FIRST STEPS TO A DEMENTIA-FRIENDLY AUSTRALIA

UNDERSTAND ALZHEIMER'S EDUCATE AUSTRALIA
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Alzheimer’s Australia respectfully acknowledges the Traditional Owners of the land throughout Australia and their continuing connection to country. We pay respect to Elders both past and present and extend that respect to all Aboriginal and Torres Islander people who have made a contribution to our organisation.
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ACKNOWLEDGEMENT

Alzheimer’s Australia would like to thank the people who have shared their personal stories in this booklet. The stories of inspiration and steps that can be taken to become dementia friendly are in their own words.
There has been a sea change in attitudes to dementia since the turn of the century. For the first time people with dementia were centre stage at the opening of the 2001 Alzheimer’s Australia Conference in Canberra. How extraordinary to reflect now that an organisation set up to advocate for people living with dementia was not inclusive of people with dementia. It is of course true that Alzheimer’s organisations were founded by family carers in the early 1980s. But the real problem has been for centuries that people with dementia have been treated like non people and locked away, and a cause of shame for the family.

We understand now that dementia is a chronic disease like any other and not simply the outcome of ageing. To the contrary dementia develops decades before first symptoms appear, but these new insights have yet to reduce the stigma and social isolation that a diagnosis of dementia often brings. A dementia-friendly community will recognise the need for a person with dementia to continue their lives and to participate in the community in activities they enjoy whether through employment, volunteering or social activities. This is the challenge.

As this publication demonstrates, no longer are people with dementia living, nor willing to live, empty lives. The good news is that there are plenty of examples of how to make our society more dementia friendly – the bad news is we have a long way to go and need the support of governments, philanthropic organisations, corporations and the community more generally to achieve the objective of a dementia-friendly Australia.

Kate Swaffer
THE ART OF SEEING THINGS DIFFERENTLY

When the National Gallery of Australia (NGA) established the Art and Alzheimer’s Program in 2007 it began a journey of discovery. The gallery initiated training to understand the needs of people living with dementia during a six-week pilot program. Staff from across the institution working in a variety of roles, from the café to front of house, were all part of the process.

Adriane Boag, Coordinator of the NGA’s Art and Alzheimer’s Program collected anecdotes from her colleagues and carers on the impact of the program designed for people with dementia.

“When the program began I was worried about how people would respond” says security officer Sylvan. “Now I feel confident. I see how much everyone enjoys it. It makes me feel good that people with dementia are supported by the gallery.”

Today the gallery is a safe and welcoming place for people with dementia, with a variety of tours that allow people living at home and in residential care to participate. Within the gallery, awareness of the program and the value it provides for participants and carers has expanded. Staff are positive in their praise of the tours and some reflect a personal perspective.

“Having people with dementia coming to the gallery reduces stigma. I care for someone with the disease and people don’t realise that it is still possible to lead a stimulating and interesting life. My Dad had never been to a gallery before; he comes along in his overalls. He finds joy in doing things he didn’t have the opportunity to do in the past. The gallery is a very accepting environment; my Dad is part of a really nice, supportive group.” This comment was made by Lisa, who works at the gallery as a Conservator. Lisa’s father, Fred, visits every month for a tour shared with carers.

Perhaps no public program has demonstrated the unique qualities of the visual arts to overcome barriers to communication as clearly as the Art and Alzheimer’s Program. Works of art provide the focus for intellectual stimulation through open-ended discussion. In a supportive environment this exchange of critical investigation and reflection leads to learning through a shared experience.

Margie Kevin, a gallery educator, reflects: “The tours make me think about my role and why people come to the gallery. People with dementia display their capacity when thoughtful communication techniques are used. We start by just looking at the work of art, and talking about what we can all see as a way to begin the process of interpretation. I have learnt to really listen and allow time for information to be processed, to be comfortable with silence.”

In 2010 the NGA developed a training workshop to assist galleries in regional and remote Australia to implement programs for people with dementia. The Art and Alzheimer’s Outreach Program workshop has been delivered in 25 galleries in six states and territories, extending the reach of one way to create dementia-friendly communities.

