



“People with dementia can still be happy”

10 insights from older people about dementia

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National Seniors
AUSTRALIA

Introduction

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

Every year we survey thousands of older people on diverse topics relevant to their lifestyle and wellbeing.

This report is based on a February 2024 survey module about dementia.

Almost 1500 older people elected to share their insights on dementia with us.

“Is there anything you have learned about dementia through personal experience or other sources that you would like people to know about?”

This was the final question we asked older Australians in the dementia module of our 2024 National Seniors Social Survey.

The question was open ended, so people could write whatever they liked.

In total, 1485 people used this question to share their insights about dementia. This report shares a selection of them. **Every round-cornered text box is a quote from a different person.**

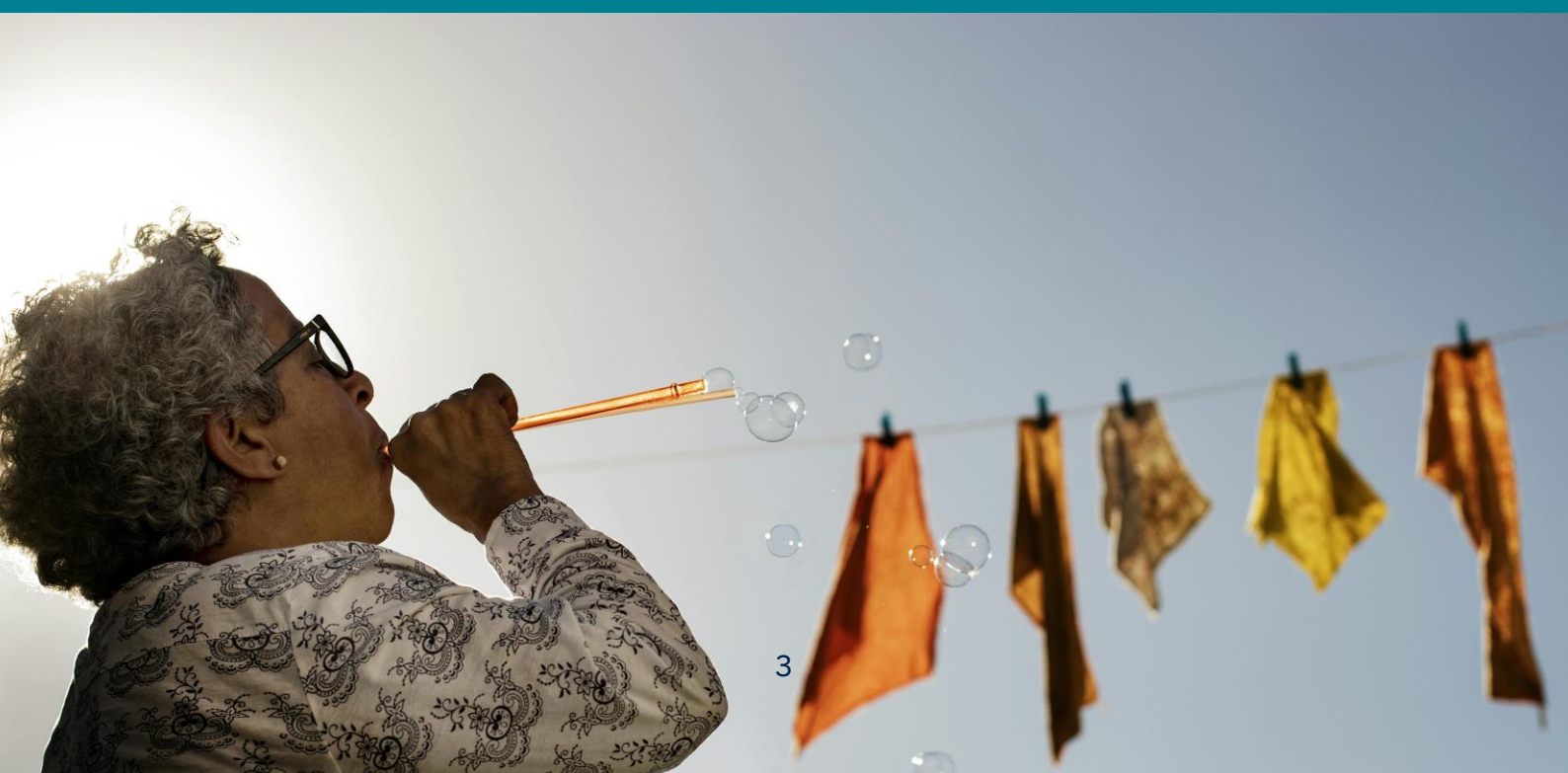
The responses took two forms: **wisdom** related to the interpersonal and cultural aspects of the dementia experience such as communication and coping, and **facts or figures** drawn from people’s interpretations of the medical aspects of dementia, such as its prevention and diagnosis.

