Australian Government
Department of Health and Aged Care

National Dementia Action Plan

2024–2034

Contents

Acknowledgement

We stand on the shoulders of 1,600 generations of First Nations people. We acknowledge and pay respects to all First Nations people across Australia, who are the Traditional Owners and Custodians of the land and waters and of the oldest continuous living culture on Earth. We pay respects to Elders past and present.

We recognise that First Nations people must have a genuine say in the design and delivery of services that affect them for better life outcomes to be achieved. We commit to ongoing partnership with First Nations people in implementing and monitoring this Action Plan, in accordance with the National Agreement on Closing the Gap.

Dedication

This Action Plan is dedicated to each and every person who has been impacted by dementia, and to those who will be impacted in the future.

We recognise the achievements and contributions they make to our society.
We acknowledge their resilience to maintain independence, identity, live well and lead a fulfilling life. We recognise the many challenges, stigma, isolation and discrimination faced. We acknowledge the care and sacrifices made by their loved ones and the physical and emotional impacts on carers and families.

We acknowledge and thank all the people and organisations who work tirelessly every day to care for people living with dementia, and whose advice and advocacy have informed the Action Plan.

Endorsement of Health Ministers

Hon Mark Butler MP
Minister for Health and Aged Care

Hon Timothy Nicholls MP
Queensland
Minister for Health and Ambulance Services

Hon Ryan Park MP
New South Wales
Minister for Health
Minister for Regional Health
Minister for the Illawarra and the South Coast

Hon Amber-Jade Sanderson MLA
Western Australia
Minister for Health and Mental Health

Hon Mary-Anne Thomas MP
Victoria
Minister for Health
Minister for Health Infrastructure
Minister for Ambulance Services
Leader of the House

Hon Chris Picton MP
South Australia
Minister for Health and Wellbeing

Hon Anika Wells MP
Minister for Aged Care
Minister for Sport

Hon Steven Edgington MLA
Northern Territory
Minister for Health
Minister for Mental Health
Minister for Alcohol Policy
Minister for Aboriginal Affairs
Minister for Housing, Local Government and Community Development
Minister for Essential Services

Ms Rachel Stephen-Smith MLA
Australian Capital Territory
Minister for Health
Minister for Mental Health
Minister for Finance
Minister for the Public Service

Hon Jacquie Petrusma MP
Tasmania
Minister for Health
Minister for Aboriginal Affairs
Minister for Veterans' Affairs

Foreword

Over the course of our lives, almost all of us will be affected by dementia in one way or another. We can experience it ourselves, become a carer to a family member or friend, or through interactions at work or in the community. In 2023, it was estimated that over 400,000 people were living with dementia in Australia, with this number estimated to more than double by 2058.[1]

The National Dementia Action Plan sets out a clear roadmap representing our national commitment to make Australia more dementia inclusive and where all people impacted by dementia can access support that meets their needs. This Action Plan sets out 8 actions, supported by measures that will tell us if we have achieved that change. These actions work to make Australia a country where people living with dementia are valued, have autonomy, feel supported and are able to participate and remain connected within their community.

This Action Plan is the result of extensive research, planning and consultation, and many people have helped us get to this point. The voices of people living with dementia, their carers and families, have been pivotal in defining how we can make real change to achieve our shared vision – **'people living with dementia, their carers and families have the best quality of life possible' and 'people living in Australia recognise and understand dementia'**. We extend our thanks to all the individuals and organisations who shared their experiences, advice, hopes and priorities for the Action Plan.

Dementia impacts people in different ways and there are some groups who need different or additional supports. That's why the Action Plan sets out actions that will address the needs of diverse and high-risk populations including for First Nations people, people from culturally and linguistically diverse (CALD) communities, people with disability and people living with younger onset dementia. These actions will also consider the overlapping needs of people who have multiple diverse characteristics and backgrounds.

This Action Plan fulfils one of Australia's obligations under the World Health Organization (WHO) Global action plan on the public health response to dementia 2017–2025.[2] It represents a commitment to improve the lives of people living with dementia by all governments – Australian, state and territory. However, the success of this plan rests on a whole of community response, inclusive of business, the non-government and services sectors and individuals – together we can create change.

This Action Plan creates the foundation for future policy that will improve the experiences and lives of people with dementia, their carers and families moving forward.

Implementing the Action Plan requires a partnership approach. The Australian Government and all state and territory governments are committed to working together to develop a staged implementation approach that supports the Action Plan across the next decade.

National Dementia Action Plan Actions

The Action Plan includes 8 actions in support of its vision. These are broad actions for the life of the Action Plan over 10 years.

Action 1: Promote equity and human rights

Action 2: Tackle stigma, improve awareness and promote inclusivity

Action 3: Empower individuals and communities to minimise risk where they can, and delay onset and progression

Action 4: Improve dementia diagnosis and post-diagnostic care and support

Action 5: Improve treatment, coordination and support for people living with dementia

Action 6: Support carers of people living with dementia

Action 7: Build capability of the workforce to care for and support people living with dementia

Action 8: Improve dementia data, maximise the impact of dementia research and promote innovation

Introduction

The National Dementia Action Plan 2024–2034 (the Action Plan) is Australia's national dementia policy framework. It sets out a plan for continuing to improve the lives and care of people living with dementia in Australia over the next 10 years.

Purpose

The purpose of the Action Plan is to:

- provide a vision, setting out where we want to be in 10 years' time
- guide action by Australian, state and territory governments so that policies, services and systems are better integrated
- engage and involve the whole community in actions to achieve a society that promotes the best possible quality of life for people living with dementia, including their emotional wellbeing and identity
- drive improvements to services and systems for people living with dementia and their carers
- enable measurement of progress against the actions.

The Action Plan has been driven by people living with dementia, their carers and families. Quotes from people with lived experience of dementia can be found throughout the Action Plan, reflecting our commitment to put them at the centre.

> *'The Action Plan provides a shared understanding of where we're at and where we want to be'.*

Audiences include the diverse range of people living with dementia and their carers*, policy makers, health professionals, care workers, service providers, advocacy groups, educators and researchers. The Action Plan also conveys Australia's intentions to international audiences.

Why do we need an Action Plan?

Dementia has a major impact on individuals, families and communities across Australia, and is a significant and growing health issue. In 2023, it was estimated that over 400,000 people were living with dementia in Australia, with this number estimated to more than double by 2058.[1] Two in 3 people living with dementia live in the community and approximately 7% of people living with dementia are under the age of 65. Dementia is one of the major causes of disability and dependency.[3] It can lead to a range of cognitive, emotional and physical changes that may limit a person's ability to perform daily activities without supports and enabling environments. Dementia is the second leading cause of disease burden and death in Australia, and is the leading cause of death for Australian women.[1]

* Although 'carer' or 'informal carer' is a commonly used term in Australia to describe people providing unpaid support to people living with dementia, the preferred term by many is 'supporter', 'care partner' or 'support networks', or 'family and friend carers'.

People living with dementia are at risk of experiencing stigma, discrimination, isolation and abuse. This can negatively impact their quality of life including emotional wellbeing, physical health, autonomy and identity. Coordinated action to address the ageist attitudes and approaches of individuals, institutions and society as a whole is required.

A shared responsibility

Dementia is a shared responsibility. People living with dementia, their carers and families, may access care and supports through a range of systems, including health (such as primary care, acute care, specialist care), aged care, disability and carer supports. All levels of government – Australian, state and territory and local governments – have some degree of responsibility in funding, delivering and/or regulating these systems. This brings complexity and underscores the need for a joint Australian, state and territory government plan to support improved integration of services.

Australian, state and territory governments invest in a range of dementia related services and programs. The Australian Government funds care and support for older people through the aged care system and programs for people living with dementia, their carers and families, as well as investments in upskilling the aged care and health workforces to better recognise their needs. State and territory governments fund (in part or full) a range of dementia related services like memory clinics, geriatric evaluations, aged care visiting services, older adult mental health services and hospital to residential aged care transition services. A range of vital dementia and carer services are also delivered by local and non-government organisations, which are integral to improving dementia outcomes.

The Australian Government expanded and developed new programs for people living with dementia, their carers and families in response to findings of the Royal Commission into Aged Care Quality and Safety (the Royal Commission), investing an additional $229 million from 2021 to 2025.[4]

Implementing the Action Plan will require a coordinated effort. The Australian Government and all state and territory governments will work together to develop a staged implementation approach that supports prioritisation and delivery of the Action Plan's actions over the next 10 years.

The case for health reform

Most recent investment by the Australian Government in direct services or care has been through the aged care system, focused on support programs for people and carers after diagnosis, respite supports for dementia carers and training for the health and aged care workforces.

There is a need to improve the care and experience of people living with dementia as they interact with the health system. The health system must be able to respond to the growing number of people who will be diagnosed with dementia in the coming decades.

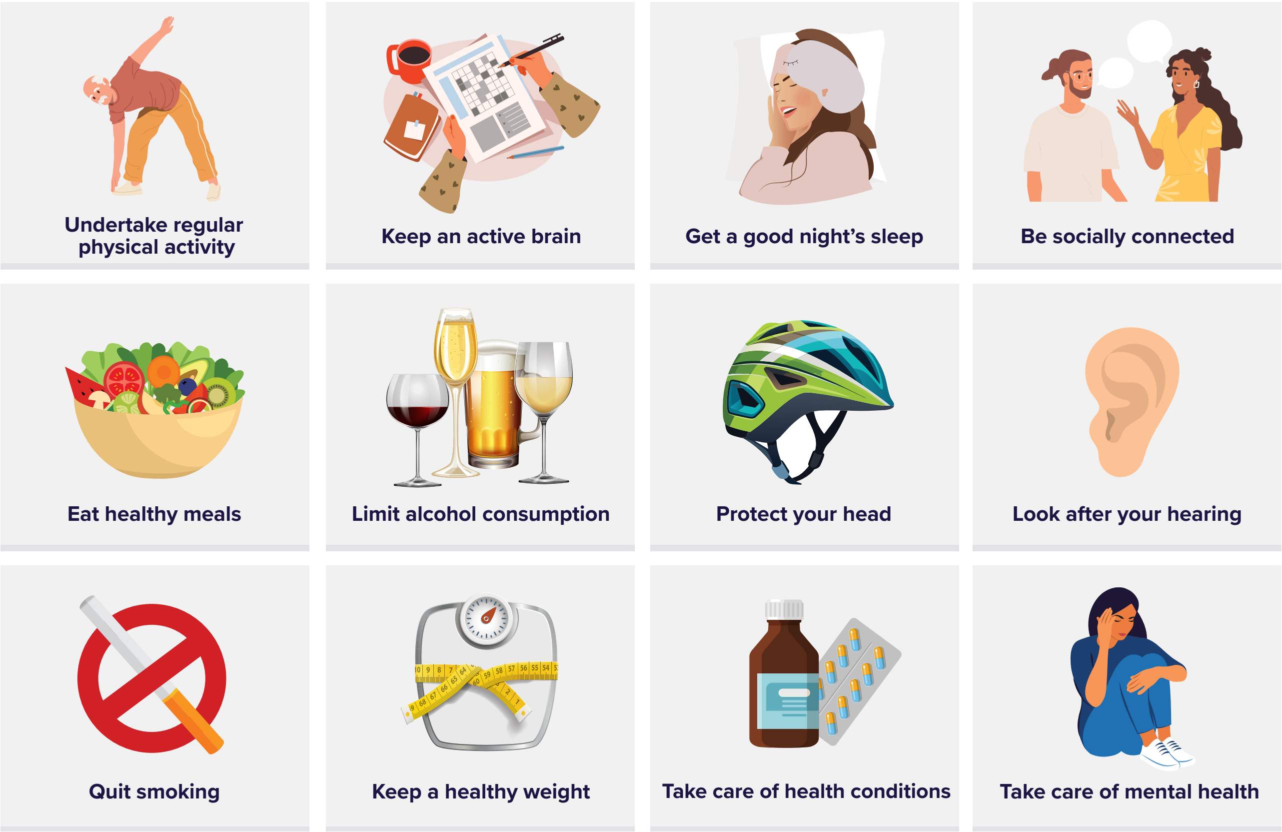
For example, people with dementia are likely to stay 5 times longer in hospital than average and more than half of the people living in residential aged care homes have dementia.[1] Health and aged care services for people living with dementia are estimated to cost governments more than $3 billion per year.[5]

The ageing population and increasing prevalence of dementia will increase demand for healthcare services, including in response to new diagnostic tests and treatments (often referred to as ‘disease modifying therapies’). Changes to the health system are also needed to make dementia diagnosis and treatment more consistent, efficient and better integrated with social care. This could reduce hospital admissions, reduce delayed discharge from hospital to care settings, improve transition between health and social care settings and allow more people to be cared for in the community.

There are opportunities to align action on dementia with preventive health approaches, including the National Preventive Health Strategy 2021–2030, to reduce individuals’ risk of developing dementia and to delay onset and progression, which will reduce pressure on health and social care systems. Many of the modifiable risk factors for dementia are common to other chronic conditions. Action to reduce lifestyle related risks such as obesity, physical inactivity, tobacco use, high blood pressure and high blood glucose could reduce the rates of dementia at a population level. International evidence suggests that a significant proportion of dementia cases could be prevented, or their onset delayed, by reducing risk factors. It is estimated that the reduction rate is between 45% and 56%.[6, 7]

There are also opportunities to align action on dementia with the National Strategic Framework for Chronic Conditions. This Framework is currently being refreshed and provides overarching policy for the prevention and management of chronic conditions, recognising there are often similar underlying actions to reduce the impact of a broad range of chronic conditions.

Proven ways to reduce the risk and/or delay the onset of dementia



Undertake regular physical activity

Keep an active brain

Get a good night’s sleep

Be socially connected

Eat healthy meals

Limit alcohol consumption

Protect your head

Look after your hearing

Quit smoking

Keep a healthy weight

Take care of health conditions

Take care of mental health

Source: Dementia in Australia Report, AIHW[1]

How can the Action Plan drive change and build on what's already being done?

This Action Plan complements current aged and disability care reforms and presents the opportunity to drive changes across the health care system through coordinated action around prevention, detection, diagnosis and treatment. The 'roles and responsibilities' table on page 81 details current roles and responsibilities across governments. Over time, this could lower the future number of new cases of dementia and support people living with dementia to live well and independently for longer, reducing pressure on health and social care systems. For example, if the Action Plan can lead to as little as 5% annual reduction in the number of new cases of dementia in people aged 65 and over, then it could result in up to $120.4 billion in savings by 2056.[8]

At the same time, governments, communities, individuals, businesses and the non-government sector all need to act where they can to reduce stigma and isolation, address discrimination and promote equity, and make all of our communities dementia friendly.

The Action Plan builds on the previous 2 National Frameworks for Action on Dementia (the frameworks), the last of which notionally expired in 2019. The frameworks were guiding documents developed by Australian, state and territory governments to create a strategic, collaborative and effective response to dementia in Australia.

An evaluation of the most recent framework found that, while it provided a guide for policy makers, people living with dementia and their carers did not feel that it had made a practical difference to their experience. The lack of indicators to measure improvements and monitoring of progress further limited the value of the framework.

The Action Plan is a roadmap that underpins planning, collaboration and coordination of activities for governments, private and not-for-profit organisations across services, policy, research and data systems. The Action Plan sets out 8 actions, supported by descriptions of how we will make a difference and measures that will tell us whether we have achieved the intended change. The Action Plan is consistent with the WHO's Global action plan on the public health response to dementia 2017–2025 and fulfils one of Australia's commitments as a member state.[2] Further information about dementia is provided in Appendix 1.

The implementation and reporting approach for the Action Plan is detailed from page 82.

Impact of dementia in Australia

Over
400,000
people are estimated to be **living with dementia**

More than
28,400
people under 65 are living with **younger onset dementia**

Number of people living **with dementia** is projected to **more than double** by the **year 2058**

5x
longer hospital stays on average

Younger onset dementia cases expected to rise to
39,000 **by 2050**

2nd
leading cause of **disease burden** in Australia

67%
of people living **with dementia** live in the community

2nd
leading **cause of death** for Australians and **leading cause of death for women**

$3 billion
annually directly spent on health and aged care for people **with dementia**

Source: Dementia in Australia Report, AIHW[1]

Vision

The Action Plan's vision is:

People living with dementia and their carers have the best possible quality of life, including their emotional and physical wellbeing. People living in Australia recognise and understand dementia.

Principles

The following principles underpin the Action Plan.

- The human rights of people living with dementia and their carers are protected and upheld, aligning with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)
- The needs of priority populations at a higher risk of developing dementia are explicitly considered in designing actions
- Action on dementia is driven by people living with dementia and their carers, through equitable inclusion and expression of their lived experience
- Action on dementia is collaborative, coordinated, integrated, planned and responsive to need
- Services and supports for people living with dementia and their carers are:
    - **holistic and strengths-based**, supporting people living with dementia in all aspects of their life, including a focus on **wellness and maintaining independence**
    - **person centred and relationship-based**, driven by the preferences of people living with dementia and their carers
    - **evidence-based, outcomes focused** and **maximise quality of life** for people living with dementia and their carers
    - **appropriate, trauma informed, accessible** and **culturally safe** for all people
    - **co-designed** and **delivered** in **partnership** with **local communities** where possible, including First Nations people, CALD communities, women and girls, young people, people with disability and LGBTIQA+ communities.

Governments, service providers, individuals and communities are committed to delivering on these principles in the design, implementation and evaluation of all actions set out in this Action Plan.

How the Action Plan was developed

People living with dementia, their carers and families were instrumental to the development of the Action Plan and throughout the process.

The Action Plan was informed by a public consultation process involving a range of activities. This included:

- a consultation paper (full and summary)
- one-page flyer with the proposed vision
- principles, objectives and action areas
- a short video to explain the Action Plan
- a postcard with ‘call to action’ in places older people frequent
- an online consumer facing survey.

The survey design included the option for translation of content into a variety of languages, the option to respond verbally, rather than online and availability of the survey in hard copy format. Submissions were invited in writing, via email or verbally through a dedicated phone line, or via the online survey.

Australian, state and territory governments promoted the consultation among their extensive networks to increase participation during the consultation process. Dementia Australia and Carers Australia supported people to respond, undertook activities to encourage feedback and ensured the voices of people living with dementia, their carers and families were heard.

A report summarising feedback from the public consultation on the key elements of the consultation paper is available on the Department of Health and Aged Care (the department) website.[#] The Action Plan's 8 actions were consistently highlighted as opportunities for improvement by people with lived experience of dementia, experts and the broader community.

Early engagement was undertaken with peak bodies that represent people living with dementia, health professionals and clinical experts, academics and researchers, and health, aged care and disability support service providers.

Throughout the development of the Action Plan, views were sought from a range of international policy teams, including the WHO and international policy teams that had recently developed their own country's dementia plan (including Canada, Germany, United Kingdom and Vietnam). Other key stakeholders approached included, but were not limited to:

- National Aged Care Advisory Council
- Aged Care Council of Elders
- National Aboriginal Community Controlled Health Organisation (NACCHO)
- Older Persons Advocacy Network (OPAN)
- Dementia Australia
- Carers Australia
- Dementia Training Australia (DTA)
- University of Tasmania's (UTAS) Wicking Dementia Research and Education Centre
- Aged Care Quality and Safety Commission (Aged Care Commission)
- Australian Commission on Safety and Quality in Health Care (Health Commission)
- Australian Medical Association (AMA)
- Australian College of Rural and Remote Medicine (ACRRM)
- Royal Australian College of General Practitioners (RACGP).

Visit www.health.gov.au/resources/publications/development-of-the-national-dementia-action-plan-summary-of-consultation-outcomes.

To address some of the key feedback stemming from public consultation, the department undertook further engagement with a range of key delivery partners, including:

- OPAN to strengthen the focus on human rights and supported decision making
- NACCHO to advise on targeted initiatives to improve outcomes for First Nations people and communities
- Partners in Culturally Appropriate Care (PICAC) Alliance to identify actions to improve outcomes for people from CALD backgrounds
- ACRRM to provide guidance on improving outcomes for people living with dementia and their carers living in rural and remote regions
- health professionals, including the AMA and the RACGP regarding the important role of GPs and mechanisms that could support GPs to assist people living with dementia.

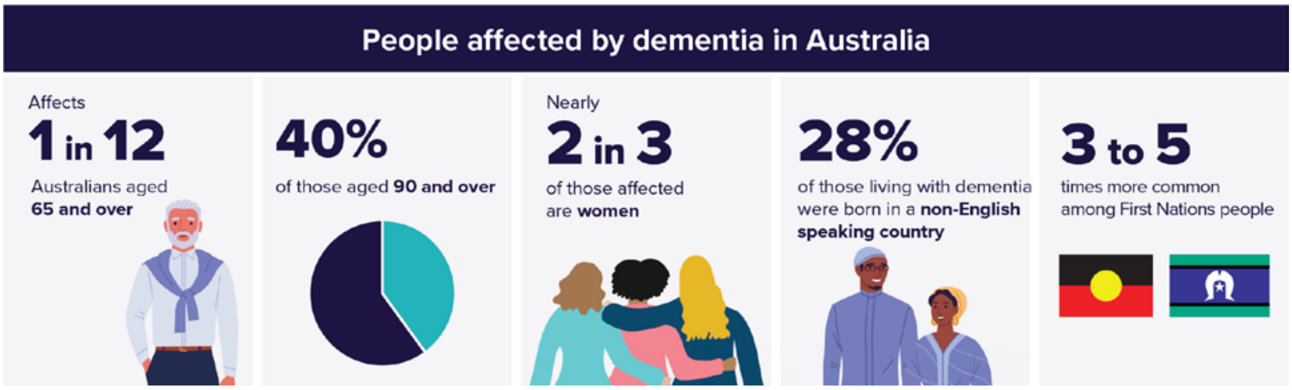
The content of the Action Plan was developed collaboratively through a Jurisdictional Working Group, with membership from Australian, state and territory government health agencies. The Action Plan was also informed by engagement with a range of government agencies that service groups of people at risk of, or living with dementia, their carers and families. This will ensure reforms are coordinated and meet the needs of different communities. This includes agencies such as the Department of Social Services, the National Disability Insurance Agency, the Department of Veterans Affairs and the Attorney-Generals' Department.

