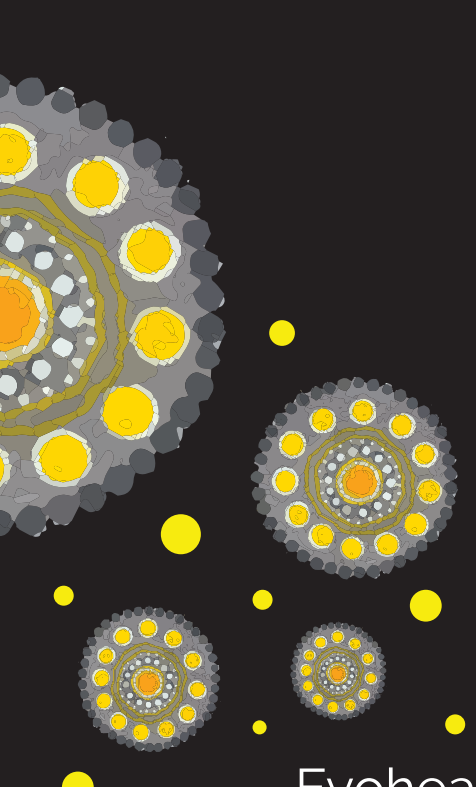# Diagnosis to dignity

A vision for Alzheimer's disease in Australia
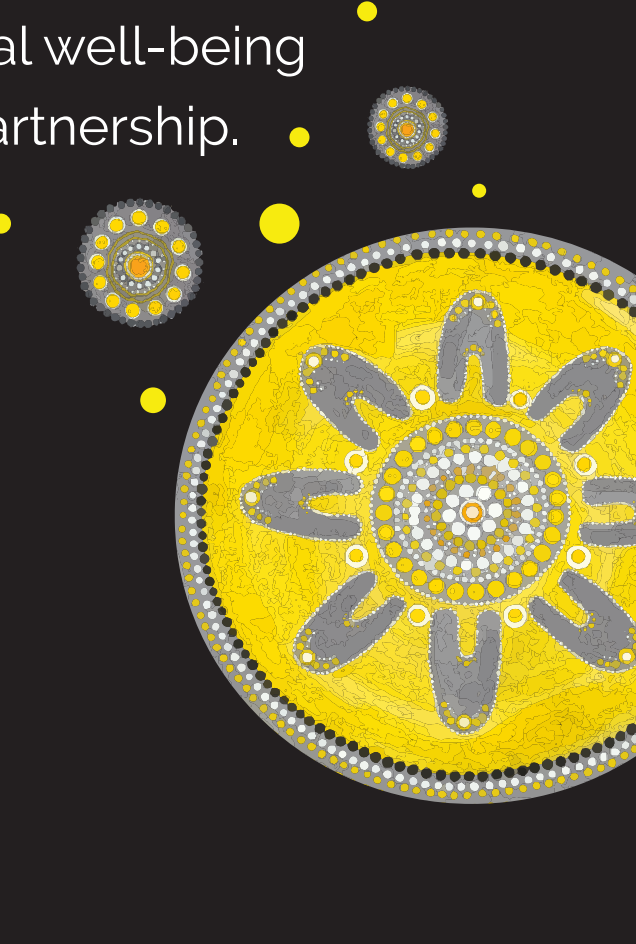
evohealth

October 2024

Evohealth acknowledges that we work on the traditional lands of many Aboriginal clans, tribes, and nations.

We commit to working in collaboration with Aboriginal and Torres Strait Islander communities and peoples to improve health, emotional and social well-being outcomes in the spirit of partnership.

About
Evohealth

The delivery of healthcare is complex.
Our focus is not.

Better health for all.

DIAGNOSIS TO DIGNITY

A VISION FOR ALZHEIMER'S DISEASE IN AUSTRALIA

CONTENT.

ABOUT **THIS REPORT**

Background

Diagnosis to dignity: A vision for Alzheimer's disease in Australia is an evidence-based report presenting a future paradigm for Alzheimer's disease in Australia. We propose seven recommendations to enable a brighter future for many Australians living with Alzheimer's disease and their carers. The report was independently authored by Evohealth, a specialist health advisory firm, in partnership with an expert Advisory Committee that includes clinicians, research leaders and patient advocates in Alzheimer's disease and dementia.

Approach

The report has been informed by:

- comprehensive review of published academic and grey literature;

- interviews with Australian clinicians, researchers and patient advocacy groups;

- cohort-based economic model and analysis to determine the direct costs, indirect costs, and the quality of life of people with Alzheimer's disease in Australia, now and into the future (see Appendix for methodology); and

- contributions of our expert Advisory Committee members.

The report received funding from Eli Lilly Australia. Eli Lilly did not participate in the development of the report to ensure the independence of Evohealth.

Unless otherwise specified all costs are in Australian dollars.

ACKNOWLEDGEMENTS

Evohealth wishes to acknowledge the ongoing support of the individuals and organisations who contributed to this project.

We would like to acknowledge the Advisory Committee who provided critical oversight and input to the development of this report. The Advisory Committee comprised the following members:

Professor Michael Woodward AM
Director Dementia Research Austin Health and Honorary Medical Advisor, Dementia Australia

Professor Henry Brodaty AO
Co-Director Centre for Healthy Brain Ageing (CHeBA), Discipline of Psychiatry and Mental Health, School of Clinical Medicine, UNSW Sydney

Professor Sharon Naismith
Neuropsychologist, School of Psychology, Faculty of Science, Brain and Mind Centre and Charles Perkins Centre, the University of Sydney

Dr Stephanie Daly
General Practitioner, Sensus Cognition (Primary care cognition clinic) MBChB, FRACGP. PGcert - Dementia Studies

Professor Tanya Buchanan
CEO Dementia Australia and Honorary Professor of Practice, School of Health and Society (Public Health), University of Wollongong

Diagnosis to dignity: A vision for Alzheimer's disease in Australia

EXECUTIVE **SUMMARY**

Alzheimer's disease is one of the most significant health challenges of our time, with the potential to impact millions of Australians and place a substantial strain on our health and aged care systems. Alzheimer's disease encompasses both mild cognitive impairment (MCI), an early stage where symptoms are less severe, and dementia, which is more advanced and marked by significant cognitive decline.
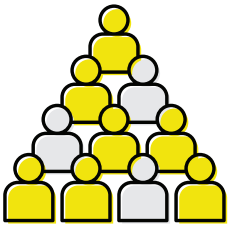
The number of people with MCI and Alzheimer's disease pathology is estimated to be between **318,000** and **477,000 in 2024**, increasing to between **590,000** and **885,000 by 2050**. [1, 2]

The number of people with Alzheimer's dementia is expected to double from **~296,000** cases in 2024 to **~600,000** in 2050. [3]

Alzheimer's dementia **total costs** are expected to grow from **$8.1 billion** in 2024 to **$17 billion** in 2050. [3]

Alzheimer's dementia is often underdiagnosed, meaning the actual prevalence and associated costs may be higher than those estimated and presented in this report.

Understanding dementia

Dementia is an umbrella term for a variety of symptoms that affect a person's ability to think, remember and communicate. Ultimately, it interferes with their activities of daily living. Alzheimer's disease is the most common cause of dementia, characterised by specific pathological changes in the brain. Alzheimer's dementia, in its most severe stage affects motor function, eventually leading to death. Dementia, including Alzheimer's disease, was the second most common cause of death in 2022. [4]

Diagnosis to dignity: A vision for Alzheimer's disease in Australia

The opportunity for change

Despite the daunting challenge ahead, the emergence of new diagnostic technologies, and disease modifying treatments, along with increasing evidence on prevention, early diagnosis and dementia management, delivers hope for the first time. Embracing this new paradigm alongside the National Dementia Action Plan, anticipated at the end of 2024, and the recently announced new *Aged Care Act*, Australia has the opportunity to transform how we approach Alzheimer's disease, making improved quality of life a more attainable goal. [5, 6]

These long-awaited innovations and changes provide Australia with a crucial opportunity to rethink, reimagine, and reshape our approach to Alzheimer's disease. Hope is finally on the horizon. We must be proactive while we have momentum. A better future will support and enhance the lives of many patients and their carers, strengthen our economy and reduce the pressure on our health and aged care system.

> *"We know that now is the time. Like cancer treatments just a few decades ago, these [disease modifying agents] are not perfect, we have to start somewhere. This is our start; these are first in class agents that offer hope."*
>
> **- Professor Michael Woodward AM**

Strengthening our workforce

Alzheimer's disease forces many people to leave work prematurely, resulting in lost productivity, potential and livelihoods. As cognitive decline takes hold, individuals lose the chance to contribute their skills, experience and expertise, while families face the heavy financial strain of care. This loss doesn't just impact those affected—it weakens our workforce, drains productivity, and places immense pressure on carers and the economy.

Our modelling reveals that 1 in 5 people over the age of 60 that live with Alzheimer's disease wish to continue to work and could do so with early diagnosis, treatment and appropriate support. This equates to 50,000 Australians in 2024. By investing in early diagnosis, innovative treatments, and better support—we can keep people contributing to their communities and professions longer. A proactive approach today will secure a stronger, more resilient future for people living with Alzheimer's disease, carers, and our entire economy.

Securing a better future by:

50,000 people over the age of 60 with **Alzheimer's disease** could continue to work with early diagnosis, treatment and support. [3]

WORK WANTED

Reducing the estimated $3.7 billion of **lost productivity** observed **each year.** [3]

Reducing the burden on our aged care system

It is commonly accepted that Australia's aged care system is facing enormous challenges. It is estimated that by 2050, 3.5 million Australians will access aged care services, including residential aged care, each year. [7] Around 40 per cent of these people will have Alzheimer's disease pathology, at an estimated cost

of $6 billion in 2050. [8] A future where we proactively support people with Alzheimer's disease to stay at home, can alleviate pressure on the aged care system by improving care models, reducing strain on resources, and enhancing the quality of life for both patients and carers.

In fact, keeping people at home for longer has been shown to improve quality of life for both people living with Alzheimer's disease and carers, as well as providing cost benefits for the government. Our modelling reveals that delaying entry for people with mild Alzheimer's dementia into aged care by just 12 months improves quality of life and saves money.

Delaying entry to aged care can:

Achieve a 25% improvement in quality of life for people living with dementia. [3]

Save $40–$48 million over four years for the Australian Governments. [3]

To imagine a future where people can continue working for as long as they choose, and live at home, surrounded by family and friends, we have created a vision - a future paradigm where people with Alzheimer's disease can live their lives with dignity, beyond their diagnosis.

Diagnosis to dignity – our vision

In the future, Australians living with Alzheimer's disease will enjoy improved quality of life through comprehensive, compassionate, and personalised care and support.

Early detection, effective interventions and post diagnostic support will prioritise their well-being, diversity and dignity.

This care and support will enable people to live safely at home.

People living with Alzheimer's disease and their carers will be able to stay engaged in meaningful work and societal activities for longer through flexible, supportive community and workplace inclusion strategies.

Society will be educated and accepting, eliminating stigma and providing strong community support for people living with Alzheimer's disease and their carers.

Continuous investment in research, caregiver support, innovative care models, and community-based resources will empower individuals and their families, ensuring they are never alone in their journey.

This future envisions managing Alzheimer's disease with empathy and excellence, reducing the burden and enhancing lives.

Diagnosis to dignity: A vision for Alzheimer's disease in Australia

Informed by research and stakeholder consultation, we have imagined a future where this vision is a reality.

A future that:

Enables early detection and diagnosis, and where appropriate, patient access to safe, efficacious therapies, as well as supporting people to mitigate modifiable risk factors to treat and delay progression of Alzheimer's disease.

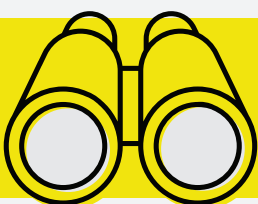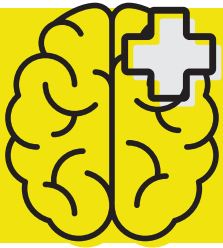People with Alzheimer's disease will enjoy improved quality of life through comprehensive, compassionate, and personalised care and support. We will move Alzheimer's disease from being underdiagnosed to understood by all Australians, and shift clinical perspectives to promote support for brain health earlier in life and comprehensive post diagnostic support, when needed. Society will accept Alzheimer's disease as a chronic condition beginning earlier in life, that can be managed with a supportive care team.

We must facilitate access to safe and effective therapies for those who may benefit, including the new disease modifying therapies such as lecanemab and donanemab[1], that offer hope for treating and delaying the onset of more severe Alzheimer's disease symptoms, including dementia. [10, 11] Ensuring access to early detection and diagnosis, effective pharmacological and non-pharmacological interventions and post diagnostic support will deliver this future, and prioritise the well-being, diversity and dignity of those living with Alzheimer's disease.

Assists and supports people with Alzheimer's disease to remain at home for longer.

Providing comprehensive, individualised and dignified care will support people with Alzheimer's disease to live independently at home for longer, surrounded by familiar faces and environments.

Advances in treatment and smart technologies for real-time health monitoring and safety, combined with comprehensive home care supports, will enable people to maintain their independence, dignity, and quality of life, reducing or delaying the need for aged care facilities

By proactively engaging service providers to offer supportive technologies and integrate memory supports and individualised cognitive care programs in their service offerings, we can ensure that individuals can manage their condition and maintain cognitive health for as long as possible.

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1 Another disease modifying therapy, aducanumab (Aduhelm®), which received accelerated regulatory approval as a treatment for Alzheimer's disease from the U.S. Food and Drug Administration (FDA) in 2021, will be discontinued by its manufacturer (Biogen) in 2024. [9]

Assists and supports people with Alzheimer's disease and their carers to remain active in society, including their communities and the workforce, for longer.

In our future, people with Alzheimer's disease and their carers will stay engaged in meaningful work and societal activities longer, through flexible, supportive community and workplace inclusion strategies.

