

# NEAC’s Advice on Dementia to the Associate Minister of Health

**5 May 2016**

## Executive summary

1. Dementia is a priority health issue for New Zealanders. It is a major cause of disability and dependency, and in recent years, it has received much international[[1]](#footnote-1) and local attention. Most people with dementia are living in the community, with support from families, whānau and friends. The financial and personal costs are significant.
2. Understanding what is important to people with dementia and their families is the focus of the National Ethics Advisory Committee’s (NEAC’s) work. Our advice considers what people with dementia and their families need, what the wider community can do, and how the health and social support workforce needs to behave. Getting these things right will ensure better health outcomes and wellbeing for people with dementia, as well as for those providing support and care.
3. NEAC recognises much is already being done and what is effective should continue to be supported. However, we consider that current activity could be strengthened and focused through a dementia action plan.
4. NEAC recommends:
5. a dementia action plan with specific actions and measures of performance across central and local government, businesses and communities.
6. NEAC’s work indicates that New Zealand can do better in ensuring people with dementia are valued and supported to maintain their independence. We can also do better in recognising and supporting families so that they can provide the best support and care possible. An important part is ensuring all health and social support services are high quality, delivered by skilled workers.

### Building a supportive community environment

1. NEAC recommends:
2. development of a cross-sector dementia friendly initiative that includes:
   * a programme to increase social inclusion and reduce stigma
   * addressing the needs of people with dementia in urban redevelopment plans
   * support for local government initiatives
   * incentives for businesses to become dementia-friendly
   * design of hospitals, health and social support centres, and residential care facilities to meet the needs of people with cognitive impairments and dementia.

### Planning ahead

1. NEAC recommends:
2. an improved system of data collection on the incidence and prevalence of dementia to inform national and local planning, alongside research that captures the views of people with dementia and their caregivers
3. increased promotion of advance care planning and training for health care professionals
4. a national approach to actively promote Enduring Powers of Attorney including widespread availability of information and use of subsidies to remove any financial barrier
5. education of attorneys so that they understand and can act in a way that is consistent with a supported decision-making model, with a particular focus on communicating with a person with dementia
6. a consistent and streamlined process for appointing a Welfare Guardian and/or Property Manager or Administrator where there is no Enduring Power of Attorney, including access to an adequate pool of paid or voluntary welfare guardians, managers or administrators.

### Supporting families, whānau and friends

1. NEAC recommends:
2. that resources developed by Alzheimers New Zealand are widely available and consistently used by health and social support providers
3. all DHBs be required to include navigator roles in their Cognitive Impairment or Dementia Pathways
4. that a family meeting and planning for the future becomes an integral part of normal clinical practice at the time of diagnosis, with referrals to Alzheimers New Zealand or other community support organisations
5. all DHBs increase availability of respite services that better meet the needs of people with dementia (including younger people) and their families.

### Delivering quality health and social support services

1. NEAC recommends:
2. development and implementation of easy to follow instructions for hospital staff admitting someone with dementia, alongside good pathways for managing confusion
3. incentives to encourage adoption of person-centred care programmes in aged residential care
4. that the Health Quality and Safety Commission and the Health and Disability Commissioner develop mechanisms to encourage health and social support providers (including aged residential care) to focus less on risk and more on quality of life

### Developing a skilled health and social support workforce

1. NEAC recommends:
2. Health Workforce New Zealand leads the development of a comprehensive, national workforce development plan for dementia covering all current and future health and social support workers
3. that dementia training for health and social support workers include understanding and implementing person-centred care
4. the Age Related Residential Care Services Agreement and contracts for home-based support services include mandatory dementia training and qualifications for all caregivers and managers
5. remuneration for all caregivers is commensurate with increased requirements for dementia training and qualifications.

## Introduction

### About dementia[[2]](#footnote-2)

1. Dementia is the term used when a person experiences a gradual loss of brain function due to physical changes in the structure of the brain. There are many causes of dementia, with the most common single cause being Alzheimer’s disease; other causes include vascular dementia, dementia with Lewy bodies and fronto-temporal dementia. The most common form in clinical practice is a combination of Alzheimer’s disease and Vascular dementia. Dementia symptoms include loss of memory, impaired reasoning, reduced language and loss of daily living skills. People with dementia do not all have the same experience; the age of onset varies, symptoms can occur in different combinations and there are differing rates of deterioration. There is a very high rate of behavioural and psychological complications during the course of dementia (up to 90% in Alzheimer’s disease) including depression, psychosis, disorientation and night walking, and aggression.
2. People with dementia are able to manage relatively well in the early stages, with support from family, whānau and friends and small lifestyle changes. People may manage with basic support for a number of months or years. Over time, more support is needed as symptoms increase and abilities change.
3. Based on the World Alzheimer Report 2015, [[3]](#footnote-3) Alzheimers New Zealand estimates that 60,000 New Zealanders had dementia in 2015. By 2030, an estimated 96,000 New Zealanders will have dementia, an increase of 60 percent. The total financial cost of dementia in 2011 was estimated as $954.8 million; health system expenditure accounted for $596.3 million (63%). Individuals with dementia and their carers bore 33% of the financial costs, the Government 55% and other payers 12%.[[4]](#footnote-4)
4. Most people with dementia are living in their own homes in the community. Alzheimers New Zealand estimates that 35,000 New Zealanders with dementia are currently living in the community and 25,000 in residential aged care (rest home and specialist dementia care). Between 60-80% of people in residential aged care have dementia.

