

# Support. Encourage. Empower.

Leading the way towards a Dementia-Friendly Community

Parliamentary Friends of Dementia paper

24 November 2021



l'm a Dementia Friend

# "

A community [that] has people living with dementia at the centre of its strategies and it puts in place actions to become more dementia-friendly. It is a community that gives people living with dementia a fair go and embraces the adage 'nothing about me without me'. 20

- Respondent, Dementia Australia, 2021 Dementia-Friendly Communities Inclusion Survey



### National Distribution of Dementia-Friendly Communities



#### NSW

- Ballina Shire
- Byron Shire
- Canterbury-Bankstown
- Central Coast Alliance
- Finley
- Hawkesbury
- Inner West
- 🔍 Kiama
- Lithgow
- Narrabri
- Nepean
- Northern Beaches
- Port Macquarie
- St George and Sutherland
- Warialda
- Western Sydney
- Woollahra

### TAS

- Bicheno
- Dementia Friendly Tasmania

#### QLD

- Biloela
- Bribie Island
- Brisbane South East
- Far North Queensland
- Fraser Coast
- Kilkivan
- 🔍 Logan
- Moreton Bay
- Proston
- Redlands Coast
- Rockhampton
- Scenic Rim
- Stanthorpe
- Sunshine Coast
- Texas
- Western Brisbane

#### WA

- Green Head
- Shire of Denmark
- Swan

#### SA

- Adelaide
- Adelaide Hills
- Loxton Waikerie
- Murray Bridge
- Onkaparinga
- Victor Harbor

#### VIC

- Ballarat
- Heathcote
- Indigo
- Macedon Ranges
- Manningham
- Yarra Dementia Alliance
- Tarrangower

### **Executive Summary**

- **Dementia is still poorly understood** in Australia and people living with dementia continue to experience stigma and discrimination.
- Improving knowledge and awareness about dementia reduces stigma and discrimination and contributes to the creation of a more dementia-friendly and inclusive society.
- Social engagement and connectivity are vital for the wellbeing of people living with dementia, their family members and carers and a dementia-friendly, inclusive community is critical to supporting social engagement.
- Dementia Australia's Dementia-Friendly Communities program plays an important role in **empowering and supporting individuals** and communities to undertake initiatives to improve knowledge and awareness about dementia, reduce stigma and discrimination and promote social engagement.
- The award-winning Dementia-Friendly Communities program **supports alliances, organisations and initiatives** in every State and Territory in varying stages of development.
- The eight case studies profiled in this paper illustrate the **diverse** range and scale of dementia-friendly initiatives supported by the program and their positive impact on communities across the country.
- The COVID-19 pandemic has necessarily imposed limitations on Dementia-Friendly Communities-related activities, but equally it has emphasised the significance of the program.
- Given the demonstrable success of the Dementia-Friendly Communities program, Dementia Australia recommends that the Australian Government extends funding for a further three years to ensure the growth, development and sustainability of current and future Dementia-Friendly communities initiatives.

### Dementia in Australia

Dementia is the term used to describe the symptoms of a large group of neurocognitive disorders which cause a progressive decline in a person's functioning. It is one of the largest health and social challenges facing Australia and the world. It is estimated that there are up to 472,000 Australians living with dementia in 2021<sup>1</sup> and around 1.6 million people involved in their care.<sup>2</sup> Without a significant medical breakthrough, it is estimated that there will be almost 1.1 million people living with dementia by 2058.<sup>3</sup>

In 2021, the estimated number of Australians living with dementia is 472,000 Without a medical breakthrough, by 2058 the number of people with dementia is expected to increase to almost **1.1 million** 

Reference: Dementia Australia (2018). Dementia prevalence data 2018-2058, commissioned research undertaken by National Centre for Economic Modelling, University of Canberra.

### Creating a Dementia-Friendly Community

When I think about it [members who have dementia and carers] exemplify why we need dementia-friendly communities. They come along to our meeting every month because they feel as though they belong. Fundamentally, that is what a dementia-friendly community is about. People living with dementia and the people who support them want to belong to the community. They want to be a part of the community. They want to feel valued. And they feel that way when they come along. They feel a sense of purpose. They're a part of something. It's changing people's lives. 22

- John Quinn, Brisbane South East Dementia Alliance member

A dementia-friendly community can be defined as a community of any size and scale where people with dementia are understood, respected and supported. The concept has been embraced and developed on a global scale over the last decade. In its analysis of dementia-friendly communities, Alzheimer's Disease International identified two core objectives that underpin successful dementiafriendly communities. The first is the desire to improve understanding of dementia and reduce stigma by meaningfully engaging people with dementia of all ages in their communities. Secondly and equally importantly, these communities recognise the rights and capabilities of people with dementia and empower them to make decisions about their lives according to their individual capacities.<sup>4</sup> A dementia-friendly community is "... an affirmation of the rights of people with dementia by giving effect to those rights in the everyday lives of our communities".<sup>5</sup>

Many factors influence the lived experience of dementia, including socioeconomic status, geographical location, ethnicity, age, gender and culture. A recent international analysis recognised that dementia-friendly communities are context-dependent, noting that the most effective dementia-friendly initiatives were those led and shaped by the specific needs of the local community.<sup>6</sup>



# What I would love to see is just an inclusive community because anyone with any type of vulnerability needs to be included. **2**

Person living with dementia,
2020 Dementia-Friendly Communities Focus Group

A community that is dementia-friendly is simply a community that is good for everyone.



## Dementia literacy, stigma and discrimination

Dementia Australia surveys during the past five years reveal that a lack of awareness and understanding about dementia persists in the Australian community. A 2018 report on Australian attitudes and beliefs found that while there was increased awareness and empathy during the past decade, two thirds of survey respondents were not confident about their knowledge of dementia. They were even less confident about talking to someone with dementia and expressed high rates of fear or unease about the way in which someone with the condition might react to them.<sup>7</sup>

Limited knowledge and understanding about dementia can have widespread repercussions. Most significantly, poor dementia literacy results in people with dementia, their family members and carers experiencing stigma and discrimination in a wide range of settings from home, community and retail spaces to the health care sector. Dementia-related stigma is a complex phenomenon that can incorporate public stigma (collective or community-imposed), internalised or self-stigma and affiliate or stigma-by-association (directed at family members or carers of the person living with dementia). The impacts of stigma can be significant and wideranging: from discouraging help-seeking behaviour to negative impacts on identity and self-worth, anxiety, depression and social isolation and disengagement.<sup>8</sup> Knowledge, understanding and beliefs about dementia vary significantly in the ethnically, culturally and socially diverse communities that characterise contemporary Australia and these differences can further complicate and compound experiences of stigma and discrimination.<sup>9</sup>

Dementia Australia's 2019 Dementia and Discrimination report reflects the ongoing realities of dementia-related stigma and discrimination.<sup>10</sup> Of the more than 5,700 survey respondents, 63 per cent of people living with dementia believed that discrimination is common, 74 per cent said people have not kept in touch as they did prior to their dementia diagnosis and 80 per cent had not been invited to social functions. Seventy-three per cent of family, friends or carers of people living with dementia believe discrimination against people living with dementia is common or very common. The report found lower levels of social engagement, inclusion and connectedness within their communities for people living with dementia. Similar findings in a Dementia Australia 2021 survey showed attitudes have not changed significantly, with 65 per cent of respondents who live with dementia and 58 per cent of those who feel at risk of dementia believing discrimination towards people living with dementia is common or very common.<sup>11</sup>