Many of the insights we classed as ‘wisdom’ seemed to be drawn from respondents’ personal dementia journeys. These are insights worth sharing with others who are experiencing similar challenges. Some are practical, some reassuring, others deeply moving. In all cases, the growing prevalence of dementia in Australian society signals the importance of understanding people’s experiences of it.

The insights we classed as ‘facts and figures’ appeared to be people’s interpretations of information drawn from both external sources and personal experiences. Reproducing them here gives some indication of what older Australians already know or believe about dementia. We have strived to ensure these comments do not reproduce common misconceptions about dementia, while acknowledging there are still uncertainties about it and leaving room for different perspectives.

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WISDOM

**cultural and interpersonal
experiences of dementia**



1. How to act when a person has dementia

Patience, respect, love, habit.

Around 350 people (24%) offered their insights or advice on appropriate ways to interact with a person who has dementia – whether as a loved one, carer, or stranger.

The concepts of patience, understanding, love, respect, and kindness commonly appeared in these comments, with patience mentioned in a third of them.

Some people suggested that it was not fruitful to contradict or argue with a person with dementia.

Others discussed the importance of introducing familiar things into the person's environment, such as music they like, regular routines, and old hobbies.

We are still community members, mothers, fathers, aunts & uncles, cousins, friends, neighbours. We deserve to be welcomed and our wants and needs respected.

I read this once and thought it would be helpful if everyone knew and remembered this. There is still a person in there, forgetful, yes, confused often, but still in need of love, conversation and laughter.

Be respectful. All interaction with my father, as him, had gone, but he still made decisions that were typical of his long term beliefs...so maybe he was still inside. Early on put in place tools, objects, routines that suit your person's way of normal thinking to help them feel safe and in control.

“Be kind and patient.”

It is NOT contagious. You need patience when being with someone who has dementia. Let them repeat something as if it is the first time you have heard it.

Treat the person with dementia as a person. Be honest, accept them as they are, encourage them in what they can do, help them with what they are unable to do. Be kind and courteous always.

People with Dementia are still living people and can be reached by being thoughtful and seeking out their personality and memories that still exist. I had a wonderful experience with a lady by playing WW2 music and she opened up quite lucidly of her experiences as a child in UK during WW2. Her eyes lit up, as she remembered me each week I went to see her before she died - the great thing was she remembered me and I am sure she looked forward to getting a visit.

I believe that the character of the person with dementia remains unchanged, even if he or she becomes less responsive to the outside world. If the person has been a sweet and kind person, those characteristics still dominate his or her personality. When I last saw my father in the assisted living facility where he spent his last few months, my mother asked him, "Tom, do you know who this is?". He looked at me, and he said, "That's our little girl." I was 50 at the time, but always his little girl. I still am.

Laugh with the person. I have long "conversations" with a special friend with dementia about nothing but we laugh a lot and that is so good for her and for me. We still have relationship but sharing is just being there and communicating in a very different way.

[People with dementia] need to be looked after treated gently and never challenged as their inability to see the truth of the matter is skewed. You need patience and tolerance of being questioned, accused and not shown much affection anymore.

It's like you're a house keeper not a partner or wife. You have to put them first as they have an intolerance of having to wait or put second. They don't think to help and often make more work for carers. They need gentle reminders and never give them a job they cannot do or will make them frustrated. Let them do their own thing as long as they are not endangering themselves or others. Most important try to maintain the [love] you felt when first together because that is a challenge every day living with a person with dementia.



When dealing with a person with short term memory loss it is important to remember that they are not forgetting intentionally. Therefore, it is counter productive to chastise them for doing things inappropriately or when they have been told not to do them or forget to do things they have been asked to do. That just causes the person to [get] defensive or upset or angry or withdrawn. The person who needs to change is the non dementia person who needs to find ways of reacting creatively.

Eg when my late wife had front temporal dementia (and MND) which affected her judgement in terms of consequences of actions she needed to use a walking frame as she also had mobility issues because of the MND... On entering our dining room to go and sit down for a meal she would push the frame away whilst still several steps from the table thinking it would be in the way, and so be in danger of falling. The first couple of times this happened I gently scolded her and gave her back the frame until she reached the table or chair to hang onto. I realised that it was much better to light heartedly say, "Oh I see you want me to take your arm and help you to sit-down!" this always made her smile, and we would walk arm in arm to her chair.



You have to get into their world, sympathize, don't get cross or upset in front of them. They can't get into your world necessarily.

