



# Alzheimer's *New Zealand*

## Alzheimer's New Zealand

### Dementia Services and Standards

*A dementia friendly New Zealand – Aotearoa, he aro nui ki te hunga mate wareware*

#### Introduction

Many New Zealanders think of dementia as a disease of older people, because it is more common as people age. Dementia also affects people as young as 40, and care partners are often young and working age. It is also increasingly understood as a chronic condition that creates a disability. There are currently around 62,300 people in New Zealand with dementia. Predictions are that this number will increase to about 102,000 in 2030, and almost triple to around 170,000 people with the disease by 2050<sup>i</sup>.

The New Zealand population is changing. Along with an increasing proportion of older people, many of whom will develop dementia, the number of people who identify as Maori, Pacifica and Asian is also increasing. The prevalence of dementia in all communities is likely to increase at a similar rate to that of the general population.<sup>ii</sup>

*“Dementia is a costly and heart-breaking epidemic with an immense impact, medically, psychologically, emotionally, and financially. I can think of no other condition that has such a profound effect on loss of function, loss of independence, and the need for care. I can think of no other condition that places such a heavy burden on society, families, communities, and economies.” Dr Margaret Chan, Director-General of the World Health Organisation.*

With timely and appropriate support, people with dementia can continue to live their everyday lives well, and as productive, valued and socially-connected members of their communities. Improving awareness and reducing risk factors, combined with early recognition and culturally appropriate intervention, increases the wellbeing and quality of life for people with dementia, and for their families and carers. Investment in good services in the community, can delay the need for residential care, and reduce the lifetime costs of dementia care for individuals, and for the state.

#### Why are the Alzheimer's NZ Dementia Services and Standards Important?

The Alzheimer's New Zealand collective of Member organisations (herein after referred to as Alzheimer's NZ), is committed to optimising the independence, health and wellbeing for people living with dementia. The availability of more nationally consistent services, that are quality assured, is a fundamental right for people living with dementia, no matter where in New Zealand they live, or who provides these services.

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Alzheimers NZ Dementia Services and Standards have been developed to honour this right. They build on previous work by Alzheimers NZ<sup>iii</sup>, and on key strategies, policies and evidence about what works.<sup>iv v vi</sup> Importantly, they focus on what people living with dementia - i.e. people *with* dementia, and people with a relationship to the disease such as carers, support partners and families - have told us they need now, and what services and supports will be needed into the future. The service model also responds to consultation with Members of Alzheimers NZ, and from individuals and organisations with expertise in dementia.

The Alzheimers NZ Dementia Services and Standards model aims to identify good practice, and to support changes that are evidence-based, and that can make a measurable difference to the services people living with dementia experience. It aligns with national strategies such as the NZ Dementia Care Framework, and the Healthy Ageing Strategy, and with initiatives such as the primary care cognitive care pathways. It integrates the principles of partnership, participation and protection, as outlined in the Treaty of Waitangi.

Our Service model is underpinned by the Principles that people living with dementia have the right

- to live their everyday lives, well;
- to high quality, culturally appropriate and responsive services, no matter where in New Zealand they live, or who provides the service;
- to be accepted, respected and valued in all our communities.

Our stakeholders (people with dementia, people living with dementia, carers and support partners, communities, funders, donors, and other service providers) will know, that an Accredited Alzheimers NZ Dementia Service provider meets quality standards, is committed to ongoing improvement, and upholds the rights of *all* people with, and living with dementia<sup>vii</sup>.

#### What are the Alzheimers NZ Dementia Services?

The Alzheimers NZ Dementia Services reflect a rights-based, life-course approach. The Services:

- Are about relationships and put people at their heart
- Are designed to be agile, resilient, and sustainable over time.
- Are *our* part in holistic, integrated and continuous support for people with dementia and their care and support partners, family and whanau
- Are based on emerging research, evidence and best practice
- Reflect a collaborative partnership between people living with dementia, the Alzheimers NZ collective of member organisations, and other health and social care providers

Our Services do not exist in a vacuum. Many people living with dementia are likely to also have multiple mental and physical health conditions, and most will be receiving care and support from other services, such as through their GP. Many people caring for people with dementia are also likely to experience mental and physical health problems, directly related to the challenges and strain of providing ongoing, day to day support and care.<sup>viii</sup>

Some components of the Alzheimers NZ Dementia Services may, in whole or in part, be offered or provided by others, for example help and advice in a crisis<sup>ix</sup>, education seminars, or some therapies.<sup>x</sup> And some people may only connect briefly with one or two Alzheimers NZ Dementia Service offerings. Support,

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education, information and advocacy may weave in and out with differing emphasis, as needs arise, and circumstances change.

