

The logo consists of a dark red horizontal bar with rounded ends. The word "LITMUS" is written in white, uppercase, sans-serif font across the center of the bar.

LITMUS

This is our story

A qualitative research report on living with dementia

Prepared for:
Alzheimers New Zealand

18 April 2019

Contents

Acknowledgements	4
A summary of our story	5
New Zealand needs research on living with dementia	11
We used a people-centred research approach	12
Overview of the report structure and terms used	18
Something's not quite right	22
Have I got dementia?	25
What having dementia means to me	35
I value my independence	40
With some changes, I can live a meaningful life	49
I need the right help and support at the right time	56
Sometimes we need a break	66
I need a community I can easily move around	69
We pull together as a couple living with dementia	72
Care partners feel love, loss and guilt when caring for people with advanced dementia	80
Conclusion: Our story matters	87
References	88
Appendices	91

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Nāu te rourou nāku te rourou, ka ora ai te iwi
With your basket and my basket, the people will thrive

A summary of our story

Living with dementia in New Zealand

This report is the voice of 49 people living with dementia.¹ We wrote this report to share their experiences with other people living with dementia. The report is also for those supporting people living with dementia, to help them further understand their lives. We hope decision-makers will read the report to better understand, increase and improve services for people living with dementia.

People living with dementia have diverse lives

Dementia is different for everyone – what people experience, and how quickly they are affected is unique to them. (Alzheimers New Zealand, 2016)

People with dementia have many varied experiences of living with dementia. These experiences are influenced by age, gender, ethnicity, dementia progression, the support they can access, level of income and personal preferences.

Having dementia affects people differently

People with dementia say dementia means becoming more forgetful, or taking longer to understand or process information. While forgetful, most describe themselves as capable of thinking and reasoning.

¹ Dementia is an umbrella term and describes the symptoms of diseases that affect how well our brains work. Dementia can affect anyone. The chances of developing dementia increase with age. The most common form is Alzheimer's disease. The most common symptom are changes in memory, thinking, behaviour, personality and emotions. These changes affect performance of everyday tasks. Dementia is progressive, and is different for everyone. (Alzheimers New Zealand, 2016)

I don't think I've lost my intellect. I follow the news. I've always been a thinker and I still am. I think that's still up there. (Younger person with dementia, Pākehā, male)

They also describe changes in their physical health such as effects on their speech, sight and balance. Changes due to their dementia mean people are continually redefining their self and life.

Most people with dementia describe going through cycles of grief, loss and acceptance as the symptoms of dementia progressed. Many people living with dementia learn to adapt to the progressive nature of the disease.

Even with acceptance, people with dementia say they feel sad, depressed and angry when they reflect on the changes in their life. However, they say reaching acceptance is important to reduce anxiety and continue to have a meaningful life.

People with dementia live meaningful lives

The one thing that I would really emphasise is that whilst the diagnosis is traumatic, and it is very traumatic... We believe quite generally, you can go on and live a meaningful life with some changes. (Care partner, spouse, Pākehā, male)

People with dementia say they like to be active and involved. Some enjoy caring for their family and spending time with friends. Others enjoy walking, biking, films and visits to the pub. They enjoy travel to new places.

People with dementia contribute positively to New Zealand. They are advocates for other people and for those living with dementia. They support their grandchildren to learn and help neighbours.

People with dementia value their independence

People living with dementia want to maintain their independence for as long as possible. However, the ongoing changes due to dementia affects their ability to live independently. People with dementia adapt or seek support to live their lives as they wish.

People with dementia appreciate the need to balance independence and safety, to reassure family. However, some feel they have little control over their life choices. People with dementia value being supported to have their say on decisions about their lives.

Living positively with dementia is not easy

For most, being diagnosed with dementia is a fearful and uncertain time. Many experience disbelief, sadness and anger. Some feel the life they live and enjoy is over and the future looks very bleak.

I'll never forget the day walking out of the office and to the car. We were just stunned ... when you think of the word Alzheimer's, you think of last stages. And that's a picture that people will have.
(Care partner, spouse, Pākehā, male)

For some people, primary care health professionals' limited understanding of dementia and the lack of empathetic support heightens this fear.

People living with dementia talk of being treated differently. Other people do not listen, give them time to think and respond, or speak down to them. Some family and friends exclude or avoid them. People living with dementia find this response disappointing and hurtful.

Person with dementia: [Care partner] will go outside and they'll [neighbours] all talk for half an hour. I'll go outside and they say 'hello'.

Care partner: They say hello and they keep walking. They stop and talk to me. I notice the difference with how you're treated.
(Older person with dementia and spouse, Pākehā, male)

Some people with dementia withdraw from social events as they feel embarrassed and uncomfortable.

People living with dementia struggle to access health and support services they need. They do not know what services are available or their eligibility.

Nobody offers help, you've got to go and find it and ask for it. You have to go to your doctor and some doctors don't want to give it [information on services] either, which to me is quite strange.
(Older person with dementia, Pākehā, male)

More services are necessary so they can be accessed when needed, particularly respite care. People with dementia and care partners also want reliable, quality services that meet their diversity of needs.

Care partners support people with dementia to live positively

Care partners are spouses, children or in-laws of people with dementia. Care partners' lives change following the diagnosis, but their relationship to the person with dementia does not. Care partners and the person with dementia learn together how to adjust their lives. Humour is a coping tool, which helps maintain their relationship.

I have become very reliant on her. I realise that she gets frustrated, and I would like her not to be frustrated, but I can't not frustrate her. (Older person with dementia, Pākehā, male)

Care partnership is based on love and commitment. However, care partners' stress increases as the disability increases. Care partners need support to maintain their wellbeing.

Care partners who are children of people with dementia, describe the pressure on their families due to supporting their parent. While committed to their care partner role, they acknowledge the impact on their families – with less time to spend with their children and spouse.

Care partners of people with advanced dementia describe a sense of loss for the person they knew and the life they had. These care partners struggle to meet the needs of the person with advanced dementia. Most care partners experience a sense of relief and guilt when the person with dementia moves into a care home.

My brother and I feel awful we had to take these steps for her own safety but we know it had to be done. She has been such a lovely Mum (still is) and so independent. Mum's feeling is that she hopes she will get better and go back to her own home. (Care partner, family, Pākehā, female)

The lives of people with dementia matter and can be better

People living with dementia are living meaningful lives, but they can live better lives. To do so, people with dementia want:

- people to understand dementia, respect and include them in their lives
- support through difficult times like diagnosis, dementia progression, and transition to residential care
- time, information and support to make their own decisions
- more health and support services tailored to their diverse needs, which are available when they need them
- support for their care partners so they can continue to care through caring for themselves.

Finally, words of advice to others diagnosed with dementia

Listen, don't worry about it, just don't, that's the last thing you do. Look after yourself and if you need help, ask for help. That's all you do. (Older person with dementia, Māori, female)

Introduction to the research and research methods

New Zealand needs research on living with dementia

Dementia is a significant and growing health challenge

Around 70,000 people in New Zealand have dementia. The number of people with dementia is increasing. By 2050, over 170,000 people will have dementia due to our ageing population. Dementia impacts more women than men. The estimated cost associated with dementia in New Zealand is \$1,676 million in 2016, rising to \$2.7 billion in 2030 (Deloitte, 2017).²

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).

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 organisations, communities, health services and national policies support people affected by dementia.

Alzheimers New Zealand commissioned this research to make known the lived experience of people with dementia and their care partners in New Zealand. The research findings are being used by Alzheimers New Zealand to support people living with dementia.

² Costs include primary and secondary care costs, drugs, pathology services and imaging, research, allied health, aged care, productivity losses, informal care, respite and carer support, mobility aids and modification, and other costs.

We used a people-centred research approach

Our research gives a voice to people living with dementia

People with dementia are often excluded from research about their lives (Carter & Rigby, 2017; Johnson, 2016) due to concerns about their ability to give consent and the potential for harm. In the past, research about living with dementia often focused on the experiences of care partners or family members. The voice of people with dementia was silent.

People with dementia are increasingly demanding the right to participate in research about them. They are developing best practice guides for their inclusion in research (Novek & Wilkinson, 2017; The Dementia Engagement and Empowerment Project [DEEP] Guides 2013a,b, 2014; The Scottish Dementia Working Group Research Sub-group 2014).

Our research adds to the knowledge of living with dementia in New Zealand

This research, commissioned by Alzheimers New Zealand, focuses mainly on the experiences of Pākehā living with dementia and includes a few Māori participants. It complements other qualitative research projects about living with dementia in Aotearoa New Zealand. These studies include a focus on:

- the experience of living with dementia (Gilmour & Huntington, 2005; Smith, Gee, Sharrock, & Croucher, 2016)
- the effects of having to stop driving (Chacko, Wright, Worrall, Adamson, & Cheung, 2015)
- sleep disturbances (Gibson, Gander, & Jones, 2014)
- the impact of admission to an acute hospital unit (de Vries, Drury-Ruddlesden, & Gaul, 2019)

- spiritual life in the dementia unit (Perkins, Egan, Llewellyn, & Peterken, B, 2015).

Work is also in progress to better understand the experiences of Māori, Pacific, Chinese and Indian communities living with dementia in Aotearoa New Zealand (Cullum et al., 2018; Dudley, Wilson, Menzies, & Elder, 2018; Dudley et al., 2017, 2018).

This research focuses on four questions

- What are the experiences of people living with dementia?
- How well do support services meet the needs of people living with dementia?
- How do people living with dementia live well?
- What is the impact of dementia on relationships with care partners, family and friends?

People living with dementia guided the research

A Research Advisory Group guided the research at the design, analysis and reporting phases. Appendix 1 lists the people on the Research Advisory Group.

We also involved Alzheimers New Zealand Advisory Group members at the design, analysis and reporting phases.

We had ethical approval to do the research

The Northern B Health and Disability Ethics Committee (18/NTB/81) granted ethics approval to conduct the research. The research was completed to the Committee's requirements. Gaining ethics approval was challenging due to concerns about participants' ability to give consent.

49 people living with dementia took part in the research

We interviewed three groups of people living with dementia:

- **18 people with dementia** – to hear their voice and understand their experience. People with dementia were included in the research if they had a dementia diagnosed and could consent to take part in an interview. We included younger people (under 65) and older people (over 65) as they can have different experiences.
- **9 people with dementia and 9 care partners (9 couple interviews)** – to understand their lives, both the challenges and how together they live well.
- **13 care partners of people living with advanced dementia** – to understand their experience and gain some insight into the lives of people with advanced dementia.

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). Using this scale, people with dementia who took part in this research had early to mid-stage dementia. People with advanced dementia were excluded due to ethics requirements relating to consent.

We interviewed people living in urban, provincial and rural areas. We did 11 interviews in Auckland, 9 in Palmerston North, 3 in Whanganui, 8 in Eastern Bay of Plenty, 6 in Tauranga, and 3 in Napier.

We interviewed a wide range of people living with dementia. We included six Māori and one Pacific person living with dementia who wanted to take part in this research. We did not seek more Māori and Pacific people as we did not want to copy other research being currently completed. Most interviews were with Pākehā.

Table 1 describes the people who took part in an interview.

Table 1: The different people who we interviewed

Types	Description	No of interviews
People	People with dementia	18
	Couple interviews: person with dementia and their care partner	9
	Care partner of person with advanced dementia	13
Living situation of the 27 people with dementia interviewed	Living alone	8
	Living with care partner	19
Age of the 27 people with dementia interviewed	Older people with dementia (over 65)	16
	Younger people with dementia (under 65)	11
Connection with dementia groups ³	Connected	29
	Not connected	11

We used a qualitative research approach based on DEEP guides⁴

People with dementia are a diverse group. We used qualitative semi-structured interviews to tailor our research to individual abilities and circumstances (Novek & Wilkinson, 2017).

Our approach was guided by the Scottish Dementia Working Group Research Sub-group principles for research with people with dementia (The Scottish Dementia Working Group Research Sub-group, 2014).

³ We included people who were connected and not connected with Alzheimers and dementia organisations.

