



Dementia experience, planning and worry: Perspectives of people aged 50-plus living in the community

September 2024

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National Seniors Australia is located in Brisbane and Canberra. We acknowledge the traditional custodians of the land and waters in which we operate, the Turrbul and the Ngannawal and Ngambri Peoples. We honour and value their continuing cultures and contributions and pay our respects to their elders, past and present.

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EXECUTIVE SUMMARY

Dementia describes a group of degenerative brain diseases that impact upon a person's memory, cognition, personality, behaviour, and mobility. The most common type of dementia is Alzheimer's disease, but it is possible to develop more than one type of dementia.

Dementia is the second leading cause of death and disease burden nationally, behind coronary heart disease. But it is the leading cause of death for women and disease burden for Australians aged 65 and over (AIHW, 2024b).

Dementia Australia estimates two in three people with dementia live in the community (Dementia Australia, 2024a) and yet the community's awareness of dementia is limited (AIHW, 2024a). The Department of Health and Aged Care (DHAC) is currently finalising the National Dementia Action Plan that aims to increase dementia understanding in the community, reduce stigma, and provide better access to diagnosis and support (DHAC, 2023).

Although dementia is a whole-of-society issue, it is one that particularly impacts older people. This is in part because increasing age is the strongest risk factor for dementia, but also because older people are frequently the ones providing dementia care whether it be for a partner, relative, or friend.

This report presents results from the Dementia module of the 2024 annual National Seniors Social Survey, an online survey of approximately 4,900 Australians aged 50 years and over living in the community.

Survey respondents answered a set of 'point and click' and free text questions focused on dementia experience, planning, and worry.

Dementia Experience

- 71% of respondents had experienced dementia via close relationships.
- Experience of dementia was associated with seeking dementia-related information, consulting a health professional about memory issues, and dementia worry.

Dementia planning

- 40% had thought about or planned for dementia in the future for themselves or someone close.
- 83% said they would consult a health professional if they noticed changes in thinking or had memory concerns.
- 47% sought out information related to dementia or to age-related memory changes.

Dementia worry

- 63% worried to some extent about developing dementia.

Respondents could elaborate on their dementia worry sentiments with a text-based response. Thematic analysis of 1,183 comments identified eight different ways of thinking about dementia worries. These included estimates of personal risk, mitigation strategies, fears about dementia's potential impacts on oneself or others, and philosophical reflections on worry.

With the number of people living with dementia expected to double over the next three decades (AIHW, 2024b), public health initiatives must focus on addressing misconceptions and stigma surrounding dementia. This will improve quality of life for people living with dementia and their carers. But it will also mitigate community dementia worry as more people experience dementia in their close relationships.

BACKGROUND

Dementia and public health in the twenty-first century

In 2017, the World Health Organization launched its *Global action plan on the public health response to dementia 2017-2025*, which recognised dementia as a global public health priority.

At present, it is estimated that 55 million people have dementia globally and almost 10 million more are diagnosed each year (WHO, 2017).

While dementia can affect younger people, more than 90% of cases are found in people aged 65 or older, and dementia is estimated to affect 5% of the elderly population (WHO, 2017). It is one of the primary causes of disability among older people globally.

Disappointingly, the actions called for by the WHO report are well behind schedule (Lancet Neurology, 2023). It is notable that even the relatively straightforward action of each nation developing its own national plan for dementia by 2025 is behind schedule, with only a fifth of UN member states having done so by August 2023. Australia was one of those without a plan, but it has a draft plan, with the final version anticipated for the second half of 2024 (DHAC, 2023).

In Australia, 2023 statistics estimate 411,000 people are living with dementia, including more than 8% of those aged 65 or older. In line with global figures, the number of people with dementia is growing in Australia. It is expected to more than double by 2058 (AIHW, 2024b).

Dementia is the second leading cause of death in this country, accounting for 10% of all deaths (AIHW, 2024b). It is the leading cause of death for women.

Dementia is not a single disease but rather the umbrella term for a large group of conditions that cause progressive decline in cognitive and physical functioning. Alzheimer's Disease, vascular dementia, and Lewy body dementias are types of dementia more common in people aged 65 years and older (Dementia Australia, 2024a).

Medications are available that slow the progression of symptoms for some people but do not cure the underlying diseases. There has been progress however in diagnosing some types of dementia earlier in a person's life and earlier in its progression (NIH, 2024).

One benefit of this is that interventions can potentially begin earlier too. However, it also has relevance to the public health statistics because early diagnosis will likely increase the number of people documented as living with dementia.

In our ageing population, dementia is a huge part of the current and future public health picture in Australia.

Attitudes to dementia

Despite being widespread and impactful in today's society, ignorance and fear abound regarding dementia.

In 2023 the Australian Institute of Health and Welfare (AIHW) launched the first Dementia Awareness Survey, a nationally representative survey of dementia and attitudes among Australians aged 18 and over (AIHW, 2024a).

The survey showed that Australians generally know little about dementia, including its causes, symptoms, risks, prevention, and ways to interact with people who have dementia. Stereotypes about dementia were common, though

positive behaviours towards people with dementia were also common.

Around 90% of people surveyed said they would seek help from a GP if they showed signs of dementia and would share a diagnosis with family members.

The survey showed that people who knew more about dementia tended to take more action to reduce their risk.

The AIHW concluded that Australians need to improve their knowledge of dementia. This is one of the needs that will be tackled through the Australian *National Dementia Action Plan*.

The need for more data on social aspects of dementia in Australia

In 2022 the Commonwealth Department of Health and Aged Care launched a consultation paper regarding its proposed *National Dementia Action Plan* (DHAC, 2023, 2024). At the time of writing, the plan was being finalised by the department in the wake of the consultation process (DHAC, 2024).

The draft plan, however, includes several points related to the Australian public's information about and experiences of dementia (AIHW, 2023; Table 2.1). These include:

- Objective 1: expanding dementia awareness, reducing stigma, and creating inclusive communities and environments for people living with dementia, their carers and families.
- Objective 2: ensuring risk factors for dementia are well understood, and that people are aware of what they can do to delay the onset and slow the progression of dementia.
- Objective 3: ensuring people can recognise and act on early signs and symptoms, access quality and timely

diagnostic services, and obtain post-diagnostic care and support.

The report on the outcomes of the consultation process also gives us insight into topics that will likely be prioritised in the final plan (DHAC, 2023; p.7). Of relevance here, the points prioritised by the stakeholders who were consulted include:

- Addressing the stigma of dementia and improving community understanding of it.
- Ensuring people are well supported and have a plan for action following a dementia diagnosis.
- Supporting those caring for people living with dementia.

The department has stated that the AIHW will monitor performance against the plan as part of a new National Centre for Monitoring Dementia (DHAC, 2024). Core to this is the *National Dementia Data Improvement Plan 2023-2033* which aims to improve national dementia data in a range of ways (AIHW, 2023).

In addition to improving epidemiological data, clinical data collection, knowledge of dementia in relevant workforces and more, the *National Dementia Data Improvement Plan's* scope also includes social aspects of dementia data, such as people's knowledge about dementia and their personal experiences of it. Currently, very little is known about these topics in an Australian context.

The aim of this report is to better understand the dementia experiences and perceptions specifically of people aged 50 years and older living in the community. This group includes not only the people most likely to develop dementia, but also those most likely to be a partner, relative, friend, or carer of someone with dementia.

METHODS

The National Seniors Social Survey

National Seniors Australia is a member-based not-for-profit research and advocacy organisation representing the views, values, and beliefs of Australians aged 50 and over.

Most years since 2012, National Seniors has examined older people's behaviours and views on topics relevant to lifestyle and wellbeing using the National Seniors Social Survey, or NSSS. The 12th NSSS (NSSS-12) was conducted in February 2024.

Anyone aged 50 years or over and living in Australia was eligible to participate. Invitations were distributed to potential participants via the National Seniors membership database and online networks, and further distribution to other eligible people was encouraged. Responses were collected online via Survey Monkey. Participants were encouraged and able to retain anonymity, with any potentially identifying information redacted.

As for other National Seniors Social Surveys, in 2024 we asked questions on multiple topics relevant to older people's lives, plus a range of demographic questions. This report draws on responses to questions in the 'Dementia' module of the NSSS-12 (wording in [Appendix 1](#)). In total, 4882 NSSS-12 respondents answered one or more of these questions. Specific numbers for each question are reported in the text.

