

**UNDERSTAND ALZHEIMER'S
SUPPORT AUSTRALIA**



**ALZHEIMER'S
AUSTRALIA NT
ANNUAL REPORT
2016-2017**

UNDERSTAND ALZHEIMER'S SUPPORT AUSTRALIA

Alzheimer's Australia NT Inc

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Mission Statement

To provide quality dementia services and leadership, in advocacy, policy and research

Cover photo

Bruce and Ros Jones having fun attending our Dementia Awareness Month 2017 Dance and Luncheon, "A Day in Paradise".

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PRESIDENT'S REPORT



It has been a year of significant change for Alzheimer's Australia NT and a historical year for Alzheimer's Australia on a national level.

This year we have seen the beginning of the Alzheimer's Australia transformation from a federation of states

and territories to become a unified national entity. The new entity will continue to deliver quality local services and education as well as continue to raise awareness of Alzheimer's disease and other dementias.

We also learned that dementia has become the leading cause of death for women in Australia and the second leading cause for all Australians. There are more than 413,000 Australians living with dementia today and without a medical breakthrough this number is expected to exceed 1.1 million by 2056. While this is a concern for us all, Alzheimer's Australia NT continues to work hard every day to fulfil our mission to make sure that no one goes through dementia alone.

In July 2015, I became a committee member of Alzheimer's Australia NT and in December 2016, I was elected as president, taking over from Dr Vicki Krause who had been our frank and fearless president for the previous 8 years. I would like to thank Vicki for her guidance and trust; as I learn to walk bravely in my own shoes.

My commitment to the organisation began when my father was diagnosed with younger onset dementia in early 2015. It is amazing what strength, support and shared stories can be found in family, friends and strangers when your world is suddenly, forever changed. Younger onset dementia is an expanding focus here in the Territory with a dedicated support group, newsletters and fundraisers. It continues to have its unique challenges and opportunities as a result of falling outside the more traditional approaches and 'picture' of dementia.

Unification

Over the past few years there have been discussions at the national and state level regarding governance reform and the importance of a unified organisation which meets the needs of all Australians living with dementia. Previously each state and territory had been an independent entity governed by its own board and management with their own constitutions, members, service delivery, staffing models and financial responsibilities. In August and September 2017, the national board together with all other state and territory boards, with the exception of Western Australia which resigned from the federation earlier this year, resolved to take the steps necessary to move towards a national unified entity with the new name Dementia Australia.

The unification project is momentous and will provide a stronger coordinated voice and service delivery for people living with dementia as well as their families and carers. This includes us here in the Territory. A coordinated national approach means that there will be substantial benefits for people in the Territory living with dementia, their families and carers as well as staff and volunteers including:

1. improved capacity to deliver services for people with dementia their families and carers;
2. a strengthened client voice and increased public profile that will maintain Dementia Australia's status as the peak charitable body for people with dementia;
3. a more nimble, agile and responsive organisation able to deal with the rapidly changing environment building long term sustainability;
4. streamlined decision making and improved efficiency;
5. increased capacity to secure financial support and improve financial sustainability; and
6. improved collaboration, strengthened organisational culture and development opportunities for staff.

The Alzheimer's Australia NT staff have always done an incredible amount of work with the limited resources at hand. The Alzheimer's Australia NT board and staff have worked tirelessly alongside CEO Kylie Beard to see this transition begin to take shape. As a result of unification it is expected that staff will notice enhanced support, opportunities, and innovation, as well as diversity of thought. The user experience will be improved while still providing the current suite of important services including day respite; Younger Onset Dementia Key Worker Program (YODKWP); education and risk reduction programs; information and awareness, support and counselling; and early intervention for those living with dementia, their family and carers.

Events and Fundraising

In May, the Gala Ball Fundraiser with the theme 'A Night of a Thousand Memories' was held at the Skycity Beach Side Pavilion. The evening commenced with three incredibly powerful, confronting and loving accounts of how families and carers find support and navigate the challenges of caring for a loved one living with dementia. We then heard from his honour the Honourable John Hardy AO, Administrator of the Northern Territory, before the night was danced away. Alzheimer's Australia NT also supported the National Institute for Dementia Research's public lecture tour with special guest speaker Professor Henry Brodaty AO, whose lecture Dementia – Inspiring Hope, Retaining Realism, attracted over 90 guests. Most recently there was a bursting month of activities for Dementia Awareness Month including the Trivia Night Fundraiser held at the Darwin Trailer Boat Club, organised by dedicated volunteers, who made sure the night was fun, competitive and full of weird and wonderful facts.

