

# **Developing a Guide to the Guiding Principles**

Australia's Disability Strategy 2021-2031

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# About Dementia Australia

Dementia Australia is the source of trusted information, education and services for the estimated half a million Australians living with dementia, and the almost 1.6 million people involved in their care. We advocate for positive change and support vital research.

We are here to support people impacted by dementia, and to enable them to live as well as possible. Founded by carers more than 35 years ago, today we are the national peak body for people living with dementia, their families and carers.

We involve people impacted by dementia and their experiences in our activities and decision-making, to make sure we are representative of the diverse range of dementia experiences. We amplify the voices of people impacted by dementia through advocating and sharing stories to help inform and inspire others.

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

## Introduction

Dementia Australia is grateful for the opportunity to contribute to The Guide to the Guiding Principles and Australia's Disability Strategy.

Dementia Australia has several resources developed in close consultation with, or by, people living with dementia, their families and carers, which may inform the Guide.

These resources include:

- **Half the Story: A guide to meaningful consultation with people living with dementia, their families and carers**
- **Let's Talk: Good communication tips for talking with people with dementia**
- **Our Solution: Quality care for people living with dementia**

Dementia Australia supports all eight guiding principles and believe they are fundamental to respecting the rights, dignity, autonomy, and inclusion of people living with dementia.

In this submission we explore how the following principles impact people living with dementia:

- Principle 1 - Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
- Principle 2 - Non-discrimination
- Principle 3 - Full and effective participation and inclusion in society
- Principle 6 - Accessibility
- Principle 7 - Equality of people
- Principle 8 - Respect for the evolving capacities of children with disabilities and for their right to preserve their identities

## Principles in action: Kaitlyn's story

“Mum and Dad had lived a rural Queensland town for many years. The town was highly inclusive of mum and dad after mum's diagnosis. Mum was always treated with respect and dignity in her pursuit of a new life, a new reality and loss of control of the life she once knew.

The community kept an eye out for her, as mum would get lost when she would walk alone. Everyone, from neighbours to hospital staff, police, and community members, became part of our family and helped us all on mum's journey living with dementia.

Mum was a constant visitor to the shops. Mum would often walk out of shops without paying and then present at a different shop to pay for the goods she had taken from the other store. Mum was never disrespected, instead the staff would take her under their wing and walk with her back to pay for her goods. There was never any fuss, no calls to police to report shoplifting and no yelling and screaming at her. Instead, she was treated with dignity and respect and the staff were calm, kind, and respectful.

My mum was a resident of a secure dementia wing. Although dad was not a resident, he was always included in the daily activities — bus trips and other planned activities that were undertaken by the residents.

Dad made many friends in mum's residential care unit. And even though mum passed away in 2021, dad remains a constant at the residential care unit, visiting friends and helping those that can no longer do things for themselves.

Dad and I are firm believers of paying it forward and helping others in the residential care unit is dad's way of paying it forward. I am completing my Bachelor of Dementia Care to enable me to support not only people living with dementia, but to advocate and support their families as they come to terms with what is to come. My mum, other people living with dementia in her residential care unit, and the kind-hearted people that looked after her, inspired me to undertake my journey as a mature aged student.”

*Names have been changed for privacy reasons*

## Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons

The 2008 United Nations Convention on the Rights of Persons with Disabilities represents an important recognition of the rights of people with dementia or cognitive impairment to make decisions about all aspects of their lives.

With no Australian 'gold standard' for assessment of legal capacity, people living with dementia are vulnerable to unconscious bias or presumptions about competency. It is often assumed that a diagnosis of dementia means a lack of decision-making capacity. But this is not the case.

Decision-making capacity in people living with dementia can fluctuate and is situation specific. Fatigue, medication, delirium, illness or sundowning can all impact the person.

Capacity is neither a person's level of cognition, nor their physical function. A person with dementia may be unable to perform a certain task, but they can still make meaningful decisions about whether they want assistance performing that task.

There will be times when a person's dementia has progressed, or the person chooses to make decisions with a care partner. In these situations, Dementia Australia endorses a spectrum model of supported decision-making — offering tailored support to the individual, according to their preferences and needs.

Dementia Australia has a position statement on supported decision-making which is available [here](#).

Dementia Australia believes that application of this principle should consider the implications of dementia or cognitive impairment on decision-making and autonomy. Proposals should be able to demonstrate the process underpinning the use of supported decision-making.

We suggest the additional prompting questions:

- How will decision-making capacity be assessed?
- Does the proposal allow for spectrum (or tailored) supported decision making?

## Principles in action: Ian's story

"My wife, Sarah, has had dementia for six years now. Fortunately, it's a slow dementia. It gets worse, but then it plateaus, then goes down a bit, then plateaus.

We've always danced. In fact, we met a dance 55 years ago. So, we've always enjoyed jiving, rock and roll type stuff.

A television programme was after people who weren't particularly dancers but enjoy dancing. I said in my online application that my wife has got dementia. If that's a problem, no problem.