My mother had dementia. She had nine children and we all spent time with her. She used to ask the same questions over and over again, and between ourselves we had a competition, how many times can you answer the same question truthfully, patiently and differently. If she ever said "Oh I have just asked that" then the person had failed. We would compare notes. It made what could have been a bit tedious seem worthwhile - more enjoyable - in some peculiar way. She loved a joke and fortunately she had a few favourites that could be brought out on a regular basis. We loved it when she laughed and it reminded us of the lengths you go to to get smiles and laughs from a baby, even though the baby won't remember it.

I need to practise patience. It is soul destroying and frustrating living close to someone who forgets so much. Especially when she is driving the car and cannot remember where we were going or how to get there. I have a street map with me all the time.

Do not change any routines for the person with dementia to try to keep them in their own home for as long as possible and don't leave them alone for long periods of time. I have seen first hand that changing routines and leaving the person home alone leads to a quicker decline in their cognitive ability. When someone has dementia and they keep getting things wrong, don't correct them and argue with them that they are wrong. Just go with the flow - even if it means you have to keep repeating yourself.

My second husband had dementia for the last six years of his life. I found a good way to manage it, and make it better for both of us, was to stick closely to a routine, ie three days a week he went to a specialised activity centre, one day a week we walked together. On the days that we were together all day, make sure meal times happened at the same time, and I always told him what was going to happen next, eg now we are going to have breakfast, and after breakfast I told him that while I did the washing and hung it out, he could listen to the radio, etc. I am not sure how much of the radio he took in, but I mostly had it on a music station.

2. What dementia feels like

Change, variability, frustration, happiness.

Around 340 people (23%) discussed aspects of how dementia manifests for diagnosed people and/or how it progresses over time.

The symptoms commenters mentioned varied, including personality changes, forgetfulness, loss of cognitive or bodily functions, communication issues, fear, and imagined realities. Some noted symptoms could vary from one day to the next.

Respondents' ideas about the progression of dementia varied too. Many suggested it was a slow and gradual decline. Others described a sudden onset and quick death. The varied time to diagnosis, and confounding factors that could disguise the presence of dementia, were also noted.

More than 50 commenters remarked that people with dementia can lead happy lives, for example if they remain connected and supported by their loved ones and community, if they continue to be involved in enjoyable activities, or if they have forgotten other sources of pain in their life.

Erratic nature especially in the early stages...1 minute on the ball & the next, muddled & unable to make decisions & plan

“Frustration in making oneself understood”

Difficult because each person is different in the effects but probably the hardest thing is the complete change in the dementia person's personality, understanding, frustration, short-temper (spits the dummy if don't like anything or things don't go right), lack of comprehension, and irregularity in memory which makes it hard to adjust - one minute they might remember something, the next it is forgotten immediately, like right here and now.

“Fantastical thinking, delusions, masking behaviours, lack of help, personality changes”

1. the person with dementia sometimes is completely unaware.
2. the person with dementia is often confused and frightened

Each case can differ. My husband's dementia can be worse according to hydration, hot weather, insufficient sleep and he suffers varying time periods of sundowning and this is also not consistent.

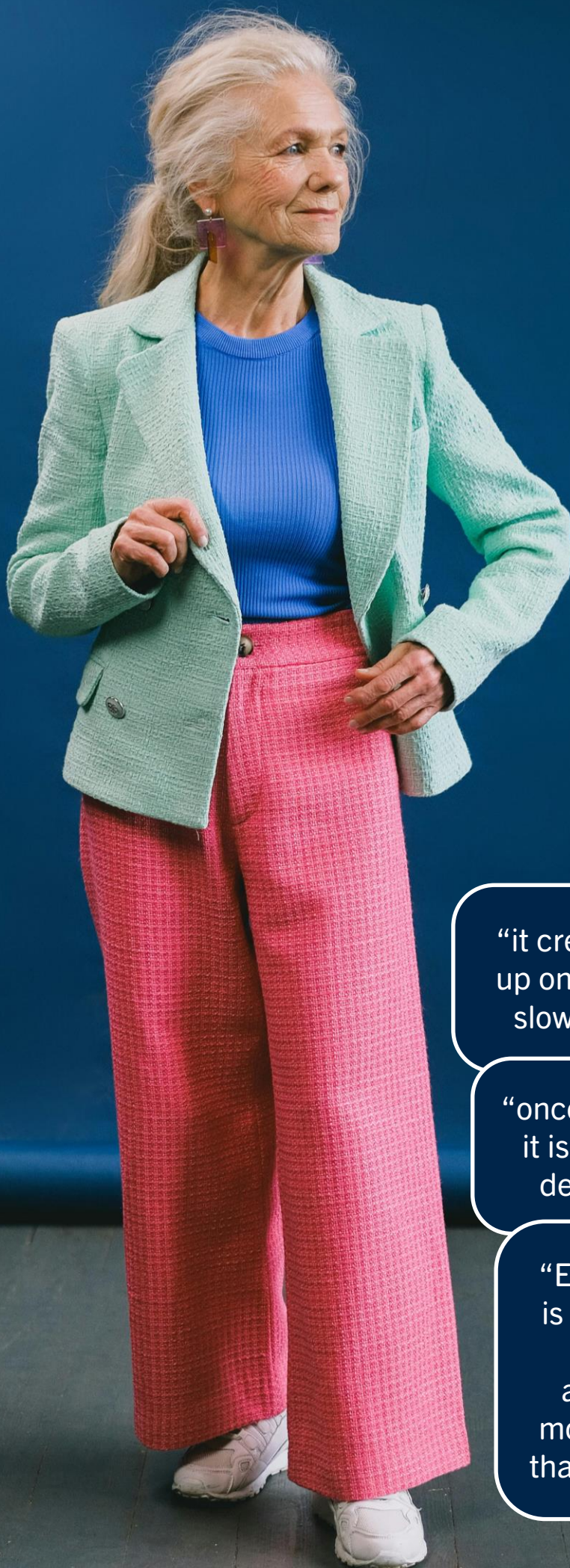
It can be very frustrating for the individuals, grasping for a word or phrase, or unable to do previous activities. Due to concerns about harm, a person I know who used to do a lot of diy is not allowed to use power tools. It's upsetting for the person.

