

# **Evaluation of services for people living with dementia provided by four local Alzheimers organisations**

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# Executive summary

## **We evaluated the services for people living with dementia provided by local Alzheimers organisations**

This document presents the findings of the evaluation of services delivered by local Alzheimers organisations. The purpose of the evaluation is to assess how well local Alzheimers organisations are meeting the needs of people living with dementia. We looked at the services provided by local Alzheimers organisations in Nelson Tasman, Manawatū, Eastern Bay of Plenty and Tauranga/Western Bay of Plenty.

Local Alzheimers organisations support people living with dementia through individualised support, day programmes and activities, information and advice, and referral to other support organisations.

Alzheimers New Zealand and local Alzheimers organisations will use the evaluation findings to improve services and address service gaps.

## **We used a dementia-friendly evaluation approach**

We involved people with dementia and care partners at all stages of the evaluation. We sent a survey to people who use the services provided by the four local organisations. We received 82 responses from people with dementia and 208 responses from care partners.

We also interviewed 31 people living with dementia and 15 staff members, board representatives and volunteers from the local Alzheimers organisations by phone or online. We completed the fieldwork between July and November 2020 during the Covid-19 response period.

## **Local Alheimers organisations are meeting the needs of people living with dementia using their services**

Local Alheimers organisations are the primary support organisation for people living with dementia using their services. People living with dementia think the support of local Alheimers organisations enables them to live well with dementia.

People with dementia say the service strengthens their sense of confidence, independence, control over decisions that affect them and builds connection and belonging. Taking part in activities helps reduce their sense of stigma about dementia. Contributing to groups and events provides a sense of purpose.

For care partners, the service provides a place of connection and community where they learn and share experiences in a confidential and trusted environment. Care partners value having someone they can call on for help and advice and time to take a break while the person with dementia is at programmes or events.

## **Local Alheimers organisations met the needs of many service users during the Covid-19 lockdown**

In 2020, local Alheimers organisations adapted quickly by expanding their technology use to deliver services online or by phone.

People living with dementia found the lockdown challenging. The support from the local Alheimers organisations was essential for maintaining their well-being and social connection. However, many people living with dementia struggled to access online support because they did not have technical skills or a computer or tablet. Phone calls remained a vital communication tool.

People living with dementia and local Alzheimers organisations want to strengthen their online skills and services and improve their access to technology. People living with dementia want to be prepared for future lockdown type events. Care partners are seeking innovative solutions to gain time for self-care during future lockdowns.

### **Local Alzheimers organisations need to do more to meet the diverse needs of people with dementia**

The older population is growing more diverse. Local Alzheimers organisations need to adapt to meet diverse needs.

- Kaumātua and whānau Māori need culturally relevant services and support. Improving services for kaumātua and whānau Māori is a priority for Alzheimers New Zealand and local Alzheimers organisations. Consideration is needed on how the organisations align with the principles of Te Tiriti o Waitangi.
- People living with dementia with multiple health conditions and disabilities (e.g., hearing or mobility impairments or diabetes) need accessible and disability-friendly services.
- People living with dementia from refugee, migrant and other cultural and ethnic communities also need services tailored to their needs. These communities need to be aware of services, feel they are relevant and know how to access them.
- People living with dementia in rural and isolated communities need accessible services and affordable transport options.

## **People living with dementia identified service improvements**

People living with dementia value and, in the main, are satisfied with the services offered by their local Alzheimers organisation. However, to live well with dementia, people want more support and services within the existing service delivery model. They want more frequent groups, care partner groups, and different groups (e.g., music, dancing, walking), and more groups and resources for people with younger onset dementia.

Other improvement suggestions from people living with dementia include:

- more training for other health and social services about living with dementia and how to support people with dementia to live well
- better connections and referral pathways from other services into local Alzheimers organisations
- information for health and other providers about the services and support available to people living with dementia through local Alzheimers organisations.

## **The current funding model prevents local organisations from providing more services and more diverse services**

Accessing sufficient and secure funding to provide dementia-focused services is an ongoing challenge for local Alzheimers organisations. District Health Board funding does not cover either the cost of the current services or the cost of additional services that people with dementia would prefer. Managers of local Alzheimers organisation spend significant time fundraising to deliver the existing range of services.

The current funding model contributes to inequities in access to and experience of services. To deliver more diverse and inclusive services, local Alzheimers organisations will need to find additional funding.

# Evaluation background

This report presents the evaluation findings on the services delivered by four local Alzheimers' organisations. These insights will inform service improvements for local Alzheimers organisations across Aotearoa.

## **Dementia is a significant and growing health challenge**

An estimated 71,000 people in Aotearoa have dementia, and the number of people with dementia is increasing (Deloitte and Alzheimers New Zealand, 2016). By 2050, an estimated 170,000 people will have dementia due to our ageing population. Dementia impacts more women than men (Deloitte and Alzheimers New Zealand, 2016).

## **The stigma around living with dementia continues**

People living with dementia face discrimination (Batsch, Mittelman, & Alzheimer's Disease International, 2012). More action is being called for to achieve a dementia-friendly world (Carter & Rigby, 2017; Górska, Forsyth, & Maciver, 2018; World Health Organization, 2017).

## **The New Zealand Dementia Action Plan identified gaps in New Zealand's health and social services for people living with dementia**

In 2020, the New Zealand Dementia Action Plan (the Action Plan) identified service gaps for people living with dementia across diagnosis, referral, and supports to live and die well with dementia. The Action Plan notes access to services is inequitable, quality is variable, and human rights are often ignored.

Population growth is increasing pressure on the existing system. Urgent service development is needed to meet this service gap.

## **Alzheimers New Zealand's mission is a dementia-friendly Aotearoa: He aro nui ki te hunga mate wareware**

A dementia-friendly New Zealand is one where people living with dementia can exercise their human rights. A dementia-friendly New Zealand means that people living with dementia can live independently in the community for as long as possible, getting the help and support they need (Alzheimers New Zealand, 2020).

Alzheimers New Zealand provides national representation for people living with dementia. Alzheimers New Zealand advocates with the government and other stakeholders to ensure dementia is a priority issue.

### **Alzheimers New Zealand supports 14 independent organisations**

Local Alzheimers organisations support people living with dementia in their community. They offer a range of services for people living with dementia, including:

- individualised support
- day programmes and activities
- networks and partnerships with other health and social care providers
- referrals to specialised services such as clinical, psychological, social, physical, or financial support
- raising awareness about dementia
- education for people living with dementia
- education for other health care providers.

Local Alzheimers organisations are funded through DHBs, private donations, fundraising events, grants, corporate partnerships, and other charitable donations.

## **The Dementia Services and Standards Model seeks to improve services for people living with dementia**

The Dementia Services and Standards Model (the Model) aims to support evidence-based changes and improve services for people living with dementia (Alzheimers New Zealand, 2017).

The Model identifies four core dementia services provided by local Alzheimers organisations. These services are:

- awareness of dementia and risk reduction for people living with dementia
- walking alongside people living with dementia
- transition through different experiences of living with dementia
- managing through a crisis.

Three standards within the Model ensure the services provided by local Alzheimers organisations are safe, high quality, culturally appropriate and routinely reviewed. The three standards are:

- dementia-friendly services
- service response and delivery
- effective organisational management.

