Welcome from our Chair

In October last year it was with great pleasure that we officially launched Dementia Australia as the new voice of Alzheimer’s Australia for the 425,000 Australians of all ages, living with all forms of dementia, their families and carers.

In the eight months since then our transition to a unified, national peak body is proving to be timely and valuable as the benefits of shared resources, knowledge and expertise make a positive impact across all our services, including education, counselling and support.

While we still have some way to go, it is encouraging and rewarding to see how far we have come. As a bigger, stronger, bolder Dementia Australia we continue to take shape, gain confidence and capacity to not only keep the subject of dementia front of mind in the political and public interest, but to seek and capitalise on opportunities to ensure the needs of every Australian living with dementia and their family are heard, respected and prioritised.

This has been evidence through continued media coverage that has constantly kept dementia in the news and in conversations around Australian dinner tables. More recently, our recommendations to the Federal Government’s Carnell-Paterson review for a simpler and more accessible safety and quality regime for aged care has resulted in the creation of the Aged Care Quality and Safety Commission that will provide a single point of contact for dealing with claims of sub-standard care.

This merging of the Australian Aged Care Quality Agency, Aged Care Complaints Commissioner and the aged care regulatory functions of the Department of Health into a single entity will benefit people living with dementia, their families and carers.

This Commission is one of many measures Dementia Australia has called for and we are pleased to see it included in the Federal Government’s 2018 budget, as part of its $5 billion dollar commitment to the aged care sector. And, while we welcome this investment to help ensure better access, better quality and overall better ageing for all Australians, we would also like to see the government recognise dementia as the significant health and social challenge that it is, as well as a core business with more than 50 per cent of residents in aged care having a diagnosis of dementia and many more remaining undiagnosed.

In addition to advocacy we continue in our role to inform people about Dementia Australia’s many services that enable people living with dementia to stay at home longer and for thousands of Australians to better understand and manage the diagnosis, its progression and to live well with dementia.

I would like to acknowledge the incredible dedication of our teams of staff and volunteers, and the contributions of our consumers around Australia.

I look forward to a future full of promise for Dementia Australia, and most importantly, for the people we are here to serve.

Prof Graeme Samuel AC
Chair Dementia Australia
Welcome to the latest edition of Connections.

This edition I would like to discuss the very important topic of raising awareness and reducing stigma around dementia. But, what does this really mean and why is it so important?

Raising awareness and reducing stigma is about supporting members of the general community to become dementia aware by being able to identify the signs of dementia, knowing how to communicate effectively and developing compassion and empathy for the challenges many people impacted by dementia experience.

People living with dementia must be supported to live the life they choose and to be treated with respect. A nationwide survey conducted by Dementia Australia last year showed that despite growing awareness about the condition, people living with dementia still report sometimes feeling incompetent, lonely and isolated. And while members of the community may be empathetic towards people living with dementia, there is a growing demand for education from the community.

Helping to lead this charge with Dementia Australia is one of the founding members of the Dementia Australia Advisory Committee, John Hiller. John is one of our extraordinary Dementia Advocates who generously contributes to our work to increase understanding of how to better support people impacted by dementia. I encourage you to read John’s inspiring story on page 8.

I’d also like to draw your attention to two campaigns Dementia Australia was pleased to launch in March – our “Dementia Friends” campaign to promote community awareness and understanding. And, our “Turn to Us” campaign to remind everyone impacted by dementia that Dementia Australia provides many fantastic services to assist people to live well with dementia, support is available and you do not have to face this alone.

Before I sign-off, I would like to acknowledge the Federal Government’s $5 billion dollar commitment to the aged care sector in its 2018 budget. We very much welcome this investment and the difference it will make to the lives of older Australians. We would also like to see a greater focus on dementia and with it the funding to address the condition now and into the future.

As we all know, dementia impacts everyone and we can all play a part to support people living with dementia to have the opportunity to remain engaged with their community and lead the life that is important to them. Together, we can make a difference.

Maree McCabe
CEO Dementia Australia
Demystifying dementia

Although more than 425,000 people are living with dementia in Australia and the figure is expected to increase to over a million by 2056, dementia is still a highly misunderstood condition. The lack of community awareness and misinformation can contribute to social stigma which can have a devastating impact on the lives of people living with dementia, leading to discrimination, social isolation, which may even affect a person’s willingness to seek help or a diagnosis.