My oldest friend has dementia and lives alone. Has carers. Was highly sociable now alone. Gets dressed up but no one comes to visit and she can no longer drive.

It's cruel. My mother-in-law had it and went from being an amazing woman to an incredibly unsocial person that took her life away.

It is very tricky to negotiate just what the person with dementia can or cannot remember on a daily basis. Some days, and even some times in the day it swings from remembering to not remembering. [It] is not consistent, some conversations can appear quite normal and then the next sentence or reply from them makes it quite evident they cannot remember.

I have learned that dementia sufferers may not appear to be aware of what is going on around them, but they are well aware, but just not reacting at the time, though they will often refer to things that have happened, weeks after they occurred.



“it creeps up on you slowly”

“once it starts it is a rapid decline”

“Every case is different. Some advance more slowly than others.”



“Some dementia patients have a happy life, just need some care and reminders”

My husband has dementia but is still functioning quite well. I love it that people treat him the same.

Fortunately my mother's dementia enhanced her joy of life and she loved every minute of her last days.

Can sometimes be a blessing in disguise as my late mother would have worried about her health problems but didn't!

a local friend is included, loved and respected by his community. The community of friends easily accommodates / shares some of his loss and his life sort of goes on.

My mum had dementia in her latter years. In some ways, due to her health issues (no mobility and blindness) when she was in her own little world it was probably a better place for her to be.

“Dementia is ok.”

I once had an interaction with a grandmother and her grandson, he came to visit grandma the look of pure joy on her face when he walked in the door was wonderful. When the grandson came out in tears very upset because she didn't remember him [it] was sad, but the visit brought joy to her even if she didn't remember [which] was precious. keep visiting and having conversations, go in pairs and talk between yourselves and the person listens and will come in with a comment, which might be way out of left field, but they are enjoying the interaction. and they especially enjoy the babies and children. They are still the same person underneath, give physical contact, hold hands, massage hands, encourage to do activities and mobilise.

My husband was diagnosed with dementia. He never complained, never wandered, remained happy, sometimes forgot people's names, he was still continent. He was so easy to care for.

3. There are impacts on others

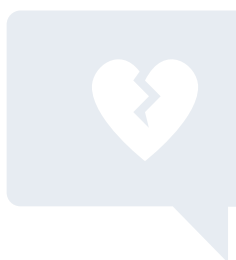
Difficulties, dilemmas, heartbreak.

Approximately 300 people (20%) mentioned impacts on the family and friends of a person with dementia.

It was relatively common for people to observe that the impact was equally bad for them as for the diagnosed person, or that it was worse for family and friends because diagnosed people are often unaware that they have dementia.

Some commenters discussed the many difficulties of caring for someone with dementia and what carers need, with contrasting views on what is okay for carers to do.

Many people also wrote about the heartbreak of watching a loved one change or even seem to disappear as their memories fade or they develop new personality traits.



All carers should have regular scheduled sessions - online or in person that support them and teach them how to deal with new behaviours/challenges as the dementia progresses. Carers need a lot more support to be able to stay mentally and physically healthy. Unless they know where to look for information they are left on their own to cope.

