

Dismantling dementia discrimination

It starts before the diagnosis

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With more **appropriate community attitudes and encouragement** people with early cognitive impairment **will seek help** as they know of other community members who are **living a quality life after a dementia diagnosis**”

Person living with dementia.





A little
support
makes a big
difference

Foreword

by Bobby Redman

Why do we need to have Dementia Action Week? Why do we need to educate people about dementia? With around 487,500 people in Australia diagnosed with the condition, surely everyone knows at least one person living with the condition: a family member, a friend, a neighbour? How is it then, when you ask people what they know about dementia, they so often talk about it being about old people forgetting things or they talk about elderly relatives nearing the end of their journey with dementia and being unable to communicate or understand what is happening around them? This is the stereotype that comes from not knowing, or not understanding, which in turn leads to the stigma attached to dementia.

This paper highlights the importance of recognising the different pathways and symptoms attached to the dementia journey, identifying the importance of early diagnosis and appropriate ongoing support as the key to living well and retaining function for longer. Once people realise that a purposeful life can continue after diagnosis, the stigma will be lifted and the fear reduced. People living with dementia can continue to participate in a meaningful way within their communities.

It recognises that although dementia is an invisible disability, the impact is clearly experienced by people living with not only the challenges of declining function, but with people, both in the medical profession and the community, minimising their experiences and dismissing their symptoms rather than providing the support and care required.

This paper offers suggestions and practical ideas on how to break down the stigma and provide a dementia inclusive community. As a person living with dementia, I urge that healthcare professionals and the general community recognise that a little support makes a big difference.

Bobby Redman

Dementia Australia Dementia Advocate

Chairman, Dementia Australia Advisory Committee (DAAC)

Dementia in Australia

Dementia is the term used to describe the symptoms of a large group of neurocognitive disorders which cause a progressive decline in a person's functioning.



In 2022, the estimated number of Australians living with **dementia** is

487,500

Without a medical breakthrough, **by 2058** the number of people with dementia is expected to increase to almost

1.1 million

It is one of the **largest health and social challenges** facing Australia and the world.



In **2022**, it is estimated that almost

1.6 million

people in Australia are involved in the care of someone living with dementia.¹



An early diagnosis and community support

The keys to living well with dementia

We often hear about the discrimination that people impacted by dementia experience in their day to day lives, but even getting a diagnosis of dementia can be a challenging process. The challenges encountered in the health care system often mirror how the community understands and supports someone living with dementia, compounding a person's sense of isolation and disengagement. And yet, the evidence is compelling that an early diagnosis, community awareness and support are all critical components of an integrated approach to ensuring that people with dementia are supported to live as well as possible.

Australian research shows that an overwhelming majority of health service consumers (92 per cent) would **want their diagnosis of dementia to be disclosed as soon as possible.**²

Awareness in the community

An early diagnosis enables people with dementia to process their diagnosis, get the information they need to understand their type of dementia, plan for the future, address changes in their family and community relationships, and remain engaged in their communities. To do this, they need healthcare professionals who understand how to diagnose or refer people with cognitive changes, communicate the benefits of having an early diagnosis and know how to refer their patients to appropriate support services. People experiencing changes to their cognition will be more likely to engage with their general practitioners (GPs) if they know that they - and their local communities - will support and not discriminate against those with a diagnosis of dementia.

We can't have one without the other. We can't improve the rates and process of diagnosis if we don't have communities that are better equipped to understand dementia.

And why is this shift across healthcare and community life so important? Because 65 per cent of people with a diagnosis of dementia live in the community. Because an early diagnosis means that people can plan for their life in the community in a more informed way. Because communities - along with the health services that lie at the heart of them - can play a vital role in encouraging inclusivity and respecting the rights of people with dementia.

For there to be true value in a healthcare professional diagnosing someone with dementia, the local community must be able to join them in facilitating access to local services, supports, activities and spaces. If we get this right, people with dementia are more likely to live fulfilling lives in their local community, stay at home longer and

Approximately **65%**
of people with dementia
live in the community



are less likely to enter residential aged care prematurely.

Dismantling discrimination

Dementia Australia surveys over the past five years show that a lack of awareness and understanding about dementia persists in the Australian community – from the healthcare professionals who diagnose dementia, to local community members who live alongside those impacted by dementia. A 2018 report on Australian attitudes and beliefs found that while there was increased awareness and empathy over the past decade, two-thirds of survey respondents were not confident about their knowledge of dementia.³ Poor dementia literacy contributes to people with dementia, their family members and carers experiencing stigma and discrimination in a wide range of settings, from healthcare services to community and retail spaces.

