CENTRAL COAST COUNCIL

Dementia-Friendly Central Coast

Framework

June 2017 Full Version



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Cover image: Forget-Me-Nots, often used as a symbol of dementia awareness. Licensed from iStock by Getty Images.

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Dementia-Friendly Central Coast Framework

Welcome to the Dementia-Friendly Central Coast Framework, our guide and resource for transforming the Central Coast into a dementia-friendly community.

The Central Coast local government area covers 937 Km² on the North West coast of Tasmania, and includes the settlements of Ulverstone, Penguin, Turners Beach and Forth. Around 22,313 people live in the Central Coast. Ours is an ageing population, and our dementia prevalence is projected to grow over the coming decades.

Dementia is an umbrella term for a number of conditions that progressively affect a person's cognition, memory and behaviour. Yet the consequences of dementia are not just felt on an individual level—dementia has profound social impacts that can diminish quality of life for people with dementia and their caregivers.

The Central Coast Council is committed to enhancing community wellbeing and positive ageing in order to help the community to live its potential. The Council recognises that meeting the challenges of dementia will require a whole-of-community approach. Creation of this Dementia-Friendly Central Coast Framework (the Framework) is our first step towards joining the growing network of dementia-friendly communities worldwide.

Our principles for a Dementia-Friendly Central Coast are as follows:

- 1. People living with dementia are valued and respected members of the Central Coast community.
- 2. Creating a Dementia-Friendly Central Coast is everybody's business.
- 3. Places, businesses and services are welcoming and enabling for people living with dementia.
- 4. Community decisions respond to the needs and aspirations of people with dementia and their carers.
- 5. Becoming a Dementia-Friendly Central Coast is a continuous process.

Consultation with our community has indicated strong initial support for the Dementia-Friendly Central Coast initiative. The consultation has also highlighted six key dimensions for change: increasing knowledge about dementia; improving attitudes and interactions; enhancing access to services; facilitating social integration; improving spaces and places; and supporting carers.

To reflect these priorities, this Framework includes a customised 'menu' of actions from which the Council and its community partners can select. By working collaboratively to reduce the negative social impacts of dementia, we will make the Central Coast a safer, more supportive and vibrant community for all.

Key terms

ALZHEIMER'S DISEASE	A disease that damages the brain, resulting in impaired memory, thinking and behaviour. Alzheimer's disease accounts for around 70% of all dementia diagnoses.
Аитолому	The perceived ability to control, cope and make personal decisions about how one lives on a day-to-day basis, according to one's own rules and preferences.
CAREGIVER/CARER	Anyone who provides care to a person with dementia. Caregivers can be family members or friends, or paid professional caregivers. Caregivers may provide full- or part-time help to the person with dementia.
COMMUNITY	A broad term to define groups of people based on geographic location, similar interest, affiliation or identity. The Central Coast community includes residents, businesses, workers, organisations and visitors.
DEMENTIA	A general term for a number of neurological conditions in which thinking, behaviour and the ability to perform everyday tasks are affected enough to interfere with the person's normal social or working life.
DEMENTIA-FRIENDLY COMMUNITY	A place where people living with dementia are supported to live a high quality of life with meaning, purpose and value [Alzheimer's Australia].
ENABLING/DISABLING	Describe the qualities of an environment or interaction that empower an individual to live autonomously (enabling) or impede an individual's ability to live autonomously (disabling).
HIGH QUALITY OF LIFE	An individual's perception of a positive position in life in the context of the culture and value systems in which they live and in relation to their goals.
POSITIVE AGEING	The ability of older people to lead productive lives in the economy and society.
RESPITE/RESPITE CARE	Respite care for a person with dementia provides the carer with a temporary break from caregiving tasks. Respite includes in-home assistance, adult day care, or a short stay in supported accommodation.
RISK FACTORS	Any attribute, characteristic or exposure of an individual that increases their likelihood of developing a condition.
STAGES	A framework for understanding the progression of dementia.
SOCIAL ISOLATION	A state of ongoing lack of contact between an individual and society, often leading to feelings of loneliness and impaired physical and mental health outcomes.
YOUNGER-ONSET DEMENTIA	Any form of dementia diagnosed in people under the age of 65.

1. Dementia-Friendly Communities

What is a dementia-friendly community?

A dementia-friendly community has a high level of dementia awareness. It provides a supportive environment for people with dementia and their carers. It recognises that people living with dementia are among the most vulnerable members of society, and that the majority of people with dementia live in their homes in the community. A dementia-friendly community understands that the challenges of dementia cannot be met by the health and social services sector alone, but require a whole-ofcommunity approach.

fantastic initiative

'I think this is a

of the Council'— Central Coast

> community member

While there are many ways to define a dementia-friendly community, this Frameworks adopts Alzheimer's Australia's definition of a dementia-friendly community as a place where people living with dementia are supported to live a high quality of life with meaning, purpose and value.

A global movement

The worldwide phenomenon of dementia-friendly communities owes much to Japan, where grassroots and governmental approaches to creating dementia-friendly communities emerged in the early 1990s.

Today, Japan is home to numerous dementia-friendly communities, and Alzheimer's Disease International has identified dementia-friendly community initiatives in the United Kingdom, Ireland, Canada, the United States, Belgium, Austria, Cyprus, Bulgaria, France, Finland, Germany, Italy, the Netherlands, Norway, Portugal, Slovenia, Spain, Switzerland, Turkey, Bangladesh, India and Indonesia, Singapore, New Zealand, Sri Lanka, Taiwan, Namibia and Nigeria. Dementia awareness-raising projects have also taken place in Latin America, the Caribbean and the Middle East.

In Australia, leading examples of dementia-friendly communities can be found in the municipalities of Port Macquarie and Kiama in NSW, and dementia-friendly community initiatives have been piloted in Beechworth (Vic), Manningham (Vic), Holdfast Bay (SA), Darwin (NT) and Bribie Island (QLD). A statewide approach has also been initiated in Western Australia. In Tasmania, the town of Cygnet became dementia-friendly in order to support the needs of a resident with dementia and his wife.

Benefits of dementia-friendly communities

Experience around the world has demonstrated the benefits of dementiafriendly communities, not just for individuals living with dementia, but also for society more broadly. For Australian dementia-friendly communities, Alzheimer's Australia highlights the following potential areas of benefit:

- Benefit to people living with dementia and their carers, as attitudinal changes in the community, active participation and enabling policies help to diminish the impacts of stigma and social isolation;
- Economic benefit to businesses, as improved accessibility and more inclusive service behaviours make businesses more desirable in the eyes of any customers seeking a more supportive and welcoming experience;
- Economic benefit to tourism, as older and more affluent travellers
 actively seek out destinations with a commitment to inclusivity and
 accessible physical environments;
- Benefit to the health budget, as increased ability for people with dementia to live at home reduces pressure on aged care facilities; and
- Benefit to the wider population, as improved levels of inclusivity and accessibility in a community can be enjoyed by people of all ages and abilities.

Elements of success

Just as there is no single definition of what it means to be dementiafriendly, there is no standard way to become a dementia-friendly community. The process of becoming a dementia-friendly community should be shaped and driven by local concerns, aspirations and actions.

Alzheimer's Australia has identified some typical 'ingredients' for successfully becoming a dementia-friendly community:

- Strong local government support at a senior level to drive the program;
- **2.** A powerful community leader to unite diverse stakeholders and bring community values to the fore;
- **3.** A dedicated project officer to identify local needs and coordinate the actions of individuals and groups;
- **4. Engagement of people with dementia** in all elements of the project;
- **5. Local willingness** and existing desire to be more inclusive and break down negative stereotypes; and
- **6. Support from a research body**, particularly in regard to evaluating outcomes.

'The more
understanding
there is, the rest
will flow on'—
Central Coast
community
member

2. Context

About dementia

One of the major causes of disability and dependency amongst older people worldwide, dementia refers to a collection of conditions in which cognitive function—a person's ability to remember, think, orientate themselves, understand, calculate, learn, perceive, use language and judgement—deteriorates over time. These symptoms are typically accompanied by a change in personality and a decline in emotional control, social behaviour or motivation. In Australia, dementia is now the second leading cause of death.

Dementia affects the individual through a series of stages:

Early stage	
('mild')	
dementia	

Can include forgetfulness, losing track of time, or disorientation in familiar places. This stage can often be difficult to identify as the onset is gradual.

Middle stage ('moderate') dementia

Can include forgetting names and recent events, disorientation at home, struggling with communication and personal care, and changes to behaviour including wandering and repeated questioning.

Late stage ('severe') dementia Can include high levels of dependence and inactivity, becoming unaware of time and place, escalating behaviour changes, difficulty recognising friends and family, and requiring help with self-care and walking.

'Those who adopt
"brain healthy"
lifestyles have a
reduced risk of
developing
dementia'—
Alzheimer's
Australia

There are over 100 different causes of dementia. Alzheimer's disease is the most common form of dementia (around 70% of cases), while vascular dementia (caused by stroke) is the next most common.

Risk factors associated with developing dementia include being overweight or obese in middle age, diabetes, depression, high cholesterol, high alcohol consumption, smoking, pesticide exposure, low social participation, traumatic brain injury, and family history of dementia.

There is no cure, although there are treatments available that may provide symptomatic relief. Protective factors against dementia include higher levels of educational attainment and a diet rich in vegetables and fish.

Prevalence

Around 5% of adults over the age of 65 will develop dementia in their lifetime. Yet while dementia is commonly associated with older adults, it can also affect people under 65 years of age. Younger-onset dementia can affect people in their 30s, 40s and 50s. It can be more challenging to achieve a timely diagnosis for younger adults, as health care providers typically do not look for dementia in this age group. Those diagnosed can be in any stage of the disease, and are more likely to have a more rare form of dementia.

It is estimated that 47.5 million people worldwide currently have dementia, with an additional 7.7 million diagnosed each year. By 2030, the number of people projected to have dementia will be 75.6 million worldwide, with this number rising to 135.5 million by 2050.

In Australia in 2017, an estimated 400,833 people have dementia, including 25,938 people living with younger-onset dementia. Nationwide, the dementia prevalence rate is growing at a rate of 3.8% for males and 2.5% for females, meaning around 244 people in Australia are diagnosed with dementia every day. Statewide, Tasmania's dementia population is expected to grow to more than 20,600 by 2056, with the fastest growth predicted over the next two decades.