Evohealth modelling reveals that, in 2024, among the 270,000 people over the age of 60 living with Alzheimer's disease who have left the workforce, 50,000 could have continued working if not for the condition. [3]

Importantly, carers, who often reduce their hours or leave the workforce, are now supported to maintain employment. Research indicates that 1 in 3 primary carers that reduce work hours, would be able to continue contributing their skills and experience to the workforce. [12] This preserves their sense of belonging, purpose, financial stability and benefits the economy by retaining experienced and skilled workers.

50,000 people over the age of 60 with **Alzheimer's disease** could continue to work with early diagnosis, treatment and support. [3]

1 in 3 primary carers can now **maintain their employment.** [12]

Just as society has made significant progress in creating accessible workplaces for people with physical disabilities and neurodivergent conditions, we now have an obligation to extend similar support to people living with Alzheimer's disease. By embracing inclusive and supportive strategies, we can empower people to retain their sense of purpose

and identity, while enriching our communities with their unique contributions. With collaborative efforts from community organisations, policymakers, and healthcare providers, we can create a more inclusive and vibrant society where everyone benefits from the diverse strengths of all its members.

Facilitates societal understanding, recognition and acceptance of people with Alzheimer's disease to support them, and their carers, to remain connected and active in their communities.

In the future, society will fully understand, recognise, and accept people with Alzheimer's disease, fostering

their active participation in communities. Stigma and fear will give way to empathy and support.

62% of people in society believe **"life is over"** after a dementia diagnosis. [13]

73% say people make jokes at the expense of their friend or relative living with dementia. [14]

Through education and supportive environments, we will ensure people with Alzheimer's disease maintain independence and dignity, and can contribute to their communities as they wish to, for as long as possible.

We will proactively connect carers to the resources they need to manage their role and maintain their own health and well-being.

1 in 3
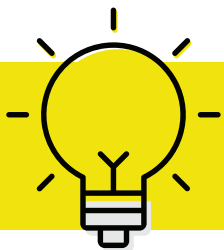Primary carers feel worried or depressed. [12]

3 in 4
Primary carers have one or more physical and/or emotional impacts due to their caring responsibilities. [12]

1 in 5
Primary carers felt angry or resentful. [12]

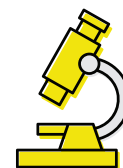**With support and understanding we can shift the carer experience from overwhelming to manageable.**

Supports research to inform continual innovation that addresses the full spectrum of the complex burden of Alzheimer's disease and other dementias.

Continuous investment in research across all stages and care models of Alzheimer's disease and other dementias, will empower individuals and their families, ensuring they are never alone in their journey. Establishing infrastructure to rapidly translate new research into practice is essential for delivering timely, impactful solutions.

To do this, we need to rebalance research spending in Australia to ensure it is commensurate with the extraordinary burden the disease places on society. Our analysis of National Health and Medical Research Council (NHMRC) data from 2016 to 2023

shows funding for Alzheimer's disease research has declined from a peak of 4 per cent in 2017 to just 2 per cent in 2023. [3] In contrast, cancer research has consistently received around 20 per cent of NHMRC funding, highlighting a critical disparity. [3]

Increase overall research funding
beyond the 2% allocated in 2023. [3]

Diagnosis to dignity: A vision for Alzheimer's disease in Australia

From diagnosis to dignity

With science bringing forth new possibilities for diagnosis and treatment, the new National Dementia Action Plan and *Aged Care Act*, we have an opportunity to change the conversation on Alzheimer's disease. Our vision is not only possible, but imperative. We must improve the lives of people with Alzheimer's disease. The benefits will accrue to us all. To achieve a better future and realise our vision, we have developed seven recommendations, these are:

RECOMMENDATION 1

Educate, upskill and support primary care clinicians to identify, diagnose and support individuals and their care/support team throughout the entirety of the disease course.

RECOMMENDATION 2

Develop a national pathway for people with Alzheimer's disease that includes early diagnosis, intervention and post diagnostic care and support options.

RECOMMENDATION 3

Increase access to cognitive rehabilitation, function, and memory support services within Aged Care Service provision, Health Care Packages, and private support offerings to help people with dementia manage their condition and maintain cognitive health.

RECOMMENDATION 4

Develop and implement national guidance to enable inclusive communities and workplaces for people with Alzheimer's disease.

RECOMMENDATION 5

Invest in a national education and awareness campaign that re-focusses Alzheimer's disease as a chronic disease that begins decades before symptoms.

RECOMMENDATION 6

Upskill and connect carers to support people with Alzheimer's disease to stay active in the community.

RECOMMENDATION 7

Invest in research and development commensurate with the Alzheimer's disease burden.

Implementing these recommendations will significantly improve the lives of Australians affected by Alzheimer's disease, their carers, and the broader community. These actions are necessary to foster an inclusive Australian society and reduce stigma. Together, these steps will ensure better care and quality of life for those living with Alzheimer's disease.

Alzheimer's disease is a progressive neurodegenerative condition that gradually destroys memory, cognitive function, and the ability to carry out simple tasks, with no cure or current effective treatment to stop its relentless progression.

MILD COGNITIVE IMPAIRMENT
IN AUSTRALIA

Between 318,000 and 477,000 in 2024 [1, 2]

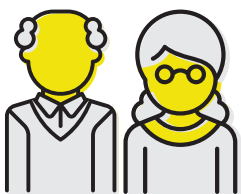**Between 590,000 and 885,000 by 2050** [1, 2]

ALZHEIMER'S DEMENTIA
IN AUSTRALIA

~296,000 cases in 2024 [3]

~600,000 cases in 2050 [3]

Dementia, including Alzheimer's disease was the **second leading cause of death** overall in 2022. [4]

64% men with dementia have Alzheimer's disease pathology. [15]

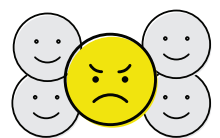**73% women** with dementia have Alzheimer's disease pathology. [15]

Women 1.9x more likely

to have dementia with Alzheimer's disease pathology compared to men. [3]

CAREGIVER IMPACT

1 in 3 Primary carers feel worried or depressed. [12]

1 in 5 Primary carers feel angry or resentful. [12]

3 in 4 Primary carers have one or more physical and/or emotional impacts due to their caring responsibilities. [12]

ECONOMIC IMPACT OF
ALZHEIMER'S DEMENTIA IN AUSTRALIA

$8.1 billion total costs in 2024 [3]

$17 billion total costs in 2050 [3]

Estimated **$3.7 billion lost productivity in 2024.** [3]

Estimated **$2.4 billion costs** for residential aged care in 2024. [3]

$40–$48 million saved by the Australian Government over four years when we delay entry of people with mild Alzheimer's disease into aged care facilities for 12 months. [3]

PATIENT IMPACT

62% of people believe **"life is over"** after an Alzheimer's disease diagnosis. [13]

22% of people believe they will lose their significant other after an Alzheimer's disease diagnosis. [13]

WORK WANTED

50,000 people over the age of 60 with **Alzheimer's disease** could continue to work with early diagnosis, treatment and support. [3]

25% improvement in **quality of life** for people with mild Alzheimer's disease if we can delay their transition into aged care facilities for 12 months. [3]

RESEARCH

Increase overall research funding beyond the 2% allocated in 2023. [3]

Diagnosis to dignity: A vision for Alzheimer's disease in Australia
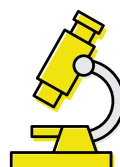
LIFTING **THE BURDEN**

Imagine a day when people with Alzheimer's disease can live safely at home, engaged in a society that treats them with care, compassion and dignity. This new future, focused on prioritising well-being and quality of life, is not only possible, but imperative with so many Australians facing a diagnosis in the coming decades. A challenge that individuals, society and Australia needs to urgently address.

Alzheimer's disease, including both mild cognitive impairment (MCI) and Alzheimer's dementia, is estimated to affect more than 600,000 Australians in the past year, with rates certain to balloon as our population ages. [3, 16]

In 2024, **between 318,000 and 477,000** Australians were estimated to be living with MCI and Alzheimer's disease pathology. [1, 2]

In 2024, around **296,000** Australians are estimated to be living with Alzheimer's dementia. [3]

Most people consider Alzheimer's disease an 'old person's disease', when in fact, pathological changes can be detected decades before symptoms significantly impact a person's daily function. [17]

Alzheimer's disease is the most common type of dementia. It affects **around 7% of Australians over 65 years and 20% of Australians over 85 years.** [15]

Beyond memory loss, progression of Alzheimer's disease to more severe stages significantly increases mortality. In fact, dementia, including Alzheimer's disease was the second most common cause of death for all Australians in 2022. [4]

Dementia, including Alzheimer's disease, was the **2nd most common cause of death** for all Australians in 2022. [4]

As the disease progresses, people require increasingly intensive and specialised care, including 24-hour supervision, assistance with daily activities, and complex medical management. [18] This escalating need for care burdens our health and aged care system. [18]

The disease burden is also growing exponentially. Our modelling reveals the number of people with Alzheimer's disease will double by 2050. [3, 19] As this complex disease continues to affect more and more Australians, it poses an unprecedented challenge to our community.

The number of people with Alzheimer's disease, including both MCI and Alzheimer's dementia, is expected to double from **600,000 in 2024 to 1,200,000 by 2050**. [3]

With this looming burden, we argue that an alternate future is not only possible, but critical. A future that envisions managing Alzheimer's disease with empathy and excellence, enhancing lives and preserving dignity.

UNDERSTANDING
ALZHEIMER'S DISEASE

Alzheimer's disease is a progressive neurodegenerative condition affecting memory, thinking, behaviour, social skills and physical ability. [20] Beginning with MCI, symptoms can progress and worsen over time from pre-clinical disease, through to severe Alzheimer's dementia (Figure 1). [20] It is estimated that around 93 per cent of people living with MCI due to Alzheimer's disease will progress to dementia. [21, 22] Typically, people are diagnosed at later stages when it is more noticeable that their function and memory has declined, often presenting as dementia.

Figure 1 - Disease pathway and symptoms for each stage of Alzheimer's disease

Birth

Genetic predisposition
Individuals may inherit genetic risk factors, such as APOE 4 allele

Middle-age

Evidence of plaques and tangles
Amyloid-beta plaques and tau tangles can begin to accumulate on the brain ~20 years before onset of symptoms

Progression of **Alzheimer's disease**

Later-life

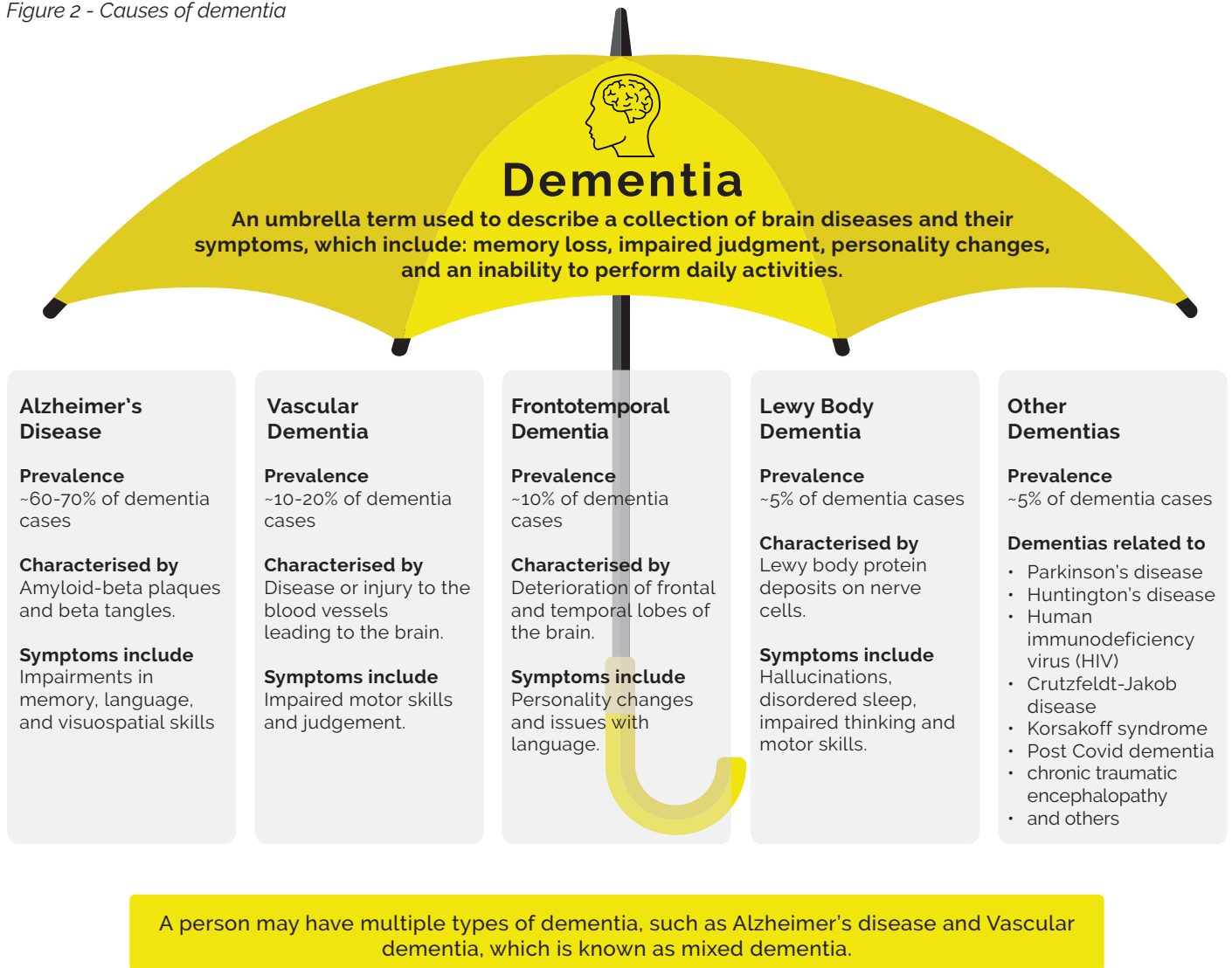| Mild cognitive impairment	Mild Alzheimer's dementia	Moderate Alzheimer's dementia	Severe cognitive impairment
Duration: 7 years	**Duration:** 2 years	**Duration:** 2 years	**Duration:** 3 years
Pathology: Disease begins in Medial Temporal Lobe	**Pathology:** Disease spreads to Temporal and Parietal Lobes	**Pathology:** Disease spreads to Frontal Lobe	**Pathology:** Disease spreads to Occipital Lobe
Symptoms: Mild symptoms that do not hinder day-to-day activities, including cognitive changes, such as short-term memory loss	**Symptoms:** Interferes with some day-to-day activities, including reading problems, poor object recognition, memory loss, word finding issues and poor sense of direction	**Symptoms:** Interferes with many day-to-day activities, including those of mild Alzheimer's dementia in addition to poor judgement, impulsivity, short attention, mood changes, sleep changes and incontinence	**Symptoms:** Interferes with most day-to-day activities, including the symptoms of mild and moderate stages and losing the ability to respond to their environment, carry a conversation, control movement and visual problems

Source: Evohealth adapted from multiple sources [17, 20, 22, 23]

Firstly, it is important to understand Alzheimer's disease and dementia are distinct terms. Dementia is not a disease itself nor is it caused by a single disease. Instead, dementia is a general term used to describe a variety of symptoms that affect a person's ability to think, remember and communicate, which interferes with their activities of daily living, such as memory and word-finding. These symptoms can be caused by different underlying conditions (Figure 2).

