

# Designing a new future

Dementia Australia's  
**STRATEGIC DIRECTION 2018-2023**



dementia  
australia™

## Chair's message



Dementia is one of the major global health challenges of our time. As the second leading cause of death in Australia and the leading cause of death among females, the impact for people living with dementia, their families and carers is profound and felt across our community.

Currently more than 436,000 Australians live with dementia and, without a medical breakthrough, this is estimated to increase to more than half a million by 2028 and more than one million by 2058.

It is our duty, as the national peak body for people living with dementia, their families and carers, to use our strength and positioning to make a real and lasting difference to the lives of people impacted by this complex and far-reaching condition.

**Designing a new future 2018-2023** outlines our strategic priorities for the next five years, which focus on the three key issues of greatest need:

- Improving access to timely diagnosis and ongoing support
- Increasing the quality of dementia care
- Reducing discrimination

As we roll out our strategy over the next five years we will continue to collaborate with people living with dementia, their families and carers, and partner with government and other stakeholders, to create significant change – now and into the future.

I invite you to join us to realise our vision for an inclusive future where people impacted by dementia are supported to remain engaged in their communities and receive the care and support they need in the environment that is important to them.

**Professor Graeme Samuel AC**  
Chair Dementia Australia

## CEO's message



When Dementia Australia was formed in 2017, bringing together our state and territory organisations to create the national peak body, we committed to becoming a bigger, stronger and bolder voice for people living with dementia, their families and carers.

To understand how best to achieve this we undertook extensive and rigorous consultation with our community to identify the focus areas that will deliver the greatest benefit for those living with dementia, their families and carers.

**Designing a new future 2018-2023** is the result of that consultation and highlights the issues that our stakeholders identified as areas of greatest need. We are committed to focusing on the priority areas that will achieve the most significant outcomes for all people impacted by dementia.

This is just the beginning. Our aim is to extend our reach so we can support more people impacted by dementia and resolve some of the biggest challenges they have told us they face.

This is a long-term strategy that we will implement over the next five years and therefore continued consultation will be crucial in helping us achieve these goals for the community we serve.

It is an ambitious plan and now is the time to use our combined strength, work with people living with dementia, their families and carers, and all our stakeholders and partners, to transform the experience of people impacted by dementia.

I look forward to the realisation of this strategy and the difference it will make.

**Maree McCabe**  
CEO Dementia Australia

# Dementia Australia

## Who we are

**Dementia Australia is the national peak body for people, of all ages, living with all forms of dementia, their families and carers.**

- We represent more than 436,000 Australians living with dementia and the estimated 1.5 million involved in their care.
- We work with individuals and families, all levels of government, and other key stakeholders to ensure that people of all ages with all types of dementia, as well as their families and carers, are appropriately supported – at work, at home (including residential aged care) or in their local community.
- We are an important advocate for those impacted by dementia and, due to our close engagement with consumers, we provide input on policy matters and identify service gaps.
- We draw on our expertise to collaborate with a wide range of stakeholders including researchers, technology experts and providers.
- We provide support services, education and information aimed at addressing the gaps in mainstream services.

Dementia Australia is a member of Alzheimer's Disease International, the umbrella organisation of dementia associations around the world.

### Our Vision

An inclusive future where all people impacted by dementia receive the care and support they choose.

### Purpose

To transform the experience of people impacted by dementia by elevating their voices and inspiring excellence in support and care free from discrimination.

### Values

- Diversity and Equality
- Respect and Inclusiveness
- Integrity and Accountability



## What we asked

Dementia Australia's strategic planning process aimed to answer two key questions:

**What are the biggest issues for people living with dementia, their families and carers?**

**How can Dementia Australia have the biggest impact?**



“ How wonderful it would be if Australia became the first country to be dementia-friendly as well as an inclusive country. Eileen Taylor, Dementia Advocate, living with dementia

## We listened

**Designing a new future 2018-2023** is the result of a robust and rigorous strategic review with extensive stakeholder consultation. Thank you to the following groups who shared their knowledge and experience, helping us to set our future direction:

- People with dementia, their families and carers
- Dementia Advocates
- Dementia Australia staff
- Ambassadors
- Volunteers
- Partners
- Researchers
- Health care professionals
- Government bodies
- International dementia organisations
- Other NGOs in the sector



“ We know we can't get a cure for all types of dementia but if we don't start we won't get anywhere. It's important to recognise these objectives when considering the size of the job that has to be done.