Australian and international studies support these survey findings, noting that stigma and discrimination associated with a dementia diagnosis can have deleterious impacts including discouraging health care-seeking behaviour, reducing social engagement with family, friends and the broader community, and associated consequences for the physical, cognitive and psychosocial health of the person with dementia.<sup>12</sup>



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### Living with dementia and COVID-19

The COVID-19 pandemic has compounded this nexus of stigma, discrimination and social isolation. Dementia Australia research has highlighted the decline in cognitive, emotional and physical wellbeing during the pandemic for people living with dementia, with evidence that in some cases this decline was likely to be irreversible.<sup>13</sup> These findings are supported by the burgeoning body of international literature looking at the damaging psychosocial impacts of the COVID-19 pandemic, including exacerbation of social isolation and the associated risks of adverse physical and mental health outcomes for people living with dementia, their families and carers.<sup>14</sup>

# Social health, inclusivity and dementia-friendly communities

In the context of ongoing stigma and discrimination, and the specific psychosocial challenges of the COVID-19 pandemic, the concept of social health in relation to dementia has become increasingly significant. The social health lens focuses attention on improving health and wellbeing by supporting the current capacities of a person living with dementia, encouraging new skills and abilities and promoting social engagement. Recognition of the importance of social health has led to the development of a wide range of initiatives and programs aimed at promoting social engagement and connectivity for people living with dementia, their family members and carers. One of the most significant of these is the Dementia-Friendly Communities movement. The dual imperatives of improving awareness and knowledge about dementia and promoting social engagement and inclusivity are an integral part of this global movement and underpin Dementia Australia's Dementia-Friendly Communities program.

### The Dementia-Friendly Communities Program

Around 70 per cent or more of people with a diagnosis of dementia in Australia live in the community. Over half of all residents living in Australian residential aged care facilities have a diagnosis of dementia.<sup>15</sup> Communities play a critical role in encouraging inclusivity, respecting the rights of people with dementia and facilitating access to the services, supports, activities and spaces that every Australian citizen is entitled to. People living with dementia who are supported to live well in the community are more likely to stay in their homes longer and are less likely to enter residential aged care prematurely. For people with dementia in residential aged care and other forms of supported accommodation, remaining connected to their communities within and beyond their care settings is vital for their physical and emotional wellbeing. In addition to the clear health benefits, keeping people with dementia and their care partners living in a community committed to dementia-friendly businesses and other services can make a significant contribution to the local and national economy.

#### The Dementia-Friendly Communities program's core objectives are:

- Supporting people living with dementia, carers and local champions to develop 'recognised' dementia alliances (working groups) across Australia to lead place-based and locally driven action.
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Promoting the inclusion and purposeful engagement of people living with dementia in their communities, by funding and supporting local community engagement projects.

Building the capacity and providing formal recognition of the work of organisations across Australia that are working towards becoming dementia-friendly.

Dementia Australia's Dementia-Friendly Communities program embraces the global agenda to improve understanding and awareness and reduce the stigma, discrimination and social isolation associated with dementia through the development of communities that welcome people living with the condition. The program's commitment to inclusive communities encompasses supporting people with dementia to live with purpose and make a meaningful contribution to changing attitudes about dementia. Acknowledging the important contribution that individuals and groups in Australia's ethnically, culturally and socially diverse communities can make is equally integral to the program's emphasis on inclusivity.

Our community is highly diverse, with 60 per cent of the population speaking a language other than English. The four largest cultural groups include the Arabic, Vietnamese, Greek and Mandarin communities. A high presence of stigma and isolation has been reported across these groups, with several barriers to help-seeking, service delivery, and education identified in a 2019 investigation and report. Having culturally appropriate and relevant support is one of our biggest needs.

Respondent, Dementia Australia,
2021 Dementia-Friendly Communities Inclusion Survey



l'm a Dementia Friend

### Case study

### The Canterbury-Bankstown Dementia Alliance

Creating culturally safe dementia-friendly communities

# ...I'm starting to realise from the seminar that you need to be patient and maybe step back and allow them to do some tasks rather than getting frustrated and taking over.

- Carer and attendee at the Canterbury-Bankstown Dementia Alliance Seminar

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### **Community context**

The City of Canterbury-Bankstown is a densely-populated municipality in South Western Sydney with one of the most culturally and linguistically diverse communities in Australia. The population of 380,000 includes people from 123 different countries and 60 per cent of households speak a language other than English at home. The South Western Sydney region is expected to have the highest increase in dementia diagnoses in NSW by 2050.<sup>16</sup>

The Canterbury-Bankstown Dementia Alliance was formed following discussions between Western Sydney University cognitive neuroscientist Dr Diana Karamacoska and City of Canterbury-Bankstown Council Ageing and Disability Officer, Sandra Loyola-Sandoval, with support from Dementia Australia's Dementia-Friendly Communities NSW Program Officer, Anthony Parker. Community consultations conducted for the 2019 Multicultural Dementia Campaign Project identified the specific needs of people with dementia in Canterbury-Bankstown and these provided the basis for the Alliance's action plan to establish the municipality as a Dementia-Friendly Community. The Alliance membership currently consists of 22 per cent people living with dementia and their family members and 78 per cent organisational body representatives. Key Alliance objectives include engaging with and supporting people living with dementia, their families and carers and providing information in culturally appropriate and accessible formats. Acknowledging that dementia-friendly communal spaces play a critical role in encouraging social engagement for people living with dementia, the Alliance has a strong focus on identifying strategies to make the built environment and communal spaces in Canterbury-Bankstown dementia-friendly.

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### Making a difference

In the year since its 2020 formation, and despite the significant restrictions imposed by the COVID-19 pandemic on the municipality, the Alliance has grown rapidly, developed an action plan with an ambitious range of initiatives and established working groups to focus on different activities. Drawing on the Dementia Australia Dementia-Friendly Communities toolkit and input from Anthony Parker, the Alliance has consulted directly with people with dementia and their carers in the community, created hard and soft copy dementia information resources in languages other than English and conducted dementia awareness and information sessions for specific cultural groups. The Alliance has collaborated with bicultural workers to identify strategies to promote improved awareness and understanding of dementia in specific cultural settings and supported these workers to become Dementia Champions in their respective communities. Information sessions and resources have been very positively received and will be expanded to reach a wider range of culturally and linguistically diverse communities.

- ...there is still long way to get people into familiar with online Webinar or training especially Vietnamese seniors. However, we can see today is the first step and it a small successful to connect them together through online for the information.
  - Vietnamese bilingual worker delivering a dementia information session to the Vietnamese community.

With the COVID-19 lockdown restrictions now easing, the Alliance will be recruiting people with dementia to conduct in-person environmental audits of the Bankstown-Lidcombe Hospital and Bankstown Central shopping centre. These audits will identify ways to make these and other communal spaces more dementia-friendly.