Figure 2 - Causes of dementia

Dementia

An umbrella term used to describe a collection of brain diseases and their symptoms, which include: memory loss, impaired judgment, personality changes, and an inability to perform daily activities.

Alzheimer's Disease

Prevalence
~60-70% of dementia cases

Characterised by
Amyloid-beta plaques and beta tangles.

Symptoms include
Impairments in memory, language, and visuospatial skills

Vascular Dementia

Prevalence
~10-20% of dementia cases

Characterised by
Disease or injury to the blood vessels leading to the brain.

Symptoms include
Impaired motor skills and judgement.

Frontotemporal Dementia

Prevalence
~10% of dementia cases

Characterised by
Deterioration of frontal and temporal lobes of the brain.

Symptoms include
Personality changes and issues with language.

Lewy Body Dementia

Prevalence
~5% of dementia cases

Characterised by
Lewy body protein deposits on nerve cells.

Symptoms include
Hallucinations, disordered sleep, impaired thinking and motor skills.

Other Dementias

Prevalence
~5% of dementia cases

Dementias related to
- Parkinson's disease
- Huntington's disease
- Human immunodeficiency virus (HIV)
- Crutzfeldt-Jakob disease
- Korsakoff syndrome
- Post Covid dementia
- chronic traumatic encephalopathy
- and others

A person may have multiple types of dementia, such as Alzheimer's disease and Vascular dementia, which is known as mixed dementia.

Source: Adapted by Evohealth from Summerfield of Redlands Blog [24]

Alzheimer's disease is the single most common cause of dementia, accounting for at least two-thirds of cases in people aged 65 and older. [15, 20] Alzheimer's disease is characterised by gradual build up of neuropathological features, including amyloid-beta plaques and tau tangles, which are not present at birth and develop over time. [20] These plaques and tangles are thought to arise from a combination of genetic and environmental factors, with certain hereditary mutations increasing the risk of formation. [20] Amyloid-beta oligomers are the most neurotoxic aggregates and play a critical role in the occurrence and development of Alzheimer's disease, causing functional neuron death, cognitive damage, and dementia. [25] This neuronal damage manifests as the hallmark symptoms of dementia, including memory loss, confusion, difficulty with language, and changes in mood and behaviour. [20]

The dilemma of diagnosis

It can be difficult to distinguish between different dementia types from symptoms alone, complicated further by around 1 in 5 people presenting with a combination of both Vascular and Alzheimer's dementia. [26] Additionally, evidence has shown that people living with Alzheimer's disease also have alpha-synuclein in their brains at autopsy, a protein typically associated with Parkinson's disease and Lewy body dementia. [27] This highlights the growing recognition of mixed pathologies, making accurate diagnosis even more challenging.

Alzheimer's disease can be confirmed through clinical assessment with cognitive testing, followed by neuroimaging, such as Magnetic Resonance Imaging (MRI) to measure brain volume changes or specialised Positron Emission Tomography (PET) scans to detect characteristic brain changes, like amyloid-beta plaques and tau tangles. Additionally, cerebrospinal fluid (CSF) tests can identify biomarkers associated with the disease, such as amyloid-beta and tau proteins. [28, 29] While these investigations are costly and invasive with limited accessibility, Alzheimer's disease is currently more identifiable than other types of dementia, such as Lewy body, which can only be definitively diagnosed post-mortem. [30]

Recently, specific blood biomarkers that reliably detect disease have been identified, providing a simple, non-invasive, cost-effective, and scalable alternative to current diagnostic methods. [29, 31, 32] These tests will enable early, effective intervention, monitoring and more targeted treatment, significantly improving patient outcomes.

First Nations People face additional diagnostic challenges

Identifying Alzheimer's disease for Aboriginal and Torres Strait Islander people can be challenging because of limited community awareness, denial and stigma, and a lack of culturally appropriate services. Often developing Alzheimer's disease symptoms earlier in life, this can create diagnostic challenges. [33]

Additionally, there is a mistrust of mainstream services, fear of being moved off Country, and competing health priorities within communities, all of which contribute to delayed diagnosis and underdiagnosis. [33] Further action is also needed to tackle the inequities faced by Aboriginal and Torres Strait Islander people in risk factor management, as well as post diagnostic supports. By working with First Nations communities, we can help reduce the disparities in dementia outcomes.
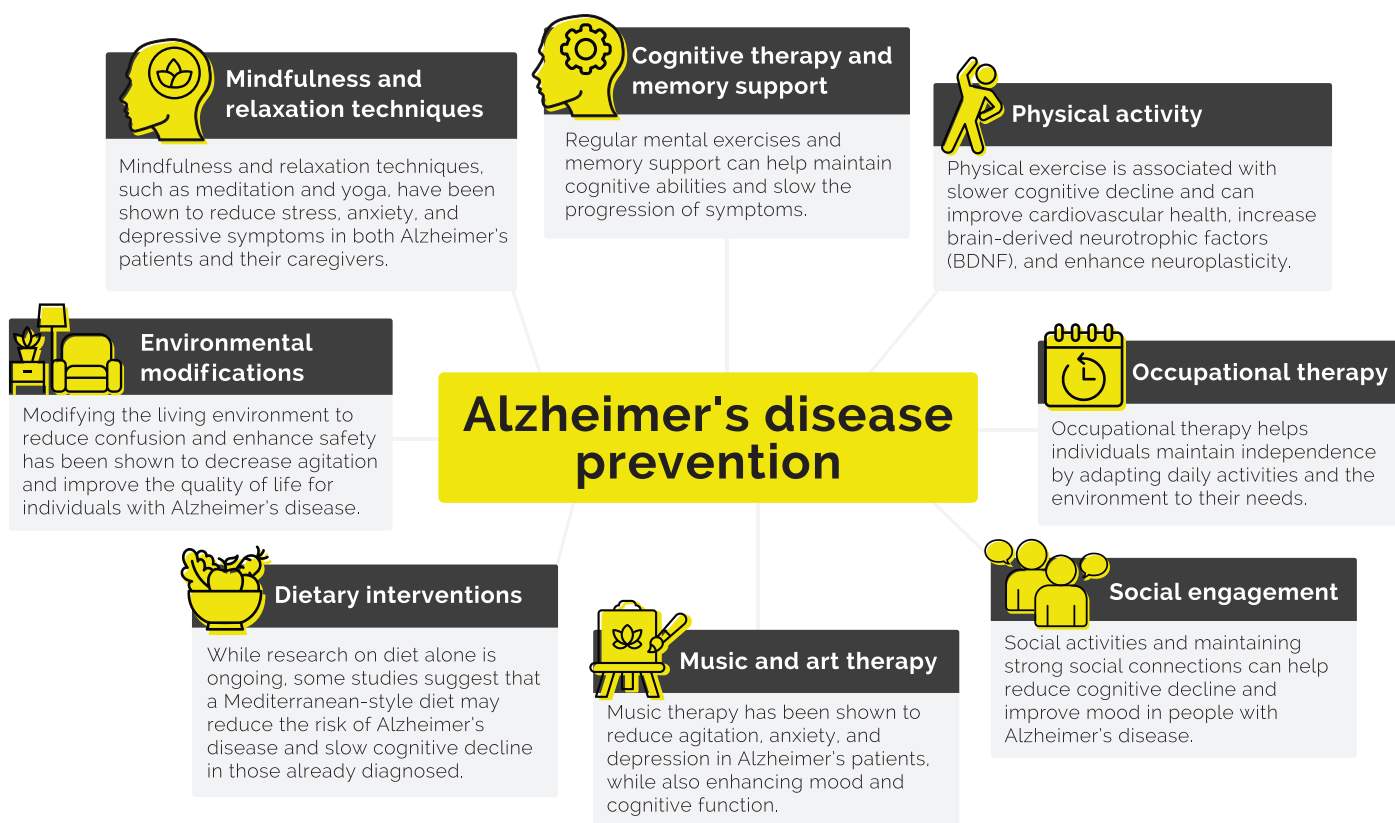
The treatment gap

There is no cure for Alzheimer's disease. Current subsidised treatment options in Australia are limited. While some medications temporarily alleviate symptoms, effects are modest and do not stop the underlying pathology of disease. [34] These treatments offer short-term improvement for cognitive symptoms like memory loss and confusion. [34] Limited treatment options, combined with fear and stigma, results in little to no incentive to intervene early in the disease trajectory. [34]

Beyond medications, non-pharmacological adjunctive approaches such as cognitive therapy, memory support, lifestyle changes, and support for carers, can offer some improvement in quality of life (Figure 3). In certain cases, non-pharmacological interventions such as exercise interventions may help slow cognitive decline. [35] It's important to note that these approaches do not impact underlying disease processes unless integrated into a broader strategy that also reduces modifiable risk factors. [35] Access to non-pharmacological approaches, such as cognitive therapy and memory support services, is currently limited. This is often due to a lack of specialised workforce, insufficient investment beyond diagnosis, or because they are primarily offered in the private sector, making them cost prohibitive. [35]

Figure 3 – Non-pharmacological support options for people with Alzheimer's disease

Mindfulness and relaxation techniques
Mindfulness and relaxation techniques, such as meditation and yoga, have been shown to reduce stress, anxiety, and depressive symptoms in both Alzheimer's patients and their caregivers.

Cognitive therapy and memory support
Regular mental exercises and memory support can help maintain cognitive abilities and slow the progression of symptoms.

Physical activity
Physical exercise is associated with slower cognitive decline and can improve cardiovascular health, increase brain-derived neurotrophic factors (BDNF), and enhance neuroplasticity.

Environmental modifications
Modifying the living environment to reduce confusion and enhance safety has been shown to decrease agitation and improve the quality of life for individuals with Alzheimer's disease.

Alzheimer's disease prevention

Occupational therapy
Occupational therapy helps individuals maintain independence by adapting daily activities and the environment to their needs.

Dietary interventions
While research on diet alone is ongoing, some studies suggest that a Mediterranean-style diet may reduce the risk of Alzheimer's disease and slow cognitive decline in those already diagnosed.

Music and art therapy
Music therapy has been shown to reduce agitation, anxiety, and depression in Alzheimer's patients, while also enhancing mood and cognitive function.

Social engagement
Social activities and maintaining strong social connections can help reduce cognitive decline and improve mood in people with Alzheimer's disease.

Source: A mixed methods systematic review of multimodal non-pharmacological interventions to improve cognition for people with dementia [35]

Hope on the horizon

For the first time, hope is on the horizon. Disease modifying agents with the potential to alter the course of Alzheimer's disease by targeting the underlying mechanism of disease, such as the accumulation of amyloid-beta plaques and tau tangles, are in sight. This offers the possibility of not just managing symptoms, but slowing disease progression and improving quality of life for people living with Alzheimer's disease and their carers. [36] As these treatments move from bench to bedside, there is growing optimism they will revolutionise treatment, providing renewed hope for people living with dementia and families facing this condition.

> *"We know that now is the time. Like cancer treatments just a few decades ago, these [disease modifying agents] are not perfect, we have to start somewhere. This is our start; these are first in class agents that offer hope."*
>
> **- Professor Michael Woodward AM**

The hope for **disease modifying therapies**

New disease modifying agents that can delay progression of Alzheimer's disease aim to alter the course of the disease rather than just manage symptoms, transforming Alzheimer's care. Many of these therapies target amyloid-beta plaques and tau tangles—proteins that accumulate abnormally in the brains of those living with Alzheimer's disease. These treatments work by either preventing formation of proteins, clearing them from the brain, or inhibiting their toxic effects on neurons.

Over 100 clinical trials are underway globally, with many focusing on monoclonal antibodies that target amyloid-beta, including lecanemab and donanemab[2]. [10] This class of therapies has demonstrated efficacy in removing and reducing plaques, as viewed and measured on specialised PET scans. [11] Whilst removal of plaques does not necessarily directly correlate with clinical benefit, there is hope, with some studies demonstrating around a 30-35 per cent delay in decline in more severe phases of the disease, and improvement in ability to perform activities of daily living when compared to placebo. [37]

> "*When it rolls out in real-world practice we'll see the full extent of it [disease modifying agents]. At this point, it is a game changer and we're all very excited about it.*"
>
> **- Professor Colin Masters** [38]

Treatment administration is via intravenous infusion given over one hour or less, either monthly or fortnightly. [11] Care models will need to be developed, including improving accessibility to appropriate treatment centres for people with cognitive impairment.

People living with Alzheimer's disease will also need to be monitored for response and adverse effects. Among the more severe of these adverse effects are amyloid-related imaging abnormalities (ARIA), including intracerebral oedema/effusion and haemorrhages. [11] Some people are at higher risk of ARIA or even contraindicated for therapy. This presents a particular challenge in an older population that often has multiple comorbidities. [11]

Of those being investigated, aducanumab received accelerated regulatory approval from the Food and Drug Administration (FDA) in the United States (US) in 2021, and lecanemab and donanemab received traditional FDA regulatory approval in 2023 and 2024 respectively. [39-41] Although registered in several countries, these medicines are still awaiting registration in Australia.