We thank everyone who took the time to contribute to this important work.

Groups at higher risk of developing dementia or facing barriers to equitable access (priority populations)

Different groups in the community may be at higher risk of developing dementia, more likely to experience stigma and discrimination following diagnosis, or face additional barriers to accessing the care and supports they need. It is acknowledged that every individual's experience is unique.

Intersectionality recognises that a person or group of people can be affected by multiple forms of discrimination and disadvantage due to the overlapping and compounding effects of their race, sex, gender identity, sexual orientation, impairment, class, religion, age, social origin, geographic location and other identity markers. Throughout the life of the Action Plan, actions will be implemented with an intersectional and diversity lens, and proactively address the needs of people at higher risk of developing dementia or facing barriers to equitable access and ensure they are able to access tailored resources, services and supports.



People affected by dementia in Australia

Affects **1 in 12** Australians aged **65 and over**

40% of those aged **90 and over**

Nearly **2 in 3** of those affected are **women**

28% of those living with dementia were born in a **non-English speaking country**

3 to 5 times more common among First Nations people

Source: Dementia in Australia Report, AIHW[1]

Older people

People over the age of 65 are at higher risk of developing and being diagnosed with dementia.[1] While age is the biggest risk factor, dementia is not a normal part of ageing and is a form of disability. A diagnosis of dementia can result in ageist responses from others as well as triggering internalised ageist beliefs. This is compounded by the fact that there is a general lack of understanding of dementia, its different causes and how it can differently affect each person.

> ‘Older persons with disabilities are subject to a greater extent to loss of power, denial of autonomy, marginalisation and cultural devaluation. They are also more prone to social isolation, exclusion, poverty and abuse.’
>
> *UN Special Rapporteur on the rights of persons with disabilities*[9]

Women

There are clear gender differences in the impact of dementia.[1] Almost two thirds of Australians with dementia are estimated to be women. Dementia is the leading cause of death for women in Australia and in 2022 was the leading cause of disease burden for Australian women, compared with the fifth leading cause for men.[1]

The number of women living in permanent residential care with dementia far exceeds the number of men with dementia. Women also undertake the majority of caring responsibilities in both the paid workforce and less formal roles.[10] Most direct care workers in aged care identify as female (up to 86% in residential aged care).

Women also undertake a majority of informal carer roles and constitute nearly three quarters of primary carers of people living with dementia.[11] This applies to women below and above 65 years of age.[1]

People from culturally and linguistically diverse backgrounds living with dementia

People from CALD backgrounds make up approximately 28% of the population of people living with dementia in Australia.[12]

People living with dementia from CALD backgrounds, especially those from non-English speaking backgrounds or whose cultures, religions and languages are not practiced widely in Australia, can face challenges accessing the supports they need. Services may not always be culturally appropriate, particularly where people have language barriers and specific cultural needs. There is also varied availability of cultural-specific services. People may be less likely to access formal care or supports due to cultural expectations and preferences and family obligations.

> *'The people who provide my care don't understand my culture.'*

Language barriers may increase social isolation, including where people return to their first language as part of the impact of dementia.[1]

> *'Carers talk to my mum in English and she can't relate – they offer her water, she says no but she doesn't mean it – she is highly dehydrated.'*
>
> *'It can be difficult to access and use respite as often the carers do not speak my language.'*

People living in regional, rural and remote areas

People living in regional, rural and remote communities can face particular challenges in accessing diagnostic and specialist support services or health professionals with expertise in dementia.

> *'There are no geriatricians or neuropsychologists where I live. And to get an MRI or PET scan I have to travel 4 hours.'*

Distance often presents a significant barrier to getting a diagnosis and accessing the services that people living with dementia and their carers need, such as respite care, transportation and in-home supports. There is generally poorer access and availability of a range of services, including psychiatry and allied health services. It is important to keep those requiring care as close to home as possible, to minimise time and cost impacts for families and to keep people connected to their community. This is further exacerbated in First Nations communities where cultural competency is required.

It is also more challenging to maintain a workforce that is qualified to support people living with dementia and their carers – there are often higher costs to attract, retain and accommodate nurses, allied health and personal care workers in remote areas.[13] Rural generalists play an important role in dementia care. They are often the only provider of medical services in rural and remote areas and, in areas where health services do exist, are often the first point of contact for people living with dementia. There are limitations associated with telehealth and fly-in-fly-out models and they may not always be appropriate or accessible for a dementia diagnosis and ongoing management.

A study found that people in rural and remote areas were much less likely to receive Alzheimer's disease medication with prescription rates reducing as both remoteness and socioeconomic disadvantage increase.[14]

People with disability

More than one in 6 Australians have a disability. People with disability can experience stigma, discrimination and exclusion, which can increase following a dementia diagnosis. People living with both dementia and other disability may require additional, tailored care and support due to their more complex needs.

Australia's Disability Strategy 2021–2031 (the Disability Strategy) is Australia's overarching policy framework that provides national leadership towards an inclusive Australian society that ensures people with disability can fulfil their potential, as equal members of the community.[15] The Disability Strategy recognises that all levels of government and all portfolios are jointly responsible for supporting this vision, working closely with the disability community, business, the non-government and services sectors to drive positive change.

People with intellectual disability are at a higher risk of developing dementia than people without intellectual disability. For example, estimates suggest that around 50% of people with Down syndrome will develop dementia due to Alzheimer's disease by the time they are in their 60s.[16] The onset of dementia in people with intellectual disability (other than Down syndrome) is on average 10 years younger than people without intellectual disability.[17]

According to National Disability Insurance Scheme (NDIS) data, as of 30 September 2022, 0.9% of people receiving NDIS support have some form of dementia recorded as either a primary or secondary disability, with half of those having no other conditions recorded on their record.

We are still learning how best to support people living with the intersecting needs of dementia and disability. While people under 65 years of age with a significant, ongoing disability may be eligible to access the NDIS, the number of people living with dementia and an approved NDIS plan in place is relatively low. As at 30 September 2022, there were 3,296 participants with an NDIS plan with a primary or secondary disability recorded as dementia.[18] People under 65 living with dementia should always be encouraged to check their eligibility for the NDIS, along with exploring support services outside those provided through My Aged Care and the NDIS.

People living with younger onset dementia

Dementia does not only affect older people. Younger onset dementia typically refers to dementia with an onset before the age of 65. Around 27,800 people are currently living with younger onset dementia (around 7% of all people living with dementia in Australia) and this is projected to increase to 39,000 by 2050.[19]

Younger people living with dementia experience different challenges, including where they may have young families (around 18% of people living with younger onset dementia have dependent children)[19], are working and/or need to access residential care to meet their care needs. The impact on, and needs of, carers of younger people living with dementia can also be different, with carers of younger people more likely to still be working and/or with other caring responsibilities.

The needs and care requirements of people living with younger onset dementia and their families are often different to those of older people. They face barriers to accessing appropriate services, as these tend to be designed around the interests and physical abilities of older people. People living with younger onset dementia often retain good physical health, which can affect their integration into dementia services that are targeted to older people.

The unique support needs of people living with younger onset dementia can also impact their ability to find suitable home and living options. There is a lack of suitable accommodation, models of care and a workforce that is appropriately trained to meet the needs of people living with younger onset dementia.

> *'I feel like I fall through the gaps and don't know which way to turn.'*

Children living with dementia

While dementia is usually associated with older people, children also experience dementia-causing disorders. There are an estimated 2,273 children living with childhood dementia in Australia.[20]

Childhood dementia results from progressive brain damage and can be caused by over 70 rare disorders. These conditions are genetic and children are born with them. The average life expectancy of all childhood dementia conditions is estimated to be 28 years, with most children (75%) dying before they reach 18.[21] About 90 children die in Australia every year from childhood dementia.[22]

Given the genetic nature of childhood dementia, many families have more than one child living with the condition. This can impact many areas of their life, including their capacity to work and socialise. Children living with dementia can face additional challenges in accessing dementia care and support services due to limited pathways and specialised services. Like people with younger onset dementia, the care and support needs of children living with dementia are different to older people and research is underway to articulate those needs more clearly.

People living with dementia who identify as LGBTIQA+

Many people who identify as lesbian, gay, bisexual, transgender, intersex, queer, asexual or sexually or gender diverse (LGBTIQA+ people) have experienced isolation and discrimination and may feel unsafe disclosing their past experiences or identities. People who identify as LGBTIQA+ may have repressed their sexual or gender identity. They may also experience particular challenges in finding services that are responsive to their identity and needs and service providers and workers with whom they feel safe.

Veterans living with dementia

International studies suggest that traumatic brain injury and posttraumatic stress disorder (PTSD) are risk factors for dementia. Veterans who suffer from these conditions could be at increased risk of depression.[23]

There is recognition that more research is needed to understand the relationship between dementia risk factors and the prevalence of dementia among veterans. As more research emerges internationally, further work will be required to understand what this means in an Australian context.

People at higher risk of repeated head injuries

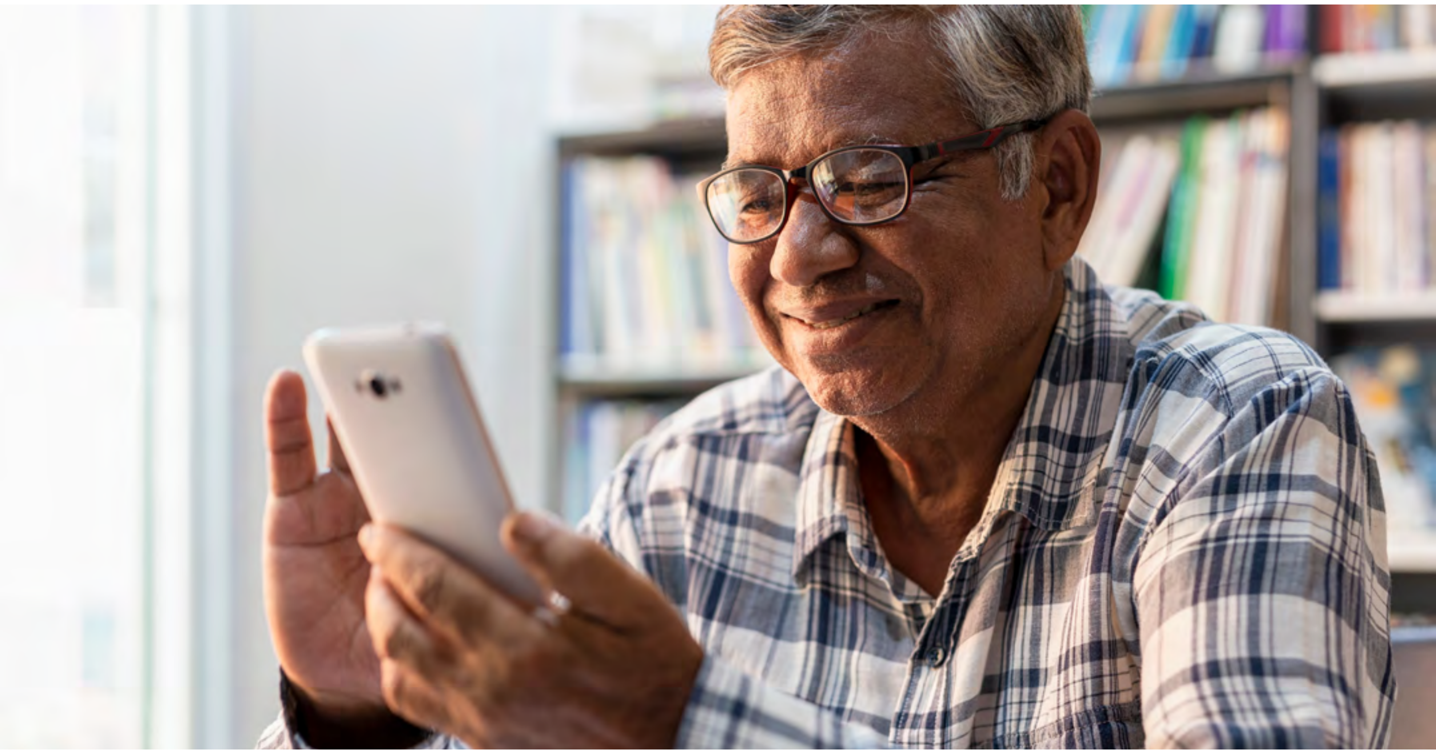
Repeated head injuries (such as those sustained by people playing sports and victim-survivors of domestic and family violence or serious brain injuries from motor vehicle accidents) can affect someone's brain function over time, enough to interfere with the person's normal or working life. This emphasises the importance of engaging in sports activities in a safe way to minimise risk of head injury.

Research also shows that people who have a significant brain injury or trauma, resulting in loss of consciousness or fracture, are more likely to develop younger onset dementia and dementia later in life.[19]

People living with dementia who are experiencing, or at risk of homelessness

There are significant numbers of people experiencing homelessness with cognitive impairment, including dementia. Many people experiencing, or at risk of homelessness, have experienced trauma, abuse, neglect and discrimination. They may also have longterm health problems as a result of poor nutrition, mental health complexities or injuries sustained due to violence.

People who are experiencing, or who are at risk of, homelessness face challenges in accessing diagnostic services and dementia supports that are sensitive and respectful to their needs. This makes diagnosing and managing dementia more difficult.



Particular considerations for First Nations people living with dementia and their communities

First Nations people living with dementia

Dementia is estimated to be 3 to 5 times higher in First Nations populations than in the general population.[1] The reasons for this are still being explored, however, it may be due to higher rates of chronic conditions and increased exposure to risk factors.[24] Rates of dementia for First Nations people in remote and rural communities are estimated to be among the highest in the world.[25]

In the decade to 2031, the population of First Nations people aged 50 and over is projected to double to almost 250,000 people. This population growth, combined with the complex health issues, including dementia, that First Nations people experience as they age, will present significant challenges for health and aged care providers in responding to the increased service needs of First Nations people. Compounding this, an estimated 33,000 of these people are Stolen Generations survivors who experience a significantly higher burden of trauma and chronic conditions and are more likely to develop dementia as they age.

Mainstream health and care pathways, designed for the general population, are unlikely to be culturally safe for First Nations people. Systems are complex and make assumptions that create barriers. Assumptions include that people reside in a fixed location, are proficient in English, computer literate, have access to records and identification documents, will trust strangers and government with sensitive information and have confidence engaging with bureaucratic processes, which may not be the case for First Nations people. Additionally, those living with dementia are likely to experience further barriers.

While there is often strong stigma associated with dementia, this can be even more so in First Nations communities. Dementia is often accepted as a part of ageing and stigma is based on fear of removal from family and/or country, particularly for Stolen Generations survivors.

We have heard that First Nations people are more likely to be discriminated against because of their Aboriginality than their dementia. This can impact their willingness to access services due to a lack of trust of health professionals and loss of autonomy in mainstream services.

First Nations people can also experience challenges in accessing services due to a lack of culturally safe supports and culturally competent workers. First Nations people living with dementia in rural and remote communities can face further barriers to accessing the services they need.

> *'Our people don't get dementia, families don't want to know'.*
>
> *'It's important to find health and aged care services that respect culture as well as care needs.'*

Effective coordination and collaboration between mainstream health and aged care pathways and Aboriginal Community Controlled Organisations (ACCOs) is required to deliver better health outcomes for First Nations people. The appointment of a First Nations Aged Care Commissioner in 2025 will strengthen engagement with First Nations stakeholders and communities, contribute to improvements for First Nations people across the aged care system and promote culturally safe dementia and aged care. An interim Commissioner was appointed in January 2024.

Alignment with the National Agreement on Closing the Gap and National Aboriginal and Torres Strait Islander Health Plan 2021–2031

Improving dementia outcomes for First Nations people aligns with the broader objectives of the National Agreement on Closing the Gap[26] and the National Aboriginal and Torres Strait Islander Health Plan 2021–31.[27] The action areas to improve dementia outcomes for First Nations people in the Action Plan align with the Priority Reform Areas in the National Agreement on Closing the Gap and with the National Aboriginal and Torres Strait Islander Health Plan 2021–31, including in relation to:

- awareness raising, risk reduction, diagnosis of dementia and access to dementia care and supports, through partnerships with Aboriginal Community Controlled Health Organisations (ACCHOs) and ACCOs
- working in partnership with First Nations communities on training and education programs
- increasing the capacity and capability of the workforce associated with First Nations communities
- improving data, research and translation of evidence on dementia in First Nations people, through engagement with the community and the workforce.

The importance of self-determination and an ACCO-led approach

Supporting self-determination and building the capacity of the community controlled sector is central to the commitment Australian governments have made as part of the National Agreement on Closing the Gap.[28] This also aligns with recommendations 47b and 47d of the Royal Commission, which seek to ensure First Nations people receive high quality, culturally safe services delivered by the community controlled sector, can access advice to make informed decisions and are treated with dignity and respect.[29]

A community controlled approach is integral to First Nations self-determination, informed decision making and capacity building. This is enabled by ACCOs, which have community input, ownership and governance to deliver holistic and culturally appropriate services.

ACCHOs provide comprehensive, multidisciplinary care to the community in a primary health setting and are important to the delivery of services to improve the health and wellbeing of First Nations people living with dementia, their carers, families and communities. ACCHOs care for First Nations people with younger onset dementia and older First Nations people, their carers, families and communities at all stages of the journey of living with dementia, from diagnosis through to treatment and accessing appropriate clinical and care services.

There is scope to build the capacity of ACCHOs and develop resources to support people in communities living with dementia.

Actions

Action 1: **Promote equity and human rights**

Outcome statement for people living with dementia

My rights are upheld. I have a sense of autonomy, meaning and identity, and live a life free from inequality and abuse. I can access the information, supports and services that meet my needs and preferences. I can access culturally safe and holistic care.

How are we going to make a difference?

1. Involve people living with dementia in reform including the identification, development and evaluation of actions within the Action Plan.
2. Promote and improve access to resources for supported decision making to better enable people living with dementia to exercise choice and make decisions that affect their lives.
3. Incorporate a human rights basis and supported decision making principles in drafting a new Aged Care Act.
4. Maintain and improve strategies to ensure people living with dementia are free from all forms of degrading or inhumane treatment, violence, exploitation, neglect or abuse.
5. Improve access to culturally appropriate dementia information, care and support for First Nations people and communities that acknowledges their unique needs in relation to information, diagnosis and care.
6. Align initiatives and funding models for First Nations people with the Priority Reforms of the National Agreement on Closing the Gap and National Aboriginal and Torres Strait Islander Health Plan 2021–2031. This will facilitate the growth of the community controlled sector to support First Nations people living with dementia and implement community led, place-based approaches to dementia care and support.
7. Improve access to culturally appropriate dementia information, care and support for CALD and other diverse communities that meet their needs for dementia awareness, risk reduction, diagnosis and care.
8. Improve alignment of initiatives and funding models for people with dementia with Australia's Disability Strategy 2021–2031 where appropriate. This will ensure people with disability living with dementia can fulfil their potential, as equal members of the community.

Need for change	Equity and human rights are at the heart of making life better for people living with dementia. This means making sure they can get to health and aged care services and that their independence and choices are protected.
Where do we want to be in 10 years?	All levels of Australian society protect and promote equity and the human rights of people living with dementia and their carers so they can feel safe and empowered to live independently with respect, equity, dignity and free from abuse. Everyone living with dementia has equitable access to quality dementia care and supports that meet their needs and preferences.
How will we know if we have made a difference?	1. People living with dementia feel they have more control over their lives. 2. Increased access to and understanding of supported decision making for all people living with dementia, including for First Nations, CALD and other diverse communities. 3. Increase in availability and use of appropriately targeted and culturally appropriate resources on dementia, including government resources, for First Nations, CALD and other diverse communities. 4. People in regional, rural and remote settings have improved access to dementia diagnosis and support.

Addressing dementia through a human rights-based approach will help protect people living with dementia, their carers and their families from breaches of human rights in all aspects of their daily lives. This includes full respect for their dignity, beliefs, autonomy and decision making. It will support equity of access to health, disability and aged care supports and services that meet their needs and preferences. This will consider the diversity of experiences of people living with dementia, including gender and those from diverse communities, who may have heightened human rights vulnerabilities and face unique challenges in equitable access to services.

Where are we now?

Human rights

> Human rights recognise the inherent value of each person, regardless of background, where we live, what we look like, what we think or what we believe.
>
> They are based on principles of dignity, equality and mutual respect, which are shared across cultures, religions and philosophies. They are about being treated fairly, treating others fairly and having the ability to make genuine choices in our daily lives.'
>
> *Australian Human Rights Commission*[30]

Human rights are recognised and protected across Australia through a range of laws at the federal, state and territory levels, the Australian Constitution and the common law. The Australian Human Rights Commission is responsible for overseeing, promoting and reporting on the protection of human rights in Australia.