Jim is living with Alzheimer’s disease. When his father was diagnosed with dementia 20 years ago, people knew very little about it. “If you don’t understand something, you walk away from it,” he says.

The Dementia and the Impact of Stigma survey undertaken by Dementia Australia last year revealed many people within the community are still unfamiliar with dementia.

The national survey found that although there is some understanding of dementia in the general community, it is alarmingly low. More than half the survey respondents did not know the relationship between Alzheimer’s disease and dementia; and more than 80 per cent did not know that dementia is the second leading cause of death in Australia. This is despite the fact that one-third of respondents reported someone close to them had a diagnosis of the condition.

Dr Kaele Stokes, Dementia Australia’s Executive Director Consumer Engagement, Policy and Research said there is evidence that suggests the stigma around dementia continues due to a lack of awareness about the condition.

“What is very clear is that there are members of the community that are still unfamiliar and uncertain about dementia,” she said.

“Many people don’t understand that dementia is a disease of the brain and that it is not a natural part of ageing.”

This lack of understanding is reflected in the way people feel about those living with dementia. According to the survey, 39 per cent of people said they felt awkward around someone living with dementia.

Jim’s wife and carer, Jan, mentioned that since her husband was diagnosed socialising has become especially difficult.

“When people do speak with him, sometimes they talk down to Jim as if he is a child.”

The way we respond as a community can leave people living with dementia and their carers feeling embarrassed and uncomfortable in social situations. In fact, 94 per cent of respondents who have a diagnosis and 60 per cent of carers said they encountered embarrassing situations as a result of dementia.

Maree McCabe, Dementia Australia CEO said we all play an important role in helping to reduce social prejudice.

“As a community, we must be inclusive, respectful, kind and understanding to enable people with dementia to live well as valued members of society,” Ms McCabe said.

Dementia Australia is working to reduce stigma in the community through groundbreaking virtual reality technologies, online resources, major initiatives such as Dementia Friendly Communities and countless community services.

Jim’s daughter, Tara, confirmed there is a growing awareness developing within the community.

“Work was really supportive when I told them about Dad’s diagnosis. They were understanding and let me take time off no questions asked,” she said.

“A family counselling session helped get us all on the same page and to reduce the stigma of dementia within our close group.”

Dementia Australia provides support for people, of all ages, living with all forms of dementia, through vital services such as the National Dementia Helpline and counselling.

You can help break down social stigma by starting a conversation and letting the person living with dementia or their carer know that they are not alone.

Find out more information on Dementia Australia at dementia.org.au. Sign up to become a Dementia Friend at dementiafriendly.org.au.
New program supports older Australians navigate car-free life

For many older Australians, and particularly those living with dementia, relinquishing their driver’s licence is a pivotal and potentially overwhelming event. The decision to hand over the car keys can prove difficult, leaving many feeling as if they have lost their independence. It also presents a challenge to primary carers and GPs often tasked with delivering the difficult news.

Dr Theresa Scott, National Health and Medical Research Centre and the Australian Research Council (NHMRC-ARC) Research Development Fellow at the University of Queensland, is working with a research team to develop CarFreeMe – a program that will provide practical and emotional support for those advised they should stop driving.

Dr Scott has found that timing is everything when it comes to relinquishing a driver’s licence.

“The transition to non-driving comes at significant personal cost, including increased risk of depression, anxiety, loneliness and isolation, identity loss and grief. As symptoms of dementia progress, people lose insight into their driving ability and how it may affect others. Therefore, the ideal situation is for voluntary and gradual driving cessation,” notes Dr Scott.

“Changes to driving status not only impact the individual who is stopping driving but also their family members supporting them. Often people are less upset with the process if they come to the conclusion themselves earlier rather than later.”

With trials currently underway, CarFreeMe is an evidence-based approach to supporting people living with dementia who are adjusting to life without driving. It is focused on emotional and practical issues. CarFreeMe participants collaborate with a trained health professional, one-on-one and in small group sessions, to develop tailored solutions to individual needs based on their location and access to alternative forms of transport.

In addition to the trials underway in Queensland, Dr Scott’s team is developing a telehealth resource for general practitioners, primary carers and health professionals to manage this significant change.

Dr Scott hopes that this resource will be particularly helpful for general practitioners in rural and remote areas, where transport options are limited, and practitioners have often developed a relationship with patients over a significant period. In these instances, delivering the news that a person can no longer drive can have long-term care implications, fundamentally changing the relationship and sometimes resulting in patients seeking care elsewhere.