I have seen friends looking after their parents with the abusive type of dementia and it destroys their lives when they should be reaping the rewards for their hard work

Being a carer for someone with dementia is the hardest most exhausting job you will ever do. It's 24/7 and relentless as the person loses all their abilities to speak, do things, drive, participate in life. Their behaviours become very difficult for the carer especially if they don't sleep through the night. They need constant monitoring and it's exhausting and not enough recognition of how hard it is for the carer and there's no where near enough daycare supports that will take them so that the carer can get a break. It's like having a 2 year old with a brain injury. We need someone to advocate for carers to get more support before we all burn out. I'm considering full time care for hubby this year as I'm at burn out stage after 10 years.

“It is very hard looking after somebody with dementia. And it makes you feel as if you never do enough”

I guess my worrying “is he OK” when I’m not is not helpful, so stay positive, read positive, speak positive and don’t beat myself up cos my house and garden are not as good as I’d like. And keep encouraging him and not get impatient. **AND HAVE A FRIEND I CAN DUMP ON WHEN NEEDED.**



When the partner of someone with dementia has to place them in aged care they will always feel guilty. The [person with dementia] will always miss their partner. They will always ask to come home every time they see their partner. Such a sad experience for people who have been together for a very long time.

You need to be very careful looking after a person with advanced dementia. I ended up with PTSD and severe anxiety as it was too much for myself and my daughters to care for my late husband when he had dementia. Doctors need to provide more advice about the emotional toll this can take on you. They need to talk to you about letting go when a dementia patient is admitted to a home. Become a wife, daughter or son again not a carer anymore. Don't visit everyday, just go 1-2 times a week. It is more settling for the person with dementia to be in the routine and with the staff in the home than being confused if you are there a lot being involved in their everyday care. Become a visitor and end being the carer.

Be strong and do not let the actions of the dementia patient make a negative experience for you.... make the best of a bad situation and remember, above all, be kind... **DONOT** put them in a home, it is SO demoralising and quite wrong to do so, don't use the excuse it's too hard, get help, there are **MANY** agencies to employ to assist when the going gets tough, you'll never forgive yourself....

For the spouse not affected, please, please do **NOT** think you can continue to keep your partner at home and caring for them, as much as you love them and think you can do it. I myself was in that exact line of thought and but by the grace of God, I realised I had to place my husband into care or I wouldn't be around for the rest of the family. I was physically and mentally drained, so much so, I was told by one medical professional I wouldn't last as long as my husband. My husband was on Package 2 when he was admitted to care and had been approved for Package 3 but the money allocated for any of these packages do not start to put a dent in what is required to home care such a person. The carer's payment is a complete joke. What I have to pay the care residence for my husband now is costing me and the government far more than if they paid the spouse a respectable amount to do the same at home along with more human help. I could go on and on but unfortunately nothing ever happens. Our savings are dwindling because of the costs I need to pay to keep my husband in care. My last monthly account was for over \$5,500 and most of them are around the same.

Even though my friend has dementia it is very important to be there for her and give as much understanding and caring support as is possible in the situation. This is not easy and can affect my thoughts after spending time with her.

It is more disturbing for the family in the latter stages when the afflicted is quite oblivious to everything but the family is remembering the person who 'was'.

The close family need a great deal of support when their family member no longer can remember them. It is very heartbreaking for a parent to not know their child due to dementia and all the child wants to do is be there for the parent but cannot reach them. Often the friends and family of people with dementia cannot bear the loss of their still alive friend or family member and prefer not [to] see them as a way of protecting themselves from the hurt.

It's a frustrating journey seeing your partner of many many years begin to decline in understanding basic things, not able to operate his BBQ any more or the microwave or TV remote. Not being able to read a complete book, guessing not understanding what he has read. acting more like a young child, but at the same time wanting to help to do things. Find it very difficult to stay patient myself, not get angry or short tempered. Feelings of frustration continually, it really gets you down.

“sad for the partner or person trying to help the person with dementia. The partner loses their partner years before the partner actually dies from dementia. It's like living with a ghost.”



4. Society's solutions have problems

Training, funding, safeguards.

About 110 people (7%) discussed societal issues that need to be addressed for people with dementia to receive the support, care, and protection they need.

These issues including better training for medical and aged care staff, better funding for homecare and carer support, more appropriate and diverse residential facilities, and safeguards against exploitation and abuse.

Don't tell the person living with someone who has dementia that they should seek counselling - it is in the early morning hours that help is needed (to mop up after urinary accidents etc) a counsellor is not there then.

Our medical staff are too young untrained and have no experience in helping this ageing problem but are extremely quick to write a prescription for drugs

I have seen a marriage celebrant marry a friend who had severe dementia and who did not understand what was happening. It was the 4th marriage of his new wife who manipulated the situation and took control of his substantial wealth. Medical advice was that my friend had severe dementia and needed to be in care.