Thank you to the outgoing Alzheimer's Australia NT board and staff

I would like to say thank you to the outgoing Alzheimer's Australia NT board who have been committed and responsible every step of the way to ensure that Alzheimer's Australia NT works towards its objective to be a strong credible voice for people living with dementia, their families and their carers, as well as delivering quality services and support. As one of the newest members of the board I am truly humbled to have collaborated with such a supportive, skilled, passionate and dedicated group.

I would also like to thank outgoing Alzheimer's Australia NT CEO and finance manager Kylie Beard for her dedication, support and commitment in pursuing Alzheimer's Australia NT's mission and objectives. Kylie has been with Alzheimer's Australia NT for nearly nine years. Kylie and I attended several unification workshops over the past year and she has been a source of strength and reason. Alzheimer's Australia NT will greatly miss her warmth and expertise. We wish her all the best in her future endeavours.

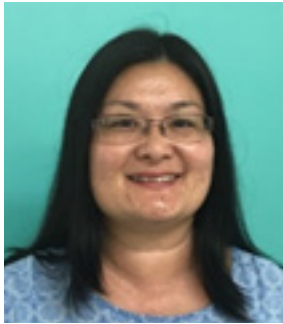
I would also like to take this opportunity to thank all the Alzheimer's Australia NT staff in Darwin and Alice Springs as well as volunteers, sponsors, and donors for their continued support throughout the year. It is this incredible network of people which helps improve the lives of people living with dementia and increases awareness about all forms of dementia.

Next Steps for Dementia Australia and the NT Division

The steps towards unification are in full flight. There is now one national board for Dementia Australia and one national CEO. It has been a whirlwind of a year and I look forward to the opportunities, challenges and friendship in the year ahead.

Jenna Dennison
President
Alzheimer's Australia NT

CHIEF EXECUTIVE OFFICER'S REPORT



Alzheimer's Australia NT Inc provides an extensive suite of services ranging from the delivery of education, information and risk reduction programs to health workers and to members of the community. We also provide early

intervention support, and counselling services for people living with dementia and their carers.

Our programs include day respite, assistance with navigating and connecting to the aged care and national disability systems, and the provision of support to those with younger onset dementia (under 65 years).

On 15 February 2017, Alzheimer's Australia commissioned and launched '**The Economic Cost of Dementia in Australia 2016-2056 Report**' by The National Centre for Social and Economic Modelling (NATSEM).

The NATSEM report found that:

1. dementia is the second highest leading cause of death in Australia;
2. more than 413,106 Australians are living with dementia; and
3. there are more than 1,644 Territorians recorded as living with dementia.

This year has seen significant changes across the aged care and disability sectors as the Australian Government moves away from a block funded model to one which is market driven and focused on consumer choice. These changes are evident through the introduction of the My Aged Care Gateway (MAC), the staged rollout of the National Disability Insurance Scheme (NDIS), and the implementation of a consumer directed care model in which clients can choose the services they want and determine how their funding is allocated.

These changes have had a significant impact on our organisation in terms of funding, resources, systems and staffing. Funding has been reduced substantially, with this having a negative effect on both resource availability and staffing levels. In addition, systems, procedures and regulations relating to both MAC and NDIS are in a constant state of evolution, as the government seeks to refine and optimise both systems in response to feedback from consumers and service providers.

Despite the difficulties associated with such large-scale system changes, Alzheimer's Australia NT staff have continued to provide high quality services and programs and are to be commended on their capacity to adapt, their dedication, and their continued willingness to go above and beyond the call of duty.

I would also like to thank our Board for their support and guidance. We have been very fortunate that our board members are experts in their field and they have all demonstrated a strong commitment to the mission of Alzheimer's Australia.

And finally, I would like to acknowledge the generosity of our sponsors and supporters who donate, or give in kind, of their services and time. This generosity complements government funding and without it we would be unable to continue to provide these vital services or to meet the growing needs of Territorians living with dementia.

Kylie Beard

CEO

Alzheimer's Australia NT

JOY ANDERSON CENTRE

The Joy Anderson Centre provides day respite for carers five days a week and continues to be popular and well attended. The Stepping Out program, which is run from the centre, provides clients with the opportunity to participate in a wide range of activities and to maintain connections with the broader community. The program has a varied focus and includes social and recreational activities, such as visiting the wetlands, ten pin bowling, and the maintenance of acquired art skills through the weekly art group, gardening, baking, and craft sessions.