⁴ The Dementia Engagement and Empowerment Project [DEEP] Guides (2013a,b, 2014).

We followed DEEP guides (2013a,b, 2014) to develop the research tools and guide the interview process.

We used a multi-stage thematic analysis process involving people living with dementia. We placed people living with dementia at the centre of our analysis. We wanted to understand their lives and how their experiences were influenced by their family, community and the wider New Zealand society.

We reported findings back to people who took part in the research.

Appendix 2 provides more details on the research and analysis approach and the research team.

We are confident this report reflects the experiences of research participants

We have developed the report so you can hear the participants' voices and experience the diversity of their dementia journeys. We have been careful to remain true to the language used by people living with dementia.

We did not include all experiences of people living with dementia

This research did not include the diversity of all people living with dementia. More research is needed into the lived experience of people with advanced dementia, those who deny they have dementia, those living alone, LGBTQI populations⁵, those on low income or living solely on the state pension, and people with dementia who are in employment.

⁵ LGBTQI population refers to lesbian, gay, bisexual, transgender, questioning (or queer), intersex.

Report structure and terminology

Overview of the report structure and terms used

Report structure

The report follows people's dementia journey. We describe below the sections of the report and the voices speaking in each section.

The following sections lead with the voice of people with dementia, with input from care partners

- **Something's not quite right** presents the start of the dementia journey when people notice something is changing.
- **Have I got dementia?** steps into the next phase of the dementia journey, seeking a medical diagnosis and an understanding of what is happening.
- **What having dementia means to me** shares how people with dementia describe having dementia and how they are redefining their identity and life.
- **I value my independence** highlights the importance of independence to people with dementia.
- **I can live a meaningful life** describes how people with dementia continue to live a meaningful life and what they do to achieve this.
- **I need the right help and support at the right time** describes the support services people living with dementia need and their challenges accessing support services.
- **I need a community where I can move around easily** presents the challenges people with dementia face in moving around their communities.

The following sections shift to the voices of people with dementia and their care partners.

- **We pull together as a couple** presents couples' experiences of living with dementia.
- **Sometimes we need a break** highlights the importance of respite care and the challenges of accessing care that meets diverse needs.

The final section presents the voice of care partners of people aged over 65 years with advanced dementia. Half of these care partners were either living with the person with advanced dementia or the person with dementia was living in residential care.

- **Care partners feel love, loss and guilt when caring for people with advanced dementia** describes care partners' lives when supporting people with advanced dementia.

Report terms

We use the following common terms throughout the report:

- 'Person with dementia' or 'people with dementia': someone with a dementia diagnosis.
- 'An older person with dementia': someone over 65 years.
- 'A younger person with dementia': someone under 65 years.
- 'People with mid or early stage⁶ dementia': People with dementia were able to give consent or be supported to give consent to take part in the research
- 'People with advanced dementia': People who were not able to give consent using the Older Adults' Capacity to Consent to Research Scale, or where the person with dementia was living in residential settings. In these cases, we interviewed their care partners.

⁶ We did not clinically define the stage of dementia. We used ability to consent and feedback from the people with dementia and care partners to estimate stage.

- 'People living with dementia': the person with dementia **and** their care partner.
- 'Care partners': those who support people with dementia. In this research, care partners were spouses or members of the family (e.g., daughter/son/in-law).
- 'Spouse': the person with dementia's wife, husband or partner.
- 'Family': the wider family who do not live with the person with dementia and who are not the main care partner.
- 'Most', 'some' and 'few': refers to the people who took part in this research, and not all people living with dementia.
 - The terms are used to highlight whether the experience described was shared by most people interviewed, about half, or only a small number of people interviewed.
 - Given the nature of the research, other people interviewed may have had similar experiences but did not mention them in the interview.

Research findings

Something's not quite right

This section presents the beginning of the dementia journey when people start to notice something is changing.

Overview of findings

- For many the dementia journey starts in a gradual way.
- At first, many older people think the changes are 'just old age'
- A sense of shame stops some older people seeking help.
- Younger people with dementia notice how changes affect their paid employment.

For many the dementia journey starts in a gradual way

Many people with dementia know something is not quite right for some time before they seek help. However, some do not see any changes.

I suppose it was when I got to about 70. Maybe a bit earlier, I'm not sure exactly. Then I slowly felt as though as I wasn't quite there. Yeah. Just slowing down and forgetting things. (Older person with dementia, Pākehā, male)

Sometimes, spouses notice these changes before the person with dementia. A few spouses saw these changes, not as a health issue, but growing disinterest in them and their relationship.

Care partner: I began to feel he was ignoring me...I felt he was shutting himself off and ignoring me. There was a lot of misunderstanding because I didn't know what it was. I just felt that he was being ...

Person with dementia: An asshole.

Care partner: Yes. Once we got to the stage of understanding that it wasn't within his control, I began to adjust. There was a hell of a lot of them for me to make. (Older person with dementia and spouse, Pākehā)

How people with dementia experience or interpret the changes depends on their age.

At first, many older people think the changes are ‘just old age’

Most people with dementia aged over 65 years tend to interpret the changes as due to expected old age decline. This belief is most strongly held by those aged over 70 years.

Most older people with dementia describe becoming more forgetful, losing words and finding it hard to follow conversations. They describe having slower reactions, losing their balance, and finding it hard to organise.

I would forget words or... not use the right words and... it seemed to become more obvious, especially to my partner more than me. I would mix up spoons with... fork and... not being able to remember things. (Older person with dementia, Pākehā, male)

Some describe having difficulty sleeping but feeling drowsy all the time. A few experience vivid and frightening nightmares.

A sense of shame stops some older people seeking help

Some older people are reluctant to seek help due to a sense of shame. Others do not want to cause a fuss.

I think it just came along gradually. It probably... developed maybe one to two years ago... I'd put down my phone then forget where I left it.... I didn't do anything immediately, no. I was almost ashamed of it. Sort of, embarrassing. (Older person with dementia, Pākehā, male)

A few who had a family history of dementia tried to cover up and denied anything was wrong.

Younger people with dementia notice how the changes affect their paid employment

Most people with dementia aged under 65 notice changes that impact on their ability to do their paid employment. People talk of not being able to handle the stress of their job, being anxious, and finding decision-making hard.

I just can't handle any sort of stress. Can't handle it. Can't do it. Yet, I used to thrive on it. (Younger person with dementia, Pākehā, female)

Others comment on speech changes and difficulty with recall or pattern recognition. Some notice a loss of skills such as cooking, numeracy or strategic thinking. As a result, people talk about making uncharacteristic mistakes.

When I look back, there were changes that explain some of the things that happened. I found it harder to concentrate and to stay on target with certain tasks. With my job, there were things that I did wrong uncharacteristically. At that time, we were going through a stressful period [at work]. (Younger person with dementia, Pākehā, male)

These impacts result in some people with symptoms doing internet searches to find out possible causes.

I was struggling with numbers, letters, the computer and reading things. So, I got onto Google, I thought I might have had a bleed... a stroke. I looked at that and the symptoms didn't match. Somewhere after that, I got into Alzheimer's. I thought that matched pretty much. (Younger person with dementia, Pākehā, male)

Have I got dementia?

This section steps into the next phase of the dementia journey – seeking to understand what is happening and a medical diagnosis. Recall of the details about the diagnosis phase vary. However, people living with dementia recall the challenges and frustrations of this stage.

Overview of findings

- Both older and younger people delay seeking health advice.
- A crisis or family intervention results in a visit to the General Practitioner (GP).
- The process to get a dementia diagnosis is varied and slow.
- Tests are not always trusted.
- Experiences of GPs vary in the diagnosis process from positive experiences to ones lacking empathy and an understanding of dementia.
- Most people are deeply shocked when told they have dementia.
- Telling friends and family is hard and the response is mixed; some are supportive, others pull away.

Both older and younger people delay seeking health advice

Many people describe the initial changes as an inconvenience, and not enough to make them visit their GP. For some, the delay reflects a lack of awareness or understanding about dementia. Others, particularly those with a family history of dementia, delay seeing their GP as they are afraid the changes may be due to dementia.

It was still a shock to have it, but in the back of my mind, I thought that's what it was. (Younger person with dementia, Pākehā, male)

Fear and stigma relating to dementia also creates delay. Starting to notice changes is a time of fear and uncertainty. Some describe a period of denial – hoping the changes may relate to something else or are temporary. Care partners and families are also fearful. The sense of dread is due to an underlying suspicion that dementia may be the cause of the changes.

A crisis or family intervention results in a visit to the GP

Most older people with dementia seek help due to a crisis or family intervention. Crisis triggers vary. A physical injury from a fall or car accident may result in a visit to the hospital or their GP and start the diagnosis process. A few have a serious illness (such as influenza) that triggers wider tests.

We were away on holiday. ... Towards the end of three weeks he started to be unwell. ... The last night before we flew home, he was totally disorientated. Didn't know where he was or what he was doing. We went to the emergency doctors. They took a blood test. They did lumbar punches and they did a brain scan. The brain scan showed age related atrophy. ... About five days later they got the results, he had come in contact with Influenza and they seemed to think that was a catalyst that set it all off. Although when we looked back over the past 18 months to two years, he probably was on the pathway, but we didn't realise ourselves that was happening. (Care partner, Pākehā, female)

Family intervention tends to happen through a visit with a daughter or son who realises the impact of the changes on their parent/s' daily life.

It would be about 13 years ago. I had a couple of inklings. [Person with dementia] and we went down to... for a fortnight. And after we'd been there five days [my daughter] said to me, 'Dad, I think mum might have Alzheimer's.' I asked why, and she said it was because mum has no idea where the dishes or the forks go, and that was a sign of Alzheimer's. It sort of started there. (Care partner, spouse, Pākehā, male)

As with older people, some younger people with dementia deny anything is changing or do not recognise the change until a crisis occurs or someone intervenes. The trigger could be an accident or work contacting their spouse to see if anything is wrong.

I can recall one of the earliest days... I was driving home...I got to an intersection on a rainy night, and I just froze. I couldn't work out where the road was due to the shiny tarmac, lights, traffic lights, car lights. I didn't know where to go. That was a bit scary, and one of the indications. (Younger person with dementia, Pākehā, male)

The process to get a dementia diagnosis is varied and slow

Everyone eventually goes to their GP to discuss the changes and seek an explanation. A few have tests when in hospital and are then referred to their GP. Most people with dementia describe the process from contacting their GP to reaching a diagnosis as slow. Many people talk of a difficult 12 months or more trying to get a diagnosis. Others speak of being told to come back in 12 months and go through a frustrating 'wait and see' approach.

Diagnosing it earlier prevents more frustration, as you understand what's happening. (Care partner, family, female)

Some older people visit their GP who does memory and blood tests. They are then referred to Older Person's Health Specialist Service at their local District Health Board for further tests with a psychologist, neurologist or speech therapist. Younger people with dementia are more likely to be given brain scans.

When we went to the doctor, I mentioned my family history and asked if it was a possibility for me. The doctor did some testing and said, 'you seem to be fine,' but said they would refer me to a neurologist anyway. The neurologist did the same type of test, then they said they were going to refer me to an older person's health place. (Younger person with dementia, Pākehā, male)

Tests are not always trusted

Some people do not believe memory tests related to drawing shapes can determine whether they have dementia. Some are able to do the drawings at home, after not being able to do them at the GPs, so question the validity of the results.

They did a test which I thought was ridiculous. To draw a box. How many people can draw a box in 3D? Very few people, because all the angles are 45 degrees. [He] couldn't do it, at the time. When we came back home [he] could do it, just not on the spot. (Care partner, spouse, Pākehā, female)

Those who had a brain scan felt they received a conclusive diagnosis.

Experiences of GPs varies in the diagnosis process

People living with dementia say GPs play a key role in diagnosis, ongoing care and support, and advice on living with dementia. People living with dementia have varying GP experiences during the diagnosis stage. Some GPs are described as excellent, while others lack empathy and an understanding about dementia.