> *'The Action Plan must be framed by international human rights, including the UN Convention on the Rights of Persons with Disabilities. International human rights are universal and are not limited because of dementia, age or disability.'*

The Australian Government introduced the Aged Care Bill 2024 to parliament on 12 September 2024. The new Aged Care Act is expected to commence from 1 July 2025 and will outline the rights of older people seeking and receiving aged care. It will include specific rights relating to control and choice, so older people have self-determination and autonomy, allowing them to be actively involved in their decision making.

The first National Plan to Respond to the Abuse of Older Australians (2019–2023) (the first National Plan on Elder Abuse) introduced a framework to address the abuse of older people through the cooperation and engagement of Australian, state and territory governments and community, finance and legal sectors across the following 5 priority areas:

- **Priority Area 1** – Enhancing our understanding
- **Priority Area 2** – Improving community awareness and access to information
- **Priority Area 3** – Strengthening service responses
- **Priority Area 4** – Planning for future decision-making
- **Priority Area 5** – Strengthening safeguards for vulnerable older adults.

The Australian Government and the states and territories are developing a second National Plan to build on the initiatives delivered to date.

Equitable access to care

Equitable access to care is a human rights issue. Equity of access to care, and inequities in health outcomes, can be an issue for different groups across our community, such as communities living in rural, regional and remote areas of Australia and other groups.

People living with dementia can experience barriers to receiving care, including delays or difficulties with returning to their residential aged care home after being discharged from hospital. People living with dementia also face longer hospital stays while awaiting entry to a new residential aged care home compared to people without dementia.[31]

Equity of access to care is a particular issue for First Nations people. Racial discrimination is an important social determinant of health and accounts in large part for the disparity in health outcomes between First Nations people and other Australians.[28] The experience of systemic and interpersonal racism can lead to unequal or inappropriate health service provision, undermine equitable access to care and contribute to higher rates of early discharge from services.[32-34] First Nations peoples access to health and support services is therefore mediated by the cultural appropriateness of those services.[28] Services and systems need to acknowledge the difference between First Nations' understanding of health and wellbeing and that of mainstream Australia.

Promoting the right to make and communicate decisions through supported decision making

Most people require support for making decisions at some point in their life. The need for support to make and communicate decisions may be higher for people with cognitive impairments or communication difficulties due to dementia.

There has been increasing acknowledgement of the need to promote the rights of people living with dementia to make decisions that affect their lives, from day-to-day decisions about how they want to live, for example when to shower, to decisions with significant health, financial and/or legal implications. Ensuring people have the support they need to engage in decision making is central to Australia's obligations under the UNCRPD.

The Australian Law Reform Commission has set out National Decision-Making Principles.

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission) published its final report on 29 September 2023, which made recommendations to improve supported decision making in disability services.[35]

They involve:

- implementing recommended supported decision making principles and establishing a new framework for supported decision making
- amending NDIS Quality Indicators for greater focus on supported decision making and developing practical guidance for service providers.

The NDIS Review published its report on 7 December 2023, which made recommendations to provide better support for people with disability to make decisions about their lives, whether they are NDIS participants or not.[36] These include that people with a cognitive disability should be provided with support to build their decision making capacity and that their decision-supporters should also receive information and training.

The National Disability Insurance Agency (NDIA) released an NDIS Supported Decision Making Policy and has committed to revise this policy in response to the recommendations of the Disability Royal Commission. The policy covers the role of the NDIA and NDIS in supporting people with disability to make decisions. It includes how the NDIA can help people with a disability to understand their right to make decisions and support them to make decisions, and the role of nominees, guardians, family members and others in supporting people with disability to make decisions about the NDIS.

The first National Plan on Elder Abuse includes initiatives to better inform people of rights and obligations when entering into arrangements that enable others to make decisions on their behalf and to improve arrangements for future decision making, including efforts to achieve greater consistency in enduring power of attorney laws across Australia. Forward with dementia provides resources to support people living with dementia and their carers to understand and engage in supported decision making.

The Cognitive Decline Partnership Centre has developed a range of documents relating to supported decision making in aged care, with a focus on cognitive decline including policy guidelines, a consumer handbook, help sheets in 4 languages, and webinars.

OPAN has a Position Statement on supported decision making in aged care and promotes supported decision making in its advocacy service provision, and in advocacy by others.

Aged and Disability Advocacy (ADA) Law in Queensland has a range of resources on its website. It includes a guide for adults and those supporting them (with Informal Supports Checklists) and access to advocacy support for people who feel their service provider, guardian or administrator is not upholding supported decision making principles.

ACT Disability, Aged and Carer Advocacy Service (ADACAS) provides information for both decision-makers and their supporters. They have developed a website titled 'Support My Decision' with a range of resources relating to supported decision making.

What challenges are we currently facing?

The human rights of people living with dementia are not always upheld

People living with dementia can face isolation and human rights abuse, which leads to a poor quality of life (including reduced emotional wellbeing and identity), substandard care and avoidable deaths.

There is increasing recognition of the deeply entrenched day-to-day practices that overlook people's human rights based on the preconceptions that people living with dementia do not have the ability to make decisions about their life. This includes what they want to do, who they want to spend time with, the support and services they receive and the risks they are willing to take. This can contribute to limited approaches to policy making and service provision and abuse of people living with dementia by carers and family members. It also leads to many other forms of discrimination throughout their daily life (see Actions 2 and 5 for further context and reforms).

Community co-designed resources, tools and training

There is a need for community awareness resources, training and tools that foster dementia inclusive societies and dementia friendly communities, are co-designed and delivered in partnership with communities and take into account local community settings and contexts. This is particularly important for First Nations, CALD and other diverse communities. It includes improved access to interpreters, information and training on dementia in multiple languages developed in partnership with relevant communities (e.g. ACCOs).

The voices of people living with dementia are often not heard

> *'True inclusion of cognitive diversity is required in order to make meaningful change.'*

People living with dementia are often excluded from consultations on policy development and service provider leadership and governance. This results in systems and services that do not meet the needs of people living with dementia and that lack mechanisms to identify and respond to abuse of their rights.

There is a lack of safeguards for people living with dementia

People living with dementia who have cognitive and communication limitations may be reliant on their carers, substitute decision makers and/or service providers for support. They are particularly vulnerable to abuse as they find it hard to comprehend, remember the abuse, or may want to report the abuse but feel unable to do so as people will discount their account or experience. Family members and service providers are often the perpetrators of abuse against older people,[37] with cognitive impairment, social isolation and dependence on others increasing the risk of abuse.[38] People living with dementia and cognitive impairment are vulnerable to domestic and family abuse, including physical, financial, sexual and psychological abuse.

Specialist services focused on the effects of abuse of older people are limited. Much elder abuse goes unreported, especially neglect, and there are limited resources to investigate or manage allegations of abuse. Complaints mechanisms and advocacy services are often established for a particular service or program. This provides limited avenues for people living with dementia to seek support in resolving any breach of rights they experience.

Finally, concerns have been raised that advocacy and peer support programs for people living with dementia and their carers are often delivered by the same organisations and can be delivered jointly (i.e. people living with dementia and their carers attend together). This can conflate the needs of the 2 groups. Furthermore, there are concerns that this does not allow for a safe space for abuse by carers to be voiced by people living with dementia, or the abuse of carers by people living with dementia. Supports need to be available for people living with dementia to attend with and without their carers.

Broader work continues in line with Priority Areas 3 and 5 of the first National Plan on Elder Abuse, which complements this Action Plan, to strengthen service responses and safeguards for vulnerable older adults. It will expand front line support services for older people experiencing abuse and ensure that institutions and laws responsible for keeping older people safe are effective.

There is a need for supported decision making

There is limited information and training for health and aged care professionals on how to support people with communication difficulties and/or cognitive decline to make decisions.

In comparison to other cognitive disabilities, progress in promoting approaches to supported decision making for professionals who work with people with cognitive and/or communication impairments due to dementia has been slow. For example, the NDIS provides policy, guidance and training for service providers on supported decision making, but an equivalent government resource is not available for aged care providers. There is also a need for culturally appropriate supported decision making models for people from First Nations and CALD communities.

There are still instances of inappropriate use of restrictive practices for people living with dementia

Despite the legislative requirements and practice guides in place for the use of restrictive practices there are still occurrences of the inappropriate use of a restrictive practice in residential aged care, as well as home and community settings. Restrictive practices should only ever be used as a last resort but sometimes they are an important last measure to help prevent harm. The use of restrictive practices in residential aged care needs to be considered on a case-by-case basis after trialling alternative best practice behaviour management strategies and should only ever be used for the shortest time possible and in the least restrictive form to prevent harm (see Action 5 for current practices and reforms).

Action 2: **Tackle stigma, improve awareness and promote inclusivity**

Outcome statement for people living with dementia

I feel safe and engaged in society, and I have a sense of meaning and identity. I live a life free from stigma, discrimination and abuse.

How are we going to make a difference?

1. Expand awareness about dementia, including lived experience storytelling, to improve dementia understanding across the Australian population.
2. Partner with people living with dementia and their carers to develop, co-design, test and tailor dementia related communications.
3. Partner with people living with dementia, including First Nations people, CALD communities, women and girls, young people, people with disability and LGBTIQA+ communities to co-design, test and tailor dementia awareness information and resources.
4. Improve the uptake of dementia enabling design and practices in aged care and disability support services, hospitals, public spaces, businesses and local services. This will maximise opportunities for participation by people living with dementia.

Need for change	We want to make sure everyone understands, accepts and is aware of dementia. This means people living with dementia can be a part of the community and enjoy life with meaning and dignity.
Where do we want to be in 10 years?	Australia is a dementia inclusive society that understands people living with dementia and their carers. It actively enables them to fully participate in society and supports them to live independently in their communities for longer.
How will we know if we have made a difference?	1. Reduced stigma and improved attitudes among Australians towards people living with dementia. 2. Improved knowledge among Australians about what dementia is and how it affects people living with dementia. 3. Increased willingness of people to: a) seek help if they think they have symptoms of dementia b) share their dementia diagnosis. 4. Increased number of dementia friendly communities. 5. Decreased number of people living with dementia experiencing stigma, discrimination and abuse.

Increasing society's understanding, awareness and acceptance of dementia will reduce stigma, isolation and discrimination experienced by people living with dementia. Dementia inclusive communities will increase opportunities for people living with dementia to participate in social, economic and civic life and live with meaning, purpose and value. Organisations and service providers can also be dementia inclusive by making changes to practices and environments to meet the needs of people living with dementia. This will empower people living with dementia to maintain their independence, continue to contribute to society, stay at home for longer and enjoy a more fulfilling life.

Where are we now?

Awareness raising

Dementia Australia is funded to deliver the National Dementia Support Program (NDSP), which seeks to improve dementia awareness and understanding, including by delivering:

- information, resources and education sessions available via Dementia Australia's website
- campaigns aimed at improving public awareness of dementia and reducing the stigma
- education for GPs and health professionals about dementia diagnosis, the value of early detection and what can be done to support people living with dementia
- the National Dementia Helpline (1800 100 500), which provides free information for anyone interested in learning more about dementia.

Dementia Action Week is an annual awareness raising campaign that seeks to address misconceptions about dementia through the provision of information and tips to encourage people living in Australia to increase their understanding of dementia. The campaign helps people to understand how they can make a difference to the lives of people around them who are impacted by dementia and help to eliminate discrimination. The Dementia Action Week website includes practical tips to help people to support a person living with dementia and to help healthcare professionals make their practice more dementia enabling.

The National Ageing Research Institute (NARI) raises dementia awareness through film and media in CALD communities through their Moving Pictures initiative. There are 3 films in 9 languages aimed at raising dementia awareness: 1. Detection and Diagnosis, 2. Navigating Care and 3. The Carer Journey.

Promoting inclusion in society

The Dementia Friendly Communities program seeks to build understanding of dementia and more dementia inclusive communities. It aims to do this by:

- supporting local dementia alliances to lead the creation of dementia friendly communities
- providing grant funding to local projects to encourage community led action
- supporting community organisations and businesses to be more inclusive of people living with dementia and recognising the work of these organisations in creating change.
- As of 30 June 2023, there were 71 Dementia Alliances across Australia.[39]

Dementia Friends is part of the Dementia Friendly Communities program. People can sign up to become a Dementia Friend through Dementia Australia and learn more about dementia and how to help people living with dementia through a series of short videos.

As at 30 June 2023 there were 37,800 registered Dementia Friends in Australia.[39]

Scope Australia's National Communication Access initiative provides training, tools and resources to assist organisations and services to be communication accessible. They have developed a range of communication resources and training for various services and workforces, including health, hospitality, retail and recreation services. The aim is to ensure they are inclusive and accessible for customers who have communication difficulties. This promotes inclusive communication diversity practices which benefit people with communication impairments as a result of dementia.

Australia's Disability Strategy also includes an outcome area around community attitudes that focuses on policy priorities, including:

- employers value the contribution people with disability make to the workforce and recognise the benefits of employing people with disability
- key professional workforces are able to confidently and positively respond to people with disability
- increasing representation of people with disability in leadership roles
- improving community attitudes to positively impact Policy Priorities under the Disability Strategy.

A Community Attitudes Targeted Action Plan has also been developed under the Disability Strategy, which sets out key actions between 2021 and 2024 to improve community attitudes towards people with disability, including dementia, to influence behaviour.

Dementia awareness

There are a range of organisations providing resources, education and training aimed at improving awareness and understanding of dementia. These are described in Action 7.

What challenges are we currently facing?

Many people don't understand dementia and the different ways it impacts people

While people have a general concept of dementia, many do not know the signs of dementia and how it impacts people in different ways.[40, 41] Older people living with dementia are likely to experience the stigma associated with the disease, as well as the broader stigma of ageism where people face negative stereotypes associated with old age. For example, although the chances of getting dementia increase with age, people often think that dementia is an inevitable consequence of ageing or that it only impacts a person's memory.

There is also limited understanding of less common forms of dementia, such as younger onset dementia and childhood dementia. This lack of understanding can contribute to stigma and discrimination and may stop people from addressing potential risk factors or seeking timely diagnosis. A timely diagnosis can enable early interventions, delay the progression of dementia and improve treatment outcomes. A diagnosis can also help people access the supports and services they need.

> *'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.'*

There continues to be stigma associated with dementia

Stigma and discrimination can be experienced in different ways, including changes to sense of identity and self-esteem for a person living with dementia or discrimination experienced by a carer or family member of a person living with dementia. Discrimination can be experienced in the community, in interactions with professionals or in institutional settings.

> *'Addressing stigma and discrimination experienced by people living with dementia is important, as it can be a factor in the loss of meaningful relationships and reduced community engagement'.*

People living with dementia report experiencing discrimination, judgement and preconceived ideas about their abilities. While some people living with dementia want to share their story with others to dispel myths, they are rarely given the opportunity to do so. People often don't know how to talk about dementia comfortably, with 40% of people reporting they feel awkward around people living with dementia and find talking to them confronting.[40,41]

> *'We need to normalise the word 'dementia' in daily dialogue to reduce stigma and stereotypes.'*

The response to a dementia diagnosis can be confronting

People are often fearful of sharing their diagnosis with their family, loved ones and broader communities or workplaces due to the stigma or negative responses. The stigma following a dementia diagnosis can lead to low self-esteem, isolation, poor mental health and quality of life for the person living with dementia and their carer.[42]

This Action Plan adopts the WHO definition of Quality of Life as 'an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns'.

WHO[43]

Services and environments are not often dementia enabling

Many services, organisations and environments can be overwhelming, confusing and difficult for people living with dementia to navigate. As a result, people living with dementia may avoid going into the community, which could make them more socially isolated.

> *'I can't go to my local council knitting group anymore since they don't let people living with dementia attend, even with a support person.'*
>
> *'If we don't make them [our environments] enabling, people living with dementia won't go out into the community. And will become more isolated.'*

Action 3: Empower individuals and communities to minimise risk where they can, and delay onset and progression

Outcome statement for people living with dementia

I am supported to take steps where I can maintain a healthy lifestyle, minimise risks and delay the progression of dementia.

How are we going to make a difference?

1. Improve Australians' awareness of risk factors and preventive actions that can be taken to reduce the risk of developing, delay the onset or slow the progression of dementia. This includes health promotion and prevention programs which support overall health.
2. Promote the brain health benefits of people regularly and safely participating in sports, exercise and movement.
3. Increase awareness of strategies to improve brain health and establish whole of population brain health approaches for earlier dementia detection and intervention.
4. Develop targeted strategies and messages for people from diverse communities or at higher risk of developing dementia in partnership with relevant communities.
5. Implement evidence-based interventions to reduce the risk of dementia, including for higher risk populations and people with mild cognitive impairment (MCI).

Need for change	Getting older is just one factor that can lead to dementia. Things like our health, environment, and genetics can also play a part.
Where do we want to be in 10 years?	People understand the factors that increase their risk of dementia and are supported to take actions to reduce risks where they can across all stages of life.
How will we know if we have made a difference?	1. Improved knowledge among the general population and communities at higher risk of developing dementia about risk factors for dementia. 2. Increased understanding in the primary care workforce of ways to reduce the risk and delay the onset of dementia. 3. Increased number of Australians taking steps to reduce their risk of developing dementia.

We can all do something to reduce our dementia risk. As the World Alzheimer's Month 2023 theme put it: it's 'never too early, never too late' to do something to delay or prevent the onset of dementia or to take action even if you already have a diagnosis. There is growing awareness that dementia can start many years before symptoms appear.

Whole of population approaches to improving overall health and cognition can reduce rates of dementia at a population level (prevention). While individuals can reduce their own risk of developing dementia through lifestyle changes (risk reduction), they can't completely prevent dementia. This is because ageing and genetics contribute to an individual's risk.

Where are we now?

Modifiable risk factors

The Lancet Commission identified 14 potentially modifiable risk factors for dementia. These are lower levels of education, hypertension, obesity, alcohol, traumatic brain injury, hearing loss, smoking, depression, physical inactivity, social isolation, diabetes, air pollution, vision loss and high cholesterol.[7]

Factors that can reduce risk or slow the progress of dementia (even after a dementia diagnosis) include:

- eating a healthy diet
- regular physical exercise
- taking care of your mind by staying socially engaged and learning new things
- adopting healthy sleeping practices
- reducing alcohol consumption
- stopping smoking
- controlling your blood pressure
- looking after your hearing and having it checked in midlife
- protecting your head and minimising head injury.

> *'There is hope for you – not a cure yet, but if you're diagnosed with dementia, there are things that you can do to slow down the progress.'*

Maintaining and promoting good mental health and wellbeing can also address risk factors and delay onset and progression of dementia.

Dementia awareness activities

Some of the existing initiatives described under Action 2 (including activities under the NDSP and Dementia Action Week), also educate people on the risk factors for dementia and ways people may reduce their risk or potentially slow the progression of dementia.

Risk reduction resources

Dementia Australia has a range of information and resources that can support people to reduce their risk of dementia or help to delay the progression of cognitive decline. Risk reduction can be seen to focus in 4 main domains: a healthy heart, healthy body, healthy mind and a healthy environment.

Dementia Australia provides people with simple tips on lifestyle changes to maintain a healthy brain at any stage of life. It includes a website and social media content, providing advice to empower people to 'eat well, play often and rest regularly'.

Healthy living promotion

Governments across Australia undertake campaigns and awareness raising initiatives encouraging people to live healthy, active lifestyles. These campaigns can help people to reduce their risk of dementia (as well as many other chronic health conditions), although many don't explicitly acknowledge dementia.

Health promotions encouraging involvement in sport can provide strong physical benefits, as well as mental and social benefits by promoting social inclusion and community engagement.

> *'We need to get the balance right with talking about modifiable risk factors so that we don't end up being blamed for getting dementia. Sometimes you get dementia even if you have eaten healthy food and exercised your whole life.'*

National initiatives complement international public health frameworks, such as the United Nations Decade of Healthy Ageing Plan of Action (2021–2030) global collaboration, which include actions for governments and society to achieve healthy ageing, good health and wellbeing at all stages of life.

Chronic condition management

A number of chronic conditions including diabetes and hypertension are associated with development of dementia, and effective management of chronic conditions can reduce the risk of dementia. As the modifiable lifestyle and cardiovascular risk factors for dementia are also associated with other chronic conditions, addressing these risks will provide cumulative preventive health benefits and assist in managing conditions. A range of 'chronic disease management' services are covered by the MBS. GPs, specialists and the person themselves have a role in ensuring that chronic conditions are effectively managed.

Allied health supports

Allied health professionals can play an important role in supporting someone living with dementia to regain or maintain function. Physiotherapists, occupational therapists and speech pathologists, psychologists, dietitians and others can be crucial in helping people living with dementia to manage the symptoms of their dementia, slow cognitive decline, support pain management and improve mobility and dexterity.

What challenges are we currently facing?

People aren't aware that there are things they can do to reduce their risk of developing dementia

It is estimated that between 45% to 56% of dementia cases worldwide could have been prevented or their onset delayed by reducing risk factors.[6, 7]

According to the Australian Institute of Health and Welfare (AIHW), about 43% of the dementia disease burden (human and financial costs that result from poor health) in Australia is attributable to 6 modifiable risk factors (in order of importance):

- overweight and obesity
- physical inactivity
- impaired kidney function
- high blood plasma glucose
- high blood pressure in midlife, and
- tobacco use.[1]

Despite this, people often don't know what they can do to lower their risk of dementia or delay its onset (particularly in comparison to other prevalent health conditions, such as diabetes, cancer and heart disease).

