

Awareness and understanding of dementia in New Zealand

Alzheimers NZ

Telephone survey

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Key findings

■ More people claim they know or have known someone with dementia.

81% said they personally know or have known someone with dementia, an increase of 14% from 2014. 56% of all respondents said they know or have known was a family member.

Those who have or had immediate family (parent/sibling/partner/child) with dementia were more likely to give more accurate answers to questions on their knowledge of dementia.

■ Declared knowledge has remained steady from 2014.

54% said they knew a lot or fair amount about dementia, consistent with 2014.

On the whole people who claimed more knowledge of dementia generally gave more accurate answers around dementia, than those who claimed lesser knowledge.

Word of mouth, media and personal experience were the most frequently used sources of information on dementia.

■ Most gave answers that showed their perceptions about dementia were correct, except for the effects of alcohol and whether dementia is fatal

60% or more were confident mental stimulation, a healthy diet, an active social life, a healthy blood pressure and not smoking were ways to reduce the risk of developing dementia. However less than half were confident about the effects of alcohol on the risk of developing dementia.

Over three quarters recognised all eight common symptoms of dementia presented to them.

The majority of respondents were generally aware (63% or more) of most of the range of facts around dementia presented to them

The one fact that had less than a majority was whether dementia is fatal. Only 42% recognise that dementia is a fatal condition, however, progress has been made on this misconception. In 2014, 27% believed it was fatal.

■ Approximately half were concerned about getting dementia

42% of respondents were concerned about getting dementia. Level of declared knowledge and age had no significant impact on people's level of concern.

Respondents who were concerned about getting dementia were more likely to know or have known someone with dementia, find it hard to talk to someone with dementia, be confident in their knowledge about risk reduction factors and support government action and increased taxation for supporting people with dementia.

20% said they fear getting dementia the most out of cancer, dementia, stroke, heart condition, diabetes and depression. This was second only to cancer (39%). Respondents over 60 were most afraid of having a stroke (27%) and equally as afraid of getting dementia or cancer (25%).

Very few agreed (15%) they would rather be diagnosed with dementia than care with someone with dementia.

- **A majority agreed that family should provide most care for people with mild dementia, but also agreed it can be lonely and can affect the health of the carer.**

A majority (60%) agree family should provide most care for people with mild dementia.

At least half of people agreed caring for someone is often lonely, could be rewarding and often means the carers' health suffers.

31% worry they may have to provide care for someone with dementia in the future

- **While most people said they would continue to include someone who developed dementia in social activities, a proportion of people said they would worry about how they may act in public.**

The clear majority (87%) claimed they would continue to include a friend in their regular social activities if that person developed dementia.

Four in ten people agreed if they were in public with someone with dementia they would worry about how they may act and a quarter agreed they would find it hard to talk to someone with dementia.

- **The clear majority of people think government action on helping to address dementia in New Zealand is important. Fewer, but still half, think it is important to raise taxes to provide that support.**

88% said the government increasing support for voluntary caregivers of people with dementia was important.

81% said it was important to do more to support people with dementia and half (51%) of respondents said it was important to increase taxation if it meant more was done to support people with dementia.

- **Females tended to give answers that indicated they were more knowledgeable, understanding and concerned about dementia.**

- **Older respondents were more likely to know or have known someone with dementia and declare a higher knowledge of dementia. However, they were no more or less likely to get knowledge testing statements about dementia right than any other age group.**

Executive summary

■ Personal experience

A majority (81%) of people said they know or have known at least one person with dementia, up 14% from 2014. The increase has largely come from younger respondents, under 30s rose 27% from 2014 to 72% in 2017. 18% of respondents in 2017 said they know or have known six or more people with dementia.

Over half (56%) of all respondents said they know/have known a family member with dementia.

81% said they personally know or have known someone with dementia

■ Knowledge

Just over half (54%) of respondents said they knew 'a lot' or 'a fair amount' about dementia. This was consistent with the 2014 survey where 53% said they had the same level of knowledge.

Over three fifths (61-66%) said they have learned about dementia via word of mouth, media and personal experience. Other methods were through the internet (33%), professionals (25%) and Alzheimers NZ or similar organisation (19%).

Prevention factors

Most (84%) of respondents were confident that doing mentally stimulating things can reduce the risk of developing dementia. The next highest reduction factor recognised (out of seven tested) was eating a healthy diet (75%), followed by having an active social life (67%), maintaining a healthy blood pressure (62%) and not smoking (60%). Respondents were less confident about the effects of alcohol. Less than half, (41%) were confident that drinking moderate amounts of alcohol would reduce risk. Those under 30 were less likely to be confident about most the risk reduction factors than their older counterparts.

*84% were confident mentally stimulating things would reduce risk of dementia
44% were confident in not drinking alcohol would do so.*

Symptoms

Over half of the sample (54%) correctly identified eight out of eight symptoms as common symptoms of dementia and a further 26% identified all but one of the symptoms correctly. The symptoms that had the highest recognition were confusion and disorientation, difficulty remember things, and wandering (94-95%). The least recognised symptoms were decreased judgement (81%) and changeable moods (77%).

54% identified eight out of eight common dementia symptoms

Knowledge testing

Most respondents correctly identified the following as true; Alzheimers is only one of many types of dementia (86%), and people in their thirties and forties can develop dementia (84%). Less than half (42%) said they think it is true dementia is a fatal condition; an increase of 15% from the research in 2014.

*86% thought Alzheimers is only one of many types of dementia
42% thought dementia is a fatal condition*

Just over a quarter (27%) thought dementia is a normal part of aging, and the same number said they thought dementia can be cured. 16% of respondents incorrectly identified dementia is a disease that can be inherited.

