DEMYSTIFYING DEMENTIA

Bringing dementia into focus through understanding and awareness

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KEEPING DEMENTIA IN THE SPOTLIGHT

It was with great pleasure that in October last year we officially launched Dementia Australia as the new voice of Alzheimer’s Australia for the 425,000 Australians 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. We continue to 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 evidenced 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, which 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 for the people we are here to serve.

Professor Graeme Samuel AC
Chair, Dementia Australia

CEO’S MESSAGE

MAKING A DIFFERENCE

Welcome to the latest edition of In Touch magazine. 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 being 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 affected 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 might 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 contribute to our work to increase understanding of how to better support people affected by dementia. I encourage you to read John’s inspiring story on page 9.

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 affected by dementia that Dementia Australia provides many fantastic services to assist people 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 affects everyone, and we can all play a part to support people living with dementia to have the opportunity to remain united with their community and lead the life that is important to them. Together we can make a difference.

Maree McCabe,
CEO, Dementia Australia
FUNDING SUPPORTS AUSTRALIA’S BEST AND BRIGHTEST RESEARCHERS

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 was awarded a $50,000 Hazel Hawke Research Grant in Dementia Care. She 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, their families and carers.

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

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

FRIENDS OF DEMENTIA AUSTRALIA HONOURED ON AUSTRALIA DAY

This January, two people close to Dementia Australia were included in the Australia Day Honours, each being named Officer of Australia in the General Division.

Paul Robertson AO is a Dementia Australia Board member and was recognised for his distinguished service to the community through ethical leadership and management of – as well as philanthropic contributions to – health, social enterprise, research, education and arts organisations.

Emeritus Professor David Ames AO has been an invaluable supporter of Dementia Australia for more than 20 years. He was honoured for his distinguished service to psychiatry – particularly in the area of dementia and the mental health of older persons – as an academic, author and practitioner, and as an adviser to professional bodies.

Dementia Australia extends its congratulations on these well-deserved achievements, and thanks both Paul and David for everything they have done and continue to do to improve the lives of all people impacted by dementia.
MEALS ON WHEELS JOINS THE RANKS OF DEMENTIA-FRIENDLY BUSINESSES IN THE TWEED AREA

Dementia Australia’s work with the Tweed Dementia-Friendly Steering Committee and Dementia Action Group has seen yet another local enterprise added to its list of supporters.

Tweed Community Support (Meals on Wheels) offers a meal delivery service and provides social support outings for individuals and groups, with participants aged over 65. The dementia-friendly accreditation is in response to a demonstration of staff awareness about the condition and the increased risk of dementia associated with ageing, and a commitment to help combat social isolation among people living with dementia in the community.

Christine Vannucci, Dementia Australia Diversity and Inclusion Officer based in Tweed Heads, says she is pleased to see more businesses and services taking the steps required to become more dementia-friendly.

“It all helps towards building a community where people with dementia feel understood, engaged, included and valued. It is inspiring to see the concept of dementia-friendly communities taking shape, with more and more organisations coming on board,” Christine says.

The Tweed Dementia-Friendly Steering Committee was launched in August 2016 as an initiative of the NSW Liveable Communities Program. The Committee comprises people living with dementia, carers, services, individuals and church representatives.

HOT OFF THE PRESS: FAMILY, FRIENDS AND COMMUNITY

Thanks to the generous support of the NSW Department of Family and Community Services, we have released a new resource for Aboriginal and Torres Strait Islander people who are supporting a family member or friend living with dementia. ‘Family, Friends and Community’ assists carers to better understand the disease and how to support their loved one.

The development of this resource included consultation with community and elder groups in Ballina, Dubbo, Newcastle and Wollongong.

Thank you to the Koori Yarning Carers Group, Bundjalung Elders Group, Bunjum Families NSW Mothers’ Groups, Worimi Community Elders, Global Village Creativity Centre and Illawarra Aboriginal Corporation Elders Group.