“It’s Not a Disgrace, It’s Dementia”

A series of short films produced by Dementia Australia in different languages aims to address the myths and stigma about dementia that often exist in Culturally and Linguistically Diverse (CALD) communities.

The award-winning, 'It's Not a Disgrace, It's Dementia' series includes 12 films aimed at non-English speaking communities in Australia, and is designed to encourage acceptance of dementia as a medical condition, not a normal part of ageing. It also encourages families to seek support within their local service network.

“Dementia is a condition that affects us all; it doesn’t discriminate,” Dementia Australia Sector and Capacity Program Manager Gary Thomas said.

“Australia is one of the most multicultural societies in the world, which is why it’s so important that we make sure our resources are accessible to everyone, no matter what language they speak.”

The films are around 15 minutes in length and are available in Spanish, Italian, Portuguese, Mandarin, Arabic, Serbian, Cambodian, Vietnamese, Assyrian, Croatian, Ukrainian and Hindi - all with English subtitles.

Each film features carers of people living with dementia giving personal accounts of their experiences in their own language, along with health professionals who provide insight into the condition.

The series can be viewed online at the Dementia Australia Australia YouTube channel.
Primary school student raises money for Dementia Australia

Year six primary school student, Esther Worthington, recently held a successful cake stall fundraiser for Dementia Australia, to honour her grandmother, Denise, who was diagnosed with dementia in 2007, and passed away four years ago aged 73.

Esther has beautiful memories of her grandmother, who she lovingly called Dinny.

“One thing I remember about Dinny was that she was so kind. Even if you did something naughty she never got cross and she was always calm. She was also a giver. She spent most of her time giving everything she had to people less fortunate. For most of her life she settled refugee families. Without her help they would have had nothing when they arrived in Australia,” Esther said.

“Everyone she met immediately became Dinny’s friend. She loved her grandchildren to bits and loved to spoil us whenever she got a chance. I cannot think of one boring moment with her, even if it was something like going for a walk, Dinny would find a way to make it fun. I could never ask for a better grandmother because she was the best.”

In the intervening years, and as the condition progressed, Esther acknowledges that it was a difficult time for her family. They knew the condition would be fatal so they cherished the time they had with Dinny. They also reached out to Dementia Australia and were grateful for the support they received.

“It was a challenging time for my family but I can remember the wonderful support we received from Dementia Australia and the community,” she said.

Below Esther with her grandmother, Denise, in earlier days
Esther never forgot the support her family received from Dementia Australia, and when an opportunity arose to undertake a school project to raise money and awareness for a charity, she chose Dementia Australia.

“I wanted to do something to give back to everyone who helped us. So, when we were given our homework task I knew I would do it for Dementia Australia.”

“In memory of Dinny I wanted to raise money and awareness about dementia by putting together a cake stall.”

Esther mobilised her friends to help bake cakes, cupcakes and chocolate crackles to sell at her cake stall. Thanks to community support, Esther raised an impressive $730 for Dementia Australia.

“It was incredible to have my local community come together for a good cause. It was a really good feeling to be doing something to honour my Grandma and to help other people going through what Dinny and my family went through.”

---

**Men’s Shed boosted by donor generosity**

Dementia Australia has long been supporting a number of male consumers to attend the Majura Men’s Shed in the ACT. The group meets each Wednesday at 10:00 am to build various items including dog houses, insect hotels, bird feeders, chopping boards and much more.

We thank Adam McCormack from Icon Water who generously donated tools and a BBQ to the group, which will support them in their activities for years to come.

For more information on the Woodworking group or any other social activations occurring in the ACT, please contact 02 6255 0722 or act.admin@dementia.org.au. For further queries, please contact the National Dementia Helpline on 1800 100 500.
Sharing personal experiences through advocacy

In 2011, John Hiller was diagnosed with younger onset dementia. John’s doctor referred him to Dementia Australia for support and care to assist him to live a fulfilling life after his diagnosis.

A lack of community awareness of dementia prompted John to become a Dementia Advocate. He wanted to tackle dementia head-on; challenge what he saw as the existing stigma and myths that cloud the lives of people living with dementia, their carers and families.

John was also motivated to dispel the belief that dementia is a normal process of ageing and affects only the elderly.