As a Retired Ambulance I dealt with patients' dementia issues and saw how badly many of them were treated and ignored. I also saw cases where they were subject to abuse of all kinds.

People with dementia should not be "warehoused" in hospitals [that] are not set up to address the complex needs that arise.

my brother is beset with early onset dementia and the biggest issue he faces is that there are no specific living facilities for him to find a stimulating environment. He currently lives in an aged care facility and they really don't have a program suited to his needs.

I saw how scared Dad could feel at times. I was horrified by the way [his residential care] home placed those close to the end in a little room all together with nothing to do. At first Dad was in the low care area and loved the sound of chatter around him.

Aged care can be very risky for a person with dementia. My father fell & fractured a hip 3 times in 4 months & of course never walked again. One day his wheelchair rolled away down a slope from where he had been placed & he fell out, hitting his head on concrete. [On] many occasions, I or another family member would feed dad & other residents whose lunch sat in front of them.



5. Plan for later life and death

Control, choice, dignity.

A theme discussed by around 80 people (5%) was future planning.

Around half of these commenters stressed the importance of planning for a future with dementia through key documents such as an advance care directive and enduring power of attorney. Alternative options were discussed by the rest.

Some commenters expressed their desire to see voluntary assisted dying laws changed so that people with a dementia diagnosis can choose how and when to end their lives before they experience cognitive decline.



“I've completed an advanced care directive before I lost my cognitive resources and I wish to be treated in a certain way as I age. Please respect my wishes.”

I think that the older community must be educated about the importance of planning for a time when they may become affected by dementia. This planning includes the preparation of advanced health directives, a will and enduring power of attorney documents, all of which provide clear direction of a person's desires for the future but must be completed whilst the person is of sound mind.

consider moving into suitable accommodation if not already in suitable accommodation while person with dementia still has capacity to be involved in decision making and adjust to changes

People in the earliest stages of dementia should be able to access voluntary assisted dying while their minds are still able to do so. It is inappropriate for them to have to wait until they have lost control and are subject to the wishes and whims of other people.

Keeping expensive providers like the public trustee or other professionals out of my affairs. Use family and friends.

By about 55 if you haven't already, before you retire you need to have your life sorted. So wills EPOA and statement of choices needs to be done. My mother in law was at the very early stages of dementia we had talked about EPOA and had made an appointment with a solicitor to draw it up. The Friday night before she had a fall, fractured her hip, had emergency surgery and after all of that her thought process was screwed after 6 months she passed away

6. Stay informed with tips and resources

Education, information, advice.

Approximately 120 commenters (8%) shared their views on the importance of education, information, and helpful resources.

Some spoke in general terms about the importance of widespread education and information campaigns about dementia with all groups of people.

Others shared specific information sources they had found to be helpful or offered other tips for people experiencing a dementia diagnosis in themselves or a loved one.



It would be good if more people of all ages (including young school age) had a basic understanding of Dementia. Too many people, including seniors, haven't done any real research, and are afraid of it, don't know how to deal with it in others.

I think it's important that older people know where to look for the information and understand the symptoms

“have it readily discussed in the home in a straightforward manner”

Society needs to communicate information about dementia including how widespread it is and will become.

Conversations about dementia are now much more common and not judgmental as they used to be and that is a good thing.

How does someone who has dementia know what to do when they are on their own - no partner, children or grandchildren?

Do the research

It is still very much misunderstood

articles in magazines, on tv would help... what to do and not to do

Yes, families need to discuss the event of aging and/or dementia before it happens. They need to encourage sensible conversations.

A parent had early onset dementia. My sister and I donated her brain to the University for medical research.

People can contribute to funds to support Dementia Australia and research into the disease and its prevention and treatment. One way is participating in or organising Walks for Dementia.

“Make use of Dementia Australia”

Dementia Australia do fantastic courses and have a decent level of documentation for use.

Dementia Australia has a wonderful library and some of the biographies are excellent in describing everyday life (e.g. A Shower for Two). It helps to know that others are going through the same situation, and that my family is not the first and only one.

The My Longevity website

Creating Moments of Joy
by Jolene Brackley

a book like 'we need to talk about aging'

this book: Travellers to unimaginable lands: dementia, carers and the hidden workings of the mind

“The Wicking Centre in Tasmania.”

the Tasmanian University MOOC on dementia.

Oma’s Applesauce videos

Online uni course "understanding dementia" was very useful for me.

I am currently attending a course of video sessions about the latest brain function research, theories and treatment approaches via U3A which is most impressive and promising for treatment of dementia. It is called "Regain Your Brain". This program is not well known but should be made widely available.

i did a course on Futurelearn, which was interesting, but more about how to treat others with dementia

“there is a lot of information available”





“Help is out there.”

“it’s survivable!”