> *'By making good lifestyle choices, we can at least stack the odds in our favour.'*

Studies show that it is never too early or late to reduce individual dementia risk. However, there are a range of factors that influence an individual's risk and these may not all be within someone's control. Overall brain health is affected by social determinants of health (non-medical factors such as economic, housing and education), environment, lifestyle and other diseases. Risk factors may differ at different stages of life.

For example, education in early life can impact the 'brain reserve' of a person, which means that they may be more resilient to dementia and develop dementia more slowly. Hearing loss, hypertension and obesity are key midlife (45 to 65 years) risks. Smoking, depression, physical inactivity, social isolation and diabetes are later life (above 65 years) risks.

Mid and later life risks influence a person's resilience to dementia but also the mechanisms that cause the disease, so it is particularly important to be mentally, physically and socially active in mid and later life.

People at risk of developing dementia often aren't supported to take preventive action

People living with MCI or in the early stages of dementia often aren't provided with information about the things they can do to delay the onset or progression of dementia. It is estimated that delaying onset by a few years could reduce the number of people living with dementia by up to one-third a few decades later.[44]

The risk of dementia can be reduced by focusing on maintaining a healthy brain by being physically, mentally and socially active across all stages of life. The onset of dementia can be delayed if changes to brain activity linked to dementia are picked up early, which can reduce the personal, family and societal costs of care. There is also strong evidence that cognitive training can help against the functional deterioration of individuals with dementia. It can help to maintain or improve their thinking, enhance learning and improve cognitive abilities, such as verbal fluency.[45] The benefits of cognitive training also appear to be maintained in the medium term and in some studies, has shown to improve the mood of people living with dementia.[46]

Community co-designed, multidisciplinary risk reduction approaches are important for high risk and diverse population groups. This includes First Nations people who have elevated risks related to low education, smoking, diabetes, hypertension and depression, as well as social factors influencing health. This could include low-cost health promotion initiatives (such as walking and yarning groups) focused on heart and brain health, chronic condition management, improved social and emotional wellbeing and health literacy.

There is also emerging evidence that traumatic and repeated brain injury can contribute to the risk of developing chronic traumatic encephalopathy (CTE) and traumatic encephalopathy syndrome (TES), the symptoms of which can follow the typical pattern of dementia. There are several different populations at risk of CTE/TES, including victim-survivors, military personnel and contact and other sports participants. We've heard that each at-risk population has its own specific needs for services and supports.

Regular involvement in sports activities promotes a healthy lifestyle and helps maintain wellbeing by creating opportunities to socialise, improve self-esteem and mood. This can ultimately result in reduced cognitive decline and memory loss. It is also important to recognise that there are risks associated with participating in sport, particularly contact sport, around potential head trauma. These risks can be minimised by individuals through adopting proper techniques, appropriate safety equipment and adhering to the rules of the sport. The benefits of sport to improve physical and brain health, and therefore reduce risk of dementia, should also be recognised. Whilst participation in contact sport comes with inherent risk of head injuries, the value of sport in achieving overall positive health outcomes should not be diminished.

Health promotions that foster involvement in sport to improve physical and brain health, while further understanding the relationship between head injuries and developing dementia in contact sports, could reduce risk of dementia.

The department is currently developing a new National Sports Plan which encourages all Australians to participate in sport to achieve positive health outcomes. The Australian Government has also provided its response to the Senate Inquiry into Concussions and Repeated Head Trauma in Contact Sports.[47] Recommendations include further research into traumatic brain injuries in sport and the short and long-term effects on brain health. The Australian Institute of Sport has also developed a position statement bringing together standardised, evidenced-based, and accessible concussion and head trauma information and supporting resources.

Women and children experiencing violence can also suffer traumatic and repeated brain injury. The National Plan to End Violence against Women and Children 2022–32 includes objectives to prevent violence against children and women and ensure victim-survivors are supported through trauma-informed, culturally safe and accessible services that support long term recovery.

Not all modifiable risk factors can be changed by an individual

Structural barriers and social determinants of health can affect people's ability to change behaviours, and reducing their modifiable risk factors may be outside their control. There is a need to understand and address social factors influencing health, including housing, education and employment, particularly in First Nations communities. Dementia in First Nations people often does not present alone and a dementia diagnosis may also be layered with other elements of identity and life experience. Factors can include the experience of members of the Stolen Generations, intersectionality, trauma, remoteness, fear of institutionalised care and the government.

Action 4: **Improve dementia diagnosis and post diagnostic care and support**

Outcome statement for people living with dementia

I can recognise the signs of dementia and understand where to go if I have concerns. I can access health professionals who are willing and able to assess my symptoms and provide a timely diagnosis. I am linked with information and supports to assist me, my carer and my family immediately following a dementia diagnosis.

How are we going to make a difference?

1. Review and update clinical practice guidelines and principles of care for people living with dementia every 3 to 5 years.
2. Review how the Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS) support effective dementia diagnosis and ongoing management every 3 to 5 years.
3. Clarify pathways for dementia screening, assessment and diagnosis across the country, including identification of best practice.
4. Increase the capacity and reach of memory clinics and review the funding model.
5. Embed memory clinics in targeted Aboriginal Controlled Community Health Organisations (ACCHOs) and Aboriginal Controlled Community Organisations (ACCOs) to support improved access, diagnosis and care for First Nations people.
6. Develop and promote culturally appropriate cognitive assessment tools in partnership with diverse communities and experts, and support training for clinicians to use these tools.
7. Improve support, care coordination and planning for people living with dementia and their carers following a dementia diagnosis, including models for First Nations, CALD and other diverse communities.
8. Improve diagnostic and post-diagnostic services and supports for groups facing additional barriers to care, such as people living with younger onset dementia and children living with dementia and their families.
9. Improve and embed supports for people living with dementia in disability support services.

Need for change	Finding out about dementia early is essential. Support from health, aged care, and disability services should help people living with dementia to enjoy their lives as much as possible.
Where do we want to be in 10 years?	Dementia signs are recognised, and people are diagnosed as early as possible, helping them to slow the progression, maximise their abilities and plan for the future. People are provided with information and connected to coordinated supports immediately following their dementia diagnosis.
How will we know if we have made a difference?	1. Improved national consistency in services offered across memory clinics for assessment and post-diagnostic care and support. 2. Increased number of people being assessed for dementia in memory clinics. 3. Increased number of First Nations people seen and supported through memory clinics, including through clinics embedded in ACCHOs and ACCOs. 4. Increased number of people with signs and symptoms of dementia who are seen by a specialist within three months of receiving a referral. 5. Reduction in the average time taken for people to receive a diagnosis of dementia from the onset of first symptoms. 6. Increased number of people living with dementia with a chronic disease management plan in place with their GP. 7. Increased number of people living with dementia and their carers reporting a positive experience of diagnostic and post-diagnostic care. 8. More people living with younger onset dementia and children with dementia are accessing and satisfied with diagnostic and post-diagnostic services and supports, including through disability services.

People living with dementia need a timely diagnosis to delay the progression of dementia, followed by coordinated and personalised care and support across health, aged care and disability services to maintain quality of life and live well. This includes collaboration between formal and informal carers and professionals across different disciplines from the first sign of symptoms until the end of life.

Where are we now?

Assessment and diagnosis

There is no single test for diagnosing dementia. Assessment often examines the behavioural, functional and psychosocial changes in a person, together with medical tests and scans and ruling out other conditions that may lead to similar symptoms. Discussions with the person and those close to them can also be an important step in confirming cognitive and/or behavioural changes. The diagnosis process varies significantly from person to person and across locations depending on the services and health professionals available.

Most people's first point of contact when they identify changes or concerns is their GP, with dementia accounting for approximately 1.6% of general practice encounters.[48] Often GPs will refer people to specialist services – such as geriatricians, old age psychiatrists and neurologists – for assessment and testing due to the complexity of diagnosis.

Memory clinics

Memory clinics are specialist centres where people can go to be assessed and diagnosed with dementia. Memory clinics exist across Australia and may have different names, including cognitive decline assessment service and dementia and memory service.[49] These memory clinics may also be embedded in public hospitals. They generally have specialist clinicians and the capacity for testing, including magnetic resource imaging (MRI), positron emission tomography (PET) and single photon emission computed tomography (SPECT) scans. People can seek a referral to a memory clinic through their GP.

The Australian Dementia Network (ADNeT) has established the Memory Clinics Network to support people to find memory clinics and provide a consistent framework for their operation.

Primary Health Network dementia support pathways

Dementia specific support and referral pathways have been established to reflect the optimal pathway for seeking dementia diagnosis and post-diagnostic supports. GPs use these pathways during consultations with patients to give them the confidence to initiate a conversation and support them to identify when and how to refer to a specialist diagnostic service, such as a memory clinic. These pathways also include a handout on local dementia supports for a person or their family to take home and refer to after the consultation.

Brain health apps

Dementia Australia's BrainTrack is a mobile phone app to support timely diagnosis of dementia. Through playing a selection of mini games, each addressing major domains of cognition, users' performance over time is recorded by BrainTrack and offered as an aid to GPs and health professionals during conversations with patients about potential cognitive decline.

Guidance for health professionals

Guidance for health professionals on dementia prevention, diagnosis and support is provided in a number of key resources:

- National Memory and Cognition Clinic Guidelines describe the standards for assessment and post-diagnostic support to be provided by memory clinics.
- Clinical Practice Guidelines and Principles of Care for People with Dementia support health and aged care staff who work with people living with dementia in community, residential and hospital settings.
- RACGP aged care clinical guide (Silver Book) provides advice to GPs on the care of older people.
- Guidelines for preventive activities in general practice (Red Book) provides guidance to GPs on who is most at risk, for whom screening or preventive care is most appropriate and on opportunistic and proactive preventive care.
- National guide to a preventive health assessment for Aboriginal and Torres Strait Islander people provides GPs and other health professionals with an accessible, user-friendly guide to best practice preventive healthcare for First Nations patients.
- Let's Chat Dementia in Aboriginal and Torres Strait Islander Communities provides a range of community and clinical resources, assessment tools and webinars to improve detection of cognitive impairment and dementia for First Nations people.

Resources to support people who have been recently diagnosed with dementia and their carers

The NDSP provides dementia information, referral, education, counselling and group support activities for people living with dementia, their carers and families.

Dementia Australia offers an enquiry service that identifies the supports available to an individual based on what they are seeking and where they are located.

Dementia Australia also offers free counselling through the National Dementia Helpline (1800 100 500). It provides personalised post-diagnostic support to develop strategies to maximise quality of life and plan for changes. There are also support programs aimed at keeping people living with dementia socially engaged and mentally stimulated.

Forward with dementia is a guide for the first year after diagnosis. It provides a range of information, tools and helpful strategies for people living with dementia and for carers. It also provides information and tools for health professionals to improve communication of the dementia diagnosis and post-diagnostic support.

The Carer Gateway (1800 422 737) provides a range of practical information and advice, online supports and services to unpaid carers in their local area. Services offered include counselling, coaching, respite, peer support and financial packages.

Dementia Alliance International offers free online peer to peer support and advocacy for people diagnosed with dementia of all ages, from the time of diagnosis.

The USA-based National Aphasia Association provides online resources, events and groups attended by many people living with dementia in Australia.

Diagnostic tools

Diagnostic tools are useful in helping identify mental health conditions and assist with determining whether someone's symptoms are caused by dementia or an underlying mental health condition such as depression, or a combination of both.

Managing mental health and wellbeing

Ongoing treatment and review during the diagnostic journey and immediately following a diagnosis, helps with meeting a person's mental health and wellbeing care needs. It also assists to ensure the right balance of dementia and mental health services are provided.

Chronic condition management

People living with dementia commonly have multiple chronic conditions. Good chronic disease condition management, including the effective use of GP Management Plans, multidisciplinary care plans and/or Team Care Arrangements are important for maximising the wellbeing of people living with dementia. These plans help people to manage their chronic medical conditions by providing an organised approach to care. They identify the person's health and care needs, set out the services to be provided by their GP, allied health and other providers and list the actions people can take to help manage their condition.

The establishment and ongoing review of chronic disease management arrangements is covered by the MBS. A range of dementia and chronic conditions online toolkits to improve support for people living with cognitive impairment or dementia and other chronic conditions are available on the Dementia Australia website.

What challenges are we currently facing?

The diagnostic process can be unclear

There is no nationally agreed pathway for accessing a dementia diagnosis and people's experiences vary widely. There is little consistency across assessment and diagnostic processes and people can be referred to several different types of health professionals before a diagnosis is made.

The average timeframe from initial onset of symptoms to receiving a dementia diagnosis is around 3 years for all types of dementia.[50, 51] For people living with younger onset dementia, it is closer to 5 years.[52] Symptoms have been recorded in GP medical records as early as 5 years before diagnosis.[53]

On average, people wait more than a year after the onset of symptoms to raise this with their GP. Over 40% wait more than 3 months after being referred for an appointment at a dementia and cognition clinical service, compared to approximately 30 days in Ireland, Canada and the UK.[48, 54] An early diagnosis improves the effectiveness of treatments, helps plan for the future and make informed choices about health, legal, financial and care matters so that they can access the right support services and live independently for longer.

> *'Diagnosis gives people opportunity to change their life. We can't wait until people are at the pointy end until it's acknowledged.'*

People may not recognise or may knowingly ignore the signs of dementia

Half of all people living with dementia never receive a formal diagnosis.[54] There are a range of factors that limit people's ability to recognise and respond to signs of dementia, including:

- often people aren't well educated about dementia and may not recognise the signs
- the symptoms of less common forms of dementia (such as younger onset dementia and fronto-temporal dementia) are not well known
- people are often fearful of a dementia diagnosis and may knowingly ignore the signs of dementia or reject the suggestion of dementia
- stigma and fear can limit people's motivation to seek a diagnosis, particularly in First Nations and CALD communities. Many people don't understand the benefits of early detection and diagnosis, including actions that can be taken to slow the progression and plan for the future.

As a result, many people aren't motivated to get a diagnosis as they 'don't see the point'. The lack of curative or disease modifying drugs for dementia contributes to the perception that getting a diagnosis won't lead to an improved quality of life.

> *'We need to change the perception of dementia – it's not a death sentence.'*
>
> *'We need to reduce the stigma against dementia to encourage people to seek diagnosis.'*

GPs may not always recognise the signs and symptoms of dementia

As no 2 people living with dementia present in the same way, GPs may not pick up early signs and symptoms within a short consultation timeframe. Symptoms can often be mistaken for other conditions, such as mental health conditions or menopause (particularly for people with younger onset dementia). The importance of engaging with people close to the person to understand changes is not aways recognised.

> *'GPs need to listen to the people who know the person. We know our people, we can see when they've changed and something is not right.'*

While most GPs may have a long-standing relationship with the person and their family, they may feel unsupported to have conversations about early signs of MCI or dementia. The diagnosis process is complex and there is not always a clear pathway for GPs to screen patients for cognitive decline and escalate their concerns.

People often don't present to a GP until their symptoms impact on their daily lives. As a result, it is not usual practice for GPs to discuss early detection of dementia with patients. In addition, the ongoing dementia supports or post-diagnosis services available, and benefits of early intervention activities, are not widely promoted among the GP population.

GPs may face a number of barriers to diagnosing dementia, such as:

- patient/carer resistance to raising concerns or undergoing tests or screening
- limited information sharing and coordination with other health, disability and aged care services
- long waits for specialist advice.

GPs and primary care teams may also benefit from additional training to maintain and build upon their skills in dementia diagnosis and care.

People living with cognitive decline or dementia, or people who support them, may reject a diagnosis or suggestion of dementia

This may be out of fear, feeling confronted and undervalued despite how carefully and compassionately this is handled by everyone. It can lead to diagnostic delay, avoidance of health care and other supports, and deterioration which could have been helped with earlier diagnosis. Health care professionals and family will often participate in this denial for fear of causing further distress.

There are challenges accessing specialists skilled in assessing and diagnosing dementia

Not everyone needs to see a specialist to receive a diagnosis, but when they do, people can face long delays, ranging from 10 weeks up to 12 months, for a specialist clinical assessment (compared to about 4 weeks in other developed nations).[54] Recent data suggests that over 40% of people waited more than 3 months before having an appointment at an expert clinical assessment service after being referred by their GP.[48]

Delays can be due to a lack of specialists (there is currently only capacity to diagnose 35% to 40% of new cases[55]), challenges accessing specialists (due to cost or distance) or lack of awareness of assessment services.[1] Diagnosis and care pathways must consider the lack of specialist providers, particularly for people in regional, rural and remote settings.

These issues are heightened for people in rural and remote communities and higher risk groups such as First Nations people, who are often unable to access specialist services or are reluctant to do so, which delays diagnosis and care. Specialist memory clinics may not serve the needs of First Nations people and communities, especially in rural and remote areas where there may not be a deep understanding of culturally safe care.

There is an opportunity for new models of care and support to be established within primary health care settings, such as ACCHOs, to ensure diagnosis, treatment and support services are culturally safe and tailored to the needs of First Nations communities. This may require additional dementia training and support for Aboriginal and Torres Strait Islander Health Workers and Health Practitioners and cultural safety training for dementia care professionals.

Clinical and service decisions may also be based on evidence that do not reflect the needs of CALD people living with dementia. There is scope to train clinical health and care staff to build cultural literacy and improve understanding of unique issues CALD communities experience in relation to dementia.

Screening and assessment tools are not always fit for purpose

Diagnostic testing is not always sensitive enough to detect changes, and results are often not clear cut or subject to interpretation.

Dementia screening and assessment tools are not appropriate or accessible for all people, including people with low literacy levels or living in remote regions. First Nations people and people from CALD backgrounds face further barriers due to limited use of culturally appropriate validated dementia assessment tools.

Screening programs should be evidence-based and need to include consideration of cultural context and the social determinants of health. There is also a need to expand the use of culturally safe diagnostic tools and processes, that have been developed in partnership with community, such as the ACCHO sector and by mainstream providers. For example, the Kimberley Indigenous Cognitive Assessment (KICA) Tool, which is widely used to support culturally appropriate evaluation of cognitive impairment in First Nations communities and has also been modified for use with First Nations people in regional and urban settings.

Diagnosis is not always delivered sensitively

The way people receive a diagnosis matters. Receiving a dementia diagnosis is life changing, not just for the person with dementia but also their family and friends. While many professionals communicate the diagnosis well, some don't. People report not being provided with necessary information and being too overwhelmed to ask questions. They often leave without the information they need to start understanding their diagnosis and planning their next steps.

> *'I was told to go home and get my affairs in order. Like I only had 6 months to live.'*

A diagnosis of dementia can be devastating, and people often feel a sense of grief immediately following a diagnosis

A diagnosis of dementia can be incredibly overwhelming for people. People often experience a deep sense of grief, and a loss of independence (including possible loss of their driver's licence and employment). This can leave them feeling isolated, devalued and without purpose. Due to the stigma associated with dementia, some people are fearful of telling their families and friends about their diagnosis, further adding to the sense of isolation. Given the progressive nature of the condition, many people have expressed feeling despair or hopelessness following a diagnosis.

> *'When I was diagnosed, I felt moribund, I didn't have a pathway out, I spent 2 years on the couch in the darkness'.*

> *'I was shell shocked when I received the diagnosis. I lost any purpose or meaning in my life.'*

The diagnosis can be similarly overwhelming for people's families and friends who have to come to terms with the impact the diagnosis will have on their lives, particularly where they may become the primary carer.

There is not always a clear plan or pathway for post-diagnostic care, treatment and support

People who have been diagnosed with dementia are often not provided with hope or told how they can live positively with dementia. They often have limited access to proven information and support that could reduce decline and help them live well. There is a need for consistent supports and a care pathway after diagnosis, including for people with complex symptoms and behaviours and co-morbidities such as mental health conditions like depression.

Some people living with dementia describe difficulties with managing their care as they don't know what supports are available to them. They may be eligible to access services from across an array of programs and systems (including health, aged care and disability support), which can be difficult to navigate. Dementia can also impact on a person's ability to engage with complex systems or remember appointments.

> *'With other diseases, there is often a rehab or treatment plan. That doesn't exist for people living with dementia'.*

Chronic disease management support is not adequate

Chronic disease management support, including MBS allied health services can improve the lives of people living with dementia. For example, post-diagnosis, people living with dementia can benefit significantly from allied health services, cognitive rehabilitation strategies and other interventions such as music, sensory stimulation and creative therapies.[56] The MBS does not cover all allied health services, some services are funded through other programs or require people living with dementia to access them independently.

Multidisciplinary coordinated post-diagnostic care for people living with dementia is often inadequate, unavailable and unaffordable

People living with dementia often require multidisciplinary care from multiple parts of the health and social care systems. This care is often not well coordinated within or between systems, which can worsen quality of life and health outcomes, including accelerated cognitive decline.

Barriers to multidisciplinary care include:

- poor communication and lack of clarity around healthcare provider roles
- limited opportunities for information sharing (including radiology and pathology results)
- a lack of current established pathways for communication or direct referrals
- lack of continuous and coordinated care for patients.

Action 5: **Improve treatment, coordination and support for people living with dementia**

Outcome statement for people living with dementia

I have hope and access to necessary supports to live as well as possible with dementia, even as my abilities and needs change. I have support to make, communicate and participate in decisions regarding the services I receive.

How are we going to make a difference?