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### **Future directions**

Despite the restrictions imposed by the pandemic, the Canterbury-Bankstown Dementia Alliance has continued to develop a range of exciting future initiatives. These include ongoing support for bicultural workers as Dementia Champions in their communities and an expanded series of dementia information sessions targeting specific cultural groups. In November 2021, Dr Karamacoska will be hosting an interactive webinar for council staff, State planning representatives, and South Western Sydney local health district officers to raise awareness in relation to dementia-enabling environments. The webinar aims to identify strategies to transform South Western Sydney into a dementia-friendly region and if it is well received, the Alliance hopes to offer similar sessions to other local government areas in the future. Dementia Australia will be supporting this webinar with all participants receiving a certificate acknowledging their involvement. In the longer term, the Alliance plans to develop and deliver culturally-sensitive dementia competency training programs for Canterbury-Bankstown council staff and those employed in neighbouring municipalities including Fairfield, Parramatta and Liverpool. Staff will be evaluated pre and post-training to assess the efficacy of the program in improving understanding of how best to support people living with dementia in relation to council policy development and service provision.

"Canterbury-Bankstown's Dementia Alliance speaks to the 'wholeof-community' approach needed to support people with dementia, and their carers, in the community. We're fortunate to be engaging with academics, council officers, not-for-profit multicultural care and disability service providers, and the local dementia carers group to co-design and deliver initiatives that are needed in this culturally vibrant region," said Dr Karamacoska.



### Case study

### Western Australia

Bringing two towns together: The Green Head Community Association



### Community context

The Green Head Community Association in Western Australia was established in 2018 and received a community alliance grant in July 2020. It is working with the local shire and community care providers to form a Dementia-Friendly Alliance to work towards being a safe and dementia-friendly community. An audit of the town has been completed and the association is now looking at working with people living with dementia, community and business groups on strategies and activities to support people living with dementia to engage in the community.

A regional town comprising 300 community members from Green Head and 300 members from Leeman with an average age of 64, the Green Head Community Association has seen a significant impact of engagement activities within the community.

# Quite a few people live on their own and see this as a social occasion and enables them to get out and socialise and stops the isolation.

- Association member, Green Head Community Association

### Making a difference

Green Head is a small community and lacks the typical supports and services that larger towns have access to, so the association relies on its organisers and volunteers to drive its impact. It holds forums where it communicates information about dementia and tailors activities according to community preferences. For example, the group suggested dancing and a man living with dementia (undiagnosed) ran a bootscooting session which he now regularly attends.

#### G Everyone who came just loved it and are still talking about it. 🤊

- Association member, Green Head Community Association

Since the association started, it has raised the profile of dementia and helped dispel the myths that surround it.

### 66 The profile of dementia is becoming a lot more understandable and they're not as afraid of it.

- Association member, Green Head Community Association

The language people are using is changing too. The way people within the group speak about dementia is having a positive impact more broadly. There are no longer negative nuances, it has become more about possibilities and showing respect to the people living with dementia in Green Head. Two or three years ago this conversation would have looked very different. The association has created more social engagement and community connectedness, a connection that had been historically absent. This initiative and the positivity of the organisers and volunteers continues to raise key community issues and strengthen supports and services within the town.

### We want to make it inclusive for everybody. For the community to join in. 🤧

- Association member, Green Head Community Association

Even with limited resources, the association is achieving so much with 10 per cent of the community attending events. The impact of the association's activities has expanded to surrounding towns, helping to facilitate information-sharing within the community on issues such as Aged Care Assessment Team assessments, home care package support and respite accommodation.

### 😘 We just keep evolving into something new and better. 🤧

- Association member, Green Head Community Association

The success of the Association is based on knowing the community, building on this knowledge, listening to people and fulfilling their needs. Organisers engage people living with dementia and bring them together to encourage their ideas and initiatives. The Dementia-Friendly Communities program supports and empowers the Green Head community through the integration of an assetbased community development model. Working in collaboration with Dementia Australia has provided the Green Head Association with access to dementia information and other resources and expertise. The support from the Dementia-Friendly Communities Program Officer, Althea Manievannan, has created opportunities for local community forums and presentations to educate and inform the Green Head and Leeman communities about dementia and make information more accessible to the public.

### Future directions

The Association has a range of plans to increase support and activities within the community. One initiative already underway is a collaboration with the local library to use their space as a dropin centre for community members to connect for a couple of hours a day. This will be supported by volunteers who will be trained in using the library and setting up activities, and this opportunity will be advertised to the community. The environment will be made as dementia-friendly as possible, and the activities program will be sustained through community fundraising and gold coin donations.

### Four Tiers of Dementia-Friendliness

Inaugurated in 2016, Dementia-Friendly Communities is a national community development program with a team of seven program officers overseeing every State and Territory, a national project officer and national manager. The Dementia-Friendly Communities team liaise closely with the Dementia Australia Consumer Engagement Team, Client Services, Centre for Dementia Learning and Business Services. The program officers and the national project officer facilitate and support initiatives across four tiers of "dementia-friendly" involvement: Dementia Friends, Dementia Alliances and Dementia-Friendly Organisations, and grant funded Community Engagement Program demonstration projects.

There are currently:



Source: Dementia Australia, Dementia-Friendly Communities data reporting, 1 Jan to 30 June 2021

Becoming a Dementia Friend is the starting point for creating a dementia-friendly community. It involves learning about dementia through a series of Dementia Australia short videos, information and personal stories-including resources with culturally specific information for Aboriginal and Torres Strait Islander communities. The information covers the challenges faced by people living with dementia, how to support people living with dementia to stay connected and how a dementia-friendly community can play an important role in social engagement.

Dementia Friends can go on to encourage others to become Friends, raise awareness in their community on an individual level, become a Dementia Friends host or expand their commitment by becoming involved in or forming a Dementia-Friendly Organisation or Alliance. The Dementia-Friendly Communities team can support individuals, communities and businesses to explore ways of creating a dementiafriendly community, for example, by holding a forum or workshop.

Dementia-Friendly Organisations work towards ensuring that people living with dementia are welcome and valued in local business settings. Changes that can be implemented to achieve this include increasing the dementia awareness and communication skills of staff, environmental modifications and enhancing the readability of forms and documents.

Dementia Alliances work to make their community more dementiafriendly and can include people living with dementia, families and carers, businesses, aged care and other service providers, community groups and local councils. To be formally recognised by Dementia Australia, an Alliance must have an approved action plan that outlines the steps that will be taken to make the community dementia-friendly. They must also demonstrate how people living with dementia and carers have been meaningfully involved in the development of the action plan and its implementation. The Dementia-Friendly Communities team manages the assessment and allocation of the Community Engagement Grant Program, a scheme that awards grants of up to \$15,000 to support dementiaspecific community development projects and initiatives. Successful applicants must demonstrate the active engagement and inclusion of people living with dementia in both the design and delivery of the project. Projects are selected based on collaborative partnerships with local Alliances, councils, businesses, education services and community organisations, aimed at meeting the needs of Aboriginal and Torres Strait Islander communities, culturally and linguistically diverse communities, and rural and remote communities.