The demographic characteristics of respondents who answered any of these questions are provided in [Appendix 2](#). We use demographics to characterise the sample as our recruiting strategy was open rather than attempting to reflect group proportions in the broader population.

Quotes from survey respondents were selected to illustrate the variety and prevalence of ideas expressed. When possible, we reproduce quotes verbatim, occasionally omitting or altering parts for clarity or anonymity (indicated with square brackets []). Minor typos were corrected for readability (no brackets). All other phrasing idiosyncrasies are retained.

Analysis methods

The software package Stata v18 was used for all quantitative analysis. Chi-square tests evaluated differences between groups and multiple logistic regression models evaluated the relative independent contribution of demographic factors to the dementia outcomes, recoded as binary variables. Sociodemographic variables were selected for inclusion in models according to significant Chi-square tests and theoretical plausibility.

Most questions included 'prefer not to say' and 'unsure' options. Proportions for these are presented in some figures and tables but coded as missing for statistical analyses. Values for the variables included in statistical models are presented in [Appendix 4](#).

We analysed text comments made in response to the question about dementia worry using the thematic analysis framework described by Braun and Clarke (2006). We identified themes via inductive analysis guided by a critical realist approach that aimed for accuracy and objectivity in interpreting respondents' views. We acknowledge the influence of our pre-existing knowledge and understandings on identified thematic categories.

The number of comments comprising any given theme was estimated to give a sense of its prominence. Comments could contribute to more than one theme.

FINDINGS

Personal experience with dementia

Survey respondents were first asked if they had past or current experience of someone close to them living with dementia. Figure 1 shows that just under three-quarters of respondents had experienced dementia through one or more of their close relationships.

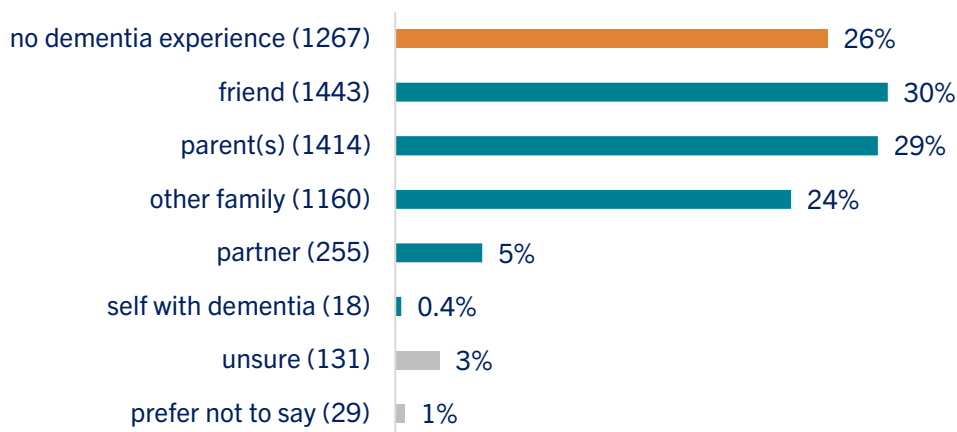


Figure 1. Experience of dementia through a close relationship (n=4868).

People who experienced dementia with their partners tended to be older (average age 77 years) than those who had experienced it through other relationships or had no dementia experience (average age 73 years).

Planning for dementia and seeking advice or information

Planning for a future with dementia

Most people had not thought about or planned for a future with dementia either for themselves or someone they were close to. Of those who had, just over half said they discussed it with at least one other person (Figure 2).

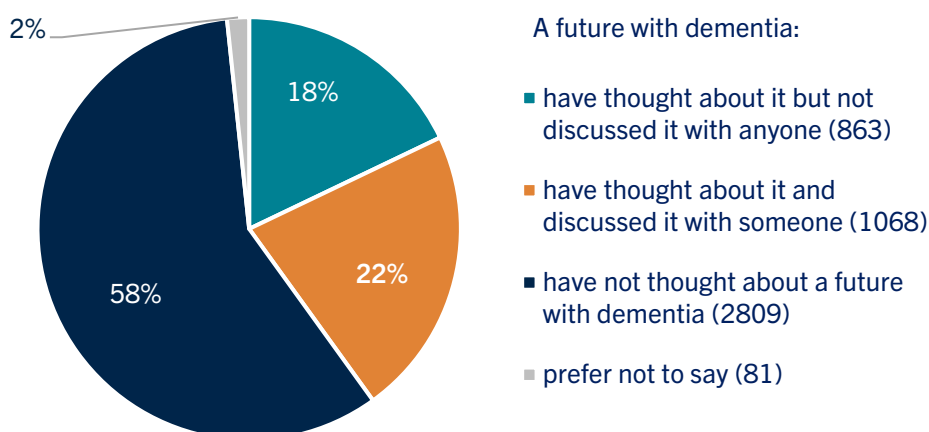


Figure 2. Thinking about or planning for a future with dementia (n=4821).

The highest proportion of planners (44%) were in the youngest age group, 50-64-year-olds. Older people (aged 75-plus) who had thought about or planned for dementia were more likely to have discussed it (24%) compared to the younger age groups (20%).

Planning was also associated with higher education, having a partner, being in poorer health, and being a woman. The strongest association with planning was with exposure to dementia through personal relationships (Appendix 4, Table S1). Most planners (84%) had experience of dementia.

Consulting a health professional

Over 80% of respondents said it was likely they would consult a health professional if they were concerned about their memory or thinking skills (Figure 3), and this did not differ significantly by age group. As with many other health issues, more women (84%) than men (82%) said they were likely to consult with a health professional. The only demographic factor apart from gender associated with intention to consult a health professional about memory issues was being in better health (Appendix 4 Table S2).

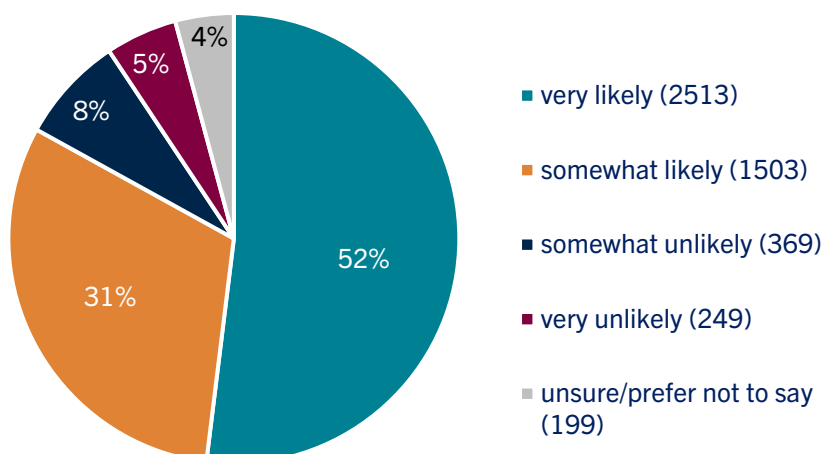


Figure 3. Likelihood of consulting with a health professional about thinking and memory concerns (n=4833).

Seeking information

Respondents were also asked whether they had sought out general information about dementia and/or the changes in thinking and memory that may occur in later life.

Almost half (47%) said they had. This proportion differed substantially between women and men, with 54% of women compared to 40% of men seeking dementia information.

Differences in information-seeking according to age groups are presented in Figure 4 (next page). Information-seeking was more common in the oldest age group, despite lower proportions of this group thinking about or planning for a dementia diagnosis.

Poorer health, higher levels of education, and experience of dementia through personal relationships were also positively associated with seeking out dementia information (Appendix 4, Table S3).

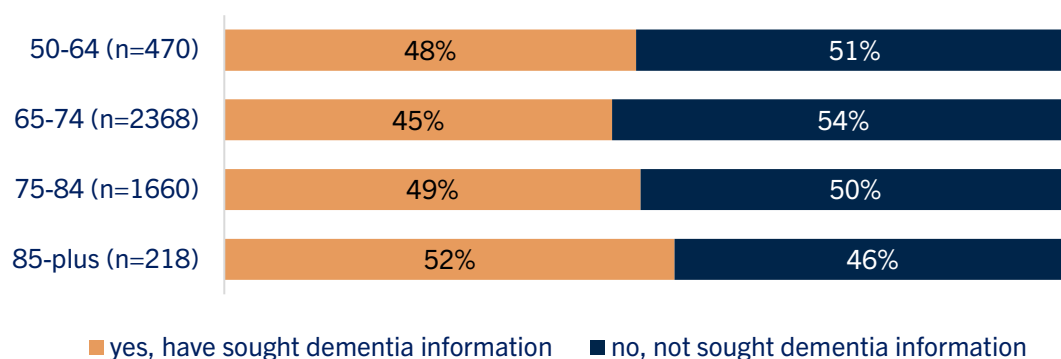


Figure 4. Age group differences in seeking dementia information.