Projects such as the great gnome makeover provide a source of considerable satisfaction for both clients and members of the public. This is an ongoing project where people with old dilapidated garden gnomes can bring them to the centre and have them freshly painted for a small fee.

Staff continue to develop and maintain relationships with a wide range of organisations such as Bunnings, Wongabilla Equestrian Centre, Tracy Village sports club and emergency fire services. These relationships facilitate community connectedness as well as increase community awareness of dementia. The relationship with Bunnings has been going for almost seven years, with four groups of clients from the centre attending each month.

For many clients, the centre is like a home away from home. One of the best things about the centre is the way it integrates activities in a meaningful way and enables clients to have a sense of ownership of the programs and services we offer. They know their way around the centre, they have their favourite places for lunch and recreational activities. The dementia-friendly garden, which was completed in 2016, is flourishing and provides a calm place to relax as well as an opportunity to maintain gardening skills. One highlight was a client who attended the centre with his wife and baked a banana cake together which won second prize in the Royal Darwin Show.

The centre also provides a focal point for raising awareness and educating people about dementia, both through the display of art works at community events and through regular student placements from Charles Darwin University.

CLIENT SERVICES DARWIN

The 2016-2017 financial year has been one of significant change in the aged care and disability sectors. This has inevitably impacted on staff who deliver client services. In addition to managing their usual workload, staff have had to deal with the inevitable teething problems associated with the implementation of the complex government systems (MAC and NDIS) that are now an integral part of accessing aged care and disability services. Implementation of these systems has also led to a range of new policies and procedures.

These changes have affected service providers across the sector including Alzheimer's Australia NT. Staffing in the organisation is lower than in previous years and there has been considerable staff turnover during the past year.

Alzheimer's Australia NT has continued to provide high quality services and support to people living with dementia, their family and carers. Core programs, such as counselling, information, and advocacy; early intervention; social support; and day respite have been maintained, and some new programs have been initiated. Support sessions have remained strong over the last year, with many of these delivered on a one-to-one basis.

Overall, client demographics continue to reflect the diversity of the Northern Territory population, and over the course of this year there has also been a slight increase in the number of Aboriginal and Torres Strait Islander clients.

A range of early intervention, outreach, therapeutic and social activities have continued to play an important role in building awareness of dementia among the general public and in helping people with dementia and their carers to maintain links with the community. Activities, such as our brain-gym risk reduction program, have been particularly popular with members of the public and provided an opportunity to raise awareness of dementia while at the same time increasing opportunities for older people to forge new social connections.

The art group, which was initially held fortnightly, has proved so popular that it is now held on a weekly basis. The art group provides an opportunity for people with dementia and members of the general public to work together, and has resulted in the creation of a social enterprise called 'Gone Potty'. Through 'Gone Potty', members of the art group create a range of products which are sold to the general public, with proceeds from sales being used to support the purchase of materials for the art group, making it self-sustainable. Products from the 'Gone Potty' enterprise are frequently showcased at

community events such as the Darwin Garden Spectacular, Seniors' Expos and the Darwin Show, and create an excellent focal point from which to initiate discussions about dementia.

Another highly successful program, Meaningful Memories through Music, was run by one of our dementia advisors who is also a registered music therapist. Feedback from members of this group indicate that the program had assisted in speech recovery, social engagement, better health, and improved mood.

Dementia Awareness Month, held in September 2016, was highly successful and included a number of awareness raising events such as the annual Tea Dance, a high tea held at the centre, two seniors' morning teas, and a range of pop-up booths and education sessions.

The Tea Dance has become an annual event and this year was held in partnership with the Multicultural Council NT (MCNT). The event raised awareness about dementia and also celebrated cultural diversity in the Darwin seniors' community. The partnership with the MCNT built on the strong linkages created with the local CALD community through the CALD community engagement project which ended in June 2016.

Through the MCNT, we were linked to the International College of Hospitality and 20 students from the college were involved in hospitality service at the event. This contributed to their final assessment by providing the opportunity for a practical activity to demonstrate their ability to put their theoretical learnings into practice. An information session about dementia was held for the students prior to the event to foster understanding of the condition. The Tea Dance was highly popular, with more than 100 people attending.

