Attachment 1
to
item 207

Draft Dementia Friendly Hawkesbury
Plan 2019-2021

date of meeting: 12 November 2019

location: council chambers

time: 6:30 p.m.



# **DEMENTIA**Friendly

Hawkesbury Plan 22 2019 - 2021



This document contains important information. If you do not understand it, contact the Telephone Interpreter Service on 131 450.



#### **Hawkesbury City Council**

Address:

Mailing Address:

366 George Street
Windsor NSW 2756
PO Box 146
WINDSOR NSW 2756
(02) 4560 4444
(02) 4587 7740
council@hawkesbury.nsw.gov.au
www.hawkesbury.nsw.gov.au
Monday to Friday 8:30am-5pm

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#### **Acknowledgements**

The Dementia Friendly Hawkesbury Plan has been developed with reference to feedback provided by:

- participants of the focus groups for people with dementia;
- participants of the focus groups for carers;
- all of the respondents to the community survey;
- local businesses, services and organisations
- Hawkesbury Dementia Working Group;
- Dementia Australia;
- Hawkesbury Access and Inclusion Advisory Committee

Council thanks the Dementia Working Group for their initiative and work developing this plan.

For questions relating to the Dementia Friendly Hawkesbury Plan, please contact:

Community Programs Coordinator Hawkesbury City Council P: 02 4560 4444 PO Box 146, Windsor NSW 2756

#### **Executive Summary**

Over the next 30 years, the prevalence of dementia in the Hawkesbury is due to increase 241% (*Alzheimer's Australia NSW and Deloitte Access Economics, August 2014*), exceeding the forecasted general population growth within the Hawkesbury of 49% (*NSW Department of Planning and Environment*) over the same period. Council recognises the need for a targeted response to develop a more inclusive and accessible community for people living with dementia who live, work or visit the Hawkesbury.

The Dementia Friendly Hawkesbury Plan aims to encourage and support organisations, businesses, community groups and individuals to make practical changes that will have a positive impact on the lives of people living with dementia and their carers. "A dementia-friendly community is a place where people living with dementia are supported to live a high quality of life with meaning, purpose and value" (*Dementia Australia*).

The nine priority areas in the Draft Plan are:

- 1. Empower people living with dementia and their carers to have a voice
- 2. Improve availability and access to information
- 3. Increase community awareness and understanding about dementia
- 4. Increase opportunities to engage and participate in the community
- 5. Increase support to maintain economic participation
- 6. Improve access to affordable and convenient transportation options
- 7. Improve access to appropriate health and care services for people to continue to live at home for as long as possible
- 8. Improve access, safety and inclusivity of public environments
- 9. Identify and promote dementia-friendly businesses and services

#### **Dementia-Friendly Communities**

#### What is a Dementia-Friendly community?

The majority of people with dementia live in the community. Often people feel socially isolated and wish they had more opportunities to interact with people in the community and to participate in social or other activities.

With the support of their employer, community, local businesses and organisations, neighbours, and friends and family members, people with dementia can continue to do many of the things they did before they received a diagnosis.

#### How does a Dementia-Friendly community benefit people with dementia?

Dementia-friendly communities encourage organisations, businesses, community groups and individuals to make practical changes that will have a positive impact on the lives of people living with dementia and their carers.

#### What does a Dementia-Friendly community look like?

- people are aware of and understand dementia
- people with dementia continue to be active participants in their own lives
- health staff are educated about dementia and treat people living with dementia with respect and empathy
- businesses provide accessible services to people with dementia, including having staff who understand dementia and know how to communicate effectively
- employers provide support for people living with the disabilities of dementia to continue with paid employment
- the physical environment enables people with dementia to get out and about safely
- social groups and organisations are welcoming and inclusive of members with dementia.

#### **Definitions**

#### **Dementia**

Dementia is the term used to describe the symptoms of a large group of illnesses which cause a progressive decline in a person's functioning. It is a broad term used to describe a loss of memory, intellect, rationality, social skills and physical functioning. There are many types of dementia including Alzheimer's disease, vascular dementia, frontal temporal dementia and Lewy body disease. Dementia can happen to anybody, but it is more common after the age of 65 (Dementia Australia).

#### **Younger Onset Dementia**

The term younger onset dementia is used to describe any form of dementia diagnosed in people under the age of 65 (Dementia Australia).

#### Carer

The definition for carer is someone who gives care and support to a relative or friend who:

- has disability
- has a mental health problem
- has a medical problem (including an ongoing problem or an illness that will end in death)
- is frail because they are old (known as 'frail aged')

Carer Recognition Act 2010 (Cth)

#### **Policy Statement**

Hawkesbury City Council is committed to the principles of a dementia-friendly community and implementing initiatives that engage the community, particularly people living with dementia and their carers. Council recognises that a dementia-friendly community contributes toward creating an accessible and inclusive community for all people with disabilities.

Council's Access and Inclusion Policy commits Council to work with the community to eliminate barriers which may prevent residents and visitors from participating fully in community and civic life. The Policy recognises that Council is in a position to influence and support community initiatives to improve access and inclusion within the Hawkesbury.