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2 Aducanumab (Aduhelm®), which received accelerated approval as a treatment for Alzheimer's disease from the U.S. Food and Drug Administration (FDA) in 2021, will be discontinued by its manufacturer (Biogen) in 2024. [9]

Other therapies include anti-tau treatments, which aim to prevent the formation of tau tangles, and neuroprotective agents safeguarding neurons from the damaging effects of these proteins. [10] While these therapies are still in various stages of investigation, early data is promising.

The pathway to patient access in Australia includes registration with the Therapeutic Goods Administration (TGA) and Health Technology Assessment (HTA) via the Pharmaceutical Benefits Advisory Committee (PBAC). This framework stands ready to consider these treatments to ensure they are safe, clinically and cost-effective, in order to realise the hope of many Australians affected by Alzheimer's disease.

ALZHEIMER'S DISEASE IN AN **AGEING AUSTRALIA**

Alzheimer's dementia touches around 300,00 Australians and their carers. The opportunity exists to improve their quality of life and provide a better future. We can also reduce the strain on health and aged care systems, as well as the broader economy, by investing in the right support, innovative care models and empowering individuals and their families.

The time is now. Our economic modelling reveals that in our ageing society, by 2050 the number of people with Alzheimer's disease will double, along with the number of carers (Figure 4 & Figure 5). [3]

Figure 4 – Projected growth in Alzheimer's disease cases (2024–2050)   *Source: Evohealth modelling [3]*
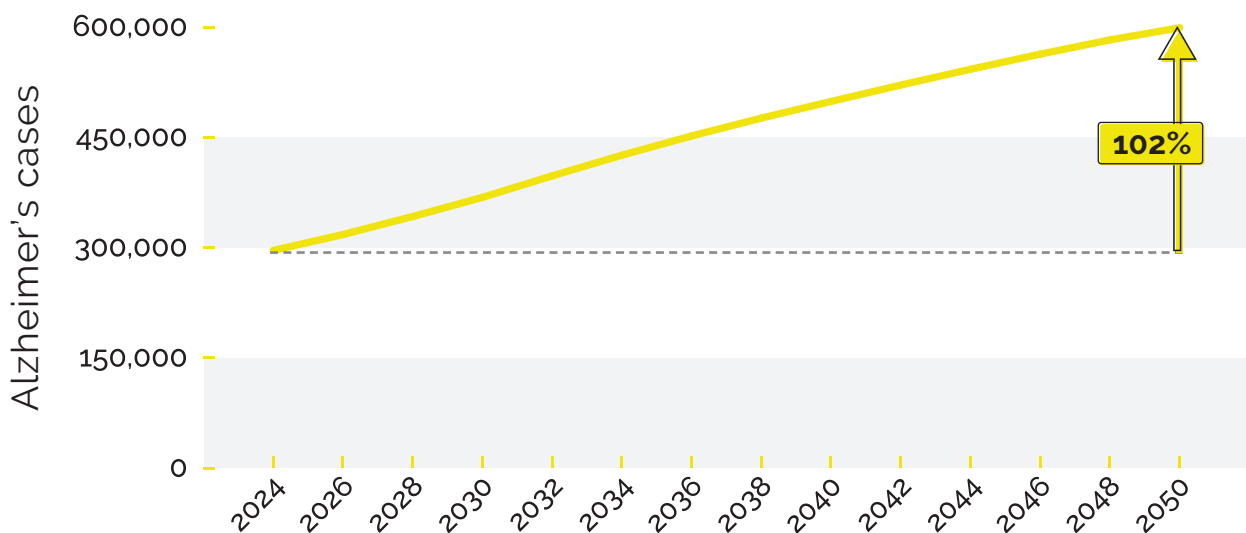
Figure 5 – Projected growth in formal carer FTE (2024–2050)   *Source: Evohealth modelling [3]*
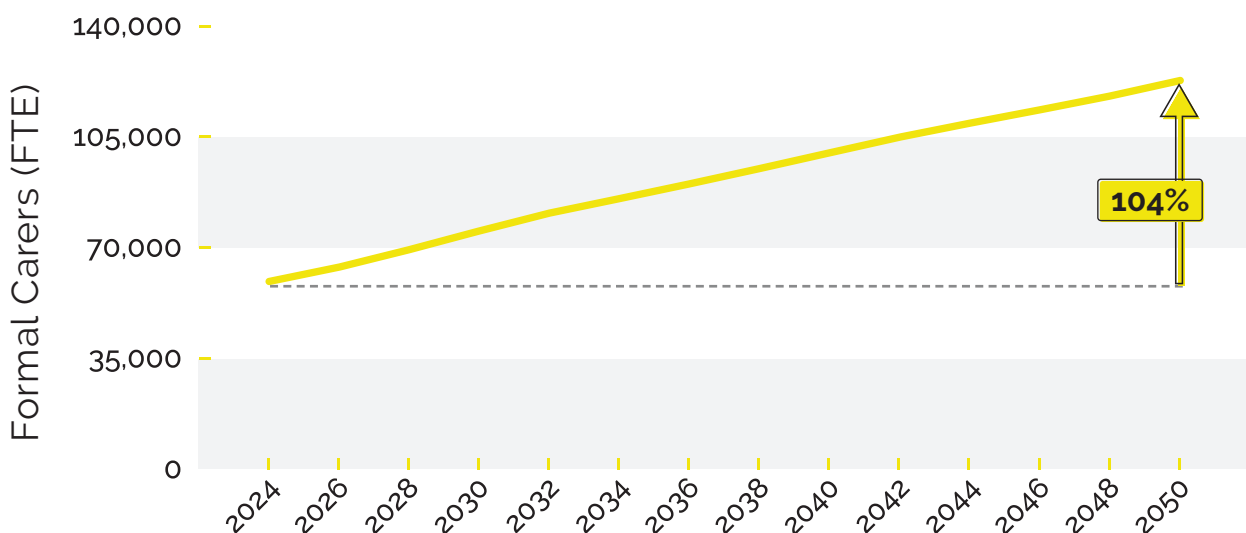
Caring conundrums

Informal carers are people who provide care to those who need it within the context of an existing relationship, such as a family member, a friend or a neighbour. 92 per cent of informal care is provided by family members, with half (55 per cent) by spouses, who are often elderly. [42] The gradual loss of independence as the disease progresses, requires constant care and supervision, leading to a heavy emotional and physical toll.

Often referred to as the "invisible second patients," carers play a critical role in managing the daily needs and quality of life of people with Alzheimer's disease. [43] The impact causing significant emotional, physical, and financial burden.

1 in 3
Primary carers reported feeling **worried or depressed.** [12]

1 in 5
Experienced feelings of **anger or resentment.** [12]

1 in 10
Have been **diagnosed with a stress related illness** due to their care responsibilities. [12]

More must be done to support carers.

Supporting their loved one for a median of 60 hours or more per week, these carers face significant challenges, which can lead to social isolation and financial strain from reduced work hours or job loss. [42] Approximately three in four primary carers report experiencing one or more physical or emotional impacts, leading to issues such as burnout, depression, and further financial difficulties. [12] Despite these challenges, many find meaning and fulfillment, highlighting the complex emotional landscape of caregiving. [43]

These challenges are particularly pronounced among informal carers, who account for roughly 45 per cent of all carers in Australia. [42] The demands of the role are beyond normal relational expectations. [44] With a lack of resources, the burden of care falls heavily, and is often considered a natural extension of family responsibilities. [45]

Reducing pressure on our health and aged care systems

It is estimated that by 2050, each year 3.5 million Australians will access aged care services, including residential aged care. [7] Around 40 per cent of these individuals will also have Alzheimer's disease. [8] Most people living with dementia in residential aged care will also have at least two or more chronic conditions, such as hypertension, diabetes, or cardiovascular disease, which complicates management and amplifies the burden. [46]

Providing care for people beyond the initial Alzheimer's disease diagnosis is complex. [47] This impacts our hospitals. The mean length of stay for hospitalisations among people with Alzheimer's disease is more than double, at 19 days, compared to nine days for people without the disease. [48]

Our aged care system plays a primary role supporting people to stay at home, but it is struggling to meet the growing demand. Wait times for home care support packages are expected to rise significantly, from two months in 2023 to an estimated 10–12 months by 2025. [49]

We must reduce the pressure and costs associated with Alzheimer's disease in hospital and aged care, by supporting people to live safely at home for longer, along with innovative care models and community-based resources. It is good for the patient, their carer and our economy.

Reducing barriers for vulnerable populations

Australia is a vast country with a proud history of cultural and linguistic diversity. But people from culturally and linguistically diverse (CALD) backgrounds, as well as those living in regional, rural and remote Australia, with Alzheimer's disease face additional challenges.

In 2021, **7 million people (28%)** in Australia were **born overseas.** [50]

In 2021, **6 million people (23%)** reported **speaking a language other than English** at home. [50]

In 2021, **7 million people (28%)** in Australia lived in **rural or remote areas.** [51]

While the disease itself poses significant challenges, these Australians experience compounded difficulties due to a range of factors that worsen their health outcomes. For CALD communities, barriers such as language difficulties, lower health literacy, and cultural differences, often impede their ability to navigate the healthcare system effectively, resulting in delayed diagnoses, less access to appropriate care, and poorer overall health outcomes compared with the general population. [52] Additionally, families of CALD backgrounds tend to shoulder higher carer burden and are less likely to access formal support services. This is often due to cultural expectations and lack of awareness about available

resources, causing strain on carers and exacerbation of the health decline of people with Alzheimer's disease, as they miss out on timely and necessary interventions. [53]

Similarly, people from regional, rural and remote areas encounter significant obstacles in accessing healthcare services, with fewer specialists, longer wait times, suboptimal access to diagnostic technologies, and the need to travel long distances for care. These factors contribute to delayed diagnosis and reduced access to ongoing support and treatment, leading to worse outcomes for those affected by Alzheimer's disease.[54]

The combination of these factors makes Alzheimer's disease a challenging diagnosis, particularly in priority populations. Addressing these disparities requires targeted efforts to improve access to culturally sensitive care, enhance health literacy, and ensure support systems are robust and inclusive for all communities, particularly those most at risk. [53]

Good for the economy

Economically, Alzheimer's disease imposes substantial direct and indirect costs on both the health system and society at large. Direct costs include expenses related to hospitalisations, residential aged care, medications, and research, while indirect costs encompass the loss of productivity due to caregiving responsibilities and the premature retirement of people with the disease.

In Australia alone, the financial burden associated with Alzheimer's disease is staggering and will continue to escalate with our ageing population.

Dementia **global costs** estimated at **$1.3 trillion US** in 2019. [55, 56]

Evohealth modelling suggests these costs will rise sharply as the population ages (Figure 6). This highlights a critical challenge, demanding urgent attention and resources, as the impact of Alzheimer's disease extends far beyond the individual, affecting the broader economy and society.

| **Total economic costs in Australia** | **$8.1 billion** in 2024 [3] | **$17 billion** by 2050 [3] | **2.9%** year-on-year growth rate [3] |

Diagnosis to dignity: A vision for Alzheimer's disease in Australia
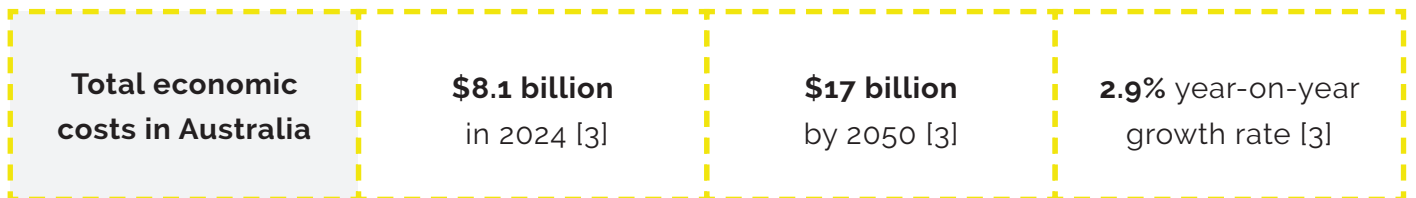
Figure 6 – Projected growth in Alzheimer's disease total costs (AUD 2024, 2024–2050)
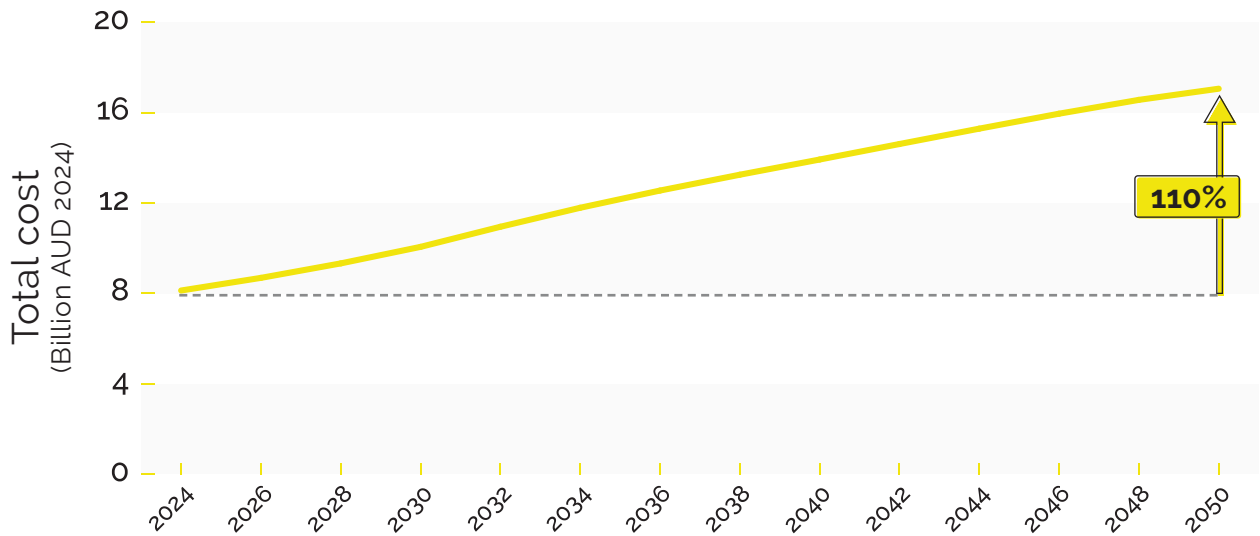
Source: Evohealth modelling [3]

With so much pressure, change is imperative. We need to support population level risk reduction activity, earlier diagnosis, effective treatment, and better care and support mechanisms. This, alongside investment to reduce fear and stigma, is what is required to deliver a future where we manage Alzheimer's disease with empathy, excellence and enhance lives.