All local Alzheimers organisations are working towards meeting the service standards. An audit process assesses each organisation's progress towards achieving the Services and Standards. Organisations that achieve all requirements of the Model become accredited providers of the Alzheimers New Zealand Services and Standards.

Insights from this report will contribute to improving services delivered by local Alzheimers organisations.

# Evaluation purpose and approach

This evaluation assesses how well the support and services provided by local Alzheimers organisations meet the needs of people living with dementia in their regions.

To evaluate local Alzheimers services, we assessed services provided in four regions—Alzheimers Nelson Tasman, Alzheimers Manawatū, Alzheimers Eastern Bay of Plenty and Alzheimers Tauranga/Western Bay of Plenty.

We selected these organisations as they are reasonably representative of other local Alzheimers organisations. These organisations had been assessed against the Dementia Services and Standards before the evaluation started. Each organisation agreed to take part in the evaluation before the Covid-19 response began.

The evaluation gives voice to people with dementia and their care partners. The findings identify the strengths of local organisations, service gaps, and service improvements to meet the needs of people living with dementia.

## Key evaluation questions

We developed the following key evaluation questions:

- How well do local Alzheimers organisations' services meet the needs of people with dementia and their care partners in their region?
- How well have local Alzheimers organisations met the needs of people with dementia and their care partners during and after the Covid-19 lockdown?
- How equitable and culturally appropriate are the services?
- What aspects of the services work best for whom, under what conditions, and why?

- What are the outcomes from the services for people with dementia and their care partners, and how useful are they?
- What service improvements could be introduced to better meet the diverse and changing needs of people living with dementia?

## **We used a dementia-friendly evaluation approach**

A dementia-friendly approach means we worked to be inclusive and accessible for people living with dementia. We involved people with dementia and care partners at all stages of the evaluation.

We established a multi-disciplinary Evaluation Advisory Group to provide advice to the evaluation team. The Evaluation Advisory Group included people with dementia, care partners, academics, and service providers. Appendix 1 lists all members of the Evaluation Advisory Group.

## **We completed the following evaluation activities<sup>1</sup>**

### **In each location, we invited all service users to take part in a survey**

We received 291 survey responses. Of these, 28 percent were from people with dementia (82 responses).<sup>2</sup> Most of the responses, 71 percent, were from care partners (208 responses). One person did not specify who was completing the survey.

- In Tauranga/Western Bay of Plenty, we received 135 responses; 19 percent were from people with dementia (25 people).
- In Nelson, we received 57 responses; 23 percent were from people with dementia (13 people).

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<sup>1</sup> The evaluation methods are detailed in the Technical Appendices: Appendix 2.

<sup>2</sup> People with dementia include people who completed the survey with a care partner or who received support from someone else to complete the survey.

- In Manawatū, we received 69 responses; 46 percent were from people with dementia (32 people).
- In Eastern Bay of Plenty, we received 28 responses; 43 percent were from people with dementia (12 people).

We have estimated the survey response rate was around 20 percent. The survey was open from September to November 2020.

### **The survey was completed mainly by Pākehā, older people and those on a lower income**

Of the 291 people who took part in the survey:

- 89 percent are Pākehā (257 people), 8 percent are Māori (24 people), and 7 percent are other ethnicities (19 people).
- 52 percent of the people with dementia are women (43 people), and 48 percent are men (39 people).
- 70 percent of care partners are women (145 people), and 30 percent are men (62 people).
- 72 percent are 70 years or older (184 of 255 people).
- 49 percent have an individual income below \$30,000 per year (121 of 246 people), and 17 percent have an income of over \$50,000 (41 of 246 people).<sup>3</sup>

### **We interviewed service users and people who deliver the services**

We interviewed 31 people living with dementia between September and November 2020. These interviews were with:

- Ten people with dementia
- Four paired interviews of care partners and people with dementia
- 17 care partners.

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<sup>3</sup> Some people did not answer all survey questions.

We also interviewed 15 staff members, board members or volunteers from the four local Alzheimers organisations. All interviews were by phone or online. Interviews were around 30 minutes to one hour long and were audio-recorded.

### **Participants gave informed consent to take part in an interview**

People living with dementia consented to take part in the evaluation during recruitment and before the interview. Participants provided either verbal consent, written consent, or both. We used audio consent if people could not print and send back the written consent forms.

We used a modified version of the Older Adults' Capacity to Consent to Research Scale to assess participants' ability to consent to the research (Lee, 2010). We only interviewed people with dementia who could consent to take part. The consent process excluded people with more advanced dementia from taking part. We received ethics approval for the evaluation from the New Zealand Ethics Committee.

### **We did the fieldwork during the Covid-19 lockdown**

Face-to-face interviews were initially planned for March to May 2020. We worked with Alzheimers New Zealand to agree on the best approach during the Covid-19 restrictions. Due to the risks to people with dementia, all interviews were by phone or online (Zoom or Skype). We were responsive to participants' interview preferences and their needs. We limited the interview length or ended an interview early if needed.

### **We are confident in the evaluation findings**

Recruiting participants and distributing the survey was challenging as staff were busy with their Covid-19 response services. We extended the fieldwork period to avoid putting pressure on staff in the local Alzheimers organisations.

Moving to phone or online interviews did not affect the evaluation findings. Based on our previous experience interviewing people living with dementia (Smith et al., 2019), we assessed the quality of the information gathered during online or phone interviews as high. Our interview data enabled us to respond to the evaluation questions. During analysis, we triangulated interview data with the survey and information provided by the local Alzheimers organisations.

The evaluation focuses on people who use services provided by the local Alzheimers organisations. The views and experiences of people who do not use the services are not included.

## **Technical notes**

In this report, ‘people with dementia’ and ‘care partners’ refers to people who completed a survey or interview for this evaluation. Quotes in this report are from either the interviews or open-ended questions in the survey.

Most percentages refer to survey responses. In reporting survey percentages, we also identify the number of people who gave each answer and the number of people who answered the question (for example, 89 percent know about the services available (156 out of 176 people)).

The survey data is based on two questionnaires:

- 1) the questionnaire for people with dementia
- 2) the questionnaire for care partners.

The questionnaires are similar, but questions have different wording to be meaningful for people with dementia or care partners.

In some cases, both people with dementia and care partners in a single household completed one or both surveys. The Technical Appendices provides the evaluation tools, including the survey.

## Terminology

In this report, we have used the following terms:

- ‘Person with dementia’ or ‘people with dementia’: someone with a dementia diagnosis.
- ‘A younger person with dementia’: someone with dementia who is under 65 years old.
- ‘People living with dementia’: the person with dementia and their care partner.
- ‘Care partners’: people who support people with dementia, including spouses or family members (e.g., daughter/son/in-law).
- ‘Whānau Māori’: people living with dementia who are Māori and their care partners and whānau.
- Service users: people who use the services provided by local Alzheimers organisations.
- ‘Kaumātua’: an older Māori woman or man who has status as an older person within the whānau
- ‘Family’ or ‘whānau’: the whānau or extended family who do not live with the person with dementia and are not the primary care partner.
- ‘Most’, ‘some’ and ‘few’: refers to the people who took part in this evaluation. It does not refer to all people living with dementia.
- ‘Dementia Advisors’ or ‘Navigators’: usually trained health or social service professionals who support service users. Advisors or Navigators may facilitate groups, visit homes or phone people, assess people’s needs, direct or refer them to support from other service providers, or provide information about living with dementia.