The Dementia Friendly Hawkesbury Plan commits Council to operate in accordance with Dementia Australia's principles for dementia-friendly communities being:

- people are aware of and understand dementia
- people with dementia continue to be active participants in their own lives
- health staff are educated about dementia and treat people living with dementia with respect and empathy
- businesses provide accessible services to people with dementia, including having staff who understand dementia and know how to communicate effectively
- employers provide support for people living with the disabilities of dementia to continue with paid employment
- the physical environment enables people with dementia to get out and about safely
- social groups and organisations are welcoming and inclusive of members with dementia

#### **Key Facts, Statistics and Demographics**

#### **Dementia Statistics in Australia**

- Dementia is the second leading cause of death of Australians contributing to 5.8% of all deaths in males and 11.3% of all deaths in females each year
- In 2016 dementia became the leading cause of death among Australian females. In 2017, dementia remained the first leading cause of death in females, and the third leading cause of death in males. Overall, accounting for 13,729 deaths
- In 2019, there is an estimated 447,115 Australians living with dementia
- Without a medical breakthrough, the number of people with dementia is expected to increase to an estimated 589,807 by 2028 and 1,076,129 by 2058
- Currently, an estimated 250 people are joining the population with dementia each day. The
  number of new cases of dementia is expected to increase to an estimated 318 people per day
  by 2025 and more than 650 people per day by 2056
- Three in 10 people over the age of 85 and almost one in 10 people over 65 have dementia
- In 2019, there are an estimated 27,247 people with younger onset dementia, expected to rise to 29,353 people by 2028 and 41,249 people by 2058
- An average of 36 people died per day where dementia was the underlying cause of death in 2016. Of the 13,126 people that lost their lives, 8,447 were female
- In 2019, it is estimated that almost 1.5 million people in Australia are involved in the care of someone living with dementia

Dementia Australia: Dementia Key Facts and statistics Factsheet April 2019

#### **Dementia in the Hawkesbury**

The prevalence of dementia in the Hawkesbury is estimated to grow 241% from 2016 to 2050 compared to 137% for the whole of NSW.

Hawkesbury LGA Dementia	2016	2017	2018	2019	2020	2050
prevalence projections	858	897	939	983	1029	2920

(Dementia Prevalence in NSW by State Electoral District. SED by Alpha Source: Alzheimer's Australia NSW and Deloitte Access Economics, August 2014)

It is estimated that the population of the Hawkesbury will increase by 49% from 2011 to 2051.

Hawkesbury LGA	2016	2021	2026	2031	2036	2041	2046	2051
Population projections	67,700	70,900	74,750	79,450	85,050	87,927	91,987	96,047

(NSW Department of Planning and Environment: 2016 New South Wales State and Local Government Area Population and Household Projections, and Implied Dwelling Requirements)

# **Demographic Profile**



# **PEOPLE**

**POPULATION** 64,193 (Average yearly growth 0.9%)

**AREA** 2,776km<sup>2</sup>

**POPULATION DENSITY** 24 persons per km²

## If the Hawkesbury was a village of 100 people

With Dementia

50 Are Male 50 Are Female 49 Males & 51 Females In the Greater Sydney Area

2 With Dementia in **NSW** 

of People need 5 assistance due to their disability In the Greater Sydney Area

28 Are 14 or younger 14 Are aged 25-34 12 Are aged 65 & over 19 are 14 or younger &

Provide 12 unpaid care In the Greater 11 Sydney Area

14 are 65+ In the Greater Sydney Area **16** are aged 25-34

Aboriginal & 4 **Torres Strait** Island People

12 Were born Overseas

In the Greater Sydney Area

In the Greater Sydney Area

In the Greater Sydney Area

Are Unemployed 4

In the Greater 6 Sydney Area

Have 27 Vocational (Trade) Qualifications

In the Greater Sydney Area

23 **Have Degrees** or Diplomas In the Greater Sydney Area

\* Ref Census 2016

#### **Policy and Legislative Context**

The Dementia Friendly Hawkesbury Plan is underpinned by the following international, national and state based legislation:

#### United Nations Convention on the Rights of Persons with Disabilities

The Convention on the Rights of Persons with Disabilities offers sufficient standards of protection for the civil, cultural, economic, political and social rights of persons with disabilities on the basis of inclusion, equality and non-discrimination. It makes clear that persons with disabilities are entitled to live independently in their communities, to make their own choices and to play an active role in society.

# Disability Discrimination Act 1992 (Cth)

The Disability Discrimination Act 1992 makes it illegal for any person, business or authority to discriminate on the basis of a person's disability. The legislation ensures that people with a disability have the same opportunities to access employment, education, transport, accommodation and buildings as other members of the community who do not have a disability

#### The Disability Inclusion Act 2014 (NSW)

The Disability Inclusion Act 2014 (NSW) provides the legislative framework to guide state and local government disability inclusion and access planning. The Act supports people with disabilities to access:

- the same human rights as other members of the community and that governments and communities have a responsibility to facilitate the exercise of those rights;
- independence and social and economic inclusion within the community; and
- choice and control in the pursuit of their goals and the planning and delivery of their supports and services

#### Anti-Discrimination Act 1977 (NSW)

The Anti-Discrimination Act 1977 prohibits racial, sexual and other types of discrimination and promotes equality of opportunity for all people. The Act covers discrimination in employment, education and other areas on the grounds of sex (including, breastfeeding and pregnancy), race (including colour, ethnicity and national identity), marital and domestic status, disability, homosexuality, age, transgender status and carers' responsibilities (in employment only).

#### **Council's Dementia Working Group**

In January 2019 Council convened a Dementia Working Group, a subcommittee of the Hawkesbury Access and Inclusion Advisory Committee. The objectives of the Working Group are to:

- 1. Develop a draft Dementia Friendly Hawkesbury Plan that includes all of Dementia Australia's minimum elements for endorsement, within the context of the Council's core business and Community Strategic Plan.
- 2. Establish a collaborative/consultative process for engaging people living with a diagnosis of dementia and their carers to inform the development of the Dementia Friendly Hawkesbury Plan.
- 3. Develop a timeline to guide development, launch and implementation of the Dementia Friendly Hawkesbury Plan, including consultation with Dementia Australia at such milestones.
- 4. Consider Dementia Friendly Hawkesbury Plan implementation issues to inform consultation with relevant community groups and stakeholders.
- 5. Design and present final draft of Dementia Friendly Hawkesbury Plan to be reported to the Hawkesbury Access and Inclusion Advisory Committee for the ultimate consideration of Council.