Population ageing in Tasmania is predicted to be more pronounced in the regions than in urban areas, and the Central Coast is no exception. As of 2011, nearly one-in-five of the Central Coast population was aged 65 or older. By the year 2030, the proportion of people aged 65 or older in the Central Coast will be one-in-three.

'Dementia is one of the fastest growing conditions in Australia'— Alzheimer's Australia

There is currently no national data on dementia prevalence in Australia based on clinical diagnoses. Dementia information is captured in the ABS Disability, Ageing and Carers Survey, but this study relies on self-reporting and is likely to under-report where dementia is in its early stages or remains undiagnosed. In the absence of epidemiological data, dementia can be estimated by applying dementia prevalence rates to population data.

Applying these prevalence rates to the Central Coast indicates that, based on population data from 2011, there were an estimated 332 residents of the Central Coast local government area with dementia. Based on population forecasts for 2027, the population of people with dementia is projected to be 579. By the year 2037, this number is projected to be 795.

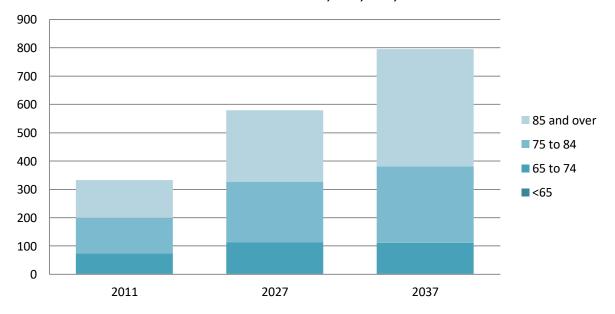
Women and people aged 85 and older have a proportionally higher prevalence of dementia. The projected numbers of people with younger-onset dementia in 2027 and 2037 are too small to be visible on the graph below.

TABLE 1: ESTIMATED DEMENTIA PREVALENCE, CENTRAL COAST LGA BY AGE & SEX, 2011, 2027, 2037

	20)11	2027		2037		Prevalence rates	
	Males	Females	Males	Females	Males	Females	Males	Females
<65	1	1	1	1	1	1	0.01%	0.01%
65 to 74	34	39	51	60	49	60	3.1%	3.4%
75 to 84	51	74	96	117	115	155	8.8%	10.4%
85 and over	35	98	87	166	158	255	24.4%	32.3%
Total	120	212	235	344	323	472		

Population data and projections: .id community, Treasury Dept 2014. Prevalence rates: AIHW 2012.

CHART 1: ESTIMATED NUMBER OF CENTRAL COAST RESIDENTS WITH DEMENTIA BY AGE, 2011, 2027, 2037



Community impacts of dementia

In Australia, a majority of people with dementia (83% of males and 71% of females) live at home in the community. In addition to dementia's cognitive and behavioural impacts, having dementia can negatively impact how a person with dementia experiences life as a member of their community.

Some of these impacts are due to the disabling effects of particular physical, cultural and social environments. A disabling environment is one that is incompatible with the particular physical, sensory, wayfinding or communication needs of a person with dementia.

Other impacts are due to misunderstandings and negative perceptions of dementia. There is no stereotypical dementia experience—individuals living with dementia experience the syndrome in their own way and maintain different strengths, capacities and abilities. However, common misunderstandings about dementia include the belief that a person with dementia lacks any capacity or competency, or would not benefit from support. Misunderstandings also include the belief that symptoms are just due to 'old age', or that if a person 'looks fine' on the outside, they do not require special accommodations.

Negative perceptions (stigma) can have a profound effect on social interactions, and can be associated with dementia as a whole as well as with specific symptoms. People living with dementia may be the targets of disrespect, abuse and exploitation as others react inappropriately to, or take advantage of, their cognitive impairments. Fear of stigmatisation can cause a person with dementia to delay or avoid diagnosis, to resist treatment, or to self-exclude from community participation.

SOCIAL PARTICIPATION

Establishing and maintaining meaningful relationships can enhance the wellbeing of a person with dementia and help them to remain physically and emotionally healthy for longer.

Yet research by Alzheimer's Australia with people with dementia has found that social isolation is strongly associated with a diagnosis of dementia. A person with dementia may find it harder to follow a conversation, to find enough energy to participate, or to stay focused. These changes in ability can cause anxiety, frustration or feelings of loss for the person with dementia, and can cause them to withdraw from social activities.

'[It's] a bit confronting to tell people'—Central Coast community member

A diagnosis of dementia can also change how people respond to an individual. Public misunderstanding and negative perceptions mean that social environments themselves—clubs, community events, organised activities, or simply activities in the public realm such as shopping or using transport—are unwelcoming or unsafe for people living with dementia.

In Australia, there are an estimated 118,000 individuals with dementia who live alone.

More than four-in-ten people with dementia surveyed by Alzheimer's Australia in 2014 said they wished they had more social contact with people in the community.

FAMILIES

Dementia has a profound effect on families. Feelings of grief, loss and guilt amongst family members are common, and relationships and roles must adapt and change with a dementia diagnosis. It can be difficult for both the person with dementia and their family members to adjust to these new roles and responsibilities. A person with dementia may find themselves excluded from family conversations and decisions, or may experience an unwanted level of dependence on family members.

Family members may take on a caregiver role. There are nearly 200,000 people in the Australia community currently caring for a person with dementia, most of whom are informal carers. The majority of these are spouses and partners (35% of carers) or a daughter or son (41%), followed by other family members (15%) such as a sibling, a daughter- or son-in-law or grandchildren.

The experience of caregiving can deepen family bonds and be a rewarding experience; yet it can also be challenging for carers to negotiate behavioural and personality changes in the person with dementia. Carers themselves can also experience negative health outcomes (including mental health) and high levels of social isolation.

Family members of a person with younger-onset dementia may face special challenges. Children may have strong reactions to their parent's diagnosis and struggle to cope with the change in family dynamics as their parent becomes more dependent. Partners or adult children may find they need to reduce or give up work in order to care for the person with dementia.

'It will be interesting how my kids react'— Central Coast community member

ECONOMIC PARTICIPATION

For a person still working at the time of onset of dementia, loss or change of employment can be a significant impact. As a person with dementia's capacities change, they may find themselves unable to maintain their usual position or responsibilities in the workforce. Some people may experience losing their job upon disclosing their dementia diagnosis to their employer. Loss or reduction in employment has a negative impact not only on the person's social wellbeing and their identity, but also on their income.

Younger-onset dementia can present challenges in the workplace. Prior to a formal diagnosis, the early signs of dementia can become apparent to colleagues or supervisors, who may struggle to correctly identify the signs and direct the individual to appropriate diagnostic and support services. Without a dementia policy and plan in place, workplaces may also find it difficult to provide appropriate supports and accommodations to an individual with dementia who wishes to remain at their job after a diagnosis.

Diminished economic participation can also occur when a person with dementia finds it difficult to obtain goods and services in the public realm. Cognitive and behavioural barriers can impact upon a person's ability to navigate public spaces such as shopping centres or medical offices, to interact successfully with retail or service staff, and to manage investments, banking and transactions.

'I may need a little help along the way'—Central Coast community member

DIVERSITY

In Australia, more women than men live with dementia and comprise the majority of people with dementia who live alone. Global analysis of the impact of dementia on women notes that women with dementia may find it more difficult to give up their traditional roles as care providers in their families, and also that the combination of gender, advanced age and dementia makes women especially vulnerable to discrimination and abuse. Women also tend to provide the majority of familial and formal care for people with dementia.

Cultural diversity is another factor in the dementia experience. Today, one in every five persons with dementia in Australia is from a culturally or linguistically diverse (CALD) background. Cultural backgrounds can affect perceptions of dementia (including community stigmatisation), beliefs about the role of the family, attitudes towards residential and community care, and attitudes towards counselling and the role of religion. Together, these elements underscore the importance of culturally appropriate diagnosis, services and care options.

Aboriginal and Torres Strait Islanders have 3-5 times the risk of developing dementia compared with non-Indigenous Australians, with younger-onset dementia also more common in the Indigenous community. Culturally appropriate dementia diagnosis, services and care options are very important to this community.

Higher rates of dementia are also experienced by Australia's more socially and economically disadvantaged communities.

People living in regional and remote areas can face shortages of specialist services as well as difficulties accessing appropriate dementia supports and services. Distance can also compound the social isolation experienced by people with dementia and their carers.

Individuals who identify as lesbian, gay, bisexual, transgender and intersex (LGBTI) face a range of additional challenges in dealing with dementia. These include barriers to finding non-discriminatory medical services for both diagnosis and ongoing care, difficulties in locating accepting and supportive dementia services and facilities, and the issue of disclosing LGBTI status to care providers.

LOCAL GOVERNMENT

The particular needs of the dementia population present special challenges for local government. These challenges are likely to become more pressing in the context of an ageing population and an increase in dementia prevalence over time.

Some of these challenges for local government are associated with planning and providing services and facilities in a way that ensures the particular needs of people with dementia are accounted for. This may include access to universal services or else provision of specialised service responses. Other challenges are associated with facilitating public safety, particularly in relation to the staging of events and the design of enabling public environments.

Another key challenge relates to interactions between council staff and individuals with dementia. Such interactions may take place when individuals are using facilities such as libraries or swimming pools, receiving council services, or attempting tasks such as paying rates and dealing with other regulatory matters. The behavioural and cognitive changes of dementia can affect these interactions.

'Councils play a key role in ensuring that local communities are vibrant, inclusive and supportive of all citizens'— Alzheimer's Australia

The policy and planning context

NATIONAL CONTEXT

Dementia was designated a National Health Priority Area in Australia in 2012, and in 2015 the Australian Health Ministers Advisory Council developed the National Framework for Action on Dementia 2015-2019. Based on a national consultation process, the National Framework aims to guide the development and implementation of actions, plans and policies that reduce the risk of dementia and improve outcomes for people with dementia and their carers.

The National Framework emphasises taking a collaborative approach to dementia-friendly communities in order to raise dementia awareness and promote improved health outcomes. In part, the National Framework says:

'The development of dementia-friendly services and approaches may help to promote awareness and create communities which are more inclusive and accepting of people with dementia. For this to occur, the communities, including local businesses, health care professionals and other service providers should improve their understanding and awareness of dementia. The provision of amenities, goods and services in a user-friendly manner that meets the needs (including co-vulnerabilities) of people with dementia and their carers may help to facilitate inclusion.'