If you would like a copy of this new resource, call the National Dementia Helpline on 1800 100 500.
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 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 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 dementia diagnosis.

Dr Kaele Stokes, Dementia Australia’s Executive Director Consumer Engagement, Policy and Research, says 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 says.

“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, says that since her husband was diagnosed, socialising has become more challenging.

“Group dinners can be especially difficult,” she says.

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

The way we respond as a community can leave people living with dementia and their carers feeling embarrassed.

Although more than 425,000 people are living with dementia in Australia and the figure is expected to increase to more than a million by 2056, it is still a misunderstood condition. The lack of community awareness and misinformation contributes to social stigma, which can have a devastating impact on the lives of people living with dementia, leading to discrimination and social isolation. It may even affect a person’s willingness to seek help or a diagnosis.
and uncomfortable in social situations. In fact, 94 per cent of survey 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, says 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 says.

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 community services.

Jim’s daughter Tara confirms 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 says.

“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 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.
BRINGING DEMENTIA TO PARLIAMENT

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

Co-convened with Members of Parliament (MPs) 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 experiences 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 MPs from all sides, and the events are consciously bipartisan in their approach.

Parliamentary Friends of Dementia are not only reducing the stigma of dementia within communities, but they provide Senators and MPs with insight into the issues that impact their electorates. Dementia Australia is currently developing a national strategy to ensure we have Parliamentary Friends around the country.

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 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 within the community.

Do you follow us? Visit Dementia Australia on each of our social media platforms.
NATIONAL DEMENTIA HELPLINE ANSWERS THE CALL TO LEND SUPPORT

Each week the National Dementia Helpline receives hundreds of calls from people around the country seeking support and information about accessing services and resources, or who simply want to have a chat about memory loss and dementia. The Helpline is staffed by skilled and passionate advisors who provide a sense of comfort by supporting callers and directing them to information and valuable services. They also help people to unravel the knots surrounding dementia and discuss some of the challenges they face.

We speak with sons, daughters, husbands, wives, in-laws, siblings, friends, carers and health workers alike. We speak to people who have been diagnosed with dementia, people caring for someone with dementia, or people just wanting to find out more about dementia or how to reduce their risks. All contacts to the National Dementia Helpline are free and confidential. Turn to us for dementia support or information.

The National Dementia Helpline can be called on 1800 100 500, 9am to 5pm, Monday to Friday. Or email anytime at helpline.nat@dementia.org.au or webchat at dementia.org.au/helpline/webchat

IT’S NOT A DISGRACE, IT’S DEMENTIA

A series of short films produced by Dementia Australia aims to address the myths 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,” says Gary Thomas, Dementia Australia Sector and Capacity Program Manager.

“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 15 minutes long and are available in Spanish, Italian, Portuguese, Mandarin, Arabic, Serbian, Cambodian, Vietnamese, Assyrian, Croatian, Ukrainian and Hindi.

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 YouTube channel.

ARE YOU A DEMENTIA FRIEND?

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. This change begins with us.

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.

Visit dementiatriendly.org.au where you will be guided through a short module designed to increase your knowledge of dementia and it’s impacts. Upon completion, you will receive a Dementia Friend certificate and badge.

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 full and fulfilling life after his diagnosis.

A lack of community awareness 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 says.

“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 of 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 healthy to help reduce their chances of getting dementia.”

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.
RESEARCH

TAILORED APPROACH

RESEARCH TO DETERMINE WHAT PEOPLE LIVING WITH YOUNGER ONSET DEMENTIA NEED FROM FORMAL SERVICES.

New research from the INSPIRED study at UNSW Sydney has surveyed people living with younger onset dementia, their families and carers to make service design recommendations. An estimated 26,450 Australians are living with younger onset dementia, where symptoms emerge before age 65. Despite this, studies suggest that people with younger onset dementia underuse the formal services available to them.