■ Concern

From a list of six diseases, 20% of respondents said they were most afraid of getting dementia, second to cancer (39%) and about equal with stroke (19%).

When asked outright, over two fifths (42%) of respondents were concerned of getting dementia, and 25% said they were not concerned. Respondents who know/have known an immediate family member with dementia declared a higher level of concern at 54%.

42% were concerned about getting dementia

Six out of ten respondents agreed family should provide most care for people with mild dementia and 53% agreed they would be willing to pay more tax for support for people with dementia. About a third (31%) were worried they may have to care for someone with dementia in the future.

53% would be willing to pay more tax for supporting people with dementia
58% agreed caring for someone with dementia is often lonely
15% would rather be diagnosed with dementia than care for someone with dementia

Over half (58%) agreed caring for someone with dementia is often lonely and 57% thought it could be rewarding. Slightly fewer (50%) agreed that caring for someone often means your own health suffers.

Very few people (15%) agreed they would rather be diagnosed with dementia than care for someone with dementia; this was marginally lower than 2014 (18%).

■ Perceptions and attitudes

Effects of having dementia

The clear majority agreed people with dementia can become isolated from friends and the community (87%), but 83% agree they can still be involved in activities. Over half (58%) agreed they can still enjoy life to the fullest.

Care for people with dementia

Less than half (44%) agreed it is better for people with dementia if they are cared for in a residential unit, while a similar number (42%) agreed they are unable to make decision about their care.

Socialising with people with dementia

Most respondents (87%) said they would continue to include someone in social activities if that person were diagnosed with dementia. About half agreed (52%) people are unlikely to want to spend as much time with friends when they have developed dementia.

87% agreed people with dementia can become isolated
42% agreed people with dementia are unable to make decisions about their own care
27% agreed they would find it hard to talk to someone with dementia
10% said they would not want to tell people if a family member was diagnosed with dementia

Interacting with people with dementia

About four in ten (38%) people agreed if they were in public with someone with dementia they would worry about how they may act and fewer people (27%) agreed they would find it hard to talk to someone with dementia.

If a family member had dementia

Only 10% said they would not want to tell people if it was an immediate family member, and this was down 9% from 2014.

■ Government action

46% of the whole sample gave important ratings to all nine actions the Government could take to address dementia, and each of them were rated as important by over three quarters of the respondents. The action that had the highest level of importance rating was the government increasing support for voluntary caregivers of people with dementia (88%). Other actions which received between 77% and 83% importance ratings, included increased training for GPs, providing more information on prevention, supporting research, recognition of dementia as a major health priority and support and funding for dementia organisations.

88% government increasing support for voluntary caregivers was important

51% said increasing tax for supporting people with dementia was important

Half (51%) of respondents said it was important to support people with dementia even if it meant increasing taxation.

■ Demographic trends

Females tended to give answers that indicated they were more knowledgeable, understanding and concerned about dementia.

Older respondents (60 and over) were more likely to know/have known someone with dementia and to declare a higher knowledge of dementia. However, they were no more or less likely to get knowledge testing statements about dementia right than any other age group.

Respondents who declared a lot or a fair amount of knowledge tended to give answers that supported their claim. They were more likely to, know someone with dementia, get knowledge testing questions correct, appreciate the difficulties of care and were less likely to find it hard to talk to someone with dementia.

Those who declared a high level of concern about getting dementia in the future, were more likely know or have known someone with dementia, be confident about the prevention factors for dementia, find it difficult to talk to someone with dementia and be willing to pay more tax in support of people with dementia.

1 Methodology

1.1 Background and objectives

Alzheimers New Zealand is a non-profit organisation focused on supporting all people affected by dementia; people with dementia, their home-based carers, families/ whānau and friends. They do this by raising awareness, providing advocacy, information services and resources to the public generally, as well as health professionals and health providers in the dementia sector/ community.

■ Past Research

A benchmark survey was first conducted in 2013, but the survey was completed by an all-female panel predominately aged over 35 years and as such the results were not representative of the general population.

In 2014, Alzheimers NZ secured funding to continue their national awareness raising campaign through to 2016. They commissioned UMR in 2014 to conduct a research study to measure the level of awareness and understanding of dementia, and of Alzheimers NZ, amongst the New Zealand public.

In May 2015 and 2016, UMR repeated a shortened version of the 2014 benchmark survey to measure any changes in awareness and understanding during the intervening period.

The May 2015 research also included an additional module of questions to measure the awareness of media activity generally and the 'Let's get our heads around dementia' campaign specifically and to provide benchmarks for future research.

This research was conducted four months after the January 2015 media campaign.

The media questions were repeated in October 2015; immediately following the completion of five weeks of media activity which covered the period W/C 23rd August to W/C 20th September and again in July 2016; immediately following a period of media activity.

Separate reports are available for the three Awareness and Understanding and three Advertising Tracking studies.

■ 2017 Research

In 2017, Alzheimers NZ commissioned UMR to undertake a broader and more detailed survey than in 2015 and 2016; more like the 2014 survey in size and scope, with the overall objective of measuring understanding and awareness of dementia in New Zealand and comparing key measures of awareness and understanding against key measures in previous surveys.

The survey included several questions from the earlier surveys and additional questions were added on risk and prevention; the possible role of government in responding to Alzheimers NZ; personal level of concern about dementia, and perceptions and attitudes. The media activity questions were not included.

This information will inform future advocacy and educational activities.