The National Framework anticipates the following actions and outcomes in relation to dementia-friendly communities and awareness-building:

- Develop dementia-friendly communities, where all aspects of the community's built environment and approaches are dementiafriendly, inclusive, promote respect and acceptance, and enable participation.
- Support and resource community-based programs and initiatives to promote social engagement and develop dementia-friendly environments.
- Develop communities and workplaces that are dementia-friendly.
- Conduct awareness activities that highlight the need to understand and respect the rights of the person with dementia and treat people with dementia with dignity and respect.

'People with dementia are valued and respected, including their rights to choice, dignity, safety and quality of life'—Kev *Principle, National* Framework for Action on Dementia

STATE CONTEXT

The Tasmanian Plan for Positive Ageing (2007-2012) acknowledged the ageing profile of the Tasmanian community, and envisioned a Tasmania in which people of all ages are recognised and valued, treated with dignity and respect, and encouraged to contribute their wealth of experience and skills. Among the Plan's key principles was the recognition that positive ageing depends on the actions of individuals supported by the wider community, including business and government.

The Council of The Ageing (COTA) Tasmania is the primary organisation representing the rights of older Tasmanians. COTA is committed to supporting a network of age-friendly communities in Tasmania and to assisting local governments to work with communities to become agefriendly. COTA has recently conducted an extensive program of consultation and compiled an Active Ageing: Strategic Directions Paper to support the Tasmanian Government in the development of an Active Ageing Plan.

Dementia services and initiatives in Tasmania are spearheaded by Alzheimer's Australia Tasmania, the leading dementia charity and peak organisation for advocacy on behalf of Tasmanians living with dementia.

LOCAL CONTEXT

In Tasmania, the Local Government Act 1993 (Section 20) requires Councils to provide for the health, safety and welfare of the community in a way that consults with, involves and is accountable to the community. As part of its strategic work to meet these requirements, the Central Coast Council recognises the challenges of an ageing community, and has embedded an emphasis on positive ageing within a number of policy and strategy documents.

The Central Coast Council Strategic Plan 2014-2024 sets out the following Vision for the Central Coast: 'We are a vibrant, thriving community that continues to draw inspiration and opportunities from its natural beauty, land and people and is connected by a powerful sense of belonging'.

The Strategic Plan describes four key Directions and Actions for the Central Coast Council. Actions with strong alignment to the Dementia-Friendly Central Coast initiative include community capacity-building, connecting people with services, contributing to a safe and healthy environment, effective communication and engagement, and achieving meaningful positive ageing outcomes.

The Central Coast Social Planning Framework is designed to guide Council's efforts to make a positive difference to the community's health and wellbeing. The Framework notes that Council may play several roles in achieving this goal (as Provider, Facilitator or Advocate), and emphasises building relationships and working collaboratively with local people and groups within the Central Coast community.

The stated Vision of Council's Positive Ageing Strategy 2007-2012 is: 'Leading a growing and innovative community.' The Strategy is inclusive of people of all ages, but is particularly focused on those aged 50 and older. It defines positive ageing policies as those designed to support people as they grow older in leading productive lives in the economy and society.

The main objectives of the Positive Ageing Strategy are as follows:

Acknowledge that older people are valued members of our community. Recognise and foster the strengths and skills of older people and the contribution that they make to the community. Identify the current and likely future needs of older people within the Central Coast Community. Identify ways in which older people can maintain a healthy and active way of life. Identify the roles and responsibilities that Council would need to undertake in addressing the needs of its older residents. Develop reliable information to support planning and service development to meet the changing needs of older people.

'We must be responsive to the needs of older people as valued members of our community'— Central Coast Positive Ageing Strategy

By pursuing the above objectives, the Council anticipates that the Central Coast community will enjoy better physical and social wellbeing, increased self esteem and established social networks, increased community participation by older people, and a higher level of understanding and awareness about the needs of older people.

3. Central Coast perspectives

Community consultation

The Central Coast Council affirms that those who are affected by a decision have the right to be involved in the decision-making process. This approach is consistent with good practice in establishing dementia-friendly communities, in which priorities for change are shaped by people with dementia, caregivers and a broad spectrum of community members.

Community consultation for the Dementia-Friendly Central Coast Framework has consisted of the following:

- Online community survey (n=90), hosted on the Council website between 27 March and 8 April, 2017;
- Focus group with people living with dementia in the Central Coast (n=3 + one attending dementia specialist nurse), facilitated on 3 April, 10am-12pm at the Ulverstone Civic Centre;
- Focus group with dementia service providers and carers in the Central Coast (n=6); facilitated on 4 April, 4pm-6pm at the Ulverstone Civic Centre; and
- 3x mid-project presentations and discussions held with senior Council management, the Central Coast Community Safety Partnerships Committee, and elected Councillors on 26 April/1 May respectively.

In addition to these activities, a Community Forum was held in Ulverstone by the Wicking Centre of the University of Tasmania on 15 March. At the time of writing this Framework, community feedback gathered at this Forum had not yet been shared with the Central Coast Council.

Due to the sensitive nature of some of the feedback and the small population size of the Central Coast community, input from the community survey and focus groups is discussed here in summary form rather than in detailed sub-reports.

'[Participation in the focus group] has been very helpful for me personally'— Central Coast Community Member

Support for the initiative

Over two-thirds (67%) of respondents to the survey reported having no personal connection to someone with dementia in the Central Coast (family member/partner, close friend, acquaintance, co-worker or employee). When asked about their caregiver activities, 4% of respondents reported caring for a family member, friend or neighbour in their home; 10% reported they were a nurse or professional care worker for a client or patient with dementia; and 6% said they looked after a person with dementia in another way. No survey respondents self-identified as having dementia.

Despite only a minority of respondents having a personal connection to dementia, the survey showed strong support for a cross-community approach to making the Central Coast a dementia-friendly community. 40% of respondents felt that people with dementia 'are not generally helped to enjoy a high quality of life in the Central Coast', and nearly three-quarters (74%) rated as 'Very important' the statement that 'Creating a dementiafriendly community is considered "everybody's business".'

When asked at the survey's conclusion if there was anything they would like to add (an open-ended text response), a large majority of respondents expressed enthusiasm for the Dementia-Friendly Central Coast initiative and expressed a call to action. Strong support for the initiative was also reflected in the two focus groups and in the mid-project presentations to Council stakeholders.

'It would be wonderful to know that there is a town in Tasmania that really cares for the ageing'— Central Coast Community Member

'Fantastic initiative, looking forward to supporting'— Central Coast Community Member

Existing strengths

In addition to the high level of community support, consultation for this Framework identified several community-defined strengths that indicate Central Coast is well-positioned to become more dementia friendly. These strengths are listed below in combination with selected community assets identified during community-wide consultation for the Central Coast Strategic Plan 2014-2024.

'I find it to be a friendly town... I think people would help you if they thought you were having trouble'—Central **Coast Community** Member

SERVICES AND FACILITIES

- Good quality primary health (including GPs) and allied health services
- Local access to dementia-specific programs and services
- High quality aged care facilities
- The presence of Alzheimer's Australia in Ulverstone—information provision and referrals

SOCIAL CAPITAL

- Strong community relationships and networks
- A sense of friendliness, safety and belonging
- High levels of community engagement
- A creative, innovative community
- **Experienced older generations**
- Leadership and collaboration/partnerships
- Community resilience

BUILT AND NATURAL ENVIRONMENT

- Beautiful and natural surroundings
- Access to parks, walking tracks and outdoor spaces for recreation
- Town centres are flat and accessible to pedestrians
- Slow pace of change

Community priorities

DEMENTIA KNOWLEDGE

Helping the community to better understand the facts about dementia has emerged as a significant priority for the Dementia-Friendly Central Coast initiative. There was a sense that the community is not currently wellequipped to support people with dementia, with only a minority (17%) of survey respondents agreeing with the statement, 'If I was diagnosed with dementia, I would be confident my community would know how to support me.'

Levels of community understanding about dementia were mixed. Around two-thirds of survey respondents reported knowing only 'Some' or 'Not much' about dementia. Notably, around one-fifth (21%) of survey respondents said they thought of dementia as a 'normal part of ageing.' Focus group participants with dementia similarly used analogies of natural wear-and-tear to describe dementia, in part as strategies to avoid the negative stigma associated with dementia.

While the existence of younger-onset dementia appeared to be widely known, only around one-third (34%) of survey respondents correctly identified all of the dementia risk factors when provided with a list. Just over three quarters (77%) were able to identify all the early signs of dementia when provided with a list.

Personal experience and word-of-mouth/common knowledge were reported by survey respondents as the main channels through which people currently find out about dementia.

Community consultation indicated that understanding dementia ideally consists of two parts: (i) knowing about the condition and its progression; and (ii) the know-how for responding positively to someone with dementia. Having prior personal experience with dementia (i.e. by having/having had a relative with dementia) emerged in the focus group as a key predictor of a person's ability to interact comfortably and positively with a person with dementia.

'Dementia is not understood very well by the wider community'— Central Coast Community Member

ATTITUDES AND INTERACTIONS

Along with improving community understanding of dementia, improving attitudes and reducing stigma is likely to be a key driver of change in the Central Coast.

The consultation indicated strong causal links between community attitudes, interactions and isolation. People with dementia in the Central Coast viewed everyday community interactions (e.g. banking, visiting the doctor, shopping) as being high risk, not just in terms of material risks such as being 'ripped off' in financial transactions, but in terms of psychological and emotional risk associated with other people's behaviours. There was a fear of 'muddling' things up and becoming 'a joke' in the eyes of others.

People with dementia have experienced, or anticipate experiencing, community interactions in which they are misjudged, disrespected or belittled. Such negative public encounters do not just produce a transitional moment of conflict or concern for the person with dementia, they accumulate and eventually erode the person with dementia's confidence, increasing their anxiety and affecting perceptions of public safety.

This diminished confidence and increased anxiety means the person is less likely to participate in activities outside the home, and more likely to withdraw and rely on their spouse or carer. Social isolation is therefore a factor for both parties.