A dementia-friendly business would allow those people who are dealing with the public to have the permission to take that extra two minutes to give good customer service and to give themselves a good experience. <sup>99</sup>

Person living with dementia, 2020
Dementia-Friendly Communities Focus Group

### Case study

### City of Casey Victoria

Growing a dementia-friendly community: The Reminiscing Garden

### 2 Community context

In 2020, the Australian-Filipino Community Services (AFCS) organisation was the recipient of a Dementia Australia Dementia-Friendly Communities Community Engagement Grant to support the creation of a dementia-friendly reminiscing garden. Located in the City of Casey, one of the fastest-growing and most populous municipalities in Australia, the Doveton garden was developed in collaboration with local Samoan and Tamil communities. The idea was inspired by an older woman in the community who had created a vibrant garden of potted plants in a small area of her apartment block and had generously shared her cuttings and plants with friends and neighbours. Project Manager and Australian-Filipino Community Services Chaplain Norminda Forteza felt that the therapeutic physical and psychosocial benefits associated with gardening and plant-sharing could be replicated on a larger scale to support people living with dementia, and their families and carers.



### Making a difference

The Reminiscing Garden was created to support people from culturally and linguistically diverse backgrounds who were living with dementia, and their families and carers. The key aims of the garden were to actively involve visitors in planting and garden maintenance, provide opportunities to socialise and talk about shared cultural experiences, and to encourage discussion about the challenges of living with dementia.

#### We have found a place we can freely share our feelings about Mum's changing behaviour and have listening ears around us.

- Carer of person living with dementia

The garden was planted in consultation with a landscape gardener but equally importantly, with input from the three communities. The garden includes culturally familiar plants and the sight, touch, smell and taste of these stimulate positive memories of the countries of birth of Tamil, Filipino and Samoan visitors. The garden has been an immediate success and has literally grown over the last year to include an expanding range of plants, visitors and activities. Dementia Australia has been actively involved in delivering information sessions about dementia and the provision of printed material about dementia in languages other than English and other resources. Other activities have included group lunches cooked with ingredients from the garden. The COVID-19 pandemic has necessarily imposed operational changes with limits to visitors and activities in recent months. Inspired by the original project model, visitors have been encouraged to grow plants in small pots that are taken home and their progress checked during regular online sessions. When permitted, smaller groups have gathered to socialise. Norminda has observed that these have allowed for more intimate conversations and for many visitors, proved to be a supportive environment for sharing experiences about dementia.

# In my culture, we cannot talk about Dad's situation all the time it makes people depress but in the Dementia Garden, we can talk and talk and we find relief.

- Carer of person living with dementia

The Reminiscing Garden has provided many benefits to visitors, from increased knowledge and understanding about dementia and a willingness to share stories about living with the condition, to an improved awareness and preparedness to access support services. The garden's supportive environment and the activities and social opportunities it offers has brought the community together and given them the confidence to address and reduce stigma associated with dementia. The recently established culturally and linguistically diverse Dementia Friends Reference Group, chaired by Norminda, will continue the garden project's valuable groundwork in making the City of Casey a more dementia-friendly community.

### Future directions

With 20 volunteers, strong interest from the community and connections with local services and organisations including garden suppliers, the Southern Region Social Support Network and the Southern Migrant and Refugee Centre (SMRC), Norminda has a range of new proposals for the next year and beyond. COVID-19 and weather permitting, there are plans for a fortnightly Multicultural Reminiscing Garden Cafe to be operational from spring to autumn, ongoing information sessions on dementia, workshops for community leaders on how to set up their own gardens, and training sessions in community group facilitation to further engage culturally and linguistically diverse communities in the City of Casey. The four tiers of Dementia-Friendly Communities involvement offer a wide range of opportunities for individuals, groups, and organisations to make dementia-friendly changes in their local environments and communities. Changes are led and implemented by the individuals and organisations involved, with support, guidance and resources supplied by Dementia Australia. These changes can be as modest as modifying small business signage to enhance dementia-friendly accessibility to a comprehensive local government action plan that consults with people living with dementia and draws on dementia-friendly principles to inform all aspects of municipal planning, policy and service provision.



### Case study

### City of Manningham Victoria

Inclusive Manningham: a dementia-friendly city

### Community context

The City of Manningham is in Melbourne's eastern suburbs; a significant section of the eastern half of the municipality is designated a 'green wedge', an area which protects Melbourne's natural environment. The 128,000 strong population includes diverse multicultural communities. The council's approach to embracing diversity and inclusivity is equally focused on consulting with people living with dementia and their carers and applying a dementiafriendly lens to planning and service provision. In 2015, the council launched the Inclusive Manningham: A Dementia-Friendly City Project. As a recognised Dementia-Friendly organisation and led by Aged and Disability Services Manager Keri Kennealy, the council has promoted its dementia-friendly city project as a Strategic Action Area and is guided by a comprehensive Dementia-Friendly City Action Plan. The establishment of the Manningham Local Dementia Alliance Group is an important part of council's strategy in creating a dementia-friendly city. The Alliance includes a person living with dementia, carers, and stakeholders from service sectors and community groups who guide and advise council on the project and other initiatives. Support from Dementia Australia Victorian Program Officer Laurel Gourlay, and Dementia Australia resources including the Dementia-Friendly Communities Toolkit and dementia-friendly language guidelines have helped inform the development of the council's action plan.



### Making a difference

The council's approach is guided by key themes: that people living with dementia and their carers are valued, connected and heard; learning together, and actively participating and advocating for change. Since the 2015 launch of the Inclusive Manningham project, a wide range of initiatives and opportunities for dementia-friendly action have been identified and implemented. These include the Manningham Dementia Information Card, a pocket-sized card designed by the Manningham Local Dementia Alliance Group, with current information about dementia, including a list of support services and organisations. Comprehensive dementia-related information is available in printed form and on council's online hub Manningham Matters.

Dementia information sessions for local traders, emergency services and other interested groups have been held in the early morning and evenings to accommodate working hours and to expand the information reach to the community. Dementia Australia-facilitated training sessions for council staff have also been part of the project. Two council staff members are Dementia Friends Hosts who conduct regular Dementia Friends sessions to raise community awareness about dementia. Information sessions are evaluated and feedback on these sessions and other dementia-friendly activities have indicated a positive shift in community attitudes and an increasing understanding of the importance of supporting people with dementia to remain in, and actively engage with, their communities. This feedback in turn continues to inform council initiatives.



### **Future directions**

In addition to the council's ongoing commitment to enacting its action plan and bringing a dementia-friendly lens to aspects of council policy, planning and service provision, it has a range of future initiatives in various stages of development. One of the most exciting of these new projects has been initiated by a local church, which has membership on the Manningham Dementia Alliance Group. The church has a newly developed building which will incorporate a café that will be a dementia-friendly venue. The project is in the advanced stages of development and will be staffed by people who have been provided with training around a dementia-friendly customer support approach. As articulated by Keri Kennealy, arguably the council's most ambitious plan is envisioning the City of Manningham as a municipality that has embedded its dementia-informed approach in such a consistent and comprehensive fashion that the council would no longer require a specific dementia-friendly action plan. The Dementia-Friendly Communities program involves specific steps, challenges and milestones for becoming an Alliance but there is no prescribed path or timeline for how a group or community develops their dementia-friendly approach. The flexible nature of the program underpins its success as groups are empowered to develop a plan on their own terms – the only requirement is that from inception to implementation, people living with dementia and care partners must be meaningful participants in whatever way is feasible.