#### Developing the Dementia Friendly Hawkesbury Plan2019 - 2021

Council consulted with people living with dementia, their carers, community service providers, local businesses and Council staff about the challenges faced by people living with dementia and ideas to improve inclusion. Consultations conducted included:

- distribution of hard copy surveys;
- online survey available through Survey Monkey;
- one on one interviews;
- facilitated forums and;
- talks at local business forums and networking events;

Council also facilitated two Dementia-Friendly Information Sessions.

Full details of consultations are captured in Appendices B, C, D and E.

Council will implement the Plan over a two year period.

#### Council's Role and when it is likely to apply

The role that Council will play in the Dementia Friendly Hawkesbury Plan will vary for each of the strategies. Although the Plan was facilitated by Council, the Plan's vision is intended for the community and key stakeholders of the Hawkesbury, and is not just focused on activities of the Council. Whilst Council has a custodial role in the Plan, it is not wholly responsible for its implementation. Council will partner and support other stakeholders, as local businesses and community groups to deliver the long-term objectives of the plan. Council's role in delivering the Plan strategies is explained in the table below.

#### Manager/Leader

Council manages, leads, delivers and communicates commitment, progress and outcomes Where Council has direct responsibility and capability to deliver the outcomes required. This will involve dedicated resources, agreed timeframes and clear responsibilities. External funding or other resources may be required to make the project happen. In taking on this role, Council also must be aware of the high level of community interest in outcomes, and needs to communicate its commitment to making it happen, the timeframe, progress and outcomes

#### **Critical Partner**

Council is an informed critical partner in the delivery of a project with mutual benefits for the partners Where Council has a direct responsibility to deliver the outcomes, and either partnerships are required in order to proceed, or the delivery of outcomes is enhanced by partnerships. Council needs to define its preferred position on outcomes, and enter the partnerships with the aim of value-adding and providing benefits for all parties

#### **Advocate**

Council develops an informed position and influences others who have the responsibility to make the decision and act

Where Council does not have the resource or the direct responsibility to enact or make the decision. Council develops a position on the strategy/issue with a defined path forward and advocates to the responsible partners for the changes to occur. In this way, Council is part of developing the solutions rather than just presenting the issues

#### Supporter

Where a project is initiated externally to Council, Council provides low level assistance to enable the project to be realised

Where others are responsible for the decisions, actions taken and outcomes, that align with the overall Community Strategic Plan, then Council might provide support by way of in-kind support or additional resourcing etc. The responsibilities and actions are those of the initiating party

#### Facilitator

Council makes it easier, and builds the capacity of others to deliver Where Council develops the capacity of others (community groups, business groups, government agencies etc.), to find their own acceptable solutions. For example, several community groups may wish to run a community project: Council could facilitate by being a neutral third party to call meetings initially, perhaps assist sourcing funds from government; develop meeting or event processes etc. The responsibility for action and ownership of outcomes lies with the community groups, business groups or agencies

#### Objective One: Empower people living with dementia and their carers to have a voice

- Community satisfaction with the way council engages the community in making decisions
- Community satisfaction with Council lobbying state and Federal Government for funding and improved service levels
- Community satisfaction with Council building strong relationships and shared responsibilities

Actions	Councils Role	Section Responsible	CSP Strategy	Financial Year	Measures
Establish a Hawkesbury Dementia Working Group for the duration of the Dementia Friendly Hawkesbury	Manager/ Leader	Community Services	2.5.2 5.4.1	2019/20	Working Group established
Plan	Loudoi		5.5.2		
Identify and develop Dementia Champions across the Hawkesbury to advocate for the needs and interests of people with dementia	Critical Partner	Community Services	1.4.1 2.1.2	2019/20	Number of local Dementia Champions identified
Facilitate a forum for people with Dementia to meet with Government representatives to discuss identified issues	Advocate/ Facilitator	Community Services	1.4.1 2.4.1	2019/20	Forum held with various levels of government Number of participants in attendance
Promote rights of people with dementia through information sessions and Council social media platforms	Facilitator	Corporate Communications/ Community Services	2.3.1	2019/20	People with dementia and their carers are aware of their rights (session evaluation survey) Number of participants in attendance Number of public promotions undertaken

#### Objective Two: Improve availability and access to information

- Community satisfaction with access to information
- Community satisfaction with Council's library services
- Community satisfaction with Council support of community and health services
  Community satisfaction with programs for people from diverse cultures (including Indigenous Australians)

Actions	Councils Role	Section Responsible	CSP Strategy	Timeline	Measures
Hold a 'Dementia-Friendly' Expo in the Hawkesbury	Manager/ Leader	Community Services/	2.2.1 2.3.1	2019/20	Dementia-Friendly Expo held
	Facilitator	Corporate Communications	5.3.2		Number of participants in attendance
					Number of types of support services exhibited
Re-design and update Council's Community Services Directory	Manager/ Leader	Community Services/	1.2.3 2.3.1	2019/20	Directory updated Directory available in various formats.
Directory	Leadei	Cultural Services	2.4.2		Directory available in various formats.
Council's library services to build a collection of books and other media about dementia and how to live a	Manager/ Leader	Cultural Services	1.3.2 5.3.2	2020/21	Increased satisfaction with Council's library services
positive life following diagnosis					Number of books related to dementia
Promote the resources available from Dementia Australia and make these available in Council reception areas	Critical Partner	Community Services	2.2.1 2.4.1	2019/20	Number of posts on Social Media Resources promoted on website Resources available in Council reception areas
Develop a 'Dementia-Friendly Guide' to showcase ideas and initiatives for businesses and services to provide their goods or services according to dementia-friendly principles	Manager/ Leader	Dementia Working Group	1.3.2 2.4.1 5.7.1 5.7.2	2020/21	Guide developed Guide promoted through business networks
Mapping of public computer kiosks to enable the general public to have access to online information.	Manager/ Leader	Customer Service/Cultural Services	1.2.1 1.2.3	2020/21	Number of public computer kiosks

