



# Annual Report

2021-2022

**Delivering** on a Roadmap  
for **Quality Dementia Care**



**Dementia  
Australia®**



**MEMORY  
WALK  
& JOG**  
GET ACTIVE. BEAT DEMENTIA.

Joanna

**MEMORY  
WALK  
& JOG**  
TRACK  
MARSHAL  
TEAM PINK



We exist to **support** and **empower** the estimated **half a million** Australians **living with dementia** and the almost **1.6 million** people involved in their care.

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Front cover: (L-R) Gwen and Jack Crombie, Dementia Advocates who featured in Dementia Australia's 2021 A Little Support Makes a Big Difference campaign to help combat dementia discrimination. The campaign featured the stories of Dementia Advocates like Jack and Gwen who generously shared their experiences and perspectives. More details on the campaign can be found on page 93 of the report.

Inside cover spread: Gold Coast Memory Walk & Jog 2022 volunteers. Dementia Australia hosted 19 Memory Walk & Jog fundraising events in 2022 with more than 10,500 people participating, helping to raise a combined \$1.6 million.

# About this annual report

This report highlights Dementia Australia's progress and achievements throughout 2021-2022, including links to its financial statements. The Dementia Australia financial statements are listed on the Australian Charities and Not-for-profits Commission website [acnc.gov.au](https://www.acnc.gov.au)

Dementia Australia was established on 18 October 2017 when the federation of Alzheimer's Australia became Dementia Australia. This report and previous years' reports for Dementia Australia and Alzheimer's Australia are available online at [dementia.org.au/annual-reports](https://dementia.org.au/annual-reports)

## Why this report looks different

This report is in line with Dementia Australia's visual identity, which has inclusivity and accessibility at its core. As a result the report may look different to other annual reports as it has larger text and tables and more empty space on pages.

Dementia Australia **acknowledges Traditional Owners of Country** throughout Australia and recognises the continuing **connection** to lands, waters and communities. We pay our **respect** to Aboriginal and Torres Strait Islander cultures; and to Elders past and present.

Dementia Australia is registered as Dementia & Alzheimer's Australia Limited ABN 79 625 582 771 ACN 607 890 317.

# What is dementia?

Dementia describes a **collection of symptoms** caused by disorders affecting the brain. **It is not one specific disease.**

Dementia can affect **thinking, memory and behaviour**. Brain function is affected enough to interfere with someone's normal social or working life.

**No two people** experience dementia in the same way.

It is **essential to get a medical diagnosis** when symptoms first appear.

People often **lead active and fulfilling lives for many years** after their diagnosis.



## Our purpose

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



# About Dementia Australia

Dementia Australia exists to support and empower the estimated half a million Australians living with dementia and the almost 1.6 million people involved in their care. Dementia is the second leading cause of death in Australia and the leading cause of death of women yet remains one of the most challenging and misunderstood conditions.

Founded by carers more than 35 years ago, today we are the national peak body for people living with dementia in Australia. We involve people living with dementia and their experiences in our activities and decision-making, to make sure we are representative of the diverse range of dementia experiences across Australia. We amplify the voices of people impacted by dementia through advocating and sharing stories to help inform and inspire others.

Dementia Australia is the source of trusted information, education and support services. We advocate for positive change for people living with dementia, their families and carers, and support vital research.

Opposite: Dementia Advocate Juanita Hughes featured in Dementia Australia's 2021 A Little Support Makes a Big Difference campaign to help combat dementia discrimination. You can read more about the campaign on page 93.

## Our vision

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

## Our values

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

# People living with dementia



# Estimates 2022

Northern Territory **2,000**

Queensland **94,000**

Western Australia **46,000**

South Australia **40,300**

New South Wales **161,600**

Australian Capital Territory **6,600**

Victoria **124,700**

Tasmania **12,200**

# Key achievements 2021-2022



## Launching new services under the National Dementia Support Program

In 2021-2022, years of successful lobbying and advocacy work culminated in one of the most significant expansions to our services for people living with dementia, their families and carers. Extensive new funding under the Federal Government's National Dementia Support Program allowed us to consult on and introduce a range of new and expanded services. These include expanding the capacity of the National Dementia Helpline to double its call capacity and introducing a new post-diagnosis outreach call service. New and expanded programs and services will come online next year.

For more information on our National Dementia Support Program service expansion see page 26.



## Expanding courses and programs to create change through education

Supporting and skilling professional carers is critical in lifting care standards and improving the quality of life of people living with dementia. This year we diversified and expanded our education programs and services. We adapted our flagship **Dementia Essentials** course for online delivery; expanded the **Communities of Practice** program nationally after a successful pilot; and the Australian Skills Quality Authority approved our new Certificate IV in Dementia Practice.

## Tackling discrimination using real-life stories

Our A Little Support Makes a Big Difference campaign, launched during Dementia Action Week 2021, was one of the ways we tackled dementia discrimination. We used television, social media, radio, newspapers and a dedicated website to share information and real-life stories, reaching tens of millions of everyday Australians to increase their understanding of dementia. At the heart of the campaign were the stories of Dementia Advocates, who generously shared their experiences and perspectives.

## Making a difference through technological innovation

This year we added more innovations to our stable of technology-based tools that help educate and inform professional and family carers and the community about dementia and quality dementia care. We prepared to launch the National Dementia Support Program funded **BrainTrack** app in October 2022, a tool to help people monitor their brain health – promoting early diagnosis; and we expanded the **Ask Annie** app - developed thanks to Gandel Foundation, which delivers “micro lessons” in dementia care for professional carers. As of April 2022 the app includes new modules that make it suitable for residential aged care workers, thanks to funding from the Rosemary Norman Foundation. In a further expansion, in June 2022 we partnered with IOOF Foundation and Insignia Financial to release a new financial elder abuse module.

# Adapting and responding to COVID-19



As Australia moved from shutting out COVID-19 to 'living with' the virus during 2021-22, Dementia Australia continued to adapt and respond to safeguard the wellbeing of our employees and the continuity of programs relied upon by so many people living with dementia, their families and carers. This is a brief overview of how COVID-19 affected our operations during the reporting period and how we responded. More detail can be found in the updates from business units contained in this report.

As with preceding pandemic years, in 2021-22 a significant number of our staff spent most of the year working from home, in accordance with state and territory requirements. Our People and Culture team oversaw our working from home arrangements and also developed and implemented an organisation-wide vaccine policy. Additionally, the People and Culture team helped support safe online and face-to-face volunteering, in line with COVID-19 rules.

We continued to adapt our services to the online environment, to ensure that we were still able to deliver for our clients. Our Client Services team maintained support to clients via online channels and with telephone services; while our Centre for Dementia Learning colleagues continued to adapt education products for online delivery. Our Advocacy and Research team ensured that Dementia Advocates continued to have a voice, arranging focus groups and other opportunities online and via telephone.

We continued our advocacy work, including on the difficult issue of the aged care **Visitor Code**. We lobbied for a solution that balanced COVID-19 safety with dignity, respect and mental well-being.



**Dementia Australia continued to adapt and respond to safeguard the wellbeing of our employees and the continuity of programs relied upon by so many people living with dementia, their families and carers.**

After COVID-19 forced cancellation and disruption of Memory Walk & Jog events in 2020 and 2021, our Fundraising team were delighted to see that our 2022 events were able to go ahead with extensive COVID-19 safety protocols. It was uplifting and inspiring to see so many supporters coming together to assist our work.

Finally, we acknowledge how difficult 2021-22 has been for so many of our community, including people living with dementia, their families and carers, staff, volunteers, clients, those living and working in aged care and people in the health care sector. To all those on the COVID-19 frontline, we express our deep appreciation. To those who lost loved ones to the virus, we send our heartfelt condolences.



# A message from our Chair

**Professor Graeme Samuel AC**  
Chair, Dementia Australia

For myself and my board colleagues, it has been immensely rewarding to see longer-term strategic initiatives come together to deliver benefits to people living with dementia, their families and carers during this reporting period.

The current expansion of Dementia Australia's client services, underpinned by an extraordinary \$229.4 million in dementia funding in the 2021-22 Federal Budget, has its roots in strategic initiatives that go back five or more years.

In 2022, we mark the milestone of five years since the formation of Dementia Australia as one national peak body for dementia. These years have been focused on implementing the **Designing a new future 2018-2023 strategic plan**; and years of consultation, strategising and advocacy.

Observing the transformation that is currently underway in Dementia Australia's service delivery capacity reinforces that the work we do is bringing fundamental and much needed change to the lives of people living with dementia, their families and carers.

During this reporting period a key priority of the board has been overseeing how the organisation navigates the ongoing COVID-19 pandemic, balancing health and safety while delivering vital services and support to people living with dementia.

I am extremely proud of the CEO and executive team and staff who have had to respond to an ever-evolving pandemic environment and make difficult decisions. That we have so successfully continued our delivery of support for people living with dementia, their families and carers is testament to not only today's staff, volunteers and advocates but those who have come before us and laid the foundations of where we are today.



“

**It has been immensely rewarding to see longer-term strategic initiatives come together to deliver benefits to people living with dementia. ”**

Professor Graeme Samuel AC,  
Chair, Dementia Australia

As a board we continue to review and refresh our composition to ensure that our skills mix matches the challenges faced by the organisation and the priorities under our strategic plan. During the reporting period we were excited to welcome three new board members - Kaylie Smith, Dominic Ryan and Wendy Carroll. We also farewelled board member Greg Fraser at the end of June. Greg joined the Alzheimer's Australia ACT board in October 2011 before joining the Alzheimer's Australia national board in November 2013 and continuing to serve until the establishment of the Dementia Australia board. I thank Greg for his extraordinary service, contribution, support and guidance.

In May 2022 we welcomed a new Federal Government, following the federal election. Along with all my colleagues, we will be working with the Albanese Government to continue to advance our important work. I also acknowledge the previous government and its contributions to improving the lives of people impacted by dementia.

Thank you to my board colleagues for supporting our strong governance. To all Dementia Advocates, staff, volunteers, patrons, ambassadors, honorary medical advisors, government, health and aged care colleagues, donors, corporate sponsors and other supporters, I thank you for your contribution to our shared success.



## A message from our CEO

**Maree McCabe AM**  
CEO, Dementia Australia

This year has resulted in an extraordinary level of activity across the organisation as we continue to advocate for and support people living with dementia, their families and carers.

A priority has been the introduction, increase and expansion of our services for clients under the Federal Government's National Dementia Support Program (NDSP).

From upgrading the National Dementia Helpline to a 24/7 service to increasing counselling and peer support programs, this unprecedented growth in services is allowing Dementia Australia to reach and support many more people impacted by dementia (read more on page 26).

It has been a long journey to reach this point. On the back of successful advocacy, including the development of our landmark **Roadmap for Quality Dementia Care** document, the 2021-2022 Federal Budget allocated \$229.4 million in dementia funding. This was the biggest government commitment to dementia funding in more than a decade. A major component of this funding was allocated to Dementia Australia for our services delivered under the NDSP.

My thanks and appreciation to everyone across the organisation who has contributed to rolling out this significant expansion of services. Bringing our **Roadmap for Quality Dementia Care** to life through the expansion of client services is an achievement for everyone at Dementia Australia.

“

**This was the biggest government commitment to dementia funding in more than a decade. ”**

Maree McCabe AM,  
CEO Dementia Australia

As I reflect on the year, there are so many other achievements. Just a few examples are: developing and gaining formal approval for the new Certificate IV in Dementia Practice; advocating for the benefits of allied health services for people living with dementia; and continuing to highlight and tackle dementia discrimination. I acknowledge everyone at Dementia Australia for their contributions, which allow us to make such a difference to the lives of people living with dementia, their families and carers.

COVID-19 continued to impact our operations, with many staff continuing to work remotely for much of the reporting period. It is a testament to the ingenuity and dedication of staff, management and executive that our work continued with minimal disruption.

The combined efforts of the Dementia Australia board, Dementia Advocates, Patrons, Dementia Australia Ambassadors, celebrity supporters, Honorary Medical Advisors, executive, staff, volunteers, governments and our aged and health care colleagues make all of our achievements possible. To all who have once again contributed so much to improving the lives of people living with dementia, their families and carers, my most heartfelt thanks.

# Dementia Australia Advisory Committee report

## **Bobby Redman**

Dementia Advocate  
Chair, Dementia Australia  
Advisory Committee

With Phil Hazell and Eileen Taylor stepping down from their respective positions as Chair and Vice- Chair after four years of inspiring leadership, 2021-2022 has been a year of change for the Dementia Australia Advisory Committee. I am honoured to have been elected as the new Chair to work closely alongside Dennis Frost, who was appointed Vice-Chair. I would like to commend Phil and Eileen on their brilliant leadership from 2017 to 2021. It is daunting to try to fill their shoes.

We welcome Natalie Ive who officially joined the committee in February 2022. Natalie joins Eileen Taylor, Kevyn Morris, Sarah Ashton, Val Schache, Ann Pietsch, Juanita Hughes, Jenni Lawson, Dennis and I. I would like to thank each member who dedicates so much of their time and energy in supporting advocacy and action to improve the lives of people living with dementia. Each member has taken up specific responsibilities, based on their special interests or experience, to help guide the direction of the

committee. They also attend additional sub-committee meetings as required.

Our role is to represent Dementia Australia Advocates right around Australia and to reflect and amplify their voices. We are currently working on a project to develop a series of committee videos that will introduce committee members, explain the role of the committee and share key learnings and knowledge with a wider network.

Sally Lambourne, General Manager, Consumer Engagement, Dementia Australia strongly supports the committee's work. We also offer the greatest appreciation to Elena Sutcliffe, Consumer Engagement Coordinator, Dementia Australia who acts as our secretariat and so much more. We are also joined by Dementia Australia Board Member Tony Newman, who is the Board Liaison Officer for the committee. This position was established to strengthen communication between the board and the committee.



Above: The Dementia Australia Advisory Committee alongside Dementia Australia board, executive and staff members.

Over the year, the committee has provided input and feedback on Dementia Australia’s current service offerings. We have also reviewed a proposal for a Dementia Australia staff recognition program, to highlight and commend programs and staff from around the country best utilising the expertise and input of Dementia Advocates.

In early 2022 the committee met to identify the priorities for the year ahead and beyond. This included a range of topics from reducing discrimination in employment, improving engagement with GPs and nurses and the development of networks and advocacy opportunities.

We held workshops with Kate Harding, Consumer Engagement Coordinator at Dementia Australia to identify priorities for projects that came out of Kate’s research on improving consumer involvement in the decision-making aspects of research.

The committee, led by Vice-Chair Dennis Frost, has had three articles published in the Australian Journal of Dementia Care. This included the creation of a regular column “Ask the experts living with dementia” where the committee answers questions from the community. We also reviewed and updated the popular Let’s Talk brochure. The brochure outlines good communication tips for talking with people living with dementia.