- 'Day programme': a service where people with dementia attend an Alzheimers organisation for a day of activities. Alzheimers Manawatū is the only organisation in this evaluation that provided a day programme.
- 'Group meeting': a social or learning group organised by local Alzheimers organisations. Usually, a staff member or volunteer facilitates group meetings. Group activities include cognitive stimulation therapy, information sessions, social activities (such as singing or walking), outings or special events, or facilitated discussion about living with dementia. Groups are available for people with dementia, care partners or both together.

# We evaluated services across four locations

This section describes the services in each location. Services across the locations vary considerably. Each organisation delivers services based on the resources available to them and the needs of people living with dementia in their region.

## Alzheimers Nelson Tasman

Alzheimers Nelson Tasman is the smallest provider in this evaluation. Two paid full-time staff provide one-to-one navigation support and advocacy, facilitate group meetings for people with dementia and care partners, provide education and information and organise group events.<sup>4</sup> Around 20 volunteers and Board members support staff to deliver the services. The organisation supports around 304 people with dementia and 290 care partners.

During the Covid-19 lockdown, Alzheimers Nelson Tasman contacted service users by phone or online. Staff also facilitated online group sessions. Staff supported service users to access online support.

At the time of the evaluation, Alzheimers Nelson Tasman did not have the physical space to host groups and groups met in cafés. They have since hired a permanent space. As in other places, limited funding restricts the organisation's ability to provide more services.

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<sup>4</sup> Statistics New Zealand defines full-time as working 32 or more hours a week.

Paid and volunteer staff from Alzheimers Nelson Tasman know of the diverse population who live in the Nelson region, including refugee and migrant communities. Staff are aware of communities that are not currently using their services. Staff do not know whether these communities are unaware of or uncomfortable using the services provided by Alzheimers Nelson Tasman.

## **Alzheimers Manawatū**

Alzheimers Manawatū provides extensive day programmes and activities for people living with dementia in multiple locations in the region.

Of the four organisations, Alzheimers Manawatū is the only one providing a regular day programme. The day programme provides social activities, cognitive stimulation therapy, day outings, quizzes, and other events.

The programme runs five days a week in Palmerston North and two to three days in Dannevirke and Fielding. Alzheimers Manawatū also provides navigator support, carer group meetings, memory cafés<sup>5</sup>, information support, and advocacy.

Alzheimers Manawatū has 17 part and full-time staff. Volunteers and Board members also support the service. At the end of 2020, the Palmerston North centre (the Marion Kennedy Club) moved into a specially designed dementia-friendly building. Alzheimers Manawatū supports 409 people with dementia and 392 care partners.

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<sup>5</sup> Memory cafés are facilitated group meetings for care partners and whānau to share experiences and learnings. In this evaluation, only Alzheimers Manawatū facilitated memory cafés.

As in other locations, the Covid-19 lockdown was a significant challenge. During this time, staff phoned service users to find out how they were going and created online cognitive stimulation resources for people with dementia. The Covid-19 lockdown encouraged staff to increase digital access to services for people living with dementia. Improving online services and digital access are areas staff continue to work on.

## **Alzheimers Tauranga/Western Bay of Plenty**

Alzheimers Tauranga/Western Bay of Plenty provides support for people living with dementia throughout their region.

The organisation provides one-to-one dementia support and advice, education programmes, group sessions with care partners and people with dementia, one-off events, and advocacy and navigation support into other services. The organisation connects people with dementia and care partners to organisations that provide day programmes for people with dementia (such as Anglican Care or Enliven).

Four part-time dementia navigators, a Client Liaison/administration manager, volunteer coordinator/education facilitator, and the manager deliver services with support from a finance administrator, Board members, and around 95 volunteers. All dementia navigators are registered health professionals. The organisation supports around 350-360 people with dementia and 392 care partners.

Alzheimers Tauranga/Western Bay of Plenty has strong technological capability. Before Covid-19, the organisation invested in upgrading technology. All notes and client files are online. Many service users now connect to the organisation by email. Technological capability enabled the organisation to connect with people through the Covid-19 lockdown.

Alzheimers Tauranga/Western Bay of Plenty faces a growing older population in the region, creating resource challenges. Staff recognise that there may be some Māori people with dementia who are not accessing their services. Six percent of service users identify as Māori. In the region, Māori make up nearly 20 percent of the population, and nine percent of Māori are 65 or older (Statistics New Zealand, 2018). Alzheimers Tauranga/Western Bay of Plenty is strengthening the services for kaumātua and whānau Māori.

## **Alzheimers Eastern Bay of Plenty**

Alzheimers Eastern Bay of Plenty provides navigator support to people living with dementia and education sessions on dementia for health and other services throughout the region, including schools, aged residential care facilities, primary health organisations, and schools. The main office is in Whakatāne, and support is available for people living in towns throughout the southern and eastern Bay of Plenty.

The service employs five part-time staff, two navigators (one is also the educator), a volunteer coordinator, an administrator, and a manager. Around 40 to 50 volunteers support the service. Alzheimers Eastern Bay of Plenty supports approximately 127 people with dementia and care partners. Staff in Alzheimers Eastern Bay of Plenty report that approximately 50 percent of service users are Māori. The total Māori population in Eastern Bay of Plenty is 43 percent in Whakatāne and rises to 60 percent in Kawarau (Bay of Plenty District Health Board, 2019).

Alzheimers Eastern Bay of Plenty covers a large rural area. Over half the clients live rurally and are isolated from services. Limited funding means staff have limited time or resources to support people living in more isolated areas.

Eastern Bay of Plenty staff were not set up for online and remote working during the Covid-19 lockdown. Since then, the organisation has invested in ensuring staff can work remotely and report that they are now fully operational for remote work.

# Service access

This section describes the different places people living with dementia access support, including from their local Alzheimers organisations.

The Services and Standards Model assesses awareness of dementia and risk reduction for people living with dementia. Awareness of and access to local Alzheimers organisations contributes to achieving this part of the Model.

People living with dementia access informal and formal support to live well with dementia. Formal support and services are usually provided by groups such as local Alzheimers organisations and health and social service providers such as general practice medical centres. Informal support usually comes from family, friends and other support networks such as faith and cultural communities.

## **Local Alzheimers organisations are the main support organisation**

Local Alzheimers organisations provide important formal support for people living with dementia.

- 73 percent of people with dementia do not get dementia-related support from any other formal services (57 of 78 people).
- 64 percent of care partners do not receive dementia-related support from any other formal services (116 of 180 people).

## **Some people receive dementia support from others**

### **Family, friends, and neighbours provide informal support**

Adult children support their parent with dementia by helping them manage finances or health appointments. Neighbours and friends also support people with dementia to go to events or activities.

Family, friends, and neighbours offer essential support to care partners. Adult children and other family members support care partners by providing respite and going shopping, particularly during the Covid-19 lockdown. They also offer emotional support for care partners by calling and checking on the person with dementia.