They had about 200 applicants, and they brought 40 of us along for an audition. They got us to sit in chairs and exercise, then stand up and move a bit. They eliminated us down to nine people.

It was a 12-week program at the Wharf Theatre, Sydney. It was two sessions a week for two and a half or three hours. We had a professional choreographer who led us through it.

The choreographer - her grandmother had dementia - and she was great. She never once chastised Sarah for doing something wrong. There was a moment where she recognized I was getting frustrated. She took me aside and said, 'Look, I know you're struggling. Just leave that to me. We'll work on this together.' I appreciated that. And Sarah got there, which was amazing. She always had a smile on her face, enjoying it

We've worked in television and movies before, so we understood production. And they were just brilliant. They were so accommodating.

It was a research program. Somebody had seen in an American medical magazine that dancing should be good for you in old age, cognitively and physically, and they wanted to prove it. They tested us before we started and, 12 weeks later, we had a physical and cognitive test again. Every one of us improved. In fact, Sarah had the best overall improvement, even cognitively. And that blew my mind.

It culminated in putting on a show at NIDA Theatre, Sydney. Which was a big thrill, of course. Sarah loved every minute of that. But even the next day, I talked to her about it, and she couldn't remember doing it.

But that's the positivity, I think. I've learned from her to live in the moment. I say to people, 'With Sarah, there's no yesterday, there's no tomorrow. It's all now.' Just live for the moment, don't worry about yesterday or tomorrow."

*Names have been changed for privacy reasons*

## Non-discrimination

Dementia Australia's report, [Discrimination and Dementia – Enough is Enough](#), reveals sobering statistics about the prevalence of discrimination within our community.

The impacts are significant and wide-ranging. Australian and international studies show that dementia stigma and discrimination discourage people from seeking health care and reduce social engagement with family, friends, and the broader community.

Because we cannot treat the underlying cause, a sense of medical futility is still strongly associated with dementia within the community. This pessimism then flows into all aspects of the person's lives.

Dementia discrimination can look like:

- The loss of family and friendships after diagnosis.
- Doctors speak only to the person's carers during appointments.
- People living with dementia aren't referred to rehabilitation or allied health.
- Employees with dementia do not receive support to continue to work.

Our discussion paper [Dismantling Dementia Discrimination: It starts before the diagnosis](#) explores this issue in detail.

Dementia Australia believes that the goal for this guiding principle should not be the avoidance of discrimination, but to actively contribute to ending discrimination.

Dementia Australia suggests an additional prompting question:

- Does the proposal contribute to the dismantling of stigma and discrimination for people living with disability?

## Full and effective participation and inclusion in society

Dementia-Friendly Communities is a growing network of local, grassroots alliances working towards a more inclusive and accessible Australia. This is achieved by:

- Supporting communities and organisations to become dementia-friendly.
- Increasing community understanding of dementia.
- Providing greater opportunity to connect, with local demonstration projects.

Dementia-Friendly Communities represents a significant commitment to ensuring people living with dementia have full and effective participation and inclusion in society.

Dementia Australia suggests that Dementia-Friendly Communities (and the wealth of formal and anecdotal knowledge generated from this programme) can inform the application of this principle.

Further information, including guides for community, business, and government, is available on the [Dementia-Friendly Communities website](#).



## Principles in action: Bonnie's story

"I'm part of a dementia-friendly alliance in Sydney.

Our alliance started off as a working group. We started learning about dementia. We gave out information, went on stations. We've done a lot of work to get information out. But then we thought we can't do this alone. We need other people, like with more professional skills, like the council, disability companies and the dementia peak.

We looked at the big [accessibility guidelines] and we just found there was not much mentioned about dementia. And we thought, 'What if we could do like a two pager, very short, but with testimonies?' Like, what's my experience when I go into cafes? What's been helpful? What hasn't been helpful?

The alliance meets every month and we set goals. I might go out and hand out information sheets or just speak about my experience. We do workshops. We do cafés where we play the Dementia Friends video. We do library presentations as well. This year I went and did an international dementia conference. The other day I spoke at a Sikh temple. We had lunch afterwards and they were so welcoming and lovely.

I'm the chairperson and that gives me confidence. I'm used to management, like running a team in a warehouse and having employees. This gives me something to put back into community. I'm not sitting here on the bed feeling sorry for myself, you know? I'm actively getting out there. The alliance has got me out even when I don't feel like it. It gives me an incentive and a sense of purpose. I feel included.

Because I'm pretty independent and I keep up with everybody, they tend to forget I have dementia. It's quite funny.

That's the other thing, we're building friendships. It's getting me out in the community. Everything I do is voluntary, but I treat it as a job. I mean, it's not a paid one, but it's absolutely a job."

*Names have been changed for privacy reasons*

## Accessibility

Accessibility is fundamental participation, independence, and dignity for people living with dementia. And yet, dementia accessibility has been overlooked for many years.