Alzheimers NZ Dementia Service providers have an obligation to support people living with dementia to reach across and into, many other services, such as for housing, welfare or legal support. Care planning, and a responsive care pathway, led by a person living with dementia, can help to identify roles and responsibilities, connect activities, including making timely referrals to other, or more specialized services, and to monitor outcomes.<sup>xi xii xiii</sup>

The service model allows for flexibility in the approaches, processes or tools used, according to local contexts (including cultural, community and geographic), and individual preferences and priorities. Strengthening *our* services, and highlighting the network of culturally relevant, quality services that people can choose to access, are key components of our service model. They are also an obligation of membership to Alzheimers NZ.<sup>xiv</sup>

The four core Alzheimers NZ Dementia **Services** are

1. Awareness and Risk Reduction – proactive and protective;
2. Walking alongside – getting and staying connected, living my everyday life, optimising health and wellbeing, skills and therapeutic, and supporting carers;
3. Transition - moving well through my journey with dementia;
4. Managing through a crisis – access to timely, knowledgeable, “real-time” response, help and support.

The Services each have several **Service Components** – or touch points - aimed at enabling and empowering people living with dementia to access the right support, at the right time, for their unique context and journey with the disease. **The Service Model is outlined in Table One.** Examples of current and potential service offerings and activities are included in the table, for illustrative purposes only.

What are the Standards for Alzheimers NZ Dementia Services?

The Alzheimers NZ Dementia Services are assessed against an agreed set of Standards. The Standards aim to provide confidence for people living with dementia, and other stakeholders, that our services are safe, of high quality, culturally appropriate, and routinely reviewed. The underpinning philosophy is that meeting the Standards provides a positive contribution and benefit for people living with dementia, without adding an unnecessary administrative burden or cost, including to service providers.

The Standards draw on, and expand, existing published Standards, so that they are dementia specific.<sup>xv</sup> They set the benchmark (minimum requirements) for services that will be acceptable for people living with dementia. And they incorporate legal and financial obligations that organisations are already required to comply with, for example those related to human rights, employment, health and safety, and financial management and reporting.

The three overarching **Standards** are: **Dementia Friendly Services; Services Respond and Deliver to the Need; and Effective Organisational Management.** The Standards are sufficiently broad, and aim to be realistic, proportionate, fair and transparent. They are intended to stimulate excellence, but at the same time, indicate the minimum standard of care and support, below which no provider is expected to operate.

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Importantly, they are designed to promote the independence, health and wellbeing and quality of life for people living with dementia.

Each Standard has several outcome-focused Components that describe an acceptable standard of level of services, from the perspective of people living with dementia. Asking what did we do, how well did we do it, did it make a difference, and what needs to change, are more important than measuring specific activities or processes. Responses can help confirm good quality care and support, identify and trace potential problems or gaps, and guide changes and improvements. **The Standards are outlined in Table Two.**

#### How do Alzheimers NZ Dementia Services and Standards work?

Members of Alzheimers NZ must be working towards offering the four core Services, and working towards meeting the Standards, however the Standards are designed to be used by any dementia service provider. The **three-yearly audit** supports organisations, in partnership with people living with dementia, to identify what's working well, and where changes might need to be made to meet the Standards.

Members that are already meet other Standards (e.g. the Home and Community Sector Standards), may use information from that audit as evidence that they meet the relevant Alzheimers NZ Standards. They are still required to undergo an Alzheimers NZ Dementia Services and Standards audit. The rationale is that the Alzheimers NZ Dementia Services and Standards are specific to the dementia context, and that other Standards are not.<sup>xvi</sup>

#### What does the audit process involve?

Members of Alzheimers NZ will be audited by small (2-3 person) audit teams. Teams will comprise people living with dementia who are from the same area as the organisation being audited, and staff or volunteers (e.g. board members) of member organisations. The team will have a good understanding about the Alzheimers NZ Dementia Services and Standards, and knowledge about dementia, in a New Zealand context. Team members should draw on their existing knowledge about good services and practice, and be encouraged to further develop their skills through experiential learning and through relevant certificate or diploma-level qualifications.<sup>xvii xviii</sup>

The three-yearly audit process is about ongoing learning and development, for the organisation being audited, and the audit team. It is designed to be enabling, to recognise existing services and local priorities. It will affirm and support organisations as they work towards meeting the Standards. Being audited and participating in the audit process as a team member, are obligations of membership to Alzheimers NZ, and help to demonstrate our commitment to people living with dementia.