The 2021 Dementia Australia Dementia-Friendly Communities Inclusion survey asked participants to rate their Alliance's level of engagement with people living with dementia. Fifty-two per cent of respondents rated their engagement as active (people living with dementia are a central part of the working group, involved in planning, implementation and participation) and 27 per cent as intermittent (people living with dementia have been involved on and off) with the remainder emerging (the group is seeking engagement or in the incipient development phase).



In the same survey, respondents rated the success of their Alliance as on average seven out of 10 and the many project highlights already achieved included the following:

- "Quiet Hour implemented weekly in local Westfield. This relationship has led to the expansion of the program across Australia, with the plan for all Westfields in Australia and New Zealand to implement Quiet Hour by the end of 2022."
- "A dementia awareness presentation made to the senior staff of all council libraries in the region. Clinical and Community forums have been held in the region to both educate and increase awareness of the needs of people living with dementia and their carers."

- "Woowookarung Dementia Friendly Forest and Sensory Trail is hugely successful as a place the local community has embraced. Automatic counters indicate 350 visitors per week now have adopted a new place to relax and exercise."
- "Two new memory lane cafés, two new carer support groups, dementia hub with sensory garden in development."
- "We have held two separate Dementia Friends sessions at a large regional high school for year seven to 11 high school students to become Dementia Friends, with badges and certificates."
- "Our Creative Dementia Workshops were instrumental in bringing people together to participate in music, art, and mindfulness sessions. Feedback from participants - those living with dementia, carers, support people, volunteers, and medical students indicates [the workshops] provide connections, social interaction, and creativity in a safe, supportive, and friendly environment."
- "Organised art workshops with artworks submitted to Dementia Australia art exhibition. An art exhibition was held at a local shopping centre where people are available to answer questions and information was available to take away."

The profiles of groups, Organisations and Alliances featured throughout this paper give a detailed picture of the breadth, creativity and commitment to inclusivity, and the significant impact these dementia-friendly initiatives have made in their respective communities. These include the development of dementia information sessions and resources in languages other than English in one of the most ethnically and culturally diverse municipalities in the country (Canterbury-Bankstown, NSW) and a collaborative dementia awareness project with a secondary school in inner city Brisbane, to culturally specific outreach programs and information sessions for the Aboriginal and Torres Strait Island communities in the Northern Territory.

### Case study

### Queensland

### Change agents for the future: Brisbane South-East Dementia Alliance and Iona College

### 🖄 Community context

John is a husband, father and has nine grandchildren. After retiring prematurely due to his condition, it was two challenging years before he was diagnosed with the familial type of Alzheimer's disease. John was 59 years old. John and his wife, Glenys, downsized to a unit in Wynnum. Although this gave them better access to services and a simpler lifestyle, John struggled with his diagnosis.

"John became depressed and spent the next four years looking at four walls. I knew he wasn't in a healthy space. He is a very social person," Glenys said. What began as a way for John to connect with his new community, quickly evolved into a nascent dementia-friendly community. As John explains: "Glenys thought it would be beneficial for me to forge relationships with local businesses. I quickly developed a routine. I'd walk down to the newsagent in the morning. On the way back, I would call in and have a coffee and a chat. I would call into the post office and collect any mail. I became very visible within our community. By becoming visible and having conversations with people, we were effectively in the early stages of a dementia-friendly community."

### **(7)**

### Making a difference

At first, the Alliance focused on local projects, such as establishing a quiet shopping hour at their local supermarket. However, John and Glenys were keen to expand their reach. In 2019, the Alliance hosted the first of its popular dementia forums. Glenys: "We printed pamphlets and I bill-walked and doorknocked for a couple of weeks. All levels of government supported us and put it in their e-newsletters and on display in their offices." Open to all, but particularly targeted at health and service professionals, John and Glenys expected 26 attendees. More than 80 people showed up on the day.

Brisbane South-East Alliance also has a monthly e-newsletter with a large readership. "We have 120 people on our email list who want to know about our forums and our conferences. We have 50 or 60 on our committee list."

With a background in education, John and Glenys understand the transformative impact of engaging younger people. As John reflects: "We believe passionately that if we are going to change mindsets and stereotypes, we need to work with our young people. We believe that if we increase their awareness and understanding of dementia, they could be our change-agents for the future."

Dementia-Friendly Communities Program Officer Marie-Louise Bone introduced John and Glenys to Father Michael Twigg of Brisbane's Iona College. Iona College is an independent Catholic secondary school for young men. Since early 2020, John has been educating Year 12 Iona College students as part of the school's personal development outreach program. Over a 90 minute workshop, John shares his story; explains the different dementia types and symptoms; and introduces the concept of enabling environments. The students complete the Dementia Friends program and explore how they can create a more inclusive school and community.

The positive impact has been felt almost immediately. Glenys recalls: "An Alliance member was checking in to the supermarket during the quiet hour. He noted a woman was having some difficulty with the QR [code]. He heard a voice behind him ask the lady, 'Would you like some help?' She said yes, and he said, 'Do you mind if I use your phone to check you in?' He showed her how he was checking her in, handed her phone back and said, 'Would you do me a favour? Would you use my phone to check me in?' And he talked her through the steps. Then his mate stepped in and said, 'Gosh, that looks easy. Would you mind checking me in as well?' The Alliance member turned around and it was two lona College students. They were so aware of how someone was struggling."

John: "On a daily basis I will get out and walk or run on the foreshore. On many occasions, I've come along a group of young men running. They would stop and say, 'Hello, John, how are you?' Because they weren't in uniform, I'd say, 'Where do I know you from?' And they'd say, 'You know us, John. You've talked to us at Iona College.'"

Glenys: "That's the impact of reaching out to younger people - the acknowledgement, the connection, the sense of belonging. You need to have Dementia-Friendly Alliances to make that connection. We're fortunate, in one way, that we have the drive and connections. Dementia closed many doors but opened so many others."

### Future directions

The Alliance has been working with Brisbane City Council and major cultural institutions to inspire them to become dementia-friendly. In October 2021, Iona College and the Brisbane South-East Dementia Alliance hosted their latest community forum, 'Creating Change: Activating a Dementia-Friendly Brisbane'. In an exciting recent development, Brisbane City Council, Queensland Art Gallery and Gallery of Modern Art and University of Queensland's Healthy Living Centre and Art Museum have made a combined commitment to a dementia-friendly Brisbane strategy, aligning with the Brisbane 2032 Olympic and Paralympic Games.

### Case study

### **Northern Territory**

#### Yarning the way to a dementia-friendly community

#### 66 A dementia-friendly community is a place that is accepting, understanding and a culturally safe environment.

- Glen Woods, Dementia Australia Dementia Support Specialist and Dementia-Friendly Communities Program Officer



### Community context

The Northern Territory is a vast area with a small population of just under 250,000 people, most of whom live in Darwin. Twenty-five per cent of the Northern Territory population identify as Aboriginal or Torres Strait Islander and more than 100 Aboriginal languages and dialects are spoken. Dementia Australia Dementia Support Specialist Glen Woods works with diverse Aboriginal and Torres Strait Islander communities. From his base in Alice Springs, his work can take him from the remote Docker River community to one of the larger Northern Territory towns of Tennant Creek.