“Learn to laugh”

FACTS & FIGURES

**interpretations of medical
aspects of dementia**

7. Know about risk and prevention

Lifestyle, genetics, chance.

Approximately 230 respondents (15%) commented on risk or prevention in some way.

Many of these comments referenced lifestyle factors that people believe could enhance dementia risk or provide some protection against dementia.

In particular, comments highlighted the roles of mental activity, physical activity, social connectedness, diet, sleep, alcohol, smoking, and hearing loss.

A few people commented on genetic aspects of dementia or the impacts of other illness, injury, or medications on dementia risk.

Others expressed cynicism about the role of lifestyle changes, or simply noted that dementia can happen to anyone.

It might be possible to prevent dementia through lifestyle modifications. I do absolutely everything I can to prevent getting dementia

Eat healthy food, moderate exercise, do something you enjoy eg reading, puzzles, cards, etc

You must keep your brain working, so reading, doing puzzles like crosswords help keep pathways going.

Maintain a healthy lifestyle including regular exercise. Maintain brain health with trying new challenges, eg learn a language do crosswords, sudoku

We need to challenge our brains to promote neuroplasticity. It has been suggested that people with more than 6 hobbies have a 38% lower chance of developing dementia

I know someone, who once had a brilliant mind and has alcoholic dementia from abuse of alcohol. Too much alcohol does terrible things

Keep active and participate in activities that require you to use your brain, especially ballroom dancing.

Wear a hearing aid!
Interact socially everyday


Exercise and weight control are two ingredients to thwarting dementia. Not a guarantee but very important.

seems to increase with the onset of other health issues (Covid as an example)

Natural remedies like coconut oil, Brahmi, Ginko Biloba, Gotu Kola. correct diet, low alcohol, no drugs. NO cholesterol lowering drugs! They bring on dementia. I could write pages on this subject.

“Anxiety seems to make it worse.”





I was very ill and having memory problems in my 50s. I went to my GP saying I thought I was getting Dementia and wanted testing. The first thing he tested was my levels of Zinc, Magnesium, Vitamin B and D. People need to take supplements that are depleted OUT of our systems with illness and bad diets.

SLEEP issues Breathing patterns - nasal, diaphragmatic Nutritional consequences - ultra processed 'food' (frankenfood) and excessive simple carbohydrates / sugars

I've seen people from all walks of life develop dementia (I worked in a rural MPS as RN): teachers, engineers, cleaners, stay at home carers, doctors, university professors - it doesn't matter what, it can still come and introduce itself to you. Yes, I've heard that there are things that can increase your risk of getting dementia, but even those with no risk factors can suffer.

I have several friends who believe that keeping the mind active by completing crossword puzzles etc would ward off the onset of dementia - and some are of questionable value.

One thing that I have learnt is that it does not discriminate. It can happen to anyone.

I have learnt that Dementia can be found in people from all walks of life and nobody can really be sure that [they are] immune.

That dementia can be diagnosed at quite an early age. It is not just a condition of very old age.

8. Dementia is diverse

Causes, effects, reactions.

Around 140 commenters (10%) mentioned that dementia is diverse, both in its underlying causes and in how it affects those who have it.

Many followed this insight with the point that dementia care needs to be tailored to individuals because of its diversity.

I think there's a lot of misinformation out there - even the use of "Alzheimer's Disease" when they mean another sort of dementia. It can take several forms, and this is not well enough known.

Dementia is an umbrella term to describe a range of illnesses. It affects people differently (although there are some common symptoms) and its progression takes different amounts of time.

Alzheimers is about 66% followed by vascular dementia at 25% some of which can be treated and then the rarer forms like fronto-temporal and Lewy body dementia

There are so many types of dementia and each person is an individual with different needs. Nursing staff and carers need to have better training in this area so that each person's needs are met.

I have become increasingly aware of how little we understand the range of conditions we label dementia.

Each person experiences dementia differently. Be prepared to be flexible in how you deal with it.

Everyone with dementia is different and there are different types of dementia so don't make assumptions but treat each person as an individual, just like people without dementia.

Not everyone with Dementia has the same level of severity and not everyone is 'beyond help'

"Dementia is a spectrum, not an off/on button"



9. Identify it early

Signs, symptoms, denial.

About 120 comments (8%) discussed the importance of getting to know potential signs and symptoms of dementia and acting early to get a diagnosis, plan around it, find support, and start treatments.

This theme also includes comments that observed some people may live in denial about dementia or try to hide the signs.

Don't leave it, speak up if you feel your memory is going backwards and continuing feeling of getting worse

Get onto trials as soon as possible. Research and medication use can assist in delaying the disease progress in many cases.