The Art and Alzheimer’s Program at the NGA has made us all aware of just how many people are affected by this health issue. The social aspect of meeting regularly enhances feelings of support the individual. The gallery program can’t cure dementia, but it can provide quality of life by maintaining a sense of belonging to a supportive and dementia-friendly community.

Want to know more?
Email Adriane: Adriane.boag@nga.gov.au
Graeme Atkins was diagnosed with younger onset dementia when he was 54 years old. Graeme tells his dementia story through his songs to help keep his brain active and to continue being involved in the community.

Graeme’s songs originate from the impact that dementia has had on him, the issues surrounding the stigma and the isolation of the disease, the diagnosis process, the pressure placed on carers, family and friends, the financial cost of this disease, and the lack of understanding of dementia across the general community.

Graeme and his partner Susan have shared their story through Graeme’s songs at more than 60 regional events. At one event, a man in the audience was crying. He was living with dementia. Being concerned about this gentleman, Susan asked him why he was crying. He looked at Susan and told her that he was happy that finally someone understood how he felt. Graeme’s songs relay the emotions and feelings of other people with dementia who sometimes cannot get their message across.

The songs are powerful, as they are coming from someone who has dementia who is able to understand and describe what is happening.

Music lights up many parts of the brain and is a great way to exercise the brain. With that in mind, Graeme and Susan continue to address issues about dementia via his music. Graeme’s latest song is about creating dementia-friendly communities across Australia.

One of Graeme and Susan’s biggest joys is performing at the Alzheimer’s Australia (NSW) Christmas party in the region during Christmas time. The Christmas sing-along at these functions is inspiring as sometimes a person with advanced dementia sings along to the well-known Christmas carols. These joyful events bring many smiles and much laughter to all who attend.

Graeme’s songs are not just about the feelings and the difficulties encountered, they encompass a broad range of issues surrounding a dementia diagnosis. Some of these songs are delivered with a touch of humour, while others dramatically tug at the heart. However, the message is always loud and clear – yes, I have dementia, but I am still here and I am a person, and yes I’m living well with dementia.
The ‘Every Bloke needs a Shed’ pilot project was an initiative of Alzheimer’s Australia NSW, funded by NSW Department of Human Services for two years, beginning in 2011. The goal of the project was to increase social engagement of socially isolated older men, with a particular focus on men with early-stage dementia and male carers of people with dementia. The project encompassed the Hunter region and involved eight Men’s Sheds.

The ‘Every Bloke needs a Shed’ project focused on:
• Improving the social engagement and sense of purpose of the project participants
• Providing education and developing an understanding and skills in shedders about dementia
• Providing spousal carers or friends with respite and guidance about dementia

The stories heard through the evaluation highlight that the project contributed to a sense of belonging and purpose, self-esteem, self-worth and social inclusion for men with dementia. This was achieved by providing: a venue and activity that is flexible and accommodating of their ability; a male setting and the company and friendship of men outside the family; a work-like setting and activities that are meaningful and provide purpose; a setting that normalises them and relegates their dementia to a minor place and a link to being part of and contributing to the broader community.

The evaluation provides evidence of a reduced burden on the spousal or other carers of men with dementia. Access to regular respite, as well as having a contact at Alzheimer’s Australia to assist with questions, all contributed to having a “happier” husband or friend who felt valued and engaged in community life.

The impact of the project extended beyond just the people with dementia and their carers. Other men at the shed gained an increased understanding of dementia and improved their skills in communicating and working with people with dementia. They gained a sense of purpose and worth by helping the men, as well as an ability to identify and assist men with early-stage dementia who were already participating in the Shed.

As a community group, the participating Men’s Sheds in the Hunter have shown what a dementia-friendly social group should look like: welcoming, informed and ready to help.

“The Cessnock Men’s Shed has kept me going. Without the shed I don’t know what I would have done, probably curl up and die.”
Jim (Participant)

“I feel like a king in this place... here at the shed I am greeted when I come to work. The guys always say, “Good morning, Reg” and I like that!”
Reg (Participant)

“Don and the Elermore Vale Shed are perfect fit. Evidently the Men’s Sheds are wonderful things!”
Val (Don’s wife)
Leslie Williams, Member for Port Macquarie and co-convener of the NSW Parliamentary Friends of Dementia group, highlights the serious challenges that Port Macquarie has to address as a consequence of the concomitant increase of the ageing population and related illnesses including dementia. Of all the 93 state electorates in NSW, Port Macquarie has the second highest prevalence of dementia and this is set to increase by 350 per cent by 2050.