In a recent study published in PLOS ONE, researchers from the School of Public Health and Community Medicine and Dementia Centre for Research Collaboration at UNSW Sydney conducted interviews and focus groups with people with younger onset dementia, their families and carers to determine the barriers to service use.

Participants reported dissatisfaction with services that were designed for and dominated by older people with dementia. They also talked about their complex circumstances and how existing services did not meet their needs. For example, lack of availability of programs after hours, contemporaneous child care, or security for physically agile participants were key barriers.

Lead author and PhD candidate Monica Cations says the research is timely, since funding for support services for younger onset dementia has recently moved to the National Disability Insurance Scheme (NDIS).

“Until now, people with younger onset dementia have not been supported by disability providers, who are likely to have limited knowledge about their needs,” she says.

From the findings, researchers developed five key recommendations for service providers. They suggest services:

1. be designed with younger people in mind;
2. acknowledge that needs vary over time and are unique to the person and their family;
3. consider the financial constraints associated with younger onset dementia;
4. use innovative methods based on the complex occupational and other care arrangements of people living with younger onset dementia and their families; and
5. provide engaging activities that go beyond ‘staying busy’.

Monica Cations was awarded a PhD Scholarship in 2013 from the Dementia Australia Research Foundation to explore risk factors for younger onset dementia.

The INSPIRED study is led by Professor Brian Draper and Dr Adrienne Withall at UNSW Sydney.

REDUCING STIGMA, INCREASING AWARENESS

A new program being developed by ANU researcher Dr Sarang Kim aims to reduce the stigma often associated with dementia. Results from a national survey conducted by Dr Kim, a recipient of the 2016 Alzheimer’s Australia Hazel Hawke Research Grant in Dementia Care, show the general public hold negative views of people living with dementia.

It’s hoped the Dementia Stigma Reduction Program (DESeReVe) led by Dr Kim will enhance understanding and 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. Dr Kim says she hopes her study sparks an interest in further studies in the area of dementia-related stigma and how it might be addressed.

“Despite stigma being identified as the number one concern for people living with dementia and their carers, research investigating [this topic] is still lacking,” she says.

“Dementia is a neurodegenerative disease, however, due to its effects on memory, judgement and behaviour, it is perceived as a mental illness.”

Furthermore, dementia is often mistakenly assumed to be a natural part of ageing.

“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 says.
MIND THE GAP

RESEARCHERS TO IDENTIFY KNOWLEDGE GAPS IN TASMANIA TO TAILOR DEMENTIA EDUCATION.

Researcher Dr Claire Eccleston from the University of Tasmania Wicking Dementia Research and Education Centre has been making good use of the $50,000 Plants Management Australia - Whetman Pinks Project Grant awarded by the Dementia Australia Research Foundation in 2016.

Dr Eccleston is focusing on creating dementia-friendly communities by determining the current attitudes and knowledge about dementia within a community. This information can be used to enable targeted education to businesses, councils, schools and service organisations.

It’s hoped this knowledge will, in turn, support those organisations and individuals to better understand dementia, its impact, and how they can contribute to enhancing quality of life for people living with dementia.

Dr Eccleston anticipates to directly address the deficit of information about dementia knowledge in communities by using the Dementia Knowledge Assessment Survey (DKAS), a new tool developed by Wicking Dementia Research and Education Centre (WDREC).

The project has two main components: a quantitative survey followed by a series of focus groups targeting a wide range of people from different Tasmanian communities.

“When developing dementia-friendly communities, dementia is everybody’s business. The consumers in this project are community members who will help form dementia-friendly communities, and will be living with, caring for and interacting with people with dementia,” she says.

“Raised awareness and reduced stigma are, I believe, central to developing communities that are dementia friendly and to the adoption of quality, evidence-based care practices.”

Dr Eccleston says the grant provides vital funding that supports the project team in surveying people from communities across regional and rural Tasmania, as well as parts of urban Tasmania that are less commonly reached.