Trevor Crosby, Dementia Advocate, living with dementia

# The challenge we face

There is a very big and growing challenge ahead of us:

- Dementia is the second leading cause of death of Australians
- Dementia is the leading cause of death among females
- More than 436,000 Australians living with dementia
- Dementia is currently estimated to cost Australia more than \$15 billion a year
- Every 3 seconds someone in the world develops dementia

## Diagnosis and support

- Diagnosis takes on average 3 years
- 83% of people would like to know more about how to reduce their risk of dementia
- 40% did not know that dementia was not a normal part of ageing
- 76% of people with dementia live in the community – 44% live alone
- Marginalised groups find it difficult to gain access to support – 2 in 5 people living with dementia live in regional, rural and remote communities

## Quality of care

- 50% of people in residential aged care facilities have a dementia diagnosis
- There are no standards specific to the care of people living with dementia in aged-care facilities
- Almost 1.5 million people are involved in the care of someone with dementia

## Discrimination

- 63% of people say they know very little about dementia
- 39% feel awkward around someone with dementia
- 41% said they found talking to someone with dementia confronting

# Our priorities

We identified the three areas on which we need to focus. These priorities will help us to transform the experience of people living with dementia, their families and carers. This is a long-term strategy that will achieve real and sustainable benefits over five years.

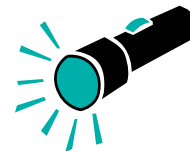
## Timely diagnosis and support



## Quality of care



## Reduce discrimination



# Transforming the dementia landscape in Australia

As the national peak body for people living with dementia, their families and carers, Dementia Australia is committed to using our unique positioning and strength to deliver systemic change and improved outcomes for people living with the condition.

Dementia Australia will tackle the biggest issues facing those living with dementia, their families and carers through the three lenses of service delivery, capacity building and advocacy.

This is the first stage of our five-year strategy for the future. In partnership with government and other stakeholders and, most significantly, in collaboration with those impacted by dementia, we will work together to create a real and lasting difference.

## PRIORITY ONE



### Access to timely diagnosis and support for all people living with dementia

All people living with dementia, their families and carers in Australia, including those living in hard-to-reach locations, have access to early diagnosis and ongoing support.

**Our aim by 2023 is to significantly reduce the time it takes to diagnose dementia and increase the number of people accessing support.**

“ The benefits of an early diagnosis means people can prepare for what might happen eventually.

Dubhglas Taylor, Dementia Advocate, husband and care partner

## PRIORITY TWO



### Quality of dementia care

Quality dementia care is defined, measured and achieved across the dementia experience.

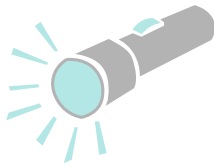
**Within the next five years, in consultation with stakeholders, we will create baseline and best practice standards for quality dementia care. We will advocate for the baseline standards, which will include provisions for training, to be implemented into aged care facilities across Australia.**

“ We aren't just keeping people alive for as long as possible. We are keeping them alive with a greater quality of life for as long as possible.

Isabelle Burke, Dementia Advocate, daughter and care partner



## PRIORITY THREE



### Reduce discrimination

People living with dementia, their families and carers are free from discrimination.

**During the next five years we will tackle discrimination head on so that no-one with dementia feels isolated.**

“ When you encounter a person with dementia remember they are foremost an individual with a unique history, a family and a lifetime of accomplishments.

Jenny Henderson, Dementia Advocate, daughter and former care partner



# Designing a new future

STRATEGIC DIRECTION 2018-2023

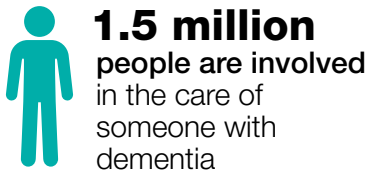
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Every **three seconds** someone in the world develops dementia

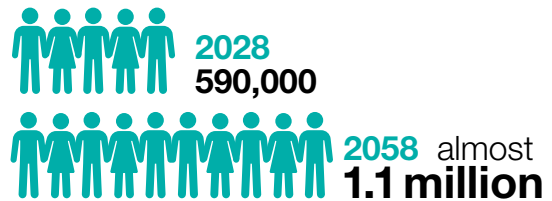
More than **436,000** Australians are living with dementia



**\$15 billion**  
Estimated cost per year



Without a medical breakthrough, the number of people with dementia is estimated to **more than DOUBLE** by 2058



## The big issues for people impacted by dementia



### Timely diagnosis and support

**Diagnosis** takes on average

**3 years**



Consumers tell us **accessing support services early improves their understanding** of dementia, their relationships and planning for the future



### Quality care



**NO dementia-specific care standards** in aged care facilities



**50%** of people in aged care facilities have dementia



### Reduce discrimination



**63%**

of people say they **know very little** about dementia



**41%**

feel **confronted** when talking to someone with dementia

## Dementia Australia aims by 2023...



To significantly reduce the time it takes to diagnose dementia and increase the number of people accessing support.



To create baseline and best practice standards for quality dementia care and advocate for these standards to be implemented into aged care facilities across Australia.



To tackle discrimination head on so that no-one with dementia feels isolated.