**Our role is to represent Dementia Australia Advocates right around Australia and to reflect and amplify their voices. ”**

In April 2022, the committee was extremely happy to meet face-to-face for the first time since March 2020. Dementia Australia CEO Maree McCabe AM, Board Member and Board Liaison Officer Tony Newman and the Executive Director of Advocacy and Research, Kaele Stokes, joined us. We were able to provide feedback and discuss a whole range of areas including:

- Quality dementia care and consumer engagement since the release of the aged care royal commission final report and recommendations.
- Planning for Dementia Action Week 2022.
- Developing, building and working in **Dementia-Friendly Communities**.

- A review of Dementia Australia's latest projects to empower people living with dementia, their families and carers.
- Development of the committee and an ongoing recruitment strategy.
- Ideas and tips proposed by Dennis Frost to help produce more professional videos and audio recordings for our community advocacy.

To close, the committee would like to acknowledge the vast range of work completed by Dementia Advocates around Australia. We recognise the great amount of time and effort given by so many of you to improve the lives of those living with dementia, their families and carers. Thank you for all you do.

“

**The committee would like to acknowledge the vast range of work completed by Dementia Advocates around Australia ”**

# Finance Audit and Risk Management Committee report

## **Ian Knight, Chair, Finance Audit and Risk Management Committee**

With the continuing impacts of the global pandemic, Dementia Australia has faced a challenging year while still maintaining services and support for those living with dementia, their families and carers. Pandemic-related challenges included significant lockdowns in Sydney and Melbourne, resulting in restricted access to aged care facilities; reduced capacity to provide face to face training; and the impact of staff contracting COVID-19. In addition, the volatility of global financial markets affected our investment portfolio.

Our financial position was adversely impacted as a result. Total comprehensive income was  $-\$9.1$  million (2021-2022) compared to  $\$7.1$  million in the previous year (2020-2021). This included the absorption of a number of special project costs that will enable us to operate more efficiently in the future. Total equity is now at  $\$43.3$ m (2021-2022) compared to  $\$52.3$ m in the previous year. A significant element of the financial result was an unrealised fall of  $\$3.7$ m in the value of investment holdings during the year.

At the end of the year, we had cash holdings of  $\$11.3$  million and investments of  $\$34.8$  million (2021-2022) compared to  $\$27.7$  million and  $\$20.1$  million respectively in the previous year (2020-2021). These funds are being actively managed to support strategic objectives and work to continue supporting people living with dementia, their families and carers.

During the year the risk profile of the investment portfolio was reviewed and adjusted in line with our strategic direction, to best position our investments for growth in these increasingly volatile times.

Work continued on back-office systems to support activities through the impact of the pandemic and position us to respond quickly to the lifting of pandemic-related restrictions affecting service delivery. This included decommissioning former state and territory IT systems, commencing the development of a comprehensive organisation-wide CRM (customer relationship management) system and undertaking a review of cybersecurity protocols.

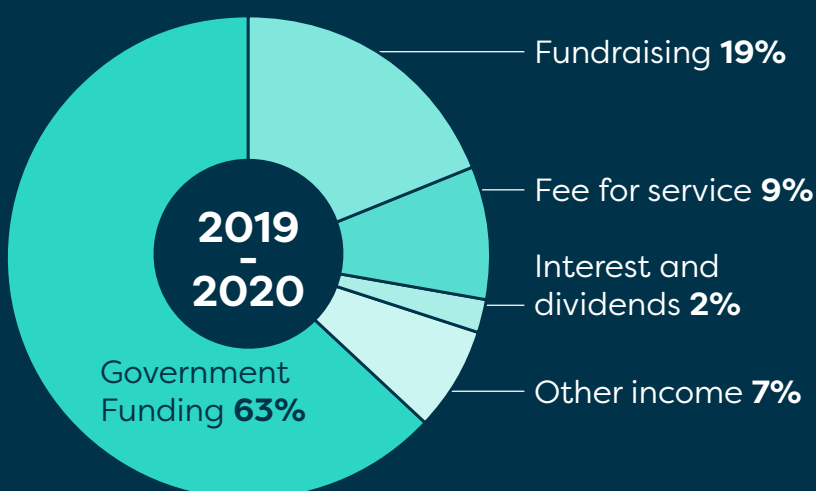
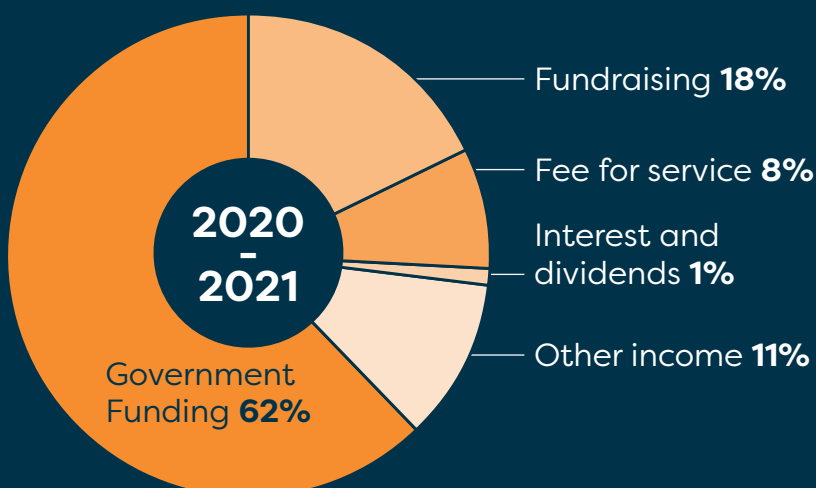
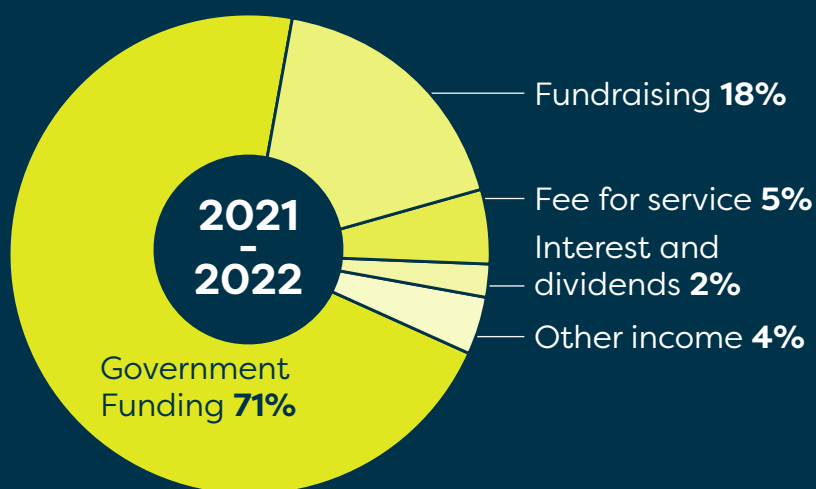
Other investment in systems during the reporting period included introduction of a national quality framework and an enhanced work health and safety process.

Continued upgrading of services remained a strong priority, including major expansion of the National Dementia Helpline to a 24/7 service (from a 12 hour a day weekday-only program). Financial reserves will fund this initiative.

I would like to take this opportunity to thank all staff who have been involved in maintaining the finances of the organisation through what has been yet another challenging year.

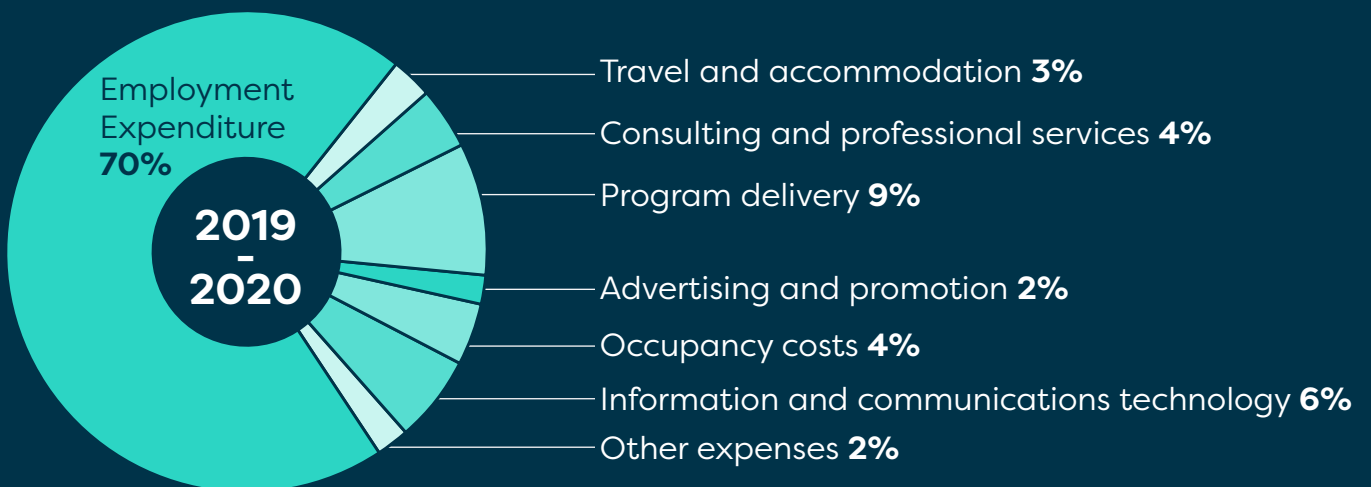
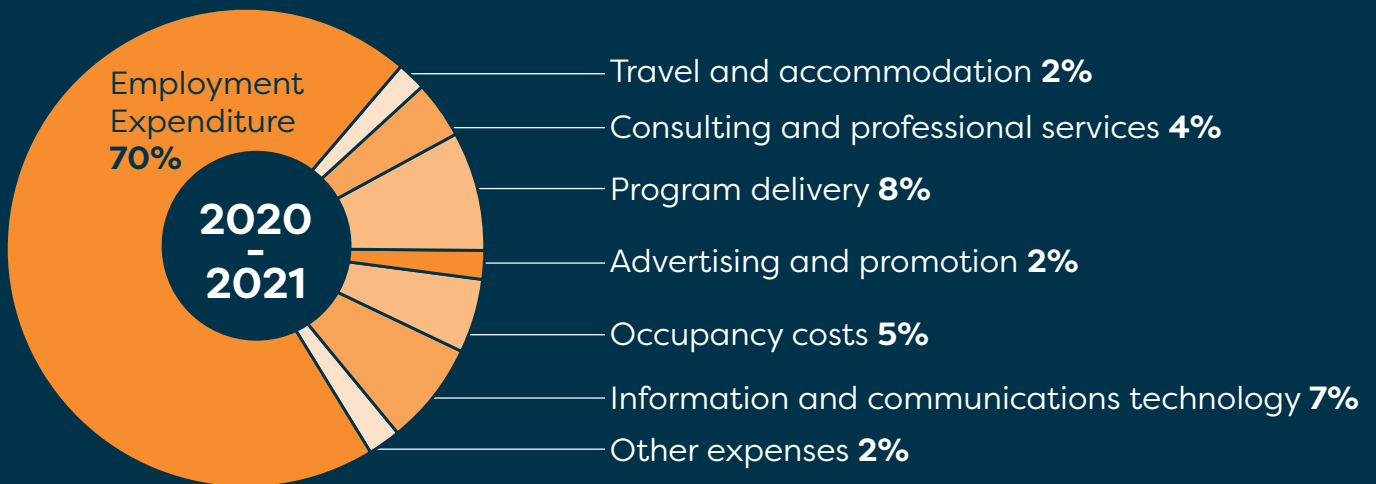
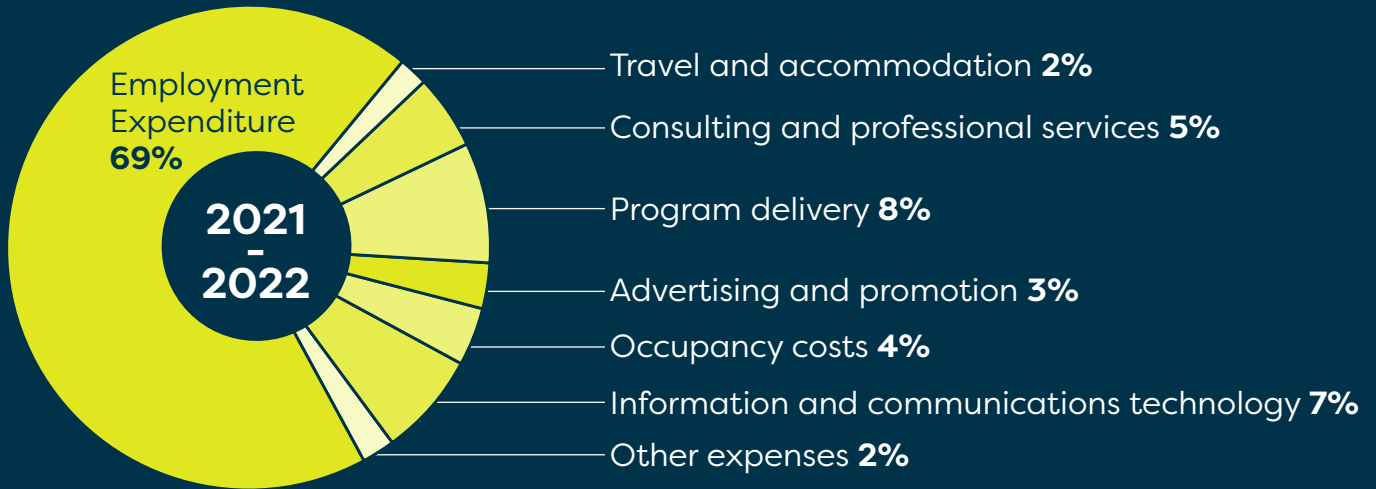
Finally, I would also like to pass on my thanks to the members of the Finance Audit and Risk Management committee for their valuable input and support during the year.

# Key Financials Revenue





# Key Financials Expenses



Dementia Australia's full financial statements are listed on the Australian Charities and Not-for-profits Commission website [acnc.gov.au](https://www.acnc.gov.au)

# Earlier diagnosis, earlier support, better outcomes



The following explains a key feature of 2021-2022 for Dementia Australia – the significant expansion of the National Dementia Support Program and the subsequent changes to Dementia Australia, its services and the impact for people living with dementia, their families and carers.

Several years of intensive strategic planning, policy development, advocacy and consultation work have culminated to deliver extraordinary benefits for people living with dementia, their families and carers, making 2021-22 a watershed year for Dementia Australia.

The 2021-22 Federal Budget allocated a record \$229.4 million over five years in dedicated dementia funding. During the reporting period a substantial portion of this funding began to flow to Dementia Australia under the National Dementia Support Program (NDSP), financing an unprecedented expansion of our services.

## A long but rewarding path: How the expansion came to be

The work to get us where we are today began as far back as 2018, when we released our 2018-23 strategic plan, with timely diagnosis and support, and quality care identified as two major priorities for the organisation.

