

# ‘People in the community’ are the challenge and the solution: Towards a dementia-friendly future

Discussion Paper



“

*It is important for me to live well now but I can't achieve this alone. I need your help. Together, we can all work to create a dementia-friendly community so that everyone feels valued and remains connected.* ”

*John, living with dementia*

## Foreword

**With the number of people in Australia living with dementia, along with the number of carers, friends and family, it is almost unbelievable that we are still having to talk about the limited awareness and understanding about the condition.**

This paper identifies the similarities between the results of a 2019 report and the 2023 AIHW Dementia Aware Survey, recognising that this lack of knowledge results in stigma, discrimination and social exclusion. As a person living with dementia, this saddens me. Why do people treat us differently? What have we done to deserve this? As a Dementia Advocate, it angers me. Why are people not listening? Why are they not changing their attitudes? All we are asking for is to be understood, respected and supported - just basic human rights.

The examples given of two areas where the community has stepped up to support the concept of Dementia-Friendly Communities are heartwarming and encouraging. There are many more examples of great community projects, yet these communities are still in the minority.

With Government recognition and the tangible support described within this report, this could change. If local councils, businesses and organisations recognise that dementia is no less of a disability because it is invisible, we could feel supported. If friends and others in our community keep an eye out for us and make sure we are included, we can feel less socially isolated.

Please remember to ***“Act now for a dementia-friendly future”***



### **Bobby Redman**

Retired psychologist,  
Dementia Australia Dementia Advocate,  
Chair, Dementia Australia Advisory Committee

## Introduction

### **Dementia is one of the most significant health and social challenges facing Australia and the world.**

It is the second leading cause of death in Australia and the leading cause of disease burden among Australians aged 65 and over, and remains one of the most challenging and misunderstood conditions.<sup>1</sup> Dementia is more commonly diagnosed in older age, but it can affect children and younger adults, including people in their 30s, 40s and 50s. In 2024, it is estimated there are almost 29,000 adults living with younger onset dementia, and this is expected to increase to more than 41,000 people by 2054.<sup>2</sup>

Without a medical breakthrough, the number of people living with dementia in Australia is expected to increase from more than 421,000 Australians in 2024 to more than 812,500 by 2054.<sup>3</sup> More than 1.6 million people are currently providing care for people living with dementia in Australia.

## Combating stigma and discrimination

### **The inaugural 2023 Australian Institute of Health and Welfare (AIHW) Dementia Awareness Survey - the largest nationally representative community survey of its kind in Australia - asked more than 5,400 people aged 18 and over what they knew about dementia and their attitudes towards the condition and people living with it.**

The broad finding of the survey was ‘Generally, Australians know little about dementia’.<sup>4</sup> The survey highlighted that misconceptions about dementia persist, including the erroneous belief that dementia is a ‘normal part of ageing’. Two thirds of those surveyed believed that people with dementia are unpredictable and need constant supervision. The survey concluded that there was a clear need to improve the Australian community’s knowledge about the condition.<sup>5</sup>

These findings are consistent with results from Dementia Australia surveys over the last decade, showing an ongoing – and profoundly concerning – lack of awareness and understanding about dementia in the Australian

community.<sup>6</sup> A 2019 report on Australian attitudes and beliefs found that, while there was increased awareness and empathy during the past decade, two thirds of survey respondents were not confident about their knowledge of dementia. They were even less confident about talking to someone with dementia and expressed high rates of fear or unease about the way in which someone with the condition might react to them.<sup>7</sup>

In the same survey, 63 per cent of people living with dementia believed that discrimination is common, 74 per cent said people have not kept in touch as they did prior to their dementia diagnosis and 80 per cent had not been invited to social functions. 73 per cent of family, friends or carers of people living with dementia believe discrimination against people living with dementia is common or very common. The report found lower levels of social engagement, inclusion and connectedness within their communities for people living with dementia.

Limited knowledge and understanding about dementia has widespread repercussions. Most significantly, lack of knowledge and insight results in people with dementia, and their family members and carers, experiencing stigma and discrimination in a wide range of settings from home, community and retail spaces to the health care sector.