#### Objective Three: Increase community awareness and understanding about dementia

- Community satisfaction with Council partnerships with residents, community and institutions
- Community satisfaction with Council long term planning for the future
- Community satisfaction as an informed community with Council initiatives that enable meaningful engagement

Actions	Councils Role	Section Responsible	CSP Strategy	Timeline	Measures
Frontline Council staff to complete Dementia Australia's online Dementia Friend Seminar	Manager/ Leader	Human Resources	1.2.3	2019/20	Number of staff trained Increase in staff awareness and understanding of dementia (survey)
Offer Dementia Awareness/Dementia Friend Training to businesses, organisations, service providers, GP's, emergency services and health professionals operating in the Hawkesbury	Critical Partner/ Advocate	Community Services	1.4.1 2.4.1 5.7.3	2020/21	Number of participants
Council to run a social media Dementia Awareness Campaign during Dementia Awareness Month in September each year	Critical Partner	Corporate Communications/ Community Services	2.2.1 2.5.1	Ongoing	Number of posts

#### Objective Four: Increase opportunities to engage and participate in the community

- Community satisfaction with access to Council services and facilitates for people with a disability
- Community satisfaction with Council Community events and festivals
- Community satisfaction with opportunities to celebrate our creativity and cultural expression
- Community satisfaction with a sense of community and wellbeing

Councils Role	Section Responsible	CSP Strategy	Timeline	Measures
Partnership	Community	2.2.1	2019/20	Consolidated directory available
	Services			Carracilla contrata da limb da Driva ano Haraldo Nadorado
				Council's website to link to Primary Health Network
				MyHealthConnector platform
		5.5.5		
Critical	Community	2.5.1	2020/21	Number of Dementia-Friendly Social Events held
Partner/	Services	5.6.1		·
Supporter	Corporate			
	Communications			
Supporter	Corporate	5.6.1	2020/21	Number of Forums held
	Communications/	5.7.3		
	Community	5.8.1		Number of new NDIS registered businesses in the
	Services	5.8.2		Hawkesbury
Facilitator	Community	2.3.1	2020/21	Number of initiative supported
	Services	2.4.1		
		5.3.1		Number of initiatives developed
	Role Partnership  Critical Partner/ Supporter  Supporter	Role Responsible  Partnership Community Services  Critical Community Partner/ Services Corporate Communications  Supporter Communications/ Community Services  Facilitator Community	Role         Responsible         Strategy           Partnership         Community Services         2.2.1 2.5.2 4.3.5 5.1.5 5.5.3           Critical Partner/ Supporter         Community Services         2.5.1 5.6.1           Supporter         Corporate Communications/ Community Services         5.6.1 5.7.3 5.8.1 5.8.2           Facilitator         Community Services         2.3.1 2.4.1	Role         Responsible         Strategy         Imeline           Partnership         Community         2.2.1         2019/20           Services         2.5.2         4.3.5         5.1.5           5.1.5         5.5.3         5.5.3           Critical Partner/ Services         Services         5.6.1         2020/21           Supporter         Corporate Communications         5.6.1         2020/21           Supporter         Communications/ Community         5.7.3         2020/21           Facilitator         Community         5.8.2         2020/21           Facilitator         Community         2.3.1         2020/21           Services         2.4.1         2020/21

#### Objective Five: Increase support to maintain economic participation

#### Outcome Measures:

- Community satisfaction with Council Supporting and valuing volunteers
- Community satisfaction with the operation of Council

Actions	Councils Role	Section Responsible	CSP Strategy	Timeline	Measures
Review Council's human resource policies and procedures to support employees with dementia or carers of people with dementia	Manager/ leader	Human Resources	1.6.2	2020/21	Council's policies and procedures are supportive of carers and their role as a carer Procedures are developed to support an employee with a diagnosis of dementia
Identify opportunities for people living with dementia to volunteer in the Hawkesbury	Facilitator	Community Services	2.3.2	2020/21	Number of actions taken by Council relating to identification and supporting volunteer groups

#### Objective Six: Improve access to affordable and convenient transportation options

#### Outcome Measures:

1. Community satisfaction with available transport options

Actions	Councils Role	Section Responsible	CSP Strategy	Timeline	Measures
Advocate for increased affordable and accessible transport options for people with dementia	Advocate	Community Services	4.1.2 4.1.4	Ongoing	Number of actions taken by Council to support increased options for affordable transport
Convene working group to improve transport options for persons with dementia in the Hawkesbury	Facilitator	Community Services	4.1.1 4.1.3 4.1.4	2020/21	Transport options mapped  Utilisation plan developed and implementation plan delivered in conjunction with transport providers  Transport options identified on Council's Community Directory

#### Objective Seven: Improve access to appropriate health and care services to continue to live at home for as long as possible

- Community satisfaction with Council support of community organisations
- Community satisfaction with Council lobbying State and Federal Government for funding and improved service levels
- Community satisfaction with Council in building partnerships with residents, community groups, and institutions