“These statistics burdened me as did the potentially poor outcomes and curbed lifestyle for the growing number of people living with dementia in our community,” Leslie said. “It equally weighed on my mind the unjustness of those who were carers isolated by limited support services, community attitudes and challenging physical environments.”

Leslie decided to seek counsel from a group of people in the community – people who she knew would share her frustrations at the future ahead for those diagnosed with this progressive terminal disease, and for the large number of families impacted by a diagnosis of dementia for someone they love. From this information and the statistics it was unanimous that there was no time to delay action to develop a dementia-friendly community.

A steering committee was established to start a conversation about the challenges that Port Macquarie faced and the need for change. The committee consisted of a range of people within the community including people with dementia, representatives from health, dementia services, local churches, registered clubs, education, service organisations, business chambers, consumers, emergency services, local council and an elder from the local Birpai community.

The committee aims to develop, plan and implement community-based initiatives that will contribute to the development of a dementia-friendly community through building relationships with these key members. The focus is to engage the community, including people with dementia and their families, to assist in publicising dementia awareness activities and develop a plan of action consistent with the needs and wants of people with dementia in Port Macquarie.

In conjunction with the steering committee being established, Leslie thought it important to continue exploring ideas to advance the development of a dementia-friendly community. In July 2013, courtesy of the Commonwealth Parliamentary Association, Leslie went on an overseas study tour to England, Scotland and Ireland to investigate strategies being implemented at a community level to engage people with dementia and their families. During her three-week tour Leslie met the people within the community who were the cornerstone for change such as psychologists, researchers, residential and respite care managers, policy advisors, hospital and community staff as well as people living with dementia and their carers.

Leslie returned to Port Macquarie with a mountain of information, facts and figures and details about specific programs in Torquay, London, York and Killaloe. Leslie did not intend to replicate any of these projects because she realised early on that the key to succeeding in this space was all about the community. The development of a dementia-friendly community had to be driven locally. It has to be based on local knowledge and local people and absolutely has to involve local people living with dementia and their carers every step of the way.
The Port Macquarie project has accomplished so much, including the increased awareness in the community about the implications for those living with the disease and the impact on their families. The support from the local media has been welcomed, with weekly narratives about dementia being broadcasted across the various local networks.

One of the real obstacles for people living with dementia and their carers to continue being engaged in the community is the physical environment. The steering committee recently made a submission to the local council inviting them to carefully consider those with dementia when planning new and upgraded public assets and spaces such as the Town Square and the Town Green.

One of the focuses of the steering committee is to engage with the business community because it cannot be overstated the important role they can play in supporting people living with dementia and their carers by being accessible and accommodating. The enthusiasm of one local café who is envisaged to become a model of a dementia-friendly business for Port Macquarie is exciting. This pilot aims to develop a checklist verifying whether staff are educated and understand the needs and challenges facing people living with dementia in our community. Central to the process for change will be the engagement with local people living with dementia and their carers to identify and address issues relating to the physical environment of the business such as access, noise and furnishings.

Across the many miles Leslie travelled and the many conversations she had it became clear that the beneficiaries of this movement to develop dementia-friendly communities was widespread - from people living with dementia to their carers to each and every person and every organisation that chooses to be involved in this transformation of local communities.
WORKING TOWARDS A DEMENTIA-FRIENDLY KIAMA

Alzheimer’s Australia, the University of Wollongong and Kiama Council are committed to test a range of innovative initiatives to address social inclusion, physical design and community understanding of dementia in the local area. There are five key areas to creating a dementia-friendly Kiama. These are:

1. Listening to people with dementia about what is important to assist them to live well with dementia in the Kiama community.

2. Establishing a Local Dementia Alliance that will work towards making Kiama dementia friendly. Members of the alliance will include people with dementia, local government, community organisations, businesses and schools, which includes people with dementia. The alliance will meet regularly to support, discuss, provide advice and promote the initiative in the local community.