Dementia Australia's 2019 Dementia and Discrimination report reflects the ongoing realities of that stigma and discrimination.⁴ Of the more than 5,700 survey respondents, 63 per cent of people living with dementia believed that discrimination is common, 74 per cent said people had not kept in touch as they did prior to their dementia diagnosis and 80 per cent had not been invited to social functions.

“ I know for me, becoming more educated about dementia helped me to understand that some of my past actions were unknowingly hurtful and discriminatory. I believe that if there is more information in the public domain regarding dementia, a lot of discrimination would cease or at least reduce. ”

Family member of someone living with dementia.



“ People don’t know what to say, or do, in social occasions. It’s like they think you’re going to do something really silly or make a scene. ”

Person living with dementia.

Seventy-three 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 for people living with dementia.

A 2021 Dementia Australia survey reinforced these findings, with 65 per cent of respondents who live with dementia believing that discrimination towards people living with dementia is still common or very common.⁵

Dementia-related discrimination can be experienced in different ways including discrimination-by-association (directed at family members or carers of the person living with dementia), self-imposed (internalised) and public discrimination (imposed by the community). Australian and international studies show that dementia-related stigma and discrimination can discourage people with cognitive changes from seeing their GP or a health care professional because they are worried about how they might be treated. Concerns about discrimination can have similarly serious impacts in a community context. Changes in cognition and personality can make people less confident to undertake their usual activities, see friends and family or engage with their community. This in turn can have consequences for the physical, cognitive and psychosocial health of the person with dementia.⁶ Knowledge, understanding and beliefs about dementia vary significantly in the ethnically, culturally and socially diverse communities that characterise contemporary Australia. These differences can further complicate and compound experiences of stigma and discrimination.⁷

Dementia as an ‘invisible’ disability

The 2008 United Nations Convention on the Rights of Persons with Disabilities (UN-CRPD) draws on the social model of disability.⁸ Rather than disability experienced because of an individual’s impairment or difference, the model identifies community attitudes, physical and social environmental factors, and other barriers as imposing disability.

“ ...the physical, attitudinal, communication and social environment must change to enable people living with impairments to participate in society on an equal basis with others.”⁹

In recent decades, the impacts of societally imposed notions of disability have been acknowledged. Shifts in community attitudes and understanding about physical disability have been reflected in diverse ways including the embrace of respectful language and more visible changes in making public transport services and retail spaces appropriately accessible.

The 2008 UN-CRPD recognised dementia as a cognitive disability but unlike physical disability, community understanding of dementia as a disability remains limited. This is at least in part because, unlike a physical disability, the cognitive and other changes that are associated with the condition are often under-recognised or rendered ‘invisible.’



Community understanding of **dementia as a disability** remains limited.



“ So although discrimination is basically about ignorance, it doesn't take away the sting... just because I have dementia it doesn't mean I am stupid. I have not lost my knowledge and life experience, it is just that I sometimes have difficulty in accessing the details. ”

Person living with dementia.



A recent British report on dementia and disability found that 98 per cent of the 2521 respondents surveyed thought the ‘hidden’ nature of dementia was one of the key reasons that people living with dementia are treated differently to those with other health conditions or disabilities.¹⁰ This has implications for the way in which people with cognitive changes might engage with (or avoid) the health care system.

Health professionals do not always well understand the complexity and variability of dementia. This can have significant consequences, including delayed diagnosis and the failure to identify clinical, psychosocial and other services that would assist someone to live as well as possible with dementia.¹¹ People living with dementia have had their condition minimised because they present ‘too well’ and as a result, have missed out on vital referrals and supports. Others have reported that a dementia diagnosis was withheld, in the GP’s mistaken belief that no treatment or supports would be beneficial. Challenging perceptions about dementia as a ‘hidden’ condition and improving knowledge can contribute to improving early diagnosis and access to appropriate treatment, care and support services.

