia support**

- Alzheimers Canterbury Memory Groups: [www.alzheimers.org.nz/canterbury/11-education-and-information](http://www.alzheimers.org.nz/canterbury/11-education-and-information)
- Alzheimers Hastings Support Groups for People with Dementia: [www.alzheimers.org.nz/hastings/60-support-services](http://www.alzheimers.org.nz/hastings/60-support-services)
- Alzheimers Napier Memory Café: [www.alzheimers.org.nz/napier/227-support-groups](http://www.alzheimers.org.nz/napier/227-support-groups)
- Alzheimers Tauranga Memory Management Course, Memory Café and Activity Club: [www.alzheimers.org.nz/tauranga/107-our-services](http://www.alzheimers.org.nz/tauranga/107-our-services)
- Alzheimers Whanganui: The Group: [www.alzheimers.org.nz/wanganui/53-wanganui-extra-pages/187-the-group](http://www.alzheimers.org.nz/wanganui/53-wanganui-extra-pages/187-the-group)
- Canterbury DHB HomeShare respite: <https://uppersouthisland.enliven.org.nz/services/homeshare>
- Presbyterian Support Blokes Club (Waikato): <https://northern.ps.org.nz/node/1516>
- When people with dementia walk – what can carers do: [www.alzscot.org/pages/info/people-with-dementia-walking-carers-do.htm](http://www.alzscot.org/pages/info/people-with-dementia-walking-carers-do.htm)

# Meeting challenges to maximise wellbeing

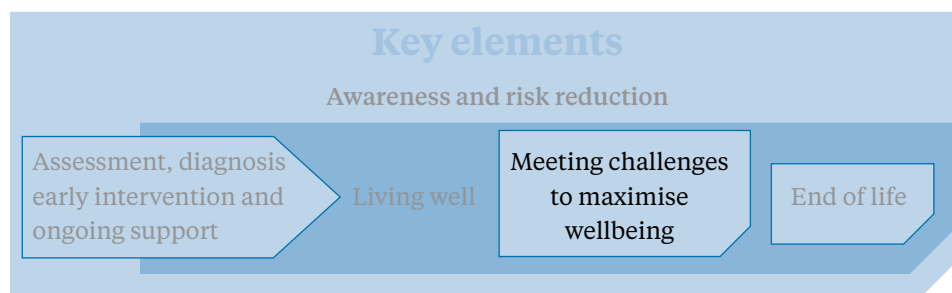
## Aim

The aim is to ensure that people with dementia are supported to maximise their wellbeing and minimise the

challenges they may face in living with dementia and to ensure that their families and whānau receive appropriate information, education and support so that they know when and how to access help and have the confidence to avoid or minimise challenges.

Health and social support workers will have the knowledge and confidence to manage the challenges of dementia appropriately and will have access to specialist advice and support and know when to seek it.

Everyone involved in the care and support of people with dementia will work towards reducing the stigma of dementia by maintaining a positive attitude and encouraging the people with dementia to retain their abilities and lead healthy and active lifestyles.



## Good practice points

### Depression and anxiety

#### The person with dementia:

- is supported to maintain relationships and social connections
- receives ongoing emotional support to prevent anxiety and depression
- is offered a range of options to reduce stress (eg, peer support groups, review of environment)
- is encouraged to help offset depression and/or anxiety by engaging in a range of daily and physical activities
- receives regular assessment for depression or anxiety, using a validated tool for people with dementia (**Good practice example:** [The Cornell Scale for Depression in Dementia \(CSDD\)](#), [Geriatric Depression Scale](#))
- has access to evidence-based treatment (both pharmacological and non-pharmacological) for episodes of depression or anxiety
- receives appropriate education and support throughout any episode of depression or anxiety.

#### The family and whānau:

- are made aware that depression and anxiety can co-exist with dementia
- are made aware of the symptoms of depression or anxiety for people with dementia (eg, passiveness, withdrawal, frustration, agitation) (**Good practice example:** [United Kingdom Alzheimer's Society: Anxiety and Depression](#)) and the importance of seeking treatment as soon as symptoms are evident
- are offered a range of response options to reduce stress
- are offered appropriate support throughout any episode of depression or anxiety to ensure that they are not overburdened.

#### The navigator:

- is aware of the detrimental impact that depression or anxiety can have on the person with dementia (eg, carer burnout resulting in hospitalisation or early entrance into long-term care)

- ensures that the family and whānau are aware of the potential for depression or anxiety
- ensures that the family and whānau know the symptoms and the importance of seeking help as soon as possible
- is aware that physical activity is successful in reducing depression
- ensures that access to assessment and intervention is available as soon as possible
- assists the person with dementia and their family and whānau to access the support they need during any episode of depression or anxiety
- informs any support services involved with the person with dementia and their family and whānau of the episode of depression or anxiety, if they have been given permission to do so
- encourages a range of response options (eg, exercise, social connections, medication, environmental changes, education and peer support for the person with dementia and their family and whānau)
- is aware that there is a point at which entry to long-term care may be appropriate to protect everyone's wellbeing and to improve the care and support for the person with dementia.