### NEAC’s work on dementia

1. NEAC provides independent advice to the Minister of Health on ethical issues of national significance in respect of health and disability matters. NEAC’s advice is based on a view of ethics that involves identifying what matters, explaining how the sector can act, and encouraging ethical decision-making.
2. NEAC’s work on dementia focuses on the role of families, whānau and friends in providing support and care for people with dementia, particularly those living in the community. Good support and care contributes to better health outcomes and wellbeing for people with dementia. Supporting people to remain safely in their own homes helps maintain a sense of self and personal identity. It also reduces expenditure on residential aged care ($371.9 million or 62% of health system expenditure on dementia in 2011).
3. Providing support and care for a person with dementia can result in significant stress and poorer psychological and physical health for caregivers.[[5]](#footnote-5) With the right help it can be a positive experience. Ensuring families, whānau and friends are well-supported will contribute to better health outcomes and reduced heath care costs.
4. NEAC has met with a range of stakeholders including family carers and people with early stage dementia to explore the ethical issues associated with providing good support and care. An important part is about having timely and appropriate access to good quality health and social support services. Increasing social inclusion and reducing stigma is also important and this will lead to a more positive community response to people with dementia and their families.

### Ethical values

1. Ethics is about the underlying values that should govern our behaviour. A significant part is about what people do, think and believe. Important values for dementia are:

* respect/mana – every person has an inherent value or mana; mana places an expectation on others and New Zealand communities to recognise and uphold the value of each person throughout the course of their life
* people first – knowing the person with dementia and what is important to them is essential
* independence – doing things for ourselves, doing what we enjoy or find important and making our own choices helps maintain a sense of self and wellbeing; people have a right to make decisions that others might disagree with or think unwise
* interdependence – we are all dependent on each other in everyday life; the person with dementia and their family, whānau and friends can be more reliant on each other and therefore these relationships are even more critical
* best interests – any person’s best interests are a balance between what is important to them and what is important for them; there are no absolutes and what is important may change over time
* solidarity – supportive communities and environments are important for people with dementia and their families, whānau and friends; everyone has a role to play.

## ADVICE

1. NEAC’s advice is about what needs to change for people with dementia and their families and whānau, whether this is strengthening current actions or starting new ones. Our advice is based on an analysis of what stakeholders told us and the ethical values that are important. It has been informed by a range of articles and publications on ethics and dementia, and best practice dementia care (see Bibliography). NEAC’s advice sets out what needs to happen for people with dementia to have lives that embrace the ethical values described above.
2. NEAC recognises that much is already being done. For example, Alzheimers New Zealand’s Let’s Get Our Heads Around Dementia campaign aims to increase understanding and the importance of timely diagnosis, and in April 2015, they adopted a new strategy to achieve a dementia-friendly New Zealand. The New Zealand Framework for Dementia Care (Ministry of Health, 2013) is supported by action in nine key areas (Improving the Lives of People with Dementia, Ministry of Health, 2014). It is important that this work is evaluated, and where effective, continues to be supported.
3. NEAC recommends an action plan for dementia to strengthen and focus activity across central and local government, businesses and communities. Work on the new Health of Older People Strategy and the revision of the New Zealand Disability Strategy provides an opportunity for dementia issues to be highlighted and a plan developed with specific actions and measures of performance.
4. A good international example is Prime Minister David Cameron’s challenge on dementia 2020. It sets out the UK Government’s key aspirations for 2020 and associated actions in dementia care, support for carers, awareness and understanding, and research. Specific measures of performance are attached to each action, for example, by 2020 all National Health Service staff will have received training on dementia appropriate to their role.
5. NEAC recommends further action to ensure:

* a supportive community environment
* planning ahead
* good support for families, whānau and friends
* quality health and social support services
* a skilled health and social support workforce.

## Building a supportive community environment

1. While recognising that dementia is a medical condition, quality of life is significantly affected by the wider social context. Disability is what happens when society and the environment do not take account of the impairments people have. We can reduce the disabling impact of dementia through community action.
2. People with dementia often experience a change in the way people see them and this can have a marked impact on their wellbeing, social inclusion and independence. Many stakeholders talked about the stigma and discrimination associated with a diagnosis of dementia.

*There is a perception about what dementia looks like (from 50 years ago) and it’s important to show people that it’s not like that.*

*Friends and community do not understand dementia takes over your brain, some expected me to go doolally straight away, others asked if I was still driving, others would prefer to ignore me, it would have been easier for them to accept my situation if I had lost the plot quicker.*

*If people know I have alzheimers, they will think I don’t know anything. They will look for problems, things I’m doing wrong.*

Comments from people with dementia

1. The language used can also be misleading. People with early stage dementia talked to us about needing support, not care. They said they were reliant on others for some things, not dependent. Their families were reliant on them for some things too. Maintaining independence was very important, with support to make decisions if required.
2. Increasing understanding of dementia and how best to assist people with dementia goes hand in hand with the dementia-friendly communities model. Dementia-friendly communities are characterised by a physical environment and social community that enhances inclusion and enables people with dementia to maintain greater independence and have greater choice and control over their lives. A whole of community response is required with local government and businesses playing a key role.
3. There is an opportunity to build on work that has already been done. For example, the New Zealand Bankers Association’s 2009 guidelines to assist banks to meet the needs of older and disabled customers could be reviewed and amended, if required, to address the particular needs of customers with dementia. Rebuilding, such as that underway in Christchurch, offers unique possibilities to consider how to design-in dementia-friendly features, which would also benefit the wider disability community and others such as tourists and families.
4. There are many international examples of dementia-friendly community initiatives. For example, Scotland’s Dementia Friends programme encourages people to learn about dementia and the small things they can do to help. Eighty-two communities across England have signed up to the national Dementia Friendly Communities recognition process. Activities include setting up regular groups for carers and people with dementia, and community awareness events in schools and libraries.
5. Local businesses can play a key role in promoting community inclusion. For example, in 2014, all Marks & Spencer’s staff became dementia friends and they are now training Dementia Champions for each store. These people will be better able to recognise and help people showing signs of dementia while shopping. They will also be active in raising awareness in their local communities.
6. In the broader context, dementia-friendly cities improve their street signage, footpaths and public transport systems to better meet the needs of people with dementia. They are designed in a way that encourages everyone to remain active, walk more, and use active transport where possible.
7. Similarly, health and social support centres can be designed to enable and support people with dementia. In the UK, the King’s Fund has developed assessment tools for hospitals, care homes, primary care premises and specialist housing providers to encourage improvements in the physical environment and the way the environment encourages people to behave and interact.[[6]](#footnote-6) Relatively inexpensive interventions, such as changes to lighting, floor coverings and signage can have a significant impact on decision-making, agitation and distress, and independence and social interaction.