“I was diagnosed at a relatively young age. Physically I haven’t changed, however people don’t understand the difficulties that I struggle with on a daily basis,” he said.

“People with dementia want to be accepted for their individuality, their value to family and community and not be defined by their condition.”

“In order to achieve this, it’s important there is increased awareness and understanding of dementia so people living with dementia can be supported to live a high quality life with meaning, purpose and value.”

“We know there is currently no cure for dementia, however people can learn risk-reduction strategies, like participating in regular physical activities and eating healthily to help reduce their chances of getting dementia,” he added.

John is proud to be one of the founding members of the Dementia Australia Advisory Committee which was established in 2013. The committee consists of 12 people living with dementia who are involved in dementia advocacy.

Committee members provide advice on policy, advocacy and national programs. They also work to promote dialogue between those living with dementia and service providers, to promote a better understanding of how to support people impacted by dementia.

Bringing dementia to Parliament

The Parliamentary Friends of Dementia program is designed to elevate the voice and experience of people living with dementia, families and carers to the level of government through a series of events at state and federal parliament houses.

Co-convened with Members of Parliament and focusing on specific issues of relevance to people impacted by dementia, the Parliamentary Friends of Dementia program raises awareness of dementia among MPs and the communities they serve. The program also gives people living with dementia the opportunity to tell their stories and share their experience with decision-makers.

Parliamentary Friends of Dementia events are typically arranged around a specific policy or consumer issue that has relevance and meaning to people living in the community, for example, access to services for people with younger onset dementia. Dementia Australia engages with Members of Parliament from all sides of politics and the events are consciously bipartisan in their approach.

The program gives people living with dementia the opportunity to share their experience with decision-makers.

Parliamentary Friends of Dementia are not only helping to reduce the stigma of dementia within communities, but they also provide Senators and Members of Parliament with an insight into the issues that impact their electorates. Dementia Australia is currently developing a national strategy to ensure we have Parliamentary Friends all over Australia.
Are you a Dementia Friend?

People living with dementia can find it challenging to participate actively in the community due, in part, to a lack of knowledge or understanding of the condition among the general public and how it can impact people.

Dementia Australia is working to change attitudes towards dementia and encourage communities in which people living with dementia, their families and carers are supported to live the life they choose, and to be treated with respect.

A Dementia Friend is someone who wants to make a positive difference to the lives of people living with dementia through increased awareness and support. It means you have increased your understanding of dementia and how small things you can do can help support people with dementia to remain included, accepted and connected with their community.

To become a Dementia Friend please visit dementiafriendly.org.au. Here you will be guided through a short module designed to increase your understanding of dementia and its impacts. Upon completion of the module you will receive a Dementia Friend certificate and badge.

Most people know someone who is impacted by dementia. It is likely one of your friends may be impacted directly, or know someone who is. Why not refer a friend to be a Dementia Friend? Together, we can be the change more than 425,000 Australians deserve.

Visit dementiafriendly.org.au to sign up and complete the Dementia Friendly Communities online program. You’ll then receive your Dementia Friend kit.

Social Media + Dementia Australia = #Winning

Dementia Australia has a highly engaged online community across its Facebook, Twitter, Instagram and LinkedIn social media platforms. Social media has proven an increasingly effective way of promoting our key messages and educating the community with our awareness campaigns. With almost 45,000 followers on Facebook and 11,000 on Twitter, social media allows us to bring dementia out of the closet and have important conversations in really interesting and innovative ways. It’s also a great way to connect with a new and younger audience.

Our social media presence hinges on interesting and purposeful content, tailored to our audience’s needs. With this in mind, content shared across our social platforms is centered on one key objective – supporting, educating and raising awareness of dementia.

Do you follow us? Visit Dementia Australia on each of our social media platforms.
Dementia Australia welcomes Ben Crocker as Ambassador

Dementia Australia’s newest Ambassador has literally hit the ground running.

Soon after being announced as an Ambassador, Collingwood Football Club’s star half forward Ben Crocker had his first official engagement at the Melbourne Memory Walk & Jog in Templestowe on Sunday 22 April.

His personal connection to dementia comes through his father, Phil, who was diagnosed with younger onset dementia in late 2014 aged just 59. Phil’s diagnosis had a life-changing impact on the whole family. When speaking about becoming an Ambassador for Dementia Australia, Ben said his family and the Collingwood Football Club were right behind him. With the support of the club, Phil has been able to stay at home and remain engaged with his family for longer, which has been important to the whole family.

