Australian Government
Department of Health and Aged Care

National Dementia Action Plan

Public Consultation Paper

November 2022

Purpose of the consultation

The purpose of this consultation is to seek feedback to inform the development of the National Dementia Action Plan 2023-2033 (the Action Plan) and ensure the voices of people with lived experience of dementia are reflected in Australia's priorities for action on dementia over the next 10 years. This consultation paper sets out:

- key elements of the proposed Action Plan
- proposed objectives, linked to possible actions and performance measures
- information about dementia, the people it impacts and the current service system
- background on dementia and the history of the proposed Action Plan
- an overview of how the Action Plan is proposed to be implemented, governed and monitored.

We are particularly interested in feedback on the key elements of the Action Plan, including the proposed vision, objectives and actions.

The proposed actions in this consultation paper are initial ideas that have been raised during early engagement with people living with dementia, carers and dementia experts. The ideas in this paper have not yet been considered by governments.

We invite you to have your say on the consultation paper by:

- Responding to the survey on the Department of Health and Aged Care's (the department's) Consultation Hub at consultations.health.gov.au
- Calling **1800 565 789** for more information or to get assistance to complete survey
- Sending us your thoughts by:
  - email to dementiaplan@health.gov.au or
  - post to National Dementia Action Plan
    MDP 765, GPO Box 9848 CANBERRA ACT 2601

We are seeking your feedback by 31 January 2023. Your feedback will inform the development of the Action Plan, which is expected to be considered by Australian Government and state and territory health ministers in mid 2023.

Thank you for taking the time to contribute to this process.

Thank you to those who have already contributed your thoughts and experiences to inform the key elements of this consultation paper.

Your experiences, thoughts and expert advice are valued and will help to improve the lives of people living with dementia, their families and carers into the future.

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Background

Purpose of the National Dementia Action Plan

The proposed purpose of the National Dementia Action Plan is to:

- provide a roadmap, setting out where we want to be in 10 years' time
- guide action by Australian Government and state and territory governments so that policies, services and systems are better integrated for people living with dementia
- drive improvements to services and systems for people living with dementia, their carers and families
- enable measurement of progress against priority areas
- engage, inform and involve the whole community in actions to achieve a society that is more understanding of dementia and more inclusive of people living with dementia.

The words of people living with dementia, their carers and families can be found in italics text inside a grey box throughout this consultation paper. This reflects our commitment to put them at the centre of this whole Action Plan.

> *The community is living with dementia – not only individuals.*

Why do we need an Action Plan?

Dementia is the second leading cause of death in Australia and the leading cause of death for women. It is estimated that between 386,200 and 472,00 Australians are currently living with dementia, with this number estimated to reach over 849,300 by 2058. Dementia is the third leading cause of disease burden in Australia and is estimated to cost governments more than $3 billion per year.

The Australian Government and state and territory governments invest in a range of dementia related services and programs. These include 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. A number of these programs have been expanded or developed in response to findings of the Royal Commission into Aged Care Quality and Safety (the Royal Commission) and benefits will be realised over time.

Opportunities for improvement

While Australia is a global leader in many aspects of dementia care, support and research, gaps and challenges remain in the current system. The Royal Commission findings, published research and consumer feedback consistently highlight the following as key areas for improvement:

- reducing stigma and discrimination for people living with dementia and their carers and families
- better recognition of the early signs and symptoms - particularly in younger onset dementia
- more timely diagnosis of dementia, including more consistent assessment processes and more empathetic delivery of a diagnosis
- better coordinated post-diagnostic care, including support to navigate the Health and Aged Care systems
- increased understanding and capacity of health and aged care workers caring for people living with dementia
- improved support for carers of people living with dementia
- better dementia data and support to translate dementia research into practice.[1]

All levels of government have some responsibility to provide support services and systems of care to all Australians. For example, the Australian Government and state and territory governments are all involved in funding, delivering and/or regulating systems for older Australians including people living with dementia.

This adds to the complexity of the dementia service system underscoring the need for a joint Australian Government and state and territory government plan to support improved integration of services.

In responding to the Royal Commission, the Australian Government committed to a number of measures to improve the lives of people living with dementia. This includes working with state and territory governments to better integrate dementia supports in the context of a new National Dementia Action Plan.

The Action Plan is intended to be consistent with the World Health Organization's (WHO) Global action plan on the public health response to dementia 2017-2025 and will fulfil one of Australia's commitments as a member state.

Impact of dementia in Australia

Between
386,200 - 472,000
people are
living with dementia

27,800
people under 65
are living with
younger onset dementia

Predicted to be over
849,000
people living with
dementia **by 2058**

5x
length of hospital stay on average than the general population

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

3rd
leading cause
of **disease burden** in Australia

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

$3 billion
annually to manage
disease burden of dementia

What is dementia?

Dementia describes a collection of symptoms that are caused by disorders affecting the brain; it is not one specific disease. Dementia can affect thinking, behaviour 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.*

Dementia is a group of symptoms – usually of a chronic or progressive nature – that leads to deterioration in cognitive function (i.e. the ability to process thought).

Alzheimer's disease is the most common form of dementia and contributes to 60–70% of cases. 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 2 people experience dementia in the same way**. Dementia affects each person in a different way, depending upon the underlying causes, other health conditions and the person's cognitive functioning.

Common signs and symptoms of dementia can include:

- memory loss
- changes in planning and problem-solving abilities
- difficulty completing everyday tasks
- confusion about time or place
- trouble processing and understanding distances, depth and space
- difficulty with speech, writing or 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 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 processing what we see and understanding distances, depth and space in our surroundings

Decreased or poor judgement

Reduced capacity to learn

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

Groups at higher risk of developing dementia or facing barriers to equitable access

There are often strong intersections between these groups. They may be an Aboriginal person living with dementia and disability/chronic disease and live in a remote area. This intersectionality compounds issues of access.

First Nations people living with dementia

Dementia is estimated to be three to five times higher in First Nations populations than in the general population.[2] Rates of dementia for Aboriginal and Torres Strait Islander people in remote and rural communities are estimated to be among the highest in the world.[3]

Although the understanding and experiences of dementia varies across First Nations communities, First Nations people living with dementia can face some particular challenges.

While there is often strong stigma associated with dementia, this can be amplified in First Nations communities.

> *Our people don't get dementia, families don't want to know.*

Health and dementia services are not always culturally safe for First Nations people. This can act as a barrier to people seeking a diagnosis or accessing the services and supports they need.

> *It's important to find health and aged care services that respect culture as well as care needs.*

First Nations people living with dementia in rural and remote communities can face further barriers to accessing the services they need.

> *People have the idea that because we're all black fellas, we're the same – we're not, we're just as individual as anyone else.*

In line with the Closing the Gap Report, the Action Plan will contribute to achieving equity for First Nations people in health, specifically in relation to the diagnosis of dementia and access to dementia care and supports.[4]

People from culturally and linguistically diverse backgrounds living with dementia

People from culturally and linguistically diverse (CALD) backgrounds make up approximately one third of the population of people living with dementia in Australia.[5]

People living with dementia from CALD backgrounds can face some particular challenges when navigating the health systems and accessing supports:

- Services may not always be culturally safe for people from diverse backgrounds (particularly where people have language barriers and specific cultural needs), and there is varied availability of cultural-specific services.[6]
- People may be less likely to access formal care or supports due to cultural expectations and preferences and family obligations.
- Language barriers may increase social isolation. People from CALD backgrounds may return to their first languages as part of the impact of dementia.

> *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.*

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

People living in regional, rural and remote areas

People living in regional, rural and remote communities can face particular challenges in accessing specialist support services and 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 four 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. It is also more challenging in rural and remote areas 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 and personal care workers in remote areas.[7]

This is further exacerbated in Aboriginal and Torres Strait Islander communities where cultural competency is required for such a sensitive topic area.

People with disability

People with disability, like anyone, can be impacted by dementia. However, 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.[8] The onset of dementia in people with intellectual disability (other than Down syndrome) is on average 10 years younger than people without intellectual disability.[9]

People with disability can experience stigma and exclusion and this can increase following a dementia diagnosis. People with disability and dementia may require additional and more tailored care and support due to their more complex needs.

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

We are still learning how best to support people living with both a disability and dementia.[10] The intersections between the health, disability and aged care systems can also be difficult to navigate. Currently, people aged under 65 years with a significant, ongoing disability may be eligible to access the National Disability Insurance Scheme (NDIS). However, data suggests that only around 3% of people aged under 65 with a primary or secondary diagnosis of dementia have an approved NDIS plan. This needs to be improved and requires a whole of government approach.

People living with dementia who identify as LGBTIQ+

Many people who identify as lesbian, gay, bisexual, transgender, intersex, queer, asexual or sexually or gender diverse (LGBTIQ+ people) have experienced isolation and discrimination and may feel unsafe disclosing their past experiences or identities. Older Australians who identify as LGBTIQ+ (or who have variations in sex characteristics) may have repressed their sexual or gender identity and may struggle to find service providers and carers with whom they feel safe.

LGBTIQ+ people living with dementia need to feel safe to access the supports they need. Services need to be appropriate, responsive and tailored, and workers need to provide support in a way that respects the person's identity and choices.

Veterans

International studies suggest an increased prevalence of dementia among veterans compared to the general population. Veterans have increased risk factors for dementia, including traumatic brain injury sustained through active duty, post-traumatic stress disorder (PTSD) and major depressive disorder.[11]

Although there is limited dementia research specifically for Australian veterans, studies suggest that:

- Behavioural and psychological symptoms of dementia (BPSD) differ among veterans compared with non-veterans, and veterans with dementia who experienced PTSD had more severe BPSD than veterans with dementia who had not experienced PTSD.[12]
- PTSD may not increase dementia risk among veterans, but antipsychotic use may be a contributor to dementia risk among veterans with and without PTSD.[13]

People living with dementia who are homeless or at risk of homelessness

There are significant numbers of people in the homeless population with cognitive impairment, including dementia. While little is known about them, they face great challenges in accessing diagnostic, good brain health interventions and dementia services and support that are sensitive and respectful to their needs.

Many homeless people have experienced trauma, abuse, neglect and discrimination. They also often experience a range of long term physical health problems as a result of poor nutrition and mental health, and injuries sustained due to violence.

This makes diagnosing and managing dementia more difficult.