Some people with dementia have positive GP experiences

People with dementia and care partners with positive GP experiences say their GP:

- Listened openly, was respectful, and gave them time to process information and ask questions
- Understood dementia, its treatment, and impact
- Informed them sensitively about their diagnosis
- Offered advice relevant to the dementia journey stage
- Informed them about other support services and how to live well.

We've had a good talk with doctors and various people. Got a fair idea. I certainly know what road I'm travelling down. I'm not at the end of it yet. (Older person with dementia, Pākehā, male)

Some GPs lack empathy and an understanding of dementia

Other people living with dementia are disappointed in their dealings with their GP through the diagnosis stage. As a result some change their GP, usually to one recommended by other people living with dementia. A few people ask family members who are health professionals to help them navigate the health system and get a confirmed diagnosis. Without this help, these people believe they would not have got a diagnosis or support needed to live well.

We did change doctors, initially. We've had the same doctor for 30 odd years, and he initially said it was just stress. But [he] wasn't accepting that so I got us into a new practice. (Care partner, spouse, Pākehā, female)

Below are examples from people with dementia of interactions with their GPs which caused distress.

My GP did not listen and downplayed my concerns

A few older people were told their symptoms were just old age, and not to worry. A few younger people with dementia were told the symptoms were due to stress, and to slow down. Some health professionals did not believe the person could have dementia due to their young age. This belief had slowed the diagnosis process.

The first one that I went to, he had a look at me and kept saying 'you're too young for this, it's probably something else'. (Younger person with dementia, Pākehā, female)

Others made the diagnosis and then offered no more help.

[After diagnosis] They [GP] signed me off – more or less. He didn't want to see me anymore and just gave me some pills and said 'there you go, not much we can do here. You're not as bad as some, keep taking the pills and if it gets worse, come see us again'. (Older person with dementia, Pākehā, male)

My health professional bluntly told me I have dementia

A few people with dementia were stunned by how GPs and other health professionals informed them they had dementia. These health professionals used very direct delivery, which heightened the stress and shock. However, a few care partners liked the honesty of this approach.

Person with dementia: [The specialist] asked how I was. And I said, 'I was fine', and she said, 'I wasn't as good as I thought'. So of course, my instant reaction was, 'how dare you talk to me like that'. And then she says, 'you're never going to be well'.

Care partner: She said there was no cure that can come out to help you for it. And you can only do the best that you can. She said that she was being a bit blunt. She said 'the thing was that you've got to realise that you've got it. There are so many people who have it, and they won't accept it'...Unfortunately [person with dementia] doesn't remember the explanation, she remembers the initial shock. (Older person with dementia, Pākeha, female and spouse)

I was told my life was over

A few people received insensitive advice from their GP after being told they had dementia. One person was told by their GP to go home and put their affairs in order. They believed they had been told to go home and die.

You're given the impression well, go home and put your affairs in order and wait. We felt that was what was going happen to us. Go home, get your affairs in order, and that's it. (Care partner, spouse, Pākehā, male)

One care partner was told to put her father in a residential home with little consideration of his needs. Other people were stunned to be told, on hearing their diagnosis, they could no longer drive their car.

I went to another specialist and she said right there and then 'you have dementia'. She said straight away 'you're not allowed to drive'... Well, it was a bit of a bolt from the blue and it still stiffs me off now. Can I say that I didn't like her? (Younger person with dementia, Pākehā, female)

Most people are deeply shocked when told they have dementia

I was stunned

The confirmation of a dementia diagnosis is upsetting. Many people with dementia speak of disbelief, sadness and anger. Some feel the life they lived and enjoyed is over and the future looks very bleak. However, a few are relieved to have their suspicions confirmed.

I'll never forget the day walking out of the office and to the car. We were just stunned ... when you think of the word Alzheimer's, you think of last stages. And that's a picture that people will have. (Care partner, spouse, Pākehā, male)

I was cheated

Care partners also experience a range of emotional reactions to the diagnosis. Most are fearful about the future and the implications for them. Some are relieved to have a confirmed diagnosis and to know what to expect.

Receiving a formal diagnosis is the start of being a care partner.

I feel sad. It's a sad state of affairs to end a life with. Our retirement, really... Just have to do the best you can, for both of us... But what am I supposed to do? No point being depressed. What help will you be to anyone else then? Nobody's fault, it just happens. That's life. (Care partner, spouse, Pākehā, female)

Some spouses talk of a sense of being cheated out of the life they wanted and had expected. Spouses under 65 who are working particularly feel this sense of unfairness – having to change their lives to be a care partner. They also resent not having the retirement they had planned.

I do feel a bit cheated. I see all these old people at the supermarket shopping, and the men are pushing the trolley, and I think 'well, I'm never going to have that.' I find that at our age a lot of people go overseas a lot and for us that's difficult. So in that respect, yes, I do feel cheated. (Younger care partner, spouse, Pākehā, female)

A few children who have stepped into a care partner role, while keen to support, are concerned about the impact on their family life if the person with dementia lives with them.

Well, I've got my family to consider, husband and kids. It was going to change our lifestyle, it changed it unbelievably... It was 24 hours, so everything to do with work and the kids had to be organised around my mum. We had to sacrifice a huge amount of things. (Care partner, family, Pākehā, female)

Telling friends and family is hard and the response is mixed

Receiving a diagnosis marks the time to tell others in their family (children, siblings and elderly parents), and to inform friends. The ways of sharing this news vary from gatherings to one-on-one discussions.

Family reactions vary from disbelief, relief, denial and pity

Children of people with dementia are shocked and upset to learn about their parent's diagnosis. Some children, particularly daughters of people living on their own, step up to make sure their parent is supported. A few invite their parent to live in their homes.

Parents of younger people with dementia are particularly upset at the diagnosis. For family not living near the person with dementia, the news is upsetting as they may not have been aware of the changes.

Following diagnosis, a few family members reduce the amount of contact with the person with dementia. Some family members, who are not spouses or care partners, seek to control how the person with dementia lives their life. A few families want the person with dementia to go into a residential care facility or want to manage their assets.

At the beginning, they [the family] didn't come around, maybe because they didn't want to face the reality of accepting what has happened... Their thought was put her in a home, and I didn't get why they wanted to do that; she's still cognitive. (Care partner, family, female)

Responses from friends vary – some pull close, others become distant

Some friends respond by pulling closer. These friends are proactive in ensuring the person with dementia remains involved in activities they enjoy (such as Friday drinks, going fishing, going shopping or for a coffee). Through these shared activities, bonds strengthen.

However, some friends start to pull away and become more distant. People living with dementia feel some friends lose contact as they do not know how to interact with the person with dementia. People living with dementia find this response disappointing and hurtful.

When it first happened, I called together some close friends and crying my eyes out, I said, 'I need your support. Please don't wait for me to call.' Well, we never heard from one couple ... I was really disappointed, quite hurt, by that ... We've come to realise that there are only certain people that will help and that do understand. Some don't totally understand what we're going through and don't understand that we need support. (Care partner, spouse, Pākehā, male)

A few people have other more pressing health issues

A few older people with dementia have other more pressing health issues. Some have cancer or 'breathing' issues. These health issues are seen as more important than dementia as they are more immediately life-threatening.

A few care partners of older people with dementia feel other illnesses trigger the progression of the dementia. These care partners speak of their vigilance and prompt action if the person with dementia gets an infection.

Every time he gets an infection of any sort his cognition is affected quite badly. So that's one of the reasons we are going to the doctor today. Because we've got to get on top of whatever happens, or he just goes downhill again. (Care partner, spouse, Pākehā, female)

Some spouses of people with dementia also have chronic long-term conditions or significant health issues. People living with dementia struggle to meet both partners' health and wellbeing needs. Some access a range of support services to live at home.

A few care partners make arrangements for the person with dementia in case they themselves are hospitalised. These care partners tend not to have other family living close by.

We had a family meeting with our GP... from which I developed the arrangements for her care if I am hospitalised or disabled. (Care partner, spouse, Pākehā, male)

What having dementia means to me

This section shares how people with dementia describe having dementia and how ongoing changes redefine their identity and life.

Overview of findings

- Most people do not define themselves by dementia.
- Most people with dementia say they are forgetful and intelligent.
- A few people with dementia have a sense of hopelessness and despair.
- Changes due to their dementia mean people are continually redefining their self and life.
- People with dementia go through cycles of grief and loss to reach acceptance, as they adapt to ongoing changes.
- Reaching acceptance is important to reduce anxiety and continue to have a meaningful life with dementia.

Most people do not define themselves by dementia

Society tends to define people with dementia by stigmatised views of dementia (Batsch et al., 2012). Talking about dementia caused sadness and tears but no one interviewed solely defined their life by having dementia.

I never gave it [dementia] a thought to be honest. C'est la vie! Life goes on. You can't dwell because you have to keep living. You have to live with it. There is nothing you can do and you cannot change it. They can't operate on it. It's the start of the body starting to die down like a plant. It's not a curse, just part of life. (Older person with dementia, Pākehā, female)

Most people with dementia have a level of acceptance. They acknowledge the changes and challenges dementia brings and the uncertainty of tomorrow.

You can't read into the future. Take it as it comes. (Older person with dementia, Pākehā, male)

Most people with dementia accept having the disease and work at living the best life they can.

It's not a nice sickness to have. I was a bit down over it. I cried. I never thought I'd get it, but I got it... I always said, 'if dad's had it and I get it then I'd be happy to have it.' I am happy to have it. So, you can't do nothing about it so you've got to put up with it. And I'm quite good with it. I don't mind. (Older person with dementia, Māori, female – said with tears in her eyes)

Others find it harder to accept they have dementia. These people tend to be more upset when talking about dementia and its effects.

Most people with dementia say they are forgetful and intelligent

When asked what dementia means, most people with dementia can describe the effects of the disease and are aware of its progressive nature. People with dementia say dementia means becoming more forgetful.

I think it is slow, slowly getting more and more forgetful. (Older person with dementia, Pākehā, male)

Others say having dementia means they take longer to understand or remember or have difficulty processing information.

Well, it takes away your ability to remember things. Sometimes you get a bit frustrated by that. But when it comes back after a while you think, 'oh, what the hell was I worried about this for. I remember it now'. (Older person with dementia, Pākehā, male)

While forgetful, most people living with dementia describe themselves as capable of thinking and reasoning.

It's all a question of admitting people with dementia have still got reasoning powers. (Older person with dementia, Pākehā, female)

One person with dementia explained that while forgetful, people with dementia are intelligent.

I don't think I've lost my intellect. I follow the news, and things like that. I've always been a thinker and I still am. I think that's still up there, but sometimes the coordination, that's the problem. (Younger person with dementia, Pākehā, male)

However, they are aware others do not see them as intelligent.

Younger person with dementia: A lot of people treated me differently and that made it harder. And I thought, you know, I'm just a normal person really.

Care Partner: Like you were a numpty.

Younger person with dementia: Yeah, I felt like I was really dumb.

A few people with dementia have a sense of hopelessness and despair

These people grieve for the life they have lost due to the progressive nature of the disease. They are frustrated that losses in memory, language and balance mean they can not do what they want. They have a sense of hopelessness, as the disease has no cure.

I feel depressed. No cure, no hope. I can't help and do the physical things I used to. For example, hobbies. I was interested in making a model yacht... I just lose concentration, and my hands would start shaking... I've got no interest in doing hobbies, I couldn't do them to the same extent. (Older person with dementia, Pākehā, male)

Changes due to their dementia mean people are continually redefining their self and life

People with dementia describe the progressive decline in their memory and their physical health (for example, speech, sight and balance).

Yes, I loved to do exercises. Not only that but be a bit clever and do a flip, which I could do. And land on your hands again. And it was fun, and it worked for years. All of those things, it affected my, not so much my brain but my balance. That's the way I understand it. ... I got these walking things. What do we call it? My chariot ... Now I have got four legs. (Older person with dementia, Pākehā, male)

These declines mean over time they change or stop activities they enjoy that define how they see themselves.

Many people with dementia say they are less motivated.

