Australian Government
Department of Health and Aged Care

National Dementia Action Plan

Consultation Paper Summary

November 2022

About the consultation

The National Dementia Action Plan is a shared project between the Australian Government and state and territory governments. It will be a ten-year plan to put people living with dementia, their families, and carers at the centre of all action on dementia.

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. This consultation paper sets out:

- key elements of the proposed Action Plan
- proposed objectives linked to possible actions
- an overview of how the Action Plan is proposed to be implemented and monitored.

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 Consultation Hub at consultations.health.gov.au
- calling 1800 565 789 for more information or assistance

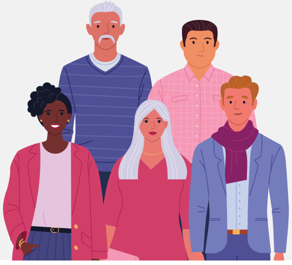
Sending us your thoughts by:

- emailing dementiaplan@health.gov.au or
- posting to National Dementia Action Plan
  MDP 765, GPO Box 9848 CANBERRA ACT 2601

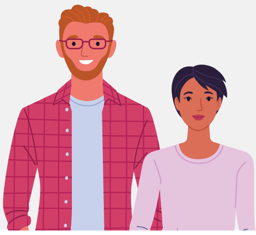
We are seeking your feedback by 31 January 2023. Your feedback will inform the development of the Action Plan, which is expected to be finalised in 2023. To access the full consultation paper or a one page overview Get involved - Ageing and Aged Care Engagement Hub (health.gov.au)

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

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.’

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.

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

Proposed objectives

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 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. - Participant in lived experience workshop.*

Challenges:

- Many people don't understand dementia
- There continues to be a stigma associated with dementia and discrimination towards people living with dementia and their carers
- The response of people to a dementia diagnosis can be confronting
- Services and environments are not often dementia friendly.

Possible actions could include:

Expand dementia awareness and reducing stigma

- Awareness raising activities to reduce misconceptions about dementia
- More education to encourage early conversations about dementia.

Creating dementia friendly public spaces and services

- Working with local councils and businesses to improve the design of public spaces
- Providing more training to first responders including police, paramedics, and fire fighters.

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.

> *By making good lifestyle choices, we can at least stack the odds in our favour.*
> *- Participant in lived experience workshop*

Challenges:

- People aren't aware that there are things they can do to reduce their dementia risk
- Modifiable risk factors have a bigger impact amongst some groups
- People living with mild cognitive impairment or in the early stages of dementia need better information and support strategies.

Possible actions could include:

Risk factors for dementia are well understood

- Supporting and encouraging people to have early conversations about dementia to increase understanding
- Continuing investment in research on risk factors.

People are aware of what they can do to delay the onset and slow the progression

- Focusing on brain health at regular health checks
- Tailoring risk reduction information for people with diverse backgrounds or at higher risk of developing dementia
- Supporting wider adoption of innovative Australian trials of online interventions to reduce dementia risk.

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

Outcome statement	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 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.*
> *- Participant in lived experience workshop*

Challenges:

- Individuals don't always recognise dementia signs
- Limited General Practitioner (GP) capacity and capability to recognise the signs and symptoms of dementia
- People living with cognitive decline or dementia may reject a diagnosis or any suggestion of it
- Barriers to accessing timely specialist assessment
- The diagnostic processes can be unclear
- A diagnosis of dementia can be devastating, and people often feel a sense of grief immediately following a diagnosis.

Possible actions could include:

Recognising and acting on early signs and symptoms

- Promoting benefits of early diagnosis to GPs, nurses, and the general community
- Better dementia education and training for health professionals
- Clearer pathways and processes for health practitioners to refer clients to diagnostic services and/or Dementia Australia.

Quality and timely diagnostic services

- Reviewing the 2016 Clinical Practice Guidelines and Principles of Care for People with Dementia
- Increasing capacity of memory clinic networks and ensuring that regional memory clinics are adequately staffed
- Reviewing the Medicare Benefits Schedule to better support dementia diagnosis
- Developing and implementing culturally competent diagnostics tools.

Post diagnostic care and support

- Strengthening coverage of dementia in the Australian Commission on Safety and Quality in Health Care Standards
- Improving care coordination and future planning following a dementia diagnosis
- Considering the rollout out of dementia care coordinators, as informed by international best practice.

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.