1. Identify, develop and promote early intervention, reablement approaches, restorative care supports and resources for people with MCI and dementia.
2. Provide flexibility in the way dementia supports are delivered, including through outreach models and innovative use of technology.
3. Enable best dementia care practice in aged care and disability support services, focused on enhancing the quality of life, wellbeing and safety of people living with dementia and that meets their social and cultural preferences.
4. Support aged, disability and health care providers in residential care and community settings as well as informal carers to better understand and respond appropriately to the needs of people living with dementia. This includes changes in behaviours and environments, without inappropriate use of restrictive practices.
5. Improve services for people with more complex or severe behavioural and psychological symptoms of dementia, including increasing the availability of appropriate residential care and innovative models of care.
6. Improve interfaces and information sharing between primary care, disability support, aged care and hospital settings at a system-level to improve integration and continuity of care.
7. Identify the needs of people living with dementia at entry to hospital. Have supports, structures and care in place to reduce the potential risk of harm, provide a person-centred approach to care and ensure safe and effective transitions into and from hospital services.
8. Identify, clarify and promote improved pathways and options for palliative care for people living with dementia.
9. Promote culturally appropriate palliative care options, advice and resources about advance care planning and palliative care for First Nations, CALD and other diverse communities.

Need for change	Working together and sharing information between health care, aged care, and disability support is key to helping people living with dementia.
Where do we want to be in 10 years?	People living with dementia and their families are connected to coordinated, dementia inclusive services that meet their individual and changing needs. People living with dementia have autonomy and are supported to make decisions about their care and other supports, if and when they need them.

Action 5: Improve treatment, coordination and support for people living with dementia

How will we know if we have made a difference?

1. Improved coordination of care for people living with dementia.
2. People living with dementia and their carers find it easier to navigate the health, aged care and disability support systems to access the services and supports they need.
3. Increase in people from First Nations, CALD and other diverse communities having access to suitable dementia services and supports.
4. Improved primary health care system experiences and outcomes for people living with dementia.
5. Increased number of people living with dementia with regular medication reviews.
6. Improved hospital and transition experiences and outcomes for people living with dementia, such as reduced number of avoidable hospitalisations and decreased inappropriate long term hospital stays.
7. Improved aged care experiences and outcomes for people living with dementia.
8. Decreased number of people living with dementia who experience use of inappropriate restrictive practices in aged care.
9. Improved advance care planning and palliative care for people living with dementia.
10. Increase in culturally appropriate advance care planning and palliative care for people living with dementia from First Nations, CALD and other diverse communities.

People living with dementia and their families need interconnected support services across health, aged care and disability care systems which respond to their individual needs and preferences. An integrated dementia care pathway will foster active collaboration between the person living with dementia, their carers and different service providers across all settings and systems. At the same time, this ensures that the person remains at the centre of decisions about their care and other supports.

Where are we now?

Health, aged care and disability services

As described under the current service system, people living with dementia access support from a range of mainstream services, including:

- primary and community care services such as GPs, nurses, pharmacists, allied health professionals and specialists who can provide health care, counselling and restorative services
- aged care services (or disability services and supports for people under the age of 65), including support to remain living at home, respite care and residential care
- health services and hospitals which provide acute, subacute and specialist level care
- palliative and end of life care to improve quality of life and address the person's needs and preferences, including physical, psychosocial and spiritual, to enable the person to die in comfort and with dignity.


Most people will interact with the following systems after a diagnosis of dementia

Source: Dementia in Australia Report, AIHW[1]

Aged care services for people living with dementia

A range of initiatives are underway to improve outcomes for people living with dementia and receiving aged care services. In 2021–22 nearly 10% of people who completed an aged care assessment had dementia and more than half of people in residential aged care have a diagnosis of dementia.[1] Ensuring aged care services deliver the care and support needed by people living with dementia remains a key priority.

- Reform to in-home aged care will establish a single program called Support at Home. From 1 July 2025, Support at Home will consolidate the existing Home Care Packages Program and Short Term Restorative Care Programme, while the Commonwealth Home Support Programme will transition to the new program no earlier than July 2027. The new program will provide access to high quality aged care services for older people who need support to stay independent and in their own homes, which will benefit people living with dementia.

- The strengthened Aged Care Quality Standards, with an increased focus on requirements for supporting people living with dementia and including a new clinical care standard developed by the Health Commission as recommended by the Royal Commission. Dementia has been embedded throughout the strengthened Aged Care Quality Standards, including:
    - ***Standard 1: The Person*** – implementing strategies to deliver care that is right for older people with specific needs and diverse backgrounds, including people living with dementia.
    - ***Standard 2: The Organisation*** – ensuring care and services are accessible to, and appropriate for, people living with dementia, and all workers are regularly trained in relation to core matters such as caring for people living with dementia.
    - ***Standard 3: The Care and Services*** – using contemporary evidence-based strategies for timely recognition of dementia and the delivery of care that best supports people living with dementia, regularly reviewing the strengths and skills of people living with dementia and encouraging use of these day-to-day, and supporting workers to understand the way different older people communicate, including people living with dementia.
    - ***Standard 5: Clinical Care*** – implementing processes for early recognition, referral and management of delirium, dementia and other forms of cognitive impairment, identifying deterioration and underlying contributing clinical factors and accessing specialist health, allied health and behavioural advisory services.
    - ***Standard 7: The Residential Community*** – maintaining connections with specialist dementia care services and accessing these services as required.
- These strengthened Aged Care Quality Standards will come into effect with the commencement of the new Aged Care Act.
- National Aged Care Design Principles and Guidelines on accessible and dementia friendly design for residential aged care (introduced 1 July 2024).
- A single assessment system workforce to assess people for all forms of aged care with an increased focus on supporting people living with dementia.
- Requiring all residential services to provide an average of 215 minutes of care per resident per day and have a registered nurse on site 24 hours a day, 7 days a week (introduced 1 October 2024).
- Building the capacity and capability of the aged care sector to manage complex cases of dementia.
- Measures to support carers and build workforce capacity (outlined under Action 6 and Action 7).

Dementia specific support services

The Dementia Behaviour Management Advisory Service (DBMAS) is delivered by Dementia Support Australia and provides support and advice to aged care providers, workers and carers of people living with dementia, particularly where a person's dementia is affecting their care. The DBMAS is accessible for people working in home care or residential aged care and for carers of a person living with dementia at home or in residential aged care.

Severe Behaviour Response Teams (SBRTs) are a mobile workforce with clinical expertise that help providers who care for people with more complex dementia in residential aged care. They help providers to understand a person's behaviours, provide assistance during a crisis and help plan and review a person's care.

The Specialist Dementia Care Program (SDCP) funds specialist dementia care units (SDCUs) in residential aged care homes. The units provide specialised care to people with very severe symptoms of dementia and aim to reduce or stabilise symptoms so that people can move into less intensive care settings.

National Disability Insurance Scheme

People with younger onset dementia that effects their ability to participate in everyday activities, may be eligible for the NDIS if they register before they turn 65 years.

The NDIS provides funding to eligible people with disability to gain more time with family and friends, greater independence, access to new skills, jobs or volunteering in their community, and an improved quality of life. The NDIS also connects anyone with disability to services in their community.

Medication reviews

People living with dementia and their carers regularly use pharmacists to manage their medications in hospital and community pharmacy settings and at transition points in their care. Pharmacists have the opportunity to conduct medication reviews to ensure safe and quality use of all medications prescribed and, where appropriate, simplify what is being taken. Medication reviews can be done by a pharmacy, at a person's home, or in a residential aged care setting at no cost to the person.

Hospital services for people living with dementia

Every year there are around 25,500 hospitalisations due to dementia. The average length of stay is 13 days, which is 5 times higher than the average length of 2.6 days for all hospitalisations.[1] People living with dementia present to hospital for a range of conditions, which may be unrelated to their dementia diagnosis. As a conservative estimate, there are approximately 78,500 hospitalisations of a person living with dementia recorded annually.[1] Each state and territory also delivers a range of hospital and health services for dementia diagnosis and post-diagnostic care and support.

Health services for people living with dementia

The Transition Care Programme helps older people to recover and regain functional independence after a hospital stay. It provides short term care for up to 12 weeks in a person's home, the community or a residential aged care home.

The Geriatric Evaluation and Management (GEM) service model is aimed at supporting older people who are unwell (and who may be experiencing complex psychosocial challenges) to regain function and live as independently as possible. GEM can be delivered in a variety of settings (including a hospital setting or in a person's home) and typically by a multidisciplinary care team.

> *'Taking a person with dementia to hospital can be a really big traumatic event.'*

National Safety and Quality Health Service Standards

The National Safety and Quality Health Service (NSQHS) Standards developed by the Health Commission, provide a nationally consistent statement about the level of care consumers can expect from health services, including those with cognitive impairment such as dementia. Actions in the NSQHS Standards that have particular relevance for those living with dementia include:

- providing a safe environment
- partnering with consumers and carers in the planning and delivery of care
- recognising and responding when people experience changes in their physical, mental or cognitive health.

The Health Commission has developed cognitive impairment resources for managers, clinicians and consumers to help improve care of people with cognitive impairment, including dementia.

The Health Commission also provides information and resources for hospitals regarding providing care for people living with dementia. For example, the Health Commission has developed a Psychotropic Medicines for People with Cognitive Disability or Impairment Clinical Care Standard, following the Joint Statement on the Inappropriate Use of Psychotropic Medicines to Manage the Behaviours of People with Disability and Older People.

The Health Commission has also worked with the department and the Aged Care Commission to strengthen the Aged Care Quality Standards, particularly Standard 5 Clinical Care, which includes a specific outcome and actions for people living with cognitive impairment. People with cognitive impairment should receive comprehensive care that optimises clinical outcomes and aligns with the person's needs, goals and preferences. Care should be developed in collaboration with the person, family and other support people. The strengthened Aged Care Quality Standards are designed to be implemented in residential and community aged care services.

Enabling people living with dementia to make decisions about their support and treatment

Supported decision making approaches can be applied for a range of decisions including those relating to supports and treatment. The current initiatives promoting support for people living with dementia to be involved in decisions relating to their day-to-day life and treatment while receiving supports and services are explored under Action 1.

Definitions of restrictive practices

The *Aged Care Act 1997* defines a restrictive practice (in relation to an aged care recipient) as 'any practice or intervention that has the effect of restricting the rights or freedom of movement of a care recipient'. The *National Disability Insurance Scheme Act 2013* defines it as 'any practice or intervention that has the effect of restricting the rights or freedom of movement of a person with disability'.

Australian, state and territory disability ministers endorsed the National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector in 2014. The NDIS Quality and Safeguards Commission has a Regulated Restrictive Practices Guide, which assists providers to meet the requirements outlined in the *National Disability Insurance Scheme (Restrictive Practices and Behaviour Support) Rules 2018*.

There are 5 types of restrictive practices:

- chemical restraint (for example, through inappropriate use of prescription medication)
- mechanical restraint (for example, use of a device like harnesses or straps to influence behaviour)
- physical restraint (for example, physical force to influence behaviour)
- environmental restraint (for example, restricting access to a room or area within their environment like watching television)
- seclusion (for example, locking a care recipient in their room).

Minimising the inappropriate use of restrictive practices in aged care for people living with dementia

There are a range of measures to minimise the inappropriate use of restrictive practices in residential aged care (including for people living with dementia). Restrictive practices must only be used as a last resort, in the least restrictive form, and for the shortest period of time possible.

The *Quality of Care Principles 2014* (made under the *Aged Care Act 1997*) contain safeguards and conditions that must be satisfied by residential aged care providers before restrictive practices are used, including (but not limited to):

- the restrictive practice is only used as a last resort to prevent harm to the care recipient or others, and after consideration of the likely impact of the use of the restrictive practice on the care recipient
- where possible, best practice alternative strategies have been used with the care recipient before the restrictive practice
- the use of the restrictive practice complies with any conditions outlined in the care recipient's Behaviour Support Plans and the Aged Care Quality Standards.

Since 1 September 2021, it has been a requirement for Behaviour Support Plans to form part of the existing Care and Services Plan for all care recipients that:

- have demonstrated behaviours of concern
- are being assessed to determine whether a restrictive practice is required
- have a restrictive practice applied to them.

The Aged Care Commission ensures providers comply with the requirements and aims to eliminate the inappropriate use of restrictive practices through its complaints handling processes and the Serious Incident Response Scheme.

A new Aged Care Act

A new Act is expected to commence in July 2025 It will place older people at the heart of the aged care system and will:

- outline the rights of older people who are seeking and accessing aged care services
- put in place new system oversight and accountability arrangements
- introduce a new approach to regulating aged care to increase provider accountability and encourage delivery of high quality and safe aged care services.

Employment support programs

Some self-advocacy and volunteer groups have formed support networks for people diagnosed with dementia who want to remain employed in their current role or find new employment.

Disability Employment Services help people with disability find work and keep a job. The disability management service supports jobseekers with disability, an injury or health condition who need assistance to find a job and occasional support in the workplace to keep a job. It also has an employment support service for jobseekers with permanent disability who need help to find a job and who need regular, ongoing support in the workplace to keep a job.

JobAccess is the national hub for workplace and employment information for people with disability, employers and service providers.

NDIS participants can receive funding for support in finding and maintaining paid employment.

Government support payments

People may be eligible for a range of income support payments and/or pensions if they need to cease work or change careers or employer as a result of their dementia diagnosis. This includes the Disability Support Pension, JobSeeker payment and the Age Pension. People caring for a person living with dementia may also be eligible for support through Carer Payment and Carer Allowance.

Supporting meaningful ageing with dementia

Spiritual care is an integral component of many aged care services. It can help people to identify and connect with what gives their life a sense of meaning. It can include supports for people who identify with a faith (also called religious care), as well as supports to connect those who experience their emotional wellbeing through a connection with Country and culture. Every person who provides direct care for a person living with dementia can play a role in spiritual and cultural care.

For example, ConnecTo is a flexible spiritual screening tool developed by Meaningful Ageing Australia for use in a range of settings including residential aged care, community care and palliative care. *ConnecTo* acknowledges that spirituality is not just about religion, and that spirituality is expressed through connectedness in five domains. The language and format of *ConnecTo* is accessible for people with cognitive and/or communication impairments.

Advance care planning for people living with dementia

Advance care planning can ensure that an individual's values, wishes and preferences are known and acted upon in the event they cannot communicate decisions about medical care for themselves at a later time.

This is especially important for people living with dementia and their carers. Advance care planning can also involve the appointment of a substitute decision maker (a person who makes decisions for an individual who no longer has decision making capacity).

Resources to support advance care planning and decision making include:

- The Advance Project, which includes a toolkit for advance care planning for people living with dementia
- Advance Care Planning Australia
- End of Life Law for Clinicians.

Palliative and end of life care for people living with dementia

Palliative care and end of life care can include specialist nursing care, pain and symptom management, personal care, physical, psychosocial and spiritual support. A third of older people die with dementia,[57] yet there is a lack of consistency in delivering palliative care to people living with dementia.[58] Health professionals and other care providers play a lead role in the delivery of quality services. Optimal service delivery requires an adequate level of awareness and understanding surrounding a palliative approach to end of life care for people living with dementia.

People living with dementia, their carers and families have access to a range of palliative and end of life information, resources and services.

Programs, services and resources to support providers, health professionals, workers and carers to deliver quality palliative and end of life care include:

- Greater Choice for at Home Palliative Care measure – aims to improve palliative care coordination across the health and aged care systems. It helps to create links between local hospitals, GPs, palliative care services and aged care providers to improve access to quality palliative care for older people living at home.
- Palliative Care Australia – is the national peak body for palliative care and supports the work of specialist palliative care teams. It educates and supports other professionals in the care of people with life-limiting illness.
- National Palliative Care Standards (5.1 edition) – articulate and promote a vision for compassionate and appropriate specialist palliative care across 9 standards. Standards 1-6 relate to care and 7-9 relate to governance.
- Caring @ Home – projects aim to improve the quality of palliative care service delivery for all people living in Australia by developing resources to support carers and families to help manage end of life for a person at home.
- End of Life Essentials – offers free peer-reviewed online education modules on health care at the end of life in acute hospitals for nurses, doctors and allied health professionals. The content of the modules has been developed from the Health Commission's National End of Life Consensus Statement.
- End of Life Directions for Aged Care (ELDAC) – provides information, guidance, and resources to health professionals and aged care workers to support palliative care and advance care planning to improve the care of older people living in Australia.
- ELDAC Dementia Toolkit – provides information and guidance to support palliative care and advance care planning for people living with dementia and their families.
- Palliative Care Online Training – is a free educational resource designed to support health professionals, family members and carers to deliver best practice palliative care in the community.
- Indigenous Program of Experience in the Palliative Approach (IPEPA) is embedding Australian Indigenous knowledges across all Program of Experience in the Palliative Approach resources and facilitating twoway learning including IPEPA Aboriginal and Torres Strait Islander Stakeholder Engagement Kit and workshops.
- The Advance Project – supports advance care planning and palliative care for people living with dementia, through free training and resources for the aged and primary care workforce.
- Palliative Care Clinic Box – is a collection of resources to assist health professionals to support First Nations people receiving palliative care at home and their families.

What challenges are we currently facing?

People living with dementia fall through the gaps between different services and systems

Depending on their age and the stage of the disease, people living with dementia can access supports through the health, disability and/or aged care systems. However, people living with dementia describe that they do not feel adequately supported by the systems. There is an absence of a nationally consistent approach to care coordination in the current service systems and there is no integration between systems (including information systems such as My Health Record, My Aged Care, the NDIS portal and systems used in hospitals). This creates barriers for access and can make it difficult for information sharing around changes to the care and support needs of a person living with dementia.

For example, people living with dementia describe that the aged care system is not as effective as the NDIS in supporting people with disability to live independently and exercise choice and control over how they want to live. On the other hand, people living with dementia have described the disability system as lacking knowledge that dementia causes disability and of the specialist dementia health support services that are available to those receiving aged care supports.

Roles and responsibilities are not always clear, and the various systems and programs available to support people living with dementia can be fragmented and difficult to navigate. This can lead to slow health care delivery, delayed discharge from hospital and premature entry to residential care. Fragmentation of the care sectors was noted as a major contributor to poor outcomes in the Royal Commissions into both the aged care and disability systems.

People living with dementia and their carers describe not knowing who to turn to for support in navigating these systems and raising concerns or complaints about their treatment. They get referred from one system to the other and services are often overreliant on people having prior knowledge of government funding and administrative services.

This can be particularly difficult for the 14% of people living with dementia in the community who are living alone.[1] This challenge is compounded by dementia itself, which can make it increasingly difficult for a person to process complex information and make decisions.

> *'It felt like I had been catapulted into a foreign territory with no road map and I didn't speak the language.'*

This is further exacerbated for CALD and First Nations populations who may face structural barriers accessing government systems (for example, internet availability and access, English literacy, requirements for identity documents). First Nations communities also reported a lack of continuity of care, collaboration and exchange of information between primary care, hospitals, aged care and NDIS providers. Effective engagement and collaboration between these services and community organisations, such as ACCHOs, is essential to provide culturally appropriate care.

First Nations people do not access aged care at a rate commensurate with their need

First Nations people are eligible for aged care services at 50 years of age. However, older First Nations people do not currently access aged care at a rate that is commensurate with their level of need.

It is estimated that 7% of aged care places need to be allocated to First Nations people aged 45 and over. As at mid-2023, just 1.3% of places were accessed by First Nations people.[59] This is partly due to barriers that prevent or discourage First Nations people from accessing aged care services, particularly in rural and remote locations. These include:

- difficulty navigating the system
- a lack of service providers close to home, which may require a person to move away from family and Country to access residential care
- a lack of culturally appropriate and/or trauma informed provision of care
- experiences of racism and distrust of institutional care.

The majority of First Nations people receive their services from mainstream aged care providers, so there is a need for providers to deliver more culturally safe services that meet the needs of First Nations people.

There is also a need for First Nations communities to receive specialist aged care services from First Nations people and organisations. This was emphasised in the Royal Commission[29] and the Australian Government is seeking to ensure equitable access to quality care for older First Nations people and ensuring services are accessible on Country, including by building the capacity of ACCOs. There should be continued support for ACCOs to deliver aged care to their communities.

Aged care assessments need to be culturally safe

Although some work is being done, there is further scope to ensure aged care assessments, including the single assessment workforce process and tool, are culturally safe for First Nations people, informed by input from the sector. The Australian Government is establishing First Nations' assessment organisations to provide a culturally safe pathway for older First Nations people to access aged care.

Lack of supports to remain engaged in employment

> *'I was diagnosed on Monday and by Friday I was packing up my desk at work. No one suggested I might be able to find other paid employment, they just gave me my diagnosis and told me to get my affairs in order. That was 12 years ago.'*

People diagnosed with dementia at all stages of life describe that they do not receive the same range of supports that people with other disabilities receive to promote their participation in society through employment. Often people diagnosed with dementia lose their employment immediately after diagnosis. This can be due to professional registration requirements but also to the stigma associated with the diagnosis, even if it currently does not impact their ability to undertake their role.

People living with dementia describe that they are not told about their rights as an employee under anti-discrimination laws or employment assistance programs and informal support networks they could join at the time of diagnosis. Instead, the assumption by service providers is that they will cease work immediately. This is partly due to a lack of knowledge of rights and available supports, a lack of recognition of dementia as a disability and ageist attitudes.