The burden of Alzheimer's disease on individuals, carers, our health and aged care systems, and the economy in 2024 is $8.1 billion and growing. [3]

A VISION FOR A **BETTER FUTURE**

Australians with Alzheimer's disease deserve a better future.

With disease modifying agents on the horizon, the time is now. We must transform Australia's understanding, acceptance and patient experience of Alzheimer's disease. We can then confront the challenges with innovative solutions that manage, treat and support people.

> *"This is the first time we have had disease modifying agents, there are still a lot of unknowns but there is some hope."*
>
> **- Professor Henry Brodaty**

We have crafted a holistic vision for this future, with the goal to manage Alzheimer's disease with empathy and excellence, reduce its burden and enhance lives.

A vision for a better future

In the future, Australians living with Alzheimer's disease will enjoy improved quality of life through comprehensive, compassionate, and personalised care and support.

Early detection, effective interventions and post diagnostic support will prioritise their well-being, diversity and dignity.

This care and support will enable people to live safely at home.

People living with Alzheimer's and their carers will be able to stay engaged in meaningful work and societal activities for longer through flexible, supportive community and workplace inclusion strategies.

Society will be educated and accepting, eliminating stigma and providing strong community support for people living with Alzheimer's disease and their carers.

Continuous investment in research, caregiver support, innovative care models, and community-based resources will empower individuals and their families, ensuring they are never alone in their journey.

This future envisions managing Alzheimer's disease with empathy and excellence, reducing its burden and enhancing lives.

Our vision for the future acknowledges that Alzheimer's disease is progressive. But delaying progression can improve lives, increase productivity and reduce strain on an already overwhelmed system. Our economic modelling demonstrates that both quality of life and the broader economy benefit when Alzheimer's disease progression from mild to moderate, as well as entry into an aged care facility, is delayed for just 12 months.

Improving lives

Quality of life matters. Delaying progression enhances quality of life for people living with Alzheimer's dementia and their carers. Our modelling reveals a 25 per cent improvement in quality of life for every year a patient can stay in their own home. It is also good for the economy, with savings of around **$40–$48 million** over four years. [3]
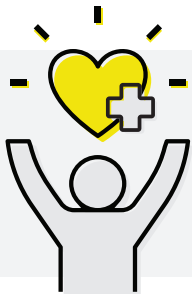
When we **delay the transition** of people with mild Alzheimer's dementia into **residential aged care**, they will experience a **25% improvement in quality of life**, with government savings of **$40–$48 million** over four years. [3]

Slowing disease progression prolongs independence, allowing people to engage in daily activities, maintain social connections, and enjoy a greater sense of control over their lives. This contributes significantly to their emotional and mental well-being, enhancing quality of life and giving a sense of belonging and community. This reduces feelings of isolation, loneliness, and respects the dignity of people with Alzheimer's disease. [57]

For carers, a slower decline in their loved one's cognitive and physical abilities translates into a more manageable care routine, reducing their emotional and physical stress. Studies have shown an 8 per cent quality of life improvement when caring for someone with mild Alzheimer's dementia compared to moderate. [58] Practically, this means that carers can better balance their own lives, including work and family responsibilities.

We can improve the quality of life of the person with a diagnosis, their loved ones and carers if we delay disease progression, tailor support and equip them to live well in their communities.

Fostering productivity and prosperity

With an ageing population, it is critical now more than ever to enable people to continue to work for as long as they desire both for their own well-being but also the broader economy. Our robust economic modelling has revealed that the loss of productivity due to Alzheimer's disease costs our economy a staggering $3.7 billion in 2024. [3] This cost is expected to balloon to $6.9 billion by 2050, with an average year-on-year growth rate of around 2.4 per cent (Figure 7). [3]

Figure 7 – Projected growth in Alzheimer's disease productivity costs (AUD 2024, 2024–2050)
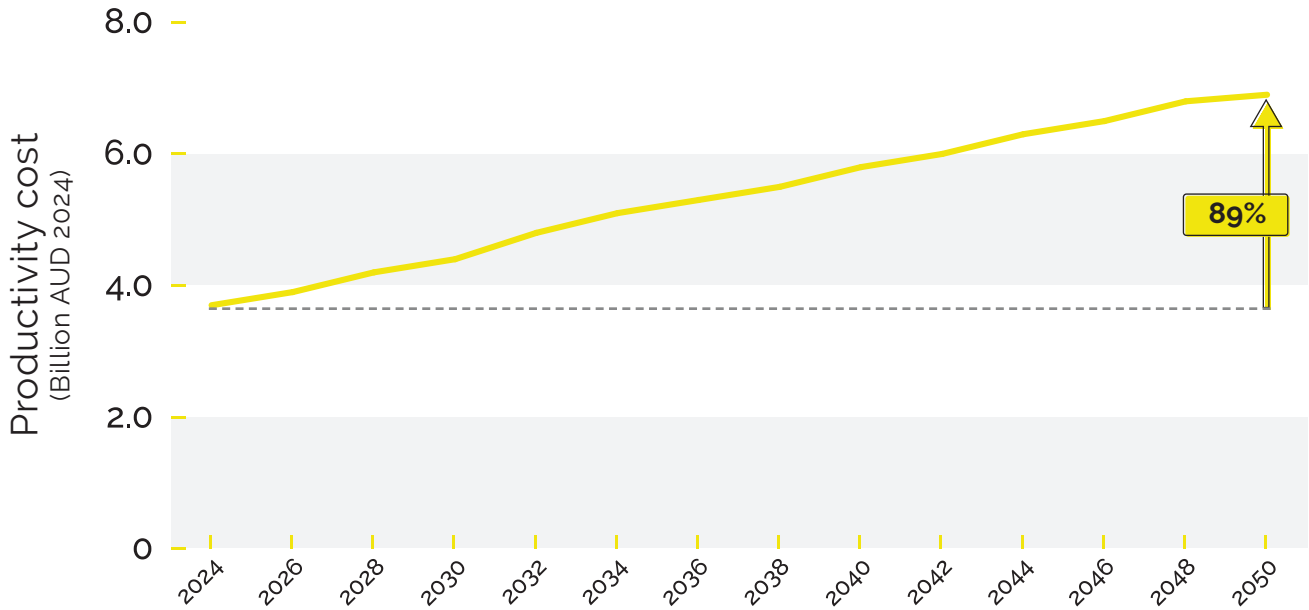
Source: Evohealth modelling [3]

Loss of productivity due to Alzheimer's disease cost Australia **$3.7 billion** in 2024. [3]

We need people to stay in the workforce longer. In our future, this will be possible with early detection, delaying disease and supportive mechanisms.

In 2024, we estimate that, of the 270,000 people over the age of 60 living with Alzheimer's disease who have been removed from the workforce, 50,000 could be supported to remain employed. [3]

This continued employment will provide a sense of purpose and achievement, allowing people to retain social interactions and mental stimulation beneficial for their overall well-being. This also means that carers could continue to work, maintaining a steady stream of economic activity and productivity. Keeping people in the workforce is good for the economy.

Reducing system strain

Our modelling reveals that delaying progression of Alzheimer's disease will reduce the burden on health and aged care systems. Aged care program costs, which include residential aged care facilities, home care packages, respite care, and community support programs, are projected to rise from $3.1 billion in 2024 to $7.48 billion by 2050. [3]

Cost-saving measures could slow this growth and alleviate financial pressures on the system. Similarly, hospitalisation costs that are expected to increase from $466 million in 2024 to $917 million by 2050, could be curtailed by effective management of the disease, reducing the need for acute care. [3]

| Aged care program expenditure in Australia	$3.1 billion in 2024 [3]	$7.48 billion by 2050 [3]	3.5% year-on-year growth rate [3]
Hospitalisation costs in Australia	$466 million in 2024 [3]	$917 million by 2050 [3]	2.7% year-on-year growth rate [3]

To realise our vision and all the opportunities on offer to improve lives, increase productivity and decrease burden on our health and aged care sectors, there are five key elements that need to be realised. These are:

- Enable early detection and diagnosis, and where appropriate, patient access to safe, efficacious therapies, as well as supporting people to mitigate modifiable risk factors to treat and delay progression of Alzheimer's disease.

- Assist and support people with Alzheimer's disease to remain at home for longer.

- Assist and support people with Alzheimer's disease and their carers to remain active in society, including their communities and the workforce, for longer.

- Facilitate societal understanding, recognition and acceptance of people with Alzheimer's disease to support them, and their carers, to remain connected and active in their communities.

- Support research to inform continual innovation that addresses the full spectrum of the complex burden of Alzheimer's disease and other dementias.

By implementing these key elements and embracing innovations in diagnosis, treatment and digital technology, the future paradigm for Alzheimer's disease management in Australia can significantly improve the lives of people affected by the disease, their families, and the broader community. Each of these elements and the specific actions required is presented in detail next.

Australians expect and deserve a better and more hopeful future for Alzheimer's disease, where every aspect of care and support is individually tailored to enhance the experience from diagnosis through to preserving dignity.

Diagnosis to dignity: A vision for Alzheimer's disease in Australia

1. ACCESS TO EARLY DETECTION, SAFE, EFFICACIOUS THERAPIES AND PERSONALISED SUPPORT
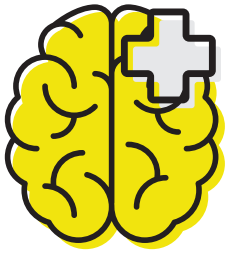
In the future, Australians living with Alzheimer's disease will enjoy improved quality of life through comprehensive, compassionate, and personalised care and support.

Early detection, effective interventions and post diagnostic support will prioritise their well-being, diversity and dignity.

The future of Alzheimer's disease is on the precipice of being redefined. For the first time, disease modifying agents are making their way from bench to bedside. Access to safe and effective therapies give hope, where none has existed before. We also have greater understanding of how to actively support younger people to mitigate their modifiable risk factors.

In the future we will improve treatment outcomes and delay disease progression, allowing people to maintain a higher quality of life, for longer. In turn, societal perception of Alzheimer's disease will shift and it will be recognised as a chronic, manageable condition. People living with Alzheimer's disease and carers will navigate clear diagnostic pathways, gain timely access to disease modifying treatments, and receive comprehensive post diagnosis support, addressing both lifestyle changes and advanced medical therapies.

Earlier intervention can lead to better outcomes. We know pathological changes in the brain occur decades before Alzheimer's disease symptoms appear. Shifting the perception of this disease will support more active conversations and diagnosis. By enabling early diagnosis, intervention and reducing modifiable risks, more people will live in better health for longer, enhancing quality of life.

From underdiagnosed to understood

MCI and Alzheimer's dementia are frequently underdiagnosed, leading to missed opportunities for early intervention, in fact, 92 per cent of MCI cases are undiagnosed. [59] Consequently, many people are unaware until the disease has significantly progressed, often to dementia, limiting their treatment options and impacting quality of life.

There are a multitude of reasons why a diagnosis may be delayed or not occur, including:

- **Lack of awareness** – Many people do not know the signs and symptoms of Alzheimer's disease including MCI and mild Alzheimer's dementia. [1]

- **Mistaken for normal ageing** – People living with dementia, families and clinicians may mistake the signs of MCI and mild Alzheimer's dementia for the normal ageing process. [1]

- **Stigma, denial and fear of diagnosis** - People living with Alzheimer's disease and their families may be hesitant to discuss symptoms with healthcare professionals due to fear of diagnosis and its implications. [1]

- **Lack of effective interventions** – People living with Alzheimer's disease and their care providers may be hesitant to diagnosis a disease for which they perceive they cannot offer a cure, effective treatment or adequate support. [60]

- **Complex diagnosis** - Alzheimer's disease shares symptoms with other forms of dementia and various medical conditions that may be difficult for clinicians without specialist knowledge to recognise. The complexity of distinguishing Alzheimer's disease from other causes of cognitive impairment can lead to diagnostic uncertainty and delays. It also currently involves confirmation via invasive methods such as CSF samples and specialised PET scans. [60]

- **Difficulty accessing care** – Long wait times to access clinicians, particularly specialists, inadequate referral pathways and lack of integrated care models make it difficult to access a clinician with the diagnostic skills to help. [60]

- **Lack of sensitive tools** - While MCI can be detected on neuropsychological testing, access to such services is limited. Mainstream cognitive tools may not detect very early changes in cognition in some people. [61]

Addressing these barriers to create a better future requires a multifaceted approach, including increasing public awareness, enhancing primary care training, improving access to diagnostic tools and specialists, and reducing the stigma associated with Alzheimer's disease.

Shifting perspectives

The lack of understanding of Alzheimer's disease contributes to social isolation and reduced quality of life for people and their carers. We need to remove stigma and ageism and offer earlier interventions to delay progression and improve outcomes. This will encourage people to seek diagnosis. A shift to understanding that Alzheimer's disease is a chronic disease that begins decades before symptoms appear is a critical first step.

Changing clinician views on what constitutes normal cognitive decline is essential, as well as empowering primary care clinicians to recognise signs of MCI as part of a chronic condition, rather than normal ageing. Clinicians would then be equipped to offer advice on brain health and modifiable risk factors earlier in a patient's life, such as assisting them to adopt healthier diets, engage in regular physical activity, manage cardiovascular health, maintain cognitive interventions, reduce alcohol consumption, avoid smoking, and manage stress effectively. [35] By addressing risk factors in younger populations, we can also move towards a more preventive approach, ultimately reducing prevalence and disease burden.

RECOMMENDATION 1

Educate, upskill and support primary care clinicians to identify, diagnose and support individuals and their care/support team throughout the entirety of the disease course.