Actions	Councils Role	Section Responsible	CSP Strategy	Timeline	Measures
Investigate options for a central contact for support and advice for consumers to access all services	Supporter	Community Services	1.4.1 2.4.1	2020/21	Options identified
Advocate for increased funding of dementia specific services to increase the availability of services and reduce wait times, including respite services	Advocate	Community Services	1.4.1 2.4.1	Ongoing	Number of actions taken by Council to support growth funding
Advocate for innovative models of respite that flexibly meet the needs of the local community	Advocate	Community Services	2.4.1 5.1.5	Ongoing	Number of actions taken by Council to support new initiatives
Continue to facilitate disability and aged care forums that enable providers to collaborate on local issues, build referral pathways and improve integration through service systems including residential aged care	Facilitator	Community Services	5.1.5	Ongoing	Number of forums convened
Support the formation of a residential aged care providers forum to explore opportunities to collaborate and develop ways to assist residents to access their community.	Support	Community Services	2.4.1 5.3.2	2020/21	Number of forums convened

#### Objective Eight: Improve the access, safety and inclusivity of environments

- Community satisfaction with Access to Council services and facilities for people with a disability
- Community satisfaction with Council Road safety initiatives
- Community satisfaction with Council Crime prevention strategies and partnerships
- Community satisfaction with community safety and disaster management
- Community satisfaction with available housing choices

Actions	Councils Role	Section Responsible	CSP Strategy	Timeline	Measures
Revise Council's Access and Inclusion Checklist to incorporate the dementia-friendly principles for physical environments	Manager/ Leader	Community Services	2.4.1	2019/20	Revise Access and Inclusion checklist available for the community to utilise
Review Council's Development Control Plan to ensure that universal design principles are reviewed relating to all public accessible development	Manager/ Leader	City Planning	5.1.3 5.1.5	2020/21	Town planning procedures comply with Universal Design Principles
Review Council's Customer Service areas for Dementia-Friendly design principles	Manager/ Leader	Customer Service	5.1.3	2019/20	All Council Customer Service areas verified as Dementia-friendly according to the Hawkesbury Access and Inclusion Checklist
Audit Council facilities using access and inclusion checklist to ensure public facilities are accessible and easy to navigate	Manager/ Leader Supporter	Community Services	2.1.2	Ongoing	Number of Council premises audited  Number of actions implemented in response to audits
Revise the Public Toilet map for currency and access times. Promote The National Public Toilet Map	Critical Partner	Community Services	2.2.1 4.3.1	2020/21	Increase in the number of available public toilets noted on the public Toilet Map
Work with social housing providers to develop strategies to enable persons with dementia living in social housing to age in place	Supporter	Community Services	5.3.2	Ongoing	Number of suitable Housing options

Actions	Councils Role	Section Responsible	CSP Strategy	Timeline	Measures
Investigate options for a Community Support Hub that provides information, resources and a place to connect in a safe and friendly environment	Supporter	Community Services	2.1.2 5.5.3	2020/21	Options identified for further consideration
Promote the roll-out of disaster preparedness toolkits to persons living in the community with dementia through education sessions to service providers	Supporter	Community Services	2.3.1 2.4.1 5.3.1	2020/21	Number of education sessions held  Number of providers in attendance  Number of persons with emergency plan

#### Objective Nine: Identify and promote Dementia-friendly business and services

- Community satisfaction with the operation of Council Community satisfaction with Council initiatives that encourage and enable our community to participant in healthy lifestyle Community satisfaction with Council initiatives to promote our community as a place to visit, work and invest

Actions	Councils Role	Section Responsible	CSP Strategy	Timeline	Measures
Allocation of a Dementia-Friendly Project Officer who will champion change within Council	Manager/ Leader	Community Services	1.6.2	2019/20	Dementia Friendly Project Officer identified
Develop a program to certify businesses, organisations and services by their accessibility	Manager/ Leader	Community Services	5.7.3	2020/21	Program developed to certify businesses and services against the accessibility and inclusive criteria Number of businesses certified Businesses identified listed in Community directory
Provide information and support to local business to encourage development of individual Dementia Friendly	Supporter	Community Services	5.7.3	2020/21	Number of businesses who develop a Dementia Friendly Plan
Identify and promote grants and community sponsorship opportunities for businesses with dementia specific support initiatives	Manager/ Leader	Community Services	2.2.1 2.4.1	Ongoing	Number of Community Sponorship opportunities

#### References

Hawkesbury City Council Disability Inclusion Action Plan 2017 – 2021

Alzheimer's Australia NSW and Deloitte Access Economics: Dementia Prevalence in NSW by State Electoral District (SED), August 2014.

NSW Department of planning and Environment: New South Wales State and Local Government Area Population and Household Projections, and Implied Dwelling Requirements, 2016

Dementia Australia: Creating Dementia-Friendly Communities: A Toolkit for local government

Hawkesbury City Council Community Strategic Plan 2017 - 2036

#### **Community Consultation, Promotions and Events**

#### **Appendix A: Dementia-Friendly Information Sessions**

# Dementia Friendly Communities



#### **Dementia Friends**

#### A Community Awareness Event

Are you interested in supporting people living with dementia in your community?

This free information session will provide an overview of the impact of dementia on the person and their families.

The session will also discuss what a Dementia Friendly Community looks like and how we can all take steps to become more Dementia Friendly.

An important start is for everyone in the community to become a Dementia Friend. Becoming a Dementia Friend is quick and easy and shows your support for people living with dementia and their families.

We can all make a difference.

#### Do you need respite to attend?

Please contact the Commonwealth Respite Centre on 1800 052 222 or your current service provider.