More specifically, the main purpose of objectives of this survey were to enable Alzheimers NZ to report on:

- > Self-assessed knowledge of dementia
- > Specific aspects of knowledge
- > Most feared condition
- > Personal knowledge of someone with dementia
- > Attitudes to people with dementia
- > Attitudes to caring
- > Knowledge of risk and prevention; and,
- > Perception of the appropriate role of government.

1.2 Method

The findings in this report are from a standalone telephone survey of a nationally representative sample of New Zealand 18 years old and over.

Fieldwork was conducted between the 18th to the 28th of April 2017.

All fieldwork was conducted using the Quancept survey system which is a leading Computer Assisted Telephone Interviewing system. It is known for its power and flexibility, as well as the ease of use for supervisors and interviewers. It works in conjunction with a fully customizable sample management system, as well as a predictive dialler.

The total sample size was $n=750$, The margin of error for a 50% figure at the 95% confidence level for a sample size of 750 is $\pm 3.6\%$. This means for a result of 50% there is a 95% chance the 'true' proportion (i.e. if the question was asked in a census) was between 46.4% and 53.6%.

The response rate for the survey was 3.7%. This was calculated by the total number of surveys (750) divided by the total number of successful calls (19,905). The majority of those who did not take part either refused or were not within the quotas.

1.3 Reporting

Unless otherwise specified as indicative, all differences mentioned in the report are significant to 95% confidence.

Where appropriate, comparisons have been made to previous surveys.

Note on rounding:

All numbers are shown rounded to zero decimal places.

This means that the specified totals are not always exactly equal to the sum of the specified sub-totals. The differences are seldom more than 1%.

For example: $2.7 + 2.7 = 5.4$, if rounded to zero decimal places would appear: $3 + 3 = 6$

2 Personal experience

2.1 Knowing someone with dementia

Respondents were asked how many people with dementia they know or have known. Previous surveys have only asked whether respondents know or have known anyone with dementia.

Knowing a person with dementia

How many people have you personally known who have or had dementia?

	Total %
None	19
One	18
Two	19
Three	13
Four	5
Five	6
Six or more	18

Base: All respondents (n=750)

Eight in ten (81%) respondents said they know or have known at least one person with dementia. This is an increase of 14% when compared with the 2014 findings, where 67% of respondents said they know or have known someone with dementia.

38% said they know or had known one or two people, 25% three to five people and 18% six or more.

- > As in 2014, older respondents were more likely to know/have known someone with dementia compared to younger respondents. However, the increase in the overall figure of people knowing or having known someone with dementia largely came from an increase amongst younger respondents. This year, 72% (up 27%) of people under 30 years old said they know or have known someone with dementia, compared to 86% (up 1%) of respondents 60 years and over.
- > Older respondents (60 and over) were also more likely to know or have known six or more people with dementia (31%) compared to those under 60 (13%).
- > Indicative results suggest Asian (55%) and Pacific islanders (57%) were less likely to know or have known someone with dementia (83% amongst other ethnicities).

2.2 Relationship to people with dementia

Respondents were asked their relationship for each person they said they know or have known. The question was open-ended and responses have been coded into categories. In the 2014 survey this question was asked of only one of the people they knew or had known, and as such is not possible to make a direct comparison. However, in 2014 it was found that out of the 67% who know or had known someone with dementia, 69% said they were a family member, 23% a friend and 8% they knew them professionally.

Nature of relationship

<i>What is your relationship to person who has dementia</i>	
	Total %
TOTAL Family	69
<i>Immediate family (Parents/siblings/partners/children)</i>	20
<i>Wider family (Grandparents/Aunts/uncles)</i>	41
<i>Other family</i>	25
Friends	53
Professional (e.g. clients, patients)	12
Neighbours/community	6
Colleagues	4
Acquaintances	4
Refused + Unsure	2

Base: 81% of respondents who know/have known someone with dementia (n=612)
Multi-response question

Among respondents who said they know or have known one or more people with dementia, 69% said they know a family member and 53% said a friend. Together this accounted for 91% of people who said they know or have known someone with dementia

Other relationships included professional acquaintances (12%), neighbours (6%), colleagues (4%) and acquaintances (4%).

Of the **total sample** 56% said they know or have known a family member with dementia, 27% a friend and 7% in a professional context.

- > Respondents 60 years old or over were more likely to say at least one of the people they know or have known with dementia was a friend (64%) than their younger counterparts (48%) while those under 60 were more likely to say a grandparent, aunt or uncle (50%) than those 60 and over (17%).
- > Indicative results suggest Asian respondents who know or have known someone with dementia were more likely to have a professional relationship (31%) than the other ethnicities (11%). They were less likely to know or have known a family member (39% compared to 71%).
- > 40% of people who know or have known six or more people with dementia said at least one of them was in a professional context.

3 Knowledge

3.1 Overall knowledge

Respondents were asked how much they knew about dementia. Responses were assessed by combining those who said they knew 'a lot' or 'a fair amount' to be those who have a high level of declared knowledge. It should be noted that this can only be a proxy for knowledge as people may overestimate or underestimate their own knowledge about a subject. However, throughout the survey results there is a strong correlation between high declared knowledge and getting statements about dementia correct.

Knowledge of dementia

<i>How much do you feel you know about dementia</i>		
	2017	2014
	%	%
A lot	14	20
A fair amount	41	33
TOTAL: A lot + A fair amount	54	53
Not that much	37	35
Hardly anything	9	11
TOTAL: Not that much + Hardly anything	45	46
Unsure	0	1

Base: All respondents (n=750, each)

Just over half (54%) of respondents said they knew 'a lot' or 'a fair amount' about dementia. This was very similar to levels in 2014 when 53% declared they knew 'a lot' or 'a fair amount'.