### **The health services:**

- monitor and assess for depression and anxiety at regular intervals after a diagnosis of dementia, or when a person with dementia shows signs of depression or anxiety (the most common psychological symptoms associated with dementia)
- consider using a validated tool when the person with dementia is unable to accurately describe symptoms or when diagnosis is complex  
**(Good practice example: [The Cornell Scale for Depression in Dementia \(CSDD\)](#))**
- rule out the possibility of underlying causes for depression or anxiety (eg, delirium, pain, medications or other mental health disorders such as psychosis)

### **Gym group rituals**

Part of the weekly ritual for the gym group is to do warm up stretches before the sporting begins! This always causes a bit of laughter. While coordination and rhythm may be a challenge, shared humour is not. While Alzheimer's Auckland has a team member and volunteer present, the stretches are led by a personal trainer to ensure all participants get a good stretch. The gym that hosts the group is pursuing a Green Prescription certification as the health benefits of this group are significant.



- ensure that the person with dementia's general practitioner (GP) is the first point of contact, and if treatment is successful, the depression or anxiety can be managed in primary care
- ensure that the person with dementia's primary health care team and navigator are readily accessible if any symptoms of depression or anxiety present
- ensure that the primary health care team is appropriately trained in preventing and managing depression and anxiety and that non-pharmacological strategies are the first intervention
- ensure that if treatment in the primary health care setting is not successful, or diagnosis is uncertain, access to psychiatric and/or psychological specialist advice, assessment and support is available
- wherever possible, ensure that access to secondary care services occurs within 24 hours for acute cases and within seven days for non-acute cases.

## Behavioural and psychological symptoms associated with dementia

### The person with dementia:

- is offered a comprehensive assessment that considers physical health (including unrecognised infections, medication regimen, electrolyte disturbances, constipation, hearing or vision problems, communication deficits, loss of confidence, loneliness and/or isolation) and mental health, sensory abilities, undetected pain or discomfort, side effects of medication, individual biography, environmental factors (including sensory overload), and behavioural/functional analysis
- is treated with respect and receives positive support to alleviate the symptoms, distress or unmet need.

### The family and whānau:

- are made aware of the behaviours that may occur (eg, calling out, aggression, agitation, hallucinations and illusions, delusions, wandering, elevated mood, 'sundowning'<sup>5</sup>, extreme anxiety, resistance or unease towards carers, intrusive behaviours, inappropriate social behaviours, day/night reversal, insomnia, apathy, reduced motivation and, in the mid to late stages of dementia, psychotic symptoms) and knows how and when to seek help and advice
- receive education, information, support and practical strategies to minimise and, where possible, alleviate behaviours that challenge and stress the carer  
(**Good practice example:** [Midland Health The Behavioural Staging Model](#)).

### The navigator:

- is aware of the detrimental impact that behavioural and psychological symptoms associated with dementia can have on the person with dementia (eg, physical and mental health decline, carer burnout, hospitalisation and/or entrance into long-term residential care)
- ensures that the family and whānau receive education, information and support to recognise and minimise the behaviours that may be challenging and know when and how to access support
- facilitates access to assessment and intervention as soon as possible
- ensures that the person with dementia and their family and whānau receive adequate support during any episode of behavioural or psychological symptoms
- is aware that there is a point at which entry to long-term residential care may be appropriate to protect everyone's wellbeing and to improve the care and support for the person with dementia.

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5 A psychological phenomenon where various behavioural problems occur in the evening.

### **The health services:**

- ensure that the person with dementia's GP is the first point of contact, and if treatment is successful, the behavioural and psychological symptoms can be managed in primary care
- ensure that the person's primary health care team and navigator are readily accessible if any behavioural or psychological symptoms present
- ensure that the primary health care team is appropriately trained in preventing and managing behavioural and psychological symptoms of dementia and that non-pharmacological strategies are the first intervention (**Good practice examples:** [Antipsychotics in Dementia: Best practice guide](#), [The Use of Antipsychotics in Residential Aged Care](#), [Canterbury DHB's Walking in Another's Shoes](#))
- ensure that, if treatment in the primary health care setting is not successful, access to specialist advice and support is available and wherever possible access to secondary care services occurs within 24 hours for acute cases and within seven days for non-acute cases
- develop an organised response for acute cases within specialist services that includes:
  - a timely response
  - increased support for the person with dementia during the period of assessment to ensure that they're not relocated before a decision is made about their future care and support options
- ensure health practitioners are aware of legislative implications/obligations (eg, being able to apply compulsory treatment legislation appropriately, being aware of the rights and protections that are available under the Protection of Person and Property Rights Act 1988)
- ensure that health and social support workers who are providing care for people with dementia are provided person-centred training to minimise and, where possible, alleviate challenging behaviours (**Good practice example:** [Midland Health The Behavioural Staging Model](#), [Canterbury DHB's Walking in Another's Shoes](#)).

## **Pain management**

### **The person with dementia:**

- is assessed for pain if they show signs of distress or unexplained changes in behaviour
- is treated with respect, with their concerns or complaints about pain taken seriously
- has access to both pharmacological and non-pharmacological (eg, massage therapy, diversion therapy) treatment options for pain, in line with the person's personal history and preferences.

### **The family and whānau:**

- are aware that it may be difficult to detect pain in some people with dementia
- are informed of the symptoms of pain to look out for (eg, delirium, agitation, body language, facial expressions, behaviours that challenge)
- know how to access care and support if pain is suspected.

### **The navigator:**

- is aware of the impact of pain on a person with dementia and the symptoms of pain to look for (eg, delirium, agitation, body language, facial expressions, behaviours that challenge)
- can either provide, or knows how to access, pain management care.