The consultation also indicated that negative attitudes make it more difficult for someone to disclose their dementia diagnosis. Disclosure was viewed as challenging and as increasing personal risk.

There was a strong desire in the Central Coast community to make the public realm a safer and more responsive place for people with dementia. A large majority of survey respondents (92%) rated as 'Very important' the statement: 'Banks, medical services, transport providers and other services understand and meet the needs of people with dementia.'

People with dementia named tolerance as their key to a dementia-friendly community. This meant creating a community where a range of cognitive and behavioural capacities are accepted. In terms of improving community interactions, one of the most highly desired attributes mentioned by people with dementia was patience, whereby businesses and service providers are willing to slow down and take extra time during interactions and transactions.

'It's important to feel comfortable where you are and who you deal with'—Central **Coast Community** Member

'Their anxiety would be reduced... this is what is holding them back'— Central Coast Community Member

Access to services

The Central Coast is perceived to be well-served with specialist dementia facilities such as aged care, day support, good quality GPs and Alzheimer's Australia. However, the community consultation indicated scope to improve access to these and other specialist services.

A major theme for improving access relates to information provision, particularly in helping spouses and other caregivers to know about, and gain access to, the range of support options available to them. Navigating the health system can be difficult. This includes complex intake forms and processes, and the trend towards online services such as the MyAgedCare portal. Carers said just 'knowing where to go to for help' was a challenge.

Another key element for improving access to services in the Central Coast is transport, as geographic proximity to services is uneven across the area. A lack of affordable, timely, appropriate transport options was described as impacting people's ability to access services as well as to participate more generally in community activities such as shopping and socialising. Improving access to diagnostic services and reducing waitlists also emerged as a priority for change.

It was noted that a person's non-acceptance of their dementia diagnosis can make it more difficult to connect that person with specialist services and supports.

SOCIAL INTEGRATION

Enhancing social integration for people with dementia was given strong priority. It was seen as providing two key benefits.

The first perceived benefit is a reduction in social isolation. To achieve this, it was seen as important to facilitate activities that unite a broad crosssection of the Central Coast community, rather than focusing solely on dementia- or aged-specific activities. There was particularly strong support for intergenerational activities that bring children/young people and older people together in mutual enjoyment and exchange.

The second potential benefit is that of 'normalising' dementia, as more people gain first-hand experience with dementia and build their skills in responding positively. Again, the inclusion of children in mixed activities (including school activities) was viewed as critical, because of the perception that prejudice might be more positively and easily addressed with children.

'Let people know what support is available'— Central Coast Community Member

SPACES AND PLACES

Although focus group participants placed somewhat less emphasis on addressing urban design and public amenity, ensuring that 'Streetscapes, parks and other public spaces are designed to help people with dementia to keep safe and find their way around,' was considered 'Very important' by a majority of survey respondents (84%).

Parks and open spaces were seen as valuable resources. Consultation identified opportunities to create safe (enclosed or semi-enclosed) public places where people with dementia could expect a positive experience, perhaps by borrowing techniques from sensory gardens or incorporating memorabilia.

Noise tolerance is lower in people with dementia. Community consultation indicated that one of the most significant opportunities to improve the amenity of shops and other public settings would be to minimise background noise through design and use of materials.

Wayfinding remains a challenge for people with dementia. There was a desire for local signage to be more dementia-friendly in both outdoor and indoor spaces, and for signage to potentially include a combination of writing and visual cues.

There was also a perception that the Central Coast lacks sufficient safe and identifiable pedestrian crossing points. Discontinuous footpaths can interrupt pedestrian journeys and cause disorientation for people with dementia. Improving walkability was viewed as contributing both to independence and to public safety (actual and perceived).

CARERS

Support for carers was considered by many in the consultation process to be an essential dimension of a dementia-friendly community.

Spouses report that their partners with dementia have a very high level of dependence on them. They face the challenge of respecting and supporting their partner's autonomy while simultaneously needing to take on a greater share of domestic roles (such as shopping and cooking) and being the primary actor in interactions with banks, doctors, shops and other services.

'Help for the carers... so they can have respite for a while and rest or catch up on things'— Central Coast Community Member

A number of key supports emerged as being especially valuable to carers:

- Effective information provision about:
 - what to expect when caring for someone with dementia (particularly when a diagnosis has just been made), and
 - the full range of service and support options available;
- Practical help in navigating the health and service systems;
- Transport options (especially on short notice);
- Access to home help packages; and
- Occasional respite when needing a break or time alone.

A minority (37%) of survey respondents agreed that 'Caring for someone with dementia can be very rewarding', indicating scope to improve both the perception and experiences of caregiving.

PROCESS

As part of making the Central Coast more dementia-friendly, community consultation identified an opportunity for Council and other leaders to advocate for the needs of people with dementia and their carers, including ensuring the area has sufficient dementia-specific services available. It was felt this leadership role should include being critical of what's not working well, for example in the case of State or federal government services.

Consultation revealed broad support for a cross-community approach to becoming dementia-friendly. When thinking about a working group or committee to drive change, there was support for this group to be as diverse as possible, and to include representatives from government, business, service and recreation groups, and residents.

It was considered particularly important to include people with dementia and their carers in such a working group, and to ensure that the structure and activities of any group to drive the initiative be dementia-friendly. Suggested strategies included: keeping meetings to around 10-12 people in size, holding meetings in a quiet environment, providing introductory material in written form, holding meetings of no more than one or two hours in duration, and holding meetings in the late morning or early afternoon.

'Ask the voices of authority... those people who are living with dementia. They know what is wanted and what is needed'— Central Coast Community

4. Creating a Dementia-Friendly Central Coast

Principles

The Central Coast Council affirms Alzheimer's Australia's definition of a dementia-friendly community, as a place where people living with dementia are supported to live a high quality of life with meaning, purpose and value.

The Council has expanded on this definition by listening carefully to our community (including our community members whose lives are affective by dementia), by aligning our approach with our values and vision, and by understanding emerging good practice in creating dementia-friendly communities around the world.

Our vision for a Dementia-Friendly Central Coast is defined by the following five principles:

1	People living with dementia are valued and respected members of the Central Coast community.	Central Coast is a vibrant, thriving community that prides itself on a sense of belonging. We are welcoming and inclusive of people of all ages and abilities.
2	Creating a Dementia-Friendly Central Coast is everybody's business.	We take a whole-of-community approach to becoming dementia friendly, in which people of all walks of life are passionate participants. Our success depends on strong partnerships and collective action.
3	Places, businesses and services are welcoming and enabling for people living with dementia.	True community participation means a person with dementia can safely access any public space, shop, facility or service, and feel confident they will be treated with courtesy, patience and kindness.
4	Community decisions respond to the needs and aspirations of people with dementia and their carers.	People with dementia and their carers are the experts in their own experiences. Successfully creating a Dementia-Friendly Central Coast means planning with—not simply for—people whose lives are affected by dementia.
5	Becoming a Dementia-Friendly Central Coast is a continuous process.	Building awareness and changing attitudes takes time. Becoming a dementia-friendly community means being willing to innovate, to draw creatively on existing resources, and to continually evaluate and communicate our progress.

Key dimensions of change

Our actions for creating a Dementia-Friendly Central Coast will focus on six key dimensions of change. These dimensions reflect the priorities highlighted in consultation with the Central Coast community, including residents with dementia, carers and local dementia service providers.

In no particular order, the key dimensions for change in Central Coast are as follows:

1. INCREASE DEMENTIA KNOWLEDGE

This means not just building awareness and understanding of dementia, but also helping people to know how to communicate positively with a person with dementia.

2. IMPROVE ATTITUDES AND INTERACTIONS

Improving community attitudes, combating stigma and facilitating more positive social interactions will help people with dementia to be and feel less 'at risk' when in the public realm.

3. ENHANCE ACCESS TO SERVICES

The ability to access the right services and supports can be enhanced by several factors, including timely information provision and dementia-aware service delivery.

4. FACILITATE SOCIAL INTEGRATION

A focus on cross-community integration will contribute to normalising dementia and reducing social isolation.

5. IMPROVE SPACES AND PLACES

The amenity, safety and accessibility of our built and natural environments play a key role in supporting the independence and wellbeing of people with dementia.

6. SUPPORT CARERS

Support for carers—whether practical, emotional or social—is an essential element of a Dementia-Friendly Central Coast.

Theory of change

A theory of change is a planning and evaluation tool designed to illustrate the relationship between inputs, activities, outputs and outcomes of an initiative or program. The theory of change below provides a 'snapshot' of how the Dementia-Friendly Central Coast initiative is intended to achieve its goals. It is anticipated that this theory of change will be reviewed and adjusted at key points in the project.

Situation

The social impacts of dementia are projected to grow as the population ages. Only a minority of Central Coast residents are currently confident their community would know how to support them if they received a diagnosis of dementia. The Central Coast Council is committed to enhancing positive ageing and community wellbeing to help the community to live its potential.

Kev dimensions of change

Knowledge

Attitudes and

Places and

Carers

Mid-term outcomes Long-term outcomes **Activities** Outputs Short-term outcomes Inputs Council leadership Develop a • Dementia-Friendly · Dementia awareness People with • Dementia's negative Framework to Central Coast and knowledge is dementia, carers and social impacts are collate community Framework Multi-sector and raised other community reduced priorities, establish members share cross-community principles, and participation • Dementia-Friendly more positive social • More people gain People with determine a suite of Central Coast Action confidence in interactions in dementia and their potential actions Expert knowledge Plan interacting positively community settings carers experience a from people with with a person with higher quality of life Assess and build dementia dementia, carers and • Dementia-Friendly • More shops, civic community interest service providers Central Coast buildings, parks, • Pressure on health **Working Group** community facilities and social services is Access to services Existing research on Recruit individuals and other places reduced and information is dementia and its and organisations to No. of actions become easier for improved a Working Group delivered in the people with impacts · Overall community Central Coast dementia to access cohesion and Feedback and ideas Select actions for Community. and enjoy • Greater inclusivity is from community implementation over opportunities for enhanced consultation the short, mid and · Evaluation of social integration are People with long term process and provided Multi-sector capacity dementia and their outcomes for achieving social Dementia-friendly carers can more Assess capacity and community guides Dementia-friendly change is enhanced easily access the implement actions · No. of project changes are made to and literature support, networks updates provided to interior and exterior • The Central Coast is and information they Existing and Evaluate actions stakeholders and spaces recognised as a need emerging good community leader in modelling a practices in creating Communicate • Carer supports are dementia-friendly dementia-friendly project impacts enhanced community communities

5. A 'menu' of actions

In becoming a dementia-friendly community, the Central Coast Council has sought to learn from promising practices around the world while also leaving room for innovation.