- > Similar to the 2014 survey, females (60%) and those 60 years or over (69%) were more likely to declare at least 'a fair amount' of knowledge about dementia. This compares to 48% of males and 39% of respondents under 30 who declared at least 'a fair amount' of knowledge.
- > Those with university level of education declared higher knowledge (61%) than those without (49%).
- > Indicative results suggest Pacific respondents are less likely to declare greater knowledge (21%), compared to 55% of other ethnicities.
- > Amongst those who did not know anyone with dementia, 25% declared at least 'a fair amount' of knowledge. By comparison 45% of those who know or have known one or two people with dementia declared 'good' knowledge, 69% four or five and 85% six or more.
- > Those who have an immediate family member (parent/sibling/partner/child) with dementia claimed higher knowledge (80%) than those who do not, as did those who know/have known someone in a professional context (86%).

3.2 Information channels

All respondents were asked about where they have learnt about dementia. They were read a list of different sources and could select multiple options.

Information channel	
<i>Please tell me if you have learned about dementia this way</i>	
	Total %
Word of mouth (talking to a friend, colleague or acquaintance)	66
Media (e.g. newspapers, television, advertising)	63
Through personal experience (for example knowing or caring for someone with dementia)	61
From the Internet	33
From a professional (e.g. doctor, nurse, social worker)	25
Through Alzheimers New Zealand or a similar organisation	19
From phone / helpline	4
Don't know / can't remember	1
Other	1

Base: All respondents (n=750)
Multi-response question

Two-thirds of respondents said they learnt about dementia via word of mouth. Slightly less (63%) said media, followed by personal experience (61%).

Internet was used by a third of respondents as a source of information, 25% used a professional and 19% said Alzheimers NZ or a similar organisation. Just 4% said they used a phone or helpline.

- > 70% of those aged 45 and over said they learnt about dementia through personal experience, compared with 52% of those aged under 45 years. Those under 30 were much more likely to have used the internet (56%) for a source of information than their older peers (27%).
- > Indicative results suggest Māori respondents were less likely to have used Alzheimers NZ or a similar organisation (7% compared to 20% of other ethnicities). Asian (35%) and Pacific (40%) respondents were less likely to have learnt through personal experience (63% other ethnicities).
- > People who declared they knew at least 'a fair amount' about dementia were significantly more likely, to have learnt about dementia through personal experience (78%), a professional (38%) and Alzheimers NZ or similar organisation (25%) than those who declared less knowledge.
- > Those who say they are concerned about getting dementia were more likely to have learnt about dementia through personal experience (67%), the internet (39%) and Alzheimers NZ or a similar organisation (25%).
- > Respondent who know or have known someone with dementia were more likely to have used personal experience (74%), word of mouth (70%), professional (29%) and Alzheimers NZ or a similar organisation (21%).

3.3 Symptoms of dementia

Respondents were given a list of eight different common symptoms of dementia and were asked whether they believed each one to be common symptoms. The 2014 and 2017 survey are not directly comparable as different symptoms were named. However, the level of knowledge of common symptoms do appear similar. In 2014 knowledge of memory loss, changes in personality and getting lost were all over 90%.

Knowledge of symptoms

<i>Please tell me which of the following you think are common symptoms of dementia</i>			
%	Yes	No	Unsure
Confusion and disorientation	95	4	1
Difficulty remembering things from the previous few days	94	4	1
Wandering or getting lost	94	5	1
Difficulty in recognising people or things	91	7	2
Difficulty making decisions or slower thinking	89	7	4
Difficulty managing daily tasks	89	10	1
Decreased or poor judgement	81	13	5
Changeable moods or behaviour	77	18	5

Base: All respondents (n=750)

The three most highly recognised common symptoms, receiving 94-95% recognition apiece, was 'confusion and disorientation', 'difficulty remembering things' and 'wandering or getting lost'.

'Difficulty in recognising people or things' (91%), 'difficulty making decisions or slower thinking' (89%) and 'difficulty managing daily tasks' (89%) all received similar levels of recognition.

'Decreased or poor judgement' (81%) and changeable moods or behaviours (77%) had the lowest levels of identification as common symptoms of dementia out of the eight tested.

By looking at the eight common symptoms and totalling the number of times they were identified we can see that 54% of respondents correctly identified all eight symptoms.

- > Females were more likely to recognise all eight (62%) compared to males (44%).
- > Indicative results suggest Asian respondents were less likely to get all eight correct (33%) compared to other ethnicities (55%).
- > Different age groups were not significantly different from each other.
- > Those who declared 'a lot' or 'a fair amount' of knowledge were also more likely (63%) to recognise the eight symptoms, as were those who know/have known someone with dementia (57%), compared to their respective counterparts (43% and 39%).

Those who do not know anyone with dementia were more likely to get 6 or less (34%) as were those with a secondary or lower level of schooling (26%).

3.4 Prevention factors

Respondents were asked how confident they were that seven listed activities would reduce a person's likelihood of developing dementia. All the activities listed, apart from 'Not drinking alcohol', have been shown to reduce the risk. Respondents who rated 7-10 on a 0 to scale where 0 means not confident at all and 10 means very confident were assessed as being 'confident'.

Reducing risk

Using a 0-10 scale, where 0 means you are not confident at all and 10 means you are very confident, how confident are you that taking the following actions now may reduce your risk of developing dementia later?