The audit process will be moderated, so that the approaches and processes used by teams are consistent and fair. The outcome of each audit will be confidential to the organisation being audited, and may be published at that organisation's discretion. Over time, all audit outcomes will be published on the Alzheimers NZ website. Alzheimers NZ Dementia Services and Standards and the audit mechanism will also be available to other dementia service providers, once rolled out to all Alzheimers NZ members. **The four step audit process is outlined in table three.**

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The outcome of an audit may be published at the members discretion. From 2019, all audit outcomes will be published on the Alzheimers NZ website. Guidelines to support the audit team are included in the Alzheimers NZ Dementia Services and Standards Toolkit.

#### Meeting the costs of audit

The costs of the audit are shared by Alzheimers NZ, the organisation being audited, and the organisations providing members of the audit team.

Costs relating to set-up, development of the toolkit, coordination, and managing moderations, will be met by Alzheimers NZ. Costs incurred by the audit team members such as travel and accommodation to attend and carry out an audit, are met by their own organisations. Costs incurred by team members who are people living with dementia, and who are from the local area where a member is being audited, are met by the Alzheimers NZ member organisation in that area.

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Table One: Alzheimers NZ Dementia Services

| Service   | Service Components / Touch Points  | for example, activities might include...  |
|---|--|---|
| <p><b>1. Awareness and risk reduction</b></p> <p>Includes:</p> <ul style="list-style-type: none"> <li>• Raising awareness</li> <li>• Community acceptance</li> <li>• Education</li> <li>• Advocacy</li> </ul>   | <p>Raising awareness about dementia</p> <p>Reducing risks - health promotion &amp; education</p> <p>Delaying the onset of dementia</p> | <p>e.g. public seminars; Marae “Warrant of Fitness’ day; Memory Walks; community displays; community champions; nutrition education; BrainMatters / BrainyApp (Alzheimers Australia).</p>                           |
|   | <p>Reducing stigma and discrimination</p>  | <p>e.g. a school education programme; social media; community education campaigns e.g. Like Minds Like Mine.</p>  |
|   | <p>Dementia friendly communities.</p>  | <p>e.g. Dementia Friendly Recognition &amp; Accreditation; Education seminars for - community &amp; health care providers (e.g. GPs, allied health, social services, local councils, pharmacy), and businesses.</p> |
| <p><b>2. Walking alongside</b></p> <p>Includes:</p> <ul style="list-style-type: none"> <li>• Getting and staying connected to support</li> <li>• Reaching into the network of services</li> <li>• Living an everyday life, well</li> <li>• Skills and therapeutic interventions</li> <li>• Supporting Carers</li> </ul> | <p>Recognising Dementia – diagnosis, and early intervention</p>  | <p>e.g. information brochures; drop-in centres; library clinics; cafes; education seminars; local “maps” of the support services network.</p>   |
|   | <p>A knowledgeable, skilled and competent workforce</p>  | <p>e.g. workforce development e.g. Open Mind Open Doors, Diploma Home and Community; induction for volunteers.</p>  |
|   | <p>Coordinated and connected care and support that reaches across and into other services</p>  | <p>e.g. care coordinator/ navigator roles; care plans &amp; care pathways; documented network of support agencies; clear referral guidelines.</p>   |
|   | <p>Optimising health, independence, sense of wellbeing</p>   | <p>e.g. health promotion; nutrition; walking groups; day activity programmes; flexible respite offerings.</p>   |