I find it a bit of a nuisance because it slows me down so much. I haven't got the words anymore. There's so much to do in the garden and around the house but it's really an effort to get myself motivated, that's the biggest problem I find. One of the positives is I don't care. I don't give a stuff. That's more frustrating for my wife than for me. (Older person with dementia, Pākehā, male)

They also describe changes in their behaviour, with some being quieter and others more outspoken and less inhibited.

I'm a lot more outgoing. I don't know why. Maybe because my inhibitions aren't as strong. (Older person with dementia, Pākehā, male)

These ongoing changes affect how people with dementia see themselves, and how others see them.

People with dementia go through cycles of grief and loss to reach acceptance, as they adapt to ongoing changes

Most people with dementia describe, to varying degrees, going through the stages of grief and loss following their dementia diagnosis. Many people living with dementia learn to cope with and adapt to the progressive nature of the disease. Over time, most (but not all) people with dementia we interviewed reached an acceptance of having the disease.

From my perspective, it is what it is. I don't like the thought of where it's going. But I have no problem accepting where we're going. I'd rather not go there though. I think that it's within me, it's my concept of life that allows me to accept it all. I get frustrated at times, but not really frustrated. Actually, it's not frustrating. I get that I've forgotten something. (Older person with dementia, Pākehā, male)

Even with acceptance, people with dementia become sad, depressed and angry when they reflect on the changes in their life. Depression and sadness are also triggered when changes mean they can no longer do activities they once enjoyed. Through this continuous change process, people experience repeated grief, loss and acceptance cycles as their dementia progresses.

Reaching acceptance is important to reduce anxiety and continue to have a meaningful life with dementia

Some people with dementia offer advice on the importance of coming to terms with the diagnosis. They believe if people don't accept the diagnosis, they cannot move forward and live a meaningful life.

I value my independence

This section highlights the importance of independence to people with dementia.

Overview of findings

- People with dementia value their independence.
- Some people living with dementia plan and make changes to support independent living.
- Familiar technology supports independence, but new technology can lessen independence.
- People with dementia appreciate the need to balance independence and safety, to reassure family.
- Some people with dementia feel they have little control over their life choices.
- People with dementia want to make choices about their lives, for example:
 - where they live
 - how to care for themselves
 - doing activities they enjoy
 - having a voice in deciding when to stop driving
 - deciding whether or not they leave their employment.

People with dementia value their independence

People living with dementia want to maintain their independence for as long as possible. However, the ongoing changes due to dementia affect their ability to live independently. People with dementia have to adapt or seek support to live their lives as they wish.

She said, 'well mum, you can live with us' and I said, 'no I don't want to live with any family, I want to still be independent on myself, and if I go into a rest home, I can still be independent on myself.' I like to be independent. I love to be independent. I think the day I go down dependent is the day I don't want to live anymore. (Older person with dementia, Māori, female)

Some people living with dementia plan and make changes to support independent living

People living with dementia who are able to accept the diagnosis take steps to plan for their future. A key change is moving to a new house. Creating an enabling environment can maintain their independence for as long as possible.

We've got to be mindful. Which is why we moved. We've been in this house for 3 months. It was just too much distance [from my work] there, and too much of a concern for me to be too far away if needed. So, we came into this place and couldn't have gotten closer. The house is just 200 metres from my workplace. (Care partner, Pākehā, male)

A few people move to a more manageable property to sustain living independently. Others choose to move to an assisted living or a lifestyle community that provides health and social support. These people recognise they need more support as dementia progresses. Some people move closer to friends, family or familiar places.

People with limited money are not able to make significant changes, such as moving to a new house to keep living independently.

Others tell family how they want to live as their dementia progresses. Some set up Enduring Powers of Attorney to have clear guidelines of who to contact and how to make decisions.

Many people living with dementia make changes to their home and wider environment to support their independence. Below are their tips.

General approach

- Set up and keep to routines
- Don't worry too much
- Tell people you have dementia, and ask them to slow down, listen, and give you time to think and answer

Changes in the home

- Label cupboards around the house
- Have noticeboards with daily and weekly activities
- Keep a diary of activities
- Keep instructions by the microwave on how to heat food
- Use a computer to find out information and communicate with family, friends and others
- Have a visitor's book, especially for those living alone, so family are aware if carers are attending as arranged and who is dropping in

Managing finance

- Put bills on automatic payment
- Use credit or debit cards with paywave to make buying easy
- Limit purchase amount on credit or debit card, or withdrawal at the bank

Offering reassurance to family

- Install a medical alarm to be able to call for help, if needed
- Have a GPS tracker so care partners can find you if you are lost

Aids to help with taking the right drugs at the right time

- Set alarms on cell phones to remind when to take drugs or ask family member to send text reminders
- Ask pharmacy to do blister packs

When out and about

- Have address on licence or a card
- Have a card telling others you have dementia (when shopping or travelling)
- Have a mobility scooter, if you have trouble walking
- Get access to subsidised taxis.

Familiar technology supports independence, but new technology can lessen independence

People with dementia continue to use familiar technology. People who live alone say cell phones enable their independence. Families are able to contact easily, usually daily, to chat, check they are well, have eaten and offer any reminders or reassurance.

Some people with dementia struggle to learn how to use new technology. Some could not learn how to use a new cell phone. As a result, they lose the ability to easily contact families and friends, or use reminders. One person stopped cooking when they changed their stove.

Care Partner: [Person with dementia] used to cook, not now. We did make a mistake a couple of months ago, bought a new stove. We shouldn't have done that.

Person with dementia: I haven't learnt it as such. It scares me to try and learn it, because the dials on it, for instance. I have to come and get my glasses and look at each one before I switch it on. I can't remember. Normally you'd go over and do the one and it pops up, or that one is the oven. (Older person with dementia and care partner, Pākehā)

People with dementia appreciate the need to balance independence and safety, to reassure family

Most people with dementia dislike people, including spouses, children or GPs, telling them how and when they have to limit their independence. Their desire for ongoing independence creates tensions with their care partners' or families' desire for their safety.

I still want some control over my affairs and how things are done...The kids are more inclined to tell me what I should be doing. And sometimes I don't take their advice after thinking it through, and they have had to learn that's ok too...If you're dealing with older people, let them make the decisions instead of forcing things. (Older person with dementia, Pākehā, female)

Many people with dementia make changes to support their safety and keep their family reassured. Many stop driving. Some have smoke alarms put into their homes. A few move to a retirement village. A few stop cooking or using a computer due to family requests. Some feel pressured by family to make these changes.

Some people with dementia feel they have little control over their life choices

Most people with dementia want to make choices about their lives. However, they tend to not have a strong voice in these decisions. Some people with dementia believe their family and others feel they could no longer make informed decisions. People with dementia say with the right information, enough time, and support they **can** make decisions.

People with quite advanced dementia can still reason, given the opportunity to do so. So that's what I've been saying all the time and wherever I go. For goodness sake, let's work things through.
(Older person with dementia, Pākehā, female)

Some care partners are aware that they sometimes push for decisions they think best, even when they know the person with dementia does not want it. For example, encouraging the person with dementia to stop working, stop driving or start going to day programmes.

People with dementia want to make choices about their lives

People with dementia want a say on where they live

Living in their home is an important marker of independence. Some people with dementia strongly feel they should make their own decision about when (or if) to move homes. People living in their homes are in familiar environments. They can engage in activities they enjoy (such as gardening and working in their shed).

They want to decide how to take care of themselves

People with dementia value being able to take care of themselves. They want to shower or bath without assistance, and do their household tasks. These activities are important in defining how they see themselves and their contribution to their family.

I do a lot of housework. My first job in the mornings is put in the washing. If it rains, I hang it out in the shed. At least that way I'm doing something [...]. I burn my own rubbish. Proper incinerator. Something else I do in the mornings is I blow all the leaves out the front door. I clean it up, no problem. (Older person with dementia, Māori, male)

As the dementia progresses, many feel a loss of independence when no longer able to do tasks they easily did before. Some people find ways to continue contributing to their family, for example, doing the baking rather than the cooking.

I was put out of the kitchen, and so I'm getting back into making my own kind of quick cooking. I'm baking. He still basically looks after dinner at night. I look after the in-betweens. (Older person with dementia, Pākehā, female)

People with dementia recognise over time they need support with day-to-day activities, such as cooking or washing. They want a say in who and how these services are provided.

People with dementia want to do activities they enjoy

Some like going out to watch movies, having a meal or a coffee, having a drink at the pub, or joining social groups. Doing these activities is important and helps to maintain friendships or create new ones, keep active and have some fun.

At the cards club, I have a cup just for me. Came from the club. I can play darts, snooker if I want to. (Older person with dementia, Māori, male)

Many people with dementia find the physical effects of dementia particularly challenging, especially those who enjoyed sport. Due to the dementia, many have to stop doing a sport or activity they loved. However, some people with dementia are supported to take up new activities, which maintains their sense of independence. They enjoy being able to go for a walk or a bike ride, on their own or with others. Others take up handicraft activities, for example, knitting.

Care partner: We have a close friend who has helped [person with dementia] get back into knitting.

Person with dementia: I just do whatever they suggest. At the moment everyone seems to be knitting up something for the hospice shop. (Older person with dementia and care partner, Pākehā)

People with dementia want a voice in deciding when to stop driving

Many people with dementia stop driving. For both men and women, the loss of driving and of their car impacts deeply on their sense of self and their independence.

I drove for a job. So, it was very hard to give the company car back. Best vehicle I'd ever had. Losing the car, I cried. I really missed it. (Younger person with dementia, Pākehā, male)

Some people with dementia are told to stop driving by their doctor or by family. For a few others, a near miss forces the decision.

My wife said...I took an intersection and just missed a car...She said, 'didn't you see it?' I said, 'no I didn't'. I wouldn't have reacted quick enough I don't think. That's what decided it for me. (Older person with dementia, Pākehā, male)

Many feel not being allowed to drive limits their independence. People with dementia are unable to go to social events as easily, and shopping is harder without a car.

You can't go anywhere, can't just jump in the car and drive here or there, now you got to wait for someone else to do it for you. (Older person with dementia, Pākehā, male)

Some care partners feel stopping the person with dementia from driving is essential, for safety reasons.

People with dementia feel incapable when they have no say in when they stop driving. They want their choices and the implications of stopping driving explained to them.

That's when they first told me I had Alzheimer's and that's why I couldn't drive... Yeah. They just told me I couldn't drive; it wouldn't be safe on the road for other people as well. I could still drive, but something could happen and it could cause an accident.

[What advice would you give to GPs?] Soften the blow. And give an explanation of why you can't drive anymore. (Older person with dementia, Pākehā, male)

Younger people with dementia want a say in when they leave their employment

Most younger people with dementia we interviewed were in paid employment at the time of their diagnosis. All had left their employment by the time they were interviewed.

Some employers work to support the person with dementia to stay in employment. Other employers do not, and put the person on immediate sick leave. A few people with dementia spoke of colleagues who were not welcoming and who treated them differently.

Those in self-employment adapt their work until they can no longer contribute to their business. Having to stop working before they intended is a significant blow to their sense of self and their ongoing financial wellbeing.

Care partner: I think [name] selling his business was hard on him. When it was finally sold, he said, 'oh well. I'm unemployed now.'

Person with dementia: It's a bit of a wrench and a loss of money...I had to just stop because I couldn't do it, and I didn't have anyone else to do it for me. You can't just carry on like that. (Younger person with dementia and spouse, Pākehā)

Leaving work also results in some people with dementia feeling depressed due to the loneliness of being at home alone when their spouse is working. As a result, some spouses quit their job or reduce their hours to offer more support to the person with dementia.

Care partner: When the diagnosis came through, we made a decision for [name] to leave work because it was causing stress. Her employer bent over backwards to help.

Person with dementia: I just felt so lonely when I was at home. (Younger person with dementia and spouse, Pākehā)

With some changes, I can live a meaningful life

This section describes how many people with dementia continue to live a meaningful life and the strategies they use to achieve this.

Overview of findings

- When diagnosed, many people are not told they could have a meaningful life with dementia.
- Despite challenges, most people with dementia live full and meaningful lives in ways reflecting them. Examples include:
 - staying physically and mentally active
 - maintaining social connections.
- Most people with dementia contribute positively to their communities by:
 - helping their family and friends
 - supporting and advocating for others
 - enjoying their hobbies.
- Stigma about dementia and limited access to services make living meaningfully difficult for some.