3. Supporting local organisations and businesses to become dementia friendly through making small changes that will have large impacts on the lives of people with dementia. A recognition process will be developed for organisations and businesses that commit to improving their services and practices to make them more accessible to people with dementia. This process will be supported through training and resources developed by Alzheimer’s Australia.

4. Raising awareness of dementia through providing information sessions, public lectures and education opportunities for all members of the community.

5. Working with organisations to promote volunteering, employment and other social engagement opportunities for people with dementia.

The partnership approach is an essential part of achieving social change in Kiama. Dementia friendly is everybody’s business and each organisation plays an important part in achieving the goal of a dementia-friendly community in Kiama being realised. The local grassroots knowledge and ownership is provided through Kiama Council. The national leadership to translate the dementia friendly concept to a locally relevant strategy is provided by Alzheimer’s Australia, and the importance of collecting social research data through the initiative to demonstrate evidence of the effect of the initiatives is critical.

Each partner organisation is committed to improving the lives of people with dementia in the community and sharing the lessons from this work with other communities. This initiative presents huge opportunities not only for the Kiama community but for all Australian communities as the prevalence of dementia increases. In 2050 there are predicted to be over 900,000 Australians living with dementia. All Australians with dementia should have the opportunity to be directly involved in the dementia-friendly initiatives and a chance to live in an accepting and inclusive community that supports, understands and encourages people to live well with dementia.
A DEMENTIA-FRIENDLY SHOPPING EXPERIENCE IN THE NT

‘Stepping Out’ is a social activity-based group for people living with memory loss. The group is supported by Alzheimer’s Australia NT to participate in social outings, group discussions and activities within the community. For many years the Alzheimer’s Australia NT ‘Stepping Out’ group has visited the Hibiscus Shopping Centre as part of the program. Hibiscus is a small northern suburbs shopping centre providing services to many local families and older Territorians.

The businesses in the centre often come together to provide a free morning tea for the ‘Stepping Out’ group. Strawberry Fields, the central café in the centre, hosts the get together with all members of the community enjoying the event.

Building relationships and connecting to people and their stories is what life in the territory is all about. Without these relationships, meetings are purely just words. Alzheimer’s Australia NT and the Thursday ‘Stepping Out’ group have grown their relationship with Hibiscus Shopping Centre to one that will not only benefit themselves but also benefit the entire community.

The ‘Stepping Out’ group has become part of the Hibiscus Shopping Centre family. The centre manager has experienced first-hand the challenges of patrons who have cognitive impairment and with that has come a yearning to provide them with the best possible experience they can have during their visit to the centre; to feel safe and included.

Alzheimer’s Australia’s NT staff have met with the centre manager on many occasions during the morning teas and discussions have now taken a new direction. There is much talk about dementia and what makes a dementia-friendly environment.

The centre manager, Laura, with the support of other key businesses has set a goal to take steps towards being the first dementia-friendly environment in the territory. Achieving this goal would also mean the centre would be creating a pathway towards reducing stigma and discrimination and would be working towards the full inclusion of people living with dementia.

The key steps towards reaching this goal will include staff education and awareness raising throughout the centre. The ‘Stepping Out’ group supports the key personnel to walk in their shoes and look at signage, lighting, noise levels and resting places through the centre, while also conducting an environmental audit as they go. Planning towards a new dementia-friendly tomorrow is well and truly underway.

As they work towards creating a dementia-friendly shopping centre, the staff and businesses at Hibiscus Shopping Centre would help to provide an opportunity for regular conversations about dementia, help change community attitudes and support acceptance for those people living with dementia. What an achievement this would be.
THE POWER OF PARTNERSHIPS

Boost Juice and Alzheimer’s Australia NT have established a new partnership to raise awareness about dementia in the community. Enjoying a cool juice with friends in the hot climate is a regular occurrence for many territorians, so the opportunity to spread awareness and challenge the stigma often associated with dementia across the NT through this partnership is enormous.

Boost Juice Casuarina and Darwin have recently made the commitment to become dementia-friendly businesses which will in turn help raise community knowledge and understanding about dementia in the NT. This commitment emerged from an understanding across the organisation of the importance of promoting a healthy body, heart and brain.