### What is currently happening

* Alzheimers New Zealand’s dementia awareness campaign – *Let’s Get Our Heads Around Dementia* – focuses on raising awareness of dementia symptoms, available support services and the advantage of an early diagnosis.
* Karen Smith, a Registered Nurse trained in dementia studies in Scotland, interviewed people with dementia in a research project[[7]](#footnote-7) about what would improve their quality of life in a rebuilt Christchurch. Based on the findings, she recommends that New Zealand adopt a dementia-friendly cities approach.
* Initial discussions in Auckland have explored how the needs of people living with dementia can be included in the Auckland Design Manual (a best practice resource on design and the built environment).
* As part of its commitment to community based dementia friendly services, Alzheimers Canterbury offers normalised activities for people with dementia including gardening at the botanical gardens, and book and art appreciation groups.
* Westpac became New Zealand’s first dementia-friendly bank in 2015; trained staff will be better able to assist where needed and a clear layout with signs, displays and lighting will help support independent navigation.
* The Office for Senior Citizens is encouraging New Zealand communities to become age-friendly.
* Alzheimers New Zealand is currently developing a programme to formally recognise organisations as being dementia-friendly and expect to launch the recognition programme by mid-2016. They are also planning a dementia friends programme to recognise individuals who are making a contribution to dementia-friendly communities.

### What does NEAC recommend?

1. NEAC recommends:

* development of a cross-sector dementia friendly initiative that includes:
  + a programme to increase social inclusion and reduce stigma
  + addressing the needs of people with dementia in urban redevelopment plans
  + support for local government initiatives
  + incentives for businesses to become dementia-friendly
  + design of hospitals, health and social support centres, and residential care facilities to meet the needs of people with cognitive impairments and dementia.

## Planning ahead

1. Having good information on New Zealanders currently living with dementia and expected numbers in the future helps us to plan ahead so that we can better meet the full range of needs for people with dementia and their families.
2. New Zealand does not collect reliable data on dementia. We are currently reliant on Alzheimer’s Disease International’s estimates of the global prevalence and incidence of dementia (the most recent updates were included in the World Alzheimer Report 2015).
3. Planning ahead is also important for individuals, no matter what age or health status. It is good for us all to think about what we want to happen should we no longer be able to make decisions for ourselves. A timely diagnosis of dementia is important for this reason. It enables families and people with dementia to talk about the future and what matters to them. It also means that people can record the things that are important to them, when they are still able to do so. It is important that all health care providers are aware of and able to access any such information.
4. The advance care planning process, involving discussion and shared planning for future health care between a person and health professionals, helps people to explore their wishes, values and preferences. An advance care plan, advance directive and Enduring Powers of Attorney (for both personal care and welfare, and property)[[8]](#footnote-8) are ways in which a person’s specific preferences can be recorded. These mechanisms provide a way for people to have some say about how they want to be treated, how they want decisions to be made as their illness progresses (eg, progressing from supported decision making to decisions being made on their behalf) and who they want involved in this
5. Enduring Powers of Attorney can also provide some protection against abuse. They need to be something that all New Zealanders pay attention to, not just people with dementia.
6. Many of the family carers we talked to told us about how the process of decision-making changed over time. People with early stage dementia were able to make decisions with little or no support. As the disease progressed, more support was required until the carer took responsibility for making decisions.

*It used to be ‘us’ when making decisions, now it’s ‘me’ – what I think is best. I try to include my partner but sometimes that can just make it too difficult. It is still good to ask; sometimes they will have a great idea.*

*A trusted family member can make a huge difference to the length of time that a person can continue to do things. My husband used to change his bank account pin number and it was really difficult when he couldn’t remember it. The bank was really resistant to me being involved but it means that my husband can continue to use his bank account.*

*Enduring Powers of Attorney needs to be about assistance, not ‘them’ or ‘me’. Currently the carer either has to be completely responsible or the person is completely responsible.*

Comments from family carers

1. Stakeholders raised concerns about:

* the response of GPs to memory and behaviour concerns, and in particular, their reluctance to make a diagnosis of dementia
* lack of information and cost acting as barriers for setting up Enduring Powers of Attorney
* lack of advice on the role and challenges of being an attorney
* the all or nothing nature of Enduring Powers of Attorney - this does not adequately recognise that capacity is decision-specific
* insufficient guidance and lengthy process for DHBs when applying for the appointment of a Welfare Guardian and/or Property Manager or Administrator where a person does not have an Enduring Power of Attorney
* lack of legal recognition for supported decision-making.