Vision

The Action Plan will set out a vision that guides all objectives within the Plan. The proposed vision is:

> 'Australians understand dementia - people living with dementia and their carers have the best quality of life possible and no one walks the dementia journey alone.'

Objectives

It is proposed that the Action Plan includes 7 objectives in support of this vision, each with a number of focus areas.

The draft objectives are:

1. Tackling stigma and discrimination
2. Minimising risk, delaying onset and progression
3. Improving dementia diagnosis and post-diagnostic care and support
4. Improving treatment, coordination and support along the dementia journey
5. Supporting people caring for those living with dementia
6. Building dementia capability in the workforce
7. Improving dementia data and maximising the impact of dementia research and innovation

Principles

It is proposed that the following principles underpin and are evident in the design and the implementation of the Action Plan. This will ensure that all actions are:

- **directly informed, and evaluated** by the views of people living with dementia, their carers and families
- **person centred** and focused on **quality of life** for people living with dementia, their carers and families
- appropriate for, and **accessible to, all people**, including priority population groups and people from diverse backgrounds
- **culturally safe** for First Nations peoples
- evidence based and **outcomes focused**
- coordinated, **integrated** and planned.

National Dementia Action Plan 2023-2033

National Dementia Action Plan

Vision

Australians understand dementia - people living with dementia and their carers have the best quality of life possible and no one walks the dementia journey alone.

Objective	Focus Area
1: Tackling stigma and discrimination	1.1 Expanding dementia awareness and reducing stigma 1.2 Creating inclusive communities and environments for people living with dementia, their carers and families
2: Minimising risk, delaying onset and progression	2.1 Risk factors for dementia are well understood 2.2 People are aware of what they can do to delay the onset and slow the progression
3: Improving dementia diagnosis and post-diagnostic care and support	3.1 Recognising and acting on early signs and symptoms 3.2 Quality and timely diagnostic services 3.3 Post diagnostic care and support
4: Improving treatment, coordination and support along the dementia journey	4.1 Quality care and ongoing support as a person's needs change 4.2 Care and support during and after hospital care 4.3 End of life and palliative care
5: Supporting people caring for those living with dementia	5.1 Recognising carers and assisting carers in their role 5.2 Increasing access to carer respite services
6: Building dementia capability in the workforce	6.1 A skilled dementia aware health and aged care workforce 6.2 Organisational culture supports quality dementia care
7: Improving dementia data and maximising the impact of dementia research and innovation	7.1 Advancing dementia research and innovation 7.2 Translating dementia research into practice 7.3 Improving dementia data and information systems 7.4 Collection of data for monitoring improvement

Principles

Dementia care is:

- **directly informed, and evaluated** by the views of people living with dementia, their carers and families
- **person centred** and focused on **quality of life**
- appropriate and **accessible to all people,** including priority population groups and people from diverse backgrounds
- **culturally safe** for First Nations peoples
- evidence based and **outcomes focused**
- coordinated, **integrated** and planned

The immediate priorities

To build momentum towards these objectives, it is proposed the following areas are given priority in the first three years of the Action Plan from 2023-2026.

- timeliness of diagnosis/detection of dementia
- better coordinated post-diagnostic care (immediately following a diagnosis) but noting this need is ongoing
- increased dementia capability of the health and aged care workforce
- improved carer supports
- improved data collection, intelligence and monitoring systems

Further information is provided later in the Implementation Blueprints section of the document.

Proposed Objectives

Overview

This section outlines 7 proposed objectives to target action on dementia.

For each objective there is:

- an outcome statement which describes what we are trying to achieve
- a statement of how this would impact the experience of people living with dementia
- a description of the current situation, including existing initiatives related to the objective
- a description of the current service system challenges as communicated in the published research and in consumer feedback[1]
- potential actions that could be undertaken to improve outcomes
- potential measures that would allow performance to be monitored over time.

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[1] unless otherwise specified, all quotes throughout this public consultation paper have been drawn from focus group workshops with people with a lived experience of dementia and/or their carers.

Objective 1: Tackling stigma and discrimination

Outcome statement	Australia is a dementia-inclusive society where people living with dementia and their carers can fully participate, feel safe and empowered to live independently with respect and dignity, free from stigma and discrimination.
Statement for people living with dementia	I feel engaged in my community and empowered to thrive. I live a life free from stigma and discrimination.

The current situation

Dementia awareness and inclusion is promoted in the community through a number of initiatives. Some of these are described below.

Dementia Action Week

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 Australians to increase their understanding of dementia. In addition, 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 friendly.

Dementia-Friendly Communities

The Dementia-Friendly Communities program seeks to build understanding, awareness and acceptance of dementia in the community. It does this by:

- supporting the development of local dementia alliances to lead the local development of dementia-friendly communities
- providing grant funding to local projects to encourage more 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 August 2022, there are 57 recognised dementia alliances and another 37 developing across Australia.

> *The most powerful vehicle is the dementia friendly communities movement – advocates get out and talk to the community, tell our stories and tell them what we need to live well.*

Dementia Friends

Dementia Friends is part of the Dementia-Friendly Communities program. People can sign up to become a Dementia Friend and learn more about dementia and how to help people living with dementia through a series of short videos. There are currently 34,959 registered Dementia Friends in Australia.

Dementia awareness training

The University of Tasmania has free Understanding Dementia and Preventing Dementia Massive Open Online Courses for people to better understand dementia, and how they can maximise their quality of life across the dementia journey.

Dementia awareness raising

The National Ageing Research Institute raises dementia awareness through film and media in CALD communities through their Moving Pictures initiative.

The National Dementia Support Program (the NDSP)

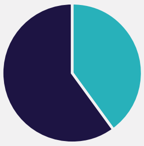
The NDSP provides a range of initiatives that aim to improve awareness and understanding about dementia. There is information, resources and education sessions available via Dementia Australia’s website. The NDSP provides support for campaigns aimed at the general population to improve their awareness of dementia and reduce stigma around dementia. There are also campaigns targeting GPs and health professionals to inform them of dementia and the value of timely diagnosis of the condition.

The National Dementia Helpline (1800 100 500) is funded under the NDSP and provides free information and education for anyone interested in learning more about dementia.

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**

3-5x
more common among First Nations people

The challenges

Despite these existing initiatives and the high prevalence of dementia in Australia:

Many people don't understand dementia

While some people have a general concept of dementia as being 'forgetfulness', many people do not know the signs of dementia and how it impacts people in different ways.[14] People think that dementia is an inevitable consequence of ageing and there is often limited awareness and understanding of less common forms of dementia, such as younger onset dementia. People often don't know that there are things people can do to reduce their risk of dementia or slow the progression of the disease. There are common misconceptions that all people living with dementia do not have decision making capacity and this can impact how engaged they are in decision making.

There continues to be a stigma associated with dementia and discrimination towards people living with dementia and their carers

People living with dementia report experiencing discrimination, judgement and preconceived ideas about their abilities. 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.[15] Stigma and discrimination can be experienced in different ways, including self-imposed (internalised to avoid being labelled), associative (where somebody is a carer or family member of a person living with dementia), social (within the community as a whole), professional (attitudes held by workforce) and structural/institutional (where people living with dementia are treated as inferior, such as within the workplace).

> “*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.*”

> “*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.[16]

Services and environments are not often dementia friendly

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, worsening social isolation.

> *It's not just the family and carers that the person with dementia interacts with.*

> *If we don't make them [our environments] enabling, people with dementia won't go out into the community. And will become more isolated.*

How could we improve the situation?

Examples of possible actions to address the challenges could include the following.

Proposed focus areas	**Proposed Actions**
1.1 Expanding dementia awareness and reducing stigma	• Undertaking media campaigns aimed at raising awareness, addressing common misconceptions and reducing the stigma associated with dementia, with consideration of how to deliver messaging effectively to priority population groups. • Supporting people to have early conversations about brain health across the life cycle. • Using popular culture to implement stigma reduction and awareness raising messaging, for example mainstream media and entertainment to depict more people living with dementia, including less common forms such as younger onset dementia. • Implementing an Australian public attitudes survey to collect baseline data regarding knowledge of and views about dementia. • Funding to continue free access to dementia training and awareness. • Developing a visible symbol, such as a dementia ribbon, to increase visibility and attention during Dementia Action week. • Building greater awareness of the various forms of dementia and how dementia manifests in the context of diversity.

1.2 Creating inclusive communities and environments for people living with dementia, their carers and families	• Ensuring all public spaces and services used by people living with dementia are dementia friendly. • Introducing a dementia friendly design rating system - for residential care services, health services including GPs, hospitals and other public/buildings and spaces. • Developing a dementia ‘tick’ accreditation process to recognise dementia friendly organisations. • Providing access to dementia training for first responders including police, paramedics, fire fighters and emergency services workers. • Working with local councils and businesses to improve the design of public spaces and local services, including businesses (retail, banks etc) and transportation. • Investigating which elements of dementia friendly design are suitable to incorporate into building codes.

How can we measure our performance?

As the proposed focus areas and actions are further refined (informed by consultation), the means for measuring their impact will be further developed. Some examples of possible ways to measure performance include the following.

Immediate (1-3 years)	Longer term (3-10 years)
• Annual increase in Dementia Action Week participation (webpage hits, social media interactions, number of people participating in community events). • Conduct a baseline public attitudes survey on dementia knowledge and awareness. • Conduct a baseline survey of the experience of people living with dementia including experience of stigma and discrimination	• At least 20% improvement in awareness of and attitudes towards dementia as demonstrated through 3 yearly public attitudes survey. • Increased number of dementia friendly communities. • At least 20% improvement in percentage of general population who know that dementia is not an inevitable part of ageing as measured by the 3 yearly public attitudes and awareness survey. • At least 20% improvement in the experience of people living with dementia as measured by the 3 yearly dementia experience survey. • Agreement by health and aged care services to audit their environments to identify areas for improvement to achieve a dementia friendly tick.

Objective 2: Minimising risk, delaying onset and progression

Outcome statement	People understand the factors that increase their risk of dementias and are supported to take actions to reduce these risks, delay the onset and progression of dementia across all stages of life.
Statement for people living with dementia	I am aware of the risk factors for dementia and supported to take steps to reduce my risks or delay the progression.