Dementia-related stigma is a complex phenomenon that can incorporate public stigma (collective or community-imposed), internalised or self-stigma and stigma-by-association (directed at family members or carers of the person living with dementia). The impacts of stigma can be significant and wide-ranging. Australian and international studies have noted that stigma and discrimination associated with a dementia diagnosis can have deleterious impacts including discouraging health care-seeking behaviour, reducing social engagement with family, friends and the broader community, and associated consequences for the physical, cognitive and psychosocial health of the person with dementia.<sup>8</sup>

Recent research has highlighted the harmful impacts of social isolation and loneliness, calculating that the effects are as significant a risk for mortality as smoking.<sup>9</sup> Knowledge, understanding and beliefs about dementia can vary significantly in the ethnically, culturally and socially diverse communities that characterise contemporary Australia and these differences can further complicate and compound experiences of stigma, discrimination and social isolation.<sup>10</sup>

Dementia Australia's 2024 Dementia and Discrimination report reflects the ongoing realities of stigma and discrimination. Of the almost 2,000 nationally representative respondents interviewed, a third suggested that people avoid or exclude their loved one with dementia, and nearly half the respondents felt that people don't keep in touch as they used to. 71 per cent of people with a family member or friend with dementia felt that people patronised their loved one and three out of four people (76 per cent) felt people treated their family member or friend with dementia as though they were not smart. People living with dementia reported being socially excluded, ignored and treated differently or with less respect.<sup>11</sup>

***“Sometimes I feel like they don't include me in conversations.”***

***“It's just being treated like you're an idiot.”***

***“Life is hard enough without being discriminated against.”<sup>12</sup>***

## ‘People in the community’ are the challenge – and the solution

**The 2024 Dementia and Discrimination report found that a majority of people believed that discrimination towards those with dementia in the community is common and two thirds of those identified ‘people in the community’ as the most common source of discrimination.**

**“The perception of discrimination marries with the act of discrimination, with a majority of our cohorts suggesting it is ether ‘common’ or ‘very common’. The source of discrimination is felt to come most from ‘people in the community,’ and this includes businesses (shops, banks) and public transport.”<sup>13</sup>**

If ‘people in the community’ are the most commonly identified source of dementia-related stigma and discrimination, ‘people in the community’ are also, incontrovertibly, part of the solution.

Two in three people with dementia are thought to be living in the community.<sup>14</sup> Decades of research in the field of dementia support and care has shown that staying in touch with family and friends and maintaining social engagement and connection plays a critical role in supporting a person with dementia to live as well as possible. As a person with dementia experiences cognitive and other changes, maintaining social connections and a continued involvement in the broader community can make a powerful contribution to maintaining a sense of identity and self.<sup>15</sup>

Given the importance of grounding an individual physically and psychologically within their local community, it is clear that communities play a critical role in encouraging inclusivity, respecting the rights of people with dementia, and facilitating access to the services, supports, activities and spaces that every Australian citizen is entitled to. People living with dementia who are supported to live well in the community are more likely to stay in their homes longer and are less likely to enter residential aged care prematurely.

The broad remit of the ‘dementia-friendly’ communities movement – improving dementia literacy and encouraging individuals and communities to be more inclusive and dementia-friendly – offers a valuable model of how we can reduce the risk of social isolation, and support people living with dementia to remain connected and engaged.

## So what makes a community dementia-friendly?

**A dementia-friendly community is “... an affirmation of the rights of people with dementia by giving effect to those rights in the everyday lives of our communities.”<sup>16</sup>**

A dementia-friendly community can be defined as a community of any size and scale where people with dementia are understood, respected and supported. The concept has been embraced and developed on a global scale over the last decade. In its analysis of dementia-friendly communities, Alzheimer’s Disease International identified two core objectives that underpin successful dementia-friendly communities. The first is the desire to improve understanding of dementia and reduce stigma by meaningfully engaging people with dementia of all ages in





their communities. Secondly and equally importantly, these communities recognise the rights and capabilities of people with dementia and empower them to make decisions about their lives according to their individual capacities.<sup>17</sup>

Dementia Australia's Dementia-Friendly Communities program promotes the core objectives of improving dementia literacy, reducing stigma and discrimination, and promoting social engagement and connectivity through its support for dementia-friendly community initiatives across Australia.

A recent international analysis recognised that dementia-friendly communities are context-dependent, noting that the most effective dementia-friendly initiatives were those led and shaped by the specific needs of the local community.<sup>18</sup> Two outstanding examples of Dementia Australia-supported, community-led initiatives are testament to this, and illustrate how a small group of dedicated people can play a powerful role in creating a dementia-friendly and inclusive community.