With the **strategic direction** for 2018-2023 set, Dementia Australia's Quality Dementia Care Initiative commenced to determine what quality dementia care looks like and how it can be achieved.



Above: Bruce Weber, a Dementia Advocate living with younger onset dementia, enjoys making art and instruments out of recycled goods. Under the expansion of the National Dementia Support Program, Dementia Australia will empower people living with dementia to manage their diagnosis on their terms.

This began with extensive consultation with people with lived experience. Consultations concluded with a national consumer summit in 2019 and a subsequent communique - **Our Solution: Quality Care for People Living with Dementia**. The communique was presented to the Federal Government in July 2019.

Following the handover of the communique, an online national symposium was held in August 2020 - **Dementia Care is Quality Care**, where more than 3,000 people joined to discuss what quality dementia care is and to hear from experts, industry leaders and people living with dementia, their families and carers.

The Quality Dementia Care Initiative has enabled Dementia Australia to provide a very clear vision of what is needed to create a connected, integrated and capable health and aged care system, where people of all ages, living with all forms of dementia, their families and carers, are placed firmly at the centre. It has led to the creation on the **Roadmap for Quality Dementia Care** - a roadmap created after extensive consultation with people living with dementia, their families and carers showing exactly how we can achieve quality dementia care. The roadmap and the Quality Care Initiative is also Dementia Australia's response to the Royal Commission into Aged Care Quality and Safety.

# A Roadmap for Quality Dementia Care

Our **roadmap** focuses on three key areas that would transform dementia care in Australia:

1. A single point of contact for people impacted by dementia, to help them find the support they need
2. Dementia-specific training for all aged care employees
3. Dementia-friendly design standards across aged care, which help people living with dementia to remain as independent as possible

With a clear roadmap in place Dementia Australia and Dementia Advocates engaged in a series of strategic government relations activities in early 2021, with the goal of receiving the funding needed to implement the roadmap.

Efforts were rewarded in May 2021 when \$229.4 million over five years in dementia funding was allocated in the 2021-22 Federal Budget to enact the large majority of the **Roadmap for Quality Dementia Care**.

## A game changer

It is difficult to over-estimate the transformational effect the funding received will have to Dementia Australia as an organisation and ultimately the lives of people living with dementia, their families and carers.

The expansion of the NDSP positions Dementia Australia as the pre-eminent provider of post-diagnostic support and the “front door” to the dementia support service system. In line with the recommendations of the Royal Commission, it will facilitate a smoother pathway from diagnosis to support for people living with dementia, as well as their families and carers. It will strive to see people living with dementia diagnosed as early as possible and accessing post-diagnostic support as early as possible, leading to better outcomes for all. Dementia Australia will also exist to empower people living with dementia, their families and carers to understand dementia and to manage their diagnosis on their terms.

## New and expanded services

A cornerstone feature of the updated NDSP is new and expanded client services. One of the most significant service expansions is to the **National Dementia Helpline**. The funding has allowed us to increase the capacity of the service, more than doubling the call volumes that can be accommodated and ensuring 75 per cent of calls can be answered in real time. As well, the helpline will now offer a new post-diagnostic outreach call service to proactively contact newly diagnosed people and help connect them to information and support.

Other critical services will expand by 25 per cent each year over four years. These include a large range of family and carer education sessions, carer support groups, post-diagnostic support program and early intervention programs, carer support and counselling.

New Memory Lane Cafes offering group peer support will be established nationwide, with 14 new cafes already up and running and more to come.

Additionally, a range of new programs and services will be established. These include a dementia-friendly home advisory service, a comprehensive specialist family counselling service for families impacted by younger onset dementia, peer support programs and a Mild Cognitive Impairment post-diagnostic support program. We will also be able to offer more Brain Hubs to bring expert information to regional and remote communities.

In coming years we will continue to build specialised services for vulnerable people, culturally and linguistically diverse people, Aboriginal and Torres Strait Islander peoples, those who are from the LGBTI community and people experiencing homelessness.



**A smoother pathway from diagnosis to support.** ”

## Connecting with GPs and health practitioners

A final exciting element of the expansion is a focus on resetting how GPs and health practitioners see dementia and dementia care.

In order for people living with dementia to receive support as early as possible and as smoothly as possible, it is vital GPs and health practitioners encourage and facilitate their patient's early connection to Dementia Australia, through the National Dementia Helpline.

It is also important all GPs and health practitioners understand dementia. Just like with other chronic diseases such as heart disease or diabetes, there is information and support that can be provided to people living with dementia, their families and carers to help them live as well as possible with dementia. To navigate challenges and changes and to continue to live meaningful lives in the community.

Quality dementia care includes offering holistic services and support including facilitating access to allied health services, support programs and services and much more. The expanded NDSP will be an exciting opportunity for Dementia Australia to connect with GPs and health practitioners and ensure people living with dementia receive the support they need at the time they need it.

# Our strategic direction

Designing a New Future 2018–2023

Dementia Australia’s strategic direction, **Designing a New Future 2018–2023**, was developed after extensive consultation with our community to understand how best to deliver the greatest benefit for people of all ages living with all forms of dementia, their families and carers.

During 2021–2022 we continued to implement the plan, making significant progress in each of the three priority areas.

Below: Dementia Advocate Benny Chan with a friend. Benny featured in Dementia Australia’s 2021 A Little Support Makes a Big Difference campaign to help combat dementia discrimination. You can read more about the campaign on page 93.





# One

## Timely diagnosis and support

**Aim:** Significantly reduce the time it takes to diagnose dementia and increase the number of people accessing support.

It can take up to three years for someone to receive a diagnosis of dementia and up to seven years for a person with younger onset dementia. This is unlike any other chronic disease. This strategic priority continues to be a major focus.

### Progress highlights 2021-22

- Expanding pre-and-post diagnostic support services to clients, delivered under an expanded federally-funded National Dementia Support Program and with a focus on offerings which facilitate and promote timely diagnosis.
- Laying the groundwork for the expansion of the **National Dementia Helpline** to become a 24/7 service from 1 July 2022, with recruitment, planning and training. A 24/7 National Dementia Helpline means there will always be someone there for dedicated dementia support and information – no matter the time or day.
- Developing the **BrainTrack** app to encourage Australians to monitor their brain health and to seek information and support from their doctor or the National Dementia Helpline as early as possible.
- Working with agencies including **My Aged Care** and **Carers Gateway** to establish stronger referral pathways so that those newly diagnosed or concerned about their brain health can get the support and services they need as early as possible.



## Two

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# Quality care

**Aim:** Advocate for the implementation of mandatory foundational dementia standards, including dementia-specific training, in all Australian aged care services.

Most aged care organisations strive to provide high quality dementia care but need support in delivering practice that is evidence-based, client-centred and sustainable.

### Progress highlights 2021-22

- Delivering our **Roadmap to Quality Dementia Care**, following an extraordinary \$229.4 million funding allocation in the 2021-2022 Federal Budget for new and expanded services under the National Dementia Support Program.
- Rolling out our **Communities of Practice** program nationally, following a successful pilot, to help professional carers come together to share knowledge and lead improvements in practice.
- Hosting the Quality Dementia Care Roundtable with government, regulators, workforce and industry, resulting in agreement for an annual ‘scorecard’ of high-impact initiatives to improve the quality of dementia care.
- Releasing new modules for the **Ask Annie** mobile phone app, created with support of Gandel Foundation, Rosemary Norman Foundation, IOOF Foundation and Insignia Financial, to help educate aged care workers in dementia, achieving 6,000 app downloads to June 2022.
- Developing and gaining Australian Skills Quality Authority approval for a new Certificate IV in Dementia Practice.





## Three

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# Reduce discrimination

**Aim:** Tackle discrimination head-on so that no-one with dementia feels isolated.

Social isolation, stigma and discrimination are common for people living with dementia. Research shows that 63 per cent of people say they know very little about dementia,\* demonstrating the need for an attitudinal shift.

### Progress highlights 2021-22

- Sharing real-life stories with tens of millions of people, including health care workers, as part of the **A Little Support Makes a Big Difference** anti-discrimination campaign.
- Continuing the expansion of the **Dementia-Friendly Communities** program. Examples of many initiatives include supporting Brisbane City Council's commitment to create a dementia-friendly Brisbane as part of the Brisbane 2032 Olympic and Paralympic Games; and funding the Woookarung Regional Park Dementia Sensory Trail near Ballarat in Victoria, which opened during the reporting period.

\* Ipsos research for Dementia Australia on Perceptions and Understandings of Dementia, 2015

# Governing our organisation



The volunteer board of directors is responsible for the governance of Dementia Australia, while the Chief Executive Officer leads the strategic management and the Chief Operating Officer oversees the operational management of the organisation.

The board defines the outcomes and results it wants the organisation to achieve, and formally delegates the responsibility for delivering this to the Chief Executive Officer.

Under the Dementia Australia constitution, the board comprises the chair and directors. In performing its duties, the board meets regularly and at all times will act lawfully and consistently with Dementia Australia policies and values. The board is also expected to:

- Approve the organisation's overall strategic direction and policies and monitor management's implementation of that strategy.
- Establish and maintain appropriate governance structures and processes.
- Set the tone for integrity and ethical behaviour and foster a culture consistent with the organisation's core values within the boardroom and across the whole organisation.
- Approve annual business plans and budgets and monitor the organisation's financial and non-financial performance.
- Ensure the organisation's financial and other reporting mechanisms produce reliable, accurate and timely information to the board.
- Monitor the organisation's compliance with legal and regulatory obligations.
- Ensure significant business and other risks to the organisation are identified and appropriately managed and adequate internal controls are in place.

## Board committees

### Finance Audit and Risk Management Committee

The purpose of the Finance Audit and Risk Management Committee is to provide ongoing support, advice and recommendations to the Dementia Australia board about all Dementia Australia entities and associated research foundations. The committee advises on finance, budgets and investments. It also provides advice on audit, compliance and risk management issues relating to risk assessment, mitigation strategies and monitoring of organisational activity.

#### Committee members:

- Ian Knight, Chair
- Greg Fraser (to October 2021)
- Tony Newman
- Gaye McMath
- Maree McCabe AM
- Dominic Ryan (from October 2021)
- Neil Samuel (independent\*)
- Geoff Knuckey (independent\*)

#### Major achievements and activity for 2021-22:

- Monitoring of financials, endorsement of draft budget and engagement with auditors
- Management of investment portfolios and risk mitigation activities through the investment funds managers
- Monitoring of significant projects, strategic risks and organisational compliance.

\*Dementia Australia has a history of seeking independent expertise to the board and committees for advice on specific areas.

## Board committees

### Governance Committee

The Governance Committee provides support in areas such as effective succession planning and renewal for the board and board committees. The Governance Committee also reviews key governance and corporate policies to promote an ethical culture within Dementia Australia.

#### **Committee members:**

- Tony Newman, Chair (until June 2022)
- Kaylie Smith (member from April 2022, Chair from June 2022)
- Meegan Fitzharris
- Greg Fraser (to June 2022)
- Wendy Carroll (from Oct 2021)

#### **Major achievements and activity for 2021-22:**

- Undertaking an extensive board recruitment campaign which resulted in the appointment of three new directors in August 2021, further recruitment underway in 2022
- Facilitating outcomes of the board improvement plan, commenced in 2021, including review of sub-committee charters, update of governance policies and structure, and content of board reporting tools
- Undertaking a skills review and updating the board profile to support targeted skills-based board recruitment.

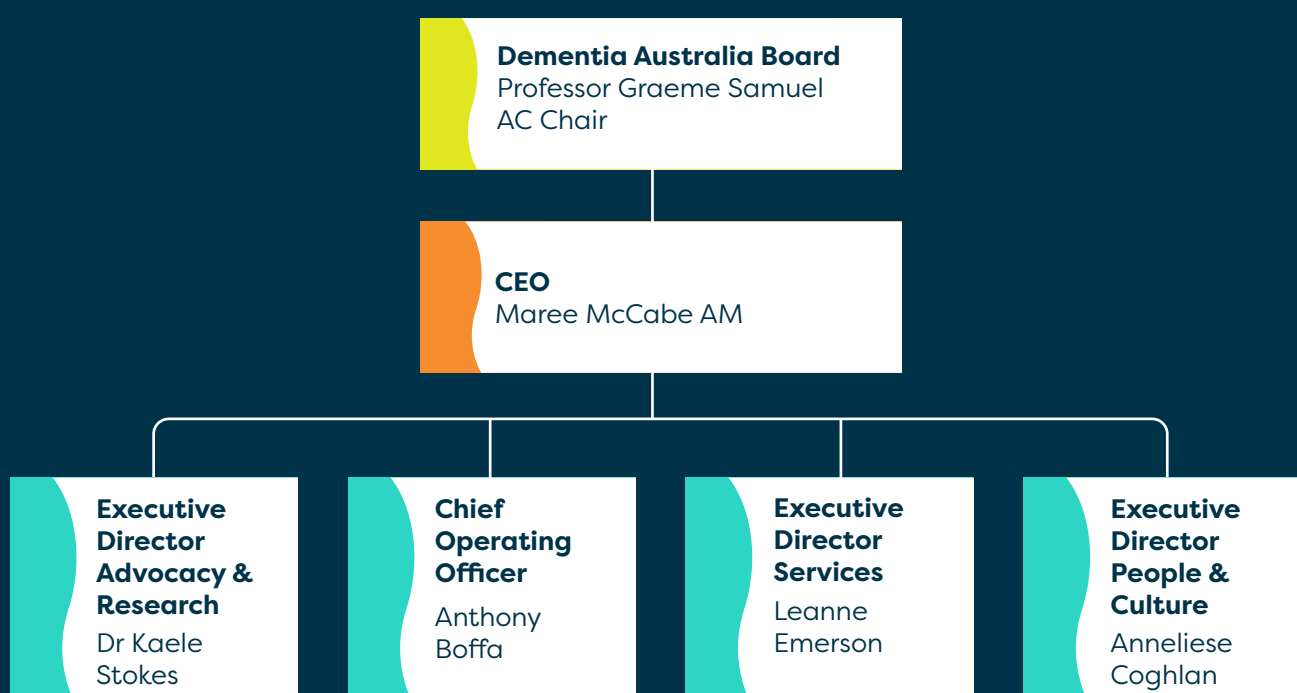
## Meetings of the board

	2021			2022				Total
	20/8	14/10	26/11	26/1	30/3	8/4	23/6	
AC Samuel, Graeme	1	1	1	1	1	1	1	7
Fraser, Greg*	1	1	1	1	1	1	1	7
Newman, Tony	1	1	1	1	1	1	1	7
AM McCabe, Maree	1	1	1	1	1	1	1	7
Ian Knight	1	1	1	1	1	1	1	7
Gaye McMath	1	1	1	1	1	0	1	6
Meegan Fitzharris	0	0	1	1	1	1	1	5
Dominic Ryan^	-	1	1	1	1	1	0	5
Kaylie Smith^	-	1	1	1	1	1	1	6
Wendy Carroll^	-	1	1	1	1	1	1	6

Throughout the year the board met virtually in August, October and June. Due to COVID-19 related travel restrictions across the country for much of the year, it was only able to meet in person in Melbourne for the annual general meeting in November and again in April, as well as a Sydney meeting in March.