Plants Management Australia (PMA) Managing Director Chris Sargent says he is pleased that PMA’s continued commitment to the Dementia Australia Research Foundation, which comes through donating a percentage of the profits from the Dianthus ‘Memories’ plants, has resulted in the funding of Claire’s research.

“Dr Eccleston’s research stood out to us as she is trying to make a difference in communities for everyday people. Her research focusing on making the lives of those affected by dementia, both directly and indirectly, easier through education and understanding, can and hopefully will reach large and small communities across Australia,” he says.

Dr Eccleston and her research team have collected more than 400 surveys completed by people from 30 different council regions of Tasmania. The researchers also spoke with six focus groups across the state from both rural and urban communities. Data analysis is currently underway.

Dr Claire Eccleston (right) and Plants Management Australia Managing Director Chris Sargent.
**FUNDRAISING**

**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 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 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 disease and want to contribute to finding a cure.”

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 organising team for making this event a success.

Show your support for the riders and donate at: bondi2berry.com

**CLIMBING MT EVEREST FOR DEMENTIA**

From 21 October to 6 November 2018, our supporters will combine a once-in-a-lifetime opportunity with raising funds for Dementia Australia.

The Dementia Australia 2018 Everest Base Camp – A Trek to Remember will take in lush forests and stunning mountain scenery with a non-technical, slow and easy hike. The trek will be supported by experienced guides from Alternative Adventure UK.

You too can sign up for the Mt Everest trek and be part of this unique adventure!

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.

**SHARING MEMORIES FOR MEMORY WALK & JOG**

The Memory Lounge is a film created for Memory Walk & Jog in which parents and grandparents share their memories with their families. It reminds us how important it is to ask your loved ones about their early life. What did they want to be when they grew up? How did they meet their partner? What is their most valued memory?

In six weeks, it has had more than 180,000 views on Facebook and YouTube, with many people requesting to do their own version of the Memory Lounge. We have taken this feedback on board and now, at every Memory Walk & Jog event, participants have the chance to tell us what their most valued memory is.

Thanks so much to everyone who participated in the Memory Walk & Jog events held in NSW this year. Thanks for your generous support, and we look forward to seeing you again next year.
COULDN’T MAKE IT TO A SCHEDULED MEMORY WALK & JOG?

Host your own DIY Memory Walk & Jog or pledge your own goal by signing up to MY Memory Walk & Jog.

Peter hosted his second DIY Memory Walk in March at Leura in the Blue Mountains in honour of his wife, Joyce, who was diagnosed with dementia in 2011. He raised an outstanding amount of money for Dementia Australia. Let’s get active and beat dementia together!

Visit memorywalk.com.au or contact Ellie at ellie.saliba@dementia.org.au or 02 8875 4625.

RUN HARD FOR DEMENTIA

Looking for ways to support Dementia Australia and want to stay fit? Why not join our team of Memory Joggers at two events coming up: The Sun-Herald City2Surf on Sunday, 12 August; or the Blackmores Sydney Running Festival on Sunday, 16 September.

Register today to receive your free Dementia Australia running singlet and ask friends and family to sponsor you to keep you motivated!


For more information, contact Arpi at arpi.achadjian@dementia.org.au or 02 8875 4606.

A NIGHT TO REMEMBER

Dementia Australia’s A Night to Remember gala event, held on 22 February at Sydney’s Le Montage, resulted in an incredible $210,000 raised. These funds will help support those living with dementia and their carers through education programs such as Enabling EDIE.

MC and Dementia Australia Ambassador Natarsha Belling was joined by guest speakers Phil Hazell, Alex Florio, Sabrina Navarra and Silvana Zaami, who all shared how they have been touched by dementia. Entertainers Luke McGregor, The Three Waiters and Judah Kelly ensured the guests were kept amused throughout the night. A big thank you to our generous host, the Navarra family, who kindly donated an additional $30,000, and to those who donated on the night and all our supporters who donated prizes for our successful auctions.