## Parrots, police and purpose: The Gold Coast Dementia-Friendly Network

### **What do a community choir, a police station and a bunch of companionable birds have in common? More than you might imagine!**

These disparate groups and a range of other initiatives on Queensland's Gold Coast are united by a shared commitment to making their local community more inclusive for people living with dementia. The driving force behind this commitment is Allison Carter and the Gold Coast Dementia-Friendly Network.

Allison describes herself as having 'a passion for supporting people living with dementia'. A registered nurse by profession, that passion has involved international experience in the dementia care and support field, including roles providing non-pharmacological approaches and psychosocial services for people living with dementia in Singapore, China and the United Kingdom.

Allison was involved in Dementia Friends in the UK as both a Friend and Host, and she was instrumental in the establishment of the Dementia

Friends program in China. She noted the absence of an equivalent initiative in her local Gold Coast area.

**“There was no Dementia Alliance on the Gold Coast which blew my mind. I couldn’t believe such a massive area didn’t have a dementia alliance.”**

With support and encouragement from Dementia Australia’s Dementia-Friendly Communities (DFC) program and DFC Team Leader Marie-Louise Bone, Allison formed the Gold Coast Dementia-Friendly working group which in turn became the Gold Coast Dementia-Friendly Network. The Network officially launched in April 2024, with local MPs, health and aged care providers, research organisations, community groups and businesses attending.

Run by a small group of committed volunteers, the Network is a community action group that includes people living with dementia, their families and carers, the City of Gold Coast, local businesses, a library, a choir, and a police station. The Network aims to promote and connect services and supports for people living with dementia and their family members to create a safe, supportive and welcoming community.

The Nerang library provides a free venue for the monthly ‘Community Connection’ meetings. Each meeting features a different speaker or dementia-related theme and focuses on the provision of information or support and services for people living with dementia, and their family members and carers. This is followed by morning tea, with the all-important opportunity to share stories and experiences.

The wide variety of groups and organisations involved in the Network aim to improve understanding about dementia and create a more dementia-friendly community. The children’s play support group Play Matters is a Network partner and plans are underway to host regular intergenerational play groups, encouraging engagement between young children, people living with dementia and family members. In Singapore, Allison witnessed the many physical and psychological benefits of co-location and regular connection between a children’s day care centre and an adult day respite centre. She is hopeful these positive outcomes can be replicated in her Gold Coast area.

The aptly named **Inspire!** choir comprises people living with dementia, family members, carers and volunteers. Inspire! is a compelling illustration

of the importance of supporting people living with dementia to be involved in something that promotes wellbeing and social connection and enables the person and their family members to make a meaningful contribution to their community.

Parrots do not automatically spring to mind when considering how to create a dementia-friendly community! However, with the aim of changing the world 'one bird at a time', **Parrots for Purpose** is a perfect fit with the Network's broader, dementia-inclusive imperatives. The not-for-profit group provides trained parrots as companions to support people living with a range of mental and physical health conditions and disabilities, including dementia. An important Network affiliate, the group has already made an impact on the lives of Network members.

The Runaway Bay Police Station has been proactive in developing its dementia-friendly credentials and was recently recognised as a Dementia-Friendly Organisation by Dementia Australia. The police station is actively involved in Network activities and has provided an influential template for other police stations in the Gold Coast area to guide development of their own plans to become more dementia-friendly.



[Watch](#) a video to find out more about the Parrots for Purpose community group



Other groups, organisations and businesses involved in Network activities include the Home of the Arts Gallery (HOTA), libraries in the Gold Coast area and the local Lions Club. Among the many ideas in development and plans for collaborative activities with other groups, the Network's committee aims to build a directory of dementia-related resources that will be available online.

The Gold Coast Dementia-Friendly Network is a textbook illustration of how a small group of motivated individuals can be the driving force for change in their community.