\* Resigned 30 June 2022  
^ Appointed 30 August 2021

## Dementia Australia leadership



# Our board



**Graeme  
Samuel AC**  
LLB LLM  
**Chair**



**Maree  
McCabe AM**  
Post Grad Dip MHN MBA GAICD  
**Director**

## **Joined board**

2014

## **Elected Chair**

2014

## **Skills**

Community sector, public administration, economic reform, corporate law

## **Other roles**

Professor at Monash University Business School and School of Public Health and Preventative Medicine, Chair of the Dementia Australia Research Foundation, Chair of Australian Dementia Network Ltd, Co-Chair of the National Network of Comprehensive Dementia Centres Steering Group

## **Joined board**

2016

## **Skills**

Executive leadership, business transformation, health, mental health, aged care

## **Other roles**

Director of Dementia Australia Research Foundation, Director of National Ageing Research Institute, Chair of the Aged Care Quality & Safety Advisory Council, member of the Australian Dementia Network Steering Committee, member and Nominations Committee chair of Alzheimer's Disease International, member of the National Aged Care Advisory Council



**Tony  
Newman**  
BEcon  
**Director**

**Joined board**  
2014

**Skills**

Finance, supply chain, sales and marketing and information technology

**Board committee roles**

Member of Finance Audit and Risk Management Committee, Chair of Governance Committee

**Other roles**

Board member of the Dementia Australia Research Foundation, board member of Dementia Australia Research Foundation Victoria



**Greg  
Fraser**  
BA FAICD FGIA  
**Director**

**Joined board**  
2013

**Skills**

Public sector and not-for-profit governance and risk management, corporate governance, program evaluation, strategic and business planning

**Board committee roles**

Member of Governance Committee

**Other roles**

Chair of Marymead Catholic Care, chair of National Blood Authority Audit and Risk Committee

# Board profiles



**Ian Knight**  
B Bus FCA AFIML MAICD  
**Director**

**Joined board**  
2018

## **Skills**

Finance, risk, audit and investment

## **Board committee roles**

Chair of Finance and Risk Management Committee

## **Other roles**

Board Member of Dementia Australia Research Foundation, board member of Dementia Australia Research Foundation Victoria, Director of Australian Dementia Network Limited



**Gaye McMath**  
B Comm MBA FCPA FAICD  
**Director**

**Joined board**  
2020

## **Skills**

Finance, strategy, planning, commercial and treasury management

## **Other roles**

Deputy Chair of Southern Ports Authority, Director of Power and Water Corporation Northern Territory, Dementia Australia Finance Audit and Risk Management Committee member





**Meegan  
Fitzharris**  
B Comm M IntlDev  
**Director**

**Joined board**  
2020

**Skills**

Public health policy, government relations

**Board committee roles**

Member of Governance Committee



**Kaylie Smith**  
B Arts (Media/Comms)  
**Director**

**Joined board**  
2021

**Skills**

Building and scaling digital businesses; product, strategy and business development; customer management

**Board committee roles**

Member of Governance Committee

# Board profiles



Wendy  
Carroll

MBA, BEng, B Comm, GAICD

**Director**

**Joined board**  
2021

## Skills

Transformation and growth, Australian healthcare system, healthcare regulation

## Board committee roles

Member of Governance Committee



Dominic  
Ryan

MBA, GAICD

**Director**

**Joined board**  
2021

## Skills

Executive leadership, entrepreneurship, finance

## Board committee roles

Member of Finance and Risk Management Committee

## Other roles

Advisory Board member of Jayride Group Limited

Opposite: Dementia Advocate Russell Martin at his farm in regional NSW. Russell was visited by local media during Dementia Action Week 2021 for a story on dementia and discrimination.



# Our executive

**Maree McCabe**  
AM

Chief Executive Officer



**Anthony Boffa**

Chief Operating Officer



**Leanne Emerson**

Executive Director Services from May 2022. Executive Director, Services and Business Development until May 2022



**Anneliese Coghlan**

Executive Director,  
People and Culture



**Dr Kaele Stokes**

Executive Director,  
Advocacy and Research



# Patrons, Ambassadors, Honorary Medical Advisors, Honourees

## Patron-in-Chief

His Excellency General the Honourable David Hurley AC DSC (Retd) Governor-General of the Commonwealth of Australia

## Patrons

Ita Buttrose AC OBE  
Allan Moffat OBE  
Sir Michael Parkinson CBE  
Sir Jackie Stewart OBE

## Ambassadors

Lyn Allison  
David Astle  
Natarsha Belling  
Stephanie Bendixsen  
Christine Bryden AM  
Ben Crocker  
Terence Donovan  
Mark Gibson  
Amy Jackson  
Takaya Honda  
Sam Mitchell  
Andrea Nicolas  
Jessica and Lisa Origliasso,  
The Veronicas  
Sue Pieters-Hawke  
Sam Poolman  
Andrew 'Reidy' Reid  
Mark Seymour  
Nicola Stevens  
Denis Walter OAM  
The Hon. John Watkins AM  
Pat Welsh  
Doris Younane

To read more about our Ambassador Program visit [dementia.org.au/patrons-and-ambassadors](https://dementia.org.au/patrons-and-ambassadors)

## Honorary Medical Advisors

Scientia Professor Henry Brodaty AO  
Professor Amy Brodtmann  
Associate Professor Michael Woodward AM

## Dementia Australia Honourees

Lyn Allison  
David Andrews  
Margaret Baulch  
Margaret Cameron  
Patricia Collett OAM  
Anne Fairhall  
Val Fell OAM  
David Galbally QC  
Pamela Galli AO  
Geoffrey Gill  
Stephen Hawke  
Carolyn Holten  
Dr Susan Koch  
Garry Lovell  
Mandy Lovell  
Mary Lyttle  
Edie Mayhew  
Lynette Moore  
Brian Moss AM  
Michael Pedler  
Barbara Potter AM  
Gordon B Robinson  
Nicholas K Rogers  
Jack Sach  
Neil Samuel OAM  
Sir David Smith  
Carmel Thorne  
Anne Tudor OAM  
Tom Valenta OAM  
Tony Walsh  
Keith Wehl  
Trevor Wheeler

# Quality, projects and continuous improvement

**Strengthening** Dementia Australia's quality, risk management and **continuous improvement** capability.

Strengthening Dementia Australia's quality, risk management and continuous improvement capability has progressed further this financial year, with ongoing and new initiatives to embed best practice across the organisation.

Our Operational Management group – the senior managers supporting our executive team – have facilitated a broad range of operational activities and supported continuous improvement and risk management functions organisation-wide.

We have increased the use of our risk management software tools by staff and managers in areas including incident, hazard and feedback management and reporting; facilities management; contract management and compliance; risk management; policies and procedures; delegations; and management of our site emergency response plans.

Across the organisation we have progressed significant projects to help deliver the operational enablers that underpin our strategic plan. This has included:

- Finalising the roll out of Microsoft Teams software to support chat, voice and video communications and information management; introduction of Office 365 to support better information management; decommissioning redundant legacy systems.
- Developing and launching our interactive human resource information system to support functions including recruitment, induction, staff on- and off-boarding, performance review activities and management of personnel records.
- Developing customer relationship management tools to support helpline function, business development, and contract management and commenced work to replace other legacy systems.



Above: The Dementia-Friendly Communities team is one of the many Dementia Australia teams now using Microsoft Teams for file storage and collaboration after it was rolled out organisation wide in the 2021-2022 financial year.

- Expanding helpline capability and client intake models to support more timely response and easier access to our services.
- Developing tools, practices and information resources to support staff to safely work and deliver services in a pandemic environment.

We developed supporting resources, guides and training materials for our staff to enable transition to improved systems and ways of working and refreshed our intranet to support better access to staff information and communication.

Finally, we continued to deliver operational support and coordination for the board and board committees to support their governance obligations.

Approximately **70%**  
of people with dementia  
**live in the community**



**We have improved systems and ways of working.**



# Client Services

**Information, support and counselling programs for people of all ages living with all forms of dementia.**

Dementia Australia's Client Services team provides information, support and counselling programs for people of all ages living with all forms of dementia, their families and carers. It also resources health and aged care workers. We provide the **National Dementia Helpline**, information kits, counselling, carer support groups, client and family education and public awareness activities.

Although COVID-19 continued to limit some of our face-to-face activities throughout the reporting period, we are pleased that we could continue to support clients through online channels and with telephone services.

## National Dementia Support Program

One of the most significant expansions of Dementia Australia's client services occurred in 2021. In the wake of the aged care royal commission and the success of our **Roadmap to Quality Dementia Care** submission, we received substantial federal funding in the 2021 Federal

Budget under the National Dementia Support Program to provide new and expanded services and improved referral processes with a focus on early diagnosis and support. Highlights include:

- Expansion of the capacity of the National Dementia Helpline to double the call volumes which can be accommodated and introduced a new post-diagnosis outreach call service to proactively contact newly diagnosed people and help connect them to information and support.
- Expansion of programs, including post-diagnostic support, counselling, family education and carer support.
- Development of new programs, including nation-wide Memory Lane Cafes; a new dementia-friendly home telephone advisory service called At Home With Dementia; and a one-to-one peer support program called Connecting Peers for people with dementia and carers.
- Work with **My Aged Care** and **Carer Gateway** to establish referral pathways.





Above: Dementia Australia clients enjoyed a ballroom dancing session at Cedar House Dementia Support Centre on the Gold Coast in January.

Extensive consultation with consumers, clients and other stakeholders has underpinned these new and expanded services. We expect more new programs to come online in 2022-23, including for people with Mild Cognitive Impairment and diverse communities such as First Nations and LGBTI.

For more information on the expansion of services under the National Dementia Support Program see page 26.

## **NDIS coordination of support service for people living with younger onset dementia**

In August 2021 we made the difficult decision to transition out of providing NDIS coordination of support services for people living with younger onset dementia. While we continue to offer other services to people with younger onset dementia, we recognise that our clients can receive NDIS support coordination services from a range of providers across Australia. We believe we are better placed to focus on our

core strengths – our support services and programs that draw on our dementia expertise and experience.

As part of a detailed transition plan, we worked with all clients to support them to move to another support coordination provider. We also supported our dedicated colleagues delivering the program to explore other roles within Dementia Australia. The transition means clients are better off as they are now receiving coordination of support from another provider and counseling, education and support from Dementia Australia.

## **Nightingale Program**

During the reporting period our **Nightingale Program** – a palliative model of care provided by specialist nurses which offers strategies and advice to support people living with dementia, their families and carers – continued its expansion in South Australia, currently the only state in which it is available. We also continued our advocacy for this incredible person-centred model of palliative care to be made available nationally, making this a key priority of our 2022 election campaign.

We were delighted to see the program receive global recognition, with a poster at the 2022 Alzheimer's Disease International conference.

## Accolades for library

The **Dementia Australia library** is the only service of its kind, offering a collection of electronic and hard copy resources focused solely on dementia. It was exciting to see our innovative and energetic staff recognised at the international **PRNEWS Nonprofit Awards** for their efforts to promote the service, earning a win in the PR on a Shoestring Budget category. Judges were impressed at the range of low-cost promotional activities implemented by library staff, which increased utilisation in regional and rural areas by 300 per cent. These included curated themed library guides, promotion of a "Pick of the Month" and an update to the library portal.

During the reporting period a review of publications and reports on the Dementia Australia website saw some items relocated from the website to the library.



Above: Dementia Advocate Mithrani De Abrew Mahadeva exploring library resources at Dementia Australia's Hawthorn office.

## League of Men

In 2021 Northern Territory Client Services staff worked with the community to develop ways to increase support services for local men living with dementia. The result is the League of Men social group, launched in July 2021. Participants enjoy weekly social activities that can range from billiards and darts at a local sports club, to museums visits and even the League of Men Olympic Games. The initiative has been a great success in reducing isolation for Top End men living with dementia.

## Dementia Expert Webinars

Our online **Dementia Expert Webinar** series launched during the reporting period, giving families and caregivers an easy way to access free, expert content. The Client Services team worked with highly qualified and respected professionals to record specialised education videos, covering topics including male carers, dietetics and nutrition and younger onset dementia.



Above: (L-R) Donna Ireland, Team Leader, Client Services enjoyed the opening of a new sensory garden on the Gold Coast in October with client Gwen Kerr.

# Client Services statistics



## Number of Helpline interactions\*

1 July 2021 to 30 June 2022

**36,575**

1 July 2020 to 30 June 2021

**33,255**

1 July 2019 to 30 June 2020

**34,497**

\* includes inbound and outbound calls, webchat and emails

1 July 2021 to 30 June 2022

**55**

1 July 2020 to 30 June 2021

**30**

1 July 2019 to 30 June 2020

**39**

## Top five categories of calls

**Service information**

**47**

**27**

**24**

**Resource material**

**28**

**16**

**14**

**Education about dementia**

**27**

**14**

**13**

**Direct care and support**

**27**

**13**

**10**

**Carer stress and grief**

**%**

**%**

**%**



## Counselling sessions delivered

1 July 2021 to 30 June 2022

**6,687**

1 July 2020 to 30 June 2021

**4,780**

1 July 2019 to 30 June 2020

**4,359**



## Library items loaned

1 July 2021 to 30 June 2022<sup>#</sup>

**5,962**

1 July 2020 to 30 June 2021<sup>#</sup>

**6,500**

1 July 2019 to 30 June 2020

**9,037**

<sup>#</sup> Decrease in items loaned in last two financial years attributed to COVID-19 related lockdowns and restrictions

# Centre for Dementia Learning

Dementia Australia is the **leading national provider of dementia education.**

Dementia Australia's **Centre for Dementia Learning** is the leading national provider of dementia education. We deliver face-to-face and online education for health professionals and support workers in the aged care, health and disability sectors. We also provide consultancy services.

Our pandemic adaptation continued during the reporting period, as we developed online delivery of more of our foundational education programs. This included our popular **Dementia Essentials** for professional carers, which covers areas such as good communication, person-centred principles, creating a supportive environment, engagement and understanding changed behaviour in people living with dementia.

The Aged Care Royal Commission and our **Roadmap for Quality Dementia Care** affirmed that foundational education on dementia is the cornerstone of quality dementia care. Our Dementia Essentials course is a key

program funded by the Commonwealth government through **Dementia Training Australia** that addresses this baseline need. A second key component in the roadmap is establishing 4,000 Dementia Practice Leaders across the country. To make this a reality, we have received approval from the Australian Skills Quality Authority for a new Certificate IV in Dementia Practice that we will shortly commence delivering nationally.

Another way we are supporting and skilling professional carers is through our **Communities of Practice** program, which commenced during COVID-19 and has been expanded nationally after a successful pilot. The program facilitates professional carers to come together to share knowledge and lead improvements in practice. This program was made possible through the valuable support of the Priceline Sisterhood Foundation.