1. Internationally, there is a growing demand for supported (rather than substituted) decision-making systems based on the person’s will and preferences, not what might be perceived as his or her best interests.[[9]](#footnote-9) The Australian Law Reform Commission’s review of equal recognition before the law and legal capacity for people with disability recommended reform of laws and legal frameworks based on decision-making principles and guidelines.[[10]](#footnote-10) The principles and guidelines are aimed at ensuring that supported decision-making is encouraged, representative decision-makers are appointed only as a last resort, and the will, preferences and rights of individuals direct decisions that affect their lives.

### What is currently happening?

* Work is underway to ensure standardised assessment and diagnosis in primary care. For example, the Northern Region Cognitive Impairment Clinical Pathway promotes early identification and intervention, and encourages collaboration with specialist services to support cognitive impairment diagnosis and treatment by GP teams. The pathway is a collaborative effort with Waitemata PHO, Procare, Alzheimers Auckland and the University of Auckland.
* Advance care planning tools and resources are available through the National Advance Care Planning Cooperative’s website. The Ministry of Health has developed ‘Advance Care Planning: A guide for the New Zealand healthcare workforce’ and NEAC has produced advice for health professionals on the ethical challenges in advance care planning. To increase awareness about advance care planning, the Cooperative promotes a ‘Conversations that Count Day’.
* The Office for Senior Citizens has developed a range of resources on Enduring Powers of Attorney, how to set one up and what an attorney does. Other resources include a checklist of things to do before seeing a legal professional and copies of the standard forms that need to be completed.
* Alzheimers New Zealand has partnered with the Public Trust to offer people with dementia and their families a free half hour consultation where they can access advice on, for example, writing or updating a will and setting up an Enduring Power of Attorney.
* Amendments to the Protection of Personal and Property Rights Act 1988 are currently being considered by the Government Administration Committee as part of the Statutes Amendment Bill. The amendments and new regulations will result in simpler forms and a standard explanation of the effects and implications of an Enduring Power of Attorney. Changes are also being made to make the witnessing requirements less cumbersome for people appointing each other as mutual attorneys. The Committee is due to report back in June 2016.
* The Office for Disability Issues is leading work, supported by the Human Rights Commission, on what is needed to ensure that disabled New Zealanders can experience their right for equal recognition before the law (under Article 12 of the Convention on the Rights of Persons with Disabilities). Analysis and recommendations will be presented to the Ministerial Committee on Disability Issues. A first step is developing a shared understanding of Article 12, and as part of this, the Office is working with Auckland Disability Law to bring together and promote good practice in supported decision-making.

### What does NEAC recommend?

1. NEAC recommends:

* an improved system of data collection on the incidence and prevalence of dementia to inform national and local planning, alongside research that captures the views of people with dementia and their caregivers
* increased promotion of advance care planning and training for health care professionals
* a national approach to actively promote Enduring Powers of Attorney including widespread availability of information and use of subsidies to remove any financial barrier
* education of attorneys so that they understand and can act in a way that is consistent with a supported decision-making model, with a particular focus on communicating with a person with dementia
* a consistent and streamlined process for appointing a Welfare Guardian and/or Property Manager or Administrator where there is no Enduring Power of Attorney, including access to an adequate pool of paid or voluntary welfare guardians, managers or administrators.

## Supporting families, whānau and friends

1. Good information and support for families, whānau and friends is critical, not only for the person with dementia but also for those providing care and support. Family carers commonly talked about feeling very stressed, alone and unsupported. There was also a sense that each family had to work things out for themselves, even though the issues they faced were similar.

*People don’t understand what it is like. I am not sleeping very well and people just say that’s normal for older people.*

*It is very hard to have a life. I am still married but it’s not a marriage; he is no longer my husband. Sometimes I feel I have mortgaged my life to the illness.*

*It can be very lonely; people stay away and there is a lot of judgement from people who are not living with the situation every day.*

*Friends and family may not understand why the person is in residential care as he seems alright to them. I also get it from my partner, why are you leaving me alone? I feel very guilty.*

Comments from family carers

1. Support needs to be flexible to meet the needs of individual families and whānau. The family carers we talked to wanted:

* accessible, easy to understand information on dementia and providing care
* someone to talk to about their situation, help them identify options and make decisions
* someone to help them access social support and health care
* practical advice and support at transition points (eg, understanding responsibilities of an enduring power of attorney, deciding on residential care)
* more respite as well as a greater range of respite options, including age-appropriate respite for younger people with dementia.

1. Information and support is available from local Alzheimers organisations or similar community groups. Stakeholders spoke very highly of the support provided by such groups, but noted that not everyone has access to a good level of support. NEAC understands that one of the reasons for variable support is an inconsistent approach to contracting such services across DHBs.
2. The importance of a navigator or first point of contact for the person with dementia and their family and whānau is recognised in New Zealand’s Framework for Dementia Care (Ministry of Health, 2013). A navigator is expected to provide active support and information throughout the dementia journey including on health and social support services, reducing or preventing challenging behaviours, the role of enduring power of attorney and transitions of care. In the UK, specialist dementia nurses (called Admiral Nurses) fill this type of role, giving practical, clinical and emotional support to families living with dementia. They help join up different parts of health and social care, offer advice on referrals, and can liaise with health and social care professionals on a person or family’s behalf.
3. All family carers we talked to experienced difficulty in accessing day programmes and residential respite. One couple had to wait seven months before there was a vacancy on a day programme. Another carer told us they had to approach five different residential facilities before they were able to making a booking for residential respite.
4. Families wanted access to short-term, ad-hoc respite so that they could have time out from caring. This is critical for the wellbeing of carers.
5. DHBs contract with residential care facilities to provide respite, but as there are not designated beds for respite, availability is variable and it can be difficult for families to plan ahead. Some DHBs are supporting innovative ways of providing respite (eg, people providing home-based respite for small groups of people with dementia) but we understand this is very limited.