As with the broader Australian community, Glen notes that there is widespread misunderstanding and apprehension about dementia in the Aboriginal communities he works with. There is no specific translation for the word dementia in Aboriginal languages, but the colloquial term "rama rama" (crazy) indicates the lack of knowledge and fearfulness associated with the condition. Dementia is commonly regarded in many Aboriginal communities as a 'Western disease', creating further barriers to understanding and engaging with health care and other support services. In promoting better awareness of dementia and encouraging a dementia-friendly community, Glen notes that there is a need for improved dementia education for Aboriginal and non-Aboriginal health care workers, particularly those working in residential aged care in communities, who often lack a good understanding of dementia and how to provide appropriate dementia care.

## 鬥

#### Making a difference

As with the broad remit of the Dementia-Friendly Communities program, Glen's approach focuses on improving understanding about dementia in Aboriginal communities, to reduce stigma and encourage people with dementia and their families and carers to access the support and services they need to live well.

Glen presents information about dementia to Aboriginal individuals and communities in a variety of ways, depending on the needs and preferences of those involved. Information sessions can consist of a casual yarn in a relaxed setting through to more formal presentations with electronic resources and PowerPoint presentations. A flexible approach is the key to engaging individuals and groups in a way that is appropriate and accessible to convey important information about brain health, dementia and related issues. Liaising with non-Aboriginal local organisations and services—including the Alice Springs Aged Care Assessment Team and Memory Service—is also an important part of Glen's role in educating teams about culturally sensitive dementia care and encouraging Aboriginal communities to access services.

Glen has established valuable connections with a range of local groups including Relationships Australia, Catholic Care, Allied Health services and senior citizens' groups, with the aim of presenting dementia information sessions in the future. As an Aboriginal Dementia Support Services Specialist, Glen has also been invited to speak on dementia-related issues to Aboriginal and non-Aboriginal groups beyond the Northern Territory including recent presentations in Townsville to health care workers and an Aboriginal men's group as part of Men's Health Week. Bi-monthly presentations on brain health and dementia to Drug and Alcohol Services Australia have been well received with feedback acknowledging the accessible and engaging way the information has been presented.

### Future directions

Glen has identified several other promising potential relationships and collaborations that will expand his work developing improved understanding of dementia in his community. His work with a local Aboriginal men's group illustrates the importance of these kinds of initiatives. The group is part of the Alice Springs Tangentyere Council and discussions with the men are underway about developing dementia information resources in language, based on similar projects the group has undertaken. These resources would translate dementia terminology and concepts into culturally appropriate and accessible texts for the local community. Plans are also in the early stages to approach the Alice Springs Akeyulerre Healing Centre about liaising with the Ngangkari, (traditional Aboriginal healers) as another way to improve understanding about dementia, provide information about accessing dementia support services and promote a dementiafriendly community. Glen is also liaising with the Royal Flying Doctor Service to conduct joint visits to remote communities. Following an approach from Aboriginal Communities Services South Australia to support Dementia Australia South Australia to reach communities in the A<u>n</u>angu Pitjantjatjara Yankunytjatjara (APY) lands, Glen will be presenting a dementia information session at the Umuwa community in November 2021. The session on brain health, dementia and related issues will address aged care staff and health workers in the A<u>n</u>angu Pitjantjatjara Yankunytjatjara communities.

# Dementia-Friendly Communities program support and resources

The initial remit of the Dementia-Friendly Communities program included the development of an online hub and from its inception in 2016, this has played an important role within the program. The website provides comprehensive information and resources to support and empower individuals, groups and local businesses to engage and act. It is an important tool for individuals and groups searching for information, resources, events and other forms of support. These include pages linking to local events, activities or Alliances, information sheets about dementia in a range of languages other than English and a comprehensive 40-page Creating Dementia-Friendly Communities Toolkit. The toolkit comprises general information about dementia, guidelines for creating a dementia-friendly community, templates for communication and other activities and is the principal resource for groups planning to become dementia-friendly Alliances.

The hub has been a particularly crucial source of support during the past 18 months of the pandemic, when face-to-face activities and events were limited, as indicated by the following website statistics. (Data relates to the period July 2020 to August 2021)



Almost **8,800 Australians** have searched for **dementia-friendly communities** in their local area\*



Visitors to **dementiafriendly.org.au** spend about **20 minutes learning about dementia**^



#### Pages with most views:

Home (communities matter) 15,295 views, 10,571 unique views

**Explore your community** (contains local directory and search) 12,020 views and 8,794 unique views

#### **Communities in action**

4,192 views and 3,155 unique views#

The online hub also documents the establishment and progress of projects that demonstrate the diverse stakeholder mix of dementia-friendly communities nationwide as illustrated in the profiles included throughout this paper and the projects highlighted above. These include initiatives in culturally, ethnically and socially diverse communities in regional, rural and metropolitan areas.

\* Source: 8794 unique hits to Explore your community page, dementiafriendly.org.au

^ Source: Pages visited: Getting to know dementia average time spent, What it feels like, Dementia in depth, Living with dementia, total average time spent on pages 1096.45 secs or 18.2 minutes

# Source: Dementia Australia, **<u>dementiafriendly.org.au</u>** traffic data and analytics

## Case study

## Tasmania

Dementia Friendly Tasmania: people, participation and pedal power

😘 Our dream is to make Tasmania a dementia-friendly State. 🤧

- Kath Shearer, President, Dementia Friendly Tasmania

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### 😩 Community context

Dementia Friendly Tasmania Inc. started seven years ago as an initiative in the small town of Snug in Kingborough, a peri-urban municipality described as the gateway to the City of Hobart. The municipality is one of the fastest-growing in the State and has a small but significant Dutch community and a range of residential and other aged care facilities. In 2021, there are an estimated 791 people living with dementia in Kingborough and without a medical breakthrough, this is expected to increase to an estimated 1,474 people by 2058.<sup>17</sup>

Alison De Vries and Di Carter were founding members and the driving force behind the formation of Dementia Friendly Tasmania. The organisation started with 30 people and the central motivation was to reduce the stigma associated with dementia by providing information and promoting awareness and understanding about the condition in the broader Kingborough community. Officially incorporated as Dementia Friendly Tasmania in 2016, the group now has an active volunteer group of 10 and is run by a committee of management including a person living with dementia. Input from people living with dementia and their carers informs the group's core objectives. Bimonthly committee meetings and ongoing strategic planning have shaped the Dementia Friendly Tasmania agenda that includes a focus on information sessions, involvement in community events across Tasmania, fundraising events and a range of other activities.