Row %	Confident (7-10)	Neutral (4-6)	Not confident (0-3)	Unsure
Doing mentally stimulating things like puzzles or learning a new language	84	10	5	1
Eating a healthy diet	75	18	6	1
Having an active social life	67	24	8	1
Maintaining a healthy blood pressure	62	26	8	4
Not smoking	60	21	15	4
Not drinking alcohol	44	33	18	4
Drinking moderate amounts of alcohol	41	34	21	4

Base: All respondents (n=750)

Most (84%) were confident that doing mentally stimulating things can reduce the risk of developing dementia and it was the activity that received the highest confidence rating.

People were also mostly confident that eating a healthy diet (75%) having an active social life (67%), maintaining a healthy blood pressure (62%) and not smoking (60%) reduced the risk of dementia.

- > Females were more confident eating a healthy diet (79%) was a risk reducing factor compared to males (70%).
- > Those 60 years and over were more confident in having an active social life (76%) than their younger counterparts (64%).
- > Those with at least 'a fair amount' of declared knowledge about dementia had higher confidence in all the factors, but significantly higher for eating a healthy diet (79%) and doing mentally stimulating things (88%).
- > People concerned about getting dementia had particularly high confidence for maintaining a healthy blood pressure (69%), having an active social life (72%) and doing mentally stimulating things (90%).
- > Those who did not know anyone with dementia were less likely to be confident that an active social life (57%) or mental stimulation (77%) may reduce the risk of developing dementia, while people who know/have known a family member with dementia had higher confidence in only drinking a moderate amount (45%). Participants who knew someone in a professional capacity had particularly high confidence that not smoking (74%) would reduce risk.

A third (35%) were confident about six or seven of the seven factors. 15% were confident about all seven and 20% were confident about six of the factors.

- > Females were generally more confident. 39% rated six or seven confidently compared to 30% of males.
- > People under 30 were generally less confident. 25% rated six or seven confidently compared to 38% of people older.
- > 40% of those with declared knowledge of a lot or a fair amount and 42% of people who were concerned about getting dementia (compared to 29% and 30% of their respective counterpart) rated six or seven factors confidently
- > Those who know or have known someone with dementia were more likely to rate six or seven confidently (37%) than those who do not (25%).

3.5 Knowledge testing

Respondents were asked to rate seven different statements about dementia as definitely true, probably true, probably false or definitely false. Three out of the seven were true and three were false. Respondents were assessed on whether they correctly identified each statement as true (by adding together probably true and definitely true answers).

The statement 'there are drugs which can reduce the symptoms of dementia' is only true for some people and then only for some of the time. As such this statement was analysed separately

Knowledge statements			
<i>Please tell me whether you think the statement is definitely true, probably true, probably false, definitely false or if you are not sure.</i>			
%	True (total)	False (total)	Unsure
<u>True statements</u>			
Alzheimers is only one of many types of dementia	86	8	7
People in their thirties and forties can develop dementia	84	11	5
Dementia is a fatal condition	42	54	4
<u>False statements</u>			
Dementia has to run in my family for me to be at risk	16	79	4
It is a normal part of the aging process	27	70	2
With the right treatment, dementia can be cured	27	63	9
<u>True only for some cases</u>			
There are drugs which can reduce the symptoms of dementia	80	10	10
Base: All respondents (n=750)			

■ Correct statements

More than four fifths of respondents were correct in saying the following are true:

- 'Alzheimers is only one of many types of dementia' (86%);
- 'People in their thirties and forties can develop dementia' (84%).

Less than half (42%) of respondents correctly identified that it is true dementia is a fatal condition. However, this was an increase of 15% from the research in 2014 when only 27% identified it as true.

- > Respondents 60 years and over were less likely to think dementia is fatal (35%) than those under 60 (44%).
- > Indicative results suggest Asian (60%) and Pacific (64%) respondents were more likely to correctly identify it as true that dementia is fatal compared to other ethnicities (40%).
- > Respondents with tertiary education were more likely to recognise that Alzheimers is only one of many types of dementia compared to their counterparts (89% to 78% respectively).
- > Those who declared at least 'a fair amount' of knowledge were somewhat more likely to be aware that Alzheimers is only one of many types of dementia (88% vs. 82% of people with less declared knowledge). No other correct statements were significantly different.
- > People who know or have known a family member with dementia were more likely to be aware people in their thirties and forties can develop dementia (89%). Knowing someone with dementia was not a significant factor in response to any of the other correct statements.

■ Misconceptions

Just over a quarter (27%) thought dementia is a normal part of aging (no significant change from 2014), and the same number said they thought dementia can be cured.

16% of respondents incorrectly identified dementia is a disease that can be inherited.

- > Males were more likely to say dementia can be cured (35%) and that it is inherited (20%) than females (20% and 13% respectively).
- > Indicative results suggest, Pacific (58%) and Asian (49%) respondents were more likely to think dementia can be cured than other ethnicities (25%).
- > Younger respondents were more likely to be misinformed about whether dementia can be cured. 46% of under 30s said so compared to 16% of people 60 and over said it could be cured.
- > Those who declared less than 'a fair amount' of dementia knowledge and people who have never known someone with dementia were more likely to think there is a cure (37% each) than their respective counterparts (19% and 25% respectively). For both sets of groups this was the only false statement where there were significant differences.

■ Drugs that can reduce symptoms

Fourth fifths of respondents said they thought the statement 'There are drugs which can reduce the symptoms of dementia' was true.

- > Respondents 60 years and over were less likely to think there are drugs which can reduce the symptoms (73%) than those under 60 (82%).