I have a brother who lives an hour away. I'll ring him and say I am bringing mum up. [...] She is there, and it gives her a break and me. (Care partner, Eastern Bay of Plenty)

### **Home-based support services help people living with dementia**

Twenty-seven percent of people with dementia (21 of 78 people) and 36 percent of care partners (64 of 180 people) receive dementia-related support from other services. Some people receive home-based care from Age Concern, Presbyterian Support Services, Support Net, and other organisations. Help received includes cooking meals, showering, home cleaning, or gardening.

I do get home help, and they check me twice a day to make sure I have had my medication. I get help to shower. (Person with dementia, Manawatū)

## **Other services also support people living with dementia**

People living with dementia access support from kaumātua groups, Parkinson's society, and medical specialists (such as Occupational Therapists, balance therapists, speech therapists, and Geriatricians). Some people are in walking groups, meditation groups, or other social groups or receive Meals on Wheels.

## **Most people living with dementia know how to access support from local Alzheimers organisations**

People with dementia have high awareness and knowledge of the types of services and support offered by local Alzheimers:

- 72 percent know about the support and services available (52 out of 72 people)
- 73 percent know how to access support and services (55 out of 75 people).

Most care partners also have high awareness and knowledge about the services offered by local Alzheimers organisations:

- 89 percent know about the support and services available (156 out of 176 people)
- 88 percent know how to access them (156 out of 177 people).

Most people living with dementia say it is easy to access support from their local Alzheimers organisation. They know the phone numbers to call for support and the local office. Care partners similarly say accessing support is easy.

## **Health and social services refer people living with dementia to local Alzheimers organisations**

Research in 2019 found that the period around diagnosis is challenging for many people with dementia and care partners (Smith et al., 2019). Accessing support services is made easier for people living with dementia when general practitioners, geriatricians, or hospital coordinators refer people to the local Alzheimers organisation. In contrast, some people did not experience a smooth referral and felt let down.

What I expected from the specialist [was] to be told this is Alzheimer's New Zealand, and this is the person you can contact. It's bad enough being told your loved one has this. I felt I was let down. (Care partner, Nelson)

Some people found out about the service through newspaper advertisements or a family member or friend telling them about it. These alternative referral pathways ensure people not informed by other services can connect with their local Alzheimers organisation.

Through 'Lions'. A representative from Alzheimers gave a talk about how Alzheimers helped people in need. (Person with dementia, Manawatū)

# Service use and experience

This section presents the feedback from people living with dementia on their use and experience of their local Alheimers organisations services.

The Services and Standards model seeks to ensure the service response and delivery meets the required standards.

Everyone who took part in the evaluation had used their local organisation at least once, either through a referral, assessment, newsletter, or more extensive engagement and participation in services.

## Overall, services and support are meeting needs

Most people with dementia (81 percent) consider the services and support from their local organisation meets their needs (56 of 69 people). Only six percent think services are not meeting their needs (four people). Twelve percent do not know whether the service meets their needs (eight people).

More than two-thirds of care partners (71 percent) consider services and support from their local Alheimers organisation meets their needs (119 of 167 people). Overall, 14 percent disagreed, and 14 percent did not know (of the 167 people, 24 disagreed and 24 did not know). The section on [Service Improvements](#) describes the suggestions of people living with dementia to improve their local Alheimers organisations services.

We detail below the feedback from people living with dementia on the local organisations' different services and support.

## **Information is essential for people living with dementia to live well**

### **People with dementia value receiving information from local Alzheimers organisations**

Around two-thirds of people with dementia agree or strongly agree:

- the information tells them what they need to know about living with dementia (66 percent or 49 of 74 people)
- the information is relevant to their needs (68 percent or 49 of 72 people)
- the information helps them understand how dementia affects everyday life (68 percent or 49 of 72 people).

Local organisations could strengthen their information, as some people with dementia disagree or strongly disagree that the information:

- told them what they need to know (6 percent, or 5 of 74 people)
- is relevant to their needs (7 percent, or 5 people of 72 people)
- helps them understand dementia (11 percent, or 8 of 72 people).

Nearly a quarter of people with dementia say 'I don't know' in response to all the questions about information from their local organisation (18 of 72 people). Their response may be due to being unsure about the information received or not remembering receiving it.

## **People with dementia want to receive information that is relevant to their changing experiences at different stages**

People living with dementia value receiving information about dementia when first diagnosed and when they join their local Alzheimers organisation. However, they often found the information received was overwhelming. Some people living with dementia want to receive the information later when they have had time to think about their needs. Others also want information repeated when their needs are changing.

People with dementia like staff or volunteers to talk them through the information. Many people with dementia value when staff or volunteers support them to go through the information many times. A few care partners agreed that repeating the information across time is helpful.

## **Care partners strongly value information from local Alzheimers organisations**

Over 80 percent of care partners agree or strongly agree:

- the information is relevant to them (82 percent, or 137 of 168 people)
- the information told them what they needed to know (82 percent, or 141 of 171 people)
- the information helps them understand how dementia affects everyday life (81 percent, or 137 of 169 people)
- they know where to get more information when their situation changes (82 percent, or 143 of 175 people).

Care partners value information that:

- tells them where to go to find out more
- helps them understand what is happening for their partner with dementia, especially when behaviour or health is changing
- offers practical advice about activities they could use to improve quality of life (such as changing diets, continuing physical activities)
- helps them understand how to work better with the person with dementia.

From the point of us getting the information, it was very helpful and made me aware of what we should be doing and going to get the help. (Care partner, Nelson)

Care partners appreciate group information sessions. Some care partners want more frequent information sessions.

### **Many care partners seek more information from multiple sources**

Care partners often seek information from medical professionals involved in their partners' care or online sources. These care partners want more advice and information about dementia and how they can better support the person with dementia.

I want to know anything and everything that can help him and can help us and the family. It's not going to go away (Care partner, Tauranga/Western Bay of Plenty)

## **People living with dementia value the groups held by local Alzheimers organisations**

Over half of the people with dementia<sup>6</sup> in this evaluation attend a day programme provided by a local Alzheimers organisation (55 percent, 44 of 80 people). Sixteen percent attend clubs and other groups through their local organisation (13 of 80 people). A third of care partners attend partner support groups (36 percent, 67 of 187 people).

### **Many people with dementia strongly value group activities**

People with dementia attend coffee groups, quiz groups, walking groups, annual dinners, and group outings through their local Alzheimers organisations. Some people also receive cognitive stimulation therapy.

We enjoy our meetings on Friday. Everyone looks forward to going. We have a chat and solve all the problems of the world. (Person with dementia, Nelson)

Most people with dementia enjoy group activities. Groups work well when:

- people want a social connection and are more socially engaged
- people feel welcomed and can contribute to the group
- they have constructive components, including cognitive stimulation therapy or enjoyable and active activities like quizzes
- they are held at an accessible location and a convenient time.

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<sup>6</sup> The highest response from people with dementia came from Manawatū where there was a day programme. People who responded to this question from other areas have interpreted day programme to include other group day activities.

## **In Manawatū, people living with dementia strongly value the day programme**

People with dementia consider the day programme an important and enjoyable support service for them. They appreciate social activities, quizzes, and discussions at the day programme. They value learning new things and appreciate the cognitive stimulation therapy provided.