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| Service  | Service Components / Touch Points  | For example, activities might include...  |
|--|--|---|
|  | Information about dementia and network of services available   | e.g. facebook; apps; library drop ins; booklets.  |
|  | Optimising function -<br>- Socialisation<br>- Group and individual therapies   | e.g. cafes; mens sheds; womens groups; buddy service; carer groups; Cognitive Stimulation Therapy; rehabilitation; art and music therapy. |
|  | Education - seminars, workshops  | e.g. working with new or challenging behaviours; maintaining /nurturing family relationships.   |
|  | Individual support, flexible respite & advocacy  | e.g. legal and financial matters; advocacy to other services, DHBs and rest homes including respite care.                                 |
| <b>3. Transition</b><br><br>Includes <ul style="list-style-type: none"> <li>• Supporting people to move well through their journey with dementia</li> <li>• Education</li> <li>• Networks</li> </ul> | Individualised and coordinated care and support  | e.g. care plans, including advanced care planning.  |
|  | Links or introduction to other health and social service providers   | e.g. provider partnerships; MOU; seminars.  |
|  | Education and information for other service providers  | e.g. education seminars with GPs, pharmacists, social workers.  |
|  | Clear and effective referral guidelines and care pathways  | e.g. informing DHB dementia / cognitive impairment pathways   |
| <b>4. Managing through a crisis</b><br><br>Includes <ul style="list-style-type: none"> <li>• Averting</li> <li>• Responding</li> <li>• Recovery</li> </ul>   | Real-time, knowledgeable expertise, information and support  | e.g. Identifying the network of "in crisis" service providers; access or referral to a real person, who can respond now...                |
|  | Education, information and resources that help reduce likelihood, severity and impact of crisis events, and optimise recovery from crisis events | e.g. Alzheimers NZ publications, booklets; online; apps; social media; interactive portals & networks                                     |

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Table Two: Alzheimers NZ Dementia Services - **Standards**

| Standard                                    | Components   | Outcome   | Criteria |
|---|--|---|----------|
| <p><b>1. Dementia friendly services</b></p> | <p><b>a) People living with dementia are at the centre of everything we do</b></p> | <p>People living with dementia are offered and receive services that</p> <ul style="list-style-type: none"> <li>• are appropriate to their unique circumstances, culture, values and beliefs</li> <li>• respect and acknowledge their rights to privacy, dignity and respect</li> <li>• are free from discrimination, abuse and neglect</li> </ul> <p>People living with dementia experience communication approaches that</p> <p>IV. are adapted and responsive to their needs and unique and changing circumstances</p> <p>V. include simple feedback mechanisms</p> <p>VI. enable a timely and appropriate response to concerns and complaints</p> |          |

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| Standard  | Components  | Outcome   | Criteria |
|---|---|---|----------|
| 2. Services respond / deliver to the need in the area | a) Service planning, delivery, and review                   | <p>People living with dementia</p> <ul style="list-style-type: none"> <li>i. are offered up-to-date, relevant information about the choice of services available and how to link with them</li> <li>ii. are equal partners in planning, reviewing and regularly adapting their care and support requirements</li> <li>iii. experience timely, appropriate and holistic services</li> <li>iv. service meet their unique needs, desired outcomes and goals</li> <li>v. experience a planned, respectful, consultative and coordinated referral to other services</li> </ul> |          |
|   | b) Preventing and responding to acute events                | <p>People living with dementia</p> <ul style="list-style-type: none"> <li>i. receive appropriate information to avert, or minimise the impact of, acute events or crises</li> <li>ii. experience relevant and timely advice, support and response to acute (dementia related) events or crises</li> <li>iii. experience support to recover well from acute events and crises</li> </ul>   |          |
|   | c) Links and networks with other organisations and agencies | <p>Alzheimers NZ Dementia Service providers</p> <ul style="list-style-type: none"> <li>i. actively build and sustain effective links with other organisations, agencies and providers</li> <li>• are an integral part of the local network of support agencies</li> </ul>   |          |

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| Standard                                      | Components  | Outcome  | Criteria |
|---|---|--|----------|
| <b>3. Effective organisational management</b> | <b>a) Governance</b>                              | Alzheimers NZ Service providers governance and organisational arrangements <ul style="list-style-type: none"> <li>i. comply with relevant legislation</li> <li>ii. demonstrate accountability to people living with dementia, and other stakeholders</li> <li>iii. ensure their financial sustainability</li> </ul>  |          |
|   | <b>b) Human resources capability and capacity</b> | <p>People living with dementia</p> <ul style="list-style-type: none"> <li>i. receive quality, relevant services from experienced, knowledgeable staff</li> <li>ii. receive quality services and support from trained volunteers</li> </ul> <p>Alzheimers NZ Dementia Service providers</p> <ul style="list-style-type: none"> <li>iii. invest in relevant and timely workforce development for their staff and volunteers</li> </ul> |          |