This section presents examples of promising practices in creating dementia-friendly communities in Australia and internationally. The selected actions reflect local priorities for the Central Coast as identified during the community consultation process. The case-study examples provided give a sense of how the action has been implemented in other locations. Each action includes a set of links to further resources.

This list of actions should not be regarded as prescriptive, but rather as a 'menu' from which Council and the Central Coast community can choose to suit its resources and capacities. It is anticipated that a selection of these actions—as well as actions and ideas that emerge at the community level will form the basis of a Dementia-Friendly Central Coast Action Plan.

Each action features a set of icons listing each of the six community-identified dimensions for change. These icons provide a ready resource for identifying actions that address specific local priorities of the Central Coast community:



Dementia Friends

Initially developed in Japan, Dementia Friends has since gained traction across the UK and North America. Dementia Friends consists of an awareness-raising and information session provided to individuals who may have contact with people with dementia in the community, such as shop staff, community volunteers, service providers and other customer service staff. The session may be delivered face-to-face or online through a series of short videos. The session provides basic information about dementia and suggests positive responses that can be used when interacting with a person with dementia. Once a person has become a Dementia Friend, they can undertake induction and become a Dementia Champion, which allows them to deliver the sessions to others. The Dementia Friends initiative has been adopted by a range of geographic communities as well as by organisations such as schools, pharmacies, retail stores and banks. Dementia Friends and Champions can be invited to 'register' as a way of tracking participation.

Knowledge

Attitudes & interactions

FEATURES

- Low resource requirements
- Provides practical resources for improving interactions
- Improvements to the lives of people with dementia can be immediate
- Changes are cumulative as more Friends are created

EXAMPLE: DEMENTIA FRIENDS IN KIAMA

As part of its broader Dementia Friendly Action Plan, the NSW local government of Kiama offers sixhour training sessions to equip people with the information, skills and resources they need to become Dementia Friends. The training is delivered by Alzheimer's Australia on behalf of Council at no cost to participants, and is split over two consecutive days. Attendance at both sessions is required in order to become a Dementia Friend. Content includes: education on dementia; opportunities to hear from people living with dementia about their experiences; engagement and communication skills; and insights on how to ensure community groups can be dementia-friendly. Kiama is particularly focused on creating Dementia Friends amongst members and leaders of community groups, clubs and sporting associations in order to ensure these groups are maintained as welcoming and supportive resources for community members with dementia.

RESOURCES

Kiama Municipal Council—Dementia Friends Brochure **Dementia Friends UK** Dementia Friends Canada **Dementia Friends USA**

Dementia-friendly finance

People with dementia can find it particularly difficult to manage personal finances. From using a bank and paying bills, to managing investments and making large purchases—there are many elements of financial management that may be impacted by changes to cognition, decision-making ability and the ability to assess risk. People living with dementia are also vulnerable to financial abuse, which may include fraud, theft, exploitation and or pressure from another person in relation to financial transactions. Positive changes to the practices of financial services businesses—as well as the financial services operations of any commercial or community organisation—can contribute to the ongoing safety and independence of a person with dementia.

Knowledge

Attitudes & interactions

Access to services

Social integration

Places & spaces

Carers

FEATURES

- Supports financial independence, therefore an individual's independence
- Reduces opportunities for financial abuse and failures in financial management

EXAMPLE: WESTPAC BANK

In 2015 Westpac became New Zealand's first dementia-friendly bank. In making this commitment, Westpac aims to help people with dementia with planning, accessing financial services, and maintaining financial independence. Training has been provided to employees to help them to recognise, understand and respond to the needs of customers living with dementia. Strategies for assisting customers include withdrawal limits, adding alternative contacts to account information, and arranging direct debits for ongoing financial commitments. The bank's special notification tool amends a customer's profile to alert bank staff about the needs of people with dementia and their carers. The commitment also includes making dementia-friendly adjustments to the design and layout of banking foyers and reception areas to create more enabling environments.

RESOURCES

Westpac—Dementia Friendly Banking

Alzheimer's Society UK—Living with Dementia: Managing your Money

Alzheimer's Society UK—Dementia-Friendly Financial Services Charter

Alzheimer's Society UK—Short Changed: Protecting People with Dementia from Financial Abuse
Alzheimer Society of British Columbia—Making your Workplace Dementia Friendly: Information for
Financial Professionals

Workplace peer support

As the workforce ages and the retirement age is increased, managing dementia in the workplace is likely to become an increasing challenge. For people with younger-onset dementia without a diagnosis, the workplace may be where the early signs of dementia first become apparent to others. Australian employers may have a duty to make workplace adjustments for staff with dementia under the Disability Discrimination Act. Potential challenges for employers include recognising the onset of dementia in a staff member, deciding on an appropriate course of action, addressing safety and liability issues, and supporting staff relationships. Employers can play a role in supporting an employee to obtain a diagnosis, building awareness among other employees, and creating opportunities for open dialogue about dementia within the workplace.

Knowledge

Attitudes & interactions

Social integration

FEATURES

- The person with dementia is supported to remain at work for longer
- Dementia is 'normalised' in a shared workplace setting
- Principles of workplace equity and access are upheld

EXAMPLE: SIDE-BY-SIDE

The Side-by-Side program was developed in 2011 in South Australia by aged care provider, Life Care, with support from Bunnings Warehouse. The program was a feasibility study to investigate the value of a workplace 'buddy' system. It provided people with younger-onset dementia who were no longer working with the chance to re-engage in the workforce. Seven people with younger-onset dementia worked at Bunnings one day per week with the support of a trained 'Work Buddy' —store employees who had undergone specialist training. Tasks included serving customers, restocking, caring for plants and assisting with a DIY programme. In addition to the supportive work environment, the program also provided training to staff and raised community awareness of dementia. Evaluation of the program found that participants benefited from improved self-esteem, increased mental alertness, and an increased interest in life in general.

RESOURCES

Alzheimer's Australia Feature Article—Side by Side Program

Alzheimer's Society UK—Creating a Dementia-Friendly Workplace: A Practical Guide for Employers

<u>Dementia Engagement and Empowerment Project (DEEP)—Tips for Employers</u>

Younger Dementia UK—Working: Advice for Employers

Alzheimer's Australia Video Tutorial—IS IT DEMENTIA?

Alzheimer's Australia—Creating Dementia-Friendly Communities: Business Toolkit

Memory Cafe

A Memory Cafe is a designated space where people with dementia, carers, or anyone with questions about dementia, can drop in without an appointment. Primarily intended as a contact point for obtaining resources and information, a Memory Cafe also plays a strong role in supporting enjoyable social interaction, facilitating peer support and reducing social isolation. Typically a Memory Cafe is managed by a health professional with specialist dementia expertise, supported by a team of volunteers or paid staff and governed by a steering group. A Memory Cafe is usually run on a regular basis, such as once per week, fortnight or month, and may include service of food such as coffee and sandwiches. There are a number of Memory Cafes currently running throughout Australia. Evaluation of Memory Cafes in Victoria in 2009 found that the Cafes were highly valued by clients and had clear social, education and service system benefits.

Knowledge

Attitudes & interactions

Access to services

Social integration

Places & spaces

Carers

FEATURES

- Tackles social isolation within a designated dementia-friendly
- Enables easy access to information and resources

Farrier et al—Neighbourhood Memory Cafe Toolkit

Informal setting facilitates participation

EXAMPLE: GARDEN CITY MEMORY CAFE

The City of Melville, WA, is home to the second-highest number of people with dementia compared to other local government areas in the State. As part of its commitment to creating a dementiafriendly community, the City (along with Alzheimer's Australia WA) has supported the establishment of a Memory Cafe at the Garden City Shopping Centre. The Cafe runs for 1.5 hours in the morning of the last Tuesday in every month, and is hosted by an existing cafe within the shopping complex. The partnership between Garden City Shopping Centre and the City of Melville has also involved initiatives such as maintaining a community information centre, providing dementia training to staff, and hiring older workers. Both Garden City and the host cafe are part of the Melville Age-Friendly & Accessible Businesses (MAFAB) network, comprised of local businesses committed to implementing accessible and age-friendly initiatives, including for people living with dementia.

RESOURCES

Industry Article—Garden City Shopping Centre launches Memory Cafe Media Article—Garden City Memory Cafe offers Safe Haven for Dementia Sufferers Video—Interview with Euro Lumb (Cafe Business owner, Garden City Memory Cafe) Alzheimer's Australia Vic—Memory Lane Cafe program NARI—Evaluation of Alzheimer's Australia Vic Memory Lane Cafes Video—Why Attend an Alzheimer's Society Dementia Cafe? David Light and Jim Delves—A Guide to Setting up a Memory Cafe Alzheimer's Australia—Community Cafe Toolkit

Men's Sheds

Men's Sheds play an important social support role in numerous communities across Australia, including the Central Coast. Men's Sheds have provided opportunities for communal woodworking in local workshop settings in Australia since 2006. Primarily aimed at improving men's mental health, Men's Sheds typically target men who are experiencing a mental illness, facing social isolation or struggling with a transition to retirement. Men's Sheds replicate a work environment and provide a low-pressure environment for companionship and dialogue. More recently, the role of Men's Sheds in the lives of men with dementia and male carers has been recognised. For these men, Men's Sheds can be an important resource for maintaining strong social connections, enjoying respite and improving overall quality of life. For other 'Shedders', doing woodwork in the company of carers and men with dementia provides an opportunity to learn more about dementia and to normalise dementia in a shared setting.