The current situation

Currently, people are encouraged to reduce their risk of dementia (or slow the progression of their dementia) through various dementia awareness-raising activities and preventative health messaging. Some of the ways people are educated and encouraged are described below.

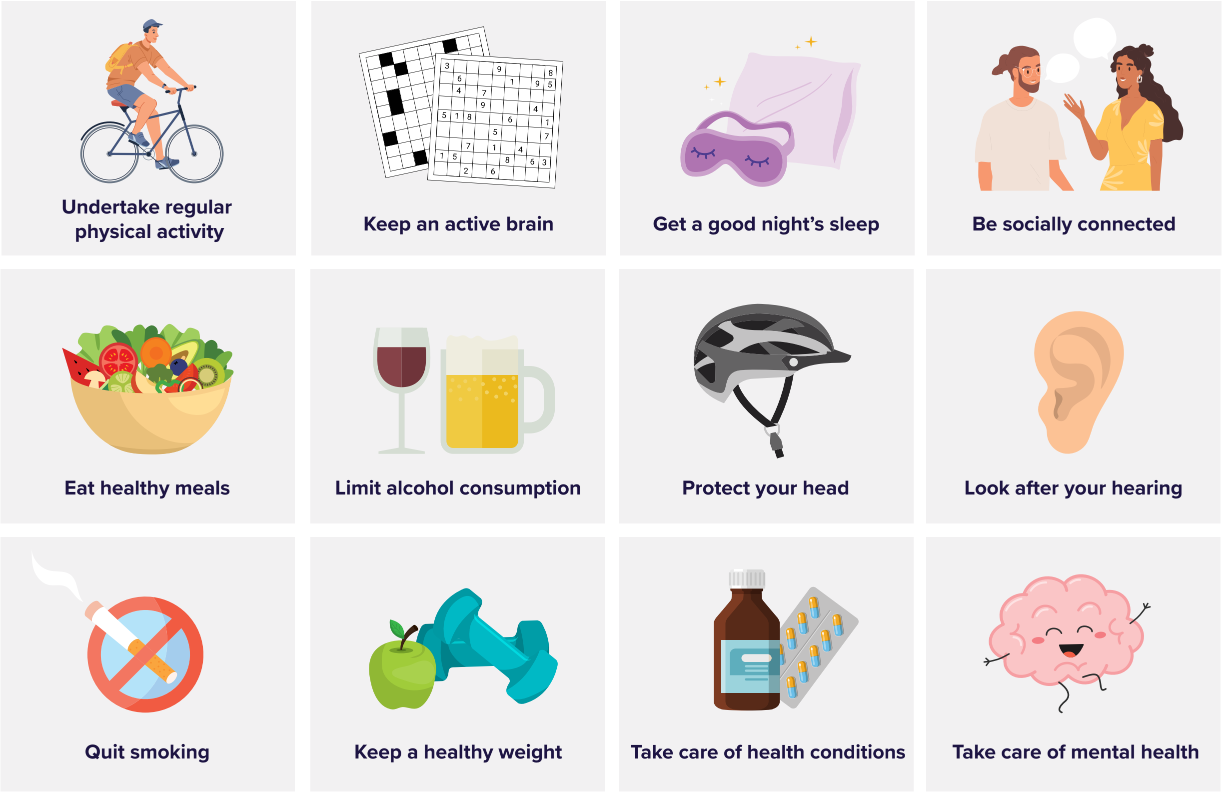
Dementia awareness activities

Some of the existing initiatives described under Objective 1 (including activities under the NDSP and Dementia Action Week), also educate people on the risk factors for dementia and ways people can reduce their risk, although prevention is not a primary focus.

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 3 main domains: a healthy heart, healthy body and healthy mind.[12]

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

Broader healthy living promotion

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

> *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.*

The Lancet Commission identified 12 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 and air pollution.[17]

In addition, evidence suggests that controlling blood pressure may reduce the risk of developing dementia.[18] Recent studies have explored the link between sleep disturbance and poor sleep quality and cognitive decline.[19] Healthy weight loss has been associated with significant improvement in attention and memory and improved cognitive and language function.[20] Reducing alcohol consumption can reduce the effects of alcohol on brain pathways, and in turn, the early onset of dementia symptoms.[21] Stopping smoking, even after a diagnosis of dementia, can also reduce the risk and onset of dementia symptoms.[22]

Research shows that people who have a significant brain injury/trauma, one that results in loss of consciousness or fracture, are more likely to develop younger onset dementia and dementia later in life.[23] However, this does not mean that a person with a head injury will develop dementia. Repeated head injuries can affect someone's brain function over time, enough to interfere with the person's normal or working life. Early research findings have found that these injuries are mostly sustained by people playing sports or serious motor vehicle accidents.[24] This emphasises the importance of engaging in sports activities in a safe way and wearing protective gear where head injury is possible.

The challenges

Given the poor community understanding of dementia, people often don't know how they can reduce their risk or delay the onset of dementia.

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

It is estimated that up to 40% of dementia cases worldwide could have been prevented or their onset delayed by reducing risk factors.[25] According to the Australian Institute of Health and Welfare (AIHW), in Australia about 43% of the dementia disease burden is attributable to 6 modifiable risk factors. These are tobacco use, overweight and obesity, physical inactivity, high blood pressure in midlife (35-64 years), high blood plasma glucose, and impaired kidney function.[26] Despite this, people often don't know what they can take to lower their risk of dementia or delay its onset (particularly in comparison to other prevalent health conditions, such as cancers and heart disease). There are many actions individuals can take to lower the risk and delay the onset and progression of dementia. There would be particular opportunities in targeting these risk factors, noting that the National Preventative Health Strategy identifies national targets for 4 of them.

Impact of risk factors on dementia varies by socioeconomic area

The amount of dementia burden attributed to these risk factors varies by socioeconomic area. That is, modifiable risk factors have a bigger impact on rates of dementia in lower socioeconomic areas than in higher socioeconomic areas. According to the AIHW, the greatest difference is for tobacco use (i.e. smoking), which is 2.4 times higher in the lowest socioeconomic area.

People living with mild cognitive impairment or in the early stages of dementia often aren't provided with information and support strategies to delay the onset 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.[27]

For people with early brain changes, delaying the onset of dementia has many obvious benefits, and can reduce the personal, family and societal costs of care. There is 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.[28] The benefits of cognitive training also appear to be maintained in the medium term and in some studies, has shown to improve the moods of people with dementia.[29]

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

How could we improve the situation?

Examples of possible actions to address the challenges could include the following.

Proposed focus areas	**Proposed Actions**
2.1 Risk factors for dementia are well understood	• Explicitly including dementia and positive messages about brain health in population health strategies and information campaigns, for people of all ages but particularly children and young people. • Implementing a public attitudes survey to collect baseline data regarding attitudes towards dementia including knowledge and use of risk reduction strategies. • Improving understanding of dementia risk factors/ preventive actions for all primary care practitioners (GPs, nurses, allied health). • Continuing to invest in research to better understand the link between risk reduction strategies and dementia diagnosis including for higher risk groups. • Exploring how international Brain Health models could be adopted locally.

2.2 People are aware of what they can do to delay the onset and slow the progression	• Increasing focus on brain health alongside physical health in regular health checks. • Including risk reduction information in broader dementia awareness campaigns. • Ensuring that risk reduction information is tailored for people with diverse backgrounds or at higher risk of developing dementia. • Funding to continue free access to online dementia education including risk reduction strategies. • Exploring options for screening programs for mild cognitive impairment and/or dementia.

How can we measure our performance?

As the proposed focus areas and actions are further refined (informed by consultation) the means for measuring their impact will be further developed. Some examples of possible ways to measure performance include the following.

Immediate (1-3 years)	Longer term (3-10 years)
• At least 10% annual increase in dementia risk reduction training enrolments. • Conduct a public attitudes survey on dementia knowledge and awareness.	• Increase in the number of population health strategies that include dementia and brain health. • 15% increase in the number of people over 65 with a current chronic disease management plan by 2033. • 10% reduction in aged adjusted new dementia cases per annum by 2033. • Increase in awareness of the general population of at least one risk factor. • Increase in understanding of dementia risk factors/preventive actions for primary (GPs, nurses and allied health) and aged care workforce. Consistent with the National Preventative Health Strategy: • Increase the prevalence of Australians (≥15 years) who are meeting the Physical Activity Guidelines for Older (65+ years) Australians by at least 15% by 2030. • Achieve a national daily smoking prevalence of less than 10% by 2025 and 5% or less for adults (≥18 years) by 2030. • Reduce the daily smoking rate among First Nations people (≥15 years) to 27% or less by 2030. • Halt the rise and reverse the trend in the prevalence of obesity in adults by 2030. • At least a 10% reduction in harmful alcohol consumption by Australians (≥14 years) by 2025 and at least a 15% reduction by 2030.

Objective 3: Improving dementia diagnosis and post-diagnostic care and support

Outcome statement	Ensure that dementia signs are recognised and people are diagnosed as early as possible, helping them to slow progression, maximise their abilities and plan for the future. People are provided with information and connected to coordinated, inclusive supports immediately following their dementia diagnosis.
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 and my family immediately following a dementia diagnosis.

The current situation

There is no single definitive test for diagnosing dementia. Assessment often examines behavioural, functional and psychosocial changes, together with radiological and laboratory tests.

Currently, the diagnosis process varies significantly from person to person and across locations depending on the services and health professionals available in the area. Most peoples' first point of contact when they identify changes or concerns is their GP. Some GPs have the skills and expertise to confidently engage with the cognitive concerns while others do not. Many GPs will refer people to specialist services for assessment and testing. This reflects the Clinical Practice Guidelines and Principles Of Care For People With Dementia released in 2016.

Other medical specialties involved in dementia diagnosis include geriatricians, psychogeriatricians (also called old age psychiatrists) and neurologists. These specialists might be providing services in the public health system or could be delivering services privately and billing patients through Medicare.

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.

Memory clinics

Memory clinics are specialist centres where people can go to be assessed and diagnosed with dementia. Memory clinics generally have specialist clinicians and the capacity for testing, including MRI and often Positron Emission Tomography (PET) scans. People can seek a referral to a memory clinic through their GP.

Memory clinics exist across Australia and can go by many different names[30], including cognitive assessment service and dementia and memory service. There are currently around 80 memory clinic type services operating across Australia.