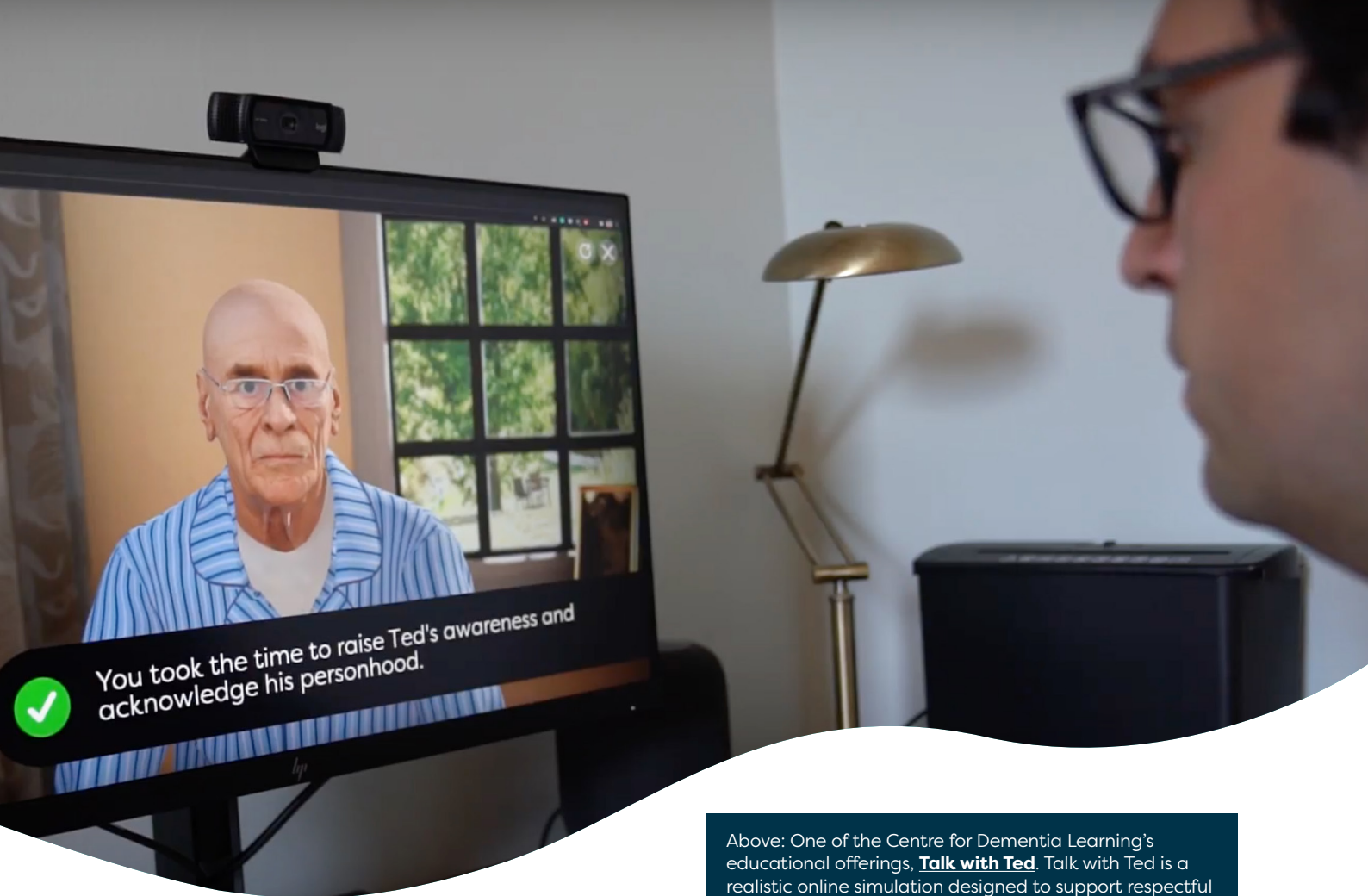
Opposite: (L-R) Priya Sanovic, Development Specialist, Dementia Australia and Carmel Kostos, Facilitator, Centre for Dementia Learning, demonstrated Dementia Australia technology and education offerings at the 2022 Dementia + Recreation National Conference in Melbourne.



Welcome!



**Dementia  
Australia®**



Above: One of the Centre for Dementia Learning's educational offerings, **Talk with Ted**. Talk with Ted is a realistic online simulation designed to support respectful communication with people living with dementia.

In early 2022 we engaged a consultant to review our Registered Training Organisation (RTO) operations to identify our strengths and any areas for improvement, ahead of our RTO re-accreditation audit later in 2022. As a result of the audit, we have introduced changes, including ensuring that numeracy and literacy testing are more robust. This important work will help us in the future as we strive to raise the standard of dementia skills across the sector.

In December 2021 we held the Quality Dementia Care RoundTable, facilitated by the director of the Centre for Dementia Learning, Dr David Sykes. The event allowed us to re-engage key decision makers within the aged care sector, including representatives from government, regulators, workforce

and industry. On the agenda was how to support the establishment of good practice across the sector and gaining a shared understanding of, and commitment to, quality dementia care. Attendees agreed on the creation of an annual 'scorecard' of high-impact initiatives that will improve the quality of dementia care.

We also continue to drive improvements in practice. Just one showcase example from the year was our **Meaningful Engagement Mentor Support program** work with Bupa Aged Care in South Australia. This program works with staff to develop advanced skills in planning and delivering individualised engagement with people living with dementia and encourages staff to take those skills back into their teams to help and mentor others.

The group comprised of direct care, lifestyle and nursing staff from three sites. In order to complete the program they were asked to share the engagement plans and the activities they developed and implemented.

The group shared their experiences with their chosen person living with dementia through pictures and videos. What we saw was meaningfully engaged people, both the carers and the person living with dementia, and it was joyful and inspiring.

The mentors demonstrated the importance of care being centred on the person and, in particular, shared their insights into how they found common ground across cultural diversity.

Lastly, our work has continued to achieve accolades and international profile. We received a Future of Ageing Award in the Service Transformation for Communities of Practice category as well as making the finals of the Hesta Excellence Award in the Team Excellence in Aged Care category. In June 2022 we showcased three technology-driven education tools—the **Ask Annie** app, the virtual avatar program **Talk with Ted** and **EDIE the Educational Dementia Immersive Experience**—at the Alzheimer’s Disease International Conference. The event is the longest running international conference on dementia and attracts delegates from around the world.



**The Centre for  
Dementia Learning  
provides nationally  
recognised courses  
and award-winning  
professional dementia  
education. ”**

# Centre for Dementia Learning statistics

## Course participants

### Achieving Purposeful Engagement

FY

2019-2020	<b>665</b>
2020-2021	<b>296</b>
<b>2021-2022</b>	<b>652</b>

Total 1,613

### Applying a Problem Solving Approach to Behaviours

FY

2019-2020	<b>1,418</b>
2020-2021	<b>2,296</b>
<b>2021-2022</b>	<b>2,923</b>

Total 6,637

### Building Relationships

FY

2019-2020	<b>n/a</b>
2020-2021	<b>90</b>
<b>2021-2022</b>	<b>117</b>

Total 207

### Dementia Essentials

FY

2019-2020	<b>3,870</b>
2020-2021	<b>2,879</b>
<b>2021-2022</b>	<b>2,341</b>

Total 9,090

In 2022, the estimated number of Australians living with **dementia** is **487,500**

Without a medical breakthrough, **by 2058** the number of people living with dementia is expected to increase to almost **1.1 million**





Above: Marie Norman, Development Manager, Dementia Australia, demonstrated the Educational Dementia Immersive Experience (EDIE) at the 2022 Alzheimer's Disease International Conference in London. The Centre for Dementia Learning runs immersive three-hour Enabling EDIE workshops to enable participants to see the world through the eyes of a person living with dementia.

### Enabling EDIE

FY

2019-2020 **2,517**

2020-2021 **2,645**

2021-2022 **2,237**

Total **7,399**

### Enabling EDIE others

FY

2019-2020 **761**

2020-2021 **279**

2021-2022 **362**

Total **1,402**

### Understanding Dementia

FY

2019-2020 **1,765**

2020-2021 **2,551**

2021-2022 **2,030**

Total **6,346**

**32,694**  
total course  
participants\*

(1 July 2019 to 30 June 2022)

\*Figure does not represent unique individuals

## Course delivery modalities

Online learning	
FY	
2019-2020	n/a
2020-2021	80
2021-2022	1,719
Total	1,799

Other workshops	
FY	
2019-2020	5,171
2020-2021	5,501
2021-2022	2,420
Total	13,092

Seminar/webinar	
FY	
2019-2020	722
2020-2021	1,176
2021-2022	1,211
Total	3,109

In **2022**, it is estimated that almost

**1.6 million**

people in Australia are involved in the **care of someone living with dementia.**



No matter **how you are impacted**  
by dementia or **who you are,**  
**we are here for you.**

# Technology



## Ask Annie

In June 2021, thanks to the support of Gandel Foundation, we launched the **Ask Annie** mobile app designed to deliver short, self-paced learning modules to improve the skills of home care and community support workers, promoting better care for people living with dementia.

In April 2022, Ask Annie was re-released thanks to funding from the Rosemary Norman Foundation and includes new modules making the app now suitable for residential aged care workers.

In a further expansion of the app, in June 2022 we partnered with IOOF Foundation and Insignia Financial to release a new financial elder abuse module.

By June 2022 the app had been downloaded more than 6,000 times.



**Dementia Australia** continues to develop **world leading** and **award-winning** technological innovations that deliver **improved learning outcomes** for participants.



## **EDIE** **Educational Dementia** **Immersive Experience**

We continued our work to make the **EDIE** (Educational Dementia Immersive Experience) virtual reality training tool more portable and therefore more accessible to a wider range of professional and informal carers.

EDIE (pronounced Eddie) shows the world of a person with dementia through the eyes of Edie, who has dementia and lives at home with his wife. The app illuminates the sensory and visual experiences that can come with dementia. It aims to build empathy, helping family members understand the world of their loved one, and assisting professional carers in better care planning and delivery.

During the reporting period we updated EDIE to make it compatible with new Oculus virtual reality headsets.

## **New online** **education platform**

Work continues on our new online education platform, which will host all Centre for Dementia Learning online education programs. The platform will also allow users to connect with each other, creating an online community of people engaged about dementia care.

## **BrainTrack app**

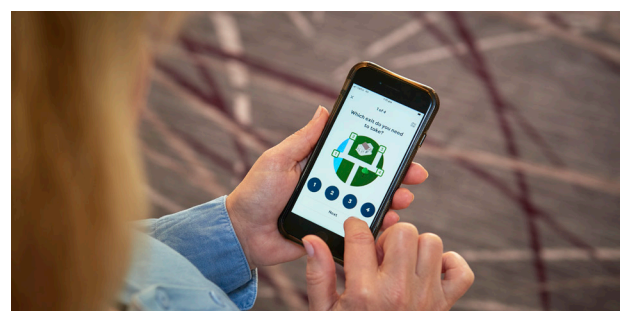
Development work continued on our new **BrainTrack** app, for launch in October 2022.

Funded by the Commonwealth Government under the National Dementia Support Program, the app is a simple tool to allow consumers to self-monitor their brain health and cognition so that, if needed, they can seek further expert support from their GP or the National Dementia Helpline.

The app features interactive elements including games that allow users to monitor their brain health and cognition over time. Users can generate reports that can be shared with their doctor, facilitating conversations and an earlier diagnosis.

The app also features brain health information and connects users to the National Dementia Helpline for further support.

BrainTrack will be an important tool for consumers, GPs and Dementia Australia as part of our push to assist Australians before, during and after diagnosis.



# Business Development



During the financial year our Philanthropy and Business Development teams merged, bringing fundraising, business development and marketing functions into a single unit, overseen by the newly created role of Director of Business Development.

The changed structure reflects our goal of continuing to strengthen and diversify our revenue streams. While Dementia Australia has had significant success in attracting government funding, particularly in recent years, we know that we need to identify and maximise all potential sources of income if we are to remain sustainable and continue to meet the needs of people who rely on our support.

We finalised a new business development strategy during the reporting period, underpinning our focus on continued growth in our commercial offerings, product offerings and partnerships.

During the period, the Business Development team achieved a 6.9 per cent increase in revenue on 2020-2021. This is an outstanding result considering the impact on clients of COVID-19 and pandemic public health measures such as lockdowns in a number of states.

## Philanthropic and corporate support for Ask Annie

Major philanthropic organisations provided significant funding for the **Ask Annie** app allowing an increased number of professional care workers to access its “micro lessons”.

The mobile app offers short, self-paced learning modules to help home support and community care workers refresh their skills and learn tips and techniques to provide better care to people living with dementia.



Above: (L-R) Dr Tanya Petrovich, Business Innovation Manager, Dementia Australia, and Vedran Drakulic OAM, CEO, Gandel Foundation, celebrated the release of new Ask Annie modules launched in April 2022.

We launched the app in June 2021, thanks to a multi-year Gandel Philanthropy Flagship Grant, which funded the design, development and build of the app, and the creation of the home and community care modules.

Generous philanthropic and corporate support allowed us to further build on the successful concept this financial year. The Rosemary Norman Foundation provided funding to develop new Ask Annie modules tailored for care workers in residential aged care, which were released in April 2022; while in June 2022 we partnered with Insignia Financial (formerly IOOF Foundation) to release a new module on financial elder abuse.

## First Nations virtual reality training

In March 2022 we secured generous financial support from the auDA Foundation to deliver the **Educational Dementia Immersive Experience (EDIE)** training program for First Nations peoples. The First Nations Virtual Reality Dementia Carer Education Program (EDIE For Carers) will undergo a pilot in every state thanks to auDA Foundation grant funding. As well as making the training more accessible to Indigenous Australians, the expansion will allow us to collect vital information to help continue to tailor our services to the needs of Aboriginal and Torres Strait Islander communities.

## Going global

International interest in our technology products continued to grow during the reporting period. For example, in June 2022, delegates from around the world at the Alzheimer's Disease International Conference 2022 in London had the opportunity to experience EDIE, when it was on demonstration at the prestigious event.

We also expanded EDIE's reach into south-east Asia. An agreement signed this financial year with the Salvation Army Singapore will see EDIE introduced and used in dementia training in Singapore.

## Dementia training for 1,200 Bupa carers

We are proud to play a leading role in developing the dementia care skills of Australia's 130,000-strong aged care workforce.

During the financial year, one of Australia's biggest aged care employers, Bupa Aged Care, committed to rolling out our flagship **Dementia Essentials** training course to its 1,200 staff nationally. This training initiative has the potential to make a real difference to the quality of life and care for more than 6,000 people who live at Bupa's 60 care homes. Bupa staff will begin receiving the training in the last half of 2022. In a further commitment to supporting staff to provide the best dementia care, Bupa will also provide its staff access to the Ask Annie training app.