This contributes to the trauma and grief associated with a diagnosis of dementia, with ongoing impacts on mental and physical health due to the loss of meaning, purpose and identity associated with employment. The loss of employment negatively impacts people living with dementia, especially people living with younger onset dementia who are often contributing to their household income, have dependants and a mortgage at the time of diagnosis. In addition, many people living with dementia are themselves carers for others for example their partners, friends, children and grandchildren and parents.

Lack of information on income supports and financial planning

People living with dementia describe that they are not advised of their options for support payments should they be unable to continue to work, or the need to plan for their financial future. A lack of financial security increases dependency on others and the risk of abuse for people living with dementia.

Advance planning is often limited to health care preferences

Despite a general awareness that people living with dementia nearing the end of their life may experience limitations in their ability to communicate and/or make decisions, there is a lack of supports for a holistic approach to advance care planning. Early advance care planning where future health-related care preferences are reflected upon, discussed and documented, is critical for people living with dementia and should be reviewed throughout their life. They should also be supported to document their wills and preferences regarding other aspects of their life, including the types of environments and activities that may be calming and/or triggering for them. Culturally appropriate advance care planning needs to be considered for people from First Nations and CALD communities living with dementia.

There is a lack of restorative support options

People often don’t know where to go for help and aren’t aware there are things they can do to slow the progression of the disease or improve their quality of life while living with dementia. People living with dementia are often not recommended to receive, or are sometimes excluded from, some restorative support options offered to others receiving government-funded aged care and NDIS services. This includes limited access to allied health and mental health services and variability in access and eligibility criteria to access Older Persons Mental Health Services for people living with dementia.

Interventions such as the Care of People with Dementia in their Environments program deliver restorative support from trained occupational therapists and nurses so people living with dementia and their families have the education and skills to prevent and manage care problems at home.

Spiritual care for people living with dementia is lacking

The spiritual care needs of people living with dementia are often overlooked, especially for those with communication and cognitive disabilities. This is due in part to beliefs about people's worth and their rights to be properly cared for.

> *'Our faith or our spirituality is crucial – we are losing our cognitive self – even a reliable and coherent emotional self. What remains is our spirituality. We need you to help us connect to whatever has given us true meaning in life, whether this is faith, nature, or art.'*

There are limited accommodation options for people living with younger onset dementia

For people living with younger onset dementia, the Younger People in Residential Aged Care Strategy 2020–25 prevents people under the aged of 65 entering residential care unless in exceptional circumstances. However, at present there is a lack of specialist disability accommodation that is suitable for people living with dementia. This can impact the length of hospital stays for some people. There is also anecdotal evidence that some residential aged care providers may be reluctant to offer places to people living with dementia due to their care needs and a perception of increased scrutiny of regulatory compliance in response to the Royal Commission. Data published by the AIHW indicates that on average people hospitalised due to dementia stay on average 5 times longer than for all hospitalisations, whilst for people with younger onset dementia the average length of stay is nearly 12 times longer than all hospitalisations.[60]

Hospital environments are not always dementia enabling

Hospitals can be difficult for people living with dementia. The physical environment, including layout of wards, poor signage, inappropriate equipment and furnishings that increase confusion and distress, is often not designed to address the safety and functional needs of a person living with dementia. The admission processes, being in an unfamiliar environment and hospital protocols (including visitation and hygiene arrangements) can be overwhelming for a person living with dementia. These factors mean that hospitalisation can lead to increased behaviours of concern and use of restrictive practices.[61] People living with dementia are also at significantly higher risk of adverse outcomes in hospital including falls, delirium and functional decline.[62] There is a need to consider the needs of people living with dementia in the design of all aspects of the hospital environment. This could be supported in planning and design guidelines such as the Australasian Health Facility Guidelines, which provide information to assist health services to design and construct health facilities.

The Health Commission's Delirium Clinical Care Standard, which is required for implementation by acute services through the NSQHS Standards, provides guidance to reduce the risk of delirium when people living with dementia attend hospital for any reason.

Hospital environments are also often not culturally safe, which further exacerbates poor experiences for First Nations people and results in suboptimal care. Having the support of the local ACCHO or a trusted support person can help mitigate these risks.

People living with dementia can be hospitalised unnecessarily and have high rates of transitions between care settings[63]

For numerous reasons, people living with dementia, particularly those with more complex and advanced dementia, may be admitted to hospital for care. While many of these admissions are necessary, a proportion of hospital admissions for people living with dementia are avoidable. On average, people living with dementia stay in hospital 5 times longer than people without dementia and many remain in hospital after their acute health needs have been stabilised.[1]

Other challenges contributing to unnecessary hospitalisations include:

- difficulty managing multiple chronic health conditions for a person living with dementia
- carer burnout, including due to lack of appropriate respite options
- limited access to GPs, specialists and other community support services (especially in regional/remote locations)
- limited and inconsistent approaches to care for people with more complex or severe behaviours (for example, aggression, severe agitation, vocalisation)
- limited accommodation options, particularly for people living with younger onset dementia and those with severe response behaviours
- reluctance from aged care providers to support people with more complex or severe behaviours, where they may lack the capacity to provide appropriate support.

People living with dementia also experience higher than average rates of transition between hospital, community and aged care settings, which increases the risk of adverse medication events, inadequate care coordination and follow up care. One in 4 people with dementia who were living in the community moved into aged care after a hospital stay, compared to one in 50 people without dementia. People living with dementia were more likely to be living in residential aged care and to die in the 7 days, 3 months, and 12 months after their first hospitalisation than people without dementia.[63]

There is a need for better coordinated care for people living with dementia, and consideration of how care needs will be met during and after hospital visits, particularly for those who are living in the community. Appropriate clinical handover notes to the person's GP or aged care provider are also required.

Care transitions and increased hospitalisations can be particularly challenging for people living with dementia near end of life and has been associated with increased risk of delirium, falls, cognitive decline and death. Early identification of palliative care needs and advance care planning, improving training for health and aged care workforces, better continuity and coordination of care between settings and better reporting of palliative care activity is necessary.[58, 64, 65]

To better understand and address issues contributing to long hospital stays for older people living with dementia and care transitions, the Australian Government has funded the Hospital to Aged Care Dementia Support Program to expand the availability of support to older hospital patients living with dementia into 11 locations across all states and territories. This builds on the success of an earlier trial and aims to help identify patients' behaviour support needs, as well as providing support before and during the transition into aged care settings, and in-person support to aged care providers during the post transition period. It also involves early intervention activities to avoid older patients living with dementia staying in hospital for extended periods.

Many aged care providers do not have the skills and capacity to adequately support people living with dementia

The Royal Commission identified that while dementia care should be ‘core business’ for aged care providers, many are delivering substandard support for people living with dementia.[29] This can lead to poor outcomes for people receiving care, aged care providers refusing to care for people with more complex dementia or severe behaviours, lack of respite for carers and unnecessary and/or prolonged hospitalisations.

People living with dementia can be subject to mismanaged medication and inappropriate restraint

People living with dementia can be subject to inappropriate use of medications, particularly people with more advanced dementia or severe behaviours or those requiring pain management. One in 5 people living with dementia in the community experience adverse drug events.[66] This has potential to increase the risk of delirium, incontinence and falls.[61] Mismanaged or undiagnosed pain can also be a cause of changed behaviour. People living with dementia may also be subject to the use of environmental restraints, such as secure wards, in aged care, hospital and other supported accommodation settings.

A range of dementia specific support services are improving access to quality dementia care and building the capacity and capability of care providers, coordinated through Dementia Support Australia. However, service providers are not always clear on how to appropriately support people living with dementia and ensure their physical safety, while respecting their right to freedom of movement, participation in society and freedom from cruel or degrading treatment.

There is a lack of awareness and understanding of the palliative care needs of people living with dementia

Palliative care tailored to the needs of people living with dementia is not widely available and palliative care services often lack coordination across different care settings leaving people feeling alone, overwhelmed and confused. The absence of consistent frameworks and training for delivering palliative care to people living with dementia can impact the quality of services delivered.

There is also a need to ensure palliative care services for First Nations people in residential aged care and hospital settings accommodate cultural needs such as return to Country as part of end-of-life considerations.

Action 6: **Support carers of people living with dementia**

Outcome statement for people living with dementia

My carers are well supported and able to maintain their own health and wellbeing.
My carers and I are able to maintain a meaningful and mutually beneficial relationship.

How are we going to make a difference?

1. Ensure active engagement of carers as partners in care, including culturally safe and inclusive approaches.
2. Support carers and families to improve their knowledge of dementia and its progression through access to education and training, including targeted information for carers from First Nations, CALD and other diverse communities.
3. Improve respite options that better meet the needs of people living with dementia and their carers.
4. Improve the accessibility and user experience of My Aged Care, the Carer Gateway and the National Dementia Helpline.
5. Improve consideration of carer needs in aged care assessment processes and promote ways to reduce carer burnout and stress.
6. Improve access to emergency or transitional residential respite care from the community or hospital, including for carers from First Nations, CALD and other diverse communities.

Need for change	Carers are a big part of Australia's health system, including our aged, disability, end of life and community care systems. They need the right information and help to handle the physical, mental, and social demands of their caring role.
Where do we want to be in 10 years?	Carers have the information, training and support they need to undertake their supporting role and maintain their own health and wellbeing.
How will we know if we have made a difference?	1. Increased carer awareness, access and satisfaction with dementia support services and resources. 2. Increased access for First Nations carers to support services embedded in ACCHOs and ACCOs. 3. Increased availability and use of respite care by people living with dementia. 4. Increased access to and use of culturally appropriate respite care by people living with dementia and carers from First Nations, CALD and other diverse communities. 5. Increased support available for carers and family members of people living with younger onset dementia. 6. Improvements in self-reported wellbeing among dementia carers.

Carers are people who provide unpaid care and support to family members or friends with disability, a medical condition, mental illness or who are frail due to age. Carers are an integral part of Australia's health system and are the foundation of our aged, disability, palliative and community care systems. Carers need to have access to information and support tailored to their needs to manage the physical, mental and social demands of their caring role. Carers can include younger children, and older adults, who may be supporting someone living with younger onset dementia.

Nearly three quarters of primary carers of people living with dementia in informal roles (for example, family, friends or significant others) are women.[1] In 2018, more than half of primary carers of people with dementia provided on average 60 or more hours of care every week. Just over half of female primary carers are aged between 15–64 years, which can have a significant economic impact.

Where are we now?

Families and friends will often recognise the early signs and symptoms of dementia (which may not be apparent to the person themselves) and seek out medical assessment and diagnosis. Over time, they may increasingly take on a role in supporting a person living with dementia. This support is often over an extended period with many different and complex experiences from diagnosis, through accessing support services, to the end of a person's life.

Being a carer can affect a person's physical, emotional and mental health and wellbeing. It can impact their ability to work, maintain their community connections and social life and can be isolating and overwhelming. Gender is an important factor in caring responsibilities and burden. Women are more likely to take on a caring role compared to male counterparts due to society's expectations and pressures, with women expected to become carers even if they do not have sufficient knowledge or preparation. Gender norms can also lead to men and women taking on different caring responsibilities, with women more likely to take on personal care duties (for example, dressing or bathing), that are considered difficult irrespective of gender. Female carers are likely to experience greater social restriction and experience higher levels of burden and depression than male carers, due to these and other factors.[11]

There are a number of initiatives and programs that provide support to carers of a person living with dementia. Some are general supports available to all carers and some are specific to carers of people living with dementia. Support for carers can include mental health treatment for themselves and increasing knowledge, understanding and awareness of strategies and practices to aid their caring responsibilities.

Respite care

Respite care gives carers (and the person living with dementia) a break. It can be delivered in different ways:

- a worker can come to a person's home
- the person may go to a respite centre during the day
- the person might access cottage-based respite overnight or over a weekend
- the person may access respite care in a residential service for a few days or a few weeks at a time.[67]

People receiving aged care services or disability supports may be eligible to access some funded respite care.

The Improving respite care for people living with dementia and their carers program supports carers and families caring for people living with dementia. It provides access to dementia-specific respite support services, and better training for health and aged care workers. The program delivers:

- carer education and wellbeing
- innovative approaches to improving the quality and experience of respite care for people with dementia
- improved respite care planning for people with dementia
- increased capability of aged care providers to deliver quality respite care.

Financial support

In recognition of the important role carers play, they may be eligible to access certain Australian Government payments, such as the Carer Payment and Carer Allowance, through Services Australia.

In response to a recommendation of the Royal Commission, the Productivity Commission considered recognition and entitlements for unpaid carers. A final report was released in September 2023.

Information, education and emotional support

Other carer services include access to information and education to support people in their supportive role, counselling and emotional and peer support.

Carer Gateway (1800 422 737) provides free services and supports for carers, no matter their circumstances or the age of the person they are caring for.

Carers can access a range of services to help them in their caring role, including:

- needs assessments and planning
- peer support groups, counselling and coaching
- tailored support packages with a focus on employment, education and respite
- access to emergency respite.

Carers can access services and supports by calling 1800 422 737 Monday to Friday, 8am to 5pm and selecting option 1 to speak to their local Carer Gateway service provider.

As part of the NDSP, Dementia Australia offers specific carer-focused support to help carers maintain their supportive role to better support people living with dementia remain in the family home for longer where practical. It also provides information, education and support to find local services, peer support groups and counselling.

Carers Australia provides information and resources for carers about topics such as accessing mainstream supports, aged care and the NDIS, supporting someone living with dementia, government payments for carers, advance care planning and palliative care. Carers Australia member organisations in each state and territory can provide local advice.

Maintaining meaningful and mutually beneficial relationships

Meaningful Ageing Australia has developed resources that promote the maintenance of meaningful relationships between people living with dementia, their family, friends and support networks.

About Carers

Up to **337,200**

unpaid carers of people living with dementia in the community

1 in 4

carers need access to more **respite care**

1 in 2

unpaid carers are caring for their **partner**

Nearly **half** of all carers provide

60 hours of care

or more each week on average

1 in 2

carers reported **financial impacts** since providing care

Source: Dementia in Australia Report, AIHW[1]

What challenges are we currently facing?

A dementia diagnosis can have a huge impact on the person diagnosed and their families who may be entering an increasingly supportive role. They may feel grief and can also be overwhelmed by the implications for their life moving forward.

While supporting a family member or friend living with dementia can be rewarding, it can also be emotionally, financially and physically challenging, particularly where people may exhibit behavioural changes associated with dementia or require full-time support. Informal carers of people living with dementia may also have cross-generational carer responsibilities themselves (such as for grandchildren or other family members).

> *'You're in the wilderness and there is no roadmap. Without support, you'll go under.'*

Lack of respite care that is responsive and meets the needs of different people

Respite care is limited and the respite options available don't always meet the diverse needs of people living with dementia and their carers. This is particularly so for people with specific needs or experiencing complex dementia or severe behaviours, where services may not have capacity to care for them.

> *'Support is critical for carers – we need this as without it, we will go under – and it needs to be flexible – different supports for different parts of the dementia journey.'*

Respite services need to be more culturally appropriate, catered to and led by First Nations communities and diverse population groups, ensuring there is continuity of care and trust facilitated by ACCOs and a liaison person such as a care coordinator (e.g. an Aboriginal Health Worker).

Respite care often isn't easy for people to access

The process of accessing respite care can be difficult and the eligibility requirements can be limiting. The cost of respite care can be high, and emergency respite may not be accessible and available when needed.

Carers can be hesitant to use respite and may not prioritise their own health and wellbeing. People tend to use respite as a 'last resort' and in response to a crisis, including extreme carer fatigue, rather than as a planned preventive measure. Carer burnout can lead to people living with dementia entering permanent residential care earlier than needed.

> *'Equitable access and early referral to respite care, both planned and emergency, is critical to ensure sustainability of care relationships, and the health and wellbeing of carers.'*

Carer commitments impact financial security

About half of all carers of people living with dementia report that the role has a financial impact on them in the form of reduced income as they give up paid employment to provide care and/or increased expenses. This can affect carer perception of respite care.

There is insufficient emotional and peer support for carers

Carers are also dealing with the change in their relationship with the person living with dementia. Carers can become isolated and may see negative impacts on their self esteem (for example, where they can no longer work or participate in other hobbies and activities due to their caring responsibilities).

Support is not always readily accessible to carers, particularly beyond the initial diagnosis. Noting that, due to the progressive nature of dementia, carers often need ongoing support at various points after the person they are supporting receives their diagnosis. There is also a lack of tailored services for younger carers, particularly those who care for a parent living with younger onset dementia.

> *'Peer support is needed, being able to talk to people and get guidance/help is very important – can give insight into what's coming up in the future.'*

Carers could also benefit from physical activity, through sport or group activity, to improve their physical and mental health, promoting overall wellness, social inclusion and community engagement.

Loss of meaningful and mutually beneficial relationships between people living with dementia and their carers

Misconceptions about the potential symptoms and progress of the disease, stigma and insufficient supports for people living with dementia and their carers may contribute to a loss of meaningful and mutually beneficial relationships between people living with dementia and their carers. A dementia diagnosis can impact families and relationships in varied and complex ways. Family members and friends may prematurely or unnecessarily adopt a carer role. Carers may experience burnout which can contribute to a lack of emotional availability for connection with other people. Impairment of verbal communication may be incorrectly interpreted as equating to a lack of ability or need to connect with others.

Challenges navigating the service systems

Carers often take on responsibility for navigating access to services and supports their loved ones need. As described under Action 4 this can be daunting and at times overwhelming.

Carers report that the multiple access points for services such as My Aged Care and the Carers Gateway is confusing and adds to the complexity of navigating service systems.

Action 7: **Build capability of the workforce to care for and support people living with dementia**

Outcome statement for people living with dementia

The people supporting me understand dementia and take time to learn about me and listen to my concerns. I am provided with care, support and information that meets my needs and is sensitive to my individual circumstances.

How are we going to make a difference?

1. Strengthen dementia training, including embedding a dementia focus within core competencies, improve training pathways and provide mentoring and supervision opportunities for health, aged care, disability support and other workforces, including carers and volunteers. This will support best practice dementia care and support, capacity building and retention.
2. Support training pathways for carers and workers from First Nations, CALD and other diverse communities to enter the dementia care workforce.
3. Support training for the primary care workforce, including GPs, nurses and nurse practitioners, allied health professionals and Aboriginal and Torres Strait Islander Health Practitioners, to better meet the needs of people living with dementia and their carers.
4. Increase access to competency-based training and resources to improve dementia understanding for those working in key community services such as police, paramedics, firefighters, emergency services and correction services.
5. Encourage dementia awareness and training by local community services, including public transport, banks, post offices and other businesses to better support people living with dementia in their customer base.
6. Encourage organisational cultures of quality, safe, person-centred and culturally safe dementia care in health, disability and aged care services.

Need for change	Having the right skills is essential to give the best care to people living with dementia and to respect their human rights.
Where do we want to be in 10 years?	The primary care, acute, community, disability, health and aged care workforces receive the training and support they need to provide high quality care to people living with dementia, their families and carers. Care focuses on optimising quality of life, is person-centred, culturally safe and delivered through a human rights based approach.
How will we know if we have made a difference?	1. Increased training opportunities and resources about dementia available for the health, aged care, disability, and community services workforce. 2. Increased number of primary care, acute, aged care, disability, and community service workers undertaking dementia specific training. This includes Aboriginal and Torres Strait Islander Health Workers and Health Practitioners. 3. Increased capability of health, community services, disability and aged care sectors in working with people living with dementia. 4. Dementia care by mainstream providers to First Nations people is culturally safe

Appropriately skilled workforces are critical to providing quality dementia care and improving the quality of life of people with dementia living in a range of settings. Training for health and aged care workforces in particular will protect human rights and focus on personalised and culturally safe care. This will result in better quality of life for people living with dementia. Other workforces who regularly come into contact with the public also play a key role in making a dementia friendly and inclusive society.

Where are we now?

Dementia training

Under the strengthened Aged Care Quality Standards, providers will be required to ensure their workers regularly receive competency-based training in core matters, including not only in caring for people living with dementia, but also in the delivery of person-centred, rights-based care, and culturally safe, trauma aware and healing informed care.

Free online training and resources available to workers and others with an interest in dementia include:

- The Dementia Training Program (DTP) provides a national approach to training healthcare professionals and support workers in dementia care. It is delivered by DTA and provides:
  - continuing professional development training on dementia assessment, diagnosis and management to GPs, nurses, pharmacists, psychologists, specialists, allied health and other professionals as appropriate
  - free accredited vocational level training courses in dementia care for care and support workers
  - onsite training to aged care providers, including a dementia skills and environment audit followed by a tailored training package.
- ADNeT's webinars and training videos for health professionals (including specialists responsible for dementia diagnosis) and annual Australian Dementia Research Forum, which include continuing education sessions for health professionals.
- The University of Tasmania's (UTAS) Wicking Dementia Research and Education Centre's Massive Online Open Courses in understanding and preventing dementia, and traumatic brain injury.
- UTAS offers a 3-year undergraduate Bachelor of Dementia Care (fees may apply).
- Fee-Free TAFE places are funded by the Australian, state and territory governments to allow care and support workers to undertake relevant vocational education and training, including providing support to people living with dementia as part of Certificate III qualifications in individual support. Funding has been extended through a 5-year National Skills Agreement that commenced on 1 January 2024.
- Dementia Australia offers a range of information and resources for health professionals seeking to learn more about dementia, including how to support people living with dementia. Dementia Australia's Centre for Dementia Learning provides tools and programs for those supporting people living with dementia.

Aged care workforce measures

The Aged Care Nursing Scholarship Program will build workforce capacity by funding scholarships for personal care workers and nurses to further their education in a range of disciplines including dementia care.