| Standard | Components                                    | Outcome   | Criteria |
|----------|---|---|----------|
|          | <b>c) Quality, safety and risk management</b> | <p>Alzheimers NZ dementia service providers</p> <ul style="list-style-type: none"> <li>i. provide services in safe and appropriate environments</li> <li>ii. have a documented quality and risk management system in place that</li> <li>iii. promotes the safety and wellbeing of people living with dementia and</li> <li>iv. promotes the health and safety and welfare of employees, other service users &amp; complies with legislation.</li> <li>v. ensure that equipment loaned or sold by them is safe</li> </ul> |          |
|          | <b>d) Information management</b>              | <p>People living with dementia know that information about them is:</p> <ul style="list-style-type: none"> <li>i. uniquely identifiable <ul style="list-style-type: none"> <li>- accurately recorded</li> <li>- current</li> <li>- confidential and secure</li> </ul> </li> <li>ii. available to them at their request</li> </ul>   |          |

Table three: Audit of the Alzheimers NZ Dementia Services and Standards

| Step                                       | Role                                       | Action   |
|--|--|--|
| 1  | Members<br>(or other organisations)        | <p>must be</p> <ul style="list-style-type: none"> <li>• <b>working towards</b> offering (or supporting with named others), the core set of Alzheimers NZ Dementia Services, and</li> <li>• <b>working towards</b> meeting the standards.</li> <li>• this will be a condition of membership of the Alzheimers NZ collective.</li> </ul> |
| 2  | The Member (or other organisation)         | <b>registers their interest</b> with Alzheimers NZ for their dementia services to be audited against the Standards   |
|  |  | <b>identifies their audit team</b> , and a proposed audit date - supported by Alzheimers NZ and other members  |
|  |  | refers to the “toolkit’ for information on the audit process, resources available, self-assessment tools, and documentation required for the audit team  |
| 3  | The Member (organisation) being audited    | conducts a <b>self-assessment</b> to prepare for the audit, using the Self-Assessment tool   |
|  |  | provides the audit team with required <b>documentation</b> for the audit   |
|  | The Audit Team                             | <b>carries out</b> the audit, using a variety of tools such as documentation review, interviews, surveys and site visits   |
|  |  | in partnership with the Member (or other service provider), identifies what’s working well, discusses areas for development, and develops an Action Plan   |
| makes and documents their recommendations. |  |  |
| The Moderator                              | moderates the audit teams’ recommendations |  |

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| Step | Role   | Action   |
|------|--|--|
| 4    | Formal <b>recognition</b> of the outcome of the audit. | <p>Fully achieved - for example</p> <ul style="list-style-type: none"> <li>• can clearly demonstrate implementation of the Alzheimers NZ Dementia Services and Standards</li> <li>• had the required systems of structures in place, including for feedback from people living with dementia, self assessment and ongoing learning and development.</li> </ul> <p><b>Outcome:</b> Certification as an Accredited Provider of Alzheimers NZ Services and Standards. Three-yearly audit to maintain Accreditation.</p> <hr/> <p><b>Partially Achieved</b> - evidence of (for example)</p> <ul style="list-style-type: none"> <li>• appropriate process (such as policy/procedure/guideline), system or structure implementation, without the required support documentation; or</li> <li>• a documented process (such as policy/procedure/guideline), system or structure is evident but the organisation or service is working towards implementation where this is required</li> </ul> <p><b>Outcome:</b> Formal acknowledgement as working towards achieving the Alzheimers NZ Dementia Services and Standards. Action Plan and possible interim review to achieve full Accreditation</p> <p><b>Not Achieved</b> - for example,</p> <ul style="list-style-type: none"> <li>• not able to demonstrate appropriate processes, systems or structures to meet the required Standards.</li> </ul> <p><b>Outcome:</b> Action Plan, including development plan, and re-audit within specified timeframe.</p> |

#### Acknowledgements

Alzheimers NZ thanks everyone that has been involved in developing the Alzheimers NZ Dementia Services and Standards, and in particular, the insights that people living with dementia shared, in focus groups and in individual conversations. This resource builds on their experiences, and aspirations, and on the collective wisdom of the Alzheimers NZ member organisations. It also reflects the contributions, expertise and evidence from individuals and organisations in New Zealand and elsewhere. Together we can more confidently walk towards a dementia friendly New Zealand.

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## Definitions

**Accreditation:** A status that is conferred on an organisation or an individual when they have been assessed as having met the standards.