### **The health services:**

- understand symptoms of pain in dementia (eg, delirium, agitation, body language, facial expressions, behaviours that challenge)
- ensure that a standardised approach is taken to pain management since good pain management can significantly reduce behavioural symptoms of dementia
- use a validated pain scale for people with dementia (**Good practice examples:** [Abbey Pain Scale](#), [MOBID-2 Pain Scale](#), [Doloplus-2 Scale](#), [Midland Health Pain and Dementia \(PAINAD\) leaflets](#))



- ensure that causes of pain are identified and addressed (eg, urinary tract infections, fractures, arthritis, chest pains) if pain is suspected
- ensure that the most appropriate option for pain treatment is offered, including pharmacological and non-pharmacological therapy options, taking into consideration the person's history and preferences
- are aware that people with dementia are sensitive to narcotic pain medication and ensure that expert advice is sought from pain services or palliative care to avoid delirium.

## Alcohol and drug addiction

### **The person with dementia and addictions:**

- is treated with dignity and respect
- has access to integrated medical and psychiatric care services, especially in acute cases.

### **The family and whānau:**

- receive emotional support
- know when and how to access services
- if needed, have support from specialist services for court or other proceedings that are required to ensure treatment for a person with a dual diagnosis.

### **The navigator:**

- is knowledgeable and competent to support the person with dementia and addictions and their family and whānau
- knows how to access specialist care and support for the person with a dual diagnosis
- has access to a specialist service for advice and support in the complex legal, privacy and health and disability aspects of the care and support of the person with a dual diagnosis.

### **The health services:**

- develop a regional approach with clear pathways for care and support of people with complex dual diagnosis cases of addiction and dementia
- are aware that people with addictions:
  - often present at a later stage of their dementia
  - may live alone
  - may be difficult to diagnose and treat
  - have the potential for their dementia to improve
- are aware that early detection and intervention provides the best chance for a positive outcome
- promote a healthy lifestyle to reduce risk factors for dementia
- ensure health practitioners are aware of legislative implications/obligations (eg, being able to apply compulsory treatment legislation appropriately, being aware of the rights and protections that are available under the Protection of Person and Property Rights Act 1988).

## Transitions of care

### **The person with dementia:**

- is given guidance about their choice of long-term care in case it is required in the future
- is supported through any transition of their care.

### **The family and whānau:**

- are able to be active partners in the care and support of the person with dementia

- receive advice on what questions to ask and what to look out for when choosing a long-term care facility
- have access to support groups at transition points of care, particularly when the person with dementia enters long-term care.

**The navigator:**

- ensures that the person with dementia and their family and whānau have their emotional wellbeing supported through any transitions of care
- ensures, wherever possible, that the person with dementia and their family and whānau receive advance warning of changes to services and transitions of care
- ensures that the person with dementia and their family and whānau have the information they need to make informed choices
- encourages services to share information during transitions of care.

**The health services:**

- provide the person with dementia and their family and whānau with increased support during a transition to a new service
- develop guidelines for the person with dementia and their family and whānau to use to help them identify long-term care options
- enable the family and whānau to be active partners in the care and support of the person with dementia
- share information between services and use the person with dementia's *Living Well* book
- ensure that appropriate consent is gained for transition to a new service (eg, enduring power of attorney, welfare guardian)
- develop a procedure for applying to the Court to appoint a personal order and/or welfare guardian under the Protection of Personal and Property Rights Act 1988 as required.

**Abuse and neglect**

**The person with dementia:**

- is made aware that they have rights
- is respected and their concerns are investigated, regardless of their capacity.

**The family and whānau:**

- are aware that people with dementia are considered more vulnerable to abuse and neglect
- receive advice and support to minimise stress, which may contribute to increased risk of abuse
- receive education on what would be considered elder abuse and neglect (eg, physical, psychological, sexual, financial abuse, and neglect)
- are aware of how to report neglect or abuse and how to access support, as family and whānau are often the first to identify problems
- are aware that the person with dementia has the same rights as everyone else  
(**Good practice example:** [Alzheimer's Disease International](#) and [BUPA's Global Dementia Charter, Charter of Rights for People with Dementia and Their Carers in Scotland](#)).

### The navigator:

- recognises that people with dementia have the same rights as everyone else  
(**Good practice examples:** [Health and Disability Commissioner: The Code of Rights, Charter of Rights for People with Dementia and Their Carers in Scotland](#))
- is aware that people with dementia are more vulnerable to abuse
- ensures that support is in place to potentially prevent abuse and neglect, for example:
  - minimising carer stress (eg, respite care, peer support groups)
  - ensuring decisions are made in the best interest of the person with dementia (eg, enduring power of attorney)
- respects the view of the person with dementia and treats the information they provide seriously
- follows the [Ministry of Health's Family Violence Intervention Guidelines: Elder Abuse and Neglect](#) if abuse or neglect is suspected
- intervenes quickly and appropriately if abuse is suspected to ensure that the safety of the person with dementia is assured
- ensures that the person with dementia is put in contact with support services for elder abuse (eg, [Age Concern](#)).