A person with dementia describes the programme and activities offered below.

When you get there in the morning, it is morning tea. We sit and talk to anyone and have a discussion. They break you up into groups, and they will pick out a subject. Yesterday was on telephones and cars. Who were the ones that invented them? We missed out on the exercise because it was so interesting. They fit in a half-hour of light exercise. Then lunch for 45 minutes.

Then there are games, and we have a singing group. We did it last year and the year before. There is a group going out—ten of us to the different rest homes. I have never played pool in my life, and they taught me how to. I still hold the record for putting the white ball in the pocket more than the others.

On occasion, they take us out for concerts, and they will ask people who want a go. Recently they took us to Fielding to a museum of tractors which I never knew about. I could have spent all day there. It gave the history back to the horse and cart and the history of Fielding. They are trying to find different things. It is a memory thing to keep the mind active. (Person with dementia, Manawatū)

Care partners value having a break and the opportunity to do activities independently while the person with dementia is at the day programme.

### **Some people with dementia do not enjoy group activities and do not attend group sessions**

Some people do not enjoy going to a group session when it does not suit them socially or intellectually. People living with dementia say groups do not work well when the people participating:

- disagree that they have dementia<sup>7</sup>
- do not have something in common with the rest of the group
- are less social and less extroverted.

For example, one woman with dementia described attending a group she did not enjoy. She found the people attending the group were not social, and the activities were not stimulating. When she switched to a more active and social group, she was more satisfied.

A few younger people with dementia find groups that are not tailored for them are less enjoyable and supportive.<sup>8</sup> Younger people with dementia have different experiences, expectations, and physical capabilities than older people with dementia (Smith et al., 2019). Younger people with dementia are seeking groups and information that are responsive to their life stage and needs.

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<sup>7</sup> Reported by care partners in interviews.

<sup>8</sup> Six younger people with dementia took part in this evaluation.

## **Many care partners strongly value care partner support groups**

For some, care partner groups are a helpful place to share experiences and learnings. Attending groups enables care partners to process issues they are struggling with and learn how other people have responded in similar situations.

Care partners appreciate being able to openly share and discuss events or changes that they are struggling with. They also strongly value the ability to learn from other people's experiences.

I look forward to the carer's meeting because I jot down little things to remind myself of her condition. So, when I have a query that someone might have, I can get the book out and chat at length about it. The others do it too. They say what worked well for them. It is really good. (Care partner, Nelson)

## **Some care partners do not want or cannot attend care partner groups**

Some care partners do not find attending a group an enjoyable experience. These care partners do not want to discuss their experiences in a group as they find it difficult and distressing.

I stopped attending the care partner groups. I am that sort of person that finds it too depressing sitting in a circle talking about it. (Care partner, Tauranga/Western Bay of Plenty)

A few care partners do not find attending groups useful. These care partners do not find social or emotional value in talking about their experiences with other care partners.

For others, local care partners groups are unavailable, or the group's timing does not work with their schedules.

They have a support group for carers once a month. I can never get there. It is the first thing in the morning, and she has caregivers coming at that time. I cannot use that, but I would really like to. (Care partner, Manawatū)

## **Staff and volunteers provide essential one-to-one support for people living with dementia**

A quarter of people with dementia reported advisors visited them (24 percent or 19 of 80 people). Nearly a third of care partners reported advisors visited them and their family member with dementia (32 percent, 60 of 187 people).

### **People with dementia view staff and volunteers very positively**

Most people with dementia agree or strongly agree that staff and volunteers:

- are respectful and treat them with dignity (94 percent, 66 of 70 people)
- listen to them (96 percent, 67 of 70 people)
- are knowledgeable about dementia (90 percent, 63 of 70 people)
- are easy and comfortable to talk to (97 percent, 68 of 70 people).

People with dementia say staff provide helpful support and are friendly and empathetic.

### **Care partners are also very positive about staff and volunteers**

Most care partners report:

- staff and volunteers listen to them (89 percent, 152 of 170 people)
- staff and volunteers are knowledgeable about dementia (86 percent, 148 of 173)

- they are comfortable talking to staff and volunteers (94 percent, 163 of 174 people)
- staff and volunteers treat them with dignity (94 percent, 161 of 171 people).

Care partners value being able to talk to staff at their local Alzheimers organisation. They value the advice provided by staff and volunteers, especially guidance on supporting the person with dementia.

If anything comes up that you are not totally gelling with, they are always there if you are asking about any type of dementia. And they always come back and give you an answer. (Care partner, Nelson)

## **Referral to other support and services is useful for people living with dementia**

Five percent of people with dementia say their local Alzheimers organisation helped them get an appointment with a specialist or support service, such as a social worker (4 of 78 people). Seventeen percent say their local organisation connects them to other clubs and groups (13 of 78 people).

Nine percent of care partners say their local organisation helped their family member with dementia get an appointment with a specialist or support service (16 of 187 people).

A few people living with dementia say they would not have received critical support without the help of staff or information from local Alzheimers organisations.

Someone comes in and makes sure he does his bloods correctly, does his insulin. They get him breakfast. Then someone comes in at lunchtime, checks his bloods and make

sure he has something to eat. ... All that has come out of meeting someone from Alzheimers and his doctor from elderly health. (Care partner, Manawatū)

## **Emergency plans are not always developed**

The Alzheimers New Zealand Service and Standards Model requires people living with dementia to have an emergency plan. For example, emergency plans may be used when a care partner becomes ill. Nearly half of people with dementia (49 percent, 33 of 70 people) and care partners (44 percent, 64 of 147 people) do not have an emergency plan or do not know if they have an emergency plan.

Some people with dementia who took part in an interview remembered creating an emergency plan. However, this service component has low recognition.

## **People living with dementia use other services provided by local Alzheimers organisations**

People with dementia access education and other support from local Alzheimers organisations. Fourteen percent attend education programmes (11 out of 80 people). Sixteen percent receive general support such as transport, staying in touch through phone calls, meeting people, and organising medication (13 out of 80 people).

Twenty-one percent of care partners received other support from Alzheimers organisations (40 of 187 people). This support included:

- a respite-like break from visits or a dementia friend
- dementia tracker or location device
- email and phone contact and support
- news and updates through the newsletter.

# Outcomes from Alzheimers services

This section describes the outcomes gained by people living with dementia from using the local Alzheimers organisations' services.

The Services and Standards Model aims to provide dementia friendly services that walk alongside people living with dementia and support them through their experiences.

## Local Alzheimers organisations help people live well with dementia

Most people with dementia say the support from their local Alzheimers organisation is very or quite important in helping them live well with dementia (84 percent, 62 of 74 people). Similarly, 81 percent of care partners consider the support very or quite important for them to live well (136 of 168 people).

Many care partners interviewed strongly feel the service and support their local Alzheimers organisation provides is essential for their well-being. Without this support, life for them and the person with dementia would be more challenging.

I think they are 100 percent the most important. You would not cope without them. (Care partner, Eastern Bay of Plenty)

## People with dementia gain confidence, connection, and contribution through using the services

### The service strengthens confidence, independence, and control

Maintaining independence is important to live well with dementia. People with dementia want to take part in making decisions about their care and support.