> *I feel like I fall through the gaps and don't know which way to turn. - Participant in lived experience workshop*

Challenges:

- Challenges navigating the health, disability and aged care systems
- Multidisciplinary care is often inadequate, unavailable and unaffordable
- Arrangements for support decision making can be difficult to understand
- Unavoidable hospital admissions and delayed discharges
- Pain often results in changes in behaviour
- Lack of reablement options
- Hospital environments need to be more supportive and inclusive
- Lack of dementia-informed palliative care services
- Barriers accessing services for children and younger people living with dementia.

Possible actions could include:

Quality care and ongoing support as a person's needs change

- Increasing the number of specialist dementia care units
- Developing optimal models of care and responsibility for people with extreme (Tier 7) BPSD
- Providing flexible delivery of dementia supports, including telehealth and outreach
- Providing new family focused counselling support for people living with younger onset dementia.

Care and support during and after hospital care

- Increasing dementia friendly environments and practices in hospitals
- 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.

End of life and palliative care

- Exploring options for dementia-specific palliative care services
- Providing more community-based palliative care for people living with dementia
- Increasing awareness of advanced care planning and end of life options for people living with dementia.

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.

> *If you don't get support, who will look after your loved one if you break?*
> *- Participant in lived experience workshop*

Challenges:

Some of the challenges those caring for a loved one living with dementia include:

- Lack of respite care that is responsive and meets the needs of different people
- Respite care often isn't easy to access
- Caring commitments impact financial security
- Insufficient emotional and peer support
- Challenges navigating the service systems.

Possible actions could include:

Recognising carers and assisting carers in their role

- Increasing family focused counselling support
- Making carer education more available
- Expanding peer support and buddy programs for carers and better support carers in managing behaviours of concern.

Increasing access to carer respite services

- Increasing the availability, flexibility, innovation, and affordability of respite services
- Improving linkages between systems to improve the user experience accessing support, including for respite bookings
- Ensuring emergency respite can be accessed from the community or hospital.

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.

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

Challenges:

There is significant room for improvement in the range of initiatives aimed at educating people on dementia and improving the capacity of those supporting people living with dementia:

- GPs are not always well equipped to recognise or manage dementia
- Dementia training is insufficient or not always taken up
- Not enough aged care workers or volunteers.

Possible actions could include:

A skilled, dementia aware health and aged care workforce

- Conducting a national audit and focusing on dementia in training across all disciplines (including for volunteers)
- Promoting 'whole of practice' dementia training in primary care
- Exploring opportunities for semi-specialist GPs or nurse practitioners
- Developing dementia practice leaders in the workforce to mentor and coach staff
- Continuing to work to increase the size of the aged care workforce.

Organisational culture supports quality dementia care

- Strengthening dementia in the Clinical Care Standards and the Aged Care Quality Standards
- Exploring tools to support workers in health and aged care settings
- Building communities of practice / learning networks and consider nurse-led models of care in primary care.

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.

> *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. - Participant in lived experience workshop*

Challenges:

While there is a substantial research base and a range of data improvement strategies being planned, challenges that need to be addressed include:

- Limited Australian data on dementia diagnosis and management
- Limited mechanisms to translate evidence into practice
- There is not a single dementia research platform
- Limited research that focuses on priority population groups living with dementia
- Limited engagement with people with lived experience
- Limited focus on finding a cure.

Possible actions could include:

Advancing dementia research and innovation

- Enabling 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 in accurate diagnosis of dementia and cures
- Understanding and promoting the role of technology to deliver care and support
- Enhancing the quality of life of people living with dementia
- Developing a National Brain Bank Network.

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.

Improving dementia data and information systems

- Having the National Centre for Monitoring Dementia develop a national dementia data framework and dementia data improvement plan
- Continuing investment in Australian dementia clinical quality registries and contributing data on dementia in Australia to the World Health Organization’s Global Dementia Observatory.

Collection of data for monitoring improvement

- Improving data collection on dementia, through clinical coding to better inform research activities
- Identifying strategies to improve the accessibility and integration of existing data sources
- Collecting data to support monitoring of the Action Plan and future policy development through the National Centre for Monitoring Dementia.

Implementing the Action Plan

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

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.

Performance Measures

- Performance measures are being developed for each of the possible action areas, which will provide important information on how well each of the actions are being achieved. The performance measures are being developed in partnership with the Australian Institute of Health and Welfare with a focus on being specific, measurable and relevant to people living with dementia.
- There are immediate performance measures, which should be achieved within 1-3 years, and longer term measures, to be achieved within 3-10 years. An example of an immediate performance measure is *increase in the number of GPs undertaking dementia training modules,* with a longer term specific measure of *50% increase in the number of GPs undertaking dementia training modules*.
- To view the full range of possible performance measures, refer to the full Consultation Paper at Get involved - Ageing and Aged Care Engagement Hub (health.gov.au)

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