“ If you just saw them and didn’t know them, how would you even know if they had dementia? ”

Australian resident with no lived experience of dementia.¹²

Changing attitudes about the ‘invisible’ nature of a cognitive disability in the broader community is equally important. Attitudinal and other societally imposed barriers mean people living with dementia may experience discrimination and other challenges when completing daily activities or interacting with people in their communities. People with dementia relate the common experience of being told that they ‘can’t possibly have dementia’ because they don’t present, speak or act in a way that corresponds with community expectations or understanding of the disabling nature of dementia.¹³

Building a ‘ramp’ to independence and wellbeing

Building a ramp for someone living with a physical disability can make all the difference to their ability to access public and private spaces, and live with independence and dignity. Dementia care scholars including Allen Power have argued that people living with dementia need the equivalent of a ‘ramp’ to mitigate the impacts of cognitive disability and promote wellbeing. Developing the metaphor further, Power suggests that building ‘ramps’ of various kinds in different contexts can expand on a person’s existing strengths and capacities to create an ‘infrastructure for ongoing success.’¹⁴

The metaphor of a ramp – a tangible form of support – is a persuasive way of thinking about how the healthcare sector and the broader community can collectively work towards reducing discrimination and promote independence and wellbeing for people living with dementia. A little bit of support – a ramp, however modest in scale – can make a big difference in the lives of people living with dementia, their families and carers. ‘Ramps’ to support independence and wellbeing can take different and diverse shapes and forms. An early diagnosis offers a ‘ramp’ to initiate referrals and access to a range of vital services and supports. Improved community dementia-awareness and engagement can make a significant difference to the autonomy and quality of life of a person living with dementia.

“ After all, once you build a wheelchair ramp, the person can use it every day, and the result is both an enhancement of her wellbeing and a reduction in excess disability.”¹⁵

Ramps for social engagement

Positive social interactions, demonstrating understanding and awareness of the challenges of cognitive disability, can improve self-esteem and wellbeing for a person living with dementia. A simple, supportive exchange at a local shopping centre can encourage a person with dementia to continue to engage and contribute in their community with confidence.

“ A dementia-friendly business would allow those people who are dealing with the public to have the permission to take that extra two minutes to give good customer service and to give themselves a good experience. ”

Person living with dementia, from a 2020 Dementia-Friendly Communities focus group.

“ As part of ensuring my husband stayed socially connected, I would take him out several times a week for a coffee. At our favourite coffee shop, the owner noticed he was struggling to hold the cup and tipping coffee everywhere. She apologised and offered to change the cup immediately to an insulated one without handles. That worked. The next visit, she greeted him by name, and while taking his order said, “I’ve got a new cup I’d like you to try and tell me if that works better for you.” Always one to comment on design functionality, my husband was delighted. The beautiful ceramic glazed cup had extra-large handles that could be held and balanced easily while drinking and came with a small wooden tray with a raised edge. With one hand on the edge of the tray, he could feel where to set it down without tipping or spilling as well. ” Ann, carer for a person with dementia.



Ann had a similarly positive experience in a health care setting. Her local medical clinic made several small but significant changes that minimised the distress and maximised positive outcomes when attending appointments. Ann's husband found the process of getting into the car, travelling to the clinic and walking to the waiting area onerous and tiring. The wait times at the clinic were sometimes lengthy and frustrating, and Ann found it was often a challenge to persuade her husband to remain in the waiting room.