When diagnosed, many people are not told they could have a meaningful life with dementia

Before diagnosis, many people with dementia have little knowledge about the disease

People's lack of understanding of dementia heightens their belief in the finality of a dementia diagnosis. This sense of hopelessness for the future is reinforced when health professionals present the diagnosis as an end-state.

They're still people. Once someone is diagnosed with something, they're almost handicapped. People treat them as if they can't do anything anymore... I just want her to continue as normal like it's not a big deal. And when you treat it that way, she's just accepting of it. (Care Partner, family, female)

Most people with dementia receive little advice on living with dementia

Most people with dementia receive little or no advice from health professionals on how to live with dementia. This lack of information reinforces people's belief that life as they knew it is over.

We did a bit of reading, talked to our psychiatrist who mentioned a few people's names. Researched... I found there are actually things I can do... (Care partner, spouse, Pākehā, male)

Older people with dementia rely on Alzheimers and dementia organisations for information on living with dementia. Younger people with dementia and their care partners tend to search online for information on living with dementia.

The one thing that I would really emphasise is that whilst the diagnosis is traumatic, and it is very traumatic. ... We believe quite generally, you can go on and live a meaningful life with some changes. (Care partner, spouse, Pākehā, male)

Despite challenges, most people with dementia live meaningful lives in ways reflecting them

Most people who are living meaningful lives with dementia have accepted their dementia diagnosis. They are engaged with decisions about how they live and what support they need. They adapt their lifestyles as their dementia progresses.

People with dementia define having a meaningful life in different ways that reflects their personality, interests and dementia stage.

The following are examples of what people with dementia do to give their lives meaning. Some people do all of these activities, others focus on one or two interest areas. The activities usually reflect interests the person with dementia had before diagnosis. Over time they adapt their activities to fit with their changing abilities.

Many people with dementia stay healthy and mentally active

People with dementia consider staying healthy and active important. Some are aware physical activity helps maintain blood flow to the brain.

I like walking, we got a dog so I try to walk the dog every day. The doctor said, 'that's a big thing you got to do, especially with your heart. Keep your blood flowing and everything working'. (Older person with dementia, Pākehā, male)

Many people with dementia do some of the following physical activities:

- going for a daily walk
- going on a bike ride, either with a friend or alone
- gardening
- going to the gym on a daily or weekly basis
- doing balancing exercises
- playing sports, like bowls, snooker, darts and pool.

I go [to the gym], I spend an hour, hour and a half there. I play on the rowing boat. I can do the 600 meters in an hour, I think. I don't rush it but I get going. I love going to the gym. (Older person with dementia, Māori, male)

People with dementia also stay mentally active. Some play computer games, quizzes or challenges, such as card games. Many read books and the newspaper every day. Some do craft hobbies such as scrapbooking, drawing and knitting. Some men with dementia are involved in the local men's shed and build and repair furniture.

A few people also change their diet to live more healthily, as they believe it will slow the progression of dementia.

We changed our nutrition. We researched into certain supplements and certain things. And that's good to do and it gave us an action plan. We can do something about this. No known cure, but there's still things we can do. (Care partner, spouse, Pākehā, male)

All agree staying active and busy helps foster their sense of purpose and wellbeing. These activities make them happy and connect them to their community.

I like being busy. I like my life to be occupied all the time. I don't like sitting around reading. I like to do things in life. (Older person with dementia, Māori, female)

Many people with dementia work to maintain their social connections

People with dementia value connections with their family and friends. Many people with dementia appreciate the help of family and enjoy spending time with them.

I have lots of friends – we have lots of friends and they're always here to chat and they make it easy... just having a chat. Just small things. (Older person with dementia, Pākehā, male)

Most people living with dementia connect with groups such as their local Alzheimers or dementia organisation, the RSA (The Royal New Zealand Returned and Services' Association), day programmes, the Cossie Club (the Cosmopolitan Club), and other groups. Connecting to these and other groups enables the opportunity to talk to others with shared experiences and interests.

I go to the RSA. There are also outings. It's good. I get around, I get to see people, especially with these people. Everyone is talking on the same level, which is good. You can discuss things amongst yourself. (Older person with dementia, Māori, male)

Connecting to groups also means people with dementia are out in their communities meeting people and enjoying new or familiar activities. For some, these groups also expand their support networks, and are important in keeping active.

Most people with dementia contribute positively to their communities

Many people with dementia maintain or redefine their sense of purpose by helping others and contributing to their communities. People with dementia change the focus and scale of their contribution to adapt to their dementia.

Many people with dementia help their family and friends

People with dementia value being able to give back to their family, friends and neighbours. Some people with dementia look after grandchildren or show children or grandchildren how to do something (for example, puzzles or knitting). Others describe making and sharing music with family and friends.

I make little toys for the grandchildren. I'm doing scrapbooks at the moment for my daughter's grandchild, my great grandchild. (Older person with dementia, Māori, female)

Some people with dementia help their neighbours and friends around their homes. For example, one older woman hung up her friend's washing when they had shoulder pain.

Well if anyone isn't feeling well or anything, I'll go do it for them, I'll tell them I'll come and do it for them. Or someone might say 'would you be able to hang our washing on the line?' And I'll do it, I'd do it...I love it. A good part of living is helping. (Older person with dementia, Māori, female)

Some help friends to learn new skills, for example, teaching others to play pool at a day programme.

Some people with dementia support and advocate for others

Some people with dementia gain a sense of purpose by helping others in their community. They visit older people to listen to how they are feeling. Some contribute to their churches and other social groups by helping to organise group activities.

A few people with dementia advocate for the rights of others living with dementia. Advocacy roles include educating others about living with dementia at day programmes. People with dementia support the governance of Alzheimers and dementia organisations. A few are linked to international forums to engage with other people with dementia for peer support, education and advocacy.

I was on the Board for a while... Now my friend with dementia is on the Board. It's important to me to be helping the new people, and I believe it is a really important job. (Younger person with dementia, Pākehā, male)

A few people with dementia contribute to the dementia community by arranging social activities such as movies or places to visit. For example, one person set up a men's discussion group where they could get together and talk about their experiences with dementia.

Sitting around that table [at the club] you can talk to people with the same language. Sometimes people don't say a word. But with those people, it's totally different... I get involved with all their problems. We all have the same ones. (Older person with dementia, Māori, male)

Some people maintain a sense of purpose through their hobbies

Some people never enjoyed being part of community groups. For these people, their sense of purpose is created through their love of gardening, cooking, woodwork or other hobbies.

Stigma about dementia and limited access to services makes living meaningfully difficult for some

Some people with dementia become isolated

Some people with dementia say they are becoming isolated from friends and their community. This sense of isolation can be for several reasons. Some people with dementia perceive other people do not understand dementia, so exclude them.

Care partner: I feel there's a lack of understanding in the community.

Person with dementia: I think there needs to be an awareness about people with dementia. I didn't know anything about it before, and I don't think most people know what it is. (Older person with dementia and care partner, spouse, Pākehā)

As their dementia progresses, a few people find they are no longer invited to their friends' houses. A few lose contact with friends who live in other areas.

Other people with dementia say their anxiety on how they would be seen means they draw back from engaging with other people. Some people with dementia do not tell others about their diagnosis for fear of being excluded. A few people with dementia are no longer confident meeting new people. They lack confidence about how they would be seen and their ability to have conversations.

People with dementia do not receive the right support

As the dementia progresses, people with dementia need more support and services to live a meaningful life. As discussed in the next section, receiving the right services and support at the right time is not easy.

I need the right help and support at the right time

This section presents feedback on support and services used and wanted by people living with dementia.

Overview of findings

- When people living with dementia have access to a range of services, they can live meaningful lives.
- Care partners are the main source of support for people with dementia.
- People living with dementia access a range of services.
- However, many people living with dementia face barriers to access these services:
 - They do not know what services are available and whether they are eligible
 - They often do not know how to increase services as the dementia progresses
 - Care partners need help to get the support they need
 - Service availability varies across New Zealand
 - Some people living with dementia are able to overcome these access barriers, others are not.
- Services are not meeting the diverse needs of people living with dementia. People living with dementia need:
 - Services that meet the cultural needs of Māori and Pacific people
 - More services and hours of service
 - Greater reliability and trust in daily living services
 - Support services appropriate to their age and dementia stage
 - More tailored support in hospitals, especially in A&E and at discharge.
- Care partners need counselling tailored to their role.

When people living with dementia have access to a range of services, they can live meaningful lives

People living with dementia want access to different types of services at different stages along the dementia journey. These services help people with dementia to maintain independence and enable meaningful and positive lives.

- Many people with early stage dementia want more advice on how to live with dementia. Their care partners want more emotional support to come to terms with their changing lives.
- Many people with mid-stage dementia living alone want more support to live independently (for example, help with cooking and cleaning).
- Many people with mid-stage dementia want more opportunities to socialise through in-home support or day programmes. Their care partners enjoy a break through these services.
- Many people living with dementia want access to more and better-quality respite care.

Care partners are the main source of support for people with dementia

Care partners support people with dementia to maintain independence through daily living activities. Family and friends also provide social support to people with dementia (for example, taking them for a walk or a coffee). This support offers care partners some time to enjoy their hobbies.

Care partners, particularly spouses, try to be the main support person for as long as possible. Seeking formal support, particularly for older people living with dementia, does not occur until they near or reach a crisis point. Crisis points vary from not being able to do daily living activities, concerns about safety or care partner ill health.

A few people living with dementia but receiving no services say they are 'coping'. For some, this reflects the early stage of dementia, or care partners' determination. For others, the person with dementia does not want other people to help with personal living activities like washing and dressing. A few do not want to go to day programmes.

In contrast, some people with dementia do not want to burden their care partners so are keen to have more support services.

People living with dementia access a range of services

Most people living with dementia access multiple services. Some people use all the services listed below and others one or two. Most are grateful to have the services and find them valuable.

Daily living services provide home support with food preparation and meals, checking medication is taken, personal care needs, and cleaning and laundry. Some also receive help in the garden. These services tend to be accessed via their District Health Boards through the Needs Assessment Service Coordination (NASC).

Socialising and connecting services are used by some people with dementia. Some people have people coming into their homes each week for a chat or to go out for a walk or coffee. Many go to day programmes where they enjoy a range of activities and a meal. Many care partners also appreciate these activities as it offers them time for themselves. These services tend to be delivered by Alzheimers or dementia organisations.

I love coming because they get people in and we learn how to do different things. I love that. ... I make little things and take it home and show them what I did today. And I make it at home and the young grandchild wants to know how to make it, so I show them.
(Older person with dementia, Māori, female)

Alzheimers and dementia organisations' support groups are appreciated by care partners as they like sharing their experiences, frustrations and advice. Care partners also like it when their support groups coincide with a group for the person with dementia.

[Support groups] give networking, sharing stories and ideas. We talk about medication, diet, funny happenings. We talk about all sorts of things. I find them very therapeutic just to discuss things. (Care partner, spouse, Pākeha, male)

Education sessions, for example, living with memory loss, are useful for people with a recent diagnosis to understand the dementia journey and how to live well. These sessions tend to be run by Alzheimers or dementia organisations. A few younger people with dementia like cognitive stimulation therapy sessions.

However, many people living with dementia face barriers to access these services

The main barriers to accessing services are described below.

They do not know what services are available and whether they are eligible

People living with dementia expect their GPs to know and inform them of the support services available. Most people living with dementia receive little or no information from their GPs. These people feel they are 'left in the dark' and they have to seek out information on support services.

The doctor lets the caregivers down. We are relying on the doctor as we had no experience. (Care partner, family, Pākehā, female)

A few feel their GPs are reluctant to share information on support services. They expect their GP to give them a list of services and how to access them. For most people living with dementia, this does not happen.