Attitudes & interactions

Social integration

Carers

FEATURES

- Fosters social engagement and a sense of purpose for men with dementia
- Provides a forum for building dementia knowledge and skills amongst other men
- Provides respite and relieves social isolation for male carers

EXAMPLE: 'EVERY BLOKE NEEDS A SHED'

The 'Every bloke needs a shed' project was piloted across eight Men's Sheds in the Hunter region of NSW in 2011-13. The project goal was to increase the social engagement of socially isolated older men, with a particular focus on men in the early stages of dementia as well as male carers of people with dementia. The program encouraged and supported these men to access and participate the range of activities available in their local Men's Shed. Project activities included education for Shedders about dementia, designing appropriate activities, and planning exit strategies for when participation was no longer suitable for the man with dementia. Evaluation of the project showed improved levels of happiness and engagement amongst carers, increased dementia understanding and a sense of purpose amongst Shed participants in general, and improved levels of self-esteem and inclusion for men with dementia. Key success factors were the flexibility of the activity and venue, the male-centric setting, and the work-like environment which had the effect of diminishing the emphasis on dementia.

RESOURCES

Video—Alzheimer's Australia and Men's Sheds: Making a Difference Alzheimer's Australia—Your Shed and Dementia: A Manual Australian Men's Shed Association **Tasmanian Men's Shed Association**

Online information portal

Access to high quality information about health and social supports is a key element of community wellbeing. In 2010 Alzheimer's UK found that despite the existence of information about dementia and care options, problems with access means that the information needs of carers and people with dementia were not being met. A key problem is that people have to ask for information—and most people do not know what to ask for. The research recommended supporting local areas to develop a framework for the provision of information about support and services for people with dementia and their carers. There are a number of emerging resources that provide guidance on how to produce and disseminate information in a format that is dementia-friendly. While internet access is not available or desirable by everyone, the role of the internet and mobile technologies in health care information dissemination is growing and likely to play an ongoing role in connecting people to dementia supports and services.

Knowledge

Access to services

Places &

Carers

FEATURES

- Online information is accessible to those with computing skills and internet connectivity
- Easily updatable
- Can provide information 'pathways' or prompts for people with new diagnoses
- Information can be tailored to a specific geographic community

EXAMPLE: DEMENTIA ILLAWARRA SHOALHAVEN

Dementia Illawarra Shoalhaven is an online portal providing access to information on dementiaspecific social and support services in the Illawarra Shoalhaven region of NSW. The site was initiated by the Illawarra Dementia Services Network and developed with support from the University of Wollongong. It is designed to help community members to better understand dementia and the steps and key contacts for obtaining assessment and diagnosis; to provide resources for people with dementia such as information about living well, care services, younger-onset dementia and multicultural information and services; and to provide information resources for carers, health professionals or anyone seeking information on dementia-friendly environments. The site also features a calendar and newsfeed of support activities, social events and training opportunities.

RESOURCES

Website—dementiaillawarra.com

Alzheimer's Society UK—The information needs of people with dementia and carers

DEEP Guide—Creating websites for people with dementia

<u>DEEP Guide—Writing dementia-friendly information</u>

Dementia-friendly shops

The importance of dementia-friendly shops has been emphasised by the Alzheimer's Society UK, who found that 23% of people with dementia surveyed had given up shopping. By understanding how dementia changes customers' needs, and by making changes to staff interactions and store environments, retailers can assist people with dementia to continue their normal shopping practices for as long as possible. The guide points out that becoming dementia-friendly can also be good for business, as it helps businesses to retain existing customers and attract new ones. Becoming dementia-friendly can help businesses to enhance overall customer service and brand reputation, to comply with equal access legislation, and to 'future proof' the business in the context of an ageing population.

Knowledge

Attitudes & interactions

Access to services

Social integration

Places & spaces

FEATURES

- Shops become safer and more welcoming places for people with dementia
- People with dementia are less likely to withdraw from shopping
- People with dementia are supported to remain visible and integrated in the community

EXAMPLE: THE RED HANDKERCHIEF IN BRUGES

As part of its strategy to become dementia-friendly, the Belgian city of Bruges has adopted the logo of a knotted red handkerchief as a symbol of dementia-friendliness. More than 90 shops in Bruges display the logo in their front windows to indicate not just that they are places where a person with dementia will be assisted with their shopping, but also that they offer other kinds of help to a person with dementia, such as wayfinding or contacting family members if an individual has become lost. The initiative was developed with the help of Foton, a centre for dementia expertise and support. Initially, adoption by Bruges retailers was slow, but the project has gained momentum through the efforts of Foton, local authorities and individual businesses. In a similar initiative, Alzheimer's Australia has trialled the use of a symbol to identify dementia-friendly businesses in Kiama and Port Macquarie.

RESOURCES

The Guardian—Is Bruges the most dementia-friendly city? Alzheimer's UK—Becoming a Dementia-Friendly Retailer: A Practical Guide Alzheimer's Australia—Creating Dementia-Friendly Communities: Business Toolkit

Slow shopping

Slow shopping is a concept founded by British woman, Katherine Vero, whose mother lived with dementia. Slow shopping is designed to provide a welcoming and safe environment for anyone who requires more time or support to do their shopping, including anyone who lives with dementia, anxiety or a mental illness, or who struggles with communication due to a disability. Slow Shopping involves stores setting aside dedicated times during the week when staff are focused on helping shoppers to enjoy more time and space. Help points and chairs are established throughout the shop, and extra assistance is on hand if required. No shopper need to identify themselves as having dementia or another disability unless they choose to do so.

Knowledge

Attitudes & interactions

Access to services

Social integration

Places & spaces

Carers

FEATURES

- Customers are not singled out—slow shopping applies to everyone
- People with dementia can shop when they know they will have a better experience
- Shops can have a positive impact with just a few hours each week

EXAMPLE: SLOW SHOPPING AT SAINSBURY'S

British supermarket chain Sainsbury's trialled 'Slow Shopping' in its Gosforth store on Tuesdays from 1-3pm. During this trial, a Sainsbury's worker greeted people at the store entrance, shopping assistance was made available, chairs were put out at the end of aisles to support people who needed rest, and two help desks provided product samples of favourite products. Sainsbury's has also invested more than 50,000 hours in training its workers how to help customers with visible and non-visible disabilities. A blog post by Katherine Vero notes that Sainsbury's found that, during the pilot, footfall in the store increased by well over 10%, staff enjoyed the experience, and both engagement and customer recognition of the store increased. The Slow Shopping website lists Sainsbury's in Gosforth as well as Marks and Spencer's in Kingston Park as currently providing regular slow shopping times.

RESOURCES

Sainsbury's Slow Shopping Concept

Accompanied walks

An accompanied walk is a research activity designed to support more dementia-friendly land-use planning and urban design. The activity involves walking with individuals with dementia around a neighbourhood to replicate daily journeys such as shopping trips or a visit to the doctor. The accompanied walk may be done either on a one-on-one basis or as part of a small walking group. Informal interviews with the person with dementia at multiple 'touch-points' or at the conclusion of the walk can yield valuable insights about the dementia-friendliness of a local environment. Site photographs with annotations about particular design concerns can add to the interview data. This data can then be utilised by local government planners, facilities managers as well as private property owners to make beneficial changes to the built environment.

Knowledge

Social integration

Places & spaces

FEATURES

- Engages people with dementia in neighbourhood design and planning
- Can yield valuable insights not otherwise known
- Data can be multi-sensory: sight, sound, touch, smell
- Facilitates a place-based planning approach

EXAMPLE: CITY OF BELFAST WALKABILITY ASSESSMENT

While not exclusively focused on people with dementia, this pilot project in Belfast engaged with older people to evaluate the age-friendliness of the local built environment and to identify barriers to and enablers of physical activity. Eight walks were conducted as part of the study. Participants were recruited through existing community networks and associations. Groups of walkers were briefed and given the opportunity to preview the questionnaire and become familiar with the assessment criteria. Each group took part in a ten-minute walk around their local area or park at their own pace. Following the walk, participants completed the questionnaire and took part in a group discussion about the positive aspects and challenges of the local built environment. The group discussion gave participants the opportunity to raise issues that had not been identified in the questionnaire. The project raised a number of common themes and highlighted that it was possible to create more supportive environments with relatively minor adjustments.

RESOURCES

City of Belfast—Walkability Assessment for Healthy Ageing Institute for Public Administration, University of Delaware—Walkability Assessment Tool AARP—Walk Audit Toolkit

Urban planning and design

Dementia-friendly built environments are environments that are safe, easy to access and navigate, familiar and distinctive. The Australian Dementia Enabling Environments Project shares information about dementia-friendly practices in architecture, interior design and landscape design. The project identifies ten principles for creating dementia enabling environments: unobtrusively reduce risks; provide a human scale; allow people to see and be seen; reduce unhelpful stimulation; optimise helpful stimulation; support movement and engagement; create a familiar space; provide opportunities to be alone or with others; provide links to the community; and respond to a vision for a way of life. Local governments can use these principles as well as other guides and checklists to ensure land-use planning, urban design and facilities maintenance contribute to dementia-friendly environments. Dementia-friendly planning and urban design policies can be applied to individual developments or to neighbourhoods or municipalities.

Knowledge

Attitudes & interactions

Access to services

Social integration

Places & spaces

Carers

FEATURES

- Promotes greater consistency across a local government area
- New developments and urban design interventions maximise amenity
- Environments become increasingly enabling over time

EXAMPLE: PLANNING FOR HEALTH IN SOUTH WORCESTERSHIRE

In 2016, three city and district councils and Worcestershire County Council, UK, together produced a Draft Planning for Health in South Worcestershire Supplementary Planning Document (SPD). The Draft SPD recognises that the promotion of healthy communities requires planning for better built and natural environments to encourage good health and prevent illness. It notes that the built environment can reduce the risk of social isolation and reduced physical activity in older adults. The SPD provides specific information about how the cognitive changes of dementia can be affected by urban design elements. It gives planning policy guidance on creating age-friendly environments for the elderly and for those living with dementia. Policy provisions include the encouragement of suitable housing developments; management agreements for maintaining and designing public realm and open spaces; supporting public safety; incorporating flexible design principles; and maximising safe and effective links and connectivity.