When informing teammates about his dad, Ben realised there was a lack of public knowledge about the second leading cause of death in Australia, particularly younger onset dementia, which contributed to his decision to join Dementia Australia in an advocacy role.

Ben joined a long list of Dementia Australia Ambassadors at the Melbourne Memory Walk & Jog including: Carlton AFLW star Nicola Stevens, Neighbours actor and Play School host Takaya Honda, Author and Broadcaster David Astle, Melbourne City W-League mid-fielder Amy Jackson, Gabrielle Williams MP as well as Ben’s Collingwood teammates and 280-game Collingwood legend and current Head Coach, Nathan Buckley.

Ben’s decision to help raise awareness about dementia in support of more than 425,000 Australians living with dementia and families in similar circumstances to the Crocker family had a positive impact on the Memory Walk & Jog at Templestowe, with the event attracting a record number of attendees.

Dementia Australia is honoured Ben and his family are supporting our role as the national peak body for people of all ages, living with all forms of dementia, their families and carers, and we are very much looking forward to working with Ben in the future.

Above A cherished family photo of Paul, Sam, Vicki and Ben Crocker

Australia’s best and brightest researchers funded

The use of songwriting to improve the relationships between people living with dementia and their families is just one of 17 new projects that will share more than $1 million in grants to conduct groundbreaking dementia research.

Dr Imogen Clark from the University of Melbourne has been awarded a $50,000 Hazel Hawke Research Grant in Dementia Care and will use the funding to explore the potential of group songwriting as a means for improving social connection, mental health, wellbeing and quality of life for people with dementia and their family carers.

Four PhD scholars will also be supported through the Dementia Australia Research Foundation, with Paulene Mackell from RMIT University receiving the Consumer Priority PhD Scholarship to explore and build on the ways in which remote Aboriginal art centres are currently providing support to older community members living with dementia.

The Chair of the Dementia Australia Research Foundation, Professor Graeme Samuel AC, said the grants provide vital support to early career researchers who are eager to make a difference in the field of dementia research.

“These grants are highly competitive and sought after in the research sector,” Professor Samuel said.

“They directly support Australian researchers who are keen to understand the causes of dementia and develop strategies to reduce dementia risk, provide accurate and timely diagnoses, and improve treatment and care options for people who live with this condition.”

To see the full list of successful applicants, visit dementiaresearchfoundation.org.au
Call for people to Turn to Us for support and services

While there is no cure for dementia, which is the second leading cause of death of Australians and the leading cause of death among Australian women, the right support, information and help can make a life-changing difference to people living with the condition.

With more than 425,000 people living with dementia in Australia and an estimated 250 people joining this population each day, Dementia Australia recently undertook a media campaign, calling for individuals, families and carers impacted to turn to Dementia Australia to access support that can empower them to live well.

“There is a perception in the community that nothing can be done following a diagnosis of dementia,” Dementia Australia CEO Maree McCabe said.

“However, with figures expected to soar to an estimated 536,000 people living with dementia by 2025 and more than 1.1 million people by 2056, it is vital people understand the right support can make the world of difference to everyone impacted by dementia.”

“These figures are cause for concern and we do know we need to make sure we continue to invest in more research to try to find ways to better treat the condition or find a cure. But in the meantime, we must also make sure the huge number of Australians impacted by dementia are accessing high quality, appropriate support and services.”

“The right support and services can help people cope better with the uncertainty and changes that come with dementia. One significant issue Dementia Australia staff often hear following a diagnosis of dementia is how isolating it can be, which can be devastating and debilitating.”

“However, the right services can help people reconnect and re-establish relationships with partners, families and friends which can be so important for their emotional well-being. Social engagement and keeping physically and mentally active are also key in contributing to better health and lifestyle outcomes following a diagnosis of dementia.”

“Having a trusted, independent source of information people can turn to means that no matter what the stage of a diagnosis, we can assist.”

“We are encouraging people to turn to Dementia Australia for support, information, counselling and education. We can also put people in touch with other organisations and partners providing great services across the country.”

Dementia Australia – the new voice of Alzheimer’s Australia – has delivered services to more than 1.5 million people living with dementia, their families and carers from across the country over the past 10 years alone – and to many, many more since the organisation started more than 35 years ago.