### The health services:

- recognise that people with dementia have the same rights as everyone else  
(**Good practice examples:** [Health and Disability Commissioner: The Code of Rights, Charter of Rights for People with Dementia and Their Carers in Scotland](#))
- are aware that people with dementia are more vulnerable to abuse and neglect than other people

### Relationship building

The Group (Alzheimers Whanganui) focuses on creating good relationships between people with dementia and their communities. A good relationship gives us the sense of connection, value, and purpose. This photo shows a get together at the Turakina Beach Village Hall. This community is very supportive of The Group and they rally together with their four wheel drive vehicles and take the group for drives along the beach. The hall has a range of activities, including pool tables, indoor bowls, darts, and cards. On this particular day two members were celebrating their birthday during the same week and you can see them shaking hands and sharing a birthday cake. The Group is very diverse but they all have a genuine care and interest in each other.



- follow the [Ministry of Health’s Family Violence Intervention Guidelines: Elder Abuse and Neglect](#) to detect and report elder abuse and neglect
- include elder abuse and neglect (including how to access support and resources) as core training for all clinical staff
- involve mental health services and/or [Age Concern](#) or another appropriate agency (eg, Police) to conduct a thorough investigation if required.

## Carer stress and depression

### The family and whānau:

- have access to education about supporting a person with dementia, particularly with behaviours that are challenging
- receive information and education on strategies to minimise carer stress  
(**Good practice example:** [The Alzheimer’s and Dementia Caregiver Centre’s 10 symptoms of carer stress and tips for managing stress](#))
- are made aware of the high prevalence of depression and anxiety due to carer stress, the symptoms to watch out for and the importance of seeking treatment and support
- are aware that they can seek additional/different support if the support needs of the person with dementia increase
- have access to interventions such as social support (eg, peer support groups), a carer support subsidy and respite care services
- have the ability to book regular short-term respite care (eg, every six weeks)
- receive the support they need to continue to participate in social and physical activities
- are encouraged to be aware of their own health and wellbeing and seek support should they need it
- receive support for their grief and loss throughout their journey with the person with dementia, particularly in times of acute illness where the outcome is unknown, at times of a transition to a new health or social service, and at the end-of-life stage.

### The navigator:

- is aware that family and whānau wellbeing is important for the wellbeing of the person with dementia
- is aware that carer stress is a possible indicator of issues with the person with dementia (eg, behavioural and psychological symptoms, physical environment issues, pain)
- is responsive to the family and whānau’s physical and mental wellbeing and considers offering a self-assessment (**Good practice example:** Comprehensive clinical assessment (interRAI))
- encourages the family and whānau to gain support from the wider family and whānau early on so that the wider family and whānau can also be involved in the care and support of the person with dementia and can maintain positive relationships
- encourages the family and whānau to access support groups.

### The health services:

- are aware that family and whānau wellbeing is important for the wellbeing of the person with dementia
- ensure that care, support and respite care services are adequate and sufficient to meet demand
- ensure that there are no barriers to access (eg, transport, availability of respite care)
- consider the health needs of the family and whānau.

## Reducing stigma

### **The person with dementia:**

- is supported to understand that dementia is not something to be ashamed of but that it is a health condition, just as heart disease, diabetes and asthma are health conditions
- is encouraged and supported to live positively and retain their abilities by maintaining their usual daily activities
- is encouraged to be actively involved in their own care and support
- is encouraged to continue to participate in, and actively contribute to, activities they enjoy in the community
- is encouraged to participate in peer support groups (eg, [Alzheimers New Zealand](#), [Dementia Advocacy and Support Network \(DASN International\)](#)).

### **The family and whānau:**

- are advised that it is important to encourage the person with dementia to retain their abilities by continuing to engage in their usual daily activities
- are advised that it is important to let the person with dementia use their abilities by doing what they can for themselves
- are advised that it is important not to make assumptions about what the person with dementia can and cannot do
- are advised that it is important to encourage other family members to take an active part in helping the person with dementia to engage in a variety of activities and stay socially connected.

### **The navigator:**

- ensures that the person with dementia and their family and whānau receive up-to-date information about dementia that they can share with others
- encourages and supports the person with dementia to be actively involved in their own care and support
- encourages and supports the person with dementia's wider family and friends to be involved and contribute to the person's support
- encourages and supports the person with dementia to continue actively participating in their community
- provides or organises advocacy where needed
- is encouraged to keep up to date with developments in dementia care and support.

### **The health and social support services:**

- promote respect and dignity for people with dementia within health and social support services
- ensure equity of access for people with dementia
- educate their workforces about the fact that dementia is a chronic condition that people can live with positively if they are well supported and have their needs met  
(**Good practice example:** [Canterbury DHB's Walking in Another's Shoes](#))
- develop peer support groups for people with dementia
- support people with dementia to continue to make an active contribution to their community.

## Useful websites, resources and good practice example links

### Depression and anxiety

The Cornell Scale for Depression in Dementia (CSDD):

[www.scalesandmeasures.net/files/files/The%20Cornell%20Scale%20for%20Depression%20in%20Dementia.pdf](http://www.scalesandmeasures.net/files/files/The%20Cornell%20Scale%20for%20Depression%20in%20Dementia.pdf)

Geriatric Depression Scale: [www.stanford.edu/~yesavage/GDS.html](http://www.stanford.edu/~yesavage/GDS.html)

United Kingdom Alzheimer's Society: Anxiety and Depression:

[www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=139](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=139)

### Behavioural and psychological symptoms associated with dementia

Antipsychotics in Dementia: Best practice guide:

[www.bpac.org.nz/a4d/resources/docs/bpac\\_A4D\\_best\\_practice\\_guide.pdf](http://www.bpac.org.nz/a4d/resources/docs/bpac_A4D_best_practice_guide.pdf)