Providing a path forward

Establishing clear, standardised diagnostic pathways facilitates early diagnosis of MCI and Alzheimer's disease. Emerging advancements such as neuroimaging, biomarker analysis, and genetic testing will play a pivotal role in the early detection, by identifying pathological changes before symptoms manifest. [62] This will allow for earlier intervention, improved patient outcomes, and ultimately reduced burden on the health system.

To maintain independence and quality of life, it is crucial to integrate post diagnostic supports, including access to assistive technologies, cognitive interventions, and community-based services. By embracing both established and emerging tools and supports, we can create a future where early planning and clinical intervention are seamlessly integrated,

offering a more comprehensive support system for people living with dementia and their families.

While current pharmacological options are limited to managing symptoms, promising disease modifying therapies on the horizon offer new hope (see page 22). [63] These therapies, once publicly subsidised, must be seamlessly integrated into care pathways. Equally important are non-pharmacological treatments, such as cognitive rehabilitation, physical exercise, and psychological counselling, which play a vital role in delaying disease progression and supporting individuals. [64] By ensuring nationally consistent care pathways, treatment and support are comprehensive and tailored to the individual's needs, we can improve both quality of care and the lives of people affected by Alzheimer's disease.

RECOMMENDATION 2

Develop a national pathway for people with Alzheimer's disease that includes early diagnosis, intervention and post diagnostic care and support options.

2. ASSIST AND SUPPORT PEOPLE TO STAY AT HOME LONGER

This care and support will enable people to live safely at home.

In the near future, advances in treatment and support will manage Alzheimer's disease more effectively, allowing people to maintain their independence and quality of life for longer. Personalised care and support will enable people with Alzheimer's disease to live in better health, surrounded by familiar faces and places, in their own home.

The future of Alzheimer's disease care will also harness smart technologies for real-time health monitoring and safety, alongside comprehensive, individualised home care support. This approach will integrate cognitive health and memory aids, empowering people to remain independent, active, and engaged. This future prioritises dignity, comfort, and a sense of belonging, ensuring they are not just cared for, but are truly able to live well at home.

Leveraging smart technologies and evolving care models will enhance safety, extend independence for people living with dementia, leading to an overall improvement in quality of life and emotional well-being. It will also reduce the strain on health and aged care systems by minimising the need for institutional care and allowing resources to be allocated more efficiently.

> *"We can provide cognitive interventions to support memory changes in other cognitive functions that occur with Alzheimer's disease. These can be both personalised and holistic, extending to sleep, mood and behaviour to optimise a person's function, support their independence and reduce the need for carer support. However, these are not widely available."*
>
> **- Professor Sharon Naismith**

Home Care Packages (HCP) in Australia provide personalised support for people over 65 with complex care needs, enabling them to live independently at home. HCP's cover a broad range of services, including personal care, nursing, meal preparation, home maintenance, social support, transportation, respite care, and care management. [65] These services are tailored to individual needs, aiming to maintain health, independence and social connections. [66] The overall goal of the HCPs is to allow older Australians to live safely and comfortably in their own homes for as long as possible. However, people living with dementia and their carers report there are limited offerings from service providers in terms of cognitive and memory support. Most offerings focus on reducing physical disability and falls risk. [65]

"I was horrified when they said I needed to go into care within the next 12 months just because I forget to turn the oven or the tap off. I'm busy. I'm not ready for a nursing home. I need help in setting up systems to manage living at home independently and safely. I'm lucky my experience means I know how to conduct my own risk assessments and identify what I need help with, but obviously not everyone with dementia will be able to do that. That's where the packages and supports should come in."

- Ms Bobby Redman
Patient advocate

Wait times for HCPs are expected to rise significantly, from two months in 2023 to an estimated 10–12 months by 2025. [49] Even after securing a support package, many people living with Alzheimer's disease encounter further challenges due to limited understanding of their entitlements and options under the consumer-directed care model. In Australian home care, communication of information is limited, leading to ineffective decision-making. This shortfall is evident in unspent funds, which totalled $600 million in 2019, or an average of $7,000 per client. [66]

Home Care Package unspent funds in Australia	**$600 million** in 2019 [66]	**$7,000** per client in 2019 [66]

Delays in receiving government-funded packages put people at risk of declining and exacerbates the burden on informal care networks.

We know, when people receive appropriate cognitive and memory support earlier, they are more likely to remain in their homes longer, leading to healthier and more fulfilling lives.

"The cognitive side of dementia is often overlooked, and that's where we really need to focus. It's not just about physical care; it's about understanding how to support someone mentally as well. People are not just losing their physical abilities; they're losing their memory, their identity. Cognitive support is essential to help them retain as much of themselves as possible."

- Ms Bobby Redman
Patient advocate

Offering more timely and tailored support can profoundly improve quality of life. But this hinges on promotion and awareness of the support by the people assessing individuals, and service providers who are positioned to offer them.

We will need to:

1. **Offer and integrate more assistive technology** - Offer digital memory aids and communication tools as assistive technologies to support daily living and cognitive function. New technologies, such as smartwatches equipped with health monitoring features, can remove risks associated with living independently by tracking vital signs, monitoring daily activities, and detecting unusual patterns that may indicate health issues or emergencies. For instance, these devices can alert carers if the wearer walks beyond a predetermined safe area or suffers a fall, allowing for immediate intervention. [67] Smart home devices, like motion sensors and smart lighting systems, prevent falls and ensure safety within the home, while voice-activated assistants will help with daily tasks, reducing cognitive load on people living with dementia. [68] These innovations will enhance independence and safety, making it easier for individuals to live at home.

2. **Offer and integrate more cognitive and memory supports** - Incorporate tailored and specialised cognitive therapies and memory support programs into care package offerings. This can include Cognitive Stimulation Therapy, which has been shown to improve memory and cognitive function in people with mild to moderate dementia. [34]

3. **Facilitate faster time to receive packages** - Expedite the process for accessing care packages and interim services to ensure timely and flexible support. Reducing wait times will allow people to receive the care they need sooner, helping them stay in their homes longer and healthier.

RECOMMENDATION 3

Increase access to cognitive rehabilitation, function, and memory support services within Aged Care Service provision, Health Care Packages, and private support offerings to help people with dementia manage their condition and maintain cognitive health.

3. ASSIST PEOPLE TO STAY ACTIVE IN THEIR COMMUNITIES AND THE WORKFORCE LONGER

People living with Alzheimer's disease and their carers will be able to stay engaged in meaningful work and societal activities longer through flexible, supportive community and workplace inclusion strategies.

We stand on the brink of a transformative shift in Alzheimer's disease care, poised to redefine how people and their carers engage with work and their community. In this new era, inclusive strategies will enable people to remain active and involved in meaningful roles, extending far beyond traditional employment, including advocacy, mentoring, and research.

Through flexible workplace accommodations and tailored community support, individuals will be empowered to contribute their unique skills and perspectives, maintaining a strong sense of purpose. This progressive approach will enhance quality of life and foster a more inclusive society that values and integrates diverse contributions.

Our economy and society stand to benefit from retaining people in the workforce longer, with their contributions extending well beyond a dollar value, to encompass valuable advocacy, mentorship, and enrichment, driving a culture of inclusivity and mutual support.

From exclusion to inclusion

Currently, many people with MCI or symptoms of Alzheimer's disease are undiagnosed. They exit the workplace prematurely due to real or perceived cognitive decline, which begins as mild cognitive impairment. Their departure affects their financial stability and the opportunity to contribute to broader community initiatives, such as advocacy, mentoring, or volunteering.

Our modelling reveals that 1 in 5 people over the age of 60 that live with Alzheimer's disease wish to continue to work and could do so with early diagnosis, treatment and appropriate support. This equates to 50,000 Australians in 2024. [3] This loss affects individuals and deprives the economy of experienced and skilled workers.

50,000 people over the age of 60 with **Alzheimer's disease** could continue to work with early diagnosis, treatment and support. [3]

Diagnosis to dignity: A vision for Alzheimer's disease in Australia

Similarly, carers often reduce work hours or leave jobs entirely to provide care and support, causing significant financial and emotional strain. [12] The lack of flexible support and inclusive workplace practices means that carers are also forced to withdraw from social and community engagement, resulting in reduced opportunities for meaningful contribution and personal fulfillment.

1 in 3 primary carers have had to **reduce their work hours** [7]

A person's contribution in the workplace extends beyond economic value, providing a sense of purpose and identity, social connection and sharing of skills and knowledge. Supporting people to remain in the workforce helps maintain their cognitive and emotional well-being, with social engagement, and a sense of purpose, being vital for mental health. [70] This continued participation can also reduce feelings of isolation, creating a more inclusive and supportive community for everyone affected by Alzheimer's disease.

It is crucial for society to ensure that people with Alzheimer's disease and their carers remain active in the workforce and other areas of community life. This inclusive approach values the strengths and experiences of those affected by Alzheimer's disease, allowing them to continue contributing through volunteering, intergenerational support, and community involvement. By fostering inclusive environments, we can empower these individuals to maintain their sense of purpose and identity, enriching both their own lives and the communities they engage with.

PALZ founder Cathy Roth

Cathy Roth was inspired to create the Professionals with Alzheimer's (PALZ) support network when her husband John, a former surgeon, was diagnosed with the disease in 2014. The day of his diagnosis, John was required to resign from practice. Soon after, he attended a respite occupational therapy group, where he was asked to roll a ball down a gutter. Frustrated by the lack of intellectual stimulation, John called Cathy and said, "Get me out of here."

Cathy realised traditional support options were insufficient. As they watched a television program on the visionary physicist Stephen Hawking that evening, Cathy thought, "I have to keep that brain working." This moment sparked the idea for PALZ, a network designed to provide intellectual and social stimulation for professionals with Alzheimer's disease.

Cathy noticed many professionals, once diagnosed with Alzheimer's disease, lost not just their careers but also their social and intellectual peer groups. She identified a gap in the support available to people like John, who needed an environment to replicate the intellectual stimulation they were accustomed to in their professional lives. Reflecting on what aspects of a professional environment needed to be replicated, Cathy pinpointed the boardroom or other similar environment as a critical setting where professionals gather to discuss, challenge, and upskill one another.

This insight led to the creation of PALZ, where each PALZ group discussion is facilitated to ensure communication between attendees and speakers, allowing participants to engage intellectually while carers provide support and connect with one another.

The PALZ initiative quickly spread, with groups forming in Victoria, Queensland, and even the United Kingdom. Each group typically consists of 3 to 13 couples. Feedback from carers has been overwhelmingly positive, as PALZ has enabled both the person with Alzheimer's disease and their carer to engage in activities that were fulfilling for both, something many other programs did not provide.

Cathy's creation of PALZ underscores the need for environments that respect and cater to the strengths of those with dementia. She has understood that while certain parts of the brain might not function as they used to, the whole brain had not stopped working, and environments should be designed to cater to the remaining strengths. PALZ has become a space where this belief was put into practice, empowering people with dementia by supporting them in a way that is both respectful and enriching.

In the workplace and beyond

> *"We could implement evidence-based strategies and develop personalised programs to assist both workplaces and people living with dementia to remain in the workforce if they wish to. This extends beyond finances. For many, being engaged in the workforce or in a role within the community can help a person with their sense of independence, identity, dignity, mental well-being and social connectedness, in turn reducing disability and enhancing quality of life."*

- Professor Sharon Naismith

Just as society has made strides in creating more accessible workplaces for people with physical disabilities and neurodivergent conditions, there is a pressing need to extend similar accommodations to those living with Alzheimer's disease. The transformation of workplaces to accommodate people with disabilities has demonstrated that with the right tools and understanding, barriers can be overcome. Accommodations such as flexible work arrangements, ergonomic adjustments to workstations, and the implementation of assistive technologies like screen readers or speech-to-text software, have all contributed to making workplaces more inclusive. [71] These same principles can be applied to people living with Alzheimer's disease. For instance, fewer work hours, trained helpers, and tailored work shifts have been proven to be effective in keeping employees with dementia safely working. More personalised strategies could also be offered, such as rest breaks, altered roles, and cognitive interventions. [72] By learning from the successes of disability and neurodivergent inclusion, and implementing workplace accommodations tailored to the needs of those with Alzheimer's disease, we can help retain this valuable segment of the workforce.

> *"I supervise several doctors in the Mild Cognitive Impairment stage of Alzheimer's disease, and they continue to provide excellent medical services."*

- Professor Michael Woodward AM

Recognising and leveraging the unique insights and experiences of those with Alzheimer's disease can lead to valuable contributions in research, advocacy, policy development, volunteering and intergenerational growth. Essential to this will be a shift in perceptions of what people can do rather than what they cannot.

A future where we involve people living with Alzheimer's disease and their carers more actively in research and policy discussions is beneficial to all. Their lived experiences provide essential insights that can inform the design of more effective care models and support services, ensuring future interventions are better aligned with the needs of those living with the disease. However, the voices of those with Alzheimer's disease and their carers are often underrepresented, leading to gaps in understanding and potential barriers to the uptake or implementation of interventions. Participatory research approaches, where people living with dementia and carers serve as co-researchers, have been shown to yield more relevant and feasible outcomes. [73]

Diagnosis to dignity: A vision for Alzheimer's disease in Australia

Volunteering offers another powerful avenue for people to remain engaged and contribute meaningfully to their communities. Whether through sharing skills, participating in community events, or mentoring younger generations, volunteering can provide a sense of purpose and help maintain social connections. Volunteering can significantly improve mental health and reduce the risk of depression, particularly in older adults. [74] This involvement benefits the individual and enriches the community by fostering a culture of inclusivity and mutual support.

In 2020, **1 in 4** Australians **aged 15 and over** participated in **unpaid voluntary work** through an organisation or group. [69]

Additionally, creating and promoting intergenerational programs can help bridge the gap between younger and older generations, fostering empathy and mutual understanding. These programs enhance cognitive functioning in older adults and improve social and emotional skills in younger participants. [75] By encouraging these initiatives, we can strengthen community bonds and improve the well-being of all involved.

Embracing a more inclusive society and valuing contributions beyond those in the workplace will lead to a society where individuals with Alzheimer's disease, and their carers, are seen as valuable contributors across society, not just within the workplace. We can help people maintain their sense of purpose and identity, while also enriching the lives of those around them. Implementing these strategies will require coordinated efforts from community organisations, policymakers, and healthcare providers, but the benefits to society will be profound.