Overall, most people with dementia agree or strongly agree:

- they can decide the services and support they receive (68 percent, 48 of 71 people)
- they can choose the support that suits them (75 percent, 54 of 72 people)
- support from their local Alheimers organisation helps them live independently (74 percent, 52 of 70 people).

Most people with dementia interviewed said attending services gives them more confidence.

I think it has given me back that confidence in remembering some of the things I have forgotten. I can sit down and talk to people, and no one is going to say that you are wrong or that you haven't remembered something. [...] It is about confidence, and it doesn't matter if you can't remember something. (Person with dementia, Manawatū)

However, a quarter of people with dementia say they do not know whether they can make decisions about the support they receive (24 percent, 17 of 71 people).

### **The service builds a sense of community and belonging**

A sense of community and belonging is a vital part of living well for people with dementia. Most people with dementia agree or strongly agree that services from their local Alheimers organisation help them:

- feel more connected with their community (70 percent, 49 of 70 people)
- connect to people with similar interests and positions (81 percent, 58 of 72 people).

People with dementia feel that joining group activities and taking part in social events builds a positive sense of community. People with dementia feel relief and happiness in meeting and talking with other people with similar experiences. They can share their experiences and speak honestly. People with dementia also build friendships and feel less isolated.

### **Taking part in activities helps reduce stigma about dementia**

Many people with dementia feel stigmatised for having dementia. Feeling stigmatised can lead people with dementia to retreat from their social activities, resulting in isolation and loneliness. Some people with dementia feel friends withdraw from them when they hear about a dementia diagnosis.

As soon as they hear Alzheimers, they jump back as if they can catch it. You find yourself isolated. (Person with dementia, Tauranga/Western Bay of Plenty)

Taking part in groups and activities helps people with dementia counter their experiences of stigma and loneliness. The group environment helps people with dementia accept they do not have to be ashamed of having dementia. They can share their experiences openly and laugh about them.

The group allows you to be who you are. We can laugh about how we used to be. We are real people. We can talk about the daft thing we did this week. We laughed the other day that I loaded the groceries into what I thought was our car and got in, and it wasn't my husband. I don't feel ashamed. It's like being with a group of friends without feeling ashamed. (Person with dementia, Nelson)

## **Contributing to groups and events provides a sense of purpose**

Having a sense of purpose enables well-being. People with dementia contribute to the service by developing group activities, such as writing the monthly group quiz. Some people contribute to public events, such as speaking at the opening of the Marion Kennedy club building in Palmerston North.

Care partners say contributing to events and activities is an essential part of well-being for the person with dementia. For example, one care partner described how her mother with dementia enjoys looking after everyone else on group outings.

I think she enjoys the van. It would only be about half a dozen in the group. She is the nurturing type. My mum would be the one to look after some of the others. She likes that small outing group. (Care partner, Eastern Bay of Plenty)

Some care partners think it is harder for the person with dementia when they do not have a sense of purpose.

## **Care partners gain connection, advice, and rest from using the services**

### **Services and support provide a place of connection and community**

Three-quarters of care partners agree or strongly agree the service helps to connect them with people of similar interests and positions (74 percent, 125 of 170 people). Connecting with care partners in similar circumstances offers friendship and social opportunities.

It also gave me the opportunity to talk to other carers. It gave me some camaraderie with others who were experiencing problems that I had. That information enabled me to talk to

others about it and to see if there was any way that we could improve the situation. (Care partner, Eastern Bay of Plenty)

Some care partners feel group sessions help to reduce their loneliness.

Carers get lonely because there is no communication with the person with dementia, so no conversations at home at all. She is happy, but there is no conversation whatsoever. The social aspect becomes important. That is where Alzheimers NZ becomes important. (Care partner, Eastern Bay of Plenty)

### **Services provide a place to share learnings in a confidential and trusted environment**

Care partners value the opportunity to learn from each other and learn from the staff at their local Alzheimers organisation. Groups provide a place for care partners to get advice on care or information about changes happening for the person with dementia.

Care partners appreciate sharing experiences in a trusted group. Some care partners feel only people with lived experience can understand their experiences. They can be open about their emotions and experiences with other care partners.

That is brilliant because once in your life you are with a group of people who don't give a hoot. You are all on the same page. Everyone there knows that they have the same problem. It is brilliant. (Care partner, Nelson)

High trust and confidentiality within the group are essential. Care partners need to know that the group is confidential to be honest and know that the information will not leave the group.

## **Care partners value having someone to call on for help and advice**

Care partners consider their local Alzheimers staff a vital source of reliable information and advice. Most care partners agree or strongly agree support from their local Alzheimers organisation helps them support their partner with dementia (80 percent, 133 of 167 people).

Care partners value being able to phone the local office for advice or help. Care partners feel confident the service will help them at any time.

I know I can ring her ... you can call on them and say can you help me on this a bit. (Care partner, Tauranga/Western Bay of Plenty)

## **Local Alzheimers organisations' services enable care partners to take a break**

Care partners may get a respite-like break when the person with dementia attends services at local Alzheimers organisations. Over a quarter of care partners say they get a break, while the person with dementia attends services (groups or a day programme) at their local Alzheimers organisation (28 percent, 52 of 187 people).

Care partners appreciate knowing the person with dementia is safe and accessing services. This knowledge enables care partners to do activities they would not be unable to complete or have a rest.

It gives me time twice a week to go and do things like grocery shopping without having to wonder where she is in the store. (Care partner, Manawatū)

Some care partners think the time apart is beneficial for both partners, allowing them to have their own space.

# Service responses to Covid-19

This section describes:

- the challenges people living with dementia experienced during the Covid-19 lockdown
- the services and support they received from local Alzheimers organisations and the value of this support
- potential improvements if another lockdown occurs.

## The Covid-19 lockdown was challenging for many people living with dementia

### People with dementia missed the face-to-face connection and struggled to access online support

People with dementia missed meeting others and going to group activities during the Covid-19 lockdown. They felt isolated.

That was the hardest part for me. Four or five weeks of not going. (Person with dementia, Manawatū)

Many people with dementia struggled to access online support and resources as learning to use new technologies with limited support was challenging. Only 14 percent of people with dementia accessed online support or online groups during lockdown (10 of 69 people).

The trouble is that when you have Alzheimers, one of the most difficult things is to learn new things. (Person with dementia, Nelson).

Care partners said the lockdown was hard for the person with dementia because they could not meet friends, attend activities, or follow their routine. Care partners also recognised the person with dementia might not remember why the lockdown was in place.

He was so upset over the lockdown because he couldn't go [to the group]. (Care partner, Eastern Bay of Plenty)

### **Many care partners also struggled with the Covid-19 lockdown**

Care partners found the closure of face-to-face support challenging because they became the sole support for the person with dementia. Many care partners did not receive mental and emotional support during the lockdown.

It was difficult and lonely living alone with someone with dementia (Care partner, survey, Manawatū)

Some care partners think the health and capability of the person with dementia decreased during the lockdown. These changes added to care partner stress as they tried to support their changing needs.

He has now deteriorated quite a lot, and I don't know if I would ever be able to get him back there. (Care partner, Nelson)

A few care partners reported changes during lockdown meant the person with dementia moved into residential care during or just after lockdown. This move had not been planned or expected before the lockdown.