4 Concern

4.1 Fear of Dementia versus other diseases

Respondents were asked to say which disease (out of six) they were most afraid of getting. This is similar to a question asked in previous research where respondents were asked if they were more scared of being diagnosed with dementia or cancer. In the 2014 research, it was found 56% of people said cancer and 16% dementia.

Fear of different diseases

I am going to read you a list of six diseases. Please tell me which of ONE these you are most afraid of getting.

	Total %
Cancer	39
Dementia	20
Stroke	19
Heart condition	7
Diabetes	4
Depression	4
None of the above	3
Don't know	3

Base: All respondents (n=750)

From the list of six diseases, 20% of respondents said they were most afraid of getting dementia; this was second to cancer (39%) and about equal with stroke (19%).

Only 7% said they were most afraid of getting a heart condition, 4% said diabetes and 4% said depression.

- > Females were more likely to choose dementia (23%) than males (16%) as the most feared condition.
- > Respondent 60 years and over had quite different responses compared to the overall. 27% of people 60 and over were most afraid of having a stroke, while both dementia and cancer was mentioned by 25%. They were also the age group most likely to say none of them (5%).
- > Those who declared they knew at least 'a fair amount' about dementia were slightly more likely to be most fearful of dementia (24% compared to 15% who said they know less), as were those who know or have known an immediate (parent/sibling/partner/child) family member with dementia (27% compared 20% who don't).

4.2 Level of concern

Respondents were asked, on 0 to 10 scale where 0 is not concerned at all and 10 is very concerned, how concerned they were about getting dementia. They were assessed as 'concerned' if they gave a rating of 7-10.

Concern of getting dementia

Regardless of your previous answer, on a scale of 0-10 where 10 means you are very concerned and 0 means you are not concerned at all, how concerned are you of getting dementia?

	Total %
0 - Not concerned at all	7
1	3
2	6
3	9
Not concerned (0-3)	25
4	6
5	16
6	11
Neutral (4-6)	33
7	13
8	14
9	5
10 - Very concerned	9
Concerned (7-10)	42
Unsure	0

Base: All respondents (n=750)

Over two fifths (42%) of respondents said they were concerned about getting dementia, 33% were neutral (4-6) and 25% were not concerned (0-3).

- > Females were more likely to be concerned (47%) than males (36%).
- > Those with secondary or lower formal education were more likely to say they were concerned (48%) than those with higher education (39%).
- > There were no statistically significant differences between age groups or those with a different declared level of knowledge about dementia.
- > Respondents who know or have known someone with dementia were more likely to declare concern (44%) than those who don't (33%). This was particularly strong for those who know an immediate (parent/sibling/partner/child) family member (54%).

4.3 Caring for people with dementia

Respondents were asked how much they agree on a 0 to 10 scale where 0 means strongly disagree and 10 means strongly agree, with seven different statements about the care of people with dementia. They were assessed as 'agreeing' if they gave a rating of 7-10. For reporting, the statements were grouped together into three common themes.

Statement testing

Thinking about those who are caring for people with dementia, using the 0-10 scale where 0 means you strongly disagree and 10 means you strongly agree, how much do you agree or disagree with the following statements?

	Agree (7-10)	Neutral (4-6)	Disagree (0-3)	Unsure
<u>Who should provide care</u>				
Family should provide most care for people with mild dementia	60	29	10	1
I would be willing to pay more taxes if that tax were used for support for people with dementia	53	30	17	1
I worry that I may have to provide care for someone with dementia in the future	31	27	41	1
<u>Effects of being a carer</u>				
Caring for someone with dementia is often very lonely	58	26	13	3
Caring for someone with dementia could be very rewarding	57	30	12	1
Caring for someone with dementia often means your own health suffers	50	28	19	2
<u>Diagnosed over caring</u>				
I would rather be diagnosed with dementia than care for someone with dementia	15	23	57	6

Base: All respondents (n=750)

■ Who should provide care

Three fifths (60%) agreed that family should provide most care for people with mild dementia and just over half (53%) agreed they would be willing to pay more taxes if that tax were used for support for people with dementia.

Nearly a third (31%) were worried they may have to care for someone with dementia in the future.

- > Respondents 60 years old and over were more likely to agree that family should provide care (66%) while respondents between 45 and 60 were less likely (52%).
- > Under 30s were more likely to agree they would be willing to pay more tax to support people with dementia (66%) compared to their older counterparts (49%).
- > Those who were concerned about getting dementia were more likely to agree they would be willing to pay more tax to support people with dementia (66%) as were those who know or have known a family member with dementia (57%), compared to their respective counterparts (43% and 49%).
- > Those who know or have known someone with dementia were more likely to be worried they may have to provide care for people with dementia in future than those who do not (33% and 23% respectively).

■ Effects of being a carer

About the same amount of people agreed caring for someone with dementia is often lonely (58%) and could be rewarding (57%). Slightly fewer (50%) agreed that caring for someone often means your own health suffers.

- > Females were more likely to think caring could be lonely (63%), rewarding (60%) and damaging to the carers health (56%).
- > Younger respondents (under 30) were less likely to agree with the negatives of caring for someone with dementia (very lonely: 34%, own health suffers: 38%) and more likely to agree with the potential rewards (65%).
- > Those 60 years old and over had higher agreement on carers being very lonely (70%) and their health suffering (60%) compared to their younger counterparts (54% and 47% respectively).
- > Respondents with at least 'a fair amount' of declared knowledge about dementia were more likely to think caring for someone could be lonely (65%) and have a negative impact on carers' health (58%) compared to people you claim less knowledge (50% and 42% respectively).
- > Those who know or have known someone with dementia were more likely to agree caring for someone with dementia can often be lonely (61%) than those who did not (45%). In particular, those who know or have known an immediate (parent/sibling/partner/child) family member were more likely to agree with (75%).