Sources of dementia information

Those who sought out information on dementia or thinking and memory changes were asked to specify where they went for this information. Figure 5 shows that searching online was the top option selected, followed by books or articles.

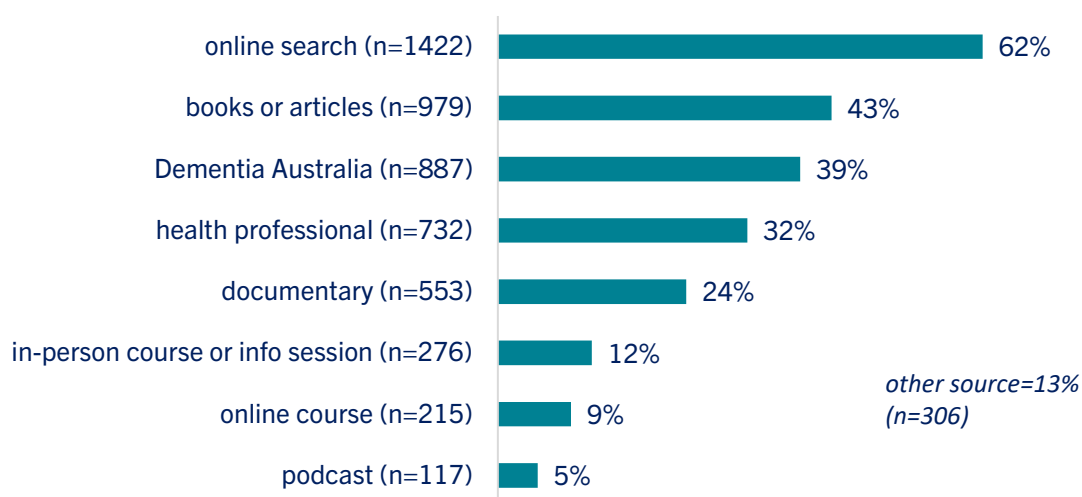


Figure 5. Sources of information about dementia and memory changes (n=2287).

There were age differences in choice of information source. Significantly higher proportions of younger respondents sought out dementia information by going online (either via a web search or online course), or through Dementia Australia, and higher proportions of older age groups consulted books or articles.

Among those who nominated 'other source', many mentioned the routes via which they had been exposed to dementia information, as opposed to actively seeking it out which was the intended focus of the question. For example, many respondents had encountered dementia information through training or workplace experiences. A summary of these 'other' responses is provided as [Appendix 3](#).

Is dementia planning associated with seeking dementia-related information?

Over a third of respondents (39%) said they had not thought about or planned for a dementia diagnosis, and they did not seek out dementia-related information (Table 1).

Approximately 27% said they had thought about or planned for a dementia diagnosis AND sought out information (Table 1).

A smaller group (20%) had sought dementia-related information but had not thought about or planned for a diagnosis. Conversely, 13% had thought about or planned for a diagnosis but did not seek out dementia-related information.

Table 1. Planning for a dementia diagnosis according to seeking dementia-related information

		Thought about or planned for dementia		Total
		NO	YES	
Sought dementia-related information	NO	1840 (39%)	608 (13%)	2,448
	YES	911 (20%)	1285 (27%)	2,196
Total		2751	1893	4,644

We tested the effects of age group, binary gender, health status, formal education level, having a partner, or dementia exposure on planning for or thinking about dementia and seeking dementia-related information.

- Thinking about or planning for dementia AND seeking information (i.e. doing both) was less likely for men than women. But it was more likely for older age groups, people with poorer health, people with more formal education, people with a partner, and those who experienced dementia through close relationships (Appendix 4, Table S4).
- Thinking about or planning for dementia but NOT seeking information was also less likely for men. It was more likely for those with a higher level of formal education and for people who have experienced dementia through close relationships (Appendix 4, Table S5).
- Seeking information but NOT thinking about or planning for dementia was less likely for older age groups and those with more formal education (Appendix 4, Table S6).

Levels of worry about dementia

One of our questions asked respondents if they worry about getting dementia. Most respondents (63%) said they worried to some extent, although only 8% worried a lot. Figure 6 (next page) shows NSSS respondents' levels of dementia worry.

Dementia worry differed according to age group and gender (Figure 7, next page). Older groups worried less. In the oldest age group, a much higher proportion said they did not think much about getting dementia. Women worried more than men.

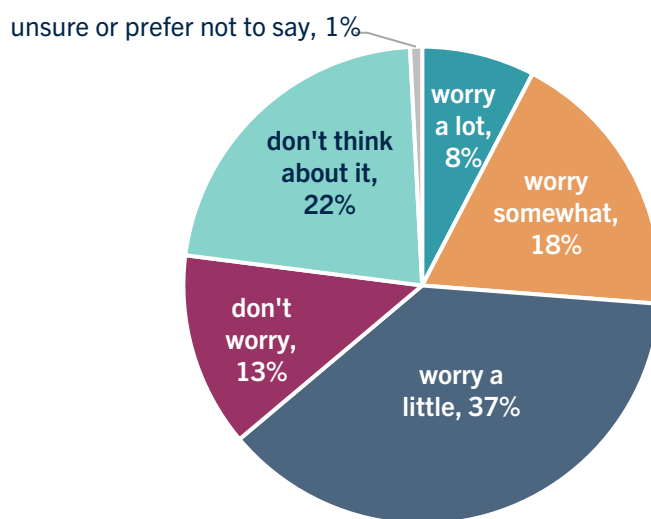


Figure 6. Levels of worry about getting dementia (n=4824).

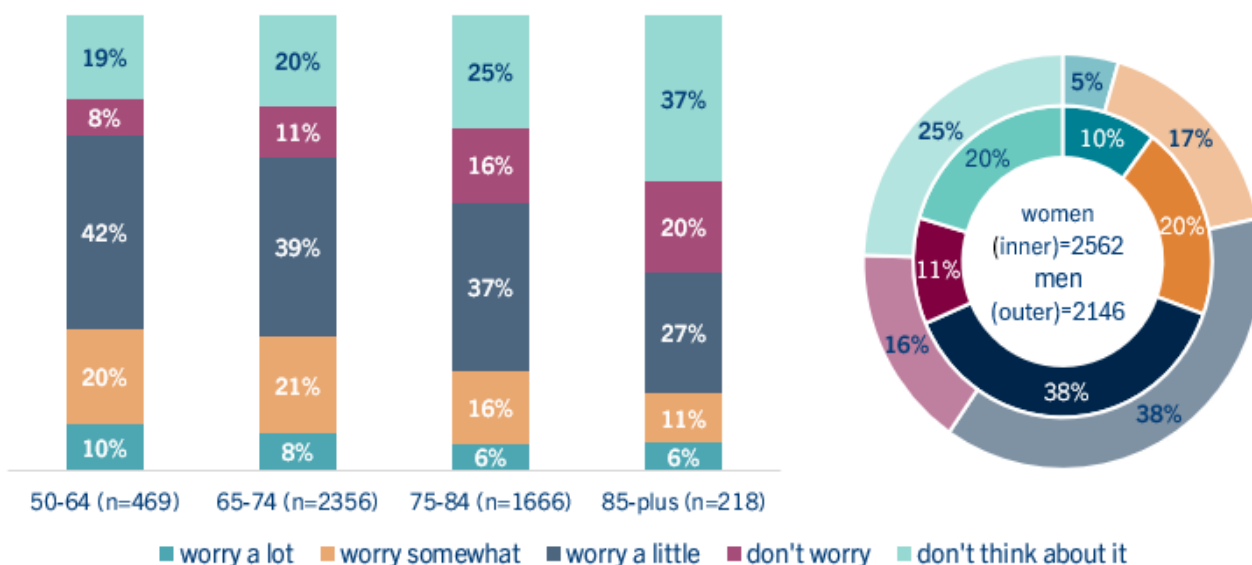


Figure 7. Age and binary gender differences in dementia worry levels.

Other factors associated with worrying about dementia were poorer health and experiencing dementia firsthand through close relationships with family and friends.

Those who worried were three times more likely to plan for the possibility of dementia and 50% more likely than non-worriers to seek dementia-related information (Appendix 4, Table S7).