Nobody offers help, you've got to go and find it and ask for it. You have to go to your doctor and some doctors don't want to give it either, which to me is quite strange. (Older person with dementia, Pākehā, male)

A few people receive information from their GPs. Some people living with dementia comment that, once they know what is available, it is easy to access support.

They often do not know how to increase services as dementia progresses

Many people living with dementia are unaware they can increase the level of services as the dementia progresses (such as respite care or home support). They also do not know the process to increase services. A few people comment that their local NASC are slow to address their changing needs.

A few people describe struggling for years when they could have received more support. Not receiving support when needed results in increased stress.

It was just mentioned to me, but it was never explained or broken down. If I find out someone knows someone who has Alzheimer's I'm going to explain clearly what carer support is, respite care, I break it down for them. I've had the option for seven years but only started it last year. I didn't know they were available. I only realised it this year. (Care partner, family, female)

Some care partners feel they are not taken seriously when they ask for support (or more support). These care partners feel they are only heard when a crisis, such as a fall, happens.

It takes a crisis to get help. Like when he had a fall and went to the hospital. Then the GP said you need more help. (Care partner, spouse, Pākehā, female)

Care partners need help to get the support they need

Care partners are busy supporting the person with dementia. They do not have time to work out what support is available. Some care partners feel they have better access to support services when they have someone advocating on their behalf.

Alzheimers and dementia organisations staff provide much-needed advocacy support. For example, some care partners reported that Alzheimers and dementia organisations contacted NASC on their behalf. Care partners also find Alzheimers and dementia organisations' information and education sessions increases their knowledge about support services.

Service availability varies across New Zealand

The support services people living with dementia receive depend on where they are living. Some regions have not-for-profit groups that offer day programmes for people with dementia five days a week. Other areas have no day programmes or offer one day programme a week. Even in more resourced areas, waitlists exist.

Some people living with dementia are able to overcome these access barriers, others are not

Those more financially secure pay privately for the services they want (for example, a live-in carer for a person with dementia living alone). These people are buying services they believe better meet the needs of the person with dementia.

Purchasing services privately reflects concerns with the quality of services for people with dementia. Quality concerns relate to safety and services not being people-centred.

Some people living with dementia do not have this choice as they can not afford to pay for additional services. A few struggle to meet their daily living costs on the state pension.

That's the other hard part, living on a pension. We've got no savings left now. We've used all that up. We've lived too long now. We can just manage on the pension. (Older person living with dementia, Pākehā, male)

Services often do not meet the diverse needs of people living with dementia

People living with dementia have differing and changing needs over time. A person-directed approach⁷ is needed to ensure individual and family needs are met.

Services do not meet the cultural needs of Māori and Pacific people

A few care partners talk about the importance of Māori and Pacific food. These care partners report culturally appropriate food is key to the wellbeing of the person with dementia. Culturally appropriate food provides comfort and familiarity.

Māori and Pacific people eat differently. We nourish our bodies with things that are provided on the earth. That's what we love. Not everything comes from a packet. I've had to go to a dietician about mum's diet. Mum loves taro, coconut cream, coconut butter, green bananas. That's her soul food. (Care partner, family, Māori, female)

Some residential care facilities and support services do not provide Māori and Pacific food. As a result, the person with dementia does not eat well. One care partner organised a menu with the residential care facility to ensure culturally appropriate food at least once a day.

⁷ A person-directed approach is where people choose the services rather than being told what services they can have. (Lines, Lepore, & Wiener, 2015).

I go in there and create dishes for her, I personally think they can do it themselves. Once a month we do a menu for her, to ensure she has the type of foods. All part of their integrating. We had a few battles. We had to compromise, club sandwiches for lunch. They have dinner at lunchtime. That's their main meal so they can work it off. (Care partner, family, Māori, female)

Having appropriate food is also a way to build trust between the person with dementia and residential care facility staff.

Eventually, I had to just bring my food anyway. The staff saw the positive impact. There are certain days where I would leave some oysters or kina there for mum, as a sort of treat. Something familiar for her when I'm not there. It helps mum trust the staff, and show they're thinking of her. It makes their relationship a little more positive. They're just some little things I've picked up. (Care partner, family, Māori, female)

Support services also need to identify how best to meet the cultural needs of Māori and Pacific people, including language. For example, one person with dementia only spoke te reo Māori as his dementia progressed. He could only communicate with people who spoke te reo Māori, which limited his interactions.

He only ever spoke in te reo. And it was just me and mum who spoke it. He would revert back to old people from his childhood. So, no one was sure what he was saying; just talking to old people. (Care partner, family, Māori, female)

People living with dementia want more services and hours of service

People living with dementia want access to more services or hours of service. Care partners who are working (both spouse and children) want more service hours in-home or at a day programme so they can continue to work.

People living with dementia need greater reliability and trust in daily living services

People living with dementia want more choice on their daily living services. They want a say on who comes into their home to provide help. They want someone who gets on well with them and treats them with respect.

Reliability of services is also important, particularly for people with dementia living alone. Family need reassurance the daily support services are delivered and want to be informed if they are not.

People living with dementia need support services appropriate to their age and dementia stage

Support services need to consider people's age and stage of dementia. In some regions, limited options are available for people with early and mid-stage dementia. Younger people with dementia want services tailored for their age group (such as support groups for younger people and forums, and age-appropriate respite care).

A few care partners feel the care partner support group is not suitable for their situation, as the person with dementia is in the early stages.

The first hour someone comes along and talks about behaviour, which is a bit remote from me since we're not into that stage. Then we talk about what's happening at home, which is women looking after their husbands. We're not there yet, I find it quite distressing. But it is better than nothing. (Care partner, spouse, Pākehā, female)

Support groups also need to be at a time convenient for care partners who are working. These care partners can not attend support meetings when they are held during work hours or when they are caring for the person with dementia.

Hospitals need to offer more tailored support to people with dementia

A few people living with dementia criticise hospital care. They feel their needs and anxieties are ignored in A&E. Care partners are also critical of inpatient care for the person with dementia. Health professionals do not include care partners in discussions about health and ongoing care. At discharge, little consideration is given to how best to transition back home to meet the health, wellbeing and safety needs of the person with dementia, particularly those living alone.

Care partners need counselling tailored to their role

A few care partners experience stress and grief caring for the person with dementia. Counselling at the time of diagnosis is particularly lacking. Some spouses want counselling tailored to care partners of people with dementia. Some care partners also want emotional support when the person with dementia moves to a residential care facility.

I'd love lessons about coping skills, and I feel like care partners get very little support in the current situation. I think it would be a big benefit to have a counsellor who was trained in this sort of stuff, but the general counsellor just told me to slow down and relax. I can't do that, I didn't feel like he understood me. (Care partner, spouse, Pākehā, female)

Sometimes we need a break

This section highlights the importance of respite care and the challenges of accessing care that meets diverse needs.

Respite care is any support or service that helps care partners to have a break from caring for the person with dementia (Ministry of Health, 2018).

Overview of findings

- People living with dementia value respite care to have a break and recharge.
- Many people living with dementia do not know how to access respite care.
- People living with dementia want more respite care.
- They want people-centred and age appropriate respite care.
- They want safe and quality respite care.

People living with dementia value respite care to have a break and recharge

Respite care is necessary to maintain care partners' wellbeing, particularly as the dementia progresses. Respite care is mostly used by older people living with dementia who live at home. Care partners feel refreshed after accessing respite care and feel they can better care for the person with dementia.

I'm just taking myself off... so I'm taking this week off. Because you know otherwise the pressure just gets too much and you start to blow up and, so that's what I'm doing but I'm really, really looking forward to it. (Care partner, spouse, Pākehā, female)

Care partners often spend time with family or friends during this time. Younger care partners (such as family members who are not spouses) use this time to work or to carry out household and other family duties.

People with dementia value respite care for the care partner.

Many people living with dementia do not know how to access respite care

Like other services, people living with dementia do not know what respite care is available, their eligibility for the service or how to access it. They do not know how to increase the hours of the service as the dementia progresses. Many people would have struggled to access respite care without the support of Alzheimers and dementia organisations.

People living with dementia want more respite care

Some care partners can not use respite care as it was often not available due to high demand.

Been over there twice to chat and walked around. And she liked it. We're on the list. The sad but true thing is we've got to wait for someone to die, in fact, more like six. But it does happen. It may not be overnight, but it will happen. (Care partner, spouse, Pākehā, male)

A few people pay for respite care privately. However, people on lower incomes do not have this option.

I could get through to respite care, but they are very busy, as they have a big list. ... I'm mainly thinking to do it privately. (Care partner, spouse, Pākehā, female)

They want people-centred and age appropriate respite care

In some cases, care partners do not use respite care because it is not suitable for the person with dementia or they do not enjoy the experience.

Some people with dementia describe respite care as depressing and lonely. They particularly find being around people at advanced stages of dementia upsetting. They feel respite care decreases their independence.

The week before, they put me into [one] home, which I didn't like, then they put me into [another], which I hated. ... These old girls and jokers just sitting in their easy chair, mouth wide open, sound asleep, I get depressed over all that. So that's finished, I can't do any more homes. (Older person with dementia, Pākehā, male)

Some respite care is not people-centred. Staff are described as not treating people who have dementia with respect.

One of the staff members [at respite care] noticed that [my wife] wasn't looking too enthusiastic. And she came up and spoke to [my wife] like she was an idiot child and said she was going to have morning tea and a lovely cup of coffee with cake. And I said, 'Oh, don't do this to [my wife]'. And [my wife] just said she didn't want to be here. I totally agreed. (Care partner, spouse, Pākehā, male)

They want safe and quality respite care

Some care partners report safety concerns around some respite care. For example, one care partner talked about her concerns with a respite care facility's safety procedures around walking.

We went around some of the places when I was thinking of putting him in for four or five days, while I went and had an [operation]. Oh, they are not good, not good. They brought up the health and safety. They said, 'if they walk out, we can't stop them'. I said, 'what do you do?'. And they said, 'we just call the Police and they go looking for them'. (Care partner, spouse, Pākehā, female)

I need a community I can easily move around

This section presents the challenges people living with dementia face in moving around their communities.

Overview of findings

- Availability of public transport is limited and alternatives are expensive.
- The built environment does not enable people with dementia to move around easily.
- Security processes in large retailers create stress for people with dementia.
- Automated processes at airports stop people living with dementia from travelling.

Availability of public transport is limited and alternatives are expensive

Limited transport options are described as socially isolating for people with dementia. Many are no longer driving their cars so are either dependent on others or use taxis.

Few people with dementia use public transport because bus stops are too far away from their house. Some people with dementia are aware of taxi subsidies but others are not. Even with subsidies, taxis are expensive for many people living with dementia.

There are groups that do walks locally but [name] can't get to them unless there is someone to take her so those things become difficult. Half priced taxis are still expensive. You know, it's a thirty-minute walk to take two buses to get to something that's only three miles away. It is ridiculous. (Care partner, spouse, Pākehā, male)

The built environment does not enable people with dementia to move around easily

Some people with dementia walk or bike around their communities. They want improvements to roads and crossings to support safe walking and biking environments.

What I notice is that crossing roads, and things like that, cars come around the corner and I'm too slow to get across. If the council could go through what could be done, it could make a difference. Even signage and things like that. (Younger person with dementia, Pākehā, male)

Security processes in large retailers create stress for people with dementia

Some people with dementia, especially those who are known locally, feel comfortable going shopping. However, others find shopping stressful. For example, demands for coats or bags to be left at the door on entering large retail shops can be misunderstood. Some people with dementia overcome these stresses by carrying a card saying they have dementia.

Person living with dementia: We had to use the dementia card once in an outlet store, didn't we? People are more understanding once I show them the card.

Care partner: Yeah, you had a puffer jacket or something quite bulky on and in those types of stores you've got to take them off.

Person with dementia: He just said, 'I want your jacket.' (Older person with dementia and spouse, Pākehā, male)

Automated processes at airports stop people living with dementia from travelling

People with dementia who travelled by air said airport security, automated technology, and baggage rules are challenging. Most people with dementia require support to travel by air.

Care partner: We did go to [foreign country]. And it was great, but it was difficult. It was difficult for him, because airports are a nightmare. And difficult for me, trying to help him. All the noise, bustling.