Canterbury DHB's Walking in Another's Shoes:

<http://akoaootea.ac.nz/ako-hub/good-practice-publication-grants-e-book/person-centred-care>

Midland Health The Behavioural Staging Model:

[www.midlandmentalhealthnetwork.co.nz/page/160-midland-regional-dementia-advisor+information-leaflets](http://www.midlandmentalhealthnetwork.co.nz/page/160-midland-regional-dementia-advisor+information-leaflets)

The Use of Antipsychotics in Residential Aged Care:

[www.bpac.org.nz/a4d/resources/docs/RANZCP\\_Clinical\\_recommendations.pdf](http://www.bpac.org.nz/a4d/resources/docs/RANZCP_Clinical_recommendations.pdf)

### Pain management

Abbey Pain Scale:

[www.dementiacareaustralia.com/images/stories/abbey%20pain%20scale.pdf](http://www.dementiacareaustralia.com/images/stories/abbey%20pain%20scale.pdf)

Doloplus-2 Scale: [http://prc.coh.org/PainNOA/Doloplus%202\\_Tool.pdf](http://prc.coh.org/PainNOA/Doloplus%202_Tool.pdf)

Midland Health Pain and Dementia (PAINAD) leaflets: [www.midlandmentalhealthnetwork.co.nz/page/160-midland-regional-dementia-advisor+information-leaflets](http://www.midlandmentalhealthnetwork.co.nz/page/160-midland-regional-dementia-advisor+information-leaflets)

MOBID-2 Pain Scale: [www.nccdp.org/resources/Mobid-2PainScaleenglish.pdf](http://www.nccdp.org/resources/Mobid-2PainScaleenglish.pdf)

### Participation

A number of volunteers help The Group (Alzheimers Whanganui) to ensure there is a volunteer for every three or four members so that everyone is fully engaged with what is happening. The Group helps people with dementia feel less socially isolated, while also providing support to their carers. This photo is of the group at Mt Lees in the Manawatu enjoying morning tea before taking part in walking groups or a quiet activity. The Group focuses on the strengths of everyone involved, including volunteers and staff. Everyone is encouraged to participate and assist when they can.



## **Alcohol and drug addiction**

Health Promotion Agency: [www.hpa.org.nz/](http://www.hpa.org.nz/)

Ministry of Health: Addictions: [www.health.govt.nz/your-health/healthy-living/addictions](http://www.health.govt.nz/your-health/healthy-living/addictions)

## **Abuse and neglect**

Alzheimer's Disease International and BUPA's Global Dementia Charter:  
[www.bupa.com/dementia/our-global-dementia-charter](http://www.bupa.com/dementia/our-global-dementia-charter)

Age Concern:

[www.ageconcern.org.nz/safety/elder-abuse/elder-abuse-and-neglect-prevention-service-0](http://www.ageconcern.org.nz/safety/elder-abuse/elder-abuse-and-neglect-prevention-service-0)

Ministry of Health: Family Violence Intervention Guidelines: Elder abuse and neglect:

[www.health.govt.nz/publication/family-violence-intervention-guidelines-elder-abuse-and-neglect](http://www.health.govt.nz/publication/family-violence-intervention-guidelines-elder-abuse-and-neglect)

Charter of Rights for People with Dementia and Their Carers in Scotland:

[www.dementiarights.org/charter-of-rights/](http://www.dementiarights.org/charter-of-rights/)

## **Family and whānau education and support:**

Age Concern: [www.ageconcern.org.nz](http://www.ageconcern.org.nz)

Alzheimers New Zealand: [www.alzheimers.org.nz/](http://www.alzheimers.org.nz/)

Carers New Zealand: [www.carers.net.nz/](http://www.carers.net.nz/)

The Alzheimer's and Dementia Caregiver Centre's 10 symptoms of carer stress and tips for managing stress: [www.alz.org/care/alzheimers-dementia-caregiver-stress-burnout.asp](http://www.alz.org/care/alzheimers-dementia-caregiver-stress-burnout.asp)

## **Choosing a long-term facility**

Age Concern: [www.ageconcern.org.nz/health/health-help/residential-care](http://www.ageconcern.org.nz/health/health-help/residential-care)

Consumer Rest Homes Checklist:

[www.consumer.org.nz/content/uploads/Image/PDFs/Resthomechecklist09.pdf](http://www.consumer.org.nz/content/uploads/Image/PDFs/Resthomechecklist09.pdf)

Eldernet: [www.eldernet.co.nz/Home](http://www.eldernet.co.nz/Home)

## **Reducing stigma**

Alzheimer's Disease International. 2012. *World Alzheimer Report 2012:*

*Overcoming the stigma of dementia:* [www.alz.co.uk/research/world-report-2012](http://www.alz.co.uk/research/world-report-2012).