## Garden show grows dementia awareness

A shared love of plants and flowers proved an accessible way to start conversations about dementia during the 2022 Melbourne International Flower & Garden Show in March-April.

At the event, award-winning landscape designer Mark Browning created a tribute garden for his mum Audrey who died with Alzheimer's disease. As well as raising valuable funds to help provide support services, education and resources for people impacted by dementia, Mark's garden helped us to raise awareness. We established an information booth at the garden, allowing us to have hundreds of conversations, resulting in almost 500 referrals to the National Dementia Helpline over the five-day event.

We are enormously grateful to Mark for nominating Dementia Australia as his charity of choice for the show garden, allowing us to raise funds and awareness.

Opposite: Award-winning landscape designer Mark Browning's show garden 'Aud' at the 2022 Melbourne International Flower & Garden Show. Mark selected Dementia Australia as his charity of choice for his show garden as a tribute to his late mother Audrey.





# Fundraising

**Support for Dementia Australia** helps to **improve quality of life for people living with dementia**, their families and carers.

We are grateful to have so many passionate and loyal supporters, whose generous donations during the 2021-22 financial year continued to underpin our work for and with people impacted by dementia. We receive support through gifts in wills, regular monthly gifts, participation in community fundraising activities, corporate partnerships, and participation and registrations in our Memory Walk & Jog events around the country.

## Memory Walk & Jog

After two pandemic-disrupted years it was exciting to see participants and volunteers return in person for our flagship **Memory Walk & Jog** series in 2022. We held 19 events, including our first ever Memory Walk & Jog in Darwin. More than 10,500 people participated, helping to raise \$1.6 million.

## Royce's Big Walk

A diagnosis of younger onset Alzheimer's disease inspired rugby league and Penrith Panthers legend Royce Simmons to walk 300 kilometres in just 10 days, as part of his aptly named Royce's Big Walk. With the support of the Penrith Panthers, Royce raised an incredible \$730,000 to aid the work of the Dementia Australia Research Foundation.

## Sir Jackie Stewart Tribute Event

After several postponements, we were delighted that the Sir Jackie Stewart Tribute Event was able to go ahead in April 2022. Around 650 guests attended the event in Melbourne, enjoying a star-studded evening and the company of motor racing legend and Dementia Australia Patron Sir Jackie Stewart OBE. The event raised \$666,230, funds earmarked for Race Against Dementia-Dementia Australia Research Foundation Post-Doctoral Fellowships.



Above: Artist Laura Holland painted an artwork at the Night of Gold fundraising event held June 2022 in Sydney, hosted by Navarra Venues.

## Community fundraising activity

Communities continued to come together in fun and inventive ways to support our work. Community fundraising highlights included:

### Marathon to Remember

\$204,522 raised

This year 653 participants tackled full-, half- or ultra-marathons, running a total of 76,915 kilometres. Sincere congratulations to top fundraiser Aaron Muller, who joined with his family to raise more than \$20,000.

### Pedal the Map

\$42,980 raised

In November 2021 we challenged some 239 participants to lap the map of Australia by bike. They well and truly overachieved, clocking up more than 88,000 kilometres. Congratulations to all the riders on a wonderful accomplishment.

### Night of Gold

\$250,000 raised

In June 2022, 600 people joined us for a Night of Gold in Sydney, raising funds for dementia research. Our thanks to hosts Navarra Venues.



Above: Participants at the start of the 2022 Darwin Memory Walk & Jog. It was the first Memory Walk & Jog hosted in Darwin.

## Fundraising income snapshot 2021-2022

Grant money acquired

**\$1.59**  
million

Revenue

**\$9.72**  
million

Funds received in  
bequests

**\$1.74**  
million

# Fundraising statistics 2021-2022



**4,689**

**new donors** acquired via **direct mail** and **telemarketing** campaigns

**584**

**new regular donors**



**31,000**

**total donors**  
(including individuals and organisations)

**19**

Memory Walk & Jog **events** held

**MEMORY  
WALK  
& JOG**



**10,500**

Memory Walk & Jog **participants**

# People and Culture

**We strive to create a positive working culture in which staff feel they are valued, supported and treated fairly.**

Dementia Australia's People and Culture team works across the organisation to help recruit, retain and develop staff. We provide specialist human resource and industrial relations advice to executives, managers and team leaders, and advise staff on employment-related issues. The People and Culture team also coordinates volunteer involvement.

## COVID-19 response

During our second pandemic year, 2021-22 saw most of our staff working from home for much of the year, in accordance with state and territory requirements. The robust risk management measures we introduced last year, such as comprehensive remote workplace safety and suitability assessments, assisted us to do this. We adopted an organisation-wide vaccine policy with input from employees, including a vote of support at an all-staff meeting. In combination with our other pandemic management protocols

introduced last year, vaccinations allowed a safe return to the workplace for many employees in February 2022. We also proudly continue to offer a hybrid workplace attendance model for the vast majority of roles.

## Bargaining agreement

An extensive and consultative process to develop a new Enterprise Bargaining Agreement concluded early in 2022, with the Fair Work Commission approval of a new agreement that delivers fair and consistent working conditions across our organisation. Key new features include provisions covering domestic violence support, study leave, paid parental leave, end-of-year shutdown leave and the ability to purchase additional leave. Importantly, the provision of consistent national conditions of employment for all our staff is now complete following the unification of Alzheimer's Australia into Dementia Australia.



Above: Sydney staff enjoyed morning tea with Maree McCabe AM, CEO, Dementia Australia, when she visited the North Ryde office in February.

## ActionHRM

During the year the People and Culture team continued to transition many human resource activities to our new centralised platform ActionHRM. Functions centralised within the platform include recruitment, onboarding and national compliance related training. This year, managers have recently been able to access personnel records for their team members, request approval to recruit, approve new employment contracts and variations and notify internal departments of a staff member who will be offboarding. When it is fully introduced for all staff next year it will become a “one-stop-shop” for all people and culture related tasks and records.

## Managing a tight labour market

Like many employers in Australia and internationally, we continued to find the tight market challenging, with average recruitment times pushed out. Using agencies where required assisted in managing this situation.

## Staff engagement survey

Our annual staff engagement survey is an important way we keep our finger on the pulse of how employees perceive their work and workplace. Global HR consultancy Mercer Sirota designed and delivered our survey, completed by almost three quarters of staff, making our results highly reliable.

Highlights of the survey this year are our continued high completion score of 79 per cent: and 90 per cent of our employees reporting they are proud to work for Dementia Australia. We continue to rate highly with our employees in questions related to safety and reporting, peer relationships and immediate manager effectiveness.

**Our post 2021 staff engagement survey action plan** (see below and following page), centred on making improvements to the areas of lower satisfaction (orange), and, ensuring we maintain good practices in the areas of highest satisfaction (green).

## Our post 2021 staff engagement survey action plan

**Lime:** Areas of highest employee satisfaction we are working to maintain

**Orange:** Areas of lower employee satisfaction we are working to improve

**Maintain work life balance at 85 per cent satisfaction**

- Retain hybrid working arrangements
- Minimise vacant roles/workload sharing across peers
- Improve automation, information access, reduce paperwork
- Grant a one-off wellbeing day

**Maintain satisfaction with immediate manager support**

- Implement leadership framework and associated development
- Retain monthly managers meetings, review satisfaction/ agenda setting/ Operational Management Group (OMG) collaboration
- Implement new HR platform to reduce manager administrative tasks and improve availability and access to relevant information

**Retain satisfaction with connection with peers**

- Consider all staff national face-to-face meeting
- Return to offices post-pandemic
- Arrange social gatherings in main locations, coinciding with meetings and events
- Trial of Zoom breakout rooms at staff meetings
- Arrange cross-departmental professional development opportunities



### **Improve change and cross-business communication and collaboration**

- Support Operational Management Group (OMG) to collaborate and communicate departmental priorities
- Create cross departmental working groups where possible to provide input on issue resolution
- Implement targeted executive/OMG planning sessions. For example development related/ budget centred

### **Improve satisfaction with career goals and potential**

- Launch GO1 learning library
- Implement capability framework
- Continue internal advertising of vacancies and promote internal transfers

### **Improve senior leadership effectiveness and sincerity**

- Conduct leadership 360 reviews and feedback
- Implement targeted leadership development for executive and Operational Management Group members
- Increase leader visibility

### **Increase survey response rate in 2022 to more than 75 per cent**

- Ensure action plan is created and achievements are articulated before invitations are sent
- Commence awareness campaign in August for September launch
- Offer a prize for highest team completion rate

### **Remuneration**

- Complete Enterprise Bargaining process

### **Reinforce purpose and strategy to retain confidence and understanding of direction**

- Ensure all staff meetings are centred on purpose, include consumers wherever possible
- Provide opportunities to present progress on strategic plan and roadmap
- Provide regular updates on National Dementia Support Program funding rollout/new programs





## Happy International Women's Day 2022

#BreakTheBias

Above: Client Services staff celebrated International Women's Day 2022 and met online for discussion and activities exploring the theme Break the Bias.

## Capability framework

During the reporting period we introduced our new capability framework, which includes a leadership element.

The new leadership capability framework articulates the priority skills and capabilities for the various levels of management and leadership in the organisation. The operational capability framework outlines functional skills, abilities and expected behaviours required for our non-managerial roles.

The framework, along with an individual employee's position description, outlines all the skills, knowledge and behaviours required for each role in our organisation. It therefore forms the basis for all future professional development planning. Assessments of an employee's current capability gaps against the requirements outlined in the framework - for either their current role,

or a potential new role or promotion, will determine how to prioritise training needs. This will assist us to better direct our professional development investment to the areas of most need. Our HR information system, Action HRM, is being built to record these gaps, and once assessments have been completed across the organisation next financial year, we will be able to collate that information to create a workforce development plan.

As part of the framework implementation, and in the first example of gap analysis at leadership levels, we introduced a bespoke 360-degree review process for our executive directors and general managers against the defined leadership capabilities outlined in the framework. The results of those surveys have been the basis for the creation of a leadership development program which will commence in July 2022.

# People and Culture statistics

## Retention rates



## Average tenure in years



## Employees by employment type

	Full time	Part time	Casual
2021-22 financial year	216	225	44
2020-21 financial year	269	281	94
2019-20 financial year	225	222	62



## Volunteers

Our national database lists more than 1,800 volunteers connected to Dementia Australia with 583 active volunteers playing a critical role in delivering Dementia Australia's work.

Our volunteers support fundraising and events, administration and program delivery directly with clients. Much of our work is only made possible through the goodwill and dedication of our volunteers and for that we are truly grateful.

With COVID-19 continuing to affect our operations, we maintained extensive COVID safe procedures and policies to keep our volunteers safe as we started the welcome return to in-person volunteering. We understand the pandemic has affected the way many people connect and has prompted personal reflection and change. We expect our volunteers will be no exception, and so we look forward to re-engaging with them, to see whether their situations have changed over the past two years.

It was inspiring and delightful to see so many event volunteers turn out to support our 19 **Memory Walk & Jog** 2022 events, which were able to go ahead after pandemic disruption over the last two years. Despite constantly changing

Above: Memory Walk & Jog volunteers at the 2022 Gold Coast event.

conditions approximately 580 people volunteered at the Memory Walk & Jog events, helping with tasks such as staffing event registration desks, information booths and marshalling. Some even helped at three or more events, travelling from their hometown to other locations to help. This volunteer contribution is invaluable – without volunteers the events could not be held – so we are extraordinarily grateful.

Other major fundraising and awareness raising events supported by volunteers include the Sir Jackie Stewart Tribute Event, Night of Gold and Mark Browning's show garden at the 2022 Melbourne International Flower & Garden Show.

During the reporting period we have seen the gradual return of many social support programs as volunteers return to Dementia Australia. Excitingly, we started our first ever national volunteer recruitment drive to support our Memory Lane Café expansion. We have received government funding for a network of 14 new cafes nationwide, and each will require two-three volunteers.

# Volunteers statistics\*

## Volunteers registered nationally



1 July 2021 to 30 June 2022

**1,891**

1 July 2020 to 30 June 2021

**1,470**

1 July 2019 to 30 June 2020

**975**

## Active volunteers



1 July 2021 to 30 June 2022

**583**

1 July 2020 to 30 June 2021

**434**

1 July 2019 to 30 June 2020

**93**

## Volunteer hours contributed



1 July 2021 to 30 June 2022

**5,795**

1 July 2020 to 30 June 2021

**3,362**

1 July 2019 to 30 June 2020

**2,359**

\* COVID-19 adversely affected volunteer involvement across the past three reporting years. All Memory Walk & Jog events in the first half of 2020 were cancelled or conducted online. Event volunteers, including Memory Walk & Jog volunteers, are a significant proportion of our annual volunteer base.

# Advocacy and Research

**Dementia Australia's advocacy and research work plays a critical role in elevating the voices of people impacted by dementia**

Dementia Australia's advocacy and research work plays a critical role in elevating the voices of people impacted by dementia. By harnessing the lived experience of our community, we influence policy makers, researchers, industry and government in support of our goal of excellent, discrimination-free care and support for people living with dementia, their families and carers.

## Advocacy and Consumer Engagement

Genuine and meaningful participation of people living with dementia, their families and carers is a principle that underpins every aspect of our work at Dementia Australia. At the frontline of this commitment are a community of Dementia Advocates – people living with various types of dementia, families and carers who generously share their lived experience inside and outside our organisation.

Dementia Advocates provide input and expertise across our operations, including client services, media, marketing, research, policy submissions and major initiatives such as Dementia-Friendly Communities, quality dementia care and learning and education products. Supporting and resourcing Advocates to undertake this vital work is a key role of our Advocacy and Consumer Engagement team.

This financial year Dementia Advocates once again came together to support the development of Dementia Action Week. Advocates collaborated on the creation of tips and resources through focus groups and sharing experiences, while others appeared on television and in social media. Many Advocates also shared stories and quotes for our Dementia Action Week report, **Discrimination and Dementia - enough is enough.**

Throughout the year, Dementia Advocates made many appearances in traditional and social media. This



Above: (L-R) Levi, Brie, Megan and Jason van Genderen at the 2022 Sydney Film Festival premiere of *Everybody's Oma*, a documentary directed by Dementia Advocate Jason about his mother Hendrika who lived with dementia and attracted love and attention from across the world with videos of their life in lockdown together.

included the ABC television program *You Can't Ask That*, where Dementia Advocates shared their honest and heartfelt experiences and views.

Through the **Dementia Australia Advisory Committee**, people living with dementia provide strategic advice to Dementia Australia and other stakeholders on shaping dementia services, programs, policy development and advocacy goals. The committee's report on page 20 has more information.

Co-designing our new Consumer Engagement Strategy has been a critical task this financial year. In May 2022, more than 60 Dementia Advocates from around the country provided input into the design of the strategy, which we expect to be implemented by the end of 2022. The Advocates gave feedback on the five guiding principles: lived/

living experience, empowerment, authenticity, collaboration and inclusion. These conversations are vital in ensuring the voices of Advocates shape the way the principles are explained and embedded in all aspects of our operations, including finance and administration.