This year, Dementia Awareness Month included a morning tea for seniors in Darwin and a lunch in Alice Springs. Both events highlighted the importance of risk reduction. The Darwin event focused on active lifestyles and social engagement, framed by Alzheimer's Australia's 'five simple steps' risk reduction messages. The theme for the luncheon in Alice Springs was similar but also included a talk from Department of Health staff on the Commonwealth Home Support Program and Home Care Packages, and the new reforms to be implemented in February 2017. Politicians and government staff were in attendance at both events, demonstrating the strong linkages we are forging with government.

CLIENT SERVICES ALICE SPRINGS

Despite having only one staff member, the Alice Springs office continues to provide a wide range of dementia support services to people in this region. Key services include: individual and group social support; dementia advisory services; community education, information and awareness; risk reduction in alcohol rehabilitation centres; and delivery of the Dementia Essentials program.

One particularly successful initiative in Alice Springs is the Living with Memory Loss café. This commenced in 2016 and provides an opportunity for people to meet once a month and to have a chat over lunch; it is a great opportunity for everyone to hear personal stories about dementia from those who are living with, or caring for someone, with this disease. One of the key achievements of the café is to assist the person with dementia to maintain social connections with other members of the community. This is because the café is for everyone - people with dementia, carers, family, friends and the general public – and does not segregate the person with dementia into a separate group.

Another program which has proved popular is 'Stepping Out'. This program provides social support on a weekly basis; it includes lunch and other activities such as visits to Connellan Airways Museum, Strehlow Museum, Alice Springs Town Council pop-up shop (History of Alice Springs), the RSPCA, and long drives in the country.

The services coordinator in Alice Springs has been providing the Dementia Essentials program since early 2017. Delivery of this program by a local staff member has enhanced attendance rates and reduced the need to cancel courses due to lack of interest. This is largely because the services coordinator can market the program more effectively due to her ability to draw on strong established relationships with local service providers – this was not possible when it was delivered by an educator based in Darwin. Increasing understanding and knowledge about dementia through the Dementia Essentials program, and other awareness raising activities, is critical in this region, as there are fewer professional development opportunities for people living and working in these areas, particularly for those working in remote communities.

The Alice Springs branch also conducts a risk reduction program in alcohol rehabilitation centres. This provides an excellent opportunity to increase awareness of dementia in Indigenous communities, as some participants in this program originate from remote communities where most urban based service providers do not get the opportunity to provide services. This program is tailored to the needs of Indigenous people and focuses on providing information about: how to reduce the risk of dementia through the adoption of healthy lifestyles; the importance of obtaining an early diagnosis; and informing participants about pathways to diagnosis that are relevant to people living in a remote community. These sessions provide effective outreach; if one person goes through the program and returns to their remote community with knowledge about dementia, then the program has been a success, as they are spreading the word faster and further afield than any service provider could achieve.

CLIENT SERVICES

YOUNGER ONSET DEMENTIA

The Younger Onset Dementia Key Worker program provides support to people under 65 who have dementia or who have concerns that they may have dementia. It provides people with assistance in seeking a diagnosis; links individuals to appropriate services; provides counselling and support to carers, families and the person with younger onset dementia; and supports those living with younger onset dementia to remain socially engaged in their community. It also seeks to build the capacity of service providers to tailor their services to more effectively meet the needs of people with younger onset dementia.

Alzheimer's Australia NT's Younger Onset Dementia Key Worker program is in the process of becoming a service provider in the National Disability Insurance Scheme (NDIS).

Over the last year, staff from Alzheimer's Australia NT have been: extending their knowledge and understanding of NDIS requirements through attendance at NDIS seminars and national Alzheimer's Australia Younger Onset Dementia Key Worker program meetings; developing linkages with NDIS staff; and developing mechanisms for supporting clients in the transition to the NDIS. The components of the NDIS relevant to the Younger Onset Dementia Key Worker program was rolled out in Katherine in July 2017 and will be rolled out in Alice Springs and Darwin in July 2018. We anticipate that we will be in a strong position to participate in the NDIS once the roll out is complete.

At the end of 2016, the staff member who was both key worker and team leader for the program, resigned. The key worker role was subsequently taken over by one of the dementia advisors and the team leader role was taken on by the programs manager. The new key worker has made a sound contribution to the program and has built on the strong foundation developed by the previous key worker and team leader, with the Younger Onset Dementia Key Worker program continuing to provide quality supports to clients as well as to service providers who work with people with younger onset dementia.