WHAT’S NEW IN YOUR LIBRARY

The Dementia Australia library offers free loans of books, DVDs, ebooks and other resources. Here are the latest on offer.

Living Your Best with Early-Stage Alzheimer’s: An Essential Guide

Recent medical advances have made it possible to diagnose Alzheimer’s disease when symptoms are mild, and new drugs are under investigation to help slow the progression of the disease.

This book is a working guide to help the person with Alzheimer’s disease feel empowered to move forward in life in light of this challenging diagnosis.

Loving Someone Who Has Dementia: How to Find Hope While Coping with Stress and Grief

This is a new kind of caregiving book. It’s not about the usual techniques, but about how to manage on-going stress and grief. Dr Boss helps caregivers find hope in the “ambiguous loss” of having a loved one with dementia.

When a Family Member Has Dementia: Steps to Becoming a Resilient Caregiver

Caring for a person with dementia is difficult and often overwhelming. In addition to the inevitable decline in memory and physical function, most persons with dementia develop behavioural problems such as depression, fearfulness, sleep disturbances, paranoia or physical aggression. This book offers caregivers a set of practical and flexible tools to enable them to become more resilient in the face of difficulty and change.

The library team has carefully selected a range of new digital resources of some of our most popular titles for people living with dementia, care partners, family members and healthcare professionals. You can download the digital resources 24 hours a day, seven days a week from anywhere! And there’s also no postage costs.

This new service is free for library members. You can now borrow popular digital media anytime, anywhere by visiting the e-library at: https://dementia-e-library.overdrive.com (link is external) and entering your login.

LOANING ITEMS

These items and more are available to members of Dementia Australia and can be found at local resources centres. Resources can also be posted to you.

E: NSW.Library@dementia.org.au T: (02) 9888 4239
POLICY UPDATE

WORKING CLOSELY WITH GOVERNMENT

THE NEW YEAR HAS STARTED OFF ON A BUSY NOTE FOR THE POLICY TEAM, WITH A SERIES OF IMPORTANT CONSULTATIONS UNDERWAY.

The first six months of this year have been busy for the Policy team. The Government has been consulting with stakeholders 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. The Government has 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. Our key messaging focused 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. Significantly, we have had correspondence from the Federal Minister for Aged Care, The Hon. Ken Wyatt MP, acknowledging our concerns, as well as expressing his commitment to protecting the rights of consumers and ensuring 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. Dementia Australia has provided strong submissions drawn from consumer input to all these inquiries, and has also seen some positive results of our advocacy.

We are also encouraged to note progress around elder abuse made in 2017. 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.

IN THE ROUND

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. Mr Shorten shared his position and commitment to the growing health issue, saying tackling dementia is our generation’s duty and it is the defining health care and aged care challenge of the next 20 years. We continue to work with all sides of Government to ensure the voices of people living with dementia, their families and carers are heard.
Lynn McGregor knew little about dementia until her husband Rod was diagnosed with younger onset dementia in 2015. Since then, she has been driven to learn as much as she can about living with the condition.

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

“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 understand what it’s like 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, while also offering important support and counselling for Lynn.

“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.”

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,” she says.

“My husband often says 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 best intentions, but most of the time we are doing this alone,” she says.

“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.”

**BECOME AN ADVOCATE**

Dementia Advocates give a voice to people living with dementia and their carers. If you would like to be a Dementia Advocate, contact the Consumer Engagement Team or visit the Dementia Australia website.

E: advocates@dementia.org.au
W: dementia.org.au
EDUCATION

DEMENTIA AUSTRALIA NSW COURSES

THE DEMENTIA AUSTRALIA EDUCATION PROGRAM OFFERS COURSES FOR CARE WORKERS, FAMILY CARERS AND VOLUNTEERS.