Due to the broad spectrum of neurological and physical symptoms associated with dementia, dementia accessibility is a multifaceted concept that involves the built environment, readability standards, and communication style.

Dementia enabling (or dementia-friendly) design principles are often associated with residential aged care, but people living with dementia, their families and carers aspire to have all public spaces made accessible. These modifications include, but are not limited to:

- Reducing the amount of sensory stimulation
- Ensuring safe levels of lighting
- Using colour to aid depth perception
- Combining words and pictures in signage
- Integrating orientating tools, like clocks and directions, into decor.

A supportive and patient attitude can be as enabling to a person living with dementia as any physical or visual modification.

Dementia Australia has a suite of tools and resources (including immersive apps) to educate the community on dementia accessible environments.

Our guide to meaningful consultation, **Half the Story**, explains how a range of consultative methods (focus groups, surveys, and meetings) can be tailored to the needs of people living with dementia.

It is important that this principle recognises that accessibility needs are diverse, and that a 'one size fits all' approach is likely to exclude people living with dementia.

Dementia Australia suggests amending the prompting question to:

- Can people with **physical and cognitive disability** access all aspects of the proposal, including the information, technology, services and location?

## Principles in action: Daniel's story

"Our experience relates to air travel. In particular, how good the support at airports is now. Brisbane is a dementia-friendly airport officially, I believe.

Our last overseas trip was in 2018. On that trip I specifically advised the airlines that we needed help for [my wife] due to her advanced dementia. That was the best thing that I could have done.

At each leg we were called up first to board. This caused some funny looks, as you cannot tell she has dementia just by looking at her. On arriving, we would be the last to de-plane, but a wheelchair or electric trolley would be waiting to take us through the airport to customs or the baggage collection.

Our plane was late into Frankfurt airport. I was sure that we would not make the next leg but, when we were picked up, the trolley went through a staff-only elevator and hidden corridors. We skipped the security check, and the staff member took our passports to the front of the customs queue to get stamped. We ended up at the next gate before anyone else!

Back at Brisbane airport we were asked if we wanted to do duty-free shopping. We said no and, next thing, we were guided through directly to the customs area and out at baggage collection in record time.

When you are responsible for someone who has dementia when travelling, it is really stressful. You are always on the alert, as bags get left, or my wife gets lost in the ladies. (Hate those toilets with multiple exits.)

Hats off the BNE international for making the experience so easy."

*Names have been changed for privacy reasons*

## Equality of people

When applying the principle of equality, it is important to consider how a person's dementia intersects with other social or economic disadvantages.

Although dementia impacts people from all backgrounds, First Nations peoples appear to be disproportionately affected. Rates in remote and rural Indigenous communities are some of the highest in the world<sup>1</sup>. And prevalence of younger onset dementia is higher than the national average.

Ample evidence indicates a preference for Aboriginal community-controlled services that support a person with dementia to live at home on Country or with community. However, Dementia Australia is aware of concerning shortages of culturally safe services and workers, particularly in regional, rural, and remote areas.

When applying this principle, we should consider how the lack of appropriate support or services impacts a person's dementia 'journey' or experience. Negative experiences with health services in the past may also affect future decisions.

Cultural norms or attitudes to dementia in both First Nations and other diverse communities can influence help-seeking behaviour for the person living with dementia and their family. Members of some communities may choose to avoid diagnosis or not disclose their condition.

By using death certificate data, we estimate that 1 in 3 people with dementia were born overseas and that 1 in 5 were born in a non-English speaking country<sup>2</sup>. This is a significant proportion of the dementia community.

The policy repercussion is a lack of representation from some backgrounds in dementia research, service design, and outcome setting. Without this experiential data, we will struggle to achieve equality or provide equitable support.

Dementia Australia recommends engagement with diverse communities regarding cognitive disability as a priority action, as well as investment in the development of culturally safe health messaging, services and support.

## Respect for the evolving capacities of children with disabilities and for their right to preserve their identities

Dementia Australia acknowledges the almost 2,300 children living in Australia with childhood dementias, as well as their parents, guardians, families and friends.

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<sup>1</sup> Australian Institute of Health and Welfare (2022) [Dementia in Australia](#), AIHW, Australian Government, accessed 29 November 2022.

<sup>2</sup> Australian Institute of Health and Welfare (2022) [Dementia in Australia](#), AIHW, Australian Government, accessed 29 November 2022.

Caused by over 70 rare genetic disorders, childhood dementia is a terminal neurodegenerative condition. Many children with dementia do not live to adulthood.

Dementia Australia supports the **Childhood Dementia Initiative** in their campaign for greater recognition of childhood dementias.

We believe this principle must recognise the unique needs of children with progressive disabilities with an additional prompting question:

- Have the needs of children with progressive or neurodegenerative disabilities been considered?

## Conclusion

Dementia Australia welcomes the opportunity to discuss how the National Disability Strategy can support and empower people living with dementia, their families, and carers.

Dementia Australia extends an offer to the Department of Social Services to facilitate further consultation with dementia advocates on this important work.