Marina’s son started noticing changes with her memory in 2012 and she was diagnosed with dementia in 2016.

Marina said reaching out to Dementia Australia for support services has been crucial in enabling her to deal well with her diagnosis and get on with her life, including the ability to remain socially active.

“They have given me social activity, respect and understanding,” Marina said. “They have allowed me to be who I am and they have assisted me in realising I am not alone - and those are the most important things.”

Isabelle was 20 when her mother was diagnosed with younger onset dementia at the age of 54.

“Being so young when mum was diagnosed, I really knew very little about dementia and the impact it was going to have on our lives,” Isabelle said.

“But through Dementia Australia we have been able to find out what information we needed at every step along the way, which has just made such a difference. “The support services have allowed me to cope with massive changes in my and my family’s life and to use what can be seen as a crushing diagnosis as a way of coming together to support each other as a family.”

---

1 Australian Bureau of Statistics (2017) Causes of Death, Australia, 2016 (cat. No. 3303.0)

Above Isabelle and her Mum
A full-time carer for her husband Rod, Lynn McGregor shares the knowledge she’s gained about dementia with others to help reduce stigma.

Lynn knew little about dementia until her husband was diagnosed with younger onset dementia in 2015. Since then, she has been driven to learn as much as she can about the disease.

“I am an advocate for dementia because of my husband. I knew a little about the condition before he was diagnosed, but not nearly enough,” she said.

“Of course I would rather we didn’t travel this road, but the more I learn the better equipped we are to continue this journey together. I want to know as much as possible and help others to understand what it is like for someone living with dementia.”

Lynn and Rod took part in Dementia Australia’s National Younger Onset Dementia Key Worker Program, which delivers individualised services and support for people living with younger onset dementia, their families and carers. The program provided Rod with weekly support groups that he could attend, whilst also offering important support and counselling for Lynn.

Lynn helps others understand dementia by sharing her knowledge with as many people as she can.

“There is still so much stigma attached to dementia and many people just don’t know what to do or how to do it,” she said.

“My husband often says that people treat him differently. I want to try and remove the stigma and make people realise that he is still the same person inside.

The biggest challenge Lynn has faced personally is isolation and loneliness.

“People say they are there for you but in reality, they are not. Family and friends have the very best intentions, but most of the time we are doing this alone,” she said.

“We do have some occasional support from family and for that I am eternally grateful. More help, particularly financially, for carers would also go a long way to improving our lives.”

Contact: advocates@dementia.org.au or visit the Dementia Australia website at dementia.org.au

---

**Education sessions 2018**

Dementia Australia offer a wide range of education courses throughout the year for family, carers, and health professionals as part of our commitment to help educate Australia on dementia and to raise dementia awareness.

All sessions are held at our office: 159 Maribyrnong Ave, Kaleen, Canberra ACT 2617

For more information on any of our education courses, please contact our Kaleen office on 02 6255 0722 or email act.admin@dementia.org.au

---

**Thursday 28 June**  
Enabling EDIE: Learning through virtual reality  
For staff and health professionals providing support to people living with dementia

**Tuesday 3 July**  
Concept Mapping in Dementia

**Tuesday 24 July**  
Montessori Method for Dementia Care

**Thursday 16 August**  
Dementia Design

**Tuesday 28 August**  
Medical Series – pain, palliative care, medications and hygiene
Minimally invasive blood test for Alzheimer’s disease announced

Researchers from Japan and Australia have teamed up to develop and validate a blood test for Alzheimer’s disease, which has the potential to massively ramp up the pace of drug trials.

The blood test measures a specific peptide in the blood to inform scientists, with 90 per cent accuracy, if a patient has the very earliest stages of Alzheimer’s disease.

One of the essential hallmarks of Alzheimer’s disease is build-up of abnormal peptide in the brain, known as beta-amyloid. The process starts silently about 30 years before outward signs of dementia, like memory loss or cognitive decline, begin to present.

Currently, levels of amyloid-beta in the brain can only be assessed reliably via brain imaging (PET scans) or by measuring amyloid-beta levels in the cerebrospinal fluid (lumbar puncture). For that reason, there is an urgent need for a more cost-effective and less-invasive diagnostic tool.

The research, a partnership between the Japanese National Center for Geriatrics and Gerontology (NCGG) and the Australian Imaging, Biomarker and Lifestyle Study of Ageing (AIBL), involved measuring the levels of several amyloid-beta-associated biomarkers in the blood in cognitively normal individuals, people with mild cognitive impairment and those with Alzheimer’s disease, with a total of 373 participants.