Canterbury DHB's Walking in Another's Shoes:

<http://ako.aotearoa.ac.nz/ako-hub/good-practice-publication-grants-e-book/person-centred-care>

Dementia Advocacy and Support Network (DASN International):

[www.dasninternational.org/](http://www.dasninternational.org/)

London: Alzheimer's Disease International. URL:

[www.alz.co.uk/research/world-report-2012](http://www.alz.co.uk/research/world-report-2012)

## **Powers to act on behalf of others**

Ministry of Justice: Family Court of New Zealand: Powers to act on

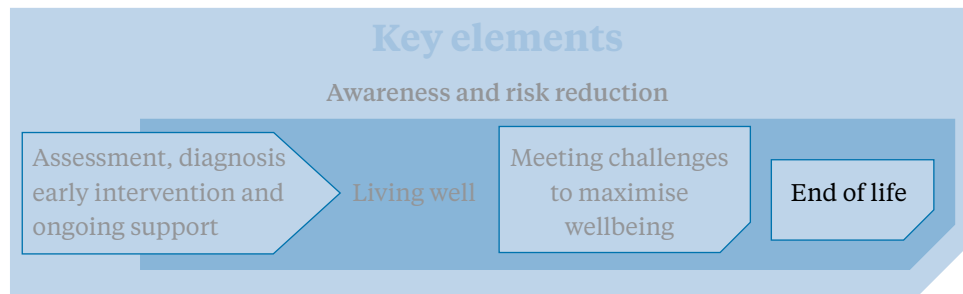
behalf of others: [www.justice.govt.nz/courts/family-court/what-family-court-does/powers-to-act#fc11](http://www.justice.govt.nz/courts/family-court/what-family-court-does/powers-to-act#fc11)

# End of life

## Aim

**The aim is to ensure that people living with dementia and their families and whānau have access to full palliative care services and have**

**confidence in and feel supported through the end-of-life stage. Their needs and preferences are taken into account, and when they are in the end-of-life stage they are not moved from their place of living where possible. Family and whānau are always active participants in care and planning at the end-of-life stage, with support from services to enable them to achieve this. The person with dementia is able to die in the place of their choice, and their family and whānau are given the space to spend time with them.**



## Good practice points

### The person with dementia:

- has their personal, cultural, spiritual and religious values and preferences respected and taken into account
- has access to palliative care services
- receives timely best practice management of all symptoms, including pain, restlessness, agitation, dyspnoea and upper respiratory tract secretions, and pre-existing conditions
- is enabled to die in their place of choice and is only moved in exceptional circumstances (unless the move is to their place of choice)
- has their physical needs met (eg, hydration, mouth care, bowel care).

### The family and whānau:

- have access to palliative care services
- have their needs and wishes respected and taken into account
- are provided with space and opportunities to spend time with the person with dementia
- are actively involved in care planning for the person with dementia
- receive education and information on what to expect at the end-of-life stage and palliative care in respect to dementia (**Good practice example:** [Dementia information for carers, families and friends of people with severe and end-stage dementia](#)).

### The health services:

- adopt a palliative care approach when a person is in the late stages of dementia, (after excluding reversible conditions) and appoint a coordinator (the navigator or a member of the person's care team) to manage end-of-life care across all services (**Good practice example:** [The Gold Standards Framework, United Kingdom](#))
- ensure that the person with dementia continues to be cared for in their place of choice and is only moved in exceptional circumstances (eg, if the provider of home support services or residential care is unable to safely provide the level of support the person needs)
- support health practitioners to access communication training and develop communication skills to ensure that they can support the family and whānau through 'difficult conversations'
- allow the family and whānau to guide them to ensure they are aware of and support the cultural, spiritual and religious needs of the person with dementia



- ensure that a health practitioner who knows the person with dementia assesses that person's needs in end-of-life care
- use a validated end-of-life care pathway
- use a validated pain scale for people with dementia (**Good practice examples:** [Abbey Pain Scale](#), [MOBID-2 Pain Scale](#), [Doloplus-2 Scale](#), [Midland Health Pain and Dementia \(PAINAD\) leaflets](#))
- ensure that the coordinator develops an end-of-life care plan that:
  - follows the person with dementia's advance care plan and/or advance directives
  - includes the person's personal, cultural, spiritual and religious preferences
  - identifies the enduring power of attorney and ensures that this role is activated if necessary
  - has a palliative approach
  - ensures that the person with dementia's assessed needs are met by engaging with the appropriate health and social support professionals at the right time
  - ensures continuity of care across services
  - ensures that services are delivered in the person with dementia's place of choice, wherever possible
  - ensures that the needs of the person with dementia and their family and whānau are met
  - ensures that, while a palliative care focus predominates, reasonable assessment and management of reversible conditions is still offered
  - provides timely end-of-life education and information to the family and whānau so that they are aware of and can appropriately support the person with dementia's physical needs (eg, nutrition, hydration, continence, pain management)
- ensure that the appointed enduring power of attorney for personal care and welfare understands their role, responsibilities and rights
- facilitate palliative care services to support primary health care providers, aged residential care facilities, disability and mental health providers and families and whānau to manage end-of-life care so that the person with dementia can remain where they are
- facilitate palliative care specialists to provide education and training to:
  - primary health care providers
  - aged residential care staff
  - disability and mental health providers
  - home support services staff
- facilitate palliative care specialists to receive dementia and intellectual disability education so that they can better support the person with dementia and their family and whānau.

#### **After the death:**

- family and whānau continue to be supported through the grieving process and are linked to relevant agencies
- a range of social support options is made available
- the person with dementia's wishes, as set out in their advance care plan, are adhered to if possible and/or appropriate
- health and social support professionals are supported after the death.