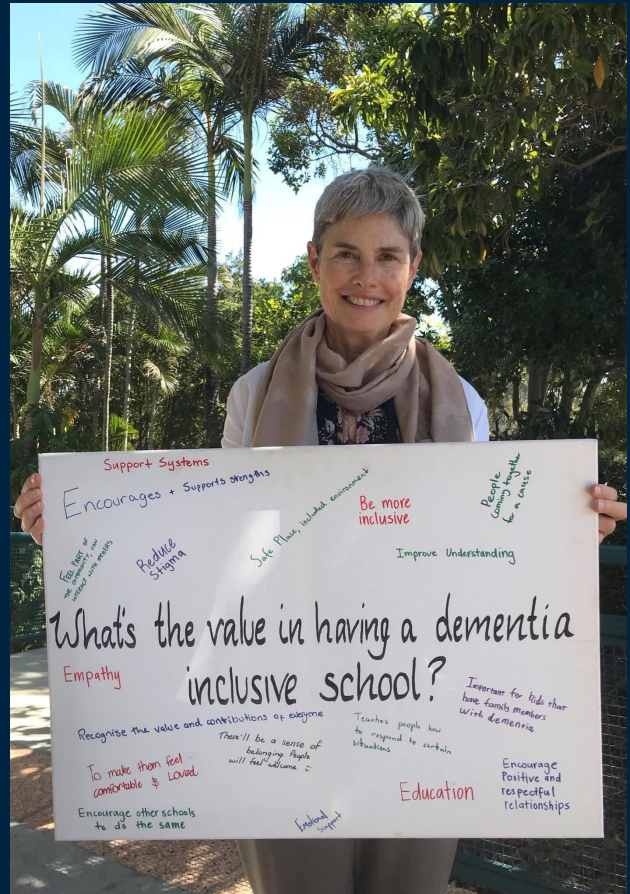
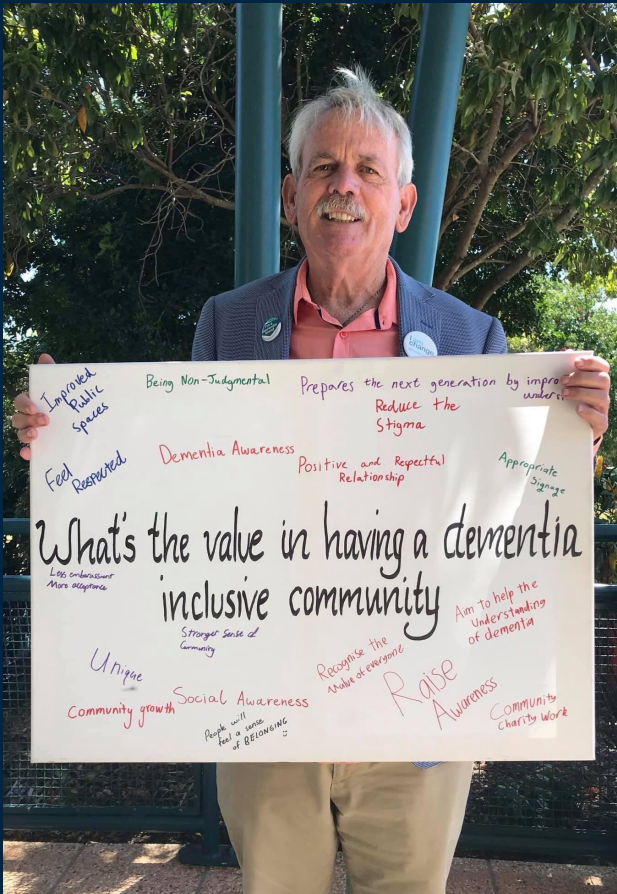
Ann negotiated with the clinic on a strategy for upcoming appointments that reduced the potential stress involved. On the day of the appointment, the clinic would notify Ann 10 minutes from when the doctor was realistically going to be available, thereby mitigating the challenges of lengthy waiting times.

“ Such a small thing made a huge difference for my husband - and for keeping my carer stress levels down. ”

Ann.

During the appointment, Ann's husband was not always able to provide the GP with the details of changes he was experiencing. After consulting the clinic, Ann arranged to provide a written summary of her husband's recent dementia and other health-related issues 48 hours before each appointment. This ensured that if her husband was unable to describe recent changes during the consultation, the doctor had a complete picture and was able to make an accurate assessment.

A little support makes a big difference



Two recent case studies from the Dementia Australia Dementia-Friendly Communities program offer additional examples of the way in which modestly scaled community actions can have a powerful impact on the lives of people living with dementia – both before and after they receive a diagnosis of dementia.

Iona College - leading the way through learning

Brisbane's Iona College was the first school in Australia to be recognised by the Dementia-Friendly Communities program for its action plan for working towards becoming a dementia-friendly organisation. Over the last three years, Iona students have been learning about dementia and how they can help to make their school, and the broader community, more inclusive and dementia-friendly.

John Quinn and his partner Glenys Petrie, both former primary school educators, have been involved in delivering the education sessions and are committed to helping young people to learn about dementia and make positive changes in the community. John lives with dementia and sharing his experiences has had a compelling effect on the students.

“ John and Glenys taught us about inclusive community, on how we can include people with dementia and how we can just change simple things to make a more dementia-inclusive community. ”

Iona College Year 12 student.

The dementia education and awareness sessions have reaped immediate and tangible rewards as illustrated in the following stories.

John Quinn

“ On a daily basis I will get out and walk or run on the foreshore. On many occasions, I’ve come along a group of young men running. They would stop and say, ‘Hello, John, how are you?’ Because they weren’t in uniform, I’d say, ‘Where do I know you from?’ And they’d say, ‘You know us, John. You’ve talked to us at Iona College.’ ”

A man living with dementia went missing from his home, which was located near a large expanse of water. There was serious concern for his wellbeing and a search commenced which included the Queensland Police aerial services. **Students from Iona College found the missing man, notified the authorities and stayed with him to offer support and reassurance.**

Glenys Petrie

“ That’s the impact of reaching out to younger people – the acknowledgement, the connection, the sense of belonging. ”

A member of the local Dementia Alliance organisation noticed a woman was struggling to check in with the QR code in a retail store. Before he had time to act, two young men behind him in the queue offered to help her. They showed the woman how to check in on her phone and then encouraged her to complete the process on their phones so she would be confident checking in the next time.