RECOMMENDATION 4

Develop and implement national guidance to enable inclusive communities and workplaces for people with Alzheimer's disease.

Diagnosis to dignity: *A vision for Alzheimer's disease in Australia*

4. FACILITATE SOCIETAL UNDERSTANDING AND ACCEPTANCE
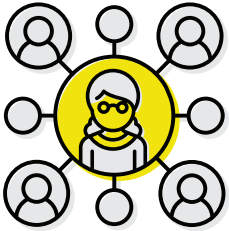
Society will be educated and accepting, eliminating stigma and providing strong community support for people living with Alzheimer's disease and their carers.

Moving forward, our society will understand, recognise, and accept people with Alzheimer's disease, allowing them to remain active participants in their communities. The stigma and misconceptions currently surrounding Alzheimer's disease will be replaced by empathy, awareness, support, and care.

From stigma to support

There is persistent fear, bias, and stigma surrounding Alzheimer's disease. This begins with outdated perceptions viewing it as a disease of old age, associated with fear of severe cognitive decline and loss of independence. As a result, many people with Alzheimer's disease and their carers experience social isolation, limiting the acceptance and support they receive from their communities. In fact, 91 per cent of people that have a loved one living with dementia report their friends cease contact as the disease progresses, and 87 per cent of people with dementia feel patronised and treated as if they are not smart. [14]

91% of people that have a loved one living with dementia report **their friends cease contact** as the disease progresses. [14]

87% of people with dementia feel **patronised** and treated as if they are **not smart.** [14]

Adding to this challenge, nearly 1 in 3 people identify Alzheimer's disease as their greatest health concern (Figure 8). [76] This stigma can deter people from seeking early diagnosis and intervention, further exacerbating the challenges faced by those living with the disease.

> " *I wish people would learn to understand me, not blame me.* "

- Person living with dementia in response to Dementia Australia's Dismantling dementia discrimination report [14]

This limited awareness leads to inadequate acceptance and support, causing social networks to shrink as friends, family, and carers withdraw out of discomfort or misunderstanding. As the disease progresses, people with dementia experience a significant reduction in their social networks, contributing to feelings of isolation and deteriorating emotional well-being. [14]

Diagnosis to dignity: A vision for Alzheimer's disease in Australia

Figure 8 – Per cent of health service consumers that stated dementia is their greatest health concern

Greatest health concern

Dementia
29%

Other
71%
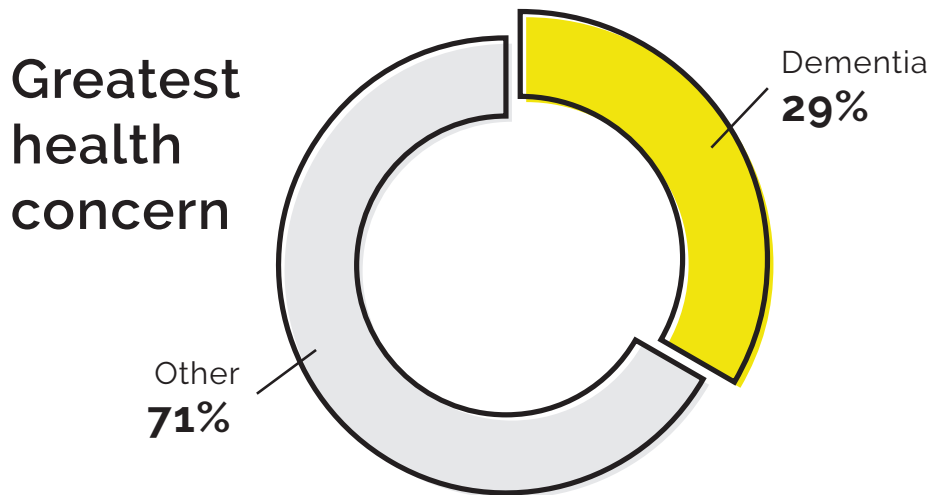
Source: Dementia is the second most feared condition among Australian health service consumers: results of a cross-sectional survey [76]

> *"I have not only lost my husband, but I have also lost many of my friends because they cannot deal with it. I find it hard to explain to people what's happening, and they find it hard to understand. So, they do not visit me anymore."*
>
> **- Ms Bobby Redman**
> *Patient advocate (sharing a friend's experience with dementia)*

The shift in understanding must be inclusive of all communities, including CALD groups and Aboriginal and Torres Strait Islander people, who may face additional barriers due to cultural stigmas and language differences. Ensuring educational initiatives and support systems are accessible and culturally sensitive will help foster a more inclusive environment where all people affected by Alzheimer's disease can feel understood, respected, and supported. By embracing a more informed and compassionate perspective, we can help break down the stigma associated with Alzheimer's disease and build a society that recognises the strengths and capabilities of all its members.

Widespread education is crucial to promoting understanding and acceptance of Alzheimer's disease as a chronic condition that can begin decades before symptoms emerge. Raising awareness about the early stages of the disease and the importance of early intervention, can help people access the support they need and better prepare loved ones for what lies ahead.

Ensuring all Australians understand the risk factors for dementia will also assist in reducing the incidence of Alzheimer's disease in the future. Reframing the perception of Alzheimer's disease to focus on what people can do will enable people to live fuller lives despite their diagnosis.

RECOMMENDATION 5

Invest in a national education and awareness campaign that re-focusses Alzheimer's disease as a chronic disease that begins decades before symptoms.

From overwhelmed to supported

Carers of people with Alzheimer's disease often bear a significant burden without sufficient resources, training, or social supports, which can lead to carer burnout, reduced quality of care, and a substantial impact on their own health and well-being. [77] Currently, carers face high levels of stress, isolation, and financial strain, often without adequate support.

[77] A study by Dementia Australia found that around 60 per cent of carers felt their caring responsibilities regularly or always negatively impacted their social life, and approximately 35 per cent reported often or always feeling lonely or isolated. [77] This lack of community support exacerbates the carer burden, leading to burnout and decreased quality of life.

> "*Peer support was really important because it showed that we were not alone and that others had gone through it and survived. Having someone to talk to who understands what you're going through makes a huge difference. Community support is essential because it helps you feel connected and less isolated.*"
>
> **- Ms Bobby Redman**
> *Patient advocate*

In the future, we will transform carer isolation into community empowerment, by providing the necessary resources, training, and social supports they need to care effectively while maintaining their own well-being. Education campaigns and training programs will play a crucial role in this transformation, fostering a supportive network that shares the responsibility of care. Evidence suggests public education can reduce misinformation and foster empathy, encouraging greater community involvement in supporting carers. [78]

As society becomes more informed and engaged, carers will receive the support they need to continue their critical role without sacrificing their own well-being. This collective approach will lead to improved outcomes for carers and those who they care for.

RECOMMENDATION 6

Upskill and connect carers to support people with Alzheimer's disease to stay active in the community.

Diagnosis to dignity: A vision for Alzheimer's disease in Australia

5. SUPPORT RESEARCH TO INFORM INNOVATION FOR THE FUTURE
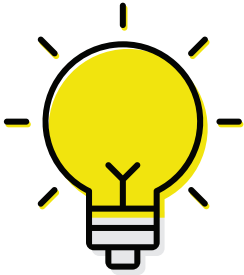
Continuous investment in research, caregiver support, innovative care models, and community-based resources will empower individuals and their families, ensuring they are never alone in their journey.

In the future, we will invest in research that reflects the significant burden of Alzheimer's disease, with the goal of improving the lives of those affected. By prioritising innovation and discovery, and timely translation of research into practice, we can advance early diagnosis, develop more effective treatments, and create personalised care and support. This investment will encompass innovative models of care and community support systems that engage all levels of society, enhancing networks and resources.

From underfunded to future-focused

Alzheimer's disease research is currently underfunded relative to societal impact. Although past grant programs have addressed broader dementia research, Alzheimer's disease, as the leading cause of dementia and the second most common cause of death in Australia, continues to receive insufficient support.

Our analysis of NHMRC funding data from 2016 to 2023 reveals Alzheimer's disease research funding peaked at around 4 per cent in 2017 but has since declined to approximately 2 per cent in 2023 (Figure 9). [79] In stark contrast, cancer research consistently receives a larger share of funding, with an average of 20 per cent over the same period. [79] This significant disparity highlights the need for increased investment in Alzheimer's disease research to ensure that detection, treatment, and support models are adequately developed and translated into practice to address the current and growing disease burden. [79]

Figure 9 - Per cent of total funding provided by NHMRC to Alzheimer's and cancer research
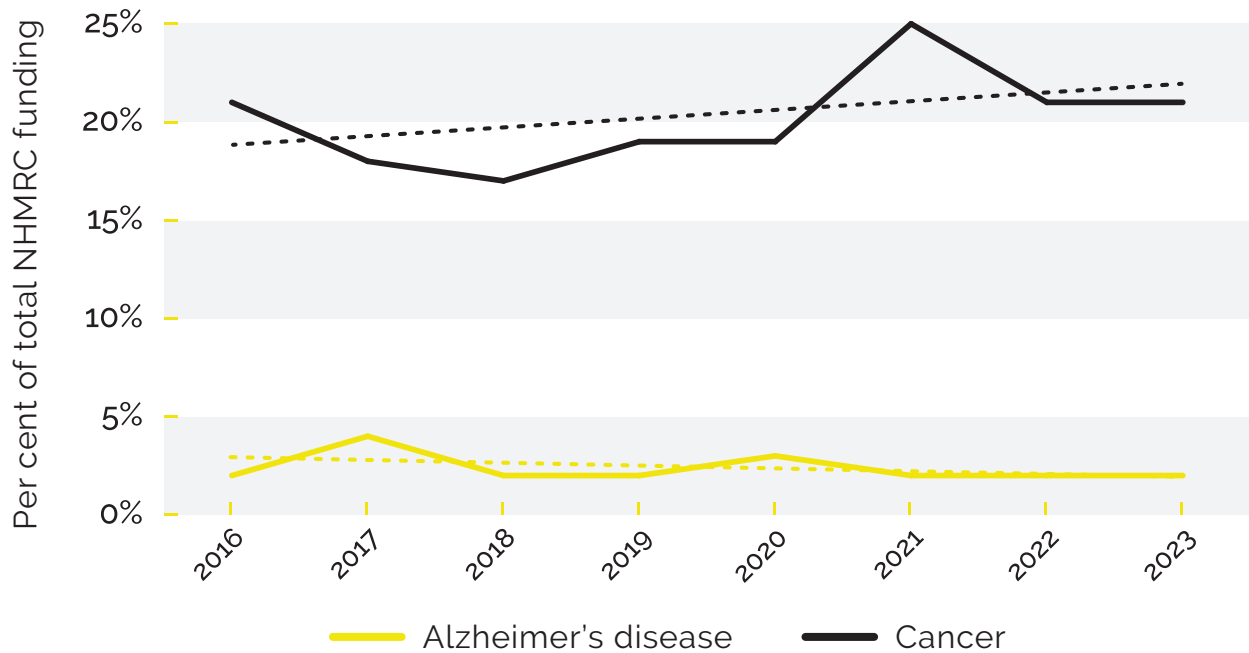
Source: NHMRC Funding Data. [79]

Just as cancer research funding surged with the discovery of life-altering treatments, Alzheimer's disease and dementia research is now at a similar tipping point. With new diagnostic tools and emerging therapies offering the potential to change the disease's trajectory, it is counter-intuitive and ageist to reduce funding at this critical juncture. Increased investment now could lead to breakthroughs that delay progression and improve quality of life, much like the advances seen in cancer care.

Early detection of Alzheimer's disease, akin to early-stage cancer detection, could significantly slow progression, offering individuals a better life and reducing long-term care costs. This approach benefits people living with dementia, their families and the healthcare system at large.

Ongoing research into community resources and supportive technologies for Alzheimer's disease must mirror the progress in cancer care, where integrated support systems are now an essential part of patient management. Developing accessible solutions and assistive technologies will enhance independence, reduce healthcare burden, and improve quality of life for people living with Alzheimer's disease and their families.

RECOMMENDATION 7

Invest in research and development commensurate with Alzheimer's disease burden.

Diagnosis to dignity: A vision for Alzheimer's disease in Australia

RECOMMENDATIONS

Delivering a better future for Australians living with Alzheimer's disease is incumbent upon us all. To support society and policy makers to deliver on this future, we have developed seven recommendations that leverage our world class health system and the Australian spirit and willingness to help those in need.
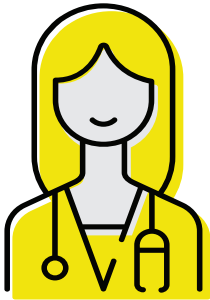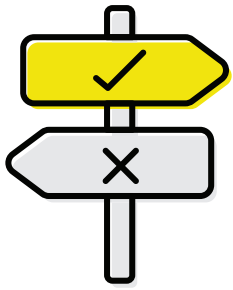
RECOMMENDATION 1

Educate, upskill and support primary care clinicians to identify, diagnose and support individuals and their care/ support team throughout the entirety of the disease course.

Primary care clinicians, including GPs, practice nurses, pharmacists, and allied health professionals, are ideally positioned to identify people with MCI or symptoms of Alzheimer's dementia.

It is crucial for clinicians to receive targeted education on Alzheimer's disease, including case finding, diagnosis, and support. While GPs will bear the primary responsibility for diagnosis, other clinicians also play a key role in providing ongoing care and support. Incorporating dementia-specific training into annual continuing professional development and enhancing its presence in resources such as the Royal Australian College of General Practitioners (RACGP)'s Red Book could improve awareness and case finding. [80]

Australia faces a significant shortfall in healthcare workers, both in numbers and specialisation, a challenge that is expected to worsen in the coming years. This shortage complicates efforts to enhance and specialise the workforce's knowledge in Alzheimer's disease. The ongoing *Unleashing the Potential of our Health Workforce - Scope of Practice Review* aims to address some of the workforce gaps, and resulting recommendations may facilitate the expansion of roles for non-medical health professionals in Alzheimer's disease care. [81] The Government's newly established Medical Workforce Advisory Collaboration (MWAC) is also set to advise on the future direction of Australia's medical workforce and may offer further solutions that enable the recommendations of this report to be realised. [82]
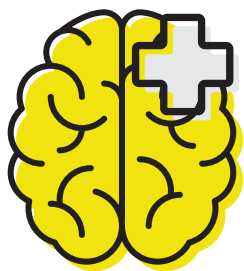
RECOMMENDATION 2

Develop a national pathway for people with Alzheimer's disease that includes early diagnosis, intervention and post diagnostic care and support options.