### What is currently happening?

* Alzheimers New Zealand is leading work to update and increase accessibility of information for people with dementia and their families. *About Dementia* provides easy to understand information on dementia, getting a diagnosis, support following a diagnosis and planning ahead. Other resources are being developed on providing good care, long-term residential care, and the later stages of dementia and end of life care.
* Providing navigation of services and increasing the quality of dementia information and education is one of nine Ministry of Health actions. [[11]](#footnote-11) NEAC understands that progress is slow with establishing navigator roles.

### What does NEAC recommend?

1. NEAC recommends:

* that resources developed by Alzheimers New Zealand are widely available and consistently used by health and social support providers
* all DHBs be required to include navigator roles in their Cognitive Impairment or Dementia Pathways
* that a family meeting and planning for the future becomes an integral part of normal clinical practice at the time of diagnosis, with referrals to Alzheimers New Zealand or other community support organisations
* all DHBs increase availability of respite services that better meet the needs of people with dementia (including younger people) and their families.

## Delivering quality health and social support services

1. People with dementia and their families and whānau interact with a range of health and social support services. It is important that all services are high quality, with a focus on understanding and meeting the needs and wants of the person with dementia and their families and whānau.

*Impact of poor quality care*

1. Poor quality care can have a significant impact on health and wellbeing. This is particularly apparent in hospital settings.
2. Australian research indicates that people with dementia are more likely to be admitted to hospital and experience worse clinical outcomes including longer stays in hospital and higher mortality.[[12]](#footnote-12) UK research found that 47% of people with dementia who went into hospital experienced a deterioration in their physical health (eg, weight loss, malnutrition, dehydration) and 54% had an increase in dementia symptoms (eg, becoming more confused, less independent and more distressed).[[13]](#footnote-13)
3. Family carers that NEAC talked to shared their stories about inadequate care in hospitals and how this had a major impact on health outcomes. One of the carers talked about how she was unable to visit her father in hospital because of a norovirus outbreak and when she finally got to see him he was severely dehydrated (water was available but he did not drink it). Another talked about the unwillingness or inability of staff to manage behavioural issues such as night walking and their insistence that the person be discharged early to avoid the disruption of their behaviour.
4. Others carers talked about how nursing staff would assist with or take over functions that the person with dementia was able to perform without assistance and this could result in a rapid deterioration in independence.
5. Poor quality care can also impact on the health and wellbeing of family carers. Carers commonly talked about how stressful it was when the person with dementia was in hospital (or respite care). For them, caring responsibilities did not stop and they were constantly worrying about level of care.

### Ethical values for high quality care

1. High quality care is underpinned by the six ethical values: respect/mana, people first, independence, interdependence, best interests and solidarity. Of particular interest to NEAC is how to ensure care is based on:

* knowing the person with dementia (people first)
* supporting their independence
* recognising the interdependence between the person with dementia and their family, whānau and friends.

1. People first is about treating the person as an individual with their own values, interests, likes and dislikes. Knowing the person with dementia and what is important to them means that care and support can be tailored to meet their particular needs and interests. An important part is helping to maintain the person’s identity through environmental cues and appropriate activities.

*I like to have a shed to make things in, being able to go for a walk and spending time on the computer.*

*I used to enjoy bringing in the hay. I would love to do that again.*

*My husband is still intellectually on the ball. He is not interested in going to the park and eating his lunch on a bench. One of the art galleries ran a tour for people with early stage dementia and he really loved that.*

Comments from people with dementia and family carers

1. Living well is about much more than physical health. It is also about social inclusion and maintaining independence as much as possible. This is particularly important for people living in the community; there needs to be good access to a range of community and home based services and support to enable the person to live well in the community for as long as possible. This includes age-appropriate services and support for younger people with dementia.
2. Maintaining independence is also important for people living in residential care. NEAC heard about residential care facilities where a focus on minimising risk was having a detrimental impact on quality of life for people with dementia. Some stakeholders suggested that policies and rules limit the ability of staff to support residents to maintain daily living skills.
3. It would appear, at face value, that the contractual requirements in the Age Related Residential Care Services Agreement adequately cover the need for services to reflect the values of people first, independence and interdependence. For example, services must be resident centred and promote independence and quality of life.[[14]](#footnote-14) However, such minimum standards do not ensure best practice in dementia care.
4. While some residential care facilities have adopted best practice models for dementia care, more needs to be done to ensure this is the expected standard. People with dementia and their families, whānau and friends need to be able to make choices about residential care facilities based on the model of care.
5. NEAC also considers there would be value in exploring how dignity of risk could be applied in residential care. Dignity of risk is about the right of people to take risks when engaging in life experiences and the right to fail. Upholding such a principle in residential care would require a shift from a focus on protection and prolonging life, to promoting and enabling residents to exercise their right to take risks in order to have a higher quality of life.

### Recognising the role of families

1. Finally, recognising the role of families is integral to quality care for people with dementia. Family carers know a lot about what the person needs day to day and if health and social support workers can tap into this knowledge, care will be much improved.
2. Some family carers wanted to have an active caring role when their family member was in hospital and suggested that New Zealand should have something similar to John’s Campaign in the UK. This campaign is about carers having the right, but not a duty, to have 24-hour access to a patient in hospital with dementia.
3. Others talked about how they were not consulted before medical treatment was provided even though, in some cases, they were the personal care and welfare attorney. One family carer talked about her husband receiving regular enemas to relieve constipation without her consent. This meant that other, less intrusive treatments that had worked in the past were not tried first. She was also concerned about the distress her husband may have experienced from the treatment.