Aged Care Research & Industry Innovation Australia (ARIIA) is bringing together older people, aged care providers and researchers to undertake research into evidence-based models of care (including in relation to dementia) and supporting workers and providers to embed these practices.

Training and guidance for other professions

The Dementia Training Program provides free training to first responders and emergency care workers to improve their understanding of dementia and ensure that they have the skills required to help people living with dementia in emergency situations.

The University of Technology Sydney's Faculty of Law offers dementia-focused, online short courses for the legal profession:

- Understanding Dementia: Facts and Foundations
- Planning Ahead: Focus on Advance Care Planning
- Elder Abuse: Strategies for Prevention.

What challenges are we facing?

There are not enough care workers or volunteers

There is pressure on care workers and volunteers, which was amplified during the COVID-19 pandemic, with reports of high burn out and staff turnover. The reliance on casual staff to fill staff shortages is also challenging in delivering quality care for people living with dementia, where consistent relationships between care staff and the person being cared for are critical. This is compounded in remote, rural and regional areas and for CALD and First Nations workforces.

People with younger onset dementia and their care partners also reported that the disability workforce has a low level of experience with dementia.[68] This, together with a lack of integration between systems, has been found to create particular barriers for people with younger onset dementia to access services.

There is not enough support to assist health professionals to care for people living with dementia

There are currently insufficient numbers of health professionals (including GPs, nurses and allied health) who receive the support to manage and support people living with dementia. Medical students often graduate with a poor knowledge and understanding of dementia.

> *'Some people living with dementia have described feeling that health professionals 'talk over' them or don't listen to them due to their diagnosis.'*

As described under Action 4, GPs are highly trained, but may benefit from additional information and support in recognising dementia symptoms. This would help to empower them to make a diagnosis of dementia and make appropriate referrals, through readily available information and ongoing professional development.

> *'GPs need more training in dementia, it needs to start at university.'*

There are also not enough specialists skilled in assessing and diagnosing dementia to meet demand. This challenge is particularly prevalent in rural and remote areas, where people may need to travel long distances to access the services they need. First Nations people experience particular challenges accessing culturally competent workers and health professionals (who are also skilled in dementia care) and have highlighted the need for more workers from First Nations backgrounds. There could also be opportunities to upskill the broader primary care workforce and allied health professionals to support the work and reduce over-reliance on GPs and specialists.

There is a reliance on carers

Friends and family often take on a large proportion of the support role for someone living with dementia. Providing informal care can be rewarding and satisfying but the caring role can also negatively impact the health, wellbeing and financial security of the person providing care. Over time, this can affect the quality of care and sustainability of the caring relationship. The dependency on others within family and social networks can increase the risk of abuse for people living with dementia.

Some people living with dementia living in the community may not have family or friends who can provide informal care. This includes not only the 14% of people living with dementia in the community who are living alone,[1] but those living with others and with personal networks who are unable to provide support.[1]

Dementia training for workforces and volunteers is insufficient or not always taken up

There is a need to improve the experience of people living with dementia in the community by building the capacity of key workforce groups to recognise, communicate and respond appropriately to people living with dementia. A particular priority would be community service workers including those in everyday services such as:

- supermarkets
- public transport
- banks and post offices
- face-to-face government services
- workers who come into contact with people with dementia under heightened circumstances, such as first responders.

Support workers, health professionals, legal professionals, volunteers and others who may be supporting and/or providing services to people living with dementia don't always receive training in dementia. This includes how to communicate and engage appropriately with people living with dementia, create enabling environments, recognise signs of unmet needs and respond to changed behaviours. This can be due to a lack of available training (particularly in rural and regional areas) or staff shortages making it difficult to release staff to attend training. The high workforce turnover within the aged care and disability sectors means the need for training is ongoing.

The training delivered does not always reflect the diverse needs and experiences of people living with dementia or is not designed in partnership with people with lived experience of dementia. Upskilling and retraining to better utilise the workforce and creating workforce pathways to build capacity is necessary. It should be based on a nationally consistent approach to education and training of non-clinical and clinical staff providing dementia care.

Within First Nations communities and CALD populations, there is an opportunity to build the capacity of Aboriginal and Torres Strait Islander Health Workers and Health Practitioners and localised training and development of community support workers to expand into aged care and disability services. There could also be more training pathways for caregivers in diverse population groups to gain skills and qualifications to enter the workforce. These initiatives could be supported by the development of nationally coordinated communities of practice for the care workforce.

Action 8: Improve dementia data, maximise the impact of dementia research and promote innovation

Outcome statement for people living with dementia

Research is focused on improving my life and the lives of other people living with dementia. I have the opportunity to participate in research. Innovative practices are in place to make it easier for me to live well with dementia. Dementia data is regularly reported so I can see if improvements are being made.

How are we going to make a difference?

1. Encourage investment in research, innovation and research translation on prevention, risk reduction, diagnosis, treatments (including a cure), holistic care and management for all types of dementia.
2. Improve alignment of Australian dementia research priorities and funding sources and include people living with dementia and their carers in setting future research priorities.
3. Improve understanding of outcomes for people living with dementia from First Nations, CALD and other diverse communities.
4. Promote whole-of-system approaches to improve dementia data, (e.g. through clinical quality registries).
5. Improve health, social and aged care data collection, accessibility and integration to support research, inform policy and service planning, monitor improvements and reporting on outcomes for all types of dementia.

Need for change	Knowing more about dementia, using what we learn in everyday care and trying new ways of doing things is important to prevent new cases and to improve treatment and care.
Where do we want to be in 10 years?	Improved national dementia data informs policies and programs and enables improvements to be monitored over time. Innovative and translatable research informs practice for early detection and diagnosis, treatment and care.
How will we know if we have made a difference?	1. Increased involvement of people with lived experience of dementia in all stages of publicly funded research projects, including people from First Nations, CALD and other diverse communities. 2. Increased number of high quality, peer reviewed, open access Australian dementia studies. 3. Increased number and value of dementia research grants approved. 4. Improved national data sources (e.g. surveys, national minimum datasets) that include data on dementia, and dementia among high priority groups, including First Nations, CALD, regional, rural and remote and other diverse communities. 5. Improved national data for measuring the number of people living with dementia.

Better monitoring and data on dementia nationally will provide the information needed for policymaking, program design and service planning for people living with dementia, their carers and families. Robust data is also key to measuring the effectiveness of programs and the outcomes of people living with dementia. Translating knowledge from research into daily practice, better engaging people living with dementia and use of innovative technologies can help reduce the number of new cases of dementia and improve early detection, diagnosis and care.

Where are we now?

Dementia data and the National Centre for Monitoring Dementia

The National Centre for Monitoring Dementia (the Centre) at the AIHW was established in 2021 to monitor data on dementia so that there is more accurate information for people living with dementia, carers, scientists, policy makers and service providers. One of the main reports produced by the Centre is the Dementia in Australia Report that provides a comprehensive picture of dementia in Australia. It includes the latest statistics on dementia, burden of disease, deaths, expenditure, the use of health and aged care services and information about carers of people with dementia.

As part of this work, the Centre identifies current gaps in the data and is working to improve the quality of data to help design better dementia policies and programs. The Centre will also collect data to monitor and report annually on the progress against the 8 actions in this Action Plan to understand how much it is improving the lives of people living with dementia and their carers.

There are limitations in data collections on dementia and how existing data is used to inform policy and service planning.[69] The AIHW has linked existing administrative data from across the health and aged care systems to improve dementia monitoring in the short to medium term.

There is no single dataset to capture dementia diagnosis or management. ADNeT's clinical quality registry for people newly diagnosed with dementia and MCI is an important step in providing this much needed data. Since its commencement in early 2020, the registry has included data from memory clinics, other dementia and MCI diagnostic services and individual medical specialist services (for example, geriatricians, neurologists and psychiatrists) across Australia.

Dementia research

There is a substantial Australian dementia research base with a significant number of journal articles relating to dementia and Alzheimer's disease published in the last 5 years.

Dementia was one of 9 priority areas of the National Health Medical and Research Council (NHMRC), which invested $200 million between 2014–19 through the Boosting Dementia Research Initiative and has since allocated dementia funding in its broader initiatives.[70]

The Medical Research Future Fund Dementia Ageing and Aged Care Mission seeks to improve outcomes for people living with dementia and older people. The research includes evidence-based models, tools and pathways that enable earlier and fast dementia detection, diagnosis and intervention, innovative therapies and technologies to halt or cure dementia. This is supported by projects that address key data gaps and provide information that can inform dementia monitoring, health and aged care policy and service delivery.

The use of innovative technologies

Technology has a key role in enhancing the quality of life of people living with dementia. Supportive aids (sometimes called assistive technologies) are things that can assist an individual to perform a task they would otherwise be unable to do or makes the task easier to perform. These can range from very simple equipment, such as calendar clocks and touch lamps, to the application of technology-based solutions such as smart home devices. They can help to reduce the risk of accidents, support independence and choice, reduce premature entry into aged care homes and reduce the stress and improve the lives of carers and people living with dementia.

Artificial Intelligence and machine learning offer opportunities to enhance research, with ethical safeguards. These are already being used in some research fields and eventually could assist with earlier diagnosis, understanding how dementia symptoms develop and supporting people to live at home for longer.

Emerging drugs and disease modifying therapies

There have been recent high-profile developments in disease modifying treatment trials for people living with the early stages of Alzheimer's disease or MCI, although none of the treatments have yet been approved for use in Australia outside of clinical trials. These new treatment options can slow the progression of disease so people can continue to do what they want to do for a longer period of time. The treatment trials show that some people experience common but manageable side effects that don't usually cause symptoms, while they can be serious in other people. They are not a cure and they are not suitable for everyone with Alzheimer's disease.

Drug development and clinical trials for dementia take a long time, are expensive and prone to high rates of attrition, due to the slow progression and complexity of disease. There is a need for more innovative and adaptive models of clinical trials. Improved access and participation of Australians in trials of the latest potential therapies is necessary and trials should be inclusive of women and diverse population groups, including First Nations and CALD communities, for greater equity.

NHMRC and the Medical Research Future Fund both support clinical trials activities to test the effectiveness of treatments and lead to improvements in health care.

Promoting the participation of people living with dementia in research

There are opportunities for people with and without dementia to participate in research, but people living with dementia and others in the community might not know how to access them or what it involves.

Advance research planning or directives involves planning ahead about preferences for participation in research during future periods where the ability to make or communicate decisions may be limited. A dementia focused Advance Research Directive and accompanying guidance booklet is available at the StepUp for Dementia Research website.

What challenges are we currently facing?

Australian data on dementia diagnosis and management is limited

Like a number of other countries, Australia has no reliable data on the number of people living with dementia or the number of people newly diagnosed each year. This significantly hampers efforts to predict current and future service needs and to inform future policies. In addition, the lack of integration between datasets and systems makes it difficult to obtain data on people living with dementia.

It’s important that dementia data collections are gender disaggregated and include intersectional data, which will support the development of policies, programs and services that are appropriately designed. Data used to monitor dementia is currently reported by sex, but disaggregated gender data (how a person identifies) and intersectional data, such as on LGBTIQA+ Australians living with dementia, is generally not well-captured in administrative and statistical data collections, which limits reporting capabilities. The Dementia National Best Practice Data Set, developed by the AIHW, will promote nationally consistent definition, collection and recording of information on people with dementia, including data on gender and intersectional data, across health, aged care and social care sectors, over the life of the Action Plan.

Limited mechanisms for translating evidence into practice

There are currently limited pathways that promote and support the translation of current evidence-based research into practice across the entire range of dementia related needs. There is often a lack of understanding on where the responsibility for translation into practice sits, and a disconnect between research and how this is then put into practice.

> *‘More research needs to be done on reducing the risk of dementia.’*

No single dementia research platform

There is no centralised dementia research platform making it difficult for researchers to know what work is being undertaken and for dementia research findings to be used to promote evidence-based practice. This includes centralised research data and research samples such as brain banks to collect brain and tissue samples to support researchers to discover the causes and consequences of different brain disorders. As a result, innovative practices and models often aren’t translated into practice and/or shared.

Limited research for some groups of people

There is a lack of dementia research and knowledge translation specific to the experiences of people who may be at higher risk of developing dementia or experience barriers to access services and supports due to a range of factors. This includes First Nations people, people from CALD backgrounds, people living in rural and remote areas, people with other disability, people who identify as LGBTIQA+, veterans, people with younger onset dementia, children with dementia, people at higher risk of repeated head injuries and people who are homeless or at risk of homelessness.

Limited engagement with people with lived experience

People living with dementia and their carers are often not involved in setting dementia research priorities. More broadly, people living with dementia are often not consulted on the design of services or supports they use due to an assumption that they do not have the capacity to contribute. There is also an absence of service providers, clinicians and workers being actively engaged in research, which hampers the translation of evidence into practice.

Focus on finding a cure has been limited

Dementia is the leading cause of death for women in Australia and second leading cause of death overall.[1] There has been limited research on finding a cure, compared to other diseases. Sustained investment in research has resulted in remarkable improvements and survival rates for other diseases, such as some cancers.[1]

Implementation and accountability

> *'I really care about people in the future having a better experience so we need to hold people accountable.'*

Roles and responsibilities

Australian, state and territory and local governments are committed to working together with people living with dementia, their carers and families, service providers, business, the community and non-government sector to implement the Action Plan in a coordinated and meaningful way. The implementation of the Action Plan over its life will be responsive to changing needs and developments in research, diagnosis and treatment. Implementation details will be published on the department's website.

All levels of government play a role in providing services, supports and infrastructure to people living with dementia their carers and families. Listing key government roles and responsibilities helps everyone to understand which level of government is responsible for the systems that may be used by people living with dementia.

In many cases, more than one level of government has some responsibility for a support or service system. However, in most cases one level of government has primary responsibility for administration of a system. The table below gives some examples but is not exhaustive.

Specific governance arrangements and roles and responsibilities for implementing actions under the Action Plan will be finalised as part of implementation.

Australian Government	State and territory governments	Local governments	Responsibility is shared
Medicare Benefits Schedule, Pharmaceutical Benefits Schedule Funding community controlled Aboriginal and Torres Strait Islander primary healthcare services	Managing and administering public hospitals and memory clinics		Funding public hospitals Preventive health services Transition care services Palliative care
Aged care regulation and funding Dementia programs	Multipurpose services	Municipal services and community aged care services	Older adult mental health services
NDIS administration			NDIS funding and governance
		Accessible buildings and urban planning and design	Community infrastructure

Implementing the Action Plan

Implementation will be supported by:

- **Collective Priority Frameworks** – will set out priorities that governments will focus on for the first 3 years of the Action Plan. It is anticipated there would be 3 collective priority frameworks spanning the life of the Action Plan.
- **Monitoring and data improvement** – Data will be collected and analysed over the life of the Action Plan to help measure progress and achievements against activities over time.
- **Reporting** – There will be annual reporting on the difference being made under the Action Plan, looking at both changes in the measures of progress and at activities delivered. A comprehensive mid-point review will also be conducted.

Governance – Clear governance arrangements will underpin implementation of the Action Plan to drive implementation, oversee monitoring and reporting and to keep governments accountable and on track.

National Dementia Action Plan 2024–2034

Actions

- Promote equity and human rights
- Tackle stigma, improve awareness and promote inclusivity
- Empower individuals and communities to minimise risk where they can, and delay onset and progression
- Improve dementia diagnosis and post-diagnostic care and support
- Improve treatment, coordination and support for people living with dementia
- Support carers of people living with dementia
- Build capability of the workforce to care for and support people living with dementia
- Improve dementia data, maximise the impact of dementia research and promote innovation

VISION

People living with dementia and their carers have the best possible quality of life, including their emotional and physical wellbeing. People living in Australia recognise and understand dementia.

Annual dashboards on National Dementia Action Plan measures

2024
Action Plan Released

2025
1st Collective Priority Framework

2028
2nd Collective Priority Framework

Midpoint review

2031
3rd Collective Priority Framework

2033
Development of a new Action Plan

2034
Final evaluation

Principles

The **human rights** of people living with dementia and their carers are protected and upheld

The needs of **priority populations** are explicitly considered in designing action against this plan

Action on dementia is **driven by people living with dementia** and their carers, through equitable inclusion and expression in their lived experience

Action on dementia is **collaborative, coordinated, integrated, planned** and **responsive** to need

Services and supports for people living with dementia and their carers are:

- **holistic and strengths-based,** supporting people living with dementia in all aspects of their life, including a focus on **wellness and maintaining independence**
- **person-centred and relationship-based,** driven by the preferences of people living with dementia and their carers
- **evidence-based, outcomes-focused** and maximise quality of life for people living with dementia and their carers
- **trauma-informed, accessible** and **culturally safe**
- **co-designed** and **delivered** in **partnership** with **local communities** where possible, including for people from First Nations, culturally and linguistically diverse and other diverse backgrounds.

Key partners

Australian Government and state and territory governments
Health and aged care service providers and professionals
Researchers
Community members

Accountability

National Centre for Monitoring Dementia
World Health Organisation reporting
Annual reporting on performance measures and activities, and a midpoint review
Implementation group made up of Australian government and state and territory government representatives

Collective Priority Frameworks

Collective priority frameworks will detail the specific activities to be prioritised by governments to progress the 8 actions created by the Action Plan over smaller, specific periods of time.

The first framework will focus on priorities agreed by governments for improving outcomes for people living with dementia, their carers and families.

The collective priority frameworks will be developed by the Australian Government in collaboration with state and territory governments, with input from dementia experts and people with lived experience of dementia and will be published on the department's website.

Monitoring our progress

The Centre (described under Action 8) will have a key role in collecting data and monitoring progress against the Action Plan. It will do this by:

- collecting agreed data to directly assess progress against the Action Plan, to be updated annually
- addressing gaps in Australian dementia data through the National Dementia Data Improvement Plan so there is more accurate information over time
- reporting and publishing a range of dementia data and statistics in the annual Dementia in Australia report. This will keep people aware of dementia and help identify emerging issues that need attention within future collective priority frameworks.

A Monitoring and Reporting Framework will accompany the Action Plan to describe the roles and responsibilities around monitoring more fully, along with details on how we plan to monitor and report on progress. It will also provide accountability to the public on whether the Action Plan is on track to achieve its outcomes.

Improving the data

Australian, state and territory governments are working together to improve the collection, sharing and use of data to track changes over time and measure progress under the Action Plan.

Implementing data improvement activities from the Centre's National Dementia Data Improvement Plan will ensure the data needed to measure progress under the Action Plan is collected. This includes where linking deidentified data across systems can provide deeper insights into how and why certain outcomes occur.

This will improve our ability to measure progress against the Action Plan over time. Where data sources need to be developed or improved, the Centre will consider appropriate alternative ways to measure change under the Action Plan using 'proxy' or short-term data sources.

Reporting under the Action Plan

Dashboard on National Dementia Action Plan measures

The Centre will publish and maintain a web-based Action Plan Dashboard, which will be updated each year to report on the measures of progress set out in the “How will we know if we are making a difference?” statements under each action in the Action Plan. The Dashboard will provide a comprehensive picture of progress, including:

- data from a range of sources to measure progress in accordance with the Monitoring and Reporting Framework
- data or information to support the analysis of trends over time
- any limitations or gaps in the data – for example, where baseline data is not available, or data collection did not occur (e.g. some data may not be collected annually) – and progress made in improving data collection and use.

In instances where there is data development underway and no baseline data yet available, the Dashboard will provide information on the current state of data development for measuring whether the Action Plan is making a difference. As data gaps improve and new data become available over time, the Dashboard will increasingly provide a more comprehensive picture of progress under the Action Plan.

The Dashboard will also inform national reporting on Australia’s progress against the WHO’s Global action plan on the public health response to dementia 2017–2025 every 3 years.

Reporting on activities

Annual reporting on progress against activities outlined in the collective priority framework and progress against any other actions identified in the Action Plan will also be published. This will support accountability by Australian, state and territory governments and make it clear how activities align with the Action Plan’s actions.

Mid-point review

A formal mid-point review will be undertaken to comprehensively assess progress against the Action Plan and consider:

- progress made on implementing the actions set out in the Action Plan and the impact of these actions in improving outcomes for people living with dementia, their carers and families
- any factors impacting implementation or limiting the ability of governments and others to make progress towards the 8 actions described in the Action Plan
- opportunities for improvement, including to better target actions to meet the needs of people living with dementia, their carers and families, to improve the effectiveness and efficiency of implementation or to improve governance, monitoring and reporting arrangements
- any new developments made in dementia research, technology or supports and how these could be incorporated into the Action Plan moving forward.

The review would be undertaken in close collaboration with people with lived experience of dementia and a report on the outcomes of the review would be made publicly available.

Governance

Implementation of the Action Plan will be driven by a group of Australian and state and territory government officials and people with lived experience of dementia. The Implementation Group will also be supported by an expert reference group and community representatives, and will report to Health Ministers through the Health Chief Executives Forum.

The Implementation Group will meet periodically throughout the duration of the Action Plan to:

- discuss progress and collaborate on implementation
- share learnings
- identify gaps or barriers to implementation
- identify opportunities for improvement
- celebrate success and contribute to future priorities.