**Audit:** A systematic, independent, objective and documented evaluation of the extent to which health care providers meet standards and processes, based on particular audit criteria.

**Carers:** People who provide (mostly) unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness or general frailty. Carers include parents and guardians caring for children.

**Care plans:** are developed in partnership with people living with dementia, and should enable them to identify and receive care and support in a way that responds to their unique circumstances, aspirations and preferences. Care plans should reflect that service providers: are accountable to the people for whom they are providing care and support; need to be able to justify their services based on the best available evidence; and are accountable to their own organisations, funders and other stakeholders to deliver a good quality service to their communities.

**Consumer-focused support / care (also referred to as person-centred, person-directed):** focuses on a person's individuality, relationships, needs, communication, feelings, and abilities. It takes a holistic view of the person's situation as the starting point for determining choices about the type and level of support that could be provided. It is support that is centred on the whole person rather than the disease of the brain, on the abilities, emotions and cognitive capacities of the person...not on the losses, and that gives equal weight to the psychological and social background and context of the individual and their families.

**Counselling:** The New Zealand Association of Counsellors defines counselling as the process of helping and supporting a person to resolve personal, social, or psychological challenges or difficulties.

**Cognition:** refers to the mental processes involved in gaining and applying knowledge and comprehension. These processes include thinking, knowing, remembering, judging, and problem solving, and encompass language, imagination, sensory perception, planning and the initiation or inhibition of behaviour.

**Day programmes:** refer to programmes or activities that people living with dementia can access, provided by Alzheimers NZ members or others, and could include social activities, art or music groups, outings etc. Some Members provide specific day programmes funded through their local District Health Board.

**Dementia** refers to a group of symptoms affecting cognition, behaviour and social abilities severely enough to interfere with daily functioning, that occurs because of physical changes in the structure of the brain. Dementia indicates problems with at least two brain functions, such as memory loss and impaired judgment or language, and the inability to perform some daily activities. Many causes of dementia symptoms exist, such as Alzheimer's disease or a series of strokes. Early-stage dementia describes the beginning stages of dementia regardless of the age of the person. Early-stage dementia is different to young-onset dementia which describes a person who develops dementia at between 40 to 50 years of age.

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**Experiential learning:** contains all the following elements:

1. Reflection, critical analysis and synthesis
2. Opportunities to take initiatives, make decisions and be accountable for the results
3. Opportunities to engage intellectually, creatively, emotionally, socially, or physically
4. A designed learning experiences that includes the possibility of learn from natural consequences, mistakes, and successes.

**Mild cognitive impairment:** occurs when the thinking functions of the brain such as memory, language, attention and problem solving are not as good as what they once were, but they do not significantly interfere with daily life, and are not severe enough to make a diagnosis of dementia.

**Moderation:** refers to a quality management system designed to achieve valid, fair and consistent assessment and audit. A moderator may be an external agency, or internal moderator, responsible for moderation of assessment activities within an individual training or other organisation accredited for assessment.

**Optimising functionality:** includes the activities that a person wants or needs to undertake to live their everyday life, well. These include routine tasks that a person must perform, or have help with, to stay functional, such as eating, bathing, dressing, maintaining their belongings, etc.

**People living with dementia:** includes people who have dementia, people with a relationship with/to dementia, people who provide day-to-day care and support for people with dementia, carers, care partners, and organisations representing consumers' interests.

**Rehabilitation / Restorative support:** refers to support based on honouring strengths, maximising independence and supporting active participation based on goals identified by the person and the accomplishment of those goals.

**Respite care** provides carers and support people a temporary rest or break, and social and/or rehabilitative opportunities for the person with dementia. The person with dementia continues to receive care and support in a safe and support environment. Respite care and support should be flexible, tailored around what the person with dementia, their carers and support people living with dementia tell us they need. Respite care might be provided in a person's home, a community facility, or a residential setting.

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## References and explanatory notes

<sup>i</sup>World Alzheimers Report 2015: The Global Impact of Dementia. Alzheimers Disease International; and World Alzheimers Report 2016: Improving healthcare for people living with dementia. Coverage, quality and costs, now and into the future, Alzheimers Disease international.

<sup>ii</sup> Dementia Economic Impact Report 2016. Commissioned by Alzheimers New Zealand. Prepared by Deloitte. Published March 2017.