■ Being diagnosed with or caring for someone with dementia

Very few people (15%) agreed they would rather be diagnosed with dementia than care for someone with dementia. This was marginally lower than the 2014 survey where 18% of respondents would have preferred to be diagnosed.

- > Respondents 45 years old and over were more likely to agree they would rather be diagnosed than care for someone with dementia (18%) than their younger counterparts (11%).

5 Perceptions and attitudes towards dementia

Respondents were asked how much they agree on a 0 to 10 scale where 0 means strongly disagree and 10 means strongly agree, with ten different statements about their perceptions and attitudes toward people with dementia. They were assessed as 'agreeing' if they gave a rating of 7-10. For reporting, the statements were grouped together into five common themes.

Statement testing

Using the 0-10 scale where 0 means you strongly disagree and 10 means you strongly agree, how much do you agree or disagree with the following statements?

	Agree (7-10)	Neutral (4-6)	Disagree (0-3)	Unsure
<u>Effects of having dementia</u>				
People with dementia can become isolated from their friends and community	87	9	3	1
People with dementia can be involved in activities in the community. For example, attend a wedding, church, social club or other social events.	83	13	2	2
People with dementia can still enjoy life to the fullest	58	26	14	2
<u>Care for people with dementia</u>				
It is better for people with dementia if they are cared for in a residential unit or nursing home	44	33	17	6
People who have been diagnosed with dementia are unable to make decisions about their own care.	42	36	19	4
<u>Socialising with people with dementia</u>				
If someone I knew was diagnosed with dementia I would continue to include them in our regular social activities	87	11	2	1
People are unlikely to want to spend as much time with friends when they have developed dementia.	52	28	15	5
<u>Interacting with people with dementia</u>				
If I was in public with a person with dementia I would worry about how they may act	38	30	31	2
I would find it hard to talk to someone with dementia	27	24	48	1
<u>If a family member had dementia</u>				
If a close family member were diagnosed with dementia I would not want to tell people	10	18	71	2

Base: All respondents (n=750)

■ Effects of having dementia

The clear majority (87%) agreed people with dementia can become isolated from friends and the community.

Another clear majority (83%) agreed people with dementia can still be involved in activities in the community such as attending a wedding, church, social club or other social events.

Over half (58%) agreed people with dementia can still enjoy life to the fullest,

- > Females were more likely to agree people with dementia can be involved in the community (87%) than males (79%). As were those with university level qualifications (86%) compared to those with lower formal education (80%).
- > Indicative results suggest Pacific respondents were less likely to agree (66%) that people with dementia can become isolated from friend and community, than the overall (87%).
- > Respondents who declared they knew 'a lot' or 'a fair amount' about dementia were more likely to agree that those with dementia can become isolated from their community (91%) than those who have lesser declared knowledge (83%).

■ Care for people with dementia

Less than half (44%) of respondents agreed it is better for people with dementia if they are cared for in a residential unit. About the same amount (42%) agreed they are unable to make decisions about their own care.

- > Males (46%) and respondents 60 years and over (51%) were more likely to agree people with dementia are unable make to decisions about their own care than their counterparts (38% and 39% respectively).
- > Those with university level qualifications were less likely to believe that residential care was better for people with dementia (36%) and that people with dementia are unable make decisions about their own care (33%).

■ Socialising with people with dementia

Most respondents (87%) said they would continue to include someone in social activities if that person were diagnosed with dementia. This was relatively unchanged from the 2014 survey (up 1%).

Just over half of respondents agreed (52%) people are unlikely to want to spend as much time with friends when they have developed dementia.

- > Females were more likely to agree they would continue to include someone with dementia (91%) in their social activities than males (82%)
- > Those 60 years or over were somewhat less likely to agree they would include someone with dementia (81%) in their social activities than their younger counterparts (89%)

■ Interacting with people with dementia

About four in ten (38%) people agreed if they were in public with someone with dementia they would worry about how they may act. This was up marginally from the 2014 survey when 32% agreed.

Just over a quarter (27%) of respondents agreed they would find it hard to talk to someone with dementia.

- > Males (31%), those under 30 (38%) and people with secondary school level of education or less (34%) were all more likely to agree they would find it hard to talk to someone with dementia than the overall (27%).
- > Those with secondary school level of education or less (45%) were more likely to agree that if they were in public with someone with dementia they would worry about how they may act than those with higher formal education (34%).
- > Those who declared they knew 'a lot' or 'a fair amount' about dementia (23%) were less likely to say they would find it hard to talk to someone with dementia than those who declare less knowledge (32%). Those who were concerned about getting dementia were more likely to agree (33%) they would find it difficult to talk with someone with dementia than those who were not concerned or neutral (23%).
- > 33% of people who do not know and have not known anyone with dementia said they would find it hard to talk to someone with dementia. The proportion decreases with the number of people with dementia a respondent knows or has known. 31% of respondents who know or have known one or two people, 24% who know 3-5 people and 19% of who know 6 or more would find it difficult to talk to people with dementia.

■ If a family member had dementia

One in ten respondents said they would not want to tell people if a close family member was diagnosed with dementia. This was down from 19% from the 2014 survey when a similar statement was asked ('If a close family member was diagnosed with dementia, I would *be reluctant to tell other people about it*').