The Australian Dementia Network (ADNeT) has established the Memory Clinics Network to help people find memory clinics and provide a consistent framework for the operation of memory clinics. It is estimated that memory clinics see 8,000 patients per year[31].

National Memory and Cognition Clinic Guidelines

The National Memory and Cognition Clinic Guidelines[32] were published in late 2021 and describe the standards for assessment and post-diagnostic support to be provided by memory clinics. The Guidelines also provide advice on the referral processes, assessment procedures, effective communication and post-diagnostic support and seek to enable timely diagnosis and quality early support for people diagnosed with dementia.

Primary Health Network Dementia Pathways

Dementia specific support and referral pathways are being established to reflect the optimal pathway for seeking dementia diagnosis and post-diagnostic supports. It is intended that GPs will use these pathways during their consultations with their 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.

Brain health apps

Dementia Australia’s ‘BrainTrack’ is a mobile phone app to support timely diagnosis of dementia. Through playing a selection of minigames, 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.

Post-diagnostic supports

The aim of dementia post-diagnostic support is to empower people living with dementia, and those who care for them, with the tools, connections, resources and plans they need to live as well as possible and prepare for the future. This could include an Advance Care Plan, which allows people recently diagnosed to document what is important to them and plan how they wish to lead their lives. It is important that people living with dementia are able to maintain their independence and community engagement where possible. This can be a particular challenge in regional and remote areas where there may be limited transport.

The National Dementia Support Program delivered by Dementia Australia 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), personalised post-diagnostic support to develop strategies to live well and plan for changes, and support programs aimed at keeping people 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.

Chronic disease management

People living with dementia commonly have multiple chronic conditions. The establishment (and ongoing review) of Chronic Disease Management arrangements is covered by the Medicare Benefits Schedule (MBS), although this may not be sufficient for optimal multidisciplinary care for dementia where there are complex care needs. 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.

Good chronic disease management, including the effective use of GP Management Plans, multidisciplinary care plans and/or Team Care Arrangements are important for maximising wellbeing for 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 and other providers, and lists the actions people can take to help manage their condition.

The challenges

The average timeframe from initial onset of symptoms to receiving a dementia diagnosis is around 3 years for all types of dementia.[33] For people living with younger onset dementia, it is closer to 5 years. On average, people wait more than a year after the onset of symptoms to raise this with their GP. Countries such as England are doing better in achieving an early diagnosis.

There are a range of factors impacting peoples' ability to access a timely dementia diagnosis.

Diagnosis

Individuals don't always recognise dementia signs

As described under Objective 1, often people aren't well educated about dementia, including the potential signs and symptoms (beyond memory loss). In particular, the symptoms of less common forms of dementia, such as younger onset dementia and fronto-temporal dementia, where symptoms can often lead to a misdiagnosis. Due to the stigma, people are often fearful of a dementia diagnosis and may knowingly ignore the signs of dementia. This appears to be particularly relevant for First Nations people or people from culturally and linguistically diverse (CALD) backgrounds, where cultural stigmas against dementia may be amplified.

> *Trying to get them to see the GP was the hard part. We need to change the perception of dementia – it's not a death sentence.*

Many people don't understand the benefits of early detection, diagnosis and treatment. Benefits include helping to slow the onset or progression of dementia symptoms, and more time to plan and implement and strategies to maximise their abilities and continue to 'live well' with dementia. As a result many people aren't motivated to get a diagnosis as they 'don't see the point'.

> *We need to reduce the stigma against dementia to encourage people to seek diagnosis.*

Limited GP capacity and capability to recognise the signs and symptoms of dementia

Many GPs have not received formal education about dementia as part of their undergraduate training and report feeling poorly equipped to discuss dementia or memory concerns with their patients.[34]

Several studies have identified GPs' current dementia training as inadequate in preparing them to recognise dementia symptoms and provide post diagnostic management.[35] Symptoms can often be mistaken for other conditions, such as mental health conditions or menopause. People have reported that GPs don't always listen to patients in trying to understand the cause of their symptoms. People may have to approach their GP multiple times to raise concerns and seek a diagnosis or referral.

> *The GP did not take my concerns seriously, I was told for five years I had depression, there was no pathway for me to get a dementia diagnosis.*

> *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.*

GPs have reported finding the diagnosis process complex and are fearful of a misdiagnosis. Some GPs don't understand the benefits of early diagnosis and access to timely post-diagnostic support, including the benefits of reablement options. GPs have reported that Medicare funding arrangements for GP consultations make it hard for GPs to be remunerated for the time it takes to work through cognitive concerns, although GPs can use time-tiered consultations for this purpose.

People living with cognitive decline or dementia may reject a diagnosis or any suggestion of it

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 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.

Barriers to accessing timely specialist assessment

People 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. 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.[36]

Delays can be due to a lack of specialists (there is currently only capacity to diagnose 35% to 40% of new cases), challenges accessing specialists (due to cost or distance) or lack of awareness of assessment services. These issues are heightened for people in rural and remote communities.

Diagnostic testing is not always sensitive enough to detect changes, results are not clear cut and dementia screening tools are not appropriate for all people. First Nations people and people from CALD backgrounds face further barriers due to limited use of culturally appropriate validated dementia assessment tools.

The diagnostic process can be unclear

There is no agreed pathway for accessing a dementia diagnosis and peoples' experiences vary widely. Despite the new National Memory and Cognition Clinic Guidelines, 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.

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

Getting effective, immediate post-diagnostic support

The way people receive a diagnosis matters. Receiving a dementia diagnosis is life changing, not just for the person with dementia but also their loved ones. 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 six 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 may lose their driver's licence and their job, which can leave them feeling isolated and without purpose. Due to the stigma associated with dementia, some people are fearful of telling their loved ones about their diagnosis, further adding to the sense of isolation. Given the progressive nature of the disease, many people have expressed feeling despair or hopelessness following a diagnosis.

> *We don't have a cure, so we need hope.*

The diagnosis can be similarly overwhelming for peoples' loved ones who have to come to terms with the impact the diagnosis will have on their lives, including where they may become their loved one's carer.

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

> *I felt lost, alone. There was no pathway out of the darkness.*

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

> *There is no clear pathway or treatment plan following a diagnosis and no one to guide you on the journey. There is currently no cure for dementia and there is no agreed pathway for treating the symptoms or living well with dementia.*

Some people living with dementia describe difficulties with managing their care. This can be due to multiple complex care needs or the dementia making planning and remembering to review plans more difficult.

People living with dementia may not be able to self-manage the full range of chronic diseases to the capacity of those not living with dementia. For example, a person living with dementia managing diabetes may not remember to follow a strict diet, take medications, review their chronic disease management plan or visit allied health practitioners on a regular basis, including their podiatrist, diabetes educator, dietician, optometrist.

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

How could we improve the situation?

Examples of possible actions to address the challenges could include the following.

Proposed focus areas	**Proposed Actions**
3.1: Recognising and acting on early signs and symptoms	• Providing information to promote early conversations about memory concerns. • Developing strategies to promote benefits of early diagnosis to GPs, nurses and the general community. • Reviewing and enhancing existing dementia education and training for health professionals (see Objective 6). • Embedding clear pathways and processes for health practitioners to refer people to diagnostic services and/or Dementia Australia.
3.2: Quality and timely diagnostic services	• Reviewing Australia's first Clinical Practice Guidelines and Principles of Care for People with Dementia (2016), including the role of GPs in assessment and diagnosis. • Increasing capacity of memory clinic networks. • Ensuring regional memory clinics are adequately staffed including access to specialists through use of technology. • Reviewing the Medicare Benefits Schedule to better support dementia diagnosis. • Actively promoting and supporting the implementation of ADNeT Memory and Cognition Clinic Guidelines. • Developing and implementing culturally competent diagnostics tools and processes. • Supporting nurses working in general practice to recognise cognitive change, undertake cognitive screening and communicate with GPs and patients.

3.3: Post-diagnostic care and support	• Strengthening coverage of dementia in the Australian Commission on Safety and Quality in Health Care standards. • Identifying and implementing measures to improve care coordination and planning for the future following a dementia diagnosis, including considering rollout of dementia care coordinators informed by international best practice.

How can we measure our performance?

As the proposed focus areas and actions are further refined (informed by consultation) the means for measuring their impact will be further developed. Some examples of possible ways to measure performance include the following.

Immediate (1-3 years)	**Longer term (3-10 years)**
• Increase in the number of GPs undertaking dementia training modules. • Increase in number of people being assessed in memory clinics. • Increase in the number of diagnostic services adopting the ADNeT Memory and Cognition Clinic Guidelines.	• 50% increase in the number of GPs undertaking dementia training modules. • At least 80% of people living with dementia are seen by a specialist within 3 months of receiving a referral. • At least 50% reduction in time from onset of symptoms to dementia diagnosis. • Improvements in experience of post-diagnostic care in ongoing community surveys.

Objective 4: Improving treatment, coordination and support along the dementia journey

Outcome statement	People living with dementia are connected to coordinated, dementia-inclusive services that meet a person's changing behavioural, psychological and end of life needs
Statement for people living with dementia	I have hope and a pathway to live my best life with dementia as my needs change, and I am supported as I approach the end of my life.

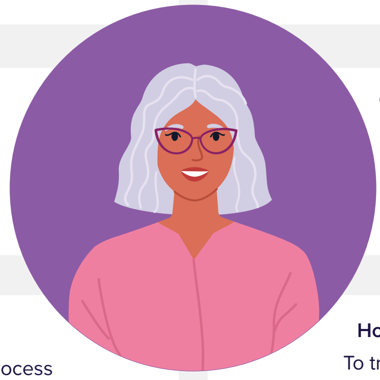
The current situation

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, allied health professionals and specialists who can provide health care, counselling and reablement, as well as providing standard health care in a dementia informed way
- 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 to provide acute, subacute and specialist level care
- palliative and end of life care to enable the person to die in comfort and with dignity.