### What is currently happening?

* The National Health IT Board is leading work to establish a single electronic health record that will enable clinicians, working in hospitals and in the community, to access patient information in one place. A single electronic health record is expected to improve care coordination. A Health Information Governance Framework will set the standards on information sharing and privacy, including access controls and ways that sensitive information can be withheld.
* All DHBs are required to develop Cognitive Impairment or Dementia Pathways. The working plans need to support better and more timely diagnosis of dementia and initiation of a comprehensive management plan. The Better Brain Care Programme in Auckland DHB hospitals includes cognitive assessments for all patients over 75, engaging with families/carers, providing appropriate care, and ensuring safe discharge and follow-up.
* The Spark of Life, the Eden Alternative and the Dementia Care Mapping approach are the main programmes for enhancing person-centred care in aged residential care in New Zealand.
  + The ‘Spark of Life’ philosophy focuses on meeting the social and emotional needs of people with dementia – to feel appreciated, joyful, loved and involved. It has been adopted by several residential care providers in New Zealand eg, Enliven, Presbyterian Support Central; Mercy Parklands, Ellerslie, Auckland; Kingswood Healthcare, Waikato.
  + The Eden Alternative aims to reduce loneliness, helplessness and boredom through loving companionship and meaningful activities. Elizabeth Knox Home and Hospital, Epsom, Auckland achieved full Eden Alternative registration in February 2014.
  + Dementia Care Mapping involves developing action plans for individuals or groups based on observing behaviours, mood and engagement, and the quality of interactions with staff.

### What does NEAC recommend?

1. NEAC recommends:

* development and implementation of easy to follow instructions for hospital staff admitting someone with dementia, alongside good pathways for managing confusion
* incentives to encourage adoption of person-centred care programmes in aged residential care
* that the Health Quality and Safety Commission and the Health and Disability Commissioner develop mechanisms to encourage health and social support providers (including aged residential care) to focus less on risk and more on quality of life.

## Developing a skilled health and social support workforce

1. The person with dementia and their family will have contact with a wide range of health and social support workers. This includes, for example, general health professionals (podiatrists, dentists, physiotherapists), day to day care workers and community support workers. All health and social support workers need to have a good understanding of dementia and how to provide high quality care. More in-depth training is required for those working with people with dementia. People first or person-centred care knowledge is critical as people living with dementia often face challenges relating to stigma and capacity-eroding aspects of their care.
2. For aged residential care there are some training requirements but these are primarily for staff in dementia units. In particular, there must be a registered nurse with experience and training in the care of people with dementia, and all caregivers (not including registered or enrolled nurses) must have passed specific unit standards no later than 12 months after their appointment. The unit standards cover knowledge of dementia, person-centred care, managing the effects of dementia and supporting people when their behaviour presents challenges.
3. While it is good to see such contractual requirements, they need to be strengthened. It is simply not good enough to have caregivers in dementia units with no training on dementia. In fact, all caregivers in residential care need such training because 60-80% of people in residential care have dementia.[[15]](#footnote-15)
4. For other workers, including those working with older people, there do not appear to be any specific training requirements. Understanding dementia and providing quality care should be included in all undergraduate courses for health professionals. There also needs to be accessible training for all current health and social support workers and ongoing development plans.
5. Further, it is important that those working with people with dementia have access to specialist support such as dementia nurse specialists and psychogeriatricians.
6. NEAC considers there would be value in developing a training framework that sets out the expectations for all health and social support workers. A good example is the UK Dementia Core Skills Education and Training Framework[[16]](#footnote-16) that sets out the essential skills and knowledge necessary for all UK health and social care staff. This Framework is based around three tiers: 1 – awareness for all workers in health and social care settings; 2 – basic skills for those having regular contact with people with dementia; 3 – knowledge, skills and attitudes for managers and other leaders working with people with dementia.
7. Several stakeholders noted that the lack of recognition for paid carers of people with dementia has a significant impact on what can reasonably be expected in training. The pay levels for community and residential care and support workers are not commensurate with the knowledge and skill required to provide high quality care for people with dementia. NEAC notes the current negotiations over pay rates for care and support workers and the joint working group on pay equity principles that was expected to report to Ministers by the end of March 2016.

### What is currently happening?

* Increasing the quality of information and education for the workforce is one of nine Ministry of Health actions (*Improving the Lives of People with Dementia*, August 2014). $1.2 million was committed in Budget 2013 to increase dementia training for support workers.
* Walking in Another’s Shoes, a New Zealand dementia care training programme, is operating in three Central DHBs and all five Southern DHBs. The focus is on training aged residential and home-based carers.
* Careerforce, in partnership with Alzheimers New Zealand and Walking in Another’s Shoes, have developed a brief person-centred care-informed training package for all home-based care workers called ‘Open Minds, Open Doors’
* DHBs are responsible for dementia behavioural support and advisory services. The objective of these services is to provide a consultation, liaison, advice, information and education service by experienced clinicians, to the community including people with dementia, carers, and other service providers. In addition, geriatricians and gerontology nurse specialists provide support and education to primary health care and aged residential care health professionals.

### What does NEAC recommend?

1. NEAC recommends:

* Health Workforce New Zealand leads the development of a comprehensive, national workforce development plan for dementia covering all current and future health and social support workers
* that dementia training for health and social support workers include understanding and implementing person-centred care
* the Age Related Residential Care Services Agreement and contracts for home-based support services include mandatory dementia training and qualifications for all caregivers and managers
* remuneration for all caregivers is commensurate with increased requirements for dementia training and qualifications.