A national diagnosis and care pathway for Alzheimer's disease is essential to ensure consistent, high-quality care and support is offered and provided across Australia. This pathway would provide people living with Alzheimer's disease with timely diagnosis, tailored treatments, and coordinated support, helping to standardise care, reduce disparities in access, and improve outcomes for both people living with Alzheimer's disease and their families.

In response to the Royal Commission into Aged Care Quality and Safety recommendations, the Federal government has recently commissioned an updated National Dementia Action Plan. [5] This plan will outline the immediate and longer-term actions aimed at improving the experiences of people living with dementia, as well as their carers and families. Additionally, the National Centre for Healthy Ageing

is in the early stages of reviewing and updating the National Dementia Clinical Guidelines. [83] While both these documents offer a strategic framework and best practice for dementia care, a national diagnosis and care pathway specifically for Alzheimer's disease is crucial for translating these guidelines into practical, standardised care across the country, that recognises the distinctions between dementia types.

This pathway will ensure that all people living with dementia receive timely and equitable access to diagnosis, treatment, and support services, bridging the gap between policy and on-the-ground implementation. By providing a clear, consistent roadmap for healthcare providers, the pathway would ensure that every person living with Alzheimer's disease receives the same high-quality care, regardless of where they live.

RECOMMENDATION 3

Increase access to cognitive rehabilitation, function, and memory support services within Aged Care Service provision, Health Care Packages, and private support offerings to help people with dementia manage their condition and maintain cognitive health.

Expanding and increasing awareness of dementia-specific cognitive and memory support services offered within Aged Care Services is crucial. Examples include cognitive stimulation therapies that enhance cognitive function, and memory aids and training programs that assist people in developing strategies to cope with memory loss. Personalised mental health

support, including counselling, managing sleep-wake disruption, mood changes, and substance use, also address the emotional challenges associated with Alzheimer's disease. Offering assistive technology interventions such as tap timers, motion sensors and voice activated assistants are practical solutions to support people to stay at home.

Integrating these supports more widely into existing care frameworks, including local public and community services, would enable people with Alzheimer's disease to maintain greater independence and quality of life. Providing these services through home services, HCPs, or other local services, as well as Aged Care Services, private providers and community services can also help delay the need for more intensive care, ultimately reducing the burden on healthcare systems.

RECOMMENDATION 4

Develop and implement national guidance to enable inclusive communities and workplaces for people with Alzheimer's disease.

Creating inclusive communities and workplaces for people with Alzheimer's disease and cognitive impairment requires national guidance that fosters accessibility, support, and understanding. This guidance should focus on several key areas:

1. **Community inclusivity:** Develop recommendations for making public spaces, transportation, and community services more accessible and accommodating for people with cognitive impairment. This includes designing environments that are safe and easy to navigate and reducing barriers that may impede participation and independence.

2. **Workplace adaptations:** Provide guidance for employers on creating inclusive workplaces for employees with Alzheimer's disease and cognitive impairment. Recommendations should cover flexible work arrangements, job modifications, and support systems that enable people to continue to contribute, and in some instances, access to skilled professionals to provide personalised cognitive screening, assessment, and support programs.

3. **Education and awareness**: Develop and promote education for the general public and employers about Alzheimer's disease and cognitive impairment to reduce stigma, enhance understanding, and promote strategies for effective communication and support. For example, retail workers workplace education programs could be extended to include information on interacting with people who have cognitive impairment, in additional to other disabilities and unique needs.

4. **Support and resources:** Outline the support systems and resources available for people with Alzheimer's disease, including information on accessing services, support networks, and understanding legal rights.

In Australia, established frameworks such as the *Disability Discrimination Act 1992* [84] can serve as a model for promoting the rights and inclusion of people with Alzheimer's disease or cognitive impairment. Dementia Australia also offers support and guidance for creating dementia-friendly communities. [85] With national guidance, leadership and local implementation, we can improve inclusivity, reduce stigma, and ensure that people receive the necessary support to lead fulfilling and engaged lives.

RECOMMENDATION 5

Invest in a national education and awareness campaign that re-focusses Alzheimer's disease as a chronic disease that begins decades before symptoms.

Alzheimer's disease is perceived as a disease of the elderly, associated with fear and a sense of hopelessness beyond diagnosis. Investing in a national education and awareness campaign that re-focuses Alzheimer's disease as a chronic condition beginning decades before symptoms emerge is essential for transforming public perceptions, reducing stigma and enhancing early intervention efforts. Alzheimer's disease is often viewed through the lens of its advanced stages, which leads to a reactive management and support approach rather than a proactive one.

To highlight the importance of early detection and prevention measures, a change in narrative is required that acknowledges the long pre-symptomatic phase of Alzheimer's disease. This campaign would aim to educate the public on the extended timeline of the disease, encouraging healthier lifestyles, regular cognitive assessments and earlier medical intervention.

Dementia Australia has demonstrated positive impact with the "Dementia-Friendly Communities" initiative that works to transform communities into supportive environments by fostering inclusivity and understanding. [85] Similarly, the "Your Brain Matters" program emphasises the importance of brain health and preventative measures, aligning with the campaign's goal to shift focus from a reactive to a proactive approach to Alzheimer's disease management. [86] These serve as successful examples of what could be done.

Greater understanding and awareness can foster a more supportive community environment, where people feel empowered to discuss their concerns and seek help without fear of judgement. This approach enhances public knowledge and drives community support initiatives, such as local support groups and educational programs, which are crucial for creating dementia-friendly environments.

Reframing Alzheimer's disease and highlighting its long-term nature will encourage a more compassionate and supportive approach to those affected by the disease. This can lead to more informed and empathetic communities, improved support networks, and better outcomes for people at risk of, or living with, Alzheimer's disease.
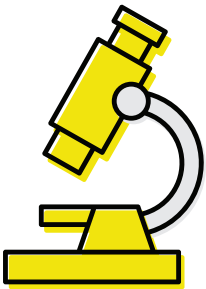
RECOMMENDATION 6

Upskill and connect carers to better support people with Alzheimer's disease to stay active in the community.

Carers need timely access to education, training, and resources to equip them with essential skills and strategies. Many formal training resources exist, such as those available through Dementia Training Australia for formal carers in health and aged care settings. [87] These programs can be tailored and made readily available for informal carers and suggest that this resource is provided for free to reduce barriers to access.

It is also crucial to connect carers with peer support networks and external services to reduce isolation, and access additional help when needed. Programs and resources from organisations like Carer Gateway, Carers Australia information resources or Dementia Australia's Connecting Peers program, address these needs and offer valuable support. [88, 89] However, referral to, promotion of, and continued development and expansion of these resources are necessary to ensure all carers receive comprehensive and ongoing assistance where and when they need it.

RECOMMENDATION 7

Invest in research and development commensurate with the disease burden.

Investing in research and development at a level commensurate with the burden of disease is essential to minimise challenges for individuals, the health and aged care systems, the economy, and society at large. It is crucial to advance medical treatments that delay disease progression and alleviate symptoms, as well as diagnostic tools, innovative care models and community support systems. By generating robust evidence through research and effective mechanisms for translation, we can ensure that investments are directed toward interventions most likely to improve quality of life for people living with Alzheimer's disease, carers, and society as a whole.

Research into community-based support networks, technology-assisted caregiving, and personalised care plans has the potential to significantly enhance lives, with holistic, person-centred care that meets the diverse needs of those living with Alzheimer's disease at every stage.

Moreover, investment is crucial for creating environments where people with Alzheimer's disease can live with dignity and as much independence as possible. Research can drive the development of programs that better integrate people living with dementia into their communities, reduce caregiver burden, and foster greater public awareness and understanding. This includes exploring new ways to train and support carers, improve access to resources, and create dementia-friendly communities that are equipped to meet the needs of an ageing population.

Promising examples of such research are already underway in Australia, including intergenerational programs that explore the benefits of engaging older adults and preschool children in structured, play-based activities. [90] These initiatives are showing potential, but further investment is needed to continue this innovation and sustain momentum in addressing the significant burden of Alzheimer's disease.

Australia must improve the lives of our citizens affected by Alzheimer's disease, their carers, and the broader community. Our recommendations provide actionable steps necessary to foster an inclusive Australian society, reduce stigma and embrace the opportunity that new disease modifying therapies provide. Together, this will ensure better care and quality of life. It is on us to create this new paradigm, one that shifts the narrative from dreaded diagnosis, to dignity.

ABBREVIATIONS

Abbreviation	Description
ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
ARIA	Amyloid-Related Imaging Abnormalities
AUD	Australian Dollar
BDNF	Brain-derived Neurotrophic Factors
CALD	Culturally and linguistically diverse
COI	Cost of Illness
CSF	Cerebrospinal Fluid
EQ-5D	EuroQol 5-Dimension
FDA	Food and Drug Administration
FTE	Full Time Equivalent
GP	General Practitioner
HCP	Home Care Packages
HIV	Human Immunodeficiency Virus
HTA	Health Technology Assessment
MCI	Mild Cognitive Impairment
MRI	Magnetic Resonance Imaging
MWAC	Medical Workforce Advisory Collaboration
NHMRC	National Health and Medical Research Council
PALZ	Professionals with Alzheimer's
PBAC	Pharmaceutical Benefits Advisory Committee
PET	Positron Emission Tomography
QoL	Quality of life
RACGP	Royal Australian College of General Practitioners
TGA	Therapeutic Goods Administration
US	United States

APPENDIX – **METHODOLOGY FOR THE ECONOMIC ANALYSIS**

Cost of illness approach

In this study, a cost of illness (COI) approach was utilised to measure the economic burden of Alzheimer's disease in Australia. This method encompasses both direct and indirect costs associated with the disease. The direct costs include healthcare expenses such as hospital admissions, medical treatments, pharmaceuticals, and residential aged care, while the indirect costs account for lost productivity, lost carer productivity, and other non-healthcare-related expenditures.

All dementia-related cost and prevalence data were sourced from the Australian Institute of Health and Welfare (AIHW). This data was then mapped specifically to Alzheimer's dementia using insights from peer-reviewed literature. The model further split Alzheimer's dementia into three stages: mild, moderate, and severe. The assumptions around proportioning costs into each of these stages were derived from peer-reviewed literature, ensuring that cost estimates accurately reflected varying economic burdens at different disease stages.

It should be noted that Alzheimer's dementia is often underdiagnosed, meaning the actual prevalence and associated costs may be higher than those estimated and presented in this study.

Quality of life modelling

The quality of life (QoL) of people living with Alzheimer's disease was modelled using data derived from peer-reviewed literature. The focus was on individuals at different stages of the disease, classified as mild, moderate, and severe Alzheimer's dementia. QoL was assessed across four key health domains: cognitive impairment, physical ability, emotional well-being, and social engagement.

The EuroQol 5-Dimension EQ-5D score was employed as the primary measure of QoL, with domain-specific scores being derived from validated tools, including the Mini-Mental State Examination, Instrumental Activities of Daily Living, Neuropsychiatric Inventory Questionnaire, and Socioeconomic Status. This approach provided a comprehensive understanding of the impact of Alzheimer's disease on different aspects of a patient's life and enabled the quantification of the broader societal burden of the disease.

Dementia prevalence estimation and projection

To estimate and project the prevalence of dementia in Australia, a standard demographic modelling approach was used. Prevalence rates for people aged 60 and over were derived from the Alzheimer's Disease International 2015 report. This report provided the most up-to-date global estimates of

dementia prevalence at the time of writing, with prevalence rates based on a systematic review of dementia prevalence literature worldwide.

Due to limitations in the Australasia-specific data, prevalence rates were derived by combining data from Australasia, North America, and Western Europe. The North American and Western European rates were based on more recent and numerous studies, making them more reliable. The resulting combined prevalence rates offered a more robust estimate for Australia.

Sex-specific rates for Australasia were not directly available in the Alzheimer's Disease International 2015 report. Therefore, sex-specific rates were calculated by averaging sex rate-ratios from Western Europe and North America and applying these to the Australasian rates. The final age and sex-specific rates for Australia were calculated by averaging the prevalence rates from Australasia, Western Europe, and North America, with equal weighting given to each region.

The dementia projections produced by the Evohealth model, based on these prevalence rates, were then compared against the AIHW model. The results showed the projections were similar, providing additional validation for the model's assumptions and methodology.

Forecasting the Economic Burden

The final step involved integrating the COI and QoL data with the dementia prevalence projections to forecast the economic burden of Alzheimer's disease in Australia. This approach facilitated the identification of future trends and potential policy implications, highlighting areas where interventions could be most effective in mitigating the disease's impact on individuals, carers, and the broader economy.

Data Sources

- Dementia Costs and Prevalence Data: Australian Institute of Health and Welfare (AIHW), mapped to Alzheimer's dementia using peer-reviewed literature.

- Population Forecasts: Australian Bureau of Statistics (ABS)

- NHMRC Grants Data: National Health and Medical Research Council (NHMRC)

- Prevalence Rates: Alzheimer's Disease International 2015 report, combining data from Australasia, North America, and Western Europe.

Limitations

There are several limitations to this study that should be acknowledged. First, mapping general dementia data to Alzheimer's dementia may introduce some inaccuracies, as not all dementia cases align perfectly with Alzheimer's-specific characteristics. This limitation may affect the precision of the cost estimates and prevalence projections.

Furthermore, the underdiagnosis of Alzheimer's dementia implies the actual prevalence and associated costs may be higher than those estimated in this study. Therefore, the findings presented here likely represent a conservative estimate of the true economic burden of Alzheimer's disease in Australia.

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Authors: Renae Beardmore, Deanna Mill, James Taylor

Economic model: James Taylor

Report design: Adam Sorgini

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