No two dementia experiences are the same

Most people will interact with the following systems
at some time over the course of their journey



Primary care
General practitioner (GP) and allied health practitioners such as physiotherapist, psychologist and speech pathologists

Medical specialists
Geriatricians, psychogeriatricians, and neurologists are commonly involved in diagnosis and ongoing support

Aged care system
Such as transition care after a hospital stay, respite services while their carer takes a break, home services, residential care

Community/social supports
Such as the National Dementia Support Program (for counselling or peer support) or Dementia Behaviour Management Advisory Service

Palliative care
To manage the end of life process

Hospital System
To treat or manage dementia related or other medical issues

There are also a range of dementia specific services. Some of these are services for people living with dementia such as the National Dementia Support Program and the Specialist Dementia Care Program. Others are services to assist aged care services and hospitals to better respond to the needs of people living with dementia, such as the Dementia Behaviour Management Advisory Service and Severe Behaviour Response Teams.

Aged care services for people living dementia

More than half of people in permanent aged care have a diagnosis of dementia.[37] Ensuring aged care services deliver the care and support needed by people living with dementia remains a key priority. A range of initiatives are underway to improve outcomes for people living with dementia and receiving aged care services. This includes:

- strengthened Aged Care Quality Standards, with an increased focus on requirements for supporting people living with dementia (from 1 July 2024)
- National Aged Care Design Principles and Guidelines on accessible and dementia-friendly design for residential aged care (from 1 July 2024)
- a single assessment workforce to assess people for all forms of aged care with an increased focus on supporting people with dementia

- requiring all residential services to provide 215 minutes of care per day for all residents and have a registered nurse on site 24 hours a day, seven days a week
- building the capacity and capability of the aged care sector to manage complex cases of dementia, including Behavioural and Psychological Symptoms of Dementia (BPSD).

Additional measures are also outlined under Objectives 5 and 6.

Dementia Support for service providers

The Dementia Behaviour Management Advisory Service (DBMAS) provides support and advice to service providers, workers and carers of people living with dementia, particularly where BPSD is affecting a person's care. The DBMAS is delivered by Dementia Support Australia and helps to build the capacity of aged care workers to care for people living with dementia. For example, DBMAS can:

- provide clinical advice and support
- provide mentoring and supervision to workers
- advise providers on dementia care that meets the needs of people from diverse backgrounds or with specific needs, and
- refer people living with dementia to the Severe Behaviour Response Team.

Severe Behaviour Response Teams (SBRTs) are a mobile workforce of clinical experts that help residential aged care providers who care for people with severe BPSD in residential aged care settings. They help providers to understand and respond to a person's behaviours, including by providing assistance during a crisis and to plan and review a person's care.

Support under DBMAS and SBRT programs was expanded in response to recommendations of the Royal Commission with increased funding commencing in 2022.

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 (Tier 6[38]) BPSD and aim to reduce or stabilise symptoms so that people can move into less intensive care settings. 10 SDCUs are in operation with a proposal to establish a further 10 units.

The impact of growing investment in dementia support programs and the aged care workforce on hospitalisations for people living with dementia is yet to be seen. Nonetheless, there are opportunities to work with state and territory governmemts to better align support for people experiencing extreme BPSD. These range from local level opportunities around increased use of transition planning through DBMAS or SBRT to design of new coordinated interventions.

Hospital services for people living with dementia

People living with dementia often present in hospitals due to a medical emergency, chronic illness, following the onset of an acute illness or due to behavioural concerns. Every year there are around 23,200 hospitalisations due to dementia, with the average length of stay between 12-14 days. In addition, there were almost 78,500 hospitalisations where dementia was recorded as an additional diagnosis.[39] To enable the delivery of better health care for people living with dementia in a hospital setting or receiving hospital in the home services, training and education programs are required to assist the health care workforce to build and put into practice their knowledge base, in addition to dementia-friendly design principles and processes.

The National Safety and Quality Health Service Standards set out actions to ensure that hospitals provide appropriate care and support for people with cognitive impairment, including dementia. The Australian Commission on Safety and Quality in Health Care also provides information and resources for hospitals regarding caring 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) is hospital delivered subacute care in which the primary clinical purpose or treatment goal is improving the functioning of a person with multidimensional needs. These needs are associated with medical conditions related to ageing, including the management of cognitive impairment. GEM is managed by a clinician with special expertise in geriatric medicine and care. A number of hospitals will also have dementia specific units to provide specialised care for patients experiencing severe or extreme BPSD.

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

End of life and palliative care for people living with dementia

Accessing appropriate end of life care is essential for people living with dementia and their carers. A third of older people die with dementia, yet there is a lack of consistency in delivering palliative care to people with dementia.[40] 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 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. These include:

- Greater Choice for at Home Palliative Care measure which aims to improve palliative care coordination across the health and aged care systems. It helps to create linkages between local hospitals, GPs, palliative care services and aged care providers to improve access to quality palliative care for older people living at home.

- Comprehensive Palliative Care in Aged Care measure which aims to help older Australians living in residential aged care, nearing the end of their life.

The National Palliative Care Strategy and Implementation Plan aims to ensure the highest possible level of palliative care is available to all people.

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.

Advance Care Planning Australia has information for individuals and health care providers on advance care planning and dementia.

Palliative Care Australia has new resources to support people living with dementia discuss their end of life wishes. There are also resources to support people living with dementia and the aged care workforce to commence end of life conversations.

Palliative Care Clinic Box provides resources to assist health professionals support the First Nations people receiving palliative care at home, and their families.

The challenges

Challenges navigating the health, disability and aged care 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. These can be difficult for people to navigate and are not always well connected. This challenge is compounded by dementia itself which can make it increasingly difficult for a person to process complex information and make decisions. They may also have difficulty accessing multiple services without assistance. This is particularly true for the 14% of people living with dementia in the community who are living alone.[41]

One common solution to this problem internationally is to assign a care coordinator to each newly diagnosed person. In Australia, arrangements are more fragmented and the absence of a nationally consistent approach to post-diagnostic care coordination is the most commonly identified gap in the current service system.

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

This can be particularly challenging for First Nations people and people from CALD backgrounds who may face language barriers and a lack of culturally safe services and supports that meet their needs.

> *The language barrier made it difficult. As my mother's dementia progressed, her ability to articulate her needs in English became more difficult as Spanish is her native tongue.*[42]

Multidisciplinary care for a lot of people living with dementia is often inadequate, unavailable and unaffordable

Chronic Disease Management funded under the Medicare Benefits Schedule items are not always adequate for chronic/complex conditions, and accessing private allied health professionals can be expensive.

Prioritising supported decision making

Some people living with dementia or with a cognitive impairment may require assistance with making decisions. Supported decision-making supports people to exercise their own preferences in the context of making legal and day-to-day decisions. Arrangements for supported decision-making can be difficult to understand and processes vary between states and territories. It is important that suitable arrangements for decision making are in place, to safe guard against risks of exploitation and abuse.

Unavoidable hospital admissions and delayed discharges

For numerous reasons, people living with dementia, and particularly people experiencing BPSD, may be admitted to hospital for care. Many of these admissions are necessary to provide specialised medical care beyond what can be reasonably provided in a person's usual place of residence. However, a proportion of hospital admissions for people living with dementia are avoidable. Some of the challenges contributing to these hospitalisations include:

- difficulty managing multiple chronic health conditions for a person living with dementia
- carer burnout
- need for greater capacity and support managing BPSD in a person's normal environment
- limited access to GPs, specialist consultation and other community support services (especially in regional/remote locations)
- limited and inconsistent approaches to care for the people exhibiting the most extreme form of BPSD (Tier 7).

People living with dementia are also at significantly higher risk of adverse outcomes in hospital including falls, delirium and functional decline. Hospitalisation can be confusing and distressing leading to increased BPSD and use of forms of restraint.[43]

On average, people living with dementia stay in hospital 5 times longer than people without dementia.[44] Many remain in hospital after their acute health needs have been stabilised. This has a negative impact for the individual and their family and also for the broader health system as limited hospital beds are available. There are many issues that contribute to this situation including the capability of carers and aged care providers to provide the care and environments needed post hospital stay and access to services such the Transition Care Programme. In addition, the lack of awareness and understanding of behaviour support plan requirements can contribute to the reluctance of providers to accept people living with dementia from hospital.

For people with younger onset dementia, the Younger People in Residential Aged Care Strategy 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 is impacting 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.

Pain often results in changes in behaviour

Mismanaged or undiagnosed pain continues to be the primary cause of changed behaviour, contributing to at least half of all DBMAS and SBRT referrals. Unfortunately, such rates of pain are experienced by most people living with dementia in aged care with as many as 80% experiencing some type of chronic or acute pain at some time.[45]

Lack of reablement options

People often don’t know where to go for help and aren’t aware that there are things they can do to slow the progression of the disease. People living with dementia are sometimes overlooked for reablement options. 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.

Hospital environments need to be more supportive and inclusive

The admission processes, being in an unfamiliar environment, emergency protocols (including security arrangements) and day-to-day care can be overwhelming for a person living with dementia. While there are cognitive impairment resources distributed by the Australian Commission on Safety and Quality in Health Care, there is no Clinical Care Standard specific to dementia as there is for delirium. The physical environment is often poorly designed to address the safety and functional needs of a person living with dementia. This includes the layout of wards, poor signage, inappropriate equipment and décor that exacerbates distress.

Lack of dementia informed palliative care services

Dementia specific palliative care is not widely available and palliative care services often lack coordination across different care settings leaving people feeling alone, overwhelmed and confused. Unlike other life-limiting illnesses, health professionals don’t understand that people living with dementia nearing the end of their life often lose their ability to make decisions around advance care planning, which emphasises the importance of early advance care planning. The absence of consistent frameworks and training for delivering palliative care to people living with dementia can impact the quality of services delivered.

Service provision for younger people living with 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.[46]

People living with younger onset dementia may face barriers to accessing appropriate support as dementia services tend to be designed around the interests and physical abilities of older people. However, people living with younger onset dementia may be eligible for support through the National Disability Insurance Scheme (NDIS). They should always be encouraged to check their eligibility for NDIS, along with exploring support services outside those provided through My Aged Care and the NDIS.

Younger onset dementia is more likely to affect a person's employment and family-raising responsibilities (around 18% of people with younger onset dementia have dependent children). People living with younger onset dementia may need particular support to discuss their diagnosis, abilities and changing needs with their family, work, community and social groups to organise flexible arrangements that enable them to continue to participate in a way that works for them.

In 2019–20 about 1,100 men and 930 women with dementia aged under 65 years were living in a residential aged care home in Australia. In response to the recommendations following the Royal Commission, there is a target to have no persons under 65 years entering residential care by 2022, apart from in exceptional circumstances.