## Useful websites, resources and good practice example links

United Kingdom Alzheimer's Society: End of Life Care:

[www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=428](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=428)

Alzheimer Scotland: Letting go without giving up: continuing to care for the person with dementia:

[www.alzscot.org/pages/info/lettinggo.htm](http://www.alzscot.org/pages/info/lettinggo.htm)

Australian Government: National Health and Medical Research Council: Guidelines for a palliative approach in residential aged care: [www.nhmrc.gov.au/guidelines/publications/pc29](http://www.nhmrc.gov.au/guidelines/publications/pc29)

NHS. 2010. *Care towards the End of Life for People with Dementia: An online resource guide*. NHS: National End of Life Care Programme. UK: National Health Service:

[www.endoflifecareforadults.nhs.uk/assets/downloads/Dementia\\_resource\\_\\_final\\_\\_20101025.pdf](http://www.endoflifecareforadults.nhs.uk/assets/downloads/Dementia_resource__final__20101025.pdf)

Nuffield Council on Bioethics. 2009. *Dementia: Ethical issues*. Bedford: Nuffield Council on Bioethics:

[www.nuffieldbioethics.org/sites/default/files/Nuffield%20Dementia%20report%20Oct%2009.pdf](http://www.nuffieldbioethics.org/sites/default/files/Nuffield%20Dementia%20report%20Oct%2009.pdf)

Department of Health, United Kingdom: Dementia: End of life care resources:

[dementia.dh.gov.uk/end-of-life-care-resources/](http://dementia.dh.gov.uk/end-of-life-care-resources/)

Ministry of Social Development: Enduring Power of Attorney: Keeping you protected:

[www.msd.govt.nz/what-we-can-do/seniorcitizens/your-rights/enduring-power-of-attorney.html](http://www.msd.govt.nz/what-we-can-do/seniorcitizens/your-rights/enduring-power-of-attorney.html)

NHS Cornwall and Isles of Scilly and Alzheimer's Society. 2011. *Preparing for End Stage Dementia*.

United Kingdom: Cornwall and Isles of Scilly Primary Care Trust:

[www.cornwallandislesofscilly.nhs.uk/DocumentsLibrary/CornwallAndIslesOfScillyPCT/WebDocuments/Internet/InformationForPatients/SelfCareInCornwall/HealthCareProfessionals/EndOfLifeCarerLeaflet.pdf](http://www.cornwallandislesofscilly.nhs.uk/DocumentsLibrary/CornwallAndIslesOfScillyPCT/WebDocuments/Internet/InformationForPatients/SelfCareInCornwall/HealthCareProfessionals/EndOfLifeCarerLeaflet.pdf)

University of Western Sydney. 2011. *Dementia: Information for carers, families and friends of people with severe and end stage dementia. 3rd edition*. Penrith: University of Western Sydney:

[www.uws.edu.au/\\_\\_data/assets/pdf\\_file/0008/7100/Dementia\\_Booklet\\_Final2011\\_PDFfor\\_web.pdf](http://www.uws.edu.au/__data/assets/pdf_file/0008/7100/Dementia_Booklet_Final2011_PDFfor_web.pdf)

Palliative Care Council of New Zealand: [www.cancercontrolnz.govt.nz/palliative-care](http://www.cancercontrolnz.govt.nz/palliative-care)

The Gold Standards Framework, United Kingdom: [www.goldstandardsframework.org.uk](http://www.goldstandardsframework.org.uk)

Abbey Pain Scale: [www.dementiacareaustralia.com/images/stories/abbey%20pain%20scale.pdf](http://www.dementiacareaustralia.com/images/stories/abbey%20pain%20scale.pdf)

MOBID-2 Pain Scale: [www.nccdp.org/resources/Mobid-2PainScaleenglish.pdf](http://www.nccdp.org/resources/Mobid-2PainScaleenglish.pdf)

Doloplus-2 Scale: [http://prc.coh.org/PainNOA/Doloplus%202\\_Tool.pdf](http://prc.coh.org/PainNOA/Doloplus%202_Tool.pdf)

*Midland Health Pain and Dementia (PAINAD) leaflets*: [www.midlandmentalhealthnetwork.co.nz/page/160-midland-regional-dementia-advisor+information-leaflets](http://www.midlandmentalhealthnetwork.co.nz/page/160-midland-regional-dementia-advisor+information-leaflets)

# Glossary

Advance care plan	<p>An advance care plan articulates the person with dementia’s wishes, preferences, values and goals for all current and future care.</p> <p>It is the desired outcome of the advanced care planning process (see below). An advance care plan can take any format, but ideally, it will be completed as a written document rather than a verbal statement.</p> <p>It should be accessible to current and future health care providers and to family and whānau members, according to the wishes of the person with dementia.</p> <p>While an advance care plan can and should be used to inform future medical treatments and procedures when the person loses the capacity to make their own decisions, it should be used in conjunction with other measures, such as discussions with the person who has been appointed as the enduring power of attorney (where one has been appointed – see below) and the family and whānau.</p>
Advance care planning	<p>Advance care planning (ACP) is a process of discussing and sharing planning for future health care. For the purposes of this framework, ACP focuses on the person with dementia and involves both that person and the health care professionals responsible for their care. ACP may also involve the person with dementia’s family and whānau if that is the person’s wish.</p> <p>ACP helps the person with dementia identify their personal beliefs and values and incorporate these beliefs and values into plans for their future health care. It provides people with the opportunity to develop and express their preferences for care, informed not only by their personal beliefs and values but also by an understanding of their current and anticipated future health status and the treatment and care options available.</p> <p>ACP may result in the person with dementia choosing to write an advance care plan (see above) and/or advance directive and/or to appoint an enduring power of attorney (see below). If the person has strong views or preferences about medical treatments and procedures, they should be advised to consider completing an advance directive.</p>
Behavioural and psychological symptoms of dementia	<p>These are the often distressing, non-cognitive symptoms of dementia. The term covers a wide range of symptoms and behaviours, including wandering, agitation and aggression. Behavioural and psychological symptoms of dementia are common, and appropriate management can significantly improve quality of life and reduce carer stress. The symptoms are usually transient and often respond to simple changes in the environment or removal of an aggravating factor.</p>
Chronic condition	<p>A chronic condition is a biological or physical condition where the natural evolution of the condition can significantly impact on a person’s overall quality of life, including an irreversible inability to perform basic physical and social functions. Chronic conditions are characterised by persistent and recurring health consequences lasting for three months or more. Serious and persistent chronic conditions are multidimensional, interdependent and complex.</p>