The Boost Juice team is creating a signature smoothie to promote dementia awareness. Working with the team from Alzheimer’s Australia NT, Boost Juice staff have enjoyed the challenge of coming up with a catchy name to promote the new smoothie. Berry Brainy and Nervous Neuron have been shortlisted. Both Boost Juice and Alzheimer’s Australia NT understand and are committed to develop this creative idea based on the evidence-based need to support people with dementia, as well as those at risk of dementia in the community.

Alzheimer’s Australia NT, with the assistance of the partnership with Boost Juice and the Healthy Darwin Council, will be incorporating the Smoothie Bikes Pedal Power and the Boost Juice signature smoothie to the activities promoting healthy exercise and brain health during Dementia Awareness month in September.

To work towards a dementia-friendly community, Alzheimer’s Australia NT will continue to strive to raise dementia awareness, provide education and training about dementia to organisations, like Boost juice, and promote the importance of a healthy brain which will benefit all territorians and the communities they live in.
Anyone living with dementia, their family and friends will be welcome to join the Come Dance with Me program. The classes cater for all ages and all ability levels. There are no steps to remember, no left and right, no wrong way to dance, just positive encouragement for everyone to express themselves through dance.

Dementia advocate, Christine Bryden has recently participated in a trial of the dance classes. She believes that having the opportunity to continue to dance regardless of having dementia is for her an important part of a dementia-friendly community.

Christine says Come Dance With Me is a fantastic way of having fun with friends and family. You don’t have to talk - just smile and enjoy yourself. It’s about gentle movement to music, so you can join in sitting down if you want. Blokes are also welcome – my husband Paul is making sure it is not too girly! Music, movement and social activity are all really good for those of us with dementia.”

The class has been developed in collaboration with Beverley Giles, a member of Act Dance who brings over 25 years experience working with people with dementia to the program. Beverley describes the purpose of the class as, ‘about giving people with dementia the opportunity to do something they love and simply move to the music’.

Beverley adds, Come Dance with me, is an activity a person with dementia can share with their partner, it brings joy, fun and laughter and has positive body and brain health benefits for both.

COME DANCE WITH ME

Come Dance with Me is a new dementia-friendly dance program being launched in Brisbane during September. The class has been designed to empower people with dementia to participate in the community while engaging in social and physical activity.
SPREADING THE WORD ABOUT DEMENTIA

Educating the general community about dementia is an important way to help reduce the stigma and dispel some of the common myths about dementia. There is also a critical need to better educate people in the health care professions about dementia, including doctors, nurses and paid carers in training.

A Townsville, QLD group of people with younger onset dementia, who have been meeting for over five years, decided to take on this challenge. They approached James Cook University (JCU) to allow the group’s members to educate the students about the lived experience of dementia and the issues they often face.

At the time, Dr Fiona Millar was running a series of tutorials for final year medical students and agreed to work with the convenor of Alzheimer’s Australia Far North Queensland Younger Onset Dementia group (YODG) and arranged for members living with dementia to attend the tutorials. Beryl Buckby PhD from the School of Psychology at JCU was also undertaking research with several members of the Younger Onset Dementia Group (YODG) and was supportive of this approach.

During the tutorials the members of the YODG who were living with dementia sat alongside the students and told their own stories about getting a diagnosis and the impact of this diagnosis on daily life. Often at the conclusion of the discussions Dr Millar would request the students to diagnose each person based on what they had heard. Students’ diagnoses given the little information they received were rarely correct and when the actual diagnoses were revealed there would typically be some in depth discussions. Dr Millar’s reasoning behind this method of presentation was for students to recognise that dementia should be considered whenever diagnosing as it wasn’t just a disease for older people.

From the YODG’s perspective, it was important to educate these emerging doctors on three key points about dementia. The first was that dementia is a condition affecting people of all ages. Although dementia has previously been considered to be an old person’s condition and within the domain of gerontologists, it is a condition that should be considered in most diagnostic situations as younger people are now increasingly being diagnosed with the disease.

The second point was that someone with dementia still has the ability to add value. Among the YODG was a former Director of Research for the Australian Institute of Marine Science (AIMS), a former highly qualified Senior Registered Nurse, a former Company Director of a marine business and a former Project Director for major IT systems; all very accomplished people regardless of receiving a diagnosis of dementia.