The Alliance member recognised the two young men as Iona College students.



A warm greeting when out for a walk.



A helping hand in the local store.



A dementia-aware approach to help find a missing person.

In each of these scenarios, small actions on the part of the Iona College students **made a significant difference to someone living with dementia** and reinforced a sense of the community as inclusive and dementia-friendly.



Ramps to navigate the physical world

The built environment can have a significant impact on people living with dementia, but their needs are rarely considered in urban or environmental planning, design, and construction. Lighting, floor coverings, layout of spaces, structural features, signage and wayfinding are all features that are significant design considerations in making it easier for people with dementia to navigate and feel comfortable in private and public spaces. Small modifications such as changes to signage and improved wayfinding – modest ‘ramps’ – can have positive impacts on independence, safety and confidence in negotiating the built environment.

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Our favourite coffee shop usually had stools for those who stayed for coffee. Now there are chairs with armrests interspersed with stools – a huge benefit when my husband was experiencing difficulty sitting and standing from a chair. An outside area was developed with additional tables and lightweight chairs which also served as a quieter area with no ‘through traffic clutter’ for him to negotiate when meeting with friends ”

Ann, carer for a person living with dementia.

Building bridges and opening doors in the Murray Bridge Community Centre

The Murray Bridge Community Centre is a vibrant, independent, not-for-profit organisation that is an important social and physical hub for the small South Australian town of Murray Bridge. The centre's mission is to provide an inclusive, accessible and welcoming space for everyone in the community.¹⁶ Two years ago, staff at the community centre participated in a community dementia alliance meeting at the Rural City of Murray Bridge Council. This included becoming Dementia Friends through Dementia Australia's Dementia Friendly Communities program. Learning about the importance of including dementia-friendly features in the physical environment prompted a review of the centre itself. People with dementia and their family members and carers were invited to do a walkthrough and identify features that could be made more dementia-friendly.

As a result of that audit, a series of small changes were made to improve the centre's accessibility. These included adding a dimmer switch for adjustable lighting in the main meeting room, painting doors in contrasting colours to identify different rooms and distinguishing the front entrance features in bright colours. Other simple dementia-friendly modifications included improving signage clarity for easier way finding, changing toilet seats to a dark colour for contrast, replacing existing doorhandles with lever style alternatives, decluttering communal spaces and offering a conventional kettle and mugs as an alternative to a coffee machine.



A brightly-coloured and welcoming front entrance.



A familiar kitchen appliance.



A dementia-friendly door handle.

The changes made in the Murray Bridge Community Centre are all modest in scale, but collectively they have a significant impact. Every modification, however small, has made a big difference to improving accessibility for people living with dementia and underscored the centre's commitment to "valuing all individuals as equal members of the community."¹⁷

Conclusion

Dismantling dementia-related discrimination is a big aspiration requiring a collective effort. But as the examples on page 10 illustrate, it can start with small actions. At the GP clinic and in the community. Receiving an early diagnosis and information from well-informed health professionals. Getting referrals to vital supports and services. Or the simple intervention to shorten the stressful wait for a doctor's appointment. Dementia-friendly spaces in the local community centre. A quiet area and comfortable chairs in a neighbourhood café. Modest but effective measures that encourage a person with dementia to remain active and engaged in their local community.

“

...we can just change simple things to make a more dementia-inclusive community. ”

Iona College year 12 student.

Endnotes

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96%



of people say **they don't know what to say** to their relative who lives with dementia.

87%



of people living with dementia surveyed felt people **patronise them and treat them as if they are not smart.**

55%



of professionals believed that a doctor will often or always speak to a carer rather than the person with dementia.

91%

of people said that **others do not keep in touch** with their loved one with dementia as they used to.

“

Decisions are often made for people living with dementia.

Healthcare professional.

”

More than 50% of professionals believed that people living with dementia **receive insufficient support** to maintain their independence.

73%

say people make jokes at the expense of their friend or relative who lives with dementia.

“

Just because I have dementia it doesn't mean I am stupid. ”

Person living with dementia.

National Dementia Helpline

1800 100 500



For language assistance
call **131 450**

Find us online
dementia.org.au