Researchers found the ratios of the different amyloid-beta-associated biomarkers in the blood accurately predicted amyloid-beta deposition in an individual’s brain.

The blood test will help researchers recruit more people into clinical trials who are accurately identified as being ‘at-risk’ of Alzheimer’s disease. Clinical trials are expected to be most effective when patients are in the earliest stages of the disease, and the blood test may aid the selection of suitable clinical trial participants.

For consumers, it is a cost-effective and less-invasive diagnostic tool. Eventually, people who have the test will be able to find out if they have an increased likelihood of developing Alzheimer’s disease, decades before obvious symptoms emerge. This would give people the opportunity to seek treatment sooner, and make some lifestyle changes, such as adjustment to sleep, exercise and diet, to potentially delay the onset of the condition.

DESeRvE program to assist in reducing stigma

A new program aimed at reducing stigma associated with dementia is being developed by the Australian National University researcher and recipient of the 2016 Alzheimer’s Australia Hazel Hawke Research Grant in Dementia Care, Dr Sarang Kim.

Social stigma has a devastating impact on the lives of people living with dementia and can often lead to social exclusion, discrimination, and disempowerment and can even affect a person’s tendency to seek help or a diagnosis.

Results from a national survey conducted by Dr Kim and her research team show the general public hold negative views and express a desire for social avoidance of people living with dementia.

It is hoped the Dementia Stigma Reduction Program (DESeRvE) led by Dr Kim will enhance understanding and awareness of dementia and discover effective ways to reduce dementia-related stigma.

The program will use focus groups to gather information about what the general public would like to learn from people living with dementia, and what people living with dementia and their carers would like the general public to know about living with dementia.

“Education and having contact with people living with the condition are believed to be the most effective ways to reduce stigma and this is what I am going to use in my intervention program,” Dr Kim said.

“After the focus groups, we will create a series of short video clips featuring people living with dementia and carers answering frequently asked questions drawn from the focus groups. These videos will be used for the general public to have virtual contact with people living with dementia and carers.”

Dr Kim said she hopes her study sparks an interest in further studies in the area of dementia-related stigma.

“Despite stigma being identified as the number one concern for people living with dementia and their carers, research investigating dementia-related stigma is still lacking.”

“Dementia is a neurodegenerative condition, however, due to its effects on memory, judgement and behaviour, it is perceived as a mental illness and is associated with the fear and misunderstanding commonly linked to other mental illnesses. Furthermore, dementia is often mistakenly assumed to be a natural part of ageing that only affects older adults.”

“By increasing the public’s understanding and awareness of dementia and subsequently reducing stigma, it is envisaged that people will be more likely to visit GPs or other health professionals as soon as early symptoms of dementia are noticed,” she said.
Policy update

Working closely with Government

The year has been busy for the policy team, with a series of important consultations underway. The Government has been consulting with stakeholders and seeking their input on Specialist Dementia Care Units (SDCU), a budget commitment they made in 2016. The units are expected to support people who experience very severe behavioural and psychological symptoms of dementia, with the Government committed to establishing at least one SDCU in each of the 31 Primary Health Network regions. Dementia Australia has been advocating on behalf of people living with dementia and their families and carers throughout this process, with our key messaging focusing on a cautious approach to the planning and implementation of these units as well as a need to ensure ongoing education and training in behavioural and psychological symptoms of dementia in the sector more broadly.

Significantly, we have recently received correspondence from the Federal Minister for Aged Care, The Hon. Ken Wyatt AM, MP, acknowledging our concerns, as well as assuring us of his commitment to protecting the rights of consumers and ensuring that the welfare of people living with dementia is the highest priority in the establishment of these units.

We have also provided a submission to the inquiry into the Quality of Care in Residential Aged Care Facilities in Australia, being conducted by the Standing Committee on Health, Aged Care and Sport. This is the third inquiry into the residential aged care system, following a Ministerial Inquiry, as well as a Senate Community Affairs Committee Inquiry held last year. Dementia Australia has provided strong submissions drawn from consumer input to all these inquiries, and has also seen some positive results of our advocacy. The report from the independent ministerial review heavily cites our submission and we were pleased to note that the review has incorporated several of our suggestions in their final recommendations to Government.