The third key message to the students from the people living with younger onset dementia was to “talk to me” rather than talking to the carer, family member or friend.
STAYING CONNECTED THROUGH THE ONLINE COMMUNITY

Kate Swaffer
Kate Swaffer was first diagnosed with younger onset dementia aged 49. Since her diagnosis many people quietly disappeared from her life, with some saying they would rather not engage in the dementia journey as it is too sad for them. As a person who has lived with younger onset dementia for six years in Adelaide, and still living in the community in her own home, it is clear to Kate the aims of creating dementia-friendly communities is a worthwhile one. To date, she does not consider her community dementia friendly, but there has been significant positive change since she was first diagnosed. The greatest challenges of living in a community that is not dementia friendly is the consequences of being excluded, the stigma and discrimination which exacerbates the shame, and not being respected enough to speak for herself.

The day Kate was diagnosed, she was advised to go home, give up work, give up study, and live for the time she had left. This Prescribed Disengagement™ was at odds with Kate’s view of living well, so she instead chose to reclaim her pre-diagnosis life and, in her words, “fight for her life.” Kate is glad to see that this is changing for people more recently diagnosed as the global awareness and dementia friendly campaigns start to make a positive impact on the discrimination and stigma around dementia, and the level of understanding of dementia in the communities.

A significant part of developing dementia-friendly communities is to understand and help people with dementia to achieve well-being and quality of life, and maintain this for as long as possible. Kate has an interest in study and was supported by the University of South Australia to continue her study and complete two tertiary degrees post diagnosis. The University of Wollongong is currently supporting her as she studies for a Master’s of Science in Dementia Care. Kate believes this is what the community needs to do for all people diagnosed with dementia. She says, “Staying positively and meaningfully engaged takes more than art classes or apps on an iPad. Yes, people may have been interested in art or online games prior to their diagnosis, but this is not always the case.

Continued engagement that is truly positive and meaningful to the individual person, without stigma or discrimination, and with full inclusion; this is what dementia friendly means. It is positive and empowering, it allows people with dementia to continue to live their pre-diagnosis lives. It reduces the isolation, stigma, discrimination, depression and loneliness. It helps retain a sense of identity for people with dementia, whether through supporting them to remain employed, or providing opportunities for them to volunteer. Support to remain engaged in life, to re-claim it from dementia is what is needed.

Each day, Kate pursues non-pharmacological and positive psychosocial interventions to feel connected. Kate is involved in activities like exercising, music therapy, hydrotherapy, volunteering, spiritual health, reading, family time, friendships, blogging, writing and advocacy. She shares her personal story and experience through writing a blog, “when I first started, it was as initially to share my world with family and friends, and as a way to discipline myself to write about my life and this experience for my children, but blogging and writing, and social media have opened up a vibrant channel of communication, and a memory bank. I blog or write, and it is always there.” Kate finds writing very therapeutic, and believes it has kept depression and chronic sadness away from me, “it has helped greatly with the complicated grief and loss of dementia.”

Creative writing, poetry and blogging has ensured the isolation experienced through the loss of many family and friends has been replaced with new friends, new conversations and new meaning for Kate. Trying to live well with dementia, with minimal social support, is difficult, and the online world is providing a lively and supportive community of like minded people. There are Facebook support groups, online memory cafes, along with a range of other online services and supports for those people who wish to connect with them. For Kate personally, without them, she would have experienced a great deal of loneliness. To live well with dementia, it is important to have a broad range of avenues for social contact, the online communities have replaced the loss of friends and the lack of face to face social contact for Kate.

Kate believes that listening and understanding the personal stories and experiences of people living with dementia has the power to bring about the greatest change. Kate is a person living with dementia, with the emphasis on living, and she says “the future is now defined by the possibilities of the dementia.” Kate and her husband are living their own lives and trying to be as normal as possible. Kate is an author, advocate and speaker for all people living with dementia, with a global focus in this work on raising their authentic voice. Alzheimer’s Disease International have a Charter that says ‘I can live well with dementia’, and this is not a joke, it can be done. They are serious about it, and so is she.
Leo met with 25 front-line staff from the local Centrelink office and spoke to them about dementia. Leo explained the different types of dementia, the difference between dementia and Alzheimer’s disease, gave his personal experience about what it was like living with dementia, and provided tips on how to better communicate with a person who has dementia.