## Bibliography

(This bibliography is a list of published work that has informed NEAC’s work on dementia.)

Alzheimer Europe. 2014. *Ethical dilemmas faced by carers and people with dementia*. URL: alzheimer-europe.org/Publications/Alzheimer-Europe-Reports

Alzheimer’s Australia. 2014. *Dementia Care in the Acute Hospital Setting: Issues and Strategies*. Australia: Alzheimer’s Australia.

Alzheimer’s Australia. 2015. *Caring for someone with dementia: The economic, social, and health impacts of caring and evidence based supports for carers.* Australia: Alzheimer’s Australia.

Alzheimer’s Disease International. 2015. *World Alzheimer Report 2015: The Global Impact of Dementia: An analysis of prevalence, incidence, costs and trends*. London: Alzheimer’s Disease International.

Alzheimer’s Society. 2009. *Counting the cost: Caring for people with dementia on hospital wards.* London: Alzheimer’s Society.

Alzheimers New Zealand. 2012. Updated Dementia Economic Impact Report, 2011, New Zealand. URL: [www.alzheimers.org.nz/getmedia/557692aa-2ccd-4f38-8fdc-db440706fd05/Updated\_Dementia\_Economic\_Impact\_Report\_2012\_New\_Zealand.pdf.aspx](http://www.alzheimers.org.nz/getmedia/557692aa-2ccd-4f38-8fdc-db440706fd05/Updated_Dementia_Economic_Impact_Report_2012_New_Zealand.pdf.aspx)

Alzheimers New Zealand. 2012. Economic Impact of Dementia in New Zealand: Executive Summary. www.alzheimers.org.nz/getmedia/2fa9d0e6-16dd-483a-9730-4216f9aaccb5/DEIR\_2012\_Executive\_Summary.pdf.aspx

Alzheimers New Zealand Incorporated. 2008. Dementia Economic Impact Report 2008. URL: [www.alzheimers.org.nz/getmedia/fecb6fcd-c93c-4647-89ed-9949b9c53e15/Dementia\_Economic\_Impact\_Report2008.pdf.aspx](http://www.alzheimers.org.nz/getmedia/fecb6fcd-c93c-4647-89ed-9949b9c53e15/Dementia_Economic_Impact_Report2008.pdf.aspx) (accessed 2 September 2015)

Australian Law Reform Commission. 2014. *Equality, Capacity and Disability in Commonwealth Laws: Summary Report*. URL: www.alrc.gov.au/publications/equality-capacity-disability-124-summary

Cook A. 2008. *Dementia and well-being: Possibilities and challenges*. Scotland: Dunedin Academic Press Ltd

Cook C, Hominick K, Murray C-A, White H. 2013. *The Dignity of Risk and Older Patients: Workshop Resource Book*. Geriatric Medicine Research. URL: dignityofrisk.com/wp-content/uploads/2014/01/DoR-Resource-Workbook-Oct-15-1.pdf

Department of Health. 2015. *Prime Minister’s challenge on dementia 2020*. www.gov.uk/government/uploads/system/uploads/attachment\_data/file/414344/pm-dementia2020.pdf

Dresser R. 1995. Dworkin on Dementia: Elegant Theory, Questionable Policy. *The Hastings Centre Report* 25(6):32-38

Downs M, Bowers B (eds). 2008. *Excellence in dementia care: Research into practice*. England: Open University Press.

Downs M, Bowers B (eds). 2014. *Excellence in Dementia Care: Research into practice*. England: Open University Press.

Dworkin R. 1986. Autonomy and the Demented Self. *The Milbank Quarterly* 64(2): 4-16

German Ethics Council. 2012. *Dementia and self-determination: Opinion*. German Ethics Council

Holm S. 2001. Autonomy, authenticity or best interest: Everyday decision-making and persons with dementia. *Medicine, Health Care, and Philosophy* 4:153-159

Hope T. 2010. Ethical issues and dementia: the Nuffield Report. *Clinical Ethics* 5: 3-6.

Hughes JC. 2014. *How we think about dementia: Personhood, rights, ethics, the arts and what they mean for care*. London: Jessica Kingsley

Ibrahim JE, Davis M-C. 2013. Impediments to applying the ‘dignity of risk’ principle in residential aged care services. *Australasian Journal on Ageing* 32(3): 188-193.

Jaworska A. 1999. Respecting the Margins of Agency: Alzheimer’s Patients and the Capacity to Value. *Philosophy and Public Affairs* 28(2): 105-138

Mental Health Foundation. 2015. *Dementia, rights and the social model of disability: A new direction for policy and practice?* URL: www.mentalhealth.org.uk/publication-download/dementia-rights-and-social-model-disability

Minister for Senior Citizens. 2014. *Report of the Minister for Senior Citizens on the review of the amendments to the Protection of Personal Property Rights Act 1988 made by the Protection of Personal and Property Rights Amendment Act 2007*. Wellington: Ministry of Social Development.

Ministry of Health. 2013. New Zealand Framework for Dementia Care. Wellington: Ministry of Health

Ministry of Health. 2014. *Improving the Lives of People with Dementia*. URL: www.health.govt.nz/publication/improving-lives-people-dementia

Ministry of Social Development. 2014. *The New Zealand Carers’ Strategy Action Plan for 2014 to 2018*. Wellington: Ministry of Social Development.

Nuffield Council on Bioethics. 2009. *Dementia: ethical issues*. London: Nuffield Council on Bioethics

Office for Senior Citizens. 2015. *2014 Report on the Positive Ageing Strategy*. Wellington: Office for Senior Citizens.