**“We're only a small committee and we're all so different but the common goal is we want to help people living with dementia.”**

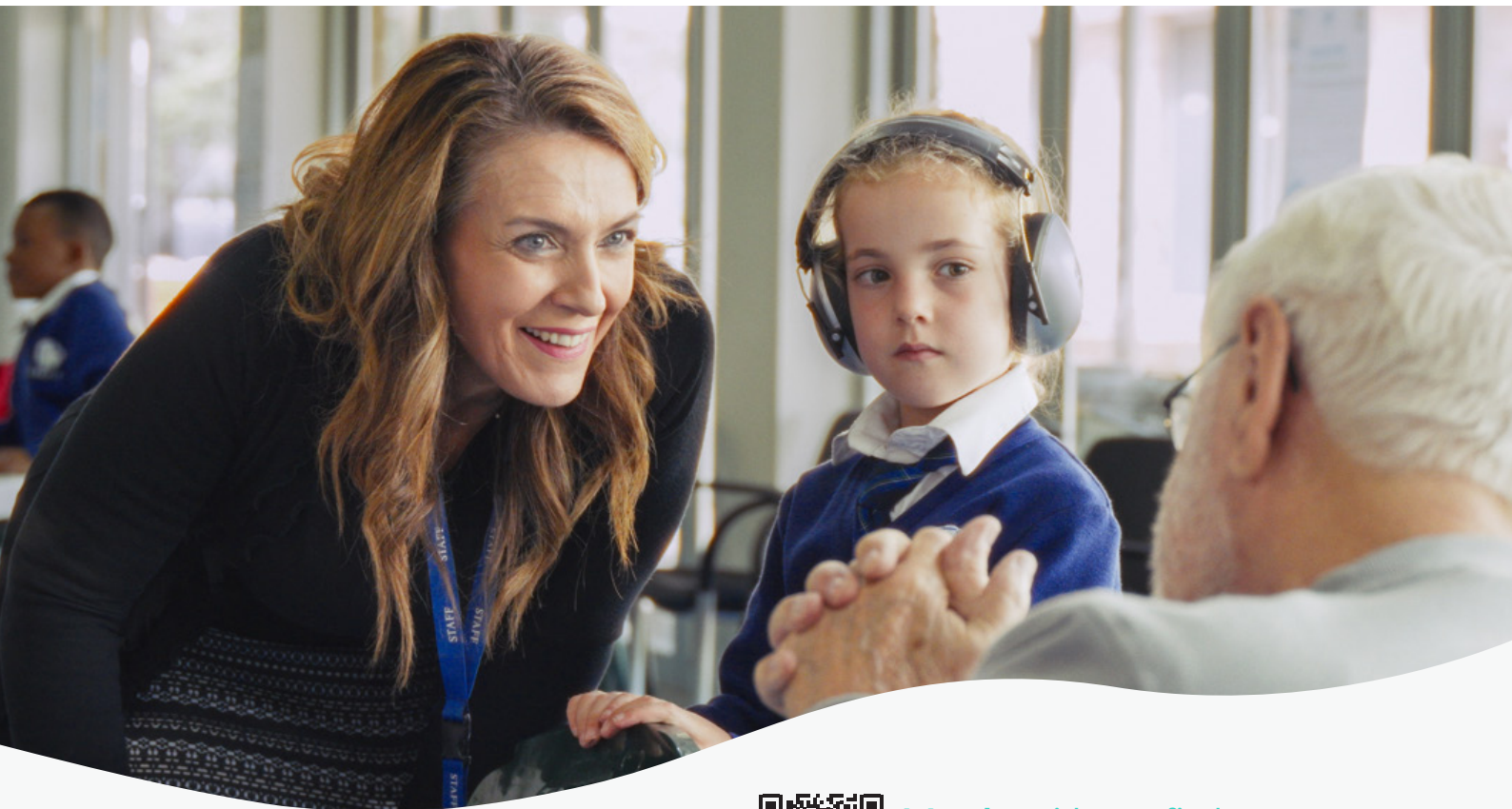
Allison notes that the key to the rapid development and success of the Network is the commitment of committee members and other people involved, and the generous support from the City of Gold Coast Council, local MPs, organisations and businesses. Her advice for anyone considering how to start making their community more dementia-friendly is two-fold – take action and ask for assistance.

**“Just do it, you know – ask people for help and see what's out there.”**

## How 6 became 52: the expanding horizons of the Swan Valley Memory Café

**The Swan Valley is a sub-region of the larger Swan District wine region and is described as a picturesque tourist mecca, about 25 minutes' drive from the West Australian capital Perth.**

It is also an area, according to retired registered nurse and Swan Valley resident Jan O'Shea, that lacked support and somewhere to meet for people living with dementia and their family members and carers. Not unlike Allison Carter, Jan's nursing experience in the aged care sector meant she had a clear understanding of how important it was for people living with dementia and their family members to stay connected and engaged with their local networks and the broader community.