People should be aware that testing is available at no charge and the sooner it can be diagnosed the better it is for all concerned.

if picked up in the early stages there are things that can be done to slow it down, so it's best to have a diagnosis early

It creeps up on you!! I could not see it in my parents but my wife picked up on it early as she is a nurse. I wouldn't believe her and would not get my parents the help they needed until it was too late!! Now my brother has dementia at 76 - my wife picked up on it when we visited him interstate last year. We got help for him stat!!!!

“Initial denial mainly from loved ones is hugely unwise.”

You need to stay alert to dementia as it can be a slow change that can go unnoticed, or be “masked” by someone's behaviour individually or together to compensate for each other and hence hide it

It is in hindsight that I recognised my parent had dementia earlier than I thought and that this affected some of her decisions and ability to care for herself. She was secretive about her concerns and thought her power and Self-control would be taken away. It is for those reasons I have not talked to anyone about concerns for myself.

when two people who live together both get dementia simultaneously, they may become co-dependent; they may also play off each other to hide the fact that they are not still doing things they should be.

I see so many people with signs of dementia that would warrant an assessment but they don't want to deal with it - Denial. And they just get more disabled and unable to be independent.

10. Not everything is dementia

Memory slips are part of life, part of ageing.

Finally, around 30 people (2%) felt that older people should know not all memory loss, cognitive impairment, or behavioural change is caused by dementia, and that some forgetfulness is simply a part of ageing.

It's normal to forget information as part of life as we get older. "If you forget where you put your car keys or why you went to the kitchen that is normal; if you forget you own a car or a kitchen that is not normal"

“Don't worry about short term memory lapses.”

Understanding also that not all you see from the individual experiencing the dementia, e.g. hallucinations, may be related to that but could be caused by something as simple as a urinary tract infection.



Our brains change as we age, whether or not we develop dementia. We need to accept this as a part of ageing and adapt to it. It doesn't mean we are becoming incompetent but we may need more time for decision making than our younger selves required.

Methods

The information in this report comes from the 12th National Seniors Social Survey, which was conducted in February 2024. The survey received ethics approval from Bellberry Ltd prior to implementation (approval 2023-11-1424).

The survey included a module about dementia. Responses to the final question – “Is there anything you have learned about dementia through personal experience or through other sources that you would like people to know about?” – were analysed for this report using the thematic analysis

framework described by Braun and Clarke. We identified themes via inductive analysis guided by a critical realist approach that aimed for accuracy and objectivity in interpreting respondents’ views. The number of comments comprising any given theme was estimated to give a sense of its prominence. The data were not cross-coded so numbers should be treated as estimates only.

Quotes from survey respondents were selected to illustrate some of the variety and prevalence of ideas

expressed. Where possible they were reproduced verbatim, occasionally omitting or altering parts for clarity or anonymity (indicated with square brackets []). Minor typos were corrected for readability (no brackets). We retained all other phrasing idiosyncrasies.

Most survey results from the survey’s dementia module are presented in our 2024 report *Dementia Experience, Planning and Worry*. Please see that report for additional aspects of context and methods.

Sample

In total, 4882 people answered one or more NSSS-12 dementia questions, around a third of whom (n=1485) offered insights on dementia that they would like other people to know about. The percentages below characterise that group of 1485 respondents’ demographic traits.

No question was compulsory, and some allowed multiple selections, so some percentages do not add up to 100%. Percentages are rounded to the nearest whole number; precise numbers of respondents are given when this is <1%.

Age group	50-64 years 13%	65-74 years 50%	75-84 years 33%	85+ years 4%
Self-rated health	Excellent 12%	Good 54%	Fair 26%	Poor/very poor 8%
Personal experience of dementia	Self 6 people	Parent 40%	Partner 11%	
	Other family member 31%	Friend 35%	None 8%	
Gender	Female 65%	Male 35%	Non-binary 1 person	
Retired or employed	Permanently retired 68%	In paid work 20%	In transition or flux 18%	
Have other duties	Unpaid care 23%	Volunteering 41%	Household chores 94%	
Education	School up to Year 12 17%	Other cert/diploma 33%	Degree or higher 46%	
Savings including super	<\$100k 27%	\$100k-\$500k 25%	>\$500k 30%	
Not metro	Regional 27%	Rural 8%	Remote 1%	
Diversity groups	First Nations, Aboriginal & Torres Strait Islander 1%	Disability 9%	LGBTI 2%	Veteran 4%
	CALD background 3%			

National Seniors Australia is located in
Brisbane/Meanjin and Canberra/Kambri.

We acknowledge the traditional custodians of the
land and waters in which we operate, the Turrbul
and the Ngunnawal and Ngambri Peoples.

We honour and value their continuing cultures,
contributions, and connections to Country, and
pay our respects to their elders, past and present.

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