Reasons for worrying or not worrying about dementia

We followed the question about worry level with an invitation to respondents to tell us more about their answer in the form of a comment, and 1183 people did so. Thematic analysis of the comments identified eight different ways of thinking about dementia worries. Each of these eight themes included multiple subthemes.



Theme 1: Risk factor presence or absence

Comments in this first theme referenced the presence, absence, or mitigation of potential dementia risk factors in the respondent's life, as rationales for their level of worry. This was by far the dominant theme with almost half of all commenters (47%) articulating views that met these criteria.

Numerous commenters wrote about potential risk factors for dementia in their lives.

- A family history of dementia featured in >20% of comments as a cause for concern with some commenters highlighting its presence across multiple generations.

"Family have been diagnosed with dementia, both parents and cousin on mothers side"

"I have a family history of dementia - grandfather and all his siblings (deceased), mother (deceased) and sister (living)."

"It is rife in our family & I believe hereditary plays a big part."

"My mother had dementia. My memory is getting bad. I don't remember things I used to remember so I am a bit worried."

"My grandfather and mother both had dementia, when I find myself forgetting things whether it be names or where I have left something, whether I took my regular medication I do feel concerned"

- Noticing recent memory or cognition problems (>15% of comments) was another risk factor motivating respondents to elaborate on their level of dementia worry.

"Ageing brain means things are not as easy to do as they once were. It is very frustrating when you can't rely on your memory and if you get confused it can be very confronting to lose your independence."

"I get unreasonably agitated when I forget something that I should remember, or if I can't do something that I feel I should be able to do"

"I am already starting to forget words and names in my general conversations with other people"

- Some people were aware of associations between particular illnesses or life experiences and the risk of developing dementia.

"Being diagnosed with early stage Parkinsons Disease is almost a guarantee that dementia will 'visit' me eventually"

"Health problems and medication are issues, as is repeated concussions in younger days"

- For a few people, recent tests indicated they may have dementia.

“I have been tested a while ago and found to be borderline.”

In contrast to these comments on risk factors, other commenters wrote about mitigating factors that kept their worry level low.

- Mitigating factors included family history and indicators of positive brain health.

“Dementia is in the genes of persons. My grandparents and my parents don't have it.”

“My family has no history of dementia and has a history of living to an advanced age”

“Having had a brain scan, and seen a neurologist who commented very confidently on the condition of my brain”

“I still have a very sharp memory and have had no problems with my memory.”

- Some offered alternative explanations for any cognition problems they were experiencing, such as other illnesses or conditions, or simply ‘ageing’.

“I occasionally forget a word, it's probably because I have so much going on in my mind that I have to do!!”

“I have had 3 brain tumours and confuse [ensuing] memory loss with dementia”

“I expect that my cognitive processes will deteriorate as I age. I am comfortable with that and I would like my family to also be comfortable with it.”

- Finally, current medical conditions or the possibility of early death from other causes worried some people more than getting dementia.

“I have recently been diagnosed with an incurable blood cancer. Dementia is not something I'm worried about. I don't have it now and don't have time to get it!”

“My father died at 70 from a massive heart attack, so I am more worried about my heart than my brain.”



Theme 2: Prevention and monitoring activities

Comments in this theme linked level of worry to personal activities people engage in to prevent dementia or monitor for symptoms. This was the second-most prevalent theme, appearing in over a fifth of comments (22%).

One dominant subtheme within the comment set was commenters' participation in activities that are thought to stave off dementia or lessen its impact (>15% of comments). Activities mentioned included:

- doing puzzles, learning languages or musical instruments, or seeking other forms of intellectual stimulation;
- staying abreast of current affairs, or conversely reducing stress related to current affairs and staying away from misinformation;

- staying fit and participating in physical exercise;
- having an active social life or community engagement; and
- following specific diets or medication regimes.

“Keeping busy, learning new things, like a new language or play some games, like jig saw puzzles word games etc.”

“I try to exercise my mind through Wordle, crosswords, and 9 letter puzzles. I also try to remain very active and maintain good fitness levels. Along with a pretty good diet and social engagement I think I have reduced my risks.”

“I try to eat an anti inflammatory diet, do exercise walking yoga. Read keep social. Work 4 days a week. Plus rest. Interact with grandchild & family”

“My lifestyle is focussed on not contracting dementia. Music, reading, walking, removal of negative influences, laughing all play a part. As does the avoidance of social media, influencers and most inaccurate news.”

“My mother had a preventable form of dementia so I’m taking medical interventions to prevent it. My mother refused these medical interventions.”

In addition, some commenters mentioned regular testing or tracking of their mental capacity, whether by:

- staying actively informed about dementia in general;
- participating in dementia research projects;
- using apps or family and friends to monitor their cognitive capacity; or
- getting tested by professionals.

“Did an online course with Open University in Tasmania. Very helpful.”

“I make a point about reading about dementia and what you can do to assist yourself to keep as well as you possibly can including medical appointments on a regular basis. A person obviously goes through a period of transition, and I would hope my friends (I have no family) that they notice a difference in me that should be medically investigated.”

“I have applied for a Dementia research study - but fortunately didn’t qualify I use the “Brain Track” app”

“My four siblings all have dementia and because of that I have seen a neurologist for tests. I have had a PET scan and a MRI scan and they all came back clear of any problems.”

On the other hand, a few commenters explained that they were unable to comply with the recommendations for prevention, they faced barriers to monitoring their cognitive status, or they would rather not know if they have developed dementia.

“I am just a little unsure with the cost of living not allowing us to socialise”

“I worry that there is not enough testing for [it] as you get older, that costs an arm & a leg to get help with”

“Living alone means no one is able to assess any changes that might occur. My family members probably wouldn’t notice enough to mention it.”

“If a blood test became available, I’m not sure if I would take it”



Theme 3: Body and mind impacts of dementia

Comments in the third theme related the respondent's level of worry to the potential biological and psychological impacts dementia may have on them if diagnosed (12% of comments).

Many commenters (>10%) articulated fears and concerns about experiencing dementia symptoms, including:

- losing their sense of self;
- losing their dignity, control, and independence;
- losing the ability to take care of themselves;
- losing their memories, intellectual capacity, or ability to make decisions;
- becoming unable to communicate with or recognise loved ones.

"I am concerned about being unable to be self sufficient and would not wish to continue being kept alive in a 'vegetable' state."

"When I am past being able to make some reasonable contribution to society, then I wish to be 'gone'."

"After watching someone I care about lose their memories is very disturbing, I don't want to lose my memories, my life would have been meaningless without my memories."

"losing control over my intellect the one thing that unambiguously defines who I am"

"I think it is one of the worst things that could happen if you could not recognize your own children or partner"

"I would hate to think or experience that I am not in control of my faculties."

"It puts one in a [dependent] category which I would like to avoid."

"I worry about strangers/authorities taking control of my life and my concerns not being considered important."

"Well let me tell you... the major concern is with me developing dementia just prior to enjoying a fulfilling and long retirement."

In contrast, a few found comfort in the beliefs that:

- they probably would not know it if they had dementia, so would suffer less than the people around them;
- some people who have dementia experience relatively mild symptoms.

"The only solace with dementia or about dementia is that you probably don't know about it!"

"I may know at the start of dementia but eventually I will live in my own little dream world. In aged care they are often the happiest people there once they have crossed right over."

"My parents conditions very mild and very late onset"

"my mother had some 'vascular dementia' but nevertheless lived well with extra caring services and always knew her family and friends"



Theme 4: Relationships with others

The fourth theme includes comments about the potential impacts a person's dementia diagnosis would have on their family and friends, or other ways that respondents linked relationships to worry about dementia (17% of comments).

Two subthemes dominated comments about family and friends:

- Some commenters were concerned they had no family or friends at hand to look after them should they develop dementia.

“As I am on my own I'm not sure how I will be cared for and who will be responsible for my health and financial matters.”

“I have no children and my partner is older than me and English is his second language. I worry that if I get dementia, whether or not anything happens to him, I/we will not be able to get the support I/we need.”

“i am single and don't really connect with my siblings, so i would be alone if i developed it. wouldn't wish the job of being my carer even upon my worst enemy!”

- For others, a primary concern was that they would become a burden to their loved ones if they developed dementia.

“I do not wish to be a burden on anyone, or to take up resources when I am past appreciating life.”

“I do not want my family and friends to have to deal with me if I am not able to fully care for myself.”