Since June 2016, Alzheimer's Australia NT has continued to focus on capacity building and strengthening networks, particularly in the disability sector. A substantial amount of effort has been expended on improving relationships through education and discussions with case coordinators from the disability coordination team and with service providers who are working alongside people

with younger onset dementia. This has resulted in better communication with the disability coordination team and a reduction in the time it takes for clients to gain access to disability supports. It has also resulted in a more efficient review process and faster implementation of amendments resulting from client reviews. This, in turn, has produced better outcomes and support plans for the clients.

Younger onset dementia clients in the Territory face a significant gap in services, particularly in relation to accessing the supports needed to assist with maintenance of social and community engagement. To address this gap, Alzheimer's Australia NT has set up a social group for clients with younger onset dementia. The group meets weekly and the social support facilitator works with participants to develop a program consistent with their interests. The Younger Onset Dementia Key Worker has also continued to provide carer support through fortnightly meetings over coffee or a meal. Many of the people who care for someone with younger onset dementia work on a full-time basis and in order to accommodate their schedules, these sessions are held after hours, between 6 and 8pm.

The majority of clients on the Younger Onset Dementia Key Worker program are based in Darwin and we receive few referrals for younger onset dementia from regional and remote areas. In Central Australia, supports for clients with younger onset dementia are available through our Alice Springs office. Alzheimer's Australia NT does not have an office in Katherine but the Younger Onset Dementia Key Worker conducts quarterly visits to this region in order to support clients in this area. Due to the small population in this region, it is not practical to provide services that are specifically designed for younger onset dementia clients. The Younger Onset Dementia Key Worker has managed this by working with local service providers to strengthen their capacity to meet the needs of younger onset dementia clients within their existing services. As a result, fortnightly morning teas and quarterly network meetings suitable for younger onset dementia clients are now being facilitated by these local providers. The Younger Onset Dementia Key Worker has also connected a carer, who lives some distance from Katherine, to support groups and events in Darwin.

EDUCATION

Over 2016-17, Alzheimer's Australia NT has continued to deliver a wide range of educational opportunities to carers, health professionals and the general community. These include the provision of risk reduction sessions in correctional facilities and alcohol rehabilitation centres in Greater Darwin, Katherine and Central Australia as well as information and awareness sessions to community groups, service providers, and the general public.

Since October 2016, Alzheimer's Australia NT has been delivering the new three day nationally accredited Dementia Essentials (DE) program. This builds on the previous Dementia Care Essentials program but comes in a more engaging format and is packed with useful tips and videos. Delivery of this program has been highly successful and we have exceeded the targets specified in our contract. Uptake of DE, particularly in Alice Springs, has been enhanced by upskilling our Alice Springs services coordinator so that delivery of the DE program is not reliant on our Darwin based educator being able to fly down from Darwin. This makes it possible for us to deliver the DE program in a flexible way that fits in with service providers' staff rosters, with courses now scheduled once a week over three weeks instead of across three consecutive days.

Feedback from participants on the value of the DE program has been overwhelmingly positive. On average, we have six participants per class, with this allowing for an interactive personalised, intensive delivery style that optimises learning, understanding and comprehension. A number of participants have reported that their care practices have improved and the quality of care given to the person with dementia has increased. This has been corroborated by their supervisors.

We have provided education and information sessions to a diverse range of organisations including Charles Darwin University, COTA, University of the Third Age, allied health professionals and service providers. These sessions have covered a variety of topics such as sexuality and dementia, what is dementia and an integrated approach to dementia care. We have also presented at two forums run by the Regional Rural and Remote Network group, one in Darwin and one in Alice Springs. These sessions were well received by service providers, many of whom are based in rural and remote areas and have fewer opportunities to participate in education about dementia.

The need to raise awareness and strengthen community understanding continues to be a key focus of our educator and also of staff across our organisation. Information and awareness activities have taken a number of forms, including pop-up booths in shopping centres, at community events and at the Darwin, Alice Springs and Katherine shows. These events are excellent public relation exercises as they raise awareness about dementia and of the services provided by Alzheimer's Australia.

ACKNOWLEDGEMENTS

We would like to acknowledge the great work of the staff here at Alzheimer's Australia NT Inc.



Above 'A Day in Paradise' annual client luncheon



Above and right 'A Night of a Thousand Memories' gala fundraising ball

We extend our thanks to our volunteers, our fundraising volunteers and our corporate sponsors.