## **(7)**

### Making a difference

Dementia Friendly Tasmania's aim is to transform the Kingborough municipality into a Dementia-Friendly Community. A key part of this objective is providing accurate and accessible information about dementia to the community in a range of different forms and forums. The group's development was assisted by support from Dementia-Friendly Communities Program Officer for Tasmania, Pat Baines, and by Dementia Friends training opportunities, information sheets and other Dementia Australia resources. The group has also collaborated with the University of Tasmania's Wicking Dementia Research and Education Centre in providing community information forums and lectures. Dementia Friendly Tasmania has developed a unique CARES motto (Community and compassion, Awareness and action, Respect and recognition, Engage and encourage, Support and share stories) as a central part of the endeavour to improve dementia awareness and this is incorporated into print and other information resources that have been distributed widely in the community.

## CARES

- C community and compassion
- A awareness and action
- **R** respect and recognition
- E engage and encourage
- **S** support and share stories.

In addition to the organisation's broader educative and awarenessraising role, Dementia Friendly Tasmania's objectives include acknowledging the potential of people living with dementia and engaging them, their family members and carers in community life, offering community-based solutions to enable people to live independently and promoting easy-to-navigate environments including accessible, dementia-friendly businesses, services and communal spaces.

Dementia Friendly Tasmania has held a series of well-attended Ageing Wonderfully Well Expos in Kingston, Kettering and Taroona. These expos and information stalls at other community events have provided valuable opportunities for engaging with the community on broader issues of ageing and health that have then provided opportunities for one-on-one conversations about dementia that have proven to be as effective as more formal information sessions.

#### 66 People respond well to a little bit of learning in a safe space with some structured discussions that help them think a bit more deeply about the issues. 99

- Di Carter, Co-founder and current Vice-President, Dementia Friendly Tasmania A generous private donation facilitated the purchase of a trishaw (a first for Tasmania) which has been enjoyed by people living with dementia and is currently leased out to aged care facilities to encourage community engagement. A Dementia Australia Dementia-Friendly Communities Community Engagement Program Grant funded the organisation's Inclusive Wellbeing Initiative. Feedback from surveys and community forums informed the focus and choice of activities for the program. This includes an ongoing marketing and information campaign featuring a poster series 'I do live with dementia', drawing on the words and experiences of a person living with dementia. A singalong at a dementia-friendly café and an art and craft afternoon have also been part of the well-received Inclusive Wellbeing Initiative. As part of its broader commitment to community engagement, Dementia Friendly Tasmania's volunteers talk regularly to community groups, politicians and businesses about the importance of making changes to the social and built environment to work towards a more dementiafriendly and inclusive community.

#### Future directions

Dementia Friendly Tasmania has an impressive action plan comprising short and long term goals, the most ambitious of which is transforming the whole of Tasmania into a dementia-friendly State. In the shorter term, the group is working towards growing the organisation and achieving formal Dementia-Friendly Alliance status. A key short-term goal is expanding the Inclusive Wellbeing program to local communities beyond Kingborough including Bruny Island, Devonport and other locations. Local neighbourhood houses, medical clinics, councils, schools, libraries, Technical and Further Education colleges, businesses and public transport services have been identified as a focus for the group's ongoing commitment to providing information and encouraging improved understanding of dementia in working towards a genuinely dementia-friendly and inclusive community.

## COVID-19 and the Dementia-Friendly Communities Program

The COVID-19 pandemic has imposed wide-ranging challenges for communities around the world. The psychosocial and other impacts for people with dementia and their carers have been significant and well-documented, compounded by reduced access to services and supports critical to social engagement and community connection. The Dementia-Friendly Communities program has of necessity changed the way it has provided support to individuals and groups during the past two years, including shifting many activities and events online. This has not always been an easy transition for program staff, nor for people living with dementia. Equally, it has served to highlight how critical the program—and the services and support it provides—continues to be. This is evidenced by feedback from respondents to the 2021 Dementia-Friendly Communities Inclusion Survey including the testimonials below.

- "During the pandemic, [we have held] weekly social Zoom meetings which have not only involved people within the community, but also nationally and Internationally." (Kiama Alliance)
- "Lockdown has certainly put a dampener on the group meeting and activity is at a standstill. Unfortunately, this brings about further isolation in an already isolated disease." (Narrabri Dementia-Friendly Community Committee)
- "We developed a project to improve digital literacy amongst our community in times of COVID-19 lockdown." (Ballina Shire Dementia-Friendly Community Alliance)
- "To be honest, if it wasn't for Marie-Louise [Queensland Dementia-Friendly Communities Program Officer] we would have folded.
  COVID-19 was a huge stumbling block. Before COVID-19, I set up a little group that we called the Advisory Panel. This was a positive thing, but COVID-19 knocked it. COVID-19 scared a lot of people who were vulnerable. They didn't want to come out." (Glenys Petrie, Brisbane South-East Dementia Friendly Community Alliance member)

## Case study

## South Australia

Cutting through with community cafés: The Onkaparinga Dementia-Friendly Alliance of South Australia (ODFASA)



### **Community context**

## I have observed the amount of joy that you get out of most people. People are becoming engaged and a lot happier.

- Person living with dementia

The City of Onkaparinga is a local government area located on the southern fringe of Adelaide, South Australia, with a population of over 174,000 people. The Onkaparinga Dementia-Friendly Alliance of South Australia (ODFASA) was established in 2020 and incorporated in 2021. It is a group of people living with dementia, carers, and community members who have had some experience of dementia and want to establish a dementia-friendly Onkaparinga region.

Bringing together people living with dementia, business owners, community stakeholders and other members of the community, the Alliance coordinates and facilitates activities which contribute to creating an Onkaparinga region that is respectful of people with dementia and their carers and dementia-friendly.

66 We can see that it's needed and when you see the smiles on people's faces it's lovely. We let people know that they're not alone. 99

- Carer

The goals of the Alliance are to:

- Build an understanding of dementia.
- Encourage the Onkaparinga region to become dementia-friendly and respectful of people living with dementia and their carers.
- Support community activities for people living with dementia.
- Acknowledge the potential of people living with dementia to confidently engage in community life to feel a sense of belonging.
- Offer community-based solutions to enable people to live independently as much as possible.
- Promote strategies to make local businesses and service providers easy to access and navigate.



### Making a difference

The impact of the Alliance comes down to the commitment of its members. Positive changes that have taken place in the community include:

- People living with dementia, their families and carers becoming more socially engaged.
- Improved awareness of dementia and relevant services and supports.
- People living with dementia being more involved and participating within the community.
- Reducing loneliness and isolation.
- People living with dementia being central to the working group, involved in planning, implementation and participation in community events and activities.
- Supporting and mentoring other groups to create Dementia-Friendly Alliances in nearby communities, and sharing knowledge and experience.

Local businesses and organisations becoming more accessible and dementia-friendly, including local pharmacies, community centres (including an Aboriginal and Torres Strait Islander community centre), retirement villages, some seniors' services and local allied health services.

An example of the Alliance's work is the active engagement with local pharmacies in Christies Beach. Suggestions have been provided on how to enhance accessibility for people living with dementia and their families. Following walkthroughs of the pharmacies, clearer clocks, calendars and signage have been sourced to assist people to orient to their surroundings and improve wayfinding. The pharmacies have also been displaying the Alliance's community café flyer. This has enabled people who were previously isolated to make new connections with people who understand their experience.

#### I was sceptical but now I throw myself into it.



- Carer

The community café has enabled the development of friendships at a time when a safe and caring space to socialise with like-minded people was urgently needed.