CARER COURSES
1-Day Carer Course
Hunter: 4 October
North Ryde: 19 July, 10 October

4-Evening Carer Course
North Ryde: 7, 14, 21, 28 November

Family and Friends Information Evening
North Ryde: 1 August and 23 October

WEBINARS
Communication: 23 August
Understanding Dementia: 25 July

For more information or to register, please contact:
T: (02) 8875 4640
E: nsw.education@dementia.org.au

MEMORY VAN

The Dementia Australia Memory Van raises awareness of the impact of brain health and provides information on dementia for people living with dementia and their families, service providers and the community.

The Van Also Visited:
- Bungarribee and Pyrmont
- Baulkham Hills
- Gunnedah
- Tamworth
- Carnes Hill
- Temora
- West Wyalong
- North Richmond
- Boggabri
- Stockton-Medowie “Dementia Run”
- Llandilo
- Tumbarumba
- Ulladulla
- Tullamore
- Hillston
- Greystanes
- Wangi Wangi
- Cessnock
- Fairfield Heights
- Lavington
- Morisset
- Ettalong Beach
- Marsden Park
- Cameron Park
- Grawin
- Erina

THE VAN ALSO VISITED:
COMMUNITY EVENTS

OPPORTUNITIES FOR PEOPLE WITH DEMENTIA, THEIR CARERS AND FAMILIES TO SOCIALISE, BUILD SUPPORT NETWORKS AND LEARN.

CAFÉ CONNECT

Bowral
10.30am – 12pm
19 July, 16 August
Jane Bushell & Alison Hall
(02) 4869 5651

Bundanoon
10.30am – 12pm
5 July, 2 August
Alison Hall
(02) 4869 5651

Coffs Harbour
10 – 11.30am
4 July, 1 August
Margaret-Anne Young
02 6584 7444

Goulburn
10.30am – 12pm
25 July, 29 August
Jane Bushell
(02) 4869 5651

Maitland
11am – 12.30pm
19 July, 16 August
(02) 4962 7000

Nelson Bay
9.30 – 11am
12 July, 9 August
(02) 4962 7000

Newcastle
10 – 11.30am
16 July, 10 August
(02) 4962 7000

Sutherland Shire (The Camellia Gardens)
9.30 – 11am
26 June
Sladana Pavkovic
(02) 9531 1928

Sutherland Shire (Tradies Club Gymea)
9.30 – 11am
19 June
Sladana Pavkovic
(02) 9531 1928

Toronto
10 – 11.30am
10 July, 14 August
(02) 4962 7000

YOUnger Onset Dementia Cafe Connect (Under 65)

Newcastle
10am – 12pm
4 July, 1 August
Emma Wells
0438 727 841

Central Coast
10.30am – 12pm
19 July
Justine Sneddon
0438 715 518

North Sydney
1.30 – 2.30pm
14 June
Iris Ng
0427 204 297

YOUnger Onset Dementia Support Groups (Under 65)

Milton
10 – 11.30am
18 July, 22 August
Sandra Kay 0438 702 418

North Ryde
(Carer support group)
2 – 4pm (booking required)
5 June
Robyn McKern (02) 8875 4642

North Ryde
(Carer support group)
6.30 – 8.30pm (booking required)
12 June
Lyndell Huskins (02) 8875 4615

Wollongong
10 – 11.30am
31 July, 28 August
Sandra Kay 0438 702 418

Newcastle
5.30 – 7.30pm
23 July, 27 August
Emma Wells 0438 727 841

COFFEE AND CHAT

Bega
10 – 11.30am
4 July, 1 August
Kylie Ramsay (02) 6492 6158

Batemans’ Bay
10.30am – 12pm
4 July, 1 August
Gaye Finch (02) 4474 3843

Crockwell and District
10.30am – 12pm
18 July, 15 August
Jane Bushell (02) 4869 5651

Forster
12 – 2pm
17 July, 21 August
Alison Fowles (02) 6554 5097

Laurieton
27 July, 24 August
Kath Storey (02) 6584 7444

Laurieton (Lunch Group)
10 August
Kath Storey (02) 6584 7444

Manning/Great Lakes
Friends and Leisure (Lunch Group)
12pm 2 July, 6 August
Alison Fowles (02) 6554 5097