Glossary of terms

Term / acronym	Definition
ACCHO	An Aboriginal and Community Controlled Health Organisation is a primary health care service initiated and operated by the local Aboriginal community to deliver holistic, comprehensive, and culturally appropriate health care to the community.
ACCO	An Aboriginal and Community Controlled Organisation delivers services, including land and resource management, that builds the strength and empowerment of Aboriginal and Torres Strait Islander communities.
Aged Care Commission	The Aged Care Quality and Safety Commission protects and enhances the safety, health, wellbeing and quality of life of people receiving aged care.
ADNeT	Australian Dementia Network
Advance Care Planning	The process of planning for future health and personal care, whereby the person's values, beliefs and preferences are made known so they guide decision-making at a future time when that person cannot make or communicate their decisions.
Advocate	A person who publicly supports or recommends a particular cause or policy or puts forth a case on someone else's behalf.
Ageist/ageism	Discrimination against persons of a certain age group, especially older people.
AHRC	Australian Human Rights Commission
AIHW	Australian Institute of Health and Welfare
Alzheimer's disease	The most common form of dementia, more common in older age. Alzheimer's disease is a physical brain condition resulting in impaired memory, thinking and behaviour. It disrupts the brain's neurons, affecting how they work and communicate with each other.
ARIIA	Aged Care Research and Industry Innovation Australia
CALD	Culturally and linguistically diverse
Carer	Carers are people who provide unpaid care and support to family members and friends who require assistance. In the context of the Action Plan, carers are people supporting a person living with dementia.
The Centre	The National Centre for Monitoring Dementia
CTE	Chronic Traumatic Encephalopathy. CTE is a progressive degenerative brain disease affecting people who have suffered repeated concussions and head injuries.
Cognitive impairment	A description of someones condition which may include loss of some memory or thinking abilities. A person with cognitive impairment can find it difficult to learn new things, to concentrate, or make decisions.

Term / acronym	Definition
Culturally safe care	Care and services that are planned and delivered in a way that is spiritually, socially, emotionally and physically safe and respectful for consumers. Culturally safe care and services also ensure that a person's identity is respected so that who they are and what they need is not questioned or denied.
DBMAS	Dementia Behaviour Management Advisory Service
Dementia	Dementia describes a collection of symptoms caused by disorders affecting the brain.
Dementia Alliances	A group of people who are working together to make their community more dementia friendly.
Dementia enabling	To encourage a person living with dementia to lead as full and independent a life as possible.
Dementia friendly	Considering the human experience of dementia rather than just the biological condition. It means recognising the person first, before the disease.
Dementia friendly community	A city, town or village where people living with dementia are understood, respected and supported.
Disease burden	Human and financial costs that result from poor health. The summary measure of disease burden is the disability adjusted life year (DALY). One DALY is one year of 'healthy life' lost due to illness or death and the more DALY associated with a disease, the greater the burden. Non-fatal burden (years lived with disability) and fatal burden (years of life lost based on current best life expectancy) are combined to calculate the total DALY for each disease.
Diversity	The varied needs, characteristics and life experiences, which may be social, cultural, linguistic, religious, spiritual, psychological, medical, or other care needs of consumers. Also refers to diverse gender and sexuality identities, experiences and relationships.
DSA	Dementia Support Australia helps health care professionals and family members supporting a person living with dementia.
DTA	Dementia Training Australia provides dementia specific accredited and non-accredited education, training, and professional development for aged and health care professionals.
End of life care	The care provided to a person in the period when they are nearing the end of their life. It can include physical, spiritual, emotional and psychological support
First Nations people	People who are of Aboriginal or Torres Strait Islander descent.
The Frameworks	Refers to the previous two frameworks that came before this plan, the National Framework for Action on Dementia 2015–19 and the National Framework for Action on Dementia 2006–10.
GEM	Geriatric Evaluation and Management to improve the functioning of older people with complex health needs.
GP	General practitioner

Term / acronym	Definition
Health Commission	The Australian Commission on Safety and Quality in Health Care works in partnership with patients, consumers, clinicians, managers, policy makers and healthcare organisations to achieve a sustainable, safe and high quality health system.
Human rights	Human rights recognise the inherent value of each person, regardless of background, where we live, what we look like, what we think or what we believe.
Jurisdictions	The Commonwealth Government and State and Territory governments.
LGBTIQ+	People who identify themselves as lesbian, gay, bisexual, transgender, intersex, queer or questioning.
MBS	Medicare Benefits Schedule
MCI	Mild cognitive impairment
Memory clinic	Specialist centre where people can be assessed for dementia. Also referred to as cognitive assessment service and dementia and memory service.
Monitoring and reporting framework	A resource that will accompany this Action Plan and describe the roles and responsibilities around monitoring more fully, along with details on how we plan to monitor on report on progress against the Action Plan's actions.
More complex or severe behaviours	These may include aggression, severe agitation, vocalisation such as talking constantly, cursing or screaming, severe depression or anxiety or being suicidal
NARI	National Ageing Research Institute
National Dementia Data Improvement Plan	Priority dementia data improvement activities to be undertaken nationally, developed by the AIHW National Centre for Monitoring Dementia.
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NDSP	National Dementia Support Program
NHMRC	National Health and Medical Research Council
OPAN	Older Persons Advocacy Network
Palliative care	Person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary goal is to optimise the quality of life.
PBS	Pharmaceutical Benefits Scheme
People with lived experience of dementia	Anyone whose life has been impacted by dementia, including people living with dementia, people caring (or who have cared for) people living with dementia and people with a family member or loved one living with dementia.
The Action Plan	The National Dementia Action Plan
PTSD	Post-traumatic stress disorder

Term / acronym	Definition
Quality of life	An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.
Reablement	A person-centred process to support restoration of function or adapt to some loss of day-to-day function and regain confidence and capacity for daily activities. It may promote independence, capacity or social and community connections.
Respite care	Care designed to give carers a break. It can be delivered in a person's home, in the community or in a residential setting.
Restrictive practice	As per the *Aged Care Act 1997*, a restrictive practice in relation to a care recipient is any practice or intervention that has the effect of restricting the rights or freedom of movement of a care recipient. The five subtypes of restrictive practices are defined further in the *Quality of Care* Principles 2014.
Royal Commission	Royal Commission into Aged Care Quality and Safety
Rural generalists	Specialist GPs who provide comprehensive primary care, secondary care, population and public health services and emergency care in rural and remote locations.
SBRT	Severe Behaviour Response Team
SDCP	Specialist Dementia Care Program
Social care	Social care refers to care or support given to children or adults in need or at risk, including needs arising from illness, disability and old age.
Social determinants of health	Are the non-medical factors that influence health outcomes. They are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life. They include economic policies and systems, development agendas, social norms, social policies and political systems.
Substitute decision making	Refers to the legal power given to another person to make decisions on behalf of someone who does not have the capacity to make decisions for themselves.
Supported decision making	The process of enabling a person who requires support to make and/or communicate decisions about their own life. The decision making is supported, but the decision is theirs.
Telehealth	Providing health services through video or telephone, rather than face to face.
TES	Traumatic Encephalopathy Syndrome
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WHO	World Health Organization
Workforce	Paid professionals and care workers in the health, disability, acute, and aged care industries.
Younger onset dementia	Any form of dementia in people under the age of 65.

Appendix 1 – What is dementia?

Dementia describes a collection of symptoms that are caused by disorders affecting the brain. It is not one specific disease. Dementia affects everyone differently and can affect memory, emotional state or behaviour (e.g. involving repetitive actions or questioning, anxiety, agitation) and the ability to perform everyday tasks. While dementia is more common in older people, it is not a normal part of ageing.

> *'Dementia is personal, everyone has a different situation, with different individual needs.'*

Alzheimer's disease is the most common form of dementia and contributes to 60–70% of cases.[3] Other major forms include vascular dementia, dementia with Lewy bodies and a group of diseases that contribute to frontotemporal dementia. The boundaries between different forms of dementia are blurred and mixed forms often coexist. No two people experience dementia in the same way, depending upon the underlying causes, other health conditions and the person's cognitive functioning. Dementia may affect a person's ability to care for themselves, interact with their community and live their lives as they would choose. People living with dementia may benefit from programs to improve their overall functional day-to-day living and health status, for example, their nutrition, mental health, as well as oral and eye health.

Common signs and symptoms of dementia can include:

- changes in memory recall
- changes in planning and problem-solving abilities
- difficulty completing everyday tasks
- confusion about time or place
- trouble with spatial awareness
- difficulty in communicating through speech and writing or difficulties with comprehension
- misplacing things and losing the ability to retrace steps
- decreased or poor judgement
- withdrawal from work or social activities
- changes in mood and personality.

Brain function is often affected enough to interfere with someone's normal social or working life.

> *'People don't know that spatial awareness is a problem for people living with dementia. I struggle to see things properly, colours impacted… I had to get a bright pink handbag so I didn't lose it. Simple things like this can be a big problem for people.'*

Common signs and symptoms of dementia

Memory loss

Changes in planning and problem-solving abilities

Difficulty completing everyday tasks

Confusion about time or place

Trouble with spatial awareness

Decreased or poor judgement

Changes to sleep patterns

Changes in mood and personality

Withdrawal from work or social activities

Misplacing things and losing the ability to retrace steps

Difficulty with speech, writing or comprehension

Source: Dementia in Australia Report, AIHW[1]

References

1. Australian Institute of Health and Welfare (AIHW), *Dementia in Australia* AIHW, Editor. 2023, Australian Government: Canberra.
2. WHO, *Global action plan on the public health response to dementia 2017–2025*. 2017.
3. World Health Organisation (WHO). *Dementia - Fact Sheet*. 2023; Available from: https://www.who.int/news-room/fact-sheets/detail/dementia.
4. Department of Health, *Aged Care – Reforms to support people living with dementia and their carers*, in *Budget 2021–22*. 2021.
5. AIHW, *Dementia in Australia Summary Report*, AIHW, Editor. 2023, Australian Government: Canberra.
6. Welberry, H., et al., *Have We Been Underestimating Modifiable Dementia Risk? An Alternative Approach for Calculating the Combined Population Attributable Fraction for Modifiable Dementia Risk.* American Journal of Epidemiology, 2023. 192(10): p. 1763–1771.
7. Livingston, G., et al., *Dementia prevention, intervention, and care: 2024 report of the Lancet Commission.* The Lancet, 2024. 404(10452): p. 572-628.
8. National Centre for Social and Economic Modelling (NATSEM), *Economic Cost of Dementia in Australia: 2016–2056*. 2017, Institute for Governance and Policy Analysis: Canberra.
9. United Nations General Assembly, *Report on the rights of older persons with disabilities*. 2019.
10. Australian Government, *Aged Care Workforce Census Report, Available from:* https://www.health.gov.au/resources/publications/2020-aged-care-workforce-census. 2020.
11. Alzheimer's Disease International. *Women as carers: gender considerations and stigma in dementia care*. 2019; Available from: https://www.alzint.org/news-events/news/women-as-carers-gender-considerations-and-stigma-in-dementia-care/#:~:text=Female%20carers%20are%20likely%20to%20experience%20greater%20social,burden%20and%20depression%20when%20compared%20to%20male%20carers.
12. National Health and Medical Research Council (NHMRC), *Culturally and Linguistically Diverse (CALD) Dementia Research Action Plan*, National Institute for Dementia Research, Editor. 2020, Australian Government: Canberra.
13. Cosgrave, C., M. Maple, and R. Hussain, *An explanation of turnover intention among early-career nursing and allied health professionals working in rural and remote Australia - findings from a grounded theory study.* Rural Remote Health, 2018. 18(3): p. 4511.

14. Zilkens, R.R., et al., *Australian population trends and disparities in cholinesterase inhibitor use, 2003 to 2010.* Alzheimers Dement, 2014. 10(3): p. 310-8.

15. National Disability Insurance Scheme (NDIS), *Australia's Disability Strategy 2021–31, Available at* https://www.disabilitygateway.gov.au/ads/strategy*.* 2021.

16. de Graaf, G., et al., *Estimation of the number of people with Down syndrome in Australia and New Zealand.* Genet Med, 2022. 24(12): p. 2568–2577.

17. Evans, E. and J. Troller. *Dementia in people with intellectual disability: guidelines for Australian GPs*. 2018; Available from: https://www.3dn.unsw.edu.au/resources/professionals/health-mental-health-professionals/dementia-people-intellectual-disability-guidelines-australian-gps.

18. National Disability Insurance Scheme (NDIS), *NDIS submission to the National Dementia Action Plan consultation process*. 2023.

19. Australian Institute of Health and Welfare (AIHW), *Younger onset dementia: new insights using linked data*, AIHW, Editor. 2022, Australian Government: Canberra.

20. Tilden, D., M. Valeri, and M. Ellis, *Childhood Dementia in Australia: quantifying the burden on patients, carers, the healthcare system and our society*, Department of Treasury, Editor. 2020.

21. Childhood Dementia Initiative, *What is childhood dementia?* n.d.

22. Childhood Dementia Initiative, *Childhood dementia: the case for urgent action*. 2020: Sydney.

23. Rafferty, L.A., et al., *Dementia, post-traumatic stress disorder and major depressive disorder: a review of the mental health risk factors for dementia in the military veteran population.* Psychol Med, 2018. 48(9): p. 1400–1409.

24. Radford, K., et al. *Factors associated with the high prevalence of dementia in older Aboriginal Australians*. 2018. DOI: 10.3233/JAD-180573.

25. Haydon, H., *Easing dementia's burden on Indigenous Australians*, in *UQ News*. 2021: Queensland.

26. Closing The Gap, *National Agreement on Closing The Gap*. 2020.

27. Department of Health, *National Aboriginal and Torres Strait Islander Health Plan 2021–2031*, DoHAC, Editor. 2022, Australian Government: Canberra.

28. National Aboriginal Community Controlled Health Organisation (NACCHO), *Final Report National Dementia Action Plan: Consultation with ACCHOs*. 2023: Canberra.

29. Australian Government, *Royal Commission into Aged Care Quality and Safety*. 2021, Australian Government: Canberra.

30. Australian Human Rights Commission. *What are human rights?* n.d.; Available from: https://humanrights.gov.au/about/what-are-human-rights.

31. Australian Institute of Health and Welfare (AIHW).. *Transitions to residential aged care after hospital for people living with dementia*. 2023; Available from: https://www.aihw.gov.au/reports/dementia/transitions-to-aged-care-after-hospital-dementia/contents/summary.

32. Artuso, S., et al., *Factors influencing health care utilisation among Aboriginal cardiac patients in central Australia: a qualitative study.* BMC Health Serv Res, 2013. 13: p. 83.

33. Coory, M.D. and W.F. Walsh, *Rates of percutaneous coronary interventions and bypass surgery after acute myocardial infarction in Indigenous patients.* Medical Journal of Australia, 2005. 182(10): p. 507-512.

34. Shaw, C., *An evidence-based approach to reducing discharge against medical advice amongst Aboriginal and Torres Strait Islander patients*. 2016: Deeble Institute for Health Policy Research.

35. Australian Government, *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability: Final Report*. 2023: Canberra.

36. Department of Prime Minister and Cabinet, *Working together to deliver the NDIS - Independent Review into the National Disability Insurance Scheme: Final Report.* 2023.

37. M Joosten, P.G., P Feldman, B Brijnath, B Dow, *Seven years of elder abuse data in Victoria*. 2020, National Ageing Research Institute in partnership with Seniors Rights Victoria: Melbourne.

38. Dean, A., *Elder abuse policy and practice paper*, Australian Institute of Family Studies, Editor. 2019, Australian Government: Canberra.

39. Dementia Australia. *Dementia Annual Report 2022–2023*. 2023; Available from: https://www.dementia.org.au/sites/default/files/2024-02/DA-2022-23-Annual-Report.pdf.

40. Dementia Australia, *Awareness and understanding of dementia in Australia: research report*. 2017.

41. Australian Institute of Health and Welfare (AIHW). *Dementia Awareness Survey*. 2024; Available from: https://www.aihw.gov.au/reports/dementia/dementia-awareness-survey/contents/summary.

42. Herrmann, L.K., et al., *A Systematic Review of Dementia-related Stigma Research: Can We Move the Stigma Dial?* The American Journal of Geriatric Psychiatry, 2018. 26(3): p. 316-331.

43. World Health Organization (WHO), *The World Health Organization Quality of Life: Programme on Mental Health*. 2012.

44. Vickland, V., et al., *A computer model of dementia prevalence in Australia: foreseeing outcomes of delaying dementia onset, slowing disease progression, and eradicating dementia types.* Dementia and Geriatric Cognitive Disorders, 2010. 29(2): p. 123-30.

45. Mimura, M. and S.-I. Komatsu, *Cognitive rehabilitation and cognitive training for mild dementia.* Psychogeriatrics, 2007. 7(3): p. 137-143.

46. Bahar-Fuchs, A., et al., *Cognitive training for people with mild to moderate dementia.* Cochrane Database Syst Rev, 2019. 3(3).

47. Parliament of Australia. *Government Response to the Senate Inquiry into Concussions and Repeated Head Trauma in Contact Sports*. 2024; Available from: https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Headtraumainsport/Government_Response.

48. Australian Dementia Network (ADNeT), *The ADNeT Registry First Annual Report (2020–2021)*. 2022.

49. Australian Dementia Network (ADNeT). *ADNeT launches first national Memory and Cognition Clinic Guidelines*. 2021; Available from: https://www.australiandementianetwork.org.au/2021/11/30/adnet-launches-first-national-memory-and-cognition-clinic-guidelines/.

50. Speechly, C.M., C. Bridges-Webb, and E. Passmore, *The pathway to dementia diagnosis.* Medical Journal of Australia, 2008. 189(9): p. 487-489.

51. Natalie Su Quin Ng, D.A., Barbara Workman, Stephanie Alison Ward, *Understanding diagnostic settings and carer experiences for dementia diagnosis in Australia.* International Medicine Journal, 2021. 51(7).

52. Draper, B., et al., *Time to diagnosis in young-onset dementia and its determinants: the INSPIRED study.* Int J Geriatr Psychiatry, 2016. 31(11): p. 1217-1224.

53. Inez H G B Ramakers, P.J.V., Pauline Aalten, Jos H M Boesten, Job F M Metsemakers, Jelle Jolles, Frans R J Verhey, *Symptoms of preclinical dementia in general practice up to five years before dementia diagnosis.* Dementia and Geriatric Cognitive Disorders, 2007. 24(4): p. 300-306.

54. Pond, D., et al., *Timely diagnosis of dementia: is it happening in Australia?* Australian Journal of Dementia Care, 2021. 10(3).

55. Australian Dementia Network (ADNeT), *Memory Clinic Initiative's Submission to Request MBS Review in relation to Neurocognitive Disorders (Dementia and Mild Cognitive Impairment).* n.d.

56. Dementia Australia, *"Every Person is a World"*. 2021, Dementia Australia.

57. Aworinde, J., et al., *Dementia severity at death: a register-based cohort study.* BMC Psychiatry, 2018. 18(1): p. 355.

58. Dementia Australia. *Dying Well: Improving palliative and end of life care for people with dementia*. 2019; Available from: https://www.dementia.org.au/sites/default/files/2024-02/DA-Dying-Well-Discussion-Paper-Federal.pdf.

59. Australian Government Productivity Commission, *Report on Government Services, Aged Care Services*. 2023.

60. Australian Institute of Health and Welfare (AIHW). *First hospitalised falls among people living with dementia: risk factors and outcomes*. 2024; Available from: https://www.aihw.gov.au/reports/dementia/first-hospitalised-falls-among-people-living-with/contents/about.

61. Peisah, C. and E. Skladzien, *The use of restraints and psychotropic medications in people with dementia: A report for Alzheimer's Australia*. 2014, Dementia Australia.

62. Australian Commission on Safety and Quality in Health care (ACSQHC). *Cognitive Impairment* n.d.; Available from: https://www.safetyandquality.gov.au/our-work/cognitive-impairment/about-cognitive-impairment.

63. Australian Institute of Health and Welfare (AIHW). *Transitions to residential aged care after hospital for people living with dementia, 12-month transitions of care and mortality outcomes*. 2023; Available from: https://pp.aihw.gov.au/reports/dementia/transitions-to-aged-care-after-hospital-dementia/contents/transitions-of-care-and-mortality-outcomes/12-month-transitions-of-care-and-mortality-outcome.

64. Palliative Care Australia. *Joint Position Statement - Palliative Care and Dementia*. 2023; Available from: https://palliativecare.org.au/statement/palliative-care-and-dementia/.

65. The Snow Foundation. *Information gaps in Australia's Palliative Care*. 2019; Available from: https://www.snowfoundation.org.au/wp-content/uploads/2022/12/Final-Report-Information-gaps-in-Australias-Palliative-Care-15112021.pdf.

66. Lau, E.C.Y., et al., *Prevalence and Risk Factors for Drug-Related Problems in People With Dementia Living in the Community: A Systematic Review and Meta-Analysis.* J Am Med Dir Assoc, 2022. 23(6): p. 980-991.e10.

67 My Aged Care. Respite Care. n.d.; Available from: https://www.myagedcare.gov.au/short-term-care/respite-care.

68. Cations, M., et al., *Post-diagnosis young-onset dementia care in the National Disability Insurance Scheme.* Australian & New Zealand Journal of Psychiatry, 2022. 56(3): p. 270-280.

69. Australian Institute of Health and Welfare (AIHW), *Dementia data gaps and opportunities*, AIHW, Editor. 2020, Australian Government: Canberra.

70. National Institute for Dementia Research (NHMRC), *Boosting Dementia Research Initiative 2014–2019 Report*, National Institute for Dementia Research, Editor. 2019, Australian Government: Canberra.

Notes