Less common subthemes included:

- worry about becoming incapable of caring for a family member who is dependent on them;
- worrying more that another family member (not the commenter themselves) may develop dementia;
- some commenters simply contextualised their worry level by sharing their (usually distressing) experiences of how dementia impacts family, friends, and other people who are interacting with a diagnosed person;
- a very small number of people expressed their trust that their loved ones would look out for their interests should they develop dementia.

“Being an immigrant with no other family the country I do sometimes worry who will look after me. My partner has Parkinson's and I do worry if I will be able to look after him if I get dementia”

“I have responsibilities to my minor children so do not want anything untoward happening to me until they can look after themselves”

“I am a little concerned for myself but more concerned for my family members being diagnosed and how I would manage to care for them”

“I have just had a life long friend pass away after living 10 years with dementia. It was heartbreaking for his wife & him.”

“If it does happen will be looked after.”



Theme 5: Services and research

Comments in the fifth theme linked dementia worries to the quality of institutional supports such as services and research (12% of comments).

Some comments included in this theme expressed uncertainties or asked questions about the nature of dementia: its causes, types, diagnosis, treatment, and research directions.

“Clearly we need more research, more funding, more support services and more understanding of this awful disease.”

“What I don’t know is whether anything can be done to completely avoid the possibility of dementia, as opposed to just reducing the probability.”

“If the food that we eat, the water that we drink. the air that we [breathe] were more natural and less polluted, and the medicines less synthetic and too freely prescribed in general; just as a band aid instead of detecting the root of the problem and correcting the root of cause. we will have perpetual health problems.”

“We need answers or medication to help or assist dementia sooner or all society will be wandering around”

Others focused on what they perceived to be the poor state of support services.

- It was common for commenters to express their strong desire to stay out of residential aged care.
- Some commenters expressed fears about being neglected, abused, mocked, or otherwise mistreated by carers or society at large if they should develop dementia.
- Some commented on the poor quality (or expense) of other existing government and community supports or information availability.

“The services for dementia in aged care homes are horrific. The neglect - pressure sores etc - horrific. In home care is becoming intrusive and over-regulated. There is a real fear of unwelcome unnecessary guardianship orders eg Four Corners programs.”

“30 years working in Aged Care, 25 years as a Carer, 5 years RN. I will never go into Aged Care. They are hell on earth”

“After having a parent develop alzheimers I saw in detail how older people are treated in care and do not want to have to go into care.”

“I worry that i will be taken advantage of and have all my rights taken away”

“Having been involved with a Dementia Advisory Service as a volunteer for 10 years, I’m conscious of the lack of services available to carers of dementia patients.”

In contrast, a few people noted recent improvements in dementia-related services, care, or research.

“Having parents that had dementia am worried, but these days there is better cure on the cards than in my parents days”

“I volunteer in aged care [and] see the assistance & activities available to assist these residents.”



Theme 6: Fear and horror

The sixth theme comprises comments in which people expressed strong negative emotional responses to the idea of dementia (14% of comments).

Numerous commenters described the prospect of developing dementia in strongly negative emotional terms, for example feeling terror, horror, or the sense that dementia would be worse than any other illness or way to die. A few commenters stated dementia is too awful to think about.

“I use to work with dementia patients in an aged care facility and it scares the hell out of me becoming demented”

“it's a fate worse than death, it's natural to worry about it...”

“Terrifying disease.”

“The diagnosis of dementia is a sad, cruel disease. I wouldn't wish it on anyone.”

“It scares me and therefore I prefer not to think about it!”

Many commenters went so far as to indicate they would rather die than develop dementia. A large proportion of these people expressed the view that voluntary assisted dying (VAD) provisions should be made available to people with a dementia diagnosis irrespective of whether it was terminal or not. A few mentioned preparing documents such as a living will to ensure their wishes will be followed if they should develop dementia.

“I want VAD to be available if I specify in my AHD that I want it at a certain stage in my decline.”

“It worries me that assisted dying is not available to people with dementia. The thought of leaving it too late is horrible. I do not wish to be a burden on anyone, or to take up resources when I am past appreciating life. But neither do I want to make it easy for someone to decide when I had had enough. I have been involved with several deaths, and I can see that some people are very confident that they can judge when someone else 'just wants to let go'. I do not want them near me! Sorry this is off dementia but it is part of it.”

“I have very strong opinions on voluntary euthanasia being made available through an Advanced Care Directive (or similar) for people who may develop this condition. I have Nursed Dementia patients, and watched my beautiful intelligent sister die a terrible, haunting, traumatic, slow death. It is inhumane for this to happen.”

Theme 7: Intuitions and superstitions



The seventh theme comprises comments in which people shared their intuitive expectations about the likelihood that they would develop dementia. This was the least dominant theme, corresponding to just 4% of comments.

In some cases, the intuitions commenters shared were related to factors discussed in the previous themes, such as the presence or absence of risk factors.

- A small number of commenters said they felt it was inevitable that they would develop dementia.

“Feels inevitable and I am afraid of it.”

“I see my father’s decline and think that is me in 20 years.”

- Around the same number were confident they would not get it. Some commenters felt they were too old to get it, because they would have developed it already if it was going to happen.

“I am doing ok for my age and I believe that I can go to the grave without getting dementia. having said that one never knows what is around the corner.”

“I think that at 86 I can be fairly sure that dementia has passed me by.”

In other cases, the intuitions commenters shared seemed to be their own intrinsic rationale for the level of worry.

- A few people expressed their belief or hope that maintaining a positive outlook may help prevent dementia.

“have a very active life and are always positive in my outlook.”

“I fully intend to be the little old lady who smacks stupid people with her walking stick.”

- Conversely, a few articulated the view that worrying about dementia would make it happen.

“If I was to worry about getting Dementia I would be more likely to attract it”



Theme 8: The pointlessness of worry

The final theme includes respondents’ commentaries on worrying itself (15% of comments). Sentiments include whether it is even worth the time and effort to worry, and some relaxed attitudes to low-level worry.

Around 10% of commenters asserted or implied that worrying was not worthwhile, saying things such as:

- they accept that what will be will be;
- they can’t really control whether or not they will develop dementia;
- it may not happen at all;
- if it does, they’ll deal with it later, at the time;
- for now, they wish to get on with enjoying life.

“What will be, will be. If it happens I will just hope that I will be well cared for. There is little I can do about it except keep using my brain every day.”

“There is no point in worrying about something that you have no control over. If you have dementia then you have it.”

“It is not something I have control over so I focus on doing things that I can continue to do constructively.”

“Why deal with something that may never happen and even if it does then so be it - I will deal with it then.”

“worry is paying interest on trouble not yet due :-)”

“I work hard, I play hard, I live life to the absolute fullest every day. There is no time in my life to think about dementia or any other illness, i am just too busy being and keeping busy.”

Other commenters acknowledged that dementia is relatively common and often encountered in public and media discourse. As such, they felt dementia was a reasonable general concern while ageing but was not yet a cause of major worry for them personally.

“There is a lot of media commentary about this, so it tends to be a matter for concern.”

“I think about this but don’t constantly dwell on it.”

“Just a normal respect for something I or my husband may yet experience.”

Associating theme prevalence with worry levels

By segregating the comments according to commenters’ levels of worry about dementia, it is possible to identify some trends among the themes and subthemes described above.

The distribution pattern of several themes suggests a strong binary difference between, on the one hand, those who worry a lot, somewhat, or a little (“worriers”), and on the other hand, those who don’t worry at all or who do not think about dementia much (“non-worriers”).

- The ‘risk factor presence or absence’ theme was present in 48%-56% of worrier comments. This contrasts to its presence in 27%-28% of non-worrier comments.
- 18%-26% of worrier comments mentioned relevant relationships with other people, compared to 5%-6% of non-worriers.
- Unsurprisingly, the ‘pointlessness of worry’ theme reached much higher percentages among non-worrier comments (37%-42%), compared to between 1% and 13% of worrier comments.
- Prevention and monitoring activities were similarly present in 33% of non-worrier comments. This was considerably higher than the 22% presence in ‘worry a little comments’, 17% in ‘worry somewhat’ comments, and just 5% of ‘worry a lot’ comments.

In addition, specific subthemes that **increased** in prevalence among higher levels of worry included:

- Having a family history of dementia
- Experiencing potential symptoms of dementia
- Wishing to avoid the body and mind impacts of dementia
- Lacking family or friends to help manage a dementia scenario
- Preferring death over dementia, and desiring access to VAD
- Fearing being forced into residential aged care.