Merimbula
10 – 11.30am
Kylie Ramsay
(02) 6492 6158

Mittagong (Carers only)
10.30am – 12pm
26 June, 24 July, 28 August
Alison Hall
(02) 4869 5651

Narooma
10am – 12pm
21 June, 17 July
Gaye Finch (02) 4474 3843

Port Macquarie
28 June, 26 July, 23 August
Kath Storey
(02) 6584 7444

Port Macquarie
(Dinner Group)
14 August
Kath Storey
(02) 6584 7444

CARER SUPPORT GROUPS

Corrimal
10am – 12.30pm
11 July, 8 August
Val Fell
(02) 4229 5926

Forster
10am
25 June, 23 July, 27 August
Alison Fowles
(02) 6554 5097

Goulburn
10am – 12pm
11 July, 8 August
Jane Bushell
(02) 4869 5651

Moruya
10am – 12pm
16 May, 20 June
Mary Bills
(02) 4474 3843

Moss Vale
10.30am – 12pm
10 July, 14 August
Jane Bushell & Alison Hall
(02) 4869 5651

North Ryde
(Carer support group)
10am – 12pm
(booking required)
26 June
Jan Blenkinsop
(02) 8875 4667

North Ryde (AD-HOC Group)
12.30 (1pm start)
23 June
Patrice Teakle/Marina Agostino
(02) 9888 4268

Pambula
10am – 12pm
22 May
Nola Hergenhan
(02) 6492 6158

Coffs Harbour
10am – 12pm
17 July
Judy Bartholomew
(02) 6651 6415

Nambucca Heads
10am – 12pm
2 July, 6 August
Margaret-Anne Young
(02) 6584 7444

Port Macquarie
10am – 12pm
19 June, 17 July, 21 August
Kaylene Parker
(02) 6584 7444

South West Rocks
10.30am – 12pm
4 July, 1 August
Kaylene Parker
(02) 6584 7444

Laurieton
10am – 12pm
18 July, 15 August
Margaret-Anne Young
(02) 6584 7444

Taree
9.30 – 11am
16 July, 20 August
Alison Fowles
(02) 6554 5097

Tea Gardens
9 July, 13 August
Alison Fowles
(02) 6554 5097

Sutherland Shire (Sylvania)
10am – 12.30pm
11 June
Sladana Pavkovic
(02) 9531 1928
With more than 425,000 people living with dementia in Australia and an estimated 250 people developing the condition each day, Dementia Australia recently undertook a media campaign titled ‘Turn to Us’ calling for individuals, families and carers to turn to Dementia Australia to access the 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,” CEO of Dementia Australia Maree McCabe says.

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

“These figures are cause for concern and we do know that 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 that the huge number of Australians impacted by dementia are accessing good quality, and appropriate support and services.

“Good 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 wellbeing.

“Social engagement, and keeping physically and mentally active are also key in contributing to better health and lifestyle outcomes for individuals following a diagnosis of dementia,” Maree says.

“Having a trusted, independent source of information people can turn to means that no matter what stage people are at in their diagnosis, we can assist them.

“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 the more than 1.5 million people living with dementia, their families and carers across the country over the past 10 years alone, and to many, many more since the organisation started over 35 years ago.

**To contact Dementia Australia, call the National Dementia Helpline on 1800 100 500 or go to dementia.org.au.**
IN MEMORIAM

WE OFFER OUR CONDOLENCES TO THE FAMILIES WHO HAVE LOST THEIR LOVED ONES. WE ALSO THANK THEIR FRIENDS AND FAMILIES WHO HAVE DONATED TO DEMENTIA AUSTRALIA.

Dementia Australia would like to acknowledge and thank the families and executors of the recently received bequests from which people with dementia, carers and their families have received lasting benefit.

By the end of 2018, every Australian will have a My Health Record, unless they choose not to have one.