"Dementia-Friendly Communities is an Australian Government funded program administered by Dementia Australia"



#### **Workshop Details**

Date: 25/6/2019 Time: 5PM

Cost:

Free

Venue: Richmond Golf Club 34 Bourke Street Richmond NSW 2753

#### **Enquiries**

If you have enquiries or would like to register to attend this session please phone or email:

E: Anthony.Parker@dementia.org.au

P: 02 8875 4667

#### CONTACT

Building 21, 120 Coxs Road, North Ryde, NSW 2113 P O Box 6042, North Ryde 2113 T (02) 9805 0100 | F (02) 8875 4865 E nsw.education@dementia.org.au

#### REGIONAL OFFICES

Bega, Newcastle, Port Macquarie, Coffs Harbour, Sutherland, Wingecarribee, Blacktown and Illawarra

When: 25 June, 2019
Where: Richmond Golf Club
Who: 12 attendees

The Dementia-Friendly Communities seminar was facilitated by Anthony Parker from Dementia Australia. The Richmond Golf Club provided the training room for the event. 12 people attended the session in addition to the Councils' Dementia Working Group. Of the 12 attendees:

- all signed up as Dementia Friends at the session
- 8 people reported increased knowledge of dementia due to attending the session
- 4 people rated their knowledge the same as before, these people were all carers and/or health professionals.

When: 14 August, 2019
Where: Hawkesbury Connect

Who: 30 attendees

The Dementia-Friendly Communities seminar was facilitated by Trish Glover from Support Choices Australia. 30 people attended the session.

- 18 participants completed the Dementia Friends at the session evaluation survey
- 15 people reported increased knowledge of dementia due to attending the session
- 3 people rated their knowledge the same as before

#### Appendix B: Media

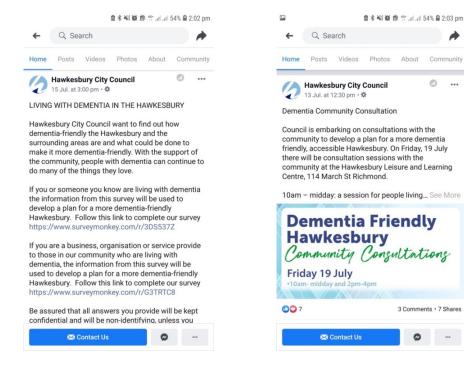
#### **Hawkesbury Gazette**

http://www.hawkesburygazette.com.au/story/6261547/community-consultations-for-a-dementia-friendly-hawkesbury/?cs=1453



#### **Hawkesbury City Council Website**

https://www.hawkesbury.nsw.gov.au/news-and-events/news/all-news/2019/july/a-dementia-friendly-hawkesbury



#### **Hawkesbury City Council Facebook**



#### **Appendix C: Business Consultations**

#### **Business Week**

When: 28/06/2019 - 01/08/2019

Where: Available online using Survey Monkey and distributed in print

Who: Surveys Distributed:

- 1. Bilpin Networking Event – June 24: 5 attendees
- 2. Colo – June 25: 4 attendees
- 3. Windsor – June 25: 18 attendees (approx.)
- Kurrajong Village June 24: 15 attendees (approx.) North Richmond June 26: 10 Attendees (approx.) 4.
- 5.
- 6. Trade Show – June 28: 13 stall holders (approx.)

#### **Windsor Business Group**

When: 25 July, 2019: 7am - 9am Where: Zazu Café, Windsor Who: 30 attendees (approx.)

Surveys were distributed to the group with a 10 minute presentation and discussion on what a Dementia-Friendly Community might look like in the Hawkesbury. Several businesses completed surveys.

#### **Hawkesbury Fest**

When: 21 July, 2019: 10am - 3pm Governor Philip Park, Windsor Where:

Who: 6-7K attendees (approx.), 35 Community Stalls, 25 Market Stalls, 12 Food Vendors

Surveys were distributed and collected in talking with stall holders. Discussions on a Dementia-Friendly Community were had with several Hawkesbury residents and stall holders throughout the day.

## **Appendix D: Facilitated Conversation Events**

#### **Individual talks with Carers**

Where: Telephone Calls

Who: 3 carers

Comments/Suggestions	DFH Plan Objective
Public toilets are often closed and not accessible so people who are incontinent don't feel comfortable going out	8
Long waiting lists for lawns and cleaning support services	6
Dementia homes are too expensive	6
Directories need to be in print. We used to get a directory with our rates	2
Community transport is too expensive - \$15 for the bus and \$10 for the meal –	7
can't afford \$25 every day to get out with support	
Under the NDIS we are charged full fare	7
Community centres such as Bligh Park need air-conditioning – unbearable in the extreme cold and heat	8
We need a central point to talk with someone and get help from	6
Garden and maintenance services have a waiting list of 18 months and have closed their books	6
When my husband was diagnosed, he wouldn't talk and withdrew from people	2,6
It starts off with the simple things that can be the hardest	2,6
Its really important to have consistency with the support person	3
He became so reliant on me	2,6
Person with dementia said he felt like things were slipping away	2,6
Small things are frustrating for the person with dementia	2,6
I am the carer for my mum and my husband thinking of selling our family home to downsize so that we can have more time for us	2, 6
We sought counselling which has been very helpful for all of us	2,6
It's frustrating as there are some things that we should know, but we just don't	2
We have purchased an mCare watch to help with daily routines	2
Hospitals staff need to understand patients with dementia so much better and be respectful	3
Transport is a huge issue for us.	7
There is no appropriate respite for people with dementia under the age of 65	6
The RMS don't keep a record of Power of Attorney, so I have to remember to take the papers with me each time or that won't assist me.	2, 7
Places need to have simple signage	8

#### People living with dementia and their carers

**When:** 19 July, 2019: 10am – 12noon

Where: Hawkesbury Leisure and Learning Centre

Who: 9 attendees

A conversational style feedback session was held for people living with dementia and their carers. Of the nine attendees, 3 people identified as living with dementia and one as a primary carer of a person living with dementia.