Worries about being a burden on family and friends, and the subtheme of strongly expressed fear and horror of dementia, were also most prevalent among commenters who indicated they worried about dementia 'a lot'.

Specific subthemes that **declined** in prevalence among higher levels of worry included:

- Feeling that worrying about dementia is not worthwhile
- Engaging in prevention activities
- Having no family history (or non-genetic history) of dementia
- Monitoring and testing for signs of dementia
- Believing that something other than dementia would likely cause one's death.

DISCUSSION

The influence of dementia experience on behaviours

In the NSSS-12, 71% of respondents said they had experience of someone close to them living with dementia. This figure is slightly higher than in the National Dementia Awareness Survey (DAS) conducted by the AIHW where 68% of Australians said they had a family member or friend living with dementia (AIHW, 2024a).

NSSS-12 respondents were aged 50-plus and dementia experience included past as well as present experience of dementia. It also included having a diagnosis oneself. These differences likely accounted for higher proportion of respondents being exposed to dementia in the NSSS-12.

Experience of dementia strongly influenced whether people sought out information about dementia and memory changes, and whether people were likely to plan for a potential diagnosis either for themselves or a family member. Previous research shows that one reason caregivers of a person with dementia may seek out information is to support their care-giving role (Mason et al., 2022). That is consistent with the connections we found between experience and information seeking or planning.

In addition, if dementia exposure occurs through a family member, a perceived increased genetic risk of it could also motivate dementia information seeking and future planning. Numerous text-based comments by NSSS-12 respondents highlighted concern about having a close relative with dementia, with some linking fears about their own memory slip-ups to this perception of a family predisposition.

Such patterns of connection may grow stronger in the future. Currently, two out of three people with dementia live in the community (Dementia Australia, 2024a). The expected increase in the prevalence of dementia, together with the move toward earlier diagnosis, means Australians' experience of dementia through relationships and everyday interactions is likely to become more common.

The NSSS-12 data suggest that increased exposure to dementia may have the flow-on effect of greater community engagement with dementia information and planning. It is critical that there are reliable and easily accessible resources available to support not only the increasing numbers of people with dementia and their carers, but the dementia literacy needs of the wider community.

Amongst NSSS-12 respondents, most people searched online for information about dementia or cognitive concerns. It is therefore paramount that we continue to invest in producing quality online materials to suit diverse audiences.

There were differences across age groups, with higher proportions of younger respondents using online resources and older people using books and articles. Nonetheless, even in the oldest age group of 85-plus, nearly 50% selected the online search option.

However, this may not be typical for older people generally. NSSS respondents are a digitally literate cohort as demonstrated by doing online surveys and by previous studies (Maccora et al., 2019; Orthia et al., 2022), so resources must still be made available to older people using a range of offline media too.

Cognitive concerns

Although dementia experience was associated with dementia information seeking and planning, it was not statistically relevant to the likelihood of consulting a health professional about one's own cognitive concerns.

The framing of the question about consulting health professionals may account for the lack of association. It was phrased in terms of 'memory concerns' or 'thinking skills' generally rather than dementia specifically. Alternatively, it may simply be that because such a large proportion of people said they would seek help (83%), dementia experience was rendered statistically irrelevant.

In the Dementia Awareness Survey, 94% of respondents said they would seek professional help for dementia symptoms – a higher proportion than in the NSSS-12. Apart from the difference in question wording (the DAS specified dementia symptoms rather than memory or thinking issues), the DAS also included all adult age groups. Potentially, younger adults would view dementia symptoms more seriously than some older adults who may dismiss memory problems as an inevitable part of getting older (Parker et al., 2020). Some of our commenters expressed exactly this view as a reason they were not worried about dementia.

The only demographic factors associated with help-seeking in the NSSS-12 were gender (men were less likely to seek help) and being in better health. The gender finding is supported in the research literature. Men are recognised as being less likely to engage with health services and typically, when they do, the condition is advanced (AMA, 2018).

However, the health association contrasts with a large national health survey from the United States. In the US study, people with poor health were more likely to seek help for their thinking and

memory concerns. The authors explained the association by highlighting that cognitive issues frequently accompany chronic diseases including coronary heart disease, stroke, diabetes, and cancer (CDC, 2020). Since the NSSS-12 cohort tends to be rather health-conscious, with two-thirds self-rating their health as good or excellent, such associations may simply be less relevant to them.

Dementia planning

Most people surveyed had not thought about or planned for dementia in the future, either for themselves or for a family member, except if they had personal experience of someone close living with dementia symptoms.

Currently, dementia planning resources tend to focus on the decisions and actions a person should consider after receiving a dementia diagnosis (Dementia Australia, 2024b). However, another way of thinking about or planning for dementia in the future is to take lifestyle actions to minimise the risk of developing symptoms.

The recent DAS found that generally, the Australian community has a poor understanding of actions that can reduce dementia risk (AIHW, 2024a). We did not ask specifically about dementia risk reduction knowledge in the NSSS-12, but respondents demonstrated the priority they gave to dementia prevention and monitoring activities in a subset of free text responses. Although this level of risk reduction awareness is not necessarily generalisable, it does speak to a growing awareness amongst 50-plus people that lifestyle actions can impact on cognitive health and reduce the likelihood of a dementia diagnosis in the future.

Dementia worry

In the NSSS-12, 63% of respondents were worried at some level about developing dementia. Dementia worry is not surprising in our society given dementia features frequently in media stories (for example, celebrities living or dying with dementia), documentaries or films, and online science journalism that delivers a confusing array of dementia-related facts and figures (Kessler, 2021). In an Australian context, the horror stories and images of abuse that emerged during the Royal Commission into Aged Care Quality and Safety are also likely to have fuelled dementia worry in the community. These were specifically mentioned by some commenters.

Dementia is undoubtedly a serious public health issue and global action is required urgently to build dementia literacy and capacity into societies and cultures worldwide (Lancet Neurology, 2023). However, communication programs and campaigns need to be very clear about the nature of dementia and dementia risk so older people and their families are supported with accurate and balanced information.

Dementia worry: misconceptions

Free text comments by survey respondents highlighted the fact that worriers compared to non-worriers focused more on the presence of dementia risk factors in their lives.

Other studies have similarly shown that dementia worry is often due to the perception of being at high risk because family members have had dementia (Martin et al., 2020). However, the main risk factor for dementia is older age rather than genetics. The AIHW estimates that at ages 70-74,

approximately 4% of people have dementia, increasing to 12% at 80-84 years and 42% in those aged 90-plus (AIHW, 2024b).

With the exception of very rare cases of some early onset dementias where symptoms appear in mid-life, there is no single gene that is responsible for developing Alzheimer's disease or other types of dementia. Rather, multiple gene combinations interact with lifestyle factors to determine an individual's risk profile in addition to their age (Alzheimer's Research UK, 2022; Dementia Australia, 2024a).

The NSSS-12 results thus indicate the widespread presence of some misconceptions about dementia risk. Future information campaigns might take steps to address this. Support for current campaigns that address it must be continued.

Dementia worry: what can be done?

Dementia worry can be harmful to older people's mental health. It can lead to anxiety and depression, and can exacerbate cognitive concerns and even cognitive decline, all of which impact on quality of life (Kinzer & Suhr, 2016). Some NSSS-12 commenters articulated this issue, but they were few in number.

Dementia worry due to perceptions about genetic predisposition may be addressed by focusing on the increasing evidence that a healthy lifestyle mitigates dementia risk (WHO, 2019). Certainly, amongst NSSS-12 respondents, those who wrote about the lifestyle activities they did to ward off dementia had lower levels of dementia worry.

There is still a lack of awareness in the general community about specific actions people can take to support their brain health (AIHW, 2024a) which makes

this an important priority for public health communication and promotion. However, knowledge of lifestyle contributions to dementia prevention will only act to reduce dementia worry and importantly, dementia incidence, if there is greater equity of access to resources enabling people to live a cognitively healthy lifestyle (Wilson & Anstey, 2024). This is an emerging area of focus for dementia prevention at a societal rather than individual level (Lock et al., 2023).

In our findings, as with others (Cutler, 2015; Kinzer & Suhr, 2016) dementia worry is also associated with experience of dementia through personal relationships. These relationships may expose the stigma, discrimination, and poor care that occurs for many people living with dementia. Comments in the NSSS-12 suggest some components of dementia worry are due to the way people with dementia are treated and perceived by society. Respondents wrote about dementia leading to loss of

important relationships, being neglected in age care, and experiencing poor end of life care or an undignified death.