Service provision for children living with dementia

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.

There are an estimated 2,273 children living with childhood dementia in Australia. Around 1 in every 100 people who are diagnosed with dementia are children.[47]

The average life expectancy of all childhood dementia conditions is estimated to be 28 years, with most children (75%) dying before they reach 18.[48]

Symptoms of childhood dementia can be similar to adult dementia with progressive loss of memory, concentration, speech and the ability to move. Children living with dementia often experience confusion and changes in their behaviour.

There is little awareness around the existence of dementia in young children. It is estimated that as many in 1 in 2,800 children born will be affected by a childhood dementia disorder. Dementia Australia is working with The Childhood Dementia Initiative to elevate awareness for these children and their families.

How could we improve the situation?

Examples of possible actions to address the challenges could include the following.

Proposed focus areas	Proposed Actions
4.1: Quality care and ongoing support as a person's needs change	• Increasing the number of SDCUs and modelling demand for future services to meet the needs of people with severe BPSD. • Developing an optimal model of care and responsibility for people with extreme (Tier 7) BPSD. • Providing flexibility in the way dementia supports are delivered including through use of telehealth and outreach models. • Improving access to information about supported decision making in each jurisdiction. • Developing new family focused counselling support for people living with younger onset dementia, including services specifically for children. • Exploring the feasibility of having Brain Hubs with multidisciplinary teams established across the country that can work holistically with the person on a range of allied health needs including physiotherapy, occupational therapy and social work. • Identifying and implementing measures to improve care coordination following a dementia diagnosis, including use of chronic disease management plans and considering rollout of dementia care coordinators informed by international best practice. • Developing and implementing early intervention restorative programs that target physical and cognitive function for people diagnosed with mild cognitive impairment and early stage dementia. • Supporting aged care providers to better understand behaviour support requirements. • Exploring the potential for innovative use of technology to deliver care and support to people living with dementia.

4.2: Care and support during and after hospital care	• Exploring options to improve the interface between aged care and hospital settings, particularly to reduce avoidable hospital admission and delayed discharges. • Increasing the number of dementia friendly environments and practices in hospitals. • Developing guidelines to improve transfers between the hospital, home and residential aged care setting. • Exploring options to embed a hospital environment audit tool across all hospitals and increase compliance with dementia friendly hospital guidelines. • Implementing early screening in the health care admission processes to enable use of a cognitive impairment identifier and/or follow up diagnostic testing. • Embedding a dementia care component in the Australian Commission on Safety and Quality in Health Care Clinical Care Standards. • Increasing dementia specific hospital services, including options for delivering hospital care in the home where appropriate. • Developing options for measuring the quality of care that people living with dementia receive in the health and aged care systems.
4.3: End of life and palliative care	• Exploring options for dementia specific palliative care services. • Increasing community-based palliative care for people living with dementia, to enable them to die in their home. • Increasing the awareness of advanced care planning and end of life options for people living with dementia.

How can we measure our performance?

As the proposed focus areas and actions are further refined (informed by consultation) the means for measuring their impact will be further developed. Some examples of possible ways to measure performance include the following.

Immediate (1-3 years)	Longer term (3-10 years)
• 15% increase in the number of people accessing the National Dementia Helpline. • Increase in the number of specialist dementia care units.	• 50% increase in the number of people accessing the National Dementia Helpline. • Consistent eligibility criteria across states and territories for older persons mental health services for people living with dementia. • Reduction in the number of critical incidents and use of restrictive practices for people living with dementia. • 15% increase in the number of people living with dementia over 65 with an active chronic disease management plan by 2033. • Increase in the percentage of people living with dementia with a medication review. • Increase in the percentage of people using TCP after a hospitalisation. • Increase in the percentage of PLWD that receive quality care in hospital. • Increase in the percentage of people living with dementia who have place of death recorded as home. • Increased community-based palliative care options. • Reduced length of hospital stay for people living with dementia. • Increase in older Australians living with dementia being accepted into residential aged care following a hospital stay.

Objective 5: Supporting people caring for those living with dementia

Outcome statement	Carers have the information, training and support they need to undertake their caring role and maintain their own health and wellbeing.
Statement for people living with dementia	As a carer, I am supported in my caring role and able to have a genuine break when I need it.

The current situation

Carers and families will often recognise the early signs and symptoms of dementia, which may not be apparent to the person themselves. Carers often play a key part in seeking out medical assessment and diagnosis and supporting the person living with dementia through the diagnosis. This support often extends throughout the dementia journey from diagnosis, through accessing support services, to the end of a person's life.

Being a carer can take a big toll on a person's physical 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.

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

There are a number of existing initiatives and programs that provide support to people caring for a loved one living with dementia, as described below. Some are general supports available to all carers and some are specific to carers of people with dementia.

Respite Care

Respite care gives carers (and their loved ones) 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 overnight or over a weekend or access respite care in a residential service for a few days or a few weeks at a time.[49]

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

The Dementia Carer Respite and Wellbeing Program is being progressively implemented and seeks to deliver innovative models of respite care for people living with dementia and their carers. It will provide:

- combined respite care, where the person living with dementia and their carer can stay together
- opportunities for carers to build knowledge and skills to support their role
- opportunities for carers to improve their physical and psychological wellbeing
- peer support for carers.

The first stage of the Program called 'Staying at Home' commenced in July 2022 and is being delivered through Dementia Support Australia.

Financial support

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

In response to a recommendation of the Royal Commission, the Productivity Commission is currently considering leave entitlements for unpaid carers. The Productivity Commission is due to report to Government by February 2023.

Information, education and emotional support

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

The Carer Gateway (1800 422 737) provides free services and supports for all carers including:

- peer support groups, counselling and coaching to plan and work towards goals
- courses to support carer wellbeing and understanding of legal responsibilities relating to the caring role
- tailored support packages to help with accessing planned respite, transport services and other help in the home
- access to emergency respite.

As part of the NDSP, Dementia Australia offers specific carer-focused support to help carers maintain their caring role to better support people with dementia remain in the family home for longer where practical. It also provides information, education, 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, caring for someone with dementia, Government payments for carers, advance care planning and palliative care.

About Carers

Up to **337,200**

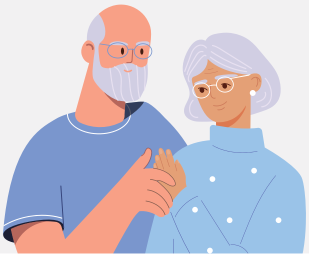
unpaid carers of people living with dementia in the community

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 since providing care

The challenges

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

While caring for a loved one can be rewarding, it is also emotionally and physically challenging, particularly as people exhibit behavioural changes associated with dementia. There are also added cultural complexities for First Nation and CALD carers of people living with dementia.

Some of the specific challenges facing those caring for a loved one living with dementia include the following.

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 severe BPSD, 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 care often isn't easy for people to access

The process can be burdensome and the requirements for the person receiving respite care can be stringent. The cost of respite care can be high, and emergency respite can't always be accessed when needed.

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

> *If you don't get support, who will look after your loved one if you break?*

Caring 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. Carers have commented that 'being at home while your loved one is receiving respite care is like being at your desk while on annual leave'.

Insufficient emotional and peer support

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 throughout the dementia journey. There is also a lack of tailored services for younger carers, particularly those who care for a parent who has 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 coming up in the future.*”

> “*Need the support of others walking in the same shoes.*”

Challenges navigating the service systems

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

How could we improve the situation?

Examples of possible actions to address the challenges could include the following.

Proposed focus areas	Proposed Actions
5.1: Recognising carers and assisting carers in their role	• Improving post-diagnostic care coordination to assist carers along the care journey, including considering rollout of dementia care coordinators informed by international best practice. • Developing new family focused counselling support for carers of people living with younger onset dementia, including a service specifically for children. • Increasing the availability of carer education and peer support services or a buddy program for carers. • Ensuring active engagement of carers as partners in care. • Increasing the availability of supports for carers in how to manage behaviours of concern.
5.2: Increasing access to carer respite services	• Increasing the availability, flexibility and affordability of respite services. • Exploring innovative models of respite care to best meet the needs of carers including carers with diverse backgrounds and experiences. • Improving linkages between My Aged Care, the Carer Gateway and the National Dementia Helpline to improve the user experience including with when making respite bookings. • Increasing the knowledge and skills of carers and families in understanding dementia as it progresses. • Ensuring emergency respite can be accessed from the community or hospital.

How can we measure our performance?

As the proposed focus areas and actions are further refined (informed by consultation) the means for measuring their impact will need to be further developed. Some examples of possible ways to measure performance include the following.

Immediate (1-3 years)	Longer term (3-10 years)

• At least 15% increase in the number of dementia carers using National Dementia Support Program.
• At least 15% increase in the number of dementia carers being referred from My Aged Care to the National Dementia Helpline or Carers Gateway.
• Increase in the number of dementia carers accessing subsidised education and training.
• Increase in dementia carer respite services established.
• Availability of younger onset dementia specific family focused counselling.
	• 25% increase in the number of people living with dementia accessing respite services by 2033.
	• Improvement in metrics for dementia carers as measured by the ABS Survey of Disability, Ageing and Carers. For example, decrease in primary carers of people living with dementia that:
	  • have one or more physical and/or emotional impacts
	  • feel weary or lack energy
	  • frequently feel worried or depressed
	  • frequently feel angry or resentful
	  • have been diagnosed with stress related illness.
	• Increase in the number of carers accessing education and training.

Objective 6: Building dementia capability in the workforce

Outcome statement	The primary care, acute, community, 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. High quality care focuses on optimising quality of life, is person-centred, culturally safe, trauma-informed and healing-aware.
Statement for people living with dementia	The people supporting my care 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.

The current situation

There are a range of existing initiatives and programs aimed at supporting health professionals and aged care workers to better understand dementia and improve their capability to support people living with dementia, including the following.

The Dementia Training Program (DTP)

The DTP provides a national approach to training healthcare professionals and support workers in dementia care. It is delivered by Dementia Training Australia (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.

DTA also offers a range of online dementia learning modules that anyone can access.

Aged care workforce measures

The Aged Care Nursing and Allied Health Dementia Care Scholarship Program is building workforce capacity in dementia care by funding scholarships for personal care workers, nurses and allied health practitioners to study dementia care.