RESOURCES

Planning for Health in South Worcestershire—Draft SPD

Alzheimer's Australia NSW—Building Dementia and Age-Friendly Neighbourhoods

Alzheimer's Australia—Creating Dementia-Friendly Communities: A Toolkit for Local Government

(includes a checklist for dementia-friendly physical environments)

Dementia Enabling Environments Project

Oxford Institute for Sustainable Development—Neighbourhoods for Life: Designing Dementia-

Friendly Outdoor Environments

Royal Town Planning Institute—Dementia and Town Planning Practice Advice

WHO—Checklist of Essential Features of Age-Friendly Cities

Dementia awareness in schools

A third of children and young people in Australia currently know someone living with dementia, and it is likely that the majority of today's young people will experience the condition in their lifetime. Yet research by the Dementia Collaborative Research Centre of Australia has found that children and children's experiences are a neglected aspect of dementia research. Living with a relative with dementia can be challenging for a child or young person, and the complexities of dementia can make it harder for children to understand dementia's progression. At the same time, childhood can be a time to raise dementia awareness and to challenge the stigma around dementia.

Knowledge

Attitudes & interactions

Social integration

FEATURES

- Normalises and demystifies dementia
- Addresses the development of stigma and discriminatory behaviour
- Supports students who have a family member with dementia

EXAMPLE: LLANFAES CP SCHOOL

Llanfaes Primary School has become the first in Wales to become a dementia-friendly school. A local 'dementia champion' (a grandparent connected to the school) provided an awareness training to staff, governors and parents. The school then ran a session for pupils in Years Five and Six, as well as awareness sessions for the local community. Following strong positive responses from the children who created posters, brochures and models to help raise dementia awareness—the program was expanded to form a collaboration between the school and the local residential care home. Activities have since included the creation of a sensory garden by students and residents with the guidance of a sensory horticulturalist. Co-creation of the garden has provided opportunities for students and people with dementia to interact in an informal and positive way. The schools' activities form part of a broader dementia-friendly community initiative in Brecon, Wales.

RESOURCES

Video—Dementia-Friendly Llanfaes School Dementia Collaborative Research Centre (Australia)—Kids4Dementia Alzheimer's UK—Teaching Resources about Dementia

Volunteer respite

Volunteer respite is designed to provide opportunities for carers to take a break from their caregiving activities. It is not designed to replace government or other formal respite services, but rather to increase the overall availability and scope of respite options within a community. In part, volunteer respite schemes are a response to the recognition that funded respite services are insufficiently resourced to meet demand. Yet as an 'organic' part of community life they also offer special benefits to people with dementia and their carers, associated with the co-location of respite facilities in a person's own neighbourhood and with the social bonds that may already exist between a local respite volunteer and the person with dementia and their carer.

Knowledge

Attitudes & interactions

Access to services

Social integration

Places & spaces

Carers

FEATURES

- Informed volunteers can be drawn from a pool of trained 'Dementia Friends'
- Low or no cost to people with dementia and their carers
- Informal respite options provide opportunities for on-demand/occasional respite to accommodate the changing needs of carers

EXAMPLE: OPEN HOUSES IN JAPAN ('SUZU-NO-YA')

Japan is currently home to around 5.4 million 'Dementia Friends', and in 2014 some of these Friends initiated an open house scheme, 'Suzu-no-ya'. The scheme applies a 'professional free zone' as a way to help normalise dementia in a community setting. The volunteer-run scheme provides a onceweekly drop-in where local residents with dementia and their carers can access all-day care meals, day trips, informal advice and carer peer support. Volunteers also provide a 24-hour helpline and referral service for carers. The scheme is delivered either in volunteers' own houses or in vacant houses rented or repurposed for scheme. By utilising local housing stock, the scheme is able to provide respite in a familiar and relaxed environment. As people with dementia receive meals and care at the open house, their carers may also enjoy a meal at the house or spend their time elsewhere. The open house volunteers also work in tandem with a neighbourhood watch network that looks out for people with dementia who have become disoriented and confused outside of their home environment.

RESOURCES

<u>Housing Learning and Improvement Network—Case Study 105</u>

<u>Guardian article—Dementia care in Japan is being solved through volunteer schemes</u>

Intergenerational learning

Remaining mentally active is considered one of the key ways an individual can lower their risk of dementia. Research conducted with older adults in the US in 2014 has found that intellectual activity in later life can delay cognitive impairment by at least three years. Yet a major finding of the study was the educational and occupational development throughout a person's entire life had the most protective effects. Compared to their mainland counterparts, Tasmanians have lower literacy and educational attainment levels. While a dementia-friendly community may not have clinical prevention as its core mission, incorporating intergenerational learning activities into a broader program of social integration may have the potential to deliver protective benefits for older adults and the wider community.

Attitudes &

Social integration

Places &

Carers

FEATURES

- Dual benefits of a single intervention (social and educational)
- Low cost when leveraging existing educational platforms
- Delivers protective/preventative benefits
- Values the strengths and gifts of older adults

EXAMPLE: EXPERIENCE CORPS

The Experience Corps is a program of the AARP (American Association of Retired Persons) Foundation. The AARP Foundation helps people over 50 who are struggling to meet their need for nutritious food, safe and affordable housing, adequate income and personal connection. The Experience Corps is an intergenerational tutoring program involving more than 2,000 trained volunteers working in 21 cities. These volunteers work with over 30,000 students each year in highneed elementary schools to help the students improve critical literacy skills. Tutoring is delivered over 6-15 hours per week, and can take the form of one-on-one tutoring, small groups or literacy assistance. Results for students are positive—the program reports that students tutored by Experience Corps volunteers see up to 60% improvement in literacy skills. Yet at the same time, clinical research with a sample of Experience Corps volunteers at risk of cognitive impairment has shown that over a six-month period the volunteers experienced improvements to both behavioural and cognitive functioning.

RESOURCES

Video—AARP Experience Corps

Vemuri et al—Study into intellectual enrichment and cognitive decline Carlson et al—Neurocognitive plasticity and the Experience Corps program

Dementia-positive language

The way we speak about dementia has the power to create positive and negative beliefs, feelings and experiences. If language is used without care, it can profoundly affect the happiness and wellbeing of a person with dementia, their family and friends; and it can also impact community perceptions of dementia and contribute to stigma and discrimination. Conversely, more positive language can raise awareness, support a person's quality of life, and foster a more inclusive community.

Central Coast Council agrees with Alzheimer's Australia that the language used in relation to dementia should be accurate, respectful, inclusive, empowering and non-stigmatising.

Alzheimer's Australia has produced a set of dementia language guidelines. These guidelines (reproduced below) form a key element of the Dementia-Friendly Central Coast Framework.

CONTEXT	PREFERRED TERMS	DO NOT USE
Talking about	Dementia	Dementing illness
dementia	Alzheimer's disease and other forms of	Demented
	dementia	Affliction
	A form of dementia	Senile
	A type of dementia	Senility
	Symptoms of dementia	Going on a journey
Talking about	A person/people with dementia	Sufferer
people with	A person/people living with dementia	Victim
dementia	A person/people with a diagnosis of	Demented person
	dementia	Dementing illness
		Dements
		Afflicted
		Offenders, absconders or perpetrators
		Patient (when used outside the
		medical context)
		Subject
		Vacant dement
		He/she's fading away or disappearing
		Empty shell
		Not all there
		Losing him/her or someone who has
		lost their mind
		He/she's an attention seeker
		Inmates (referring to people with
		dementia in care facilities)
		An onion with the layers peeling away
		Slang expressions that are derogatory,
		for example, delightfully dotty, away
		with the fairies, got a kangaroo loose

CONTEXT	PREFERRED TERMS	DO NOT USE
		in the back paddock, a couple of cents short 'They' (talking about all people with dementia rather than the individual)
A carer, family member or friend of a person with dementia (talking about themselves)	Living alongside (someone/a person/my partner/my mother, etc) who has dementia Living with/caring for/supporting a person who has dementia Living with/caring for/supporting a person with a diagnosis of dementia Living with the impact of dementia	
A carer, family member or friend of a person with dementia (talking about someone else)	Family member(s) Person supporting someone living with dementia Wife/husband/partner Child/son/daughter Parent Carer or care-giver (not everyone will like to be referred to as a carer)	
Impact of caring	Impact of supporting (someone/a person/my partner/my mother, etc) with dementia Effect of supporting (someone/a person/my partner/my mother, etc) with dementia	Carer burden Burden of caring
People with dementia under 65 years of age	Younger-onset dementia	Pre-senile dementia Early-onset dementia
Impacts of dementia	Disabling Challenging Life changing Stressful	Hopeless Unbearable Impossible Tragic Devastating Painful
Symptoms of dementia	Describe the symptom itself, e.g. memory loss, change in mood or behaviour, word-finding problems Describe the impact it is having, e.g. difficulty communicating	
Behavioural and psychological symptoms	Changed behaviours Expressions of unmet need Behavioural and psychological	When talking about the symptoms Behaviours of concern Challenging behaviours

CONTEXT	PREFERRED TERMS	DO NOT USE
	symptoms of dementia (in a clinical context)	Difficult behaviours
		When talking about the person
		Difficult
		Faded away, empty shell or not all
		there
		Disappearing
		Aggressor
		Wanderer
		Obstructive
		Wetter
		Poor feeder
		Vocaliser
		Sexual disinhibitor
		Nocturnal
		Screamer
		Violent offender
In research or in a medical	Dementia as a condition	Illness
context	A person/people with dementia	Disease (unless speaking about a type
Comcon	A person/people with a diagnosis of	of dementia such as Alzheimer's
	dementia	disease)
	A participant (if in a research trial)	Subject
		Case
		PWD (as an abbreviation for a person with dementia)
		PWYOD (as an abbreviation for a
		person with younger onset dementia)

Source: Alzheimer's Australia, Dementia Language Guidelines

Community survey

The following is a transcript of the community survey administered via the SurveyGizmo online platform between 27 March and 8 April, 2017. The survey link was publicly available on the Council website and on the Council's Facebook page. In addition, direct email invitations to complete the survey were sent by the Council to community organisations as well to Council staff.

A total of 90 complete surveys were submitted.

Respondents' qualitative (open-ended text) feedback is presented here only in summary form. Analysis of the full text responses was conducted as part of determining the six dimensions of change identified in this Framework.

WELCOME PAGE

Tasmanian Councils play a key role in ensuring communities are vibrant, inclusive and supportive of all citizens.

As part of this role, the Central Coast Council wants to help people living with dementia to enjoy a high quality of life with meaning, purpose and value. To achieve this, we are taking our first steps to transform the Central Coast into a dementia-friendly community.