Part of the mission of Dementia Australia and other dementia advocacy organisations is to change perceptions about living with dementia, reduce dementia stigma, and work towards creating dementia friendly communities so people with dementia and their carers experience better quality of life (Dementia Australia, 2022).

These initiatives aim to ensure that the inevitable increase in community exposure to dementia will be associated with less worry about developing dementia, improved dementia understanding, and more positive actions to reduce dementia risk.

The results of this study show just how important this approach is to the future wellbeing of older Australians.

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APPENDICES

Appendix 1: Survey questions analysed in this report

The NSSS-12 contained a module of questions titled 'Dementia', which provided core data for this report.

Question 1

Do you have experience either currently, or in the past, of someone close to you living with dementia?

- Yes, I myself have a dementia diagnosis
- Yes, my parent(s) has/have or had dementia
- Yes, my partner has or had dementia
- Yes, a family member (other than a partner or parent) has or had dementia
- Yes, a friend has or had dementia
- No, I have no experience of someone living with dementia
- Unsure
- Prefer not to say

[Respondents who indicated they had a dementia diagnosis skipped Questions 2-4.]

Question 2

Do you worry about getting dementia?

- I worry a lot about getting dementia
- I worry somewhat about getting dementia
- I worry a little about getting dementia
- I don't worry at all about getting dementia
- I don't think about it much either way
- Unsure
- Prefer not to say

Please tell us more about your answer if you would like to.
[free text comment box]

Question 3

If you had memory concerns or were worried about your thinking skills generally, how likely is it that you would consult a health professional about it?

- Very likely
- Somewhat likely
- Somewhat unlikely
- Very unlikely
- Unsure
- Prefer not to say

Question 4

Have you thought about or planned for a future that could include a dementia diagnosis, either for yourself or someone you are close to?

- Yes, but I have not discussed my thoughts or plans with anyone else
- Yes, and I have discussed my thoughts and plans with at least one other person
- No, I have not thought about or planned for a dementia diagnosis either for myself or someone I am close to
- Prefer not to say

Question 5

Have you sought out general information about dementia and/or the changes in thinking and memory that may occur in later life?

- No, I haven't
- Yes, I have
- Prefer not to say

[Respondents who answered 'no' or 'prefer not to say' skipped Question 6.]

Question 6

Where did you go for information on dementia or changes in thinking and memory?
Please select all that apply.

- Dementia Australia
- Health professional
- Online search
- Online course
- In-person course or information session
- Podcast
- Documentary (TV, film)
- Books or articles
- Other (please specify)

Appendix 2: Survey sample demographics

This table presents sociodemographic information about the 4882 NSSS-12 participants who responded to at least one question analysed in this report.

Table S1 Demographic traits of dementia question respondents

Respondent characteristics (n=4882)	Number	Percent of total n*
Age group		
50-64	488	10.0%
65-74	2426	49.7%
75-84	1715	35.1%
85+ (oldest respondent 99 years)	227	4.7%
Gender		
Women	2642	54.1%
Men	2210	45.3%
Non-binary or other	7	0.1%
Education level		
Schooling to year 12	1100	22.5%
Certificate or diploma	1549	31.7%
Bachelor's degree or higher	2062	42.2%
Self-rated health		
Excellent	599	12.3%
Good	2697	55.2%
Fair	1238	25.4%
Poor or very poor	318	6.5%
Savings (including superannuation)		
<\$10k	411	8.4%
\$10k-\$50k	446	9.1%
\$50k-\$100k	355	7.3%
\$100k-\$200k	391	8.0%
\$200k-\$350k	404	8.3%
\$350k-\$500k	375	7.7%
\$500k-\$750k	457	9.4%
\$750k-\$1.5M	634	13.0%
> \$1.5M	468	9.6%
Partnered and living together		
Yes	2896	59.3%
No	1970	40.4%
Membership of one or more diversity groups**		
Yes	1028	21.1%

* Percentages do not add up to 100% because respondents did not have to answer all questions.

**Diversity groups included: Aboriginal, Torres Strait Islander & First Nations people; LGBTI (lesbian, gay, bi, trans, gender diverse & intersex) people; people from a CALD (culturally & linguistically diverse) background; people living in a remote or rural area; people living with disability & disabled people; veterans. The survey also asked respondents whether they lived in a regional area, and 1307 (26.8%) did so. They are not included in the diversity numbers above unless they belonged to a diversity group listed above as well.

Appendix 3: Other sources of information about dementia

When respondents were asked where they went for information about dementia (Question 6, see Appendix 1), 271 people mentioned places or sources through which they had experienced *incidental exposure* to dementia information, as opposed to sources they *actively sought* information from. In that sense they did not answer the question as it was intended. Nevertheless, it is useful to document other sources through which people have encountered dementia information. Table S2 summarises what they reported.

Table S2 Additional sources of information about dementia (n=271)

Source	Description	Number of mentions
Work or study	Exposure through work, study, or volunteering in healthcare, aged care, research, or other relevant area	100
Friends and acquaintances	Conversations with friends, acquaintances, and family members, including some with experience caring for people with dementia or who have professional expertise in dementia	44
First-hand experience	Personal experience caring for, interacting with, or observing a family member or friend with dementia	37
Research participation	Participation in dementia-related research projects	26
Support groups	Discussions and communications within support groups, or from organisations concerned with planning for later years of life	19
Other media	News media, social media, online videos, email newsletters, blogs	17
Personal research	General information encountered, personal research into the topic, including via scientific literature	13
Other dementia organisation	Dementia organisation in Australia or New Zealand other than Dementia Australia	11
Specific expert	Specific individual dementia expert, or specific healthcare website	7
Public event	Forums, talks, seminars, or expos	5
Brain app	Brain-training app or Braintrack app	3

Appendix 4: Quantitative analyses output

Table S1. Demographic associations with thinking about or planning for dementia in the future

Planning for, or thinking about dementia	Odds ratio	Std. err.	z	p-value	95% Confidence Interval of OR	
Age group	1.04	0.05	0.82	0.415	0.95	1.13
Binary gender	0.65	0.04	-6.43	0.000	0.57	0.74
Health	1.29	0.07	4.98	0.000	1.17	1.43
Education level	1.27	0.06	5.34	0.000	1.16	1.39
Partnered	1.25	0.09	3.24	0.001	1.09	1.44
Experience of dementia	2.40	0.18	11.96	0.000	2.08	2.77
constant	0.22	0.04	-7.72	0.000	0.15	0.32

p significant at <.05

Thinking about or planning for dementia was 35% less likely for men; 29% more likely for people with poorer health; 27% more likely with higher education; 25% more likely if partnered; 2.4 times (240%) more likely for those who had experience of dementia through close relationships.

Outcome variable

Thinking about or planning for dementia:

1=Planning for or thinking about dementia

0=Not planning or thinking about dementia

Demographic variables

Age group: 1=50-64; 2=65-74; 3=75-84; 4=85-plus

Binary gender: 1=women, 2=men;

Health: 1= good or excellent health, 2=fair, 3=poor/very poor

Education level: 1=school to year 10, 2=school to year 12 and/or other certificate or diploma, 3=Bachelor's or postgraduate degree

Partnered: 0=not partnered, 1= partnered

Experience of dementia: 0=no experience of dementia, 1= experience of dementia through close relationship

Table S2. Demographic associations with likelihood of consulting a health professional about cognitive concerns

Consulting health professional about cognitive concerns	Odds ratio	Std. err.	z	p-value	95% Confidence Interval of OR	
Age group	0.98	0.06	-0.38	0.701	0.86	1.11
Binary gender	0.82	0.08	-2.13	0.033	0.68	0.98
Health	0.78	0.05	-3.64	0.000	0.68	0.89
Education level	1.08	0.07	1.2	0.232	0.95	1.22
Partnered	0.90	0.09	-1.1	0.272	0.73	1.09
Experience of dementia	1.16	0.11	1.56	0.120	0.96	1.41
constant	11.03	3.06	8.65	0.000	6.40	19.00

p significant at <.05

Consulting a health professional about cognitive concerns was 18% less likely for men than women and 22% less likely for people in poorer health.