Comments/Suggestions	DFH Plan Objective
People are friendly and they make you feel safe	3
I like to go to the football and watch the Tigers	4
I like to come to the community centre	4
I play golf and I want a handicap of 7	4
I don't go out on my own	1, 3, 6, 8
I don't feel comfortable talking about dementia. When I go out, I feel like	1, 3
everyone is looking at me	•
It's hard to explain to doctors and neurologists what my dementia is like	3
People treat me well	1, 3
I have to ask about things a couple of times	3
Carer: should not use long sentences. Use short phrases to help people follow	3
and understand	
Carer: I feel that all people should have some training in dementia awareness	3
Carer: people need to talk calmly and slowly	3
I have a great hair and nail salon.	9
Suggest everyone watch the 'do you see what I see' video	3
Men are in denial with dementia	6
Carer: I did the MOOC course. It was a good way to learn about dementia	3
Carer: Facebook support groups have been good. I don't use Facebook to talk	6
about what I cooked for dinner, I'm there for support.	•
Difficulty as lots of people cannot use computers	1
The impact on carers means friends disappear as they feel uncomfortable	4
Needs to be more 1:1 talking to people making people aware.	3
Suggest a letter is sent to every business in the Hawkesbury	9
Government should look after carers as well – it's cheaper to look after someone	2
at home rather than a nursing home	_
Pension is going down and utilities are going up	1
I want to be able to go to a restaurant and not need to explain everything to the	3, 9
people every time	٥, ٥
Training should be provided for up and coming students, especially hospital staff	3
A lot of people take dementia as a joke	3
People being locked in the hospital because they wander and the hospital staff	3, 8
thought it was funny until they realised it was my wife they were referring to	٥, ٥
Staff in dementia wards have no training.	3, 1
Care in hospital is not individual or provided on a personal basis	1
Hospital and community service have issues over jurisdictions. When a person	1, 3
with dementia goes in to hospital, the support workers that they are used to are	-, -
not able to provide the support by a person that they are familiar with	
Home care nurses forced my mother to do things that she didn't want to do	1, 3
We didn't know what an advocate was or how to access one at the time	1
Health services didn't ever use an interpreter	<u>·</u> 1
I had to fight for my wife to receive her pension because she was younger and her	<u> </u>
dementia wasn't obvious. Then her pension was cut and we had to fight again.	-
Bowling at South Windsor is great. They have a quiet session where lights are	4, 9
left on, the music is off and the ramps are out. The staff are understanding.	, -
There are a lot of places that don't recognise the companion care – staff aren't	4
trained on this	

Comments/Suggestions	DFH Plan Objective
Cafes that have staff that are dementia aware are great. They often have quieter spaces and they don't make people stand out.	3, 8, 9
Meal sizes in the clubs are too big	1
Respite is hard to get.	1, 6
Carers are overwhelmed and burn out	6, 4, 1
Home care packages are limit and have large waiting lists. They are inflexible	1, 6
and the money runs out.  Carers feel alienated	4 C
Council rates are too much, there are no subsidies for people on a pension	4, 6
I sold everything to get by and it took 11 months to get on the carers pension	2, 5 5
18 month wait for homecare packages	1, 6
People who need support access the NDIS and My Aged Care. The process is	1, 2, 4, 6
so hard. It needs to be made simpler for carers and people with dementia to understand.	1, 2, 4, 0
Face to face sessions to guide people through the process would help people through the service system	2
People can talk to providers about their experience and hope they can change the way they work	4, 1, 3
Not everyone uses computers	2
I have found that having a diary in my home helps. Like remembering to take my tablets	2
Have a day that people can come and talk to providers, learn about technology and look at things like monitoring devices. Examples of visual cue cards, diaries, continence aids and how to access funding. Have a continence nurse talk to people.	2
Maybe a client committee for the expo to help design it.	1, 2
We need to know about carers counselling services – grief counselling for carers and how to access their services	2, 6
I don't want to discuss my feelings with my kids	6
When my wife's needs changed, ACAT advised me that they cannot submit more	1, 6
than 2 assessments per month. It was so frustrating as things were changing so fast	, -
We need communication forum to help people know what is out there	1, 2, 4, 6
A booklet with information on what is available would be great and helpful	2, 6
The buses we use are rundown. They look like we are off to the funny farm.	7
Education is so important for everyone	3
Transport is really hard as it is so expensive. We need transport at a reasonable price	7
Family have been responsible for taking people out of aged care facilities. People hate it there	1, 4, 6
Respite is inflexible – you need to book a week at a time. You can't just book in a weekend.	1, 2, 6
I like to keep busy, but I can't afford to always go out	4, 5
There are issues as not as many people want to volunteer	4, 5
We need to give people more choices on things	1, 4, 7
I wish places had less steps to get up	8
We need more music. Love all music	2, 4
Small concerts that are more inclusive of people with special needs	4
What about a social event series where there is a different thing on each month. I remember the old Dine and Dance events that they used to have	4
Dementia-Friendly Exercise groups would be great	2, 4, 9
They run tai chi on Tuesday for people with dementia	2, 4, 9
The Hawkesbury gallery have Dementia-Friendly tours	2, 4, 9
I go to chair yoga which is great because I can't do it standing	2, 4, 9
i go to onali yoga willottib great because i carri do it stallullig	<u>-, -, J</u>

Comments/Suggestions	DFH Plan Objective
Activ8 are great with Heart Moves and seniors classes	2, 4, 9
Outreach day programs are needed for people who live outside of Richmond and Windsor	2, 4, 6
Mobile library is great	2, 4

#### **Businesses, Organisations and Service Providers**

**When:** 19 July, 2019: 2pm – 4pm

Where: Hawkesbury Leisure and Learning Centre

Who: 13 attendees

Attendees were split into three groups and were provided with an overview of the Hawkesbury Dementia-Friendly consultation process and the concept of a Dementia-Friendly Plan for the Hawkesbury.