Dementia Australia supports the Alliance with information, resources, expert advice and connects them to relevant forums and networks.

#### 66 Dementia Australia has been absolutely fantastic, they've come on board of recognising that we're doing what is expected of an alliance. 🤧

- Person living with dementia

Staff from Dementia Australia play an integral role in connecting the community and strengthening the capacity of Alliance members to promote dementia awareness in their community. This includes inducting Alliance members as Dementia Friends Hosts, a role that enables community members to raise the general public's awareness of dementia. Dementia Australia staff also support Alliance members through a process designed for people living with dementia and carers to provide feedback to local businesses and organisations and encourage them to make small changes that will result in a more inclusive and enabling environment for people impacted by dementia.

### >> Future directions

The Alliance wants to transform how people in the community think, act and talk about dementia. To this end, in the next 12 to 18 months, the group plans to grow and have a second café running, supported by volunteers and Wakefield House Positive Ageing Centre. They aim to make more of an impact, circulate more information into the community and expand activities and events to support more people. This will depend on obtaining funding and other forms of support as any costs currently incurred to run events are out-ofpocket expenses. Additionally, they are actively engaging with more community centres, the local council and Members of Parliament to support the Alliance and its expanding activities.

#### 🕜 Bigger and better, more people, getting it out there more. 🤧

- Person living with dementia

# The Dementia-Friendly Communities Program: current achievements and future ambitions

Dementia Australia's Dementia-Friendly Communities program was recently acknowledged in the prestigious Future of Ageing Awards, winning the Community Engagement Category. The Awards recognise collaboration, leadership and innovations across Australia's aged care industry. The Community Engagement award highlights the significant impact of the Dementia-Friendly Communities program in supporting, encouraging and empowering communities to value the contribution and be inclusive of people living with dementia. The program's success is based on the central role that people living with dementia play in all program tiers, from the establishment of Alliances and development of action plans, through to awarenessraising activities (including the Dementia Friends program element) and implementation of grassroots dementia-friendly change initiatives.

The program's primary emphasis is on building networks and making connections to drive community participation, ownership and sustainability to improve the lives of people living with dementia. As evidenced by the case studies featured throughout this paper, the program has a concerted focus on initiatives in culturally, ethnically and socially diverse communities in regional, rural and metropolitan areas. These include projects, activities and collaborations with councils, banks, cafés, regional parks management, pharmacies, artists, shopping centres, tradespeople, Technical and Further Education colleges, businesses, Men's Sheds, aged care providers, libraries, museums, hospitals, choirs, emergency and police services, community transport and secondary schools – to list just a few.

The 2021 Dementia-Friendly Communities Inclusion survey sought feedback on what would assist the future growth and development of existing groups, Organisations and Alliances in promoting a more inclusive, dementia-friendly community. The key themes that emerged included increased participation from government particularly at the municipal level—tools and strategies to engage local businesses and an increase in material support and funding to ensure the ongoing expansion of Organisations and Alliances.

The Dementia-Friendly Communities program has identified the following as central to its short-term and long-term planning priorities accordingly:

- Building the numbers of Dementia Friends and associated community capacity.
- Encourage and support current dementia Alliances and the creation of new Alliances.
- Expanding the number of dementia-friendly projects through the awarding of Community Engagement Program grants.
- Supporting existing Community Engagement Program projects to continue delivering best-practice dementia-friendly community activities.
- Further refinement of the Dementia-Friendly Organisations program element to provide a clear framework for small, medium and large businesses to engage in recognition pathways that involve self-developed and/or fee-for-services options depending on the size and complexity of the business.
- Developing a template for local and State governments that outlines how best to support dementia-friendly communities.

## Recommendations

Successful Dementia-Friendly Communities commonly are established by organisations that can access expertise, funding and commitment to allow time and innovation to make change happen. This suggests that the most likely way to drive change at a community level is through a top down approach via Dementia-Friendly Communities that is supported by the Dementia Friends program.<sup>®</sup> 22

The Dementia-Friendly Communities movement has been characterised as a global endeavour that complements the work of national governments, organisations and support services.<sup>19</sup> Dementia Australia strongly believes that rather than being simply complementary, the Dementia-Friendly Communities program offers a template for embedding dementia-informed and dementia-friendly principles for governments at every level in Australia. Governments can demonstrate tangible support for the Dementia-Friendly Communities movement by referencing dementia and dementiafriendly communities in inclusion policies, strategies and plans, and in the provision of local funding sources and mechanisms to support the creation of place-based, community-led dementia-friendly initiatives. This paper has outlined the significant impact of the Dementia-Friendly Communities program in supporting dementia-friendly communities across Australia, and their core objectives of improving dementia literacy, reducing stigma and discrimination, and promoting social engagement and connectivity. The program's demonstrated success in the nationwide range, scale and diversity of dementia-friendly initiatives makes a compelling argument for continued funding to support the growth, development and sustainability of current and future Dementia-Friendly Communities initiatives.

Dementia Australia therefore recommends a continuation of funding for a further three years to enable the Dementia-Friendly Communities program to expand its work, with a particular emphasis on encouraging, supporting and empowering Aboriginal and Torres Strait Islander, culturally and linguistically diverse and rural and remote communities. The program's key areas of focus will be to support diverse communities to build capacity, create supportive networks and develop in-language localised resources.

# Conclusion

International research has pointed to the critical role that the rapidlyexpanding dementia-friendly communities movement can play and has specifically acknowledged Australia's efforts in this context.

<sup>66</sup> The reduction of stigma and the empowerment of people living with dementia could be addressed through increased investment and focus on the creation of dementia-friendly communities, as proposed in many national dementia plans, including the UK (Department of Health, 2015) ... National dementia plans, for example, in Canada, the UK, and Australia have actions related to dementia-friendly communities, with a range of initiatives in place worldwide (further information, is available through the Alzheimer's Disease International, 2019 report - Dementia Friendly Communities: Global Developments).<sup>20</sup> <sup>99</sup>

#### The increasingly active dementia-friendly movement in Australia continues to be driven primarily by the rigorously developed and successfully implemented Dementia Australia Dementia-Friendly Communities program. In addition to the recent Future of Ageing award, the extensive section dealing with Australian initiatives in the Alzheimer's Disease International Dementia-Friendly Communities Global Report attests to the breadth and innovation of the Dementia Australia program.<sup>21</sup>

Working with key internal partners including Client Services, Consumer Engagement and the Centre for Dementia Learning, the Dementia-Friendly Communities program team is committed to continue to work towards an inclusive community, because a community that is dementia-friendly is simply a community that is good for everyone.





**The Dementia-Friendly Communities program team is** committed to continue to work towards an inclusive community, because a community that is dementia-friendly is simply a community that is good for everyone. 🤊

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## About Dementia Australia

Dementia Australia is the source of trusted information, education and services for the estimated half a million Australians living with dementia, and the almost 1.6 million people involved in their care.

We advocate for positive change and support vital research. We are here to support people impacted by dementia, and to enable them to live as well as possible.

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

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

## National Dementia Helpline 1800 100 500



For language assistance call **131 450** 

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



The National Dementia Helpline is funded by the Australian Government ©Dementia Australia 2021, 21150, November 2021