[Watch a video to find out more about the Swan Valley Memory Cafe](#)

Jan's research led her to Dementia Australia and, with their support and resources, she founded the Swan Valley Memory Café. Jan's aim was to create a space in the Swan Valley where people living with dementia and their family members and carers could find friendship, inclusion and connection and continue to feel part of their community.

The Swan Valley Memory Café was the first of its kind in the region and started on a modest scale with a handful of volunteers and half a dozen participants meeting fortnightly for morning tea. That was four years ago. The café now has more than 50 people attending regularly and has offered a range of activities during that time including music and dance therapy, chair yoga and social outings.

The café's popular weekly art classes are attended by around 25 people and delivered by a qualified and inspirational art teacher. Jan has observed the impact of these classes firsthand.

**“She’s wonderful... she engages everybody... they just love coming.”**

The café has also spawned a community singing group, the Memory and Melody choir. Now run independently of the café, the choir has about 25 choristers, including many café attendees, and performs regularly in the Swan Valley region.

Vanessa Fitzgerald met Jan through her aged care counselling and consultancy business and knew that the Memory Café aligned with her ideas and passion for working with people living with dementia. Vanessa has become an instrumental part of the café's volunteer team. Both women note the many benefits for everyone who comes to the café, with Vanessa observing:

**“Carers probably get as much, if not more, out of the café as people living with dementia. The carer can be at ease for two hours knowing their family member is happy and engaged and they themselves have the chance to connect with other people and carers.”**

Jan can see the difference it has made to her community.

**“People living with dementia and their relatives and carers get great value out of coming to the memory café. We've got three gentleman who used to bring their wives to the café; their wives went into care and subsequently died. These three gentlemen still come to the café because they made so many friends who are part of their lives now.”**

Developing relationships with other groups, businesses and local organisations has been central to the café's motivation to make Swan Valley a more dementia-friendly and inclusive community. Jan cites the intergenerational program with a local primary school as one of the most significant collaborations the café has undertaken. Vanessa has been the driving force behind the initiative which began in 2023.

If you have watched the ABC series **‘Old People's Home for Four Year Olds’**, you will have seen the powerful impact that bringing young children and older people together can make on the physical and emotional wellbeing of both groups. Inspired by the series, Vanessa identified a new local primary school as a particularly good fit for an intergenerational program with Memory Café participants.

**“I loved that show and thought if they can do it, we can do it...on whatever scale.”**



The Emmaus Catholic Primary School is situated in a young and multiculturally diverse community, with a median resident age of 35 and almost half of all households having children. Vanessa identified that many of the students didn't have grandparents or significant elders living in close proximity and lacked the opportunity to interact with older people on a regular basis.

The intergenerational program has now been running for a year and involves Memory Café attendees regularly visiting the school, where activities include musical performances from the children, shared art and craft projects and other group events and activities, followed by morning tea. Originally conceived for three-year-olds in the school's kindergarten classes, the interest in and success of the program has resulted in it being extended to older children in other grades. Both women believe that educating children from a young age about dementia, including those from diverse backgrounds where understanding and beliefs about the condition can vary widely, will contribute to creating a more dementia-friendly community.

Dementia Australia Dementia-Friendly Communities Community Development Officer Jane Wells has seen this in action for herself:

**“Some beautiful relationships have developed through this initiative and it is so heartwarming to see the connection between the students and the café participants, joining together through a craft project or sharing morning tea, the ease of conversation and laughter throughout the session. Yesterday some of the café participants decided to spontaneously join in hopscotch with the students, and why not?! There really is just a sense of genuine friendship that crosses all cultural and generational boundaries.”**

The local council, The City of Swan, has been instrumental in providing support and assistance for the café, with funding and promotion of the initiative. This year the council recognised the café's contribution to making the community more inclusive and dementia-friendly by awarding Jan the City of Swan Senior Community Citizen of the Year. The citation noted that:



**“Janice O’Shea’s development of the first memory café in the City of Swan continues to have profound positive impacts on the community. The Swan Valley Memory Café provides a supportive and engaging space for those with dementia, as well as their carers and relatives.”<sup>19</sup>**

A Dementia Australia grant and, more recently, private donations have provided important sources of financial support. With a second café already up and running in Altona, and plans for another café and dementia-friends awareness-raising for volunteers at a local hospital, the original café concept continues to expand.