Person with dementia: And my dementia affects me like when you're getting on a bus or tram, and there's a turnpike. I'd crash through them, climb over them. (Older person with dementia and spouse, Pākehā, male)

Some people living with dementia stop travelling by air. They miss out on life experiences important to them and seeing family and friends. This creates a sense of loss.

We've been very close to the friends in Wellington. We no longer are able to go down. We used to fly down and stay with them. But we no longer travel because confusion results from moving from home base. And it's more difficult to get around. ... So, we don't travel, we're pretty much confined to our home base and our family come and see us. (Care partner, spouse, Pākehā, male)

Others continue to travel, but restrict it to visiting family or close friends rather than tourism.

We pull together as a couple living with dementia

This section presents key findings of couples' experiences when one person is living with dementia. This section draws on information from interviews with nine married or long-term heterosexual couples.

Overview of findings

- For most couples, life changes with dementia but their relationship remains central.
- Couples use humour to maintain their relationship and love.
- Couples learn together how to adjust their lives.
- Couples' relationships change, with care partners taking on more responsibility.
- Most care partners become the main decision-maker.
- Some couples travel less, which decreases their connectedness and sense of adventure.
- Most couples do new activities and enjoy spending more time together.
- Couples draw on each other's strengths for daily activities.
- Most couples have active but changing social lives.

For most couples, life changes but their relationship remains central

Most couples had been together for at least 30 years, and some for over 50 years. Their relationship is a significant and defining part of their identity. They have a lifetime of loving and supporting each other.

I can understand where people fall apart. But after 54 years you don't do that. That's our story. (Care partner, spouse, Pākehā, female)

The couples value their relationship and partnership. This partnership helps them through the dementia diagnosis and the dementia progression. They describe their experience of dementia as 'rearranging' their life to fit with their changing reality.

Memory loss does create a few problems. We've got ways of handling them though. We've had a ball. (Care partner, spouse, Pākehā, male)

Couples use humour to maintain their relationship and love

Most couples use humour to describe the changes in their relationship. Humour is used when the person with dementia does or says something unintentionally funny. They feel the best way to cope on these occasions is to recognise it was funny rather than hiding or ignoring mistakes.

Care partner: My view is that if [name] forgets something we just laugh about it. ...

Person living with dementia: Yes, we don't take things too seriously. (Older person with dementia and spouse, Pākehā)

However, these people with dementia were at early stages. Stresses had not increased for these couples. These couples felt the impact of dementia was manageable. They realised this would not always be the case, and openly discussed the changes they would have to make in the future.

There may come a day I won't be able to come and go when I please. But we'll worry about that when we get to it. ... With Alzheimer's, it's slowly and seriously going to deteriorate. I'd rather that than someone come and ring the doorbell and tell me he's been killed in a car accident. Two ways of looking at it, and really this way you've got time. (Care partner, Pākehā, female)

Couples learn together how to adjust their lives

Most couples adapt to one person having dementia and identify what the diagnosis means for them. All knew this adjustment would continue as the dementia progressed.

Couples have different ways of adjusting to the changes. The key to adapting and living well together is learning about dementia and what it means for their relationship.

We decide together how to live with dementia

Most couples make choices together about how they respond to the diagnosis, and how to tell their friends and family. Together, they discuss how they want to live their lives.

We learn together about dementia

Couples learn about what having dementia means for their relationship and their lives. Couples know what the person with dementia is able to do well and where there are challenges. For example, for some couples, the person with dementia does all the same household activities as before, except the finances.

We know how to talk to each other

Couples said the length of their relationship meant they could understand each other even when it was hard for the person with dementia to communicate.

We've been living together long enough to be able to fill in the blanks in the conversation when the right words won't come out you sort of know what the other person means [...]. You know things just take a little more time and you need to be a little more patient, which can be hard at times. (Care partner, spouse, Pākehā, male)

Couples' relationship roles change, with the care partner taking on more responsibility

Most couples consider their roles and responsibilities change as the dementia progresses. Having dementia increases the dependency of the person with dementia. The person with dementia thought this change was unavoidable and was aware it created extra work for their spouses.

I have become very reliant on her. I realise that she gets frustrated, and I would like her not to be frustrated, but I can't not frustrate her. (Older person with dementia, Pākehā, male)

Most care partners become the main decision-maker

Most couples said the care partner had become the main decision-maker and organiser. The change in roles leads care partners to feel more anxious and responsible.

I feel that I'm on [name's] shoulder now. I always watch out to see where they are, what they are doing, are they comfortable. Are they looking anxious? Before, I didn't have to do that. [...]. You know I look after you. It was a huge change for me. (Care partner, spouse, Pākehā, female)

For example, a few couples described moving to a new house after the dementia diagnosis. Previously they shared decision making about where they moved and the moving process. The care partner now makes these decisions alone.

The weight when we moved! It was all my responsibility. ... We need to plan our day, plan it again, and remind him of it. Very often. And when we do go out, I'm a bit edgy, since I'm worried about him. So, I don't leave him for too long if possible. Usually, I drop him at a friend's. I don't know what else I can say about it. It's a whole new way of living, to work around the situation and plan ahead. (Care partner, spouse, Pākehā, female)

Some couples travel less, which decreases their connectedness and their sense of adventure

A few couples described travel as having been part of their identity as a couple. These couples are adventurous and curious about the world. They felt a sense of loss when they stopped travelling. As the dementia progressed, care partners struggled to support the person with dementia to travel. The person with dementia also found the travel tiring. As a result, their enjoyment of travel as a couple reduced.

We've been travelling this year too. He found it quite hard this year. I want to go, and I can't leave him behind, so I take him too. I do have to be careful with where I look at going. (Care partner, spouse, Pākehā, female)

Spouses miss their travel. A few couples continue to travel by having extra support for the person with dementia.

Most couples do new activities and enjoy spending more time together

We like spending time together

Many couples find new activities they enjoy doing together. They also value spending more time together.

We try to do things now, going places that we haven't been to out on the coast or going down to the big daffodil farm. Things we can do together, safely, and that I can drive to. (Care partner, spouse, Pākehā, female)

Some couples do something special together every day or as often as possible. For example, going for a walk, a drive or a bike ride.

We usually try to do something every day if we can. So, you've got something to look forward to, whether it's just brunch or a walk on the beach. (Care partner, spouse, Pākehā, male)

We are closer as a couple

Some couples, especially younger people living with dementia, feel that having dementia draws them closer together because they spend more time together.

In some ways, I think it's grown you and me closer together because you never really saw me. I was always travelling away so much [...]. I'm enjoying spending more time with [care partner], but also the things we can do together. Like the bike rides, travel, shows. (Older person with dementia, Pākehā, male)

However, a few couples who had previously maintained separate leisure activities find it harder to do more things together.

We've always done things independently, rather than being a couple who does everything together. And now all of a sudden, we have to be together. (Care partner, spouse, Pākehā, female)

Couples draw on each other's strengths for daily activities

We work together as a team

Many couples describe working together as a team to live well. They draw on their differing strengths as a couple and as individuals.

Amongst older couples interviewed, care partners often have other health conditions (for example, heart disease, joint pain). This means they can not do all the household tasks. They rely on the person with dementia to do heavy tasks such as vacuuming, cleaning, or lifting in the garden.

Person with dementia: If it isn't broken, don't fix it. I know she's got a far better memory than me ...

Care partner: Which is good, I'm bugged if I get down to clean, I can't get up again. (Older person with dementia and spouse, Pākehā)

One couple noted the person with dementia has a very good memory for directions. Even though the person with dementia was not able to drive, their spouse relied on his skills to get to places.

One thing [name] hasn't lost, he's still got a great sense of direction. If I'm not sure about where a street is, he can tell me straight away. But he can't put a plug into a socket. (Care partner, spouse, Pākehā, female)

Some care partners comment they have to remind themselves that the person with dementia is able to do things around the house. They are aware they need to ask for help rather than assuming the person with dementia is unable to do it.

Most couples have active but changing social lives

We maintain our friendships

Most couples have active social networks, including friends, family, work colleagues and volunteer communities. They want to maintain these relationships as much as possible after diagnosis.

You have great support from the church. They've been very, very supportive. They pretty much, if not all of them, know our situation. They really look after her and treat her well. I've seen them in action and I thought 'yeah, you're treating her like a person, not like someone who isn't a person'. (Care partner, Pākehā, male)

Some couples also build new relationships through Alzheimers and dementia organisations. They find these to be supportive and positive social networks.

We find our social activities as a couple decrease

Some people with dementia withdraw from some social events as they feel embarrassed or uncomfortable. Their care partners find this behaviour difficult because it limits their social life. These care partners have to find other events for socialising without their partner. This in turn limits their social activities as a couple.

Care Partner: He's pulled back socially.

Person with dementia: I can't remember what I was talking about. It's embarrassing. I never was a social person. I could be social if I tried hard. Now I can't. (Older person with dementia and spouse, Pākehā)

Some couples feel they are treated differently because one partner has dementia. These care partners struggle when they see their spouse treated differently or ignored. Care partners do not want their partner to experience stigma. However, they find it stressful supporting their partner by helping him or her have conversations or remember someone. A few care partners told of their frustration when people spoke down to the person with dementia.

Care partner: It's been hard, since we've just moved into a new neighbourhood. They're lovely people, and we talk across the fence and all that.

Person with dementia: [Care partner] will go outside and they'll all talk for half an hour. I'll go outside and they say 'hello'.

Care partner: They say hello and they keep walking. They stop and talk to me, I notice that difference with how you're treated. (Older person with dementia and spouse, Pākehā, male)

Care partners feel love, loss and guilt when caring for people with advanced dementia

This section describes care partners' lives when supporting people with advanced dementia. This section draws on interviews with care partners of people with advanced dementia aged over 65 years.

Overview of findings

- Care partnership is based on love and commitment.
- Care partners have a sense of loss for the person they knew and the life they had.
- Care partners' stress increases with the progression of the dementia.
- Care partners need support to maintain their wellbeing.
- Care partners feel relief and guilt when the person with dementia moves into residential care.

Care partnership is based on love and commitment

Most care partners (spouses, in-laws and children) deeply value being able to offer support and care to the person with dementia. A sense of love, for some built on a lifetime of supporting each other, is central to their caring role. For others, deeply held values of family obligation drive their desire to support their family member with dementia.

I wouldn't change what we've done, the outcomes would have been the best we could make in the situation. Even for the two odd years of her at the home, I wouldn't change that. It's what I wanted to do for her care. It was a decision we made easily. (Care partner, family, Pākehā, female)

Care partners have a sense of loss for the person they knew and the life they had

I was losing them

Care partners of people with advanced dementia see the person they care for change over the years. Care partners talk about changes in personality, behaviour, and a loss of shared memories. They feel helpless observing these changes. Many feel as if the person they love and know is disappearing.

It's just not fair. The person is still there, but you're losing them. I'm married to a stranger. Getting to the stage where to her I am [a stranger] too. (Care partner, spouse, Pākehā, male)

Our roles are changing

Care partners feel a growing sense of loss for their relationship as the dementia advances. Care partners miss talking about memories of a life together.

Care partners who are children of the person with dementia feel the roles of parent and child have been reversed.

I have lost my companion and my lover

Care partners who are spouses miss the way they used to live together as a couple. Spouses miss their previous shared connection and everyday conversations. Care partners talk about a loss of affection and intimacy.

He's always been a very lovable person, but now he's got no affection for me. (Care partner, spouse, Pākehā, female)

We've just had our 55-wedding anniversary but it doesn't mean anything to him. And that's the sad part ... it's difficult not having any conversations. You've lost your husband, completely lost him, and yes that's hard. (Care partner, spouse, Pākehā, female)

Care partners' stress increases with the progression of dementia

I am getting more stressed out

Care partners feel an increased stress and negative emotions as dementia progresses. Increased stress is tied to an increased level of support needed by the person with dementia. Care partners describe noticeable changes in the person with dementia during this time, including:

- trouble walking or an increased risk of falling
- inability to dress or eat
- not able to do household tasks such as cooking and cleaning
- unsafe walking
- challenges with communication, memory and recognition
- negative emotions and behaviour such as frustration, aggression, resentment, paranoia.