We are starting our journey by creating a Dementia-Friendly Community Framework. When complete in mid-2017, the Framework will form the basis for dialogue and action by the Council and community stakeholders.

As part of our effort to make sure the Framework reflects local perspectives and priorities, we are inviting all people with a stake in the Central Coast community to complete this survey. This survey will ask:

- A little about you
- About your dementia knowledge
- What you believe and think about dementia
- About your ideas for making the Central Coast a dementia-friendly community

We've also included some facts about dementia along the way. If you feel upset or concerned about any of the issues raised in this survey, we encourage you to call the National Dementia Helpline on 1800 100 500.

Your responses will be anonymous and not linked to you personally. Your participation is completely voluntary and you may stop the survey at any time. Data from the survey will help the Council to create a more dementia-friendly Central Coast.

ABOUT YOU

1. Thinking about the Central Coast local government area, are you currently (tick all that apply):

Living in the Central Coast?	85%
Employed in the Central Coast?	41%
Running a business or community organisation in the Central Coast?	19%
Visiting or touring the Central Coast?	1%
Connected to the Central Coast in another way? (please specify)	10%
Not connected to the Central Coast is any of these ways?	3%

[Total exceeds 100% as respondents were able to select more than one option]

2. Please tick all the statements that apply to your situation:

I have dementia.	0%
I have a partner or family member in the Central Coast with dementia.	15%
I have a close friend in the Central Coast with dementia.	2%
I have a co-worker in the Central Coast with dementia.	1%
I have an employee in the Central Coast with dementia.	1%
I have an acquaintance in the Central Coast with dementia.	17%
None of the above.	67%

[Total exceeds 100% as respondents were able to select more than one option]

3. Do you regularly look after someone with dementia? (please tick all that apply):

No.	80%
Yes, I'm a carer for a family member, friend or neighbour with dementia in their home.	4%
Yes, I'm a nurse or professional care worker for a client or patient with dementia.	10%
Yes, I look after a person with dementia in another way. (please specify)	6%

DID YOU KNOW?

In Australia around 244 people each day join the population of people with dementia. (Source: Alzheimer's Australia)

UNDERSTANDING DEMENTIA

4. How much do you feel you know about dementia?

Nothing at all.	0%
Not much.	18%
Some.	49%
Quite a lot.	23%
A great deal.	10%

5. What is your MAIN source of information about dementia?

Personal experience.	30%
'Word of mouth' or common knowledge.	24%
Learning on the job.	6%
TV or print media.	11%
Professional or formal education	14%
Other. (please specify)	8%

6. Do you think of dementia as a normal part of ageing?

Yes.	21%
No.	62%
I'm not sure.	17%

7. Who can develop dementia? (please tick all that apply)

People in their 60s and older.	4%
People in their 50s.	2%
People in their 40s.	93%
All of the above.	3%
I'm not sure.	4%

[Total exceeds 100% as respondents were able to select more than one option. The correct answer is 'All of the above'.]

8. Which do you understand to be the main risk factors for developing dementia? (please tick all that apply)

Heavy drinking	9%
One or both parents have dementia.	23%
Smoking.	4%
Poor diet.	7%
High blood pressure.	6%
All of the above.	34%
None of the above.	11%
I'm not sure.	27%

[Total exceeds 100% as respondents were able to select more than one option. The correct answer is 'All of the above'.]

9. What do you understand to be the early signs of dementia? (please tick all that apply)

Progressive and frequent memory loss	16%
Confusion.	15%
Personality change.	8%
Apathy and withdrawal.	6%
Loss of ability to perform everyday tasks.	10%
All of the above.	77%
None of the above.	2%
I'm not sure.	16%

10. If you or someone close to you was showing the early signs of dementia, where would you go FIRST for help and advice?

Partner or family member.	9%
Friend.	2%
Doctor or nurse.	72%
Internet.	3%
Church or charity.	0%
Dementia organisation.	12%
Telephone helpline.	1%
Council	0%
I'm not sure.	1%
Other. (please specify)	1%

DID YOU KNOW?

Taking these five steps may help to lower your risk of dementia: looking after your heart; being physically active; mentally challenging your brain; following a healthy diet; enjoying social activity. (Source: Alzheimer's Australia)

THINKING ABOUT DEMENTIA

11. Please provide your response to the following statements:

	Agree	Neither agree nor disagree	Disagree	I'm not sure
Someone with dementia can still live life to the full.	48%	23%	21%	9%
I would find it hard to talk to someone with dementia.	10%	26%	57%	7%
Caring for someone with dementia can be very rewarding.	37%	33%	15%	16%
Having dementia means a person cannot make their own decisions.	29%	31%	32%	9%
There is little benefit to including people with dementia in community activities.	5%	11%	79%	5%
A person with dementia retains their feelings and emotions, even if they can't always understand what is being said.	79%	8%	1%	12%
If I was diagnosed with dementia, I would want my family and friends to know.	82%	8%	3%	7%
If I was diagnosed with dementia, I would want my employer to know.	62%	16%	9%	13%
If I was diagnosed with dementia, I would be confident my community would know how to support me.	17%	35%	24%	25%

DID YOU KNOW?

In Australia the majority of people with dementia live in the community. (Source: Alzheimer's Australia)

A DEMENTIA-FRIENDLY COMMUNITY

12. Overall, would you say that people living in the Central Coast:

Are very well supported to live a high quality of life.	5%
Face some barriers to enjoying a high quality of life.	40%
Are not generally helped to enjoy a high quality of life.	13%
I'm not sure.	42%

13. What would you say are the most positive or supportive aspects of the Central Coast area for someone living with dementia?

[A majority of comments related either to services and facilities (quality, scope, location, variety, responsiveness) or the Central Coast community (inclusivity, social capital, community spirit). A significant minority of comments related to location/lifestyle and township design. A significant minority also reported they were unsure/had insufficient knowledge to comment].

14. What would you say are the most challenging or negative aspects of the Central Coast area for someone living with dementia?

[A majority of responses related to the difficulties of accessing services (transport/location, waiting lists, lack of specialist expertise, access to information). A large minority also cited poor community attitudes and lack of awareness. Other comments related to the challenges of caring, social isolation, the challenges of everyday living with dementia and signage/built environment. A small minority said they were not sure/unable to comment.]

15. What changes to the Central Coast area do you think could increase support and understanding for people with dementia?

[A majority of responses suggested education and awareness-raising (through a diverse range of channels). A large minority suggested greater social inclusion (community activities, cross-community involvement, dementia-friendly activities and facilities). A large minority also referred to services and infrastructure (transport, community hubs, public amenity, more health and specialist services). A significant minority named information provision (about dementia as well as support options) and better carer support. A minority named supporting people to remain independent at home, and building partnerships and community capacity. A significant minority said they were not sure/unable to suggest a change].

DID YOU KNOW?

There are many different types of dementia (including Alzheimer's disease). Regardless of which type of dementia is diagnosed, each person will experience their dementia in their own unique way. (Source: DementiaUK)

A DEMENTIA-FRIENDLY COMMUNITY

16. How important are each of the following to you?

	Very important	Somewhat important	Not important	No opinion
The opinions and ideas of people with dementia are reflected in community decision-making.	54%	40%	2%	3%
Everyone in the community is helped to understand dementia.	74%	23%	2%	1%
Employers support people with dementia to stay in the workforce as long as possible.	66%	28%	3%	2%
Shops ensure staff know how to communicate with people with dementia.	80%	16%	2%	1%
Banks, medical services, transport providers and other services understand and meet the needs of people with dementia.	92%	5%	1%	1%
Streetscapes, parks and other public spaces are designed to help people with dementia to keep safe and find their way around.	84%	13%	2%	1%
People with dementia are supported to participate in social and community activities.	84%	14%	1%	1%
Creating a dementia-friendly community is considered "everybody's business".	74%	21%	3%	2%

ABOUT YOU

17. What is your age in years? (please select)

19 or under	0%
20 to 29	2%
30 to 39	10%
40 to 49	19%
50 to 59	28%
60 to 69	26%
70 to 79	15%
80 to 89	0%
90 or older	0%

18. What is your gender?

Female.	67%
Male.	33%
Prefer not to say.	0%
Other identification. (please specify)	0%

19. Where were you born?

Australia.	90%
Other identification. (please specify)	10%

[Most common other country of origin was England/UK, Netherlands]

20. Are you of Aboriginal or Torres Strait Islander origin?

No.	99%
Yes.	1%

21. Do you speak a language other than English at home?

No.	96%
Yes. (please specify)	4%

[Other languages specified were Dutch, Dutch Friesian, German]

22. What is your current employment status?

Unemployed/not working.	6%
Retired.	27%
Casual work.	3%
Part-time work.	25%
Full-time work.	38%

23. What is your marital status?

Single.	8.7%
Married/Defacto.	78.3%
Divorced/Separated.	8.7%
Widowed.	4.3%

24. What are your current living arrangements?

I live alone.	12%
I live with a partner/spouse.	76%
I live with my children, without a partner.	5%
I live with a housemate.	0%
I live with my parents.	1%
Other. (please specify)	5%

25. What is the highest level of education you have completed?

Primary school.	0%
Secondary school.	22%
TAFE/VET (Certificate/Diploma/Trade)	30%
University (Undergraduate/Postgraduate)	42%
Other. (please specify)	5%

26. What is your annual household income, before tax, from all sources?

\$25,000 or less.	5%
\$25,001 to \$40,000.	10%
\$41,000 to \$55,000.	9%
\$55,001 to \$70,000.	12%
\$70,001 or more.	42%
Prefer not to say.	22%

ADDITIONAL FEEDBACK

27. Before you finish this survey, is there anything more you would like to add?

[This was a text box providing the opportunity for free comment. A large majority of respondents praised the Dementia-Friendly Central Coast initiative and expressed a call to action; a small minority of comments was issue-specific; one comment was critical of the initiative.]

THANK YOU PAGE

Thank you for your time. Your input will help us to make the Central Coast more dementia-friendly.

If you have any questions about this project, please contact: Heidi Willard, Strategy & Policy Officer, Central Coast Council PO Box 220 | 19 King Edward Street, Ulverstone TAS 7315 P: (03) 6429 8917 | F: (03) 6425 1224

[This page also provided a link and contact information to the National Dementia Helpline]

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