Every week, Jan and Vanessa witness the difference these kinds of initiatives have made to their community and are determined to ensure the Memory Cafés and the intergenerational program have a sustainable, long-term future.

## Getting government engaged

**The Dementia-Friendly Communities movement has been described as a global endeavour that complements the work of governments, organisations and support services.<sup>20</sup>**

Dementia Australia has increasing evidence that the movement, and its own Dementia-Friendly Communities program, offers a useful template for embedding dementia-informed and dementia-friendly principles for governments at every level in Australia.

Governments can demonstrate tangible support for the Dementia-Friendly Communities movement by referencing dementia and dementia-friendly communities in inclusion policies, strategies and plans, and in the provision of local funding sources and mechanisms to support the creation of place-based, community-led dementia-friendly initiatives.

It is significant that the two dementia-friendly initiatives highlighted in this paper benefitted from the interest and substantial support of their respective local councils. Allison Carter and Jan O’Shea cite the importance of this involvement in the success of their respective groups, from financial and other forms of in-kind support to the promotion of their actions and activities.



A recent Dementia Australia Dementia-Friendly Communities Inclusion survey sought feedback on what would assist the future growth and development of existing dementia-friendly groups, organisations and alliances in promoting a more inclusive community. Increased participation from government, particularly at the local municipal level, was one of the key themes that emerged.<sup>21</sup>

As a result of this feedback and in recognition of the vital role that local councils can play in actively supporting and promoting dementia-friendly community actions and initiatives, Dementia Australia's Dementia-Friendly Communities program has recently developed two important documents. The **Toolkit for Councils** outlines the way in which local governments can make changes to transform their own governance and physical environments to make councils more dementia-friendly. The second document is a community guide setting out practical tips for individuals and groups seeking to make their community more dementia-friendly: **The First Steps to Building a Dementia-Friendly Future**. The combined information in these two documents offers a

valuable template for anyone – from a local council diversity officer to a small business owner or not-for-profit community group – to undertake modest but effective steps towards a more inclusive and dementia-friendly community.

## Conclusion

**“Getting the ball rolling might seem difficult, but you can get inspiration from what other communities have done.”** <sup>22</sup>

Some of the conclusions in the 2024 Dementia and Discrimination Report and the 2023 Australian Institute of Health and Welfare Dementia Awareness Survey make for disheartening reading, but there are also positive findings. The latter survey found ‘more than four in five Australians believed that people with dementia can enjoy life (83%).’<sup>23</sup> This simple but critical consensus provides an encouraging foundation on which to build towards a dementia-friendly community and future.

The two initiatives profiled in this discussion paper are underpinned by this belief. Both started on a modest scale, with the interest and passion of one person who saw a lack of community support and services for people living with dementia and decided to take action. The Gold Coast Dementia-Friendly Network and the Swan Valley Memory Café are driven by the specific needs and involvement of people living with dementia, their family members and carers in their respective communities. Developed and expanded by the enthusiasm and support of volunteers, local councils, small businesses, and a range of other individuals, groups and community organisations, these two initiatives underscore how actions on the part of individuals and small groups can motivate communities to make real changes to create a more inclusive, supportive and welcoming place where everyone can thrive.

So, what can you do to encourage your own community to be more inclusive and contribute to creating a dementia-friendly future for Australia? Allison Carter has some advice:

**“All you have to do is ask, right? A lot of people out there want to help or want to do something, anything. There are lots of organisations that want help and get involved in all sorts of different ways.”**

## About Dementia Australia

**Dementia Australia is the national peak body for people impacted by dementia in Australia. We exist to support and empower people living with dementia, and their family members and carers.**

We involve people impacted by dementia in our activities and decision making, drawing on their experiences to ensure we are representative of the diverse range of dementia experiences across Australia. We amplify the voices of people impacted by dementia through advocating and sharing stories to help inform and inspire others. Dementia Australia is the source of trusted information, education and support services. We advocate for positive change for people living with dementia, their families and carers, and support vital research. We are here to support people impacted by dementia, and to enable them to live as well as possible.

**No matter how you are impacted by dementia or who you are, we are here for you.**



## Footnotes

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# National Dementia Helpline

## 1800 100 500



For language assistance  
call **131 450**

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Find us online  
**dementia.org.au**



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