## **For a few people living with dementia, the lockdown was not a significant struggle**

These people were not reliant on support from local Alzheimers organisations or other providers. Some people had family stay during the lockdown. As a result, the people living with dementia were not isolated, and support was shared across the family.

I did really well. It was the time to reflect and relax. I walked the beach every day. We set up a family memory page on messenger, so we are still in contact with family and sharing old photos and music that we like and things like that. I have good neighbours who take care of each other. (Person with dementia, Eastern Bay of Plenty)

## **Local Alzheimers organisations supported people living with dementia during the Covid-19 lockdown**

At the start of lockdown, local Alzheimers organisations' staff tried to contact all service users. Staff members targeted service users with high needs and contacted these people more frequently.

Staff across the four locations worked to get as many people as possible online. In Nelson, staff members phoned people living with dementia to talk them through setting up Zoom to join meetings. This process was challenging for both people living with dementia and staff. However, successfully getting people online was rewarding and gave people with dementia confidence and connection.

## **Local organisations connected to people living with dementia by phone and other means during lockdown**

During the lockdown, 85 percent of people with dementia had been contacted by their local Alheimers organisation (59 of 69 people). A phone call was the most frequently mentioned support by people living with dementia. This reflected the local organisation's work and priorities during the lockdown.

Local organisations supported people with dementia by:

- phoning them to see how they were doing (61 percent, 42 of 69 people)
- emailing updates about Covid-19 or other information (35 percent, 24 of 69 people)
- providing activity packs (32 percent, 22 of 69 people)
- helping make a support plan online or by phone (7 percent, 5 of 69 people)
- setting up online groups (7 percent, 5 of 69 people).

Twenty-three percent of people with dementia received other support, such as texts for urgent messages and emailing for non-urgent messages (16 of 69 people).

Nearly all care partners received some support from their local Alheimers organisation during the Covid-19 lockdown (92 percent, 153 of 165 people). Local Alheimers organisations supported care partners through:

- phoning to see how they were going (72 percent, 119 of 165 people)
- sending emails or letters about Covid-19 and other information (38 percent, 63 of 165 people)
- providing home-based activity resources (19 percent, 32 of 165 people)
- setting up online support groups (17 percent, 28 of 165 people)

- helping to make a support plan (13 percent, 21 of 165 people)
- setting up online access to help people see or talk to friends and family (1 percent, 2 of 165 people).

Seventeen percent of care partners also received other support such as online training or support and information texts (28 of 165 people).

### **People living with dementia valued connecting with local Alzheimers organisations during lockdown**

Two-thirds of people with dementia (67 percent, 44 of 66 people) and two-thirds of care partners consider this support during the lockdown as very or quite important (67 percent, 112 of 168 care partners).

Phone calls during the lockdown helped people living with dementia feel connected to support.

They were very good. The coordinator kept in touch. While we were locked down, we could ring at any time. They would ring once a week to make sure everything was alright. Over lockdown, they were great. You did not feel forgotten. (Care partner, Manawatū)

People with dementia and care partners who joined online groups also appreciated connecting to their local Alzheimers organisations' community.

They hooked some of us up to the computer which I have. They gave us some stuff to do. They kept in touch as best as possible. I appreciate it. (Person with dementia, Manawatū)

## **A few people got no support during the Covid-19 lockdown**

Twelve percent of people with dementia report they did not receive any contact from their local Alzheimers organisation during the lockdown (8 of 69 people).

Seven percent of care partners reported they did not receive any support or contact during the lockdown (12 of 165 people).

## **Some people struggled to get online or join online events**

In the future, people living with dementia want to ensure online, and phone systems are set up for future lockdowns or other occasions.

I would love for it to be set up in case there is another lockdown. (Person with dementia, Nelson)

## **Overall, services during lockdown were unable to meet all of peoples' needs but provided necessary support**

Many people living with dementia accepted the lockdown requirements and the resulting service limitations during that time. They accepted services were doing the best they could under the circumstances.

They gave us some stuff to do. They kept in touch as best as possible. I appreciated it. (Person with dementia, Manawatū)

## **People living with dementia identified other helpful support for future lockdowns**

For future lockdowns, people living with dementia suggested:

- having more frequent communication from local Alzheimers organisations
- facilitating ways for people to connect with someone who understands what they were experiencing (such as online groups or phone calls)

- having activities for people with dementia to do at home, including resources to maintain mental capabilities
- having a phone helpline giving information on changes happening during the lockdown
- having information about what services were available and open (for example, information about General Practices and hospitals, what to do in an emergency, and information about when services are likely to open)
- having more support for care partners, including online groups
- helping explain to people with dementia the reasons for sticking to the lockdown guidelines.

People also suggested support from other services would be useful, including:

- having more general support from other providers
- getting help for weekly or daily needs (e.g., housekeeping or shopping)
- accessing financial help for care requirements during the lockdown.

People living with dementia recognised that face to face support during lockdowns is not possible. However, they also emphasised that this kind of support is vital for their well-being in future lockdowns.

# Wider influences on service use

This section highlights challenges for local Alzheimers organisations.

## Whānau Māori want more culturally relevant support

Improving services for kaumātua and whānau Māori is already a priority objective for Alzheimers New Zealand and local Alzheimers organisations. Some Māori service users join their local Alzheimers organisation Board to hold the Board accountable for their commitment to being responsive to Māori.

Whānau Māori want local Alzheimers organisations to provide more culturally relevant support based on Te Ao Māori models of care.

Culturally relevant support may include:

- working with kaumātua groups
- going to hui at marae
- employing staff who can speak te reo Māori
- increasing visibility amongst Māori communities
- ensuring relevant information for whānau Māori affected by dementia.

## A lack of funding limits service availability and innovation

The four local Alzheimers organisations identified funding challenges as DHB funding does not cover service costs. Managers and board members spend considerable time fundraising. The current funding model for local Alzheimers organisations limits the number of services offered and restricts opportunities for service innovation.

My big fear is that it is not a sustainable model of how we work as far as the funding goes. [Our] time is spent chasing dollars as opposed to improving and growing services.

(Eastern Bay of Plenty, stakeholder)

Inconsistent funding across regions creates inequity. Organisations working in low-income and rural areas can struggle to get sufficient funding and may face higher costs to deliver services rurally. For example, Eastern Bay of Plenty staff members travel long distances for face-to-face appointments in rural areas.

People living with dementia are aware of the funding challenges and the impact on service availability.

They are part-time and work until 1pm every day. It should be longer, but there are money restraints. (Person with dementia, Tauranga/Western Bay of Plenty)

## **Inequities of service access exist for rural and low-income communities**

People living with dementia in rural and isolated areas miss out on services offered due to a lack of affordable transport options.

I know the van leaves once a fortnight from Whakatāne here, and they go out for the morning, but it would be good if they had that service for the kaumātua up the backblocks. (Care partner, Eastern Bay of Plenty)

The Covid-19 response from local Alzheimers organisations enabled more online services for people living with dementia. However, access barriers exist, such as technology, reliable internet, and the ability to use online services.

# Service improvements

This section presents the service improvements for local Alzheimers organisations suggested by people living with dementia.