The Aged Care Centre for Growth and Translational Research, now known as 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.

Research and training

Dementia Australia offers a range of information and resources for health professionals seeking to learn more about dementia and 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.

The University of Tasmania's free Understanding Dementia and Preventing Dementia Massive Open Online Courses support health professionals to better understand dementia and assist people to live the best quality of life with dementia across the dementia journey.

The challenges

Despite the range of initiatives aimed at educating people on dementia and improving the capacity of those supporting people living with dementia, there is significant room for improvement.

GPs are not always well equipped to recognise dementia or manage dementia

As described under Objective 3, GPs are provided limited training regarding dementia and some GPs are not skilled at recognising how dementia symptoms present and impact on people in different ways.

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

> “*Doctors don't understand the condition and it's symptoms, it drives me crazy.*”

Dementia training for aged care workers and other health professionals and volunteers is insufficient or not always taken up

Aged care workers and other health professionals don't always receive training in dementia. This includes how to communicate and engage effectively with people living with dementia, create enabling environments, recognise signs of unmet needs and respond to changed behaviours. The same can be said for volunteers that might be interacting with people living with dementia. For example in the Community Visitor Scheme or providing meals on wheels or community transport. This can be due to training not being available, 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 sector also means the need for training is ongoing, which places additional pressure on resources within the sector.

The training delivered does not always reflect the diverse needs of people living with dementia or is not designed in partnership with people with lived experience of dementia. Practices and procedures in aged care services, hospitals and other care settings are not always appropriate for people living with dementia, and some people fear being inappropriately medicated because staff don't have the time or necessary skills to manage BPSD.

There are not enough aged care workers or volunteers

There is pressure on the formal and informal aged care workforce, which was amplified during the 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.

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

How could we improve the situation?

Examples of possible actions to address the challenges could include the following.

Proposed focus areas	Proposed Actions
6.1: A skilled, dementia aware health and aged care workforce	• Undertaking a national audit of dementia training for medical, nursing, allied health, disability and aged care workers. • Increasing focus on dementia in professional training including embedding mandatory core competencies for medical, nursing, allied health, disability and aged care workers. • Exploring the opportunities for semi-specialist GPs or nurse practitioners to focus on dementia care, with extra training and to access to MBS remuneration. • Continuing to develop and make available dementia training opportunities and learning pathways across all disciplines, including for volunteers, designed in partnership with people of lived experience with dementia. • Considering requirement for regular dementia training for aged care staff and volunteers as part of the current process to update the Aged Care Quality Standards. • Facilitating use of the national dementia education standards being developed by DTA and the learning pathways to assist in developing dementia practice leaders. • Increasing opportunities for ‘whole of practice’ dementia training in primary care. • Developing dementia practice leaders in the health and aged care workforce who can help mentor and coach staff in the application of dementia knowledge and skills, as well as drive practice change. • Improving the capacity and capability of aged care providers to deliver quality dementia care including mandatory training on managing BPSD. • Continuing to implement measures to increase the size of the aged care workforce.

6.2: Organisational culture supports quality dementia care	• Strengthening dementia in the health and aged care quality standards. • Exploring options to embed tools to support workers in health and aged care settings to build relationships with, and understanding of, the people living with dementia that they support. • Building communities of practice/learning networks which support dementia practice leaders to share learnings and good practice to promote organisational change.

How can we measure our performance?

As the proposed focus areas and actions are further refined (informed by consultation) the means for measuring their impact will need to be further developed. Some examples of possible ways to measure performance include the following.

Immediate (1-3 years)	Longer term (3-10 years)
• Reduction in the number of restrictive practices/incident reports for people living with dementia. • Increase in the number of GPs and nurses accessing and completing dementia training. • Increase in the number of medical, nursing, allied health, disability and aged care workers who are trained to work with people living with dementia. • Implementation of updated Aged Care Quality Standards. • Conduct survey of workforce confidence and capability. • Review coverage of dementia in undergraduate curricula and CPD requirements for health professionals.	• 20% increase the number of medical, nursing, allied, disability and aged care workers undertaking dementia specific training. • Improved confidence and capability of the workforce to provide high level dementia care as assessed by a dementia workforce survey. • Percentage of dementia practice leaders that ensure dementia knowledge and skills are put into practice. • Increased confidence of medical, nursing, allied health, disability and aged care workers in working with people living with dementia. • Increase in understanding of dementia by primary and aged care workforce, including all staff. • Create XXX dementia practice leaders. • Establish XXX communities of practice/learning networks. • Review requirements for professional accreditation to ensure appropriate dementia content is included.

Objective 7: Improving dementia data and maximising the impact of dementia research and innovation

Outcome statement	Improve availability of dementia data at a national level to inform policies and programs and enable the monitoring of improvements over time. Ensure that research supports innovations in dementia including early detection and diagnosis, treatment and care.
Statement for people living with dementia	Research is focussed on improving my life and those that might be diagnosed in the future. Innovative practices are in place to make it easier for me to thrive with dementia. Dementia data is regularly reported so I can see if improvements are being made.

The current situation

Dementia data

The dementia data within Australia is poor.[50] There is no one dataset to capture dementia diagnosis or management. The Australian Dementia Network's current trial of a clinical quality registry for people newly diagnosed dementia and mild cognitive impairment (MCI) is an important step in providing this much needed data. Since its commencement in early 2020, the registry has been implemented in memory clinics, other dementia and MCI diagnostic services, and individual medical specialists (e.g., geriatricians, neurologists, and psychiatrists) across Australia. It recruited nearly 1,700 participants in September 2022.

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.

Dementia research

There is a substantial Australian dementia research base with over 286,000 journal articles relating to dementia/Alzheimer's disease published in the last 5 years.

Dementia is one of 5 priority areas of the National Health Medical and Research Council, which invested $200 million between 2014-19 via the Boosting Dementia Research Initiative and has since allocated dementia funding via its broader initiatives.

The Medical Research Future Fund Dementia Ageing and Aged Care Mission improves outcomes for people living with dementia and older Australians. 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 that 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.

Key Practice Highlight – the National Centre for Monitoring Dementia

The National Centre for Monitoring Dementia (the Centre) at the Australian Institute for Health and Welfare 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 a 'Dementia in Australia Report' that covers the full dementia journey including prevention, diagnosis, treatment and care. It includes information on:

- the main risk factors for dementia
- the number of caregivers and the time spent providing care
- the health, aged care and support services used by people with dementia
- the health and aged care expenditure on dementia.

As part of this work, the Centre will identify any gaps in the data over time and improve the quality of data to help design better dementia policies and programs. The Centre will also collect data to monitor the progress and effectiveness of key actions in the new Action Plan to understand the extent to which it is improving the lives of people living with dementia and their carers.

The challenges

While there is a substantial research base and a range of data improvement strategies being planned, there are still opportunities for improvements including to address the following.

The limited Australian data on dementia diagnosis and management

Like a number of other countries, Australia has no reliable data on the number of people living with dementia (prevalence) or the number or people newly diagnosed each year (incidence). 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.

Limited mechanisms to translate evidence into practice

There are currently limited pathways that promote and support the translation of current evidence-based research into practice across the entire dementia journey. 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.

> “*If the incidence of dementia is to be reduced and the lives of people with dementia are to be improved, research and innovation are crucial, as is their translation into daily practice.*”

> “*More research needs to be done on reducing the risk of dementia.*”

There is not a single dementia research platform

There is a lack of centralised dementia research making it difficult for researchers to know what work is being undertaken. There is also no central repository for dementia research findings that could be used to promote evidence-based practice. There is no coordination of research findings through brain banks which 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.

There is limited research that focuses on priority population groups living with dementia

There is a lack of dementia research specific to the experiences of people living with dementia who identify as Aboriginal and Torres Strait Islander, LGBTIQ+, from CALD backgrounds or veterans.

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.

Limited focus on finding a cure

Dementia is the leading cause of death for women in Australia and second leading cause of death overall. 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.[51]

How could we improve the situation?

Examples of possible actions to address the challenges could include the following.

Proposed focus areas	Proposed Actions
7.1: Advancing dementia research and innovation	• Developing an Australian dementia research strategy that enables people with lived experience, including those from priority population groups, to work with researchers, clinicians, academics, service providers and governments to inform research priorities. • Continuing investment to enable more accurate diagnosis of dementia, more effective treatments and ultimately find a cure. • Understanding and promoting the role of technology to enhance the quality of life of people living with dementia including the use of assistive technologies. • Enabling international collaboration and sharing of data. • Developing a National Brain Bank Network.

7.2: Translating dementia research into practice	• Developing a centralised dementia research clearinghouse. • Ensuring dementia policy is evidence based and informed by the latest contemporary research. • Ensuring research considers implementation strategies and principles of knowledge translation. • Developing a primary care research focus area to define best practice in primary care for people living with dementia.
7.3. Improving dementia data and information systems	• Putting systems in place to support monitoring of the Action Plan and future policy development by the National Centre for Monitoring Dementia. • Developing a national dementia data framework to be established as part of the Action Plan implementation. • Developing a dementia data improvement plan to ensure that the objectives of the national data framework can be achieved. • Continuing investment in Australian dementia clinical quality registries. • Contributing data on dementia in Australia to the World Health Organization’s Global Dementia Observatory.
7.4. Collection of data for monitoring improvement	• Improving data collection on dementia including clinical coding to better inform research activities. • Identifying strategies to improve the accessibility and integration of existing data sources relevant to dementia, for example the use of digital health records and primary care data. • Collecting data to support monitoring of the Action Plan and future policy development through the National Centre for Monitoring Dementia. • Improving the collection of data (e.g. dementia diagnosis), in primary care medical records so it can be reported on.

How can we measure our performance?

As the proposed focus areas and actions are further refined (informed by consultation) the means for measuring their impact will be further developed. Some examples of possible ways to measure performance include the following.

Immediate (1-3 years)	Longer term (3-10 years)
• Increased research is undertaken through current funding arrangements. • Fulfill WHO's Global Dementia Observatory international reporting obligations. • Develop an Australian dementia research strategy. • Develop a comprehensive dementia data framework supported by a dementia data improvement strategy in consultation with key partners. • Continue to fund the Australian Dementia Network to improve accuracy and comprehensiveness of clinical dementia data.	• Establishment of an Australian dementia research clearinghouse. • Data related to dementia is reported through the National Centre for Monitoring Dementia. • Increase in the number and value of dementia research grants approved. • Increase in the number of published Australian studies in peer reviewed journals. • Increase in the number of people with lived experience being involved in all stages of research projects. • Increase in the number of national data sources (e.g. surveys, national minimum datasets) that include data on dementia. • Define best practice in primary care for people living with dementia.