Throughout the year Dementia Advocates have contributed their expertise through other consultation processes. This includes involvement in focus groups for projects such as the new one-to-one peer support program, the strategy for accommodation for people living with younger onset dementia and aged care reform activities including the design of new aged care quality standards.

In a critical federal election year, Advocates contributed significantly to aged care reform discussions. They were involved in our federal election

campaign, which included asking all political candidates to commit to compulsory dementia education for aged care workers.

Many external organisations benefitted from the expertise of Dementia Advocates during the reporting period. These include the Older Persons Advocacy Network, the Aged Care Quality and Safety Commission and the Department of Health.

More than 50 research teams across the country have involved Dementia Advocates in the decision-making phases of their research projects. During the period, this included the Australian Dementia Network and its project to develop Australia's first memory and cognition clinical guidelines.

It is always very satisfying to see Dementia Advocates receive awards and recognition. Congratulations to Anne Tudor OAM, who was announced as the recipient of the 2021 Premier's Victorian Senior of the Year Award. Please see page 97 which lists all Dementia Australia awards and recognitions for the year and includes many other Dementia Advocates who were recognised for their achievements in 2021-22.

## Policy

The Policy team supports the organisation's systemic advocacy through a range of policy and advocacy activities that reflect and advance our objectives.

During the reporting period, ongoing work to realise the ambitious scope of our **Roadmap for Quality Dementia Care** document remained a key focus for the Policy team. Many aspects of the roadmap have been delivered through the aged care reform process and via the 2021 Federal Budget, which allocated an extraordinary \$229.4 million in increased dementia funding. In February 2022, the Policy team developed the Parliamentary Friends of Dementia paper **Delivering on a Roadmap for Quality Dementia Care**. This highlighted outstanding areas still requiring attention. The paper detailed three key aspects important to the quality of life for people living with dementia, their families and carers: improving the dementia capability and capacity of the aged care workforce; the need for a national specialist dementia palliative care program; and expansion of the Dementia-Friendly Communities program. The policy team collaborated with the Dementia-Friendly Communities team to produce the discussion paper **Support. Encourage. Empower. Leading the way towards a Dementia-Friendly Community** which was launched at the Parliamentary Friends of Dementia event in November 2021.

With the first anniversary of the findings of the Royal Commission into Aged Care Quality and Safety occurring during the reporting period, work also continued on outstanding matters arising from the commission. The Policy team continued to contribute to Dementia Australia's response to the royal commission, with work on areas including universal



adoption of an aged care COVID-19 visiting code.

During the reporting period the Policy team responded to more than 20 federal and state and territory inquiries and consultations, including the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

The team also conducted extensive consultation with Dementia Advocates to develop a series of policy position statements on issues impacting people living with dementia, families and carers. A regular webinar series conducted with the Centre for Dementia Learning highlights the statement themes with stakeholders.

Other proactive policy work included advocating on issues such as younger onset dementia and access to allied health for people living with dementia, including publishing and promoting a joint policy position statement on physiotherapy with the Australian Physiotherapy Association.

## Government relations

In the lead up to a federal election, our work building relationships with key parliamentarians and policymakers to strategically make the case for action on dementia care, led by our Government Relations team, continued to be critically important.

In our pre-Budget submission and throughout the election campaign, we called for a commitment to building workforce capability with a focus on the need for compulsory



## Trevor Crosby

Dementia Australia was saddened to lose long-term Dementia Advocate Trevor Crosby in October 2021.

Trevor was a dedicated advocate who served on committees, participated in numerous media interviews and research studies, spoke at events and much more.

Trevor's witness statement and appearance at the Royal Commission into Aged Care Quality and Safety, along with his appearance on the Focus on Aged Care episode of ABC Q+A in February 2021, were powerful and poignant moments.

dementia education. We also called for a commitment to a national dementia palliative care program and renewed funding of the Dementia-Friendly Communities program.

Our work and engagement with the new federal government, opposition and crossbench representatives will continue into the next financial year and beyond.

One way we bring together elected representatives from across the spectrum is through our biannual Federal Parliamentary Friends of Dementia events. In November 2021, our Chair, Professor Graeme Samuel AC, hosted a Parliamentary Friends event focussing on Dementia-Friendly Communities; while our February 2022 event helped hone our pre-Budget submission. Both events were hosted online due to COVID-19 restrictions. We acknowledge the support of Parliamentary Friends of Dementia Co-Chairs Dr Katie Allen MP, Member for Higgins and Senator Helen Polley, Senator for Tasmania.

While COVID-19 also impacted our ability to engage in person with state and territory governments we remained in contact with regular communications, inviting them to participate in and support Dementia Action Week, Dementia-Friendly Communities and to become active Dementia Friends. We provide discussion papers, resources, toolkits, information and ongoing updates to our services to enable them to best support their own communities and to have a well-formed understanding of dementia to inform their policy and decision-making roles.

## Communications

The Dementia Australia Communications team works to raise awareness and inspire action by amplifying our messages through the media, social media, publications and communications activity.

As always, this reporting period saw the Communications team provide support and expertise across the organisation, including for the work of the Centre for Dementia Learning and the Fundraising, Policy, Dementia Australia Research Foundation, Dementia-Friendly Communities and Client Services teams.

The Communications team contributed to and led significant campaigns across the year, including by organising high-profile media coverage. Campaigns included Dementia Action Week, the 2022 Memory Walk & Jog series, the launch of new **Ask Annie** modules and the 2022 federal election strategy (more information on this in the Government Relations section starting on page 81).

In addition, the Communications team supported the extraordinary work of the Penrith Panthers in raising awareness of Royce's Big Walk, which saw Rugby League and Penrith Panthers legend Royce Simmons walk 300 kilometres in 11 days, raising \$730,000 for the Dementia Australia Research Foundation.

Examples of successful media coverage for the year include an episode of the ABC's You Can't Ask That featuring Dementia Advocates; a major ABC 4 Corners program featuring our



Above: (L-R) Dementia Advocates Gwenda Darling and Kevyn Morris were a part of a group of Dementia Advocates who participated in an episode of ABC TV's You Can't Ask That which explored dementia.

Honorary Medical Advisors and Board Chair Professor Graeme Samuel AC; and a chapter in The Age and Sydney Morning Herald's Explain That book published in late 2021.

The Communications team continued to lead the organisation's social media strategy, including new initiatives such as InstaLives, a series of live Instagram video interviews with CEO Maree McCabe AM. Interviews included Ita Buttrose AC OBE, Dementia Australia Patron, discussing Dementia-Friendly Communities, Andrew 'Reidy' Reid, Dementia Australia Ambassador, speaking about his Sydney Harbour Splash fundraiser and Felicity 'Flick' Palmateer, Dementia Australia celebrity supporter, reflecting on Dementia Action Week. The InstaLive series allowed us to leverage the profiles of our supporters and introduce dementia to new audiences.

The team leads the internal communications strategy, which focuses on supporting and engaging staff through initiatives like the weekly staff newsletter, regular intranet news updates and all-staff meetings. During the reporting period the internal communications team developed and uploaded 280 news stories and almost 100 CEO and executive director updates to the Dementia Australia intranet, resulting in 312,958 total views.

Fittingly, the Communications team achieved recognition in the International PRNEWS Nonprofit Awards, winning in the Advocacy Campaign and Lobbying Efforts and PR on a Shoestring Budget categories and achieving an honourable mention in the PR Event category.

# Dementia-Friendly Communities

By promoting inclusive communities that enable people living with dementia to live well, the **Dementia-Friendly Communities** program aims to reduce the stigma, isolation and discrimination experienced by people living with dementia, their families and carers.

The Dementia-Friendly Communities team promotes the establishment of local Dementia Alliances; provides grant funding to local demonstration projects; and helps community organisations and businesses be more accessible and inclusive of people living with dementia. It works directly with communities and provides an online hub and forums.

It is always exciting seeing grants and advocacy work come to fruition with tangible projects in communities. Dementia-Friendly Community grants awarded in 2020 resulted in some innovative projects launched during the reporting period. These included the Woookarung Regional Park Dementia Sensory Trail in Ballarat, Victoria; and the work of the Green Head Community Association in Western Australia, which organised a town audit, moved to create a local Dementia-Friendly Alliance and provided community-led information and social activities.

Below: (L-R) Cr Lisa Atwood, Brisbane City Councillor for Doboy Ward, and John Quinn, Dementia Advocate, after Brisbane City was acknowledged in September 2021 as the first capital city in Australia to gain formal recognition in working towards becoming a Dementia-Friendly Community. Cr Atwood accepted the certificate of recognition on behalf of Brisbane Lord Mayor Adrian Schrinner.



Similarly, grassroots work by the Brisbane South-East Dementia Alliance was behind an exciting commitment by major cultural institutions to create a dementia-friendly Brisbane as a strategic element of the Brisbane 2032 Olympic and Paralympic Games. In October 2021 we held a formal event to acknowledge the vision and commitment of Brisbane City Council; Queensland Art Gallery and Gallery of Modern Art; University of Queensland's Healthy Living Centre and Art Museum; and Iona College.

In the Northern Territory, Dementia-Friendly Communities Program Officer and Aboriginal Dementia Support Services Specialist Glen Woods continued his work with diverse Aboriginal and Torres Strait Islander communities to promote awareness and dementia-friendly communities. Glen delivered formal and informal talks in communities; worked directly with aged care assessment teams and aged care providers; and participated in public speaking at events. He is working with local community organisations on projects including the development of culturally tailored dementia information resources in traditional languages and supporting Ngangkari (traditional Aboriginal healers) to promote understanding of dementia.

The Dementia-Friendly Communities team participated in Dementia Action Week with Dementia Alliances and Dementia Friends nationwide organising their own activities and

celebrations. In North-West New South Wales, the Narrabri Dementia Alliance found a creative way to celebrate the week, hosting a dementia rock hunt. Local aged care residents, staff and carers of people living with dementia painted rocks with bright images and dementia messages and left them near popular walking paths for excited children and families to find. With finders sharing their rocks on social media, the event encouraged people to think and talk about dementia.

Our political advocacy activities also continued throughout the reporting period. A Parliamentary Friends of Dementia meeting in November 2021 focussed on Dementia-Friendly Communities and saw the release of the **Support. Encourage. Empower. Leading the way towards a Dementia-Friendly Community** discussion paper. The paper detailed the ways in which the Dementia-Friendly Communities program has succeeded in improving dementia knowledge, facilitating inclusivity and reducing stigma and discrimination in the community.

A request for an extension of funding for the program was a key part of Dementia Australia's Federal Budget submission and was also a federal election priority.

# Advocacy and Research statistics

## Dementia Australia Dementia Advocate program data\*

### New Dementia Advocates who joined the program



### Dementia Advocates ages



### Dementia Advocates from a CALD background



### Indigenous Dementia Advocates

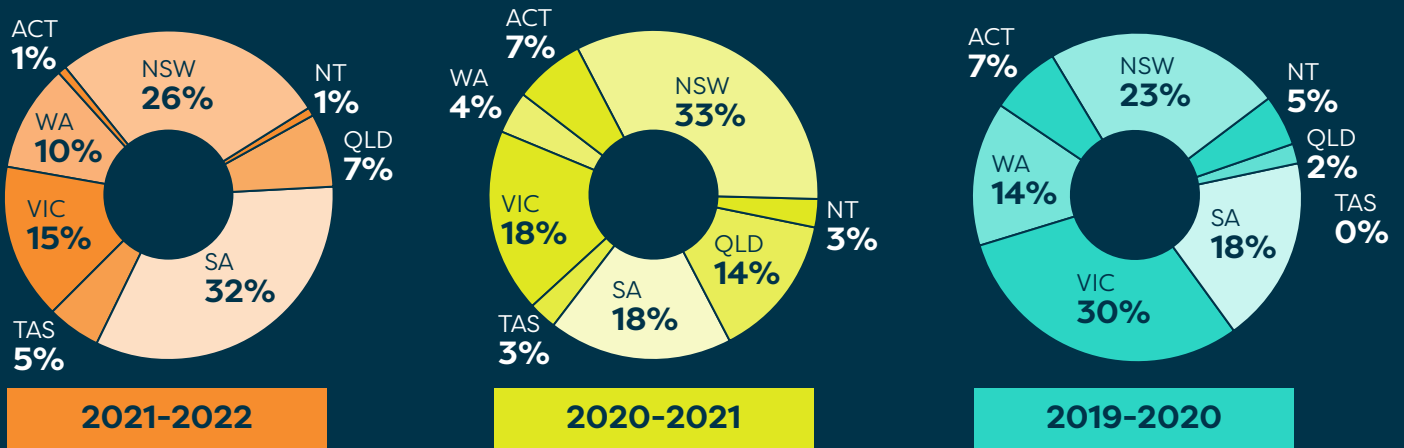


### LGBTI Dementia Advocates



\*Data is reflective of Dementia Advocates who newly joined the program within each listed year.

## Dementia Advocate locations – state and territory



## Dementia Advocate locations – regional, rural and remote



Period	Regional	Rural	Remote
2021-2022	23%	6%	2%
2020-2021	30%	9.5%	0%
2019-2020	24%	11%	1%

## Dementia-Friendly Communities

### Dementia Friends

As of	As of	As of
30 June 22	30 June 21	30 June 20
<b>34,959</b>	<b>32,632</b>	<b>13,313</b>

### Dementia Alliances

As of	As of	As of
30 June 22	30 June 21	30 June 20
<b>57</b>	<b>53</b>	<b>43</b>

# Dementia Australia Research Foundation



The **Dementia Australia Research Foundation** is the research arm of Dementia Australia. We support innovative Australian research to find an end to dementia. We work collaboratively with people living with dementia, their families and carers to ensure that our research reflects their concerns.

We believe science holds the key to ending dementia, so our annual Dementia Grants Program provides funding to support innovative Australian research to better understand the causes of dementia, develop strategies to reduce dementia risk and slow the progression of the disease, provide accurate and timely diagnoses, improve treatment and care options for people living with dementia and find a cure for dementia.

## 2021 Dementia Grants Program

Excitingly, the 2021 Dementia Grants Program was the biggest on record, with more than \$5 million distributed to 29 applicants for Project Grants, Innovation Grants and Post-Doctoral and Mid-Career Fellowships.

They included Dr Karissa Barthelson from Flinders University, the 2022 recipient of the Race Against Dementia – Dementia Australia Research Foundation Post-doctoral Fellowship program. Dr Barthelson received \$405,000 over three years, to support her work exploring similarities between adult and childhood-onset dementias.

Research projects that will test how acoustic sleep technology and a new drug treatment can help reduce toxins associated with the development of Alzheimer's disease also received major grant funding.





Above: Rugby league and Penrith Panthers legend Royce Simmons at the beginning of his walk from his hometown of Gooloogong, NSW to Penrith in which he raised \$730,000 for the Dementia Australia Research Foundation. Photo: Henry Ward, Penrith Panthers

Associate Professor Clare Anderson, from Monash University, and Professor Michael Parker, from St Vincent's Institute of Medical Research, were both awarded a Faye Williams Innovation Grant, each worth \$375,000.