Perkins C. 2013. *Dementia: What you need to know. A guide for people with dementia, and their caregivers*. Auckland: Random House.

Post SG. 2014. Dementia. In Jennings B (ed) *Bioethics 4th Edition.* USA: Macmillian Reference.

Radha Krishna LK. Accounting for personhood in palliative sedation: the Ring Theory of Personhood. *Medical Humanities* 40: 17-21

Sanderson H, Bailey G. 2014. *Personalisation and dementia: A guide for person-centred practice*. London and Philadelphia: Jessica Kingsley Publishers

Skills for Health, Health Education England, Skills for Care. 2015. *Dementia Core Skills Education and Training Framework*. URL: www.skillsforhealth.org.uk/images/projects/dementia/Dementia%20Core%20Skills%20Education%20and%20Training%20Framework.pdf?s=cw2

Smith E. 2012. *The Black Hole: the challenge of young onset Alzheimer’s*. New Zealand: AM Publishing

Smith K. *Developing a Dementia-Friendly Christchurch: Perspectives of people with dementia*. URL: [ageconcerncan.org.nz/media/files/Developing\_a\_Dementia-Friendly\_Christchurch.pdf](http://ageconcerncan.org.nz/media/files/Developing_a_Dementia-Friendly_Christchurch.pdf) (Accessed 3 September 2015)

Thomas C, Milligan C. 2015. *How Can and Should UK Society Adjust to Dementia?* Joseph Rowntree Foundation URL: www.jrf.org.uk/sites/files/jrf/society-adjust-dementia-summary.pdf

United Nations Committee on the Rights of Persons with Disabilities. 2014 *General comment No 1 (2014) Article 12: Equal recognition before the law*. URL: documents-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement

Victorian Government Department of Human Services. 2012. *Supporting Decision Making: A guide to supporting people with a disability to make their own decisions*. Melbourne: Disability Services Division, Victorian Government Department of Human Services.

Woods B, Pratt R. 2005. Awareness in dementia: Ethical and legal issues in relation to people with dementia. *Aging and Mental Health.* 9(5): 423-429

1. WHO recognises dementia as a public health priority and in 2015, hosted the First WHO Ministerial Conference on Global Action Against Dementia. At least 19 countries have a national dementia policy or plan including Australia and the UK. [↑](#footnote-ref-1)
2. Some content from the Ministry of Health website <http://www.health.govt.nz/your-health/conditions-and-treatments/mental-health/dementia> [↑](#footnote-ref-2)
3. The World Alzheimer Report 2015: *The Global Impact of Dementia: An analysis of prevalence, incidence, costs and trends*. <http://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf> [↑](#footnote-ref-3)
4. Alzheimers New Zealand’s *Updated Dementia Economic Impact Report, 2011, New Zealand* (January 2012). [↑](#footnote-ref-4)
5. Alzheimer’s Australia. 2015. *Caring for someone with dementia: The economic, social, and health impacts of caring and evidence based supports for carers.* Australia: Alzheimer’s Australia [↑](#footnote-ref-5)
6. http://www.kingsfund.org.uk/projects/enhancing-healing-environment/ehe-design-dementia [↑](#footnote-ref-6)
7. Smith K. Developing a Dementia-Friendly Christchurch: Perspectives of people with dementia. URL: <http://ageconcerncan.org.nz/media/files/Developing_a_Dementia-Friendly_Christchurch.pdf> (Accessed 3 September 2015) [↑](#footnote-ref-7)
8. Personal care and welfare covers health, accommodation and associated care decisions, and comes into effect only if a medical professional or the Family Court decides the person has become ‘mentally incapable’. Property covers money and assets and can come into effect before the person loses mental capacity. [↑](#footnote-ref-8)
9. United Nations Committee on the Rights of Persons with Disabilities, 2014 *General comment No 1 (2014) Article 12: Equal recognition before the law*. [↑](#footnote-ref-9)
10. Australian Law Reform Commission, August 2014. *Equality, Capacity and Disability in Commonwealth Laws: Summary Report*. [↑](#footnote-ref-10)
11. Ministry of Health. 2014. *Improving the Lives of People with Dementia*. Wellington: Ministry of Health. [↑](#footnote-ref-11)
12. Alzheimer’s Australia. 2014. *Dementia Care in the Acute Hospital Setting: Issues and Strategies*. Australia: Alzheimer’s Australia. [↑](#footnote-ref-12)
13. Alzheimer’s Society. 2009. *Counting the cost: Caring for people with dementia on hospital wards.* London: Alzheimer’s Society. [↑](#footnote-ref-13)
14. Services must also maximise potential for self-help and involvement in the wider community, and acknowledge, value and encourage the involvement of families/whānau in provision of care. Additional requirements for specialist dementia services include providing support and care that is flexible and individualised, focused on promoting quality of life and minimising need for restrictive practices through managing challenging behaviour. [↑](#footnote-ref-14)
15. In Alzheimers New Zealand’s 2008 Dementia Economic Impact Report it is assumed that people with dementia comprise 100% of people in specialist dementia services and 55% in all other residential care levels. URL: <http://www.alzheimers.org.nz/getmedia/fecb6fcd-c93c-4647-89ed-9949b9c53e15/Dementia_Economic_Impact_Report2008.pdf.aspx> (accessed 2 September 2015) [↑](#footnote-ref-15)
16. http://www.skillsforhealth.org.uk/images/projects/dementia/Dementia%20Core%20Skills%20Education%20and%20Training%20Framework.padfiton [↑](#footnote-ref-16)