Background

The previous National Dementia Frameworks

The Action Plan will build on the previous two National Frameworks for Action on Dementia (the Frameworks), the last of which notionally expired in 2019. The Frameworks were guiding documents developed by the Australian Government and 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 performance measures and monitoring requirements further limited the value of the Framework.

The previous Frameworks are available at Dementia | Australian Government Department of Health and Aged Care.

Implementing the Action Plan

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

Governments are committed to working together alongside people living with dementia, their carers and families, communities, academics, service providers, businesses and the non-government sector to implement the Action Plan.

Implementation will be supported by:

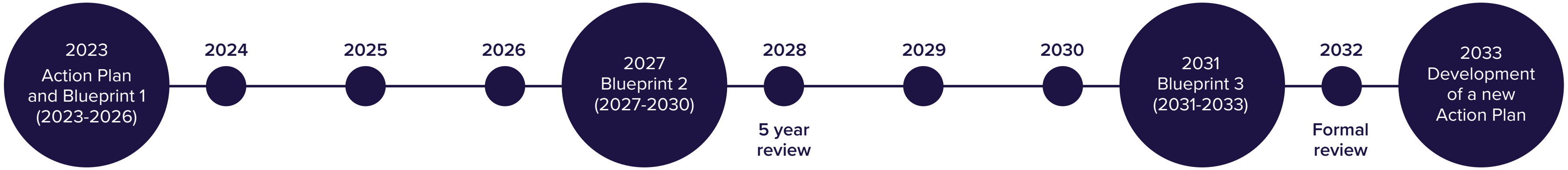
- Implementation Blueprints – will outline detail on specific activities, funding, timeframes and responsibilities.
- Monitoring – data will be regularly collected to assess progress and achievements against activities over time.
- Reporting – regular reporting against the performance measures and a mid-point evaluation in 2028.
- Governance – clear governance arrangements including a central body to drive implementation and a clear roadmap to keep governments accountable and on track.

National Dementia Action Plan 2023-2033

National Objectives

- Tackling stigma and discrimination
- Minimising risk, delay onset and progression
- Improving dementia diagnosis
- Better treatment, coordination and support along the dementia journey
- Supporting people caring for those living with dementia
- Building dementia knowledge and skills in the workforce
- Improving dementia data and maximising the impact of dementia research and innovation

Yearly Action Plan Report Cards



2023 Action Plan and Blueprint 1 (2023-2026)
2024
2025
2026
2027 Blueprint 2 (2027-2030)
2028 — 5 year review
2029
2030
2031 Blueprint 3 (2031-2033)
2032 — Formal review
2033 Development of a new Action Plan

Principles

- **Directly informed** by the views of people living with dementia, their carers and families
- Focused on **Quality of life** for people living with dementia, their carers and families
- Appropriate for, and **accessible to, all people,** including priority population groups and people from diverse backgrounds
- **Culturally safe** for Aboriginal and Torres Strait Islander peoples
- Evidence based and **outcomes focused**
- Coordinated, **integrated** and planned

Vision

Australians understand dementia, people living with dementia and their carers have the best quality of life possible and no one walks the dementia journey alone

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 Report Cards and 5 year formal review
Central body of Australian Government and state and territory government representatives

Implementation Blueprints

The first Blueprint will cover the period 2023-2026 and include specific activities, funding, timeframes and responsibilities. The Blueprints will be developed with input from dementia experts and people with lived experience of dementia. They will be signed off by Australian Government and state and territory governments and published on the Department of Health and Aged Care website.

The Blueprints detail how specific activities relate to the 7 Objectives and the performance measures.

As noted in the immediate priorities section (page 16), it is proposed that the 2023-2026 Blueprint focus on the following focus areas:

- timeliness of diagnosis/detection of dementia
- better coordinated post-diagnostic care (immediately following a diagnosis) but noting this need is ongoing
- increased dementia capability of the health and aged care workforce
- improved carer supports
- improved data collection, intelligence and monitoring systems.

It is intended that the Blueprints will be short documents and presented in tabular format similar to the table below (noting it is for illustrative purposes only).

Objectives	Key Focus Areas	Specific Activity	Funding Commitment ($m) (Timeframe)	Timeframes	Lead Organisation (Partner/s)	Link to performance measure
Tackling stigma and discrimination	1.1 Expanding dementia awareness and reducing stigma	Conduct an Australian public attitudes survey to collect baseline data regarding knowledge of and views about dementia	0.4 (2022/23)	Random sample of 5,000 people conducted in July 2023	Department of Health and Aged Care and AIHW	Increased awareness of dementia risk collected through the public attitudes survey

Funding for implementation

Many of the activities within the Action Plan are expected to focus on better coordination of existing programs and systems or modifications to existing arrangements. This will ensure the needs of people living with dementia, their carers and families will be better met. These actions are about better use of existing resources, rather than requiring new funding.

Other actions will need additional government investment. It is expected that these actions will be agreed between governments and feed into ongoing Australian Government and state and territory government budget processes.

Monitoring

The National Centre for Monitoring Dementia (the Centre) at the AIHW (described under Objective 7) will have a key role in collecting data and monitoring progress against the Action Plan. It will do this by:

- collecting a suite of agreed data to directly assess performance against the measures in an annual Action Plan Report Card
- addressing the numerous current gaps in Australian dementia data so there is more accurate information to address performance against measures over time
- reporting and publishing a range of dementia data and statistics in the Dementia in Australia report. This will keep dementia in people’s awareness and to help identify emerging issues that need attention within future Implementation Blueprints.

Performance Measures

The performance measures should be specific, measurable, and relevant to people living with dementia.

Information will be collected in one or more of the following ways:

- descriptive: listing the activities being done for the action
- categorical: giving a yes or no response to whether an action has been completed
- quantitative: contain numbers or rates to describe progress against an action.

Wherever possible the performance measures will include specific targets. For example, 85% of people attend a diagnostic service within 90 days of reference. This will ensure we are all clear about what we are aiming for.

Improving data

Governments are committed to collecting and sharing relevant data to support effective monitoring and reporting of outcomes for people living with dementia to drive change. Australian Government and state and territory government data will be essential for measuring performance and tracking the degree of change. Governments will work together to develop a comprehensive data strategy. This will ensure that data needed to measure outcomes for people living with dementia is collected, shared and progressively improved over the life of the Action Plan.

It will also identify where data needs to be linked between systems to improve our understanding of the impact of the Action Plan. Linked de-identified data will provide improved disaggregated data, support the development of new measures and deliver deeper insights into how and why certain outcomes occur.

The Aged Care Minimum dataset could provide a better understanding of how people living with dementia are supported through services and programs across multiple service systems through the linkage, improvement and sharing of de-identified data.

Governments will work together to link de-identified data between systems and to address current gaps in dementia data. This will improve our ability to measure performance over time. For this reason, the Action Plan will have immediate and future measures that that will be introduced when data are improved. The future measures may add to or replace the immediate measures as we move forward.

Reporting

An Action Plan Report Card will be prepared by the AIHW, agreed by governments and published every year. A 5-year formal review will also be undertaken in 2028 to consider progress against the Action Plan and Implementation Blueprints. Knowledge of dementia is continually improving so the 5-year review will also consider new developments and how to incorporate these going forward.

Report cards will also form the basis of the national report of Australia’s progress against the WHO Global Action Plan every 3 years.

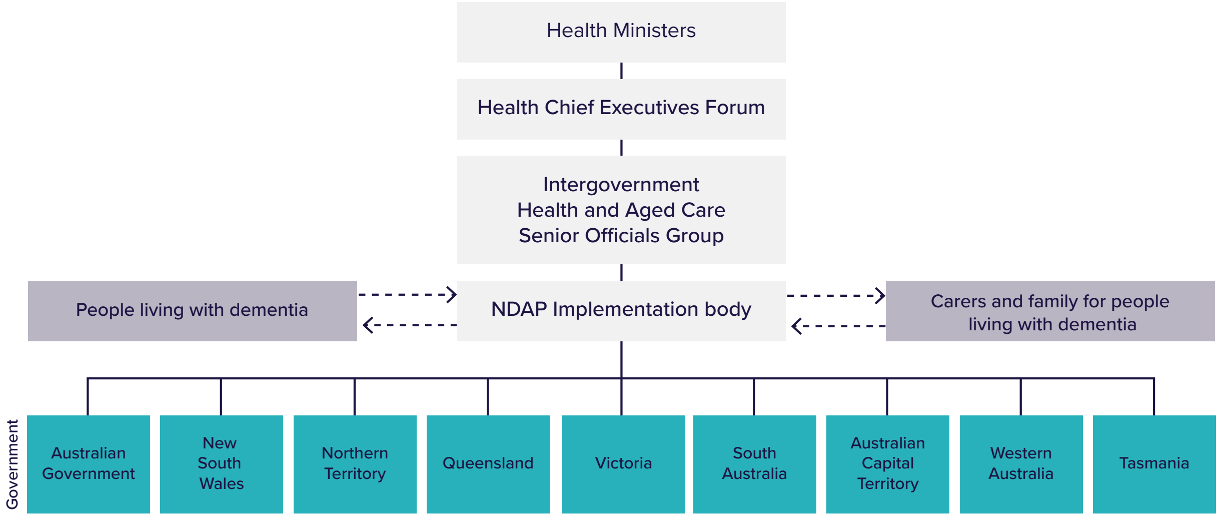
Governance

Implementation of the Action Plan will be driven by a central body made up of Australian Government and state and territory government officials. They will report to Health Ministers through the Aged Care Officials Senior Officials Group.

The central body will meet periodically throughout the duration of the Action Plan to discuss progress with implementation and opportunities for refinement and collaboration, share learnings, identify gaps or barriers to implementation, celebrate success and contribute to future Blueprint priorities.

The central body's work will be guided by the following National Dementia Action Plan governance structure as outlined below.

National Dementia Action Plan Governance Structure



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