Outcome variable

Likelihood of consulting a health professional about cognitive concerns:

1=Likely to consult health professional about cognitive problems

0=Not likely to consult health professional about cognitive problems

Demographic variables

Age group: 1=50-64; 2=65-74; 3=75-84; 4=85-plus

Binary gender: 1=women, 2=men;

Health: 1= good or excellent health, 2=fair, 3=poor/very poor

Education level: 1=school to year 10, 2=school to year 12 and/or other certificate or diploma, 3=Bachelor's or postgraduate degree

Partnered: 0=not partnered, 1= partnered

Experience of dementia: 0=no experience of dementia, 1= experience of dementia through close relationship

Table S3. Demographic associations with seeking information about dementia

Seeking information about dementia	Odds ratio	Std. err.	z	p-value	95% Confidence Interval of OR	
Age group	1.19	0.05	3.92	0.000	1.09	1.30
Binary gender	0.51	0.03	-9.81	0.000	0.45	0.59
Health	1.16	0.06	2.88	0.004	1.05	1.29
Education level	1.66	0.08	11.1	0.000	1.52	1.82
Partnered	1.11	0.08	1.53	0.127	0.97	1.28
Experience of dementia	2.86	0.21	14.44	0.000	2.48	3.29
constant	0.18	0.03	-8.76	0.000	0.12	0.26

p significant at <.05

Seeking information about dementia was 19% more likely for older age groups; 49% less likely for men; 16% more likely for those in poor health; 66% more likely with higher levels of education; 2.9 times (286%) more likely for those who had experience of dementia through close relationships.

Outcome variable

Seeking information about dementia:

1=Seeking information about dementia

0=Not seeking information about dementia

Demographic variables

Age group: 1=50-64; 2=65-74; 3=75-84; 4=85-plus

Binary gender: 1=women, 2=men;

Health: 1= good or excellent health, 2=fair, 3=poor/very poor

Education level: 1=school to year 10, 2=school to year 12 and/or other certificate or diploma, 3=Bachelor's or postgraduate degree

Partnered: 0=not partnered, 1= partnered

Experience of dementia: 0=no experience of dementia, 1= experience of dementia through close relationship

Table S4. Demographic associations with thinking about or planning for dementia AND seeking dementia information

Thinking about or planning for dementia AND seeking information about it	Odds ratio	Std. err.	z	p-value	95% Confidence Interval of OR	
Age group	1.15	0.06	2.87	0.004	1.05	1.27
Binary gender	0.56	0.04	-7.68	0.000	0.48	0.65
Health	1.27	0.07	4.17	0.000	1.13	1.41
Education level	1.53	0.08	8.25	0.000	1.38	1.69
Partnered	1.18	0.09	2.16	0.031	1.02	1.38
Experience of dementia	3.32	0.31	12.94	0.000	2.77	3.98
constant	0.06	0.01	-12.39	0.000	0.04	0.09

p significant at <.05

Thinking about or planning for dementia AND seeking information about it was 15% more likely for older age groups; 44% less likely for men; 27% more likely for those with poorer health; 53% more likely with a higher education level; 18% more likely when partnered and 3.3 (330%) times more likely for those who had experience of dementia through close relationships.

Outcome variable

Seeking information about dementia AND planning for, or thinking about it:

1=Seeking information AND planning for or thinking about dementia

0=Not seeking information AND planning for or thinking about dementia

Demographic variables

Age group: 1=50-64; 2=65-74; 3=75-84; 4=85-plus

Binary gender: 1=women, 2=men;

Health: 1= good or excellent health, 2=fair, 3=poor/very poor

Education level: 1=school to year 10, 2=school to year 12 and/or other certificate or diploma, 3=Bachelor's or postgraduate degree

Partnered: 0=not partnered, 1= partnered

Experience of dementia: 0=no experience of dementia, 1= experience of dementia through close relationship

Table S5. Demographic associations with thinking about or planning for dementia, but NOT seeking information about it

Thinking about or planning for dementia but NOT seeking information about it	Odds ratio	Std. err.	z	p-value	95% Confidence Interval of OR	
Age group	1.07	0.06	1.28	0.201	0.96	1.07
Binary gender	0.78	0.06	-2.94	0.003	0.67	0.78
Health	0.91	0.06	-1.38	0.168	0.80	0.91
Education level	1.31	0.07	4.85	0.000	1.18	1.31
Partnered	0.95	0.08	-0.56	0.573	0.81	0.95
Experience of dementia	1.31	0.12	3.07	0.002	1.10	1.31
constant	0.15	0.04	-7.94	0.000	0.09	0.15

p significant at <.05

Thinking about or planning for dementia but not seeking information about it was 22% less likely for men; 31% more likely with % with higher education level; 31% more likely for those who had experience of dementia through close relationships.

Outcome variable

Planning for or thinking dementia but NOT seeking information about it:

1=Seeking information about dementia but NOT planning for or thinking about it

0=Not seeking information about dementia but planning for or thinking about it

Demographic variables

Age group: 1=50-64; 2=65-74; 3=75-84; 4=85-plus

Binary gender: 1=women, 2=men;

Health: 1= good or excellent health, 2=fair, 3=poor/very poor

Education level: 1=school to year 10, 2=school to year 12 and/or other certificate or diploma, 3=Bachelor's or postgraduate degree

Partnered: 0=not partnered, 1= partnered

Experience of dementia: 0=no experience of dementia, 1= experience of dementia through close relationship

Table S6. Demographic associations with seeking information but NOT planning for or thinking about dementia

Seeking information but NOT thinking about or planning for dementia	Odds ratio	Std. err.	z	p-value	95% Confidence Interval of OR	
Age group	0.84	0.05	-2.66	0.008	0.74	0.96
Binary gender	1.11	0.11	1.14	0.256	0.92	1.34
Health	1.09	0.08	1.23	0.220	0.95	1.26
Education level	0.85	0.05	-2.57	0.010	0.75	0.96
Partnered	1.22	0.12	1.94	0.052	1.00	1.48
Experience of dementia	1.01	0.10	0.08	0.936	0.83	1.22
constant	0.21	0.06	-5.73	0.000	0.12	0.36

p significant at <.05

Seeking information but not thinking about or planning for dementia was 16% less likely for older age groups; 15% less likely with higher education level.

Outcome variable

Seeking information about dementia but NOT planning for or thinking about it:

1=Planning for, or thinking about dementia but NOT seeking information about it

0=Not planning for, or thinking about dementia but seeking information about it

Demographic variables

Age group: 1=50-64; 2=65-74; 3=75-84; 4=85-plus

Binary gender: 1=women, 2=men;

Health: 1= good or excellent health, 2=fair, 3=poor/very poor

Education level: 1=school to year 10, 2=school to year 12 and/or other certificate or diploma, 3=Bachelor's or postgraduate degree

Partnered: 0=not partnered, 1= partnered

Experience of dementia: 0=no experience of dementia, 1= experience of dementia through close relationship

Table S7. Factors associated with worrying about getting dementia

Dementia worry	Odds ratio	Std. err.	z	p-value	95% Confidence Interval of OR	
Age group	0.65	0.03	-8.7	0.00	0.59	0.72
Binary gender	0.79	0.06	-3.27	0.00	0.68	0.91
Health	1.32	0.08	4.61	0.00	1.17	1.48
Education level	1.06	0.05	1.26	0.21	0.97	1.17
Partnered	1.06	0.08	0.79	0.43	0.91	1.23
Experience of dementia	1.49	0.11	5.24	0.00	1.28	1.73
Planning for dementia	2.26	0.17	10.7	0.00	1.95	2.63
Seeking dementia-related information	1.45	0.11	5.01	0.00	1.25	1.68
constant	1.95	0.41	3.17	0.00	1.29	2.95

p significant at <.05

Dementia worry was 32% more likely with poorer health; 49% more likely for those with experience of dementia; 2.3 times (226%) more likely for people who plan for dementia; and 45% more likely for those seeking dementia-related information. Men were 21% less likely to worry than women.

Outcome variable

Worrying about dementia:

1=Worried about getting dementia

0=Not worried, don't think about getting dementia

Demographic variables

Age group: 1=50-64; 2=65-74; 3=75-84; 4=85-plus

Binary gender: 1=women, 2=men;

Health: 1= good or excellent health, 2=fair, 3=poor/very poor

Education level: 1=school to year 10, 2=school to year 12 and/or other certificate or diploma, 3=Bachelor's or postgraduate degree

Partnered: 0=not partnered, 1=partnered

Experience of dementia: 0=no experience of dementia, 1=experience of dementia through close relationship

Planning for dementia: 0=not planning for dementia, 1=planning for dementia

Seek dementia-related information: 0=do not seek dementia related information, 1=do seek dementia-related information

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