In an Australian first, Associate Professor Anderson's team at Monash University's Turner Institute for Brain and Mental Health will use cutting edge acoustic stimulation technology to stimulate slow wave sleep in research participants, providing a breakthrough in our understanding of the role of sleep in the development of Alzheimer's disease.

Professor Parker and his team will test a new drug that may help enhance the brain's ability to clear the toxins associated with the development of Alzheimer's disease.

We thank our supporters, donors and partners who have supported the grants, including Bondi2Berry, Faye Williams, Norma Beaconsfield, McCusker Charitable Foundation, Royce Simmons Foundation and Dementia Australia Research Foundation partners Race Against Dementia, NHMRC Dementia Centre for Research Collaboration and the Australian Association of Gerontology.

## Governance

The Board of Directors is the major decision-making body for the foundation. The board is responsible for providing leadership and strategic direction, advice on funding opportunities and oversight of our operation and financial position. This year, we welcomed Dementia Advocate Isabelle Burke to the board.

The Dementia Australia Research Foundation Scientific Panel provides research advice and external assessment of grants under our programs. During the reporting period four members completed their terms and stepped down from the panel. Thank you to Associate Professor Rosie Watson, Associate Professor Nawaf Yassi, Associate Professor Michele Callisaya and Professor Lee-Fay Low for their invaluable voluntary service.

We welcomed Associate Professor Joanne Ryan, Associate Professor Margaret MacAndrew and Associate Professor Stephanie Rainey-Smith to the panel.

## Strategic review

In April 2022, the co-Chairs of the Scientific Panel joined the board to discuss the strategic direction of the foundation. The review reaffirmed support for early and mid-career researchers and building strategic partnerships that better facilitate dementia research. It backed a further term for the newly created Dementia Australia consumer engagement coordinator (research) role, which supports people impacted by dementia to be actively involved in research studies.





## Fundraising support

In April our researchers were delighted to receive a visit from Dementia Australia Patron and Race Against Dementia Founder and Chairman Sir Jackie Stewart OBE, during his trip to Australia for the Grand Prix. Sir Jackie's visit included inviting Race Against Dementia - Dementia Australia Research Foundation Fellows to join him trackside at the Grand Prix and a special tribute event held in his honour, which raised \$666,230 for Race Against Dementia - Dementia Australia Research Foundation Post-Doctoral Fellowships. You can read more about the event on page 66 of the report.

In May it was exciting to see NRL and Penrith Panthers legend Royce Simmons, raise \$730,000 for the foundation by walking 300 kilometres from his hometown of Gooloogong in central New South Wales to Penrith.

Above: Dr Karissa Barthelson from Flinders University, was awarded a Race Against Dementia - Dementia Australia Research Foundation Post-doctoral Fellowship to explore the similarities between adult and childhood-onset dementias.

Opposite: Dementia Australia Patron Sir Jackie Stewart OBE visited the Brain and Mind Centre, The University of Sydney, while in Australia for the 2022 Formula 1 Australian Grand Prix. (L-R), Dr Andrew McKinnon, Race Against Dementia - Dementia Australia Research Foundation Post-doctoral Fellow, Brain and Mind Centre, Sir Jackie Stewart OBE, Race Against Dementia Founder and Chairman, Dementia Australia Patron, Professor Olivier Piguet, Brain and Mind Centre and Scientific Panel member, Dementia Australia Research Foundation.

# Awareness raising



Ita Buttrose, AC OBE, Dementia Australia Patron, continued her long-time commitment as a Patron helping to raise awareness in numerous ways throughout the year. This included promoting the Ask Annie app, going live on Dementia Australia's Instagram account with CEO Maree McCabe AM to discuss the importance of dementia-friendly communities and much more.

Our awareness raising work centres on designing and delivering campaigns and events that build knowledge and support, moving us closer to our vision of creating an inclusive future where all people impacted by dementia can receive quality care and support.

This reporting period our major campaigns included:

## **Eat.Play.Rest**

The **Eat.Play.Rest** campaign aimed to increase awareness of our services among younger audiences, in particular women aged 25-39.

Launched during Brain Awareness Week in March 2022, the campaign featured practical tips on how to improve and maintain brain health based on eating well, regular recreation (playing often) and regular rest.



Above: The Eat.Play.Rest campaign was launched in March 2022 and is aimed at women aged 25-39. It features practical brain health tips centred on eating well, regular recreation and rest.



Above: A still from Dementia Australia's 2021 discrimination campaign featuring Dementia Advocate Juanita Hughes.

## Discrimination and awareness campaign

During Dementia Action Week 2021 we launched our **A Little Support Makes a Big Difference** campaign to help combat dementia discrimination. We used television, social media, radio, newspapers and a dedicated website to share information and real-life stories. At the heart of the campaign were the stories of Dementia Advocates who generously shared their experiences and perspectives. The campaign continued beyond Dementia Action Week with a FAQ series on our social media channels and story-centred advertisements aired on catch-up television.

The campaign's success was recognised at the Alzheimer's Association International Conference, a major global scientific event, where we submitted an abstract which was accepted in the form of a poster presentation.

## Always-on campaign

In April 2021 we launched an always-on campaign, a new approach to ongoing promotion of our professional education opportunities to audiences such as GPs and other health care professionals, aged care professionals, people living with dementia, their families and carers, and the general public.

Using videos, advertisements, electronic direct marketing and printed materials, the campaign content highlighted dementia prevalence, our award-winning and evidenced-based experiential and flexible approaches to learning and demonstrated our commitment to quality dementia care.

## Patron, Ambassador and Honorary Medical Advisor activity

In addition, during the reporting period we were pleased to support the important advocacy and awareness raising work undertaken by our Patrons, Ambassadors and Honorary Medical Advisors.

Our Patrons, Ambassadors and Honorary Medical Advisors are high-profile and respected members of the community inspired by their own dementia experience and knowledge to champion our cause. Across the year they supported Dementia Australia through activity such as Dementia Action Week, Memory Walk & Jog, support and promotion of Eat.Play.Rest and the Ask Annie app, advocacy, media interviews, social media activity, public speaking engagements, additional fundraising activity and more. We thank all of our Patrons, Ambassadors and Honorary Medical Advisors for their significant contributions.



# Awareness raising statistics

## Media pieces generated

2021-2022	2020-2021	2019-2020
<b>5,486</b>	<b>3,300</b>	<b>3,338</b>

## Organic combined social media engagements\*

2021-2022	2020-2021	2019-2020
<b>212,738</b>	<b>242,967</b>	<b>237,568</b>

## Combined social media followers

2021-2022	2020-2021	2019-2020
<b>167,706</b>	<b>154,738</b>	<b>140,708</b>

## eNews subscribers<sup>^</sup>

2022	2021	2020
<b>33,000</b>	<b>33,000</b>	<b>29,890</b>

## Total paid social media reach

2021-2022	2020-2021	2019-2020
<b>3.5 million</b>	<b>2.5 million</b>	<b>2 million</b>

## Discrimination campaign

Impressions and engagement actions<sup>#†</sup>

2021-2022	2020-2021	2019-2020
<b>11,285,035</b> impressions	<b>4,143,403</b> impressions	<b>12,879,842</b> impressions
<b>26,811</b> engagement actions	<b>23,804</b> engagement actions	<b>14,846</b> engagement actions

## Website user visits

dementia.org.au

2021-2022	2020-2021	2019-2020
<b>1,185,350</b> total visits	<b>1,168,508</b> total visits	<b>993,382</b> total visits
<b>1,167,491</b> unique visits	<b>1,150,882</b> unique visits	<b>966,888</b> unique visits
<b>1,454,664</b> actions taken	<b>1,221,908</b> actions taken	<b>1,297,102</b> actions taken

## Website user visits

discrimination.dementia.org.au

2021-2022	2020-2021	2019-2020
<b>131,463</b> total visits	<b>212,739</b> total visits	<b>37,630</b> total visits
<b>128,493</b> unique visits	<b>210,048</b> unique visits	<b>24,425</b> unique visits
<b>37,630</b> actions taken	<b>24,183</b> actions taken	<b>n/a<sup>‡</sup></b> actions taken

\*Organic social media is the status updates (i.e. posts) that appear on Dementia Australia social media pages and are not advertisements. Engagements are a tally of all comments, likes and shares across these posts. Dementia Australia's social media channels include Facebook, Instagram, Twitter and LinkedIn.

<sup>^</sup>As of 30 June of each year.

<sup>#</sup> Impressions and engagement actions include paid TV, digital and social media content.

<sup>†</sup> Impressions equate to the number of times paid content appeared on TV, digital spaces or social media.

Engagement actions equate to each time there was a click or download from a paid content item.

<sup>‡</sup> Discrimination website was not live during 2019-2020 financial year.

# Our thanks

We would like to acknowledge all those who have generously supported Dementia Australia in 2021-22. These include substantial bequests, in memoriam donations, major sponsors, philanthropic trusts, foundations and private ancillary funds, individuals, companies, organisations, community fundraisers and volunteers.

We thank the following organisations and individuals for their support and generosity. Every gift is appreciated.

- AbbVie
- Aged Persons Welfare Foundation
- Ainsworth Foundation
- Angior Family Foundation
- Australian Philanthropy Services Foundation
- auDA Foundation
- Australian Communities Foundation
- Australian Unity Trustees Foundation
- CAGES Foundation
- Classic Ladies Foundation
- Commbank Staff Foundation
- Dick & Pip Smith Foundation
- Dubsky Lang Foundation
- Equity Trustees
- Fitzpatrick Sykes Family Foundation
- Frances Jane Edwards and Martha Elizabeth Sirovs Foundation Fund
- Gandel Foundation
- Ian Malouf Family Foundation
- IOOF Foundation
- Isabel & John Gilbertson Charitable Trust
- Jack Tilburn Endowment
- James Frizelle Charitable Foundation
- Joe White Trust
- John T. Reid Charitable Trusts
- Johnson Family Foundation
- KPMG
- Lord Mayor's Charitable Foundation
- Lucas' Papaw Remedies
- McIntyre Foundation Pty Ltd
- Mostyn Family Foundation
- Newcastle Permanent Charitable Foundation
- NSW Community Building Partnership Program – Newcastle electorate grant
- NSW Community Building Partnership Program – Ryde electorate grant
- Perpetual Foundation
- Pethard Tarax Charitable Trust
- Priceline Sisterhood Foundation
- Race Against Dementia
- Rosemary Norman Foundation
- Royce Simmons Foundation
- State Trustees Australia Foundation
- Skipper-Jacobs Charitable Trust
- Spencer Investments
- Sunrise Foundation
- Tasmanian Community Fund
- The Busby Family Fund
- The Co-Group
- The Eastern Star Foundation
- The Gauvin Family Foundation
- The Gloria and Douglas Mathews Endowment



- The Handbury Foundation
- The Jack Brockhoff Foundation
- The La Manna Family
- The Madeline Crump & Madeline Williams Trust
- The Mandy Deam Foundation
- The McCusker Charitable Foundation
- The Patrick Foundation
- The Rydge Foundation
- The Schwinghammer Foundation
- The Small Family Bequest, a fund managed by Equity Trustees
- The Sparrow Foundation
- The Stuart Leslie Foundation
- The Yulgilbar Foundation
- VPGH
- Waverley Council Staff Charitable Trust
- William Angliss Charitable Fund
- Wood Family Foundation
- Woodend Family Foundation

### **Government**

Dementia Australia acknowledges the support of the Commonwealth Government and all State and Territory Governments.

## **Awards and recognition**

Dementia Australia acknowledges and congratulates the following teams, projects, initiatives and people who have been recognised for their achievements in 2021-22.

### **Queen’s Birthday Honours**

Val Fell OAM, Dementia Advocate – Medal of the Order of Australia (OAM) for her service to people impacted by dementia – June 2022

### **Queensland Day Awards Winner, Community Champion Award**

Juanita Hughes, Dementia Australia Advisory Committee member, Dementia Advocate – June 2022

### **International PRNEWS Nonprofit Awards Winner**

Advocacy Campaign and Lobbying Efforts category for Securing a \$229.4 million commitment to dementia in Australia – March 2022

### **International PRNEWS Nonprofit Awards Winner**

PR on a Shoestring Budget category for Dementia Australia Library promotion campaign – March 2022

### **International PRNEWS Nonprofit Awards Honourable mention**

Event PR category for Memory Walk & Jog – March 2022

### **2022 Lord Mayor’s Australia Day Awards Winner, Achievement Award**

Glenys Petrie and John Quinn, Dementia Advocates – January 2022

### **innovAGEING National Awards Winner**

Increasing Access to Care and Services category for Client Services Carer Wellbeing Program – December 2021

**innovAGEING National Awards Finalist**

Enhancing Consumer Experience category for Client Services Post Diagnostic Support Program – December 2021

**Victorian Senior of the Year Awards Winner, Premier's Victorian Senior of the Year category**

Anne Tudor OAM, Dementia Advocate – November 2021

**Queensland Community Achievement Awards Finalist, Australia Pacific LNG Community Hero Award**

Juanita Hughes, Dementia Advocate – November 2021

**South Australia Community Achievement Awards Finalist**

Office for Ageing Well Tackling Ageism Award - Ian Gladstone, Dementia Advocate – November 2021

**Future of Ageing Awards Winner**

Service Transformation category for Communities of Practice, Dementia Australia – October 2021

**Future of Ageing Awards Winner**

Community Engagement category for Dementia-Friendly Communities Program, Dementia Australia – October 2021

**Future of Ageing Awards Highly-commended**

Consumer Experience category for Dementia Australia Advisory Committee – October 2021

**Future of Ageing Awards Highly-commended**

Indigenous Communities category for Exploring Dementia Program, Dementia Australia – October 2021

**Hesta Excellence Awards Finalist**

Team Excellence in Aged Care category for Centre for Dementia Learning, Dementia Australia – July 2021

**Hesta Excellence Awards Finalist**

Team Excellence in Allied Health category for Blokes in a Caring Role, Dementia Australia – July 2021

**Volunteering Victoria weVolunteer Community Champions Awards**

Winner, State Community Champions (1 of 5) category - Loren Kumeroa, Dementia Australia volunteer – July 2021



Above: Gold Coast Memory Walk & Jog 2022 participants.



**No matter how**  
you are impacted by dementia  
or who you are, **Dementia**  
**Australia is here for you.**

# National Dementia Helpline **1800 100 500**



For language assistance  
call **131 450**

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Find us online  
**dementia.org.au**



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We welcome your feedback on this  
report and any of the activity reported.  
Email: [admin@dementia.org.au](mailto:admin@dementia.org.au) or  
call **+61 2 6278 8900**

The National Dementia Helpline is funded by the Australian  
Government © Dementia Australia 2022, 22114, November 2022.  
ISSN 2652-0931