Importantly, the Government has already moved to enforce unannounced accreditation visits across residential aged care, a recommendation that Dementia Australia and the review had both made. The 2018-19 budget also includes many measures that Dementia Australia has called for including establishment of the new Aged Care Quality and Safety Commission from 2019. The commission will be supported by other significant measures such as $50 million for a Quality Care Fund, $32.6 million to enhance the regulation of aged care provider quality, and $8.8 million to improve the transparency of information on aged care provider quality.

We are also encouraged to note the progress being made around elder abuse made in 2017. The Australian Law Reform Council’s Elder Abuse report made a series of recommendations, many resonating with our own submission on the subject. The latest budget responds to key recommendations of the Australian Law Reform Commission’s Report into Elder Abuse and implements a national response on elder abuse and promoting older people’s safety. The funding will increase specialist front line services to support older people and their families seeking help with elder abuse. It includes expansion and evaluation of elder abuse service trials, including specialist elder abuse units, family counselling and mediation services, and health-justice partnerships.

The Government has also set aside funding to work with the States and Territories to establish a National Online Register for Enduring Powers of Attorney. This is very welcome funding in an area that Dementia Australia has been very active in. People living with dementia are uniquely vulnerable to abuse, and we hope to be able to work with the government to implement these measures.

The policy team also participated in and facilitated a series of consumer roundtables with Federal Opposition Leader The Hon. Bill Shorten MP in 2017. The roundtables, held in Sydney, Melbourne, Adelaide, Brisbane and Perth, culminated in a speech given by Mr Shorten at the Brain and Mind Centre in December where he highlighted his vision for improved dementia care in Australia. Mr Shorten shared his position and commitment to the growing health issue saying that “tackling dementia is our generation’s duty” and that it is “the defining health care and aged care challenge of the next 20 years”. The policy team continues to work with all sides of government to ensure that the voices of people living with dementia, their families and carers are heard.

Above  The Hon Ken Wyatt AM, MP, Federal Minister for Aged Care and Maree McCabe, Dementia Australia CEO, at the inaugural Parliamentary Friends of Ageing and Aged Care event in February at Parliament House Canberra.
Climbing Mt Everest for dementia

From 21 October to 6 November 2018 our supporters will be combining a once-in-a-lifetime opportunity with raising funds and awareness for research and care for people living with dementia.

The Dementia Australia 2018 Everest Base Camp - A Trek to Remember will take place in lush forests and take in stunning mountain scenery. The trek will not be technical, with a manageable pace and routine, with only the elements, the mountains and the beautiful character of the people to accompany you. The trek will be supported by experienced guides from Alternative Adventure UK.

With dementia being the second leading cause of death in Australia, your support is needed to help raise money for research and care of people living with dementia.

For more information visit dementia.org.au/everest-base-camp-2018. Or contact Arpi at arpi.achadjian@dementia.org.au or call 02 8875 4606.

Bondi2Berry back in 2018

The Bondi2Berry Ride to Remember, our biggest national community fundraising event, is back again in 2018!

The ride will take place during Dementia Awareness Month, taking off from Bondi on Saturday 8 September, and aims to raise more than $100,000 for Dementia Australia.

Nick Young and Pierre Sullivan have parents living with dementia, and together with a great team are using their passion for cycling to help raise awareness.

“We are proud to see the Bondi2Berry ride grow and are excited to be back this year to help raise awareness of dementia,” Nick says.

“All of the riders participate because they are touched by this condition and want to contribute to finding a cure. Thank you to our supporters, riders, volunteers and event partners for helping to make this a great event.”

Launched in 2016, 40 cyclists rode 155 km from Bondi Beach down the coast to Berry, raising $56,000. The ride grew to 60 riders in 2017 and raised more than $75,000. This year will see 80 riders take on this journey and we wish them the best of luck!

Thank you to Nick, Pierre and the Bondi2Berry team for making this event a success.

Show your support for the riders and donate at bondi2berry.com.
It starts with you.

Become a Dementia Friend today and learn how you can make a difference to the lives of people living with dementia, their families and carers. Through our services, education and information, we’re on our way to ensuring people living with dementia are understood and valued in our communities.

It only takes a few steps, visit dementiafriendly.org.au

Here you will find information about the Dementia Friends program. By having a better understanding of dementia, you can be empowered to do small, everyday things that can make a difference to someone living with dementia.