I have a 24/7 responsibility centred on their needs

Care partners describe caring for someone with advanced dementia as a 24/7 responsibility. Care partners describe the person with dementia as becoming increasingly reliant on them for their day-to-day needs. Eventually, care partners feel they could not leave them alone due to safety concerns.

I have to do everything; I am thinking for two

Care partners plan and prioritise their day around the person with dementia's comfort and safety. Daily activities like grocery shopping or outings become more complex and require careful planning.

You can never be in a situation where I don't know where [person with dementia] is because you can't switch out. Whether it's hours, a day, you just have to be thinking for two. (Care partner, spouse, Pākehā, male)

My life is restricted to meet their needs

Care partners make substantial life changes during this time to support the person with dementia. For example, a husband and wife changed their work schedules so someone was always home with their relative with dementia. As a result, they had little time for their relationship, their children or lives outside of work and caring.

We were both working full time. I have no flexibility in my work for my job, I have to do shift work. My husband is self-employed with his own business. ... He needed to be out by eight am to drop the kids off, he was coming home at about four. I advertised on Trade Me for a private dementia caregiver. ... She turned up in the morning for my husband to go to work, and one of us had to be at home by four pm to take over. That's how we've lived our life for the past two years. (Care partner, family, Pākehā, female)

Other care partners limit or stop their hobbies. Care partners believe the wellbeing of the person with dementia comes first, over their needs.

I feel isolated and lonely

Care partners, especially spouses, feel socially isolated during this time. The isolation comes from the demands of caring and from stigma. Some care partners limit or avoid social engagements if the person with dementia has communication difficulties. Some care partners also believe people do not want to interact with the person with dementia or the person with dementia does not like social events.

I get the feeling at organised meals and outings the residents prefer not to sit by [name], and therefore this affects me too. I have stopped going to village social events as this was happening and does not make an enjoyable time for me. (Care partner, spouse, Pākehā, female)

I feel it is my fault when I can't help

Care partners experience a sense of blame during this stage. Some care partners blame themselves when they can not ease the distress of the person with dementia. Care partners of people who had difficulty communicating feel they are being blamed for not being able to understand.

It's been hard. It's more frustrating than anything because he'll insist on washing the dishes at night, but he can't work out how to turn the tap on to hot. And I don't know if he's putting dishwashing detergent in. But, if I go to the sink and say, 'have you got detergent in there' or saying 'you have to turn the tap right round to get the hot water'... He just goes off his tap at me...I believe that dementia patients blame the person nearest to them. So, no it's hard, it's frustrating. (Care partner, spouse, Pākehā, female)

Care partners need support to maintain their wellbeing

Some care partners are supported by friends and family. This support is especially useful when family and friends understand dementia, are inclusive and respectful, and offer physical and emotional support.

These care partners appreciate families and friends:

- taking the person with dementia on outings
- visiting the care partner and person with dementia
- checking in with the care partner
- helping with household duties
- involving them in social events and family gatherings.

We've got a really good bunch of friends. They'll come and pick him up and take him to out if they're going and things like that. Or one took him to the movies a couple of weeks ago. They all understand, and... they're all really supportive. (Care partner, spouse, Pākehā, female)

Care partners feel relief and guilt when the person with dementia moves into residential care

I can't do this anymore

Most care partners, where the person with dementia is living at home, believe a time will come when the person with dementia will move into residential care. When care partners reach this point varies.

- Some seek residential care when they can not offer the level of care needed by the person with dementia.
- Others find they can no longer cope with the pressure and intensity of 24/7 caring.
- Others reach this point when their home is no longer safe for the person with dementia (for example, when the person with dementia is leaving the house and walking is not safe).

Moving the person with dementia into residential care often happens abruptly. For instance, the move is triggered by family intervention due to realising the effect on the care partner or through the advice of a GP or social worker.

I was too emotional. I was not great. I had a bit of an incident where I blacked out when I got the news. My body did a crash. I've had years of managing it and I was surviving on two to three hours of sleep for the past two years. So, my body just went, 'I can't do this anymore'. As much as you want to carry on, your body just says 'Nah'. I knew I wasn't at my strongest. (Care partner, family, Pākehā, female)

Many care partners worry about available space in residential care and finding the right place. Care partners report visiting many residential care units. One care partner reported a need for an up-to-date list of vacancies. A few care partners were surprised when residential care willingly made space for them.

I let them down, I failed

Most care partners feel guilty after the person with dementia moves into a residential home. Care partners feel the reason the person with dementia is in a home is because they can no longer cope in caring for them. These care partners feel they have let the person with dementia down.

Everyone said you can start being her daughter again, without having to do all the personal care. So, you can start enjoying the relationship again. I'm starting to get certain days where it's like that, but then there are days where she's just begging me please to let her come home. (Care partner, family, Pākehā, female)

Sometimes, the person with dementia asks to come home when the care partner visits. These requests to go home add to the care partners' sense of guilt. However, underlying this guilt is a sense of relief from the stress of caring.

My brother and I feel awful we had to take these steps for her own safety but we know it had to be done. She has been such a lovely Mum (still is) and so independent. Mum's feeling is that she hopes she will get better and go back to her own home. (Care partner, family, Pākehā, female)

Conclusion: Our story matters

Dementia is different for everyone – what people experience, and how quickly they are affected is unique to them. (Alzheimers New Zealand, 2016)

This report tells the story of what it is like to live with dementia in Aotearoa New Zealand. Through the stories, we learn about the many different experiences of living with dementia due to age, gender, ethnicity, dementia progress and personal preferences.

The stories of people living with dementia matter. They show how people with dementia live meaningful lives which contribute positively to their families and their communities. They showcase the strength of people living with dementia to overcome challenges to live the lives they want.

With our help, people with dementia can live even better lives. To do so, people with dementia want:

- people to understand dementia, respect and include them in their lives
- support through difficult times like diagnosis, dementia progression, and transition to residential care
- time, information and support to make their own decisions
- more health and support services tailored to their diverse needs, which they can get when they need them
- support for their care partners so they can continue to care through caring for themselves.

People with dementia offer the following words of advice to others diagnosed with dementia: you need to come to terms with having dementia, not to worry and try to live the best life you can.

Listen, don't worry about it, just don't, that's the last thing you do. Look after yourself and if you need help, ask for help. That's all you do. (Older person with dementia, Māori, female)

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Appendices

Appendix 1: Research Advisory Group members

Name	Organisation	Role
Alistar Robertson	Alzheimers New Zealand	Advisory Group
Rose Love	Alzheimers New Zealand	Advisory Group
Jenny Corry	Alzheimers New Zealand	Advisory Group
Associate Professor Nicola Kayes	AUT Centre for Person Centred Research	Qualitative research on the lived experience of people with dementia
Dr Rosemary Gibson	Massey University (Wellington)	Qualitative research on the lived experience of people with dementia focus on sleep
Dr Sarah Cullum	Senior Lecturer Auckland University	A New Zealand based clinician with expertise in dementia
Dr Margaret MacDonald	Senior Human Rights Advisor; Human Rights Commission	A human rights expert

Research Advisory Group – ex-officio members

Name	Organisation	Role
Liz Smith	Litmus	Partner: Project Lead
Dr Chelsea Grootveld	Aiko Consulting	Māori researcher
Stephen Lungley	Alzheimers New Zealand	Research commissioner – Policy Advisor
Jean Gilmour	Alzheimers New Zealand	Principal Clinical Advisor

Appendix 2: Overview of the research approach

The ethics-approved research plan contains the full details of the research methods (Smith, 2018). A copy is available on request.

We used Scottish Dementia Working Group Research Sub-group principles

The Scottish Dementia Working Group Research Sub-group (2014) principles for research with people with dementia are:

- involve, value and keep people with dementia informed about the research at all stages
- value the knowledge of people with dementia
- ensure a safe environment for people taking part in research
- keep communication and language clear and avoid stigmatising language
- be dementia aware by knowing about dementia, being empathic and respectful, and allowing time for people to think by providing questions ahead of the interview
- keep to 'dementia time' not researcher time (i.e., be flexible about the best time to visit, keep to agreed timeframes, remind people about the interview, recap previous conversations).

We used the Older Adults' Capacity to Consent to Research (OACCR) scale

We adopted a modified version of the OACCR scale to determine capacity to consent to the research (Lee, 2010). The scale asks four key questions which we used during recruitment and before starting an interview. After going through the information sheet about the research, we asked the person with dementia:

1. What is the purpose of the research?
2. Tell me some things you may be asked about?
3. What are the things that might worry you about taking part in the research?
4. If you don't want to, do you have to take part in the research?

We adopted the following decision hierarchy:

- Informed consent was reached if a potential participant answered all four questions.
- We used supported decision making, working with care partners and families and people with dementia if potential participants answered 1 and 4.
- We excluded people who could not answer questions 1 and 4.

We adopted this scale as it aligns with the best practice for everybody taking part in research. No one should take part in research they do not understand, have concerns about, or do not know they don't have to take part in.

We followed DEEP guides⁸ to develop the research tools and to complete interviews

Most interviews were held in people's homes. We audio recorded interviews if people provided consent. The interviews lasted up to an hour. People were invited to bring a support person.

Experienced qualitative researchers completed the interviews. Interviews with Māori participants were mainly undertaken by Dr Chelsea Grootveld, a kaupapa Māori researcher.

The researchers were flexible in their interview approach so the person could tell their story in their own way. Researchers were mindful and did not rush interviews.

People who took part in the research received a \$60 koha and an invitation to the Alzheimers New Zealand Conference 2018. They also received an Exit Information Pack. Researchers followed up with participants if interviews were upsetting or covered sensitive matters.

The following research tools are available on request:

- Participation information sheets (short and long versions)
- Approach and confirmation letters/emails for person with dementia, care partners and joint interview
- Information sheets (long and short versions) for person with dementia and care partner, and care partner for supported decision-making
- Consent forms for person with dementia and care partner, and care partner for supported decision-making
- Discussion guides for interviews with person with dementia, person with dementia and care partner, and care partner
- Exit information pack.

⁸ The Dementia Engagement and Empowerment Project (2013a,b, 2014).

We followed a multi-stage thematic analysis process

Interviews were transcribed. Where requested, we sent people their transcripts to review. We removed anything that created risk for relationships. About a quarter made changes to their transcripts.

All interviewers attended an analysis workshop to identify high-level findings. A detailed thematic analysis process followed to identify patterns and themes. Each researcher analysed a sub-group of interviews in depth (for example, living alone, living with care partner, older people with dementia and younger people).

We held an analysis workshop with Alzheimers New Zealand staff and members of the Research Advisory Group. We presented preliminary findings to Alzheimers New Zealand Advisory Group members.

We used an adapted social ecological model to frame the analysis

We used an adapted social ecological model (Bronfenbrenner, 1979) to place people with dementia at the centre of our analysis. We wanted to understand their lives and how their experiences were influenced by their family, community and the wider New Zealand society and culture (figure 1). Experiences appeared to vary by age of onset, stage and type of dementia, gender, ethnicity, socio-economic level, living situation and location.

Figure 1: The influences on people living with dementia



We had an experienced qualitative research team

An experienced team of health research specialists completed the research. All of the team had experience researching and interviewing on complex and sensitive issues. We included researchers with personal experience in being a care partner of a person with dementia.

Person	Role	Research responsibilities
Liz Smith	Project lead	Research design and ethics Project planning Interviews Analysis Reporting Community feedback Quality assurance Client liaison
Sandar Duckworth	Co-project lead	Peer review Interviews
Dr Chelsea Grootveld Aiko Consulting	Māori researcher	Research with Māori participants Interviews Analysis
Anna Thompson	Qualitative researcher	Interviews Analysis Reporting
Rachael Lamb-Yorski	Researcher	Project coordination and recruitment Interviews Analysis Reporting
Annette Chapman	Office manager	Financial management Health and safety File and data security

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