Delirium	Delirium (sometimes called ‘acute confusional state’) is a common clinical syndrome characterised by disturbed consciousness and impaired attention and concentration, as well as perception or other cognitive functions. It has an acute onset and fluctuating course. It can be caused by a large number of underlying medical conditions, but common causes include infections, electrolyte disturbance and medication problems. It may develop in those without pre-existing cognitive impairment or dementia but is certainly a common complication in those groups. It usually develops over a few days. It is a serious condition that is associated with poor outcomes. However, it can sometimes be prevented, and it certainly needs to be treated urgently.
Dementia	Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, that results in cognitive function including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. Impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. Dementia occurs in Alzheimer’s disease, in cerebrovascular disease and in other conditions primarily or secondarily affecting the brain (WHO 1992).
Dementia-friendly community	In a dementia-friendly community, people with dementia and their families and whānau are supported by their community and health and social support services. Communities are more inclusive of people with dementia and strengthen people with dementia’s ability to maintain and maximise their independence, optimise their sense of wellbeing and have control over their circumstances.
Dementia-friendly environment	Dementia-friendly environments are created using a flexible approach that maximises the person with dementia’s individual requirements for freedom and involvement and minimises regimentation.
Enduring power of attorney	For the purposes of this framework, an enduring power of attorney (EPA) is an authority given by a person with dementia, while they are competent, to another person in order for that second person to act for the welfare of the person with dementia only once the person with dementia is mentally incompetent. A medical certificate that the person with dementia is mentally incompetent is required before a person with an EPA can act in respect of certain matters. Note: There are two types of EPA: ‘property’ and ‘personal care and welfare’.
Family	<p>For the purposes of this framework, and in the recognition of the collaborative nature of health and social care, family includes a person or people who has/have a close, ongoing, personal relationship with the person with dementia. Such a person or people may or may not include the immediate biological family of the person with dementia and may include other relatives, a partner (including same-sex and de facto partners), a friend or a ‘person responsible’ according to any wishes expressed by the person with dementia.</p> <p>The term family also includes the person with dementia’s main carer(s), who could be a spouse, parent/guardian, family or whānau or friend who provides informal support and is responsible for supporting the person with dementia’s ongoing care and wellbeing.</p>

Integration	For the purposes of this framework, integration is the process of bringing organisations and professionals together, across the health and social support sector, with the aim of improving outcomes for people with dementia and their families and whānau by delivering coordinated care.
interRAI	An interRAI assessment is one type of comprehensive clinical assessment. The assessment identifies the medical social and rehabilitation needs of the person with dementia. interRAI methodology differs from other assessments in that the purpose of the assessment is to consider the person's functioning (as opposed to status). The assessments are specifically designed to find opportunities for improvement and/or any risks to the person's functioning, which then form the basis of a care plan.
Mild cognitive impairment (MCI)	Mild cognitive impairment (MCI) is a syndrome of cognitive decline greater than expected for a person's age and education level but without interfering notably with most of the person's activities of daily living. Its presence does not imply any pathological process, but it does need investigation and review. In some cases, MCI can be a precursor state to dementia. However, in many people, MCI does not progress or may even improve with time.
Navigator	For the purposes of this framework, the navigator is a role held by someone within the person with dementia's care team (eg, their general practitioner). The navigator is responsible for providing advice, assisting with self-management, explaining the care pathway, coordinating referrals, transition and access to services and providing a point of continuity. The navigator role can be filled within a single service or can be carried out as a collaboration between services (eg, the primary health service and a non-government organisation). The navigator will have an overview of all health and social support services for the person with dementia.
Palliative care approach	For the purposes of this framework, this is an approach that improves the quality of life for people with dementia and their families and whānau, who are facing the problems associated with this life-limiting condition. It involves active, holistic care, including managing pain and other symptoms and providing psychological, social and spiritual support.
Person with dementia	A person with dementia is the person who has received a diagnosis of dementia.
Whānau	The use of the term whānau in this framework is not limited to the traditional definition but recognises the wide diversity of families represented within Māori and other cultural communities. It is up to each whānau and person to define for themselves who comprises their whānau.
Young onset dementia	Young onset dementia is any dementia diagnosed in a person under the age of 65.

### **Enjoying the outdoors**

The Auckland Botanic Garden walking group (Alzheimers Auckland) meets once a week and always finishes their walk with a cuppa at the cafe. Often the group finds itself split into two groups – serious walkers, and people who enjoy strolling and looking at flowers. This photo is of Rosemary and Warren at the café after their walk. They have been married ‘for an age’, both have Alzheimers, and they enjoy being part of the walking group.



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