The feedback from the staff indicated that his talk had a big impact and would change the way the local Centrelink office provided services to people with dementia. One of the key takeaway points for them was the knowledge that they should always try to talk to a person who has dementia first instead of instantly directing their communication at the carer.

Two staff members also asked if Leo was willing to talk with one of their friends who seemed to be having cognitive difficulties and was having trouble admitting this. Leo met with this person and as a result they are being assessed for cognitive impairment by a local memory clinic.

Leo’s dedication and passion to educate people about dementia will continue in his local community, with his sights set on working with other local businesses to reduce the stigma of dementia.
Possibly from day one, luck has been on Di’s side when it comes to dealing with people in Cygnet, Franklin and their environs. As well as being in a beautiful area to live in scenically, its beauty appeared to extend to the positive feel within the community when Di and husband Mike moved there. People were helpful and welcoming and not excluding. Even after Di was diagnosed with dementia in 2011, when you suspect that things might change, they didn’t; the community remained non discriminatory and inclusive for both Di and Mike.

At the time Di was diagnosed, she was employed full-time, with little spare time for socialising so she found herself on the proverbial scrap heap, which could have been a very isolating experience. However, Di decided to see what was going on in the area and whether she could do some boating activities, in particular rowing.

Di and Mike had sold their own boat, but Di soon discovered a newly formed group called WoW (Women on Water). WoW would go out on a Friday morning in a fleet of wooden dinghies, courtesy of the Living Boat Trust. Di asked if she could join them which was not a problem. Di responded, “umm, what about if I’ve got dementia, which makes some things more difficult to do than would be normal?” The group replied “no problem – we can work around what you can do.” At one meeting, the WoW group specifically make a point of asking Di how best they could help her and made a note of her response. In return, Di would be clear in expressing what her specific problems are and suggest solutions that would suit everyone.

This has prevailed over the last three years and Di is completely included in everything they do. The group has gone on to build a coxed 4-man coastal rowing boat and, several members including Di, have joined the Huon Rowing Club and row skinny racing sculls.

As a group, they have a number of widely varying skills but there are also other members who have difficulties, physical or mental, and the strength of the group is that everyone is working to common goals: enjoyment, support and inclusivity. They bolster each other up and, for Di, this has been of inestimable value, which enables Di to continue to do things she loves. This attitude is also seen with other groups Di associates with, for example the Community Garden.

As well as rowing, some other activities that the group has been involved with (not everyone, all the time, depending on availability, ability and interest) include:

- bushwalks
- picnics and camping, with or without boats usually to commemorate members birthdays or special events
- boat maintenance working bees
- taking part in other social activities in the Living Boat Trust
- providing help with catering for schools’ Rowing Regattas
- taking part in the World St Ayles Skiffs Championships at Ullapool, Scotland, UK and more

Di is overwhelmed by the community support and will continue being involved in these community activities for as long as she is able.
A DEMENTIA-FRIENDLY TASMANIAN COMMUNITY

After Gordon’s dementia diagnosis in 2007, he and his wife Ginger decided to move from their isolated 45 acre property to the suburbs in Hobart, Tasmania. However, they decided these suburbs might prove just as isolated given Gordon and Ginger’s new circumstances, so they chose the town of Cygnet to establish a new home. Cygnet provided the life Gordon needed as he was supported to continue living his life, doing the activities he loved and they were supported by the entire community.

Gordon was a cheerful man, small in stature but larger than life. He was a generous person who imparted happiness everywhere he went. Gordon was an active man and the town provided a safe environment for him to perform what had become his favourite pastime… walk, walk, walk. Cygnet actually proved to be far more than just safe. The entire community looked out for and protected Gordon. His speech had reduced to a few phrases, the most memorable being “this, that and the other”, but also “can’t complain”, “okey dokey”, “marvellous”, and “bugger me”. These phrases are now in the Cygnet lexicon and are often heard in the main street.

Some examples of how the community was dementia friendly for Gordon include:

The wonderful members of Cygnet Golf Club welcomed Gordon into their midst every Sunday morning. Even with his increasing disabilities he continued to win games. One morning his team partners arrived, one with “THIS”, the second with “THAT”, and the third with “THE OTHER” printed on their t-shirts. Gordon also received a standing ovation at the Christmas dinner, the only member to receive one.