My Health Record is a secure online summary of an individual’s health information.

For more information or to register today
Go to myhealthrecord.gov.au
Call 1800 723 471

Felice Balice
Giuseppe Battato
Ruth Frances Beeren
Elaine Rae Bell
Wendy Bendixsen
Douglas Bessen
Antonio Bevacqua
Valmae June Richard
Angelo Riviano
Mary Patricia Bleazard
Flavia Briganti
Stella Buttigieg

David Carricks
Frank Cass
Caterina Cavalieri
Giovanna Chiaravalloti
Mirella Clarke
Anne Elizabeth Cleary
Glory Anne Louise Clifford
Dawn Coleman
Kathleen Margaret Eling
Peter Elliott

Shirley Fenn
Giovanna Ferla
Antonio Ferlauto
Elia Fikas

Annie Foster
Johanna Fulker

Muriel Hola Gallaway
Thomas Joseph Gardner
David Bruce Gavin
Nett Guy
Enzo Gribaldi
Gwan Thomas Gleeson
Ethel Goodwin
Ardith Grant
Loyola Grantham
Margaret Green
Bernardette Dolores Grew
Maria Grkovic

Ada Haddad
Edna Hake
Ray Harding
David Hay
Joy Irene Hickey
Gwenda Horrocks
Ronald John Hughes
Betty Urban Hurst
Elizabeth Hutchins

Kenneth Ingram
Andrew Kenneth Edward Irvine

Allan William James
Alfred Jaraffa
Leslie Ken Jones

Peter Keegan
Frank Kellaher
Gregory Lawrence Kelly
Naville Herbert King
Adamadis Kotsopoulos

Kevin Bruce Lockyer

Kevin William Mace
Caterina Marie
Ancilla Marcon
Edward James Mcdonell
Beth McKindlay
Stewart-Charles Mopherson
Politomy Megasolomon
Caterina Moga
Aliister Mercer
Maxwell John Metcalfe
Luise Marie Milas
Jane Millar
Rita May Mills
Leslie Mills
Ernest Moran
Johannes Multholland
June (Majorie)Munday

Alice Mary Nagle
Ida Natali
Emilio Neri
Agnes ‘Beryl’ Neville
Epaminondas Nikolopoulos
Rosaria Nucitella

Maureen Pearson
Stella Peoples
Mile Perkovic
Kathy Perry
Magda Hanischili Petallas
Kary James Peterson
Joan Eva Pomeroy
Luis Pilarino

Kew Quan

Margarette Rachel Riece
Ross Victor Reff
Philip And Pamela Richardson
John Roberts

Isabella Filomena Romani
Jan Rose
Travis Anthony Rutter

Grazia Salvia
Patricia Melba Schuman
George Scottman
Besse Shepherd
Ronald George Smith
Douglas Craighoun Smith
Betty Constance Southland
Peter Stathoulopoulos
Robert Stone
Valentina Sutcliffe

Amy Taylor
Rudolf Thann
Stanley Lachlan Thompson
Maria Trigas

Johannes Van Den Hende
Ava Varhon
Agatina Verzi
Maire Vinda

Ian Ronald Brogla Watson
Wu Wen Wen Hse
Gregory David Westcott
Pat Weston
David Whiteside
David Roland Williams
Alfred Willings
Amelia Tasia Wilson
Paiching Wong

Ron Yatas
Anna Yausis

Maria Zino
Dementia is life-changing.

If you, a family member or someone you know has concerns about changes to memory or behaviour, or has dementia, Dementia Australia is here to help. Our experienced and qualified staff are here to listen, understand and to support you.

There are more than 100 types of dementia – Alzheimer’s disease being one – and we are here for people of all ages, living with all forms of dementia, their families and carers.

Turn to us for information.

Support | Information | Counselling | Education

Turn to us

National Dementia Helpline
1800 100 500
Visit dementia.org.au

The National Dementia Helpline is funded by the Australian Government.