	Social and Community	DFH Plan Objective
Strengths	Some specialty services available	2, 6
	Caring Community	4, 8, 9
	Service Providers & Health Care Services are educated.	3
	Strong Community Identity Highlight & Harness	3, 4
	Local Recognition by others in the area	4, 8
	Some support services available	2, 4, 6
	Community	2, 3, 4
Challenges	Need to provide more services to support carers ie music therapy.	2, 4, 9
	Cost of business to register for NDIS is not viable.	6
	Limit funding in aged care to provide external services.	1
	Being isolated from the Community and hard to break into the Community.	1, 4
	Outlying areas access to services	7
	Not enough services	1, 6, 4
	Isolation of carers	4
	Maintaining Social Networks	4, 6
	Long waits for in home Aged Care	1
	Complexity of Process	1, 2
	Stigma	3
Activities/	Carers only meeting and activities	2, 4
Suggestions	Connect through music therapy, food, carers and people together.	4
	Community Directory to access health carer, GP's & Nurses	2, 6
	Advisory Service to Health Care Navigator	1, 6
	Linkages to NDIS with younger onset dementia	3, 6
	Support & Create linkages for "Social Care Connectors" for "Compassionate Communities" Pilot Project" (Council & NBM PHN & participating general practices)	1
	Dementia carers support group.	2, 4, 6
	Online resources	2, 3
	Facebook support	4, 6
	Forums	1
	Tap into Existing Be & Co Network – Windsor Outside Library	2, 4, 6

	Economic	DFH Plan Objective
Strengths	Employers with flexible conditions	7
	Community connections	4
Challenges	Cost of Services and lack of funding for services	1
	High cost of services	1
	Job agencies and seeking meaningful employment.	7
	Safe workplace	7
	Individual	1, 2, 4
	Respite from daily duty.	7
	Carers having established work	7
	Carers payment	7
	Enough funding for respite	1, 2, 6
Activities	Community grants etc.	1, 9
/Suggestions	Pay it Forward type group to help in gardens, home etc.	2, 4
7	More Day Programs	1, 6
	Availability of Transport	7
	Free Social Programs	2, 4
	Support of volunteers to help run or assist with programs	4, 5
	Community service groups: Church, Youth, Scouts, Girl	2, 4, 6
	Guides, Help gardening etc.	
	Respite services to assist carers to work	4, 6, 7
	Educate Centrelink about early onset dementia	3
	Quality respite for carers.	1, 6
	Health	DFH Plan Objective
Strengths	Good Health Network	6
Challenges	High level of depression and dementia	6
	Carer depression	4, 6
	Mental Health of carers and regular activities such as:	6
	Craft	
	Music	
	Understanding of Younger Onset Dementia	3
	Misinterpretation and Understanding	2, 6
	Educate religious and cultural organisations around dementia	3
	Hospitals are a nightmare	1, 3, 6, 8
	Training for staff in health services	3
	Bedside manner of medical staff	3
	Transport options when drivers licences are lost	4, 7

	Health	DFH Plan Objective
Activities /Suggestions	Regular activities in order to reduce depression, such as  Craft  Music  Social	4
	Combine therapies such as physio and music.	4, 6
	Stroke choir to help improve speech etc.	2, 4, 6
	Respite	6
	Carers Retreat asking business to contribute and bring in services such as:    Hairdresser	4, 9
	Beautician     Nail Person	
	Massage	
	Peer support group for carers	4, 6
	Early intervention cards or signs to look for to ensure correct dementia diagnosis and cognitive activities that may assist and slow effects of Dementia.	4, 8
	Develop apps or even 1 app that may assist. Seek assistance from PHD student or the like to develop:  Reminders Links to PHN or their carers/activities Brain Games Fun Games Play Music Listen to e-books Advertises new information and updates on Dementia	1, 2
	Psychologist support for carers	6
	Driving with Dementia education	2, 3, 7
	Dementia specific hospital wards	6
	Home	DFH Plan Objective
Strengths	Hawkesbury Community	4
Ob all an area	Existing Facilities	6
Challenges	Carers      Mental Health     Physical Exhaustion     Support	2, 3, 6
	Social Housing	5, 8
	Rental Market	5, 8
	Building Community around Aged Care	4, 6
Activities/ Suggestions	Therapy with  Music  Art and Craft	2, 4, 6, 9
	Social Groups  Co habituating with students	4
	Co habituating with students	4
	Vacation care in Aged Care Facility  NOTE "Innovaging" are innovators who are working in Aged Care space.	2, 3, 6, 9
	Oale space.	

	Connection & Community with the Hawkesbury Community of faith Local Police	Objective 4, 6 4
<u> </u>		1
	Local Police	
	Local Folice	1, 4
	Close by	
	Mental Health Aware	
	<ul> <li>Compassionate</li> </ul>	
	<ul> <li>Business have confidence in local Police</li> </ul>	
	Heritage Footpaths	7
	Existing services and feeling safe	6, 7
Challenges	Mandatory Reporting not applicable in Community Aged Care	1
	Inform churches and other organisations. Dementia patients	3, 4
	may now have higher risks around tasks they have always