The shopkeepers on Cygnet’s main street welcomed Gordon’s many daily visits, in which he often straightened and tidied up their counters and shelves. And the food vendors who constantly sent him home with anything from pockets full of chocolates to armfuls of food, enough for our evening meal.

There were many individuals from both Cygnet and Hobart, who gave up their time to spend quality time with Gordon over the past few years including playing golf, doing arts and crafts, including him in football coaching, or simply walking with him amongst other activities. A dementia-friendly community can have an immensely positive impact on a person with dementia and their family’s life. The entire Cygnet community accepted and embraced Gordon, from the youngest to the oldest residents. Over the years Ginger heard it was said that Gordon was a gift to Cygnet; that Cygnet ‘grew up’ around Gordon and that he changed Cygnet, bringing acceptance and an understanding of dementia.
Geoff was diagnosed with Frontal Temporal Dementia and even though the disease is progressing, he continues to enjoy going out for a coffee. Geoff’s type of dementia necessitated a need for familiarity of place and routine. He likes to sit in the same place and order the same thing each time, which has never been an issue at the local café where Geoff and Anne became regulars. The café staff made simple changes to the way they provided their service to Geoff, like greeting him with a welcoming and friendly attitude every time he visited. The staff got to know Geoff by name and always acknowledged him on arrival, they accepted that sometimes he needed more time to handle money and displayed patience and respect when talking with Geoff.

Geoff has always been a sociable person and so continuing to do something he has always enjoyed, such as a going out for a coffee, makes him feel like his old self. As a person living with dementia, Geoff still has feelings and opinions and can enjoy familiar activities, regardless of his dementia. Geoff just needed a bit more help and assistance to continue to live life well. A simple activity, like visiting a regular café and ordering a coffee and being treated with respect, has helped maintain his dignity and contributed significantly to his quality of life.

Geoff now lives in full time residential care but ‘going out for a coffee’ remains an important and familiar social outing. One of his favourite cafes is by the water’s edge, where he enjoys watching the colour and movement of families, kite flying, people exercising with their dogs, as well as boats coming and going. Geoff and Anne visit this spot most Sundays. It is not too noisy and there is never any pressure to leave. It gives Geoff the chance to continue engaging in community life.
Glenda and her husband and family carer, Bronte, have been raising awareness of dementia by speaking to groups of people in Western Australian rural communities organised by local branches of the Country Women’s Association (CWA). “I have always been an educator, and so this is something that comes naturally to me and that I want to do it while I can,” explains Glenda, a former teacher, school principal and university lecturer who was diagnosed in 2010 with younger onset dementia.

In late 2013 Glenda and Bronte started their talks in the rural communities of Wongan Hills and Moora, north-east of Perth. In 2014 the talks expanded to Pemberton, south of Perth attracting both men and women from the wider communities of the town.

The primary objective of the talks is for Glenda and Bronte to tell the story of their personal experience with dementia. However, Glenda says that inevitably, people are very interested in knowing whether they themselves, or their close relatives or friends have dementia. Glenda further explains: “As it has been an older demographic attending the forums, they are naturally very keen to know if their memory lapses are indicative of something more serious. We hand out the Alzheimer’s Australia pamphlet, Is it dementia?, and advise people to speak to their doctor if they have any concerns and, if necessary, to get access to a specialist as soon as practicable.”

Bronte speaks about the importance of getting a timely and accurate diagnosis, as people can then obtain the appropriate care for their particular form of dementia and generally help them to manage the rest of their lives.

One of the most encouraging aspects of the talks is the caring nature displayed by these rural communities. They recognise the need for more residential care facilities in their towns, they are willing to meet the needs of their residents living in the community, many of whom they recognise may have mild cognitive impairment if not formally diagnosed with dementia, and they are open to suggestions about establishing dementia-friendly facilities.

Many more people will be diagnosed with dementia over the coming decades, requiring a change in community attitudes. Education involves broadening people’s horizons through imparting information and creating understanding, and for Glenda, being able to contribute to this is personally very fulfilling, giving another purpose to her present life. As she says, she is “still educating.”
For more information:

www.fightdementia.org.au
National Dementia Helpline: 1800 100 500