<sup>iii</sup> Dementia Leadership Project on Service Delivery. Alzheimers NZ. 2011; and the Alzheimers NZ members working group on services and standards, 2014/15.

<sup>iv</sup>These include: the NZ Framework for Dementia Care; the NZ Health Strategy; He Korowai Oranga: Maori Health Strategy; the NZ Healthy Ageing Strategy; the NZ Disability Strategy; and the NZ Carers Strategy Action Plan.

<sup>v</sup>For example, Edvardsson D, Fetherstonhaugh D, Nay R. Promoting a continuation of self and normality: person-centred care as described by people with dementia, their family members and aged care staff. J Clin Nurs 2010;19(17-18):2611-2618.

<sup>vi</sup>World Alzheimers Report 2016.

<sup>vii</sup> Expectations about standards of service delivery have been part of the conditions of Alzheimers NZ membership for many years however. These expectations are found in the Alzheimers NZ Code of Practice, and in the services, roles, responsibilities outlined in the Member "Agreement".

<sup>viii</sup> *ibid*

<sup>ix</sup> The emphasis here is on information and support to reduce likelihood, severity and impact of crisis or acute events; access or referral to a real person who can respond in the time of a crisis event; and to optimise recovery from crisis events. Crises or acute events might be significant events or issues being experienced by the carer, family member, or the person with dementia, or others with a relationship to the person with dementia.

<sup>x</sup> Therapies for people with dementia is about maintaining and optimising functionality. In this context, therapy may seek to manage, change or adapt behaviours or circumstances that challenge or compromise people's ability to function well with dementia. They include consideration of the day-to-day interactions of carers and people with dementia, the physical and social environment, and all manner of informal therapies such as art sessions, or contact with animals. There is emerging interest in rehabilitation, and in Cognitive Stimulation Therapy as evidence-based approaches available to support people with dementia.

<sup>xi</sup> World Alzheimers Report 2016.

<sup>xii</sup>The World Alzheimers Report 2016 notes that case management may be an important strategy for improving integration, coordinating care, and increasing treatment coverage. The Case Management Society of America defines case management as "a collaborative process of assessment, planning, facilitation, care coordination and advocacy for options and services to meet an individual's and family's comprehensive health needs through communication and available resources to promote quality cost-effective outcomes". The case management process might involve a team of people, but ideally be coordinated by one person who maintains an ongoing, sometimes day-to-day relationship with a person living with dementia. Terms to describe this role include care-coordinator, case manager, health or care navigator.

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<sup>xiii</sup> The service model acknowledges that not all outcomes are directly or solely attributable to the services offered by Alzheimers NZ. However we have an obligation to ensure people living with dementia know what services are available, how to access them, and are supported to choose what services are most relevant to them,

<sup>xiv</sup> This network should, at a minimum, include primary care (e.g. GPs, practice nurses, dieticians, occupational therapists, social workers, pharmacists), residential and hospital care providers, home support agencies, marae and other cultural and social support organisations, and public services (e.g. work and income, legal, transport).

<sup>xv</sup> NZ Standards include:

- NZS 8158:2012 The Home and Community Support Sector Standard. NZS 8158 is a sector standard for providers offering home and community support services to a wide range of people. Consumers include people with long-term support needs including physical disability, mental illness and chronic medical needs. NZS 8158 also addresses the requirements for services to people with short-term needs such as following discharge from hospital or following referral from a primary health service.
- NZS 8134:2008 The Health and Disability Services Standard. NZS 8134 is the generic quality and risk management standard for the New Zealand health and disability sector. NZS 8134 is used by a wide range of services including hospitals and residential care. As a Designated Auditing Agency, Health Audit NZ Ltd audits providers against NZS 8134 for certification for the purposes of the Health and Disability Services (Safety) Act. Other providers who do not fall under the safety regime also use NZS 8134 as a certification standard. The standard is suitable for provider organisations that deliver a variety of healthcare services.

<sup>xvi</sup> The model is being introduced in 2017, initially with members of Alzheimers NZ, and once fully rolled-out, the intention is that it will be available for use by other dementia service providers, for a fee.

<sup>xvii</sup> Experiential learning is a process through which “students” develop knowledge, skills, and values from direct experiences outside a traditional academic setting.

<sup>xviii</sup> These qualifications could include the Open Mind Open Doors, or a diploma level Home and Community Support qualification such as that currently being developed by CareerForce.

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