We have ordered the service improvement against two of the Alzheimers New Zealand Dementia Services and Standards, namely service response and delivery and effective organisational management.<sup>9</sup> Most feedback is on strengthening service response and delivery.

## Effective organisational management

### Local Alzheimers organisations need more sustainable funding

Most people living with dementia are very grateful for the services offered by their local Alzheimers organisations. In suggesting service improvements, most people living with dementia were mindful of existing funding limitations. Many also had a 'make do' attitude.

No, I can't criticise them because I know its timing. If they had more time, I feel you would get more individual time.  
(Care partner, Tauranga/Western Bay of Plenty)

When prompted through follow-up questions by the interviewer, people living with dementia said they need more services and support to live well. Local Alzheimers organisations will need more sustainable funding to action the improvements identified by people living with dementia below.

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<sup>9</sup> No suggested improvements are linked to the criteria for dementia-friendly services.

## **The cultural competency and staff diversity needs strengthening**

Some people living with dementia want the services to be more culturally diverse and work with culturally diverse providers. People living with dementia in the Eastern Bay of Plenty greatly value the support from staff members who are Māori. They want more support for the staff so they can provide more services.

Employ more Māori navigators. Our two are stretched. They are doing a great job but need help. (Care partner, survey, Eastern Bay of Plenty)

## **Local Alzheimers organisations need to promote their services**

People living with dementia want their local Alzheimers organisations to promote their services to make sure no one misses out.

One thing that bothers me is how many people are out there that don't get any help and that don't know about it. (Care partner, Nelson)

## **Service response and delivery: delivery**

### **Frequent contact is wanted from local Alzheimers organisations**

People living with dementia want frequent phone calls or emails from their local organisations to see how they are doing. Some people living with dementia want staff to phone and tell them about service changes rather than updates through the newsletter.

A few people want regular six-monthly assessments of the person with dementia to ensure they receive appropriate support.

A home visit for a check on advancement or difficulties every six to nine months would be beneficial. (Care partner, survey, Eastern Bay of Plenty)

### **People living with dementia want detailed and relevant information**

People living with dementia want:

- advice on where to go to find out more about dementia
- information on strategies and tactics to live well with dementia
- specific advice such as medical needs, behaviour changes
- detailed education sessions on diet and exercise.
- technical information on new medications or drug options available

### **People living with dementia want more social activities and therapy**

People with dementia want day activities or groups such as music, dance, reading or kaumātua groups. People with dementia want activities with a purpose that create opportunities for contribution. Some people with dementia want access to cognitive stimulation therapy if this is not already available through their local Alzheimers organisation.<sup>10</sup>

Care partners want more events or day programmes for the person with dementia that they do not need to attend so they can have a break and do other things. Care partners also want access to care partner groups.

### **Services need to be tailored and accessible for the diversity of people living with dementia**

People living with dementia want services to be more inclusive for disabled people. People with hearing or visual impairments can struggle to take part in activities. Physical abilities can limit taking part in events.

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<sup>10</sup> Alzheimers New Zealand is working to provide cognitive stimulation therapy online in the future.

Be aware of other physical issues like eyesight when planning activities. (Person with dementia, survey, Manawatū)

People living rurally need affordable shuttle service to attend events.

### **Younger people with dementia want services tailored to their needs**

Younger people with dementia tend to want support tailored to their age groups (e.g., activities like yoga and walking groups).

All the patients will go in one room and the carers in another. But there is nothing like that for early-onset. I think once a week for early-onset, there should be a coffee group. (Person with dementia, Tauranga/Western Bay of Plenty)

### **Care partners want more support to take a break, particularly in lockdowns**

During the Covid-19 lockdown, care partners could not access respite care or the respite-like break when the person with dementia attends other services. If another lockdown occurs, care partners want solutions to have some time out.

During lockdown, if one of the workers could come out and give the carer an hour relief while she or he has time to do something without worrying. (Care partner, survey, Nelson)

## **Service response and delivery: links and networks with other organisations**

### **Local Alzheimers organisations to educate other services and the public about living with dementia**

Many people living with dementia face negative attitudes and limited knowledge of dementia by the public and health and social services. As a result, their experiences of health and social support services are not positive. Some people living with dementia want their local Alzheimers organisations to educate the public and other health and social services on dementia.

In some cases, in their training to have some sort of a talk about dementia. [...] I think sometimes it is put in a negative light, and it doesn't help the person with dementia. (Person with dementia, Manawatū)

These people living with dementia think that services and support will improve when the public and health providers better understand dementia. A few people suggested more public forums or events.

### **Better connections with other health and social services are needed**

People living with dementia want help connecting with specialists and navigator's support during these meetings. Care partners want help to reinforce messages with people with dementia after the meetings.

# Conclusions

## **Local Alzheimers organisation are supporting people with dementia to live their best lives**

This evaluation shows that Alzheimers organisations are enabling people with dementia and their care partners to live well. The findings strongly align with the vision set out in the New Zealand Dementia Declaration:

We live our best possible lives when: ... We have consistent quality support, care and information which is timely and appropriate to us; it is provided with kindness by compassionate people who have the right skills and knowledge, our interests as a focus, and with whom we are comfortable. (The Dementia Declaration, Alzheimers New Zealand's Advisory Group, 2019)

Through using local Alzheimers organisations' services, people with dementia gain confidence, remain socially connected and have a sense of belonging. Notably, the services create a sense of purpose and contribution, which strengthens their well-being.

Care partners gain indirect and direct benefit from the services. They appreciate the benefits gained by the person with dementia. They gain advice to support the changing needs of their partners and a trusted and confidential learning environment. Importantly, they get time for self-care.

## **Local Alzheimers organisations changed their services to meet the needs of people living with dementia during the lockdown**

During the lockdown, local organisations connected with most people using their service and encouraged people to use telephone support and the new online services. This shift was challenging for both staff and people living with dementia due to different access to and lower confidence in using new technologies (such as Zoom). During the lockdown, many people living with dementia felt isolated. A phone call from their local Alzheimers organisations helped them feel connected and supported.

People with dementia want local Alzheimers organisations to ensure online and phone systems are set up for future lockdowns. Care partners are also seeking innovative solutions to have some time out while following lockdown guidelines.

## **Local Alzheimers organisations need to enhance their services to meet the diversity of needs of people living with dementia**

Within the current funding model for local Alzheimers organisations, there is limited resourcing available for service improvements and innovation. The funding model is contributing to inequities of access and service experience for people living with dementia.

A key improvement area for local Alzheimers organisations is tailoring support and services to meet the diversity of needs, including whānau Māori, younger people with dementia and those living rurally. A co-design process will enable diverse groups of people living with dementia to develop a service that meets their needs.

To align with Te Tiriti o Waitangi obligations, Alzheimers New Zealand and local Alzheimers organisations need to work with iwi and local Māori providers to enable Māori governance and management, Māori self-determination, and equitable outcomes. Services need to incorporate te Ao Māori, Mātauranga Māori and te reo.

Where people living with dementia are not accessing services, local Alzheimers organisations should consider this unmet need. The services need to be more widely promoted. An area for future research is to determine why people living with dementia who are aware of the services are not using them.

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