- > People 60 years old and over were more likely to agree they would not want to tell people if a close family member had been diagnosed (16%) than those under 60 (7%).
- > Indicative results suggest Asian respondents were more likely with the statement 'If a close family member were diagnosed with Dementia I would not want to tell people' (21%) compared to other ethnicities (9%).

6 Support for Government action

Respondents were asked how important, on a 0 to 10 scale where 0 means not important at all and 10 means very important, ten different types of government action to help address dementia were. They were assessed as rating something as 'important' if they gave a rating of 7-10.

The statement 'Increase taxation if it meant more was done to support people with dementia' was the only statement that had a condition on the statement and was therefore analysed separately.

Importance of government action

I am going to read out some actions that the New Zealand Government could take to help address dementia in New Zealand. Using a scale from 0-10, where 0 means it is not important at all and 10 means it is very important, how important is it that the Government takes these actions? The Government could...?

Row %	Important (7-10)	Neutral (4-6)	Not important (0-3)	Unsure
Provide increased support for voluntary caregivers of people with dementia.	88	10	1	1
Support and train GPs to recognise and diagnose dementia earlier	83	12	3	2
Provide more information about how people could reduce their risks for dementia	83	14	2	1
Do more to support people with dementia	81	15	2	2
Fund more research into ways to cure dementia	80	15	3	1
Recognise dementia as a major health priority	79	16	3	1
Provide better support for local Alzheimers organisations	79	17	2	2
Encourage doctors to be better at diagnosing dementia	78	16	4	2
Provide funding for groups that are trying to develop dementia friendly communities	77	19	4	1
Increase taxation if it meant more was done to support people with dementia	51	34	14	2

Base: All respondents (n=750)

Over three-quarters of respondents rated all nine types of government action as important. The action that had the highest level of declared importance was the government 'increasing support for voluntary caregivers of people with dementia' (88%). Other strongly supported actions which received between 77% and 83% importance ratings, included training for GPs, providing more information about reducing risk, supporting research, recognition of dementia as a major health priority and support and funding for dementia organisations.

- > Females, those under 30 and those concerned about getting dementia generally gave higher rating across all the actions.
- > 46% of the whole sample gave important ratings to all nine actions. Indicative results suggest Asian respondents were more likely to give important rating to all nine (65%) and Māori respondents were less likely (33%).
- > Respondents who declared 'a lot' or 'a fair amount' of knowledge were more like rate '*Provide funding for groups that are trying to develop dementia friendly communities*' as important (80%) compared with those with less declared knowledge (73%).

Half (51%) of respondents said it was important to support people with dementia by increasing taxation.

- > Females (55%), those under 30 (62%) and those concerned about getting dementia (66%) were all more likely to rate this as important than their counterparts (46%, 48% and 40% respectively).

7 Demographics trends

7.1 Gender

Females tended to give answers that indicated they were more knowledgeable, understanding and concerned about dementia.

Amongst females:

- > 60% declared they knew 'a lot' or 'a fair amount' about dementia (48% amongst males).
- > 62% correctly identified all eight common symptoms of dementia tested (44% amongst males).
- > 39% rated six or seven out of seven prevention factors confidently (30% amongst males).
- > 47% said they were concerned about getting dementia (36% amongst males).
- > Were more likely to agree people with dementia can continue to be involved in the community and they would continue to include someone with dementia in their social activities.
- > Females were less likely to agree those with dementia are unable to make decisions about their own care and that they would find it hard to talk to someone with dementia.

7.2 Age

Older respondents (60 and over) were more likely to know/have known someone with dementia and to declare a higher knowledge of dementia. However, they were no more or less likely to get knowledge testing statements about dementia right than any other age group.

Amongst people aged 60 and over:

- > 86% know or have known someone with dementia (79% amongst under 60s).
- > 69% said they knew a lot or a fair amount about dementia. (49% amongst under 60s).
- > Were equally likely to be afraid of getting cancer, dementia and having a stroke.
- > Were more likely to recognize caring for someone with dementia can be lonely or impact a on a carer's health (25-27% each).
- > Were slightly more likely to prefer to be diagnosed with dementia than care for someone with dementia.

7.3 Declared knowledge

Respondents who declared a lot or a fair amount of knowledge tended to give answers that supported their claim. They were more likely to know or have known someone with dementia, get knowledge testing questions correct and appreciate the difficulties of care.

Amongst people with a lot or a fair amount of knowledge:

- > 91% know or have known someone with dementia (68% amongst their counterparts).
- > 63% recognised the all eight symptoms tested (63% amongst their counterparts).
- > 40% were confident about six or seven of the seven prevention factors tested (29% amongst their counterparts).
- > 23% said they would find it hard to talk to someone with dementia (32% amongst their counterparts).
- > Were more likely to think caring for someone could be lonely and have a negative impact on carers' health. They were also more likely to agree that those with dementia can become isolated from their community.

7.4 Concerned about getting dementia

Those who declared a high level of concern about getting dementia in the future, were more likely to know or have known someone with dementia, be confident about the prevention factors for dementia, find it difficult to talk to someone with dementia and willing to pay more tax in support of people with dementia.

Amongst those who declared a high level of concern about getting dementia in the future:

- > 84% know or have known someone with dementia (78% amongst their counterparts).
- > 42% were confident about six or seven of the seven prevention factors tested (32% amongst their counterparts).
- > 33% said they would find it hard to talk to someone with dementia (23% amongst their counterparts).
- > 66% agreed they would be willing to pay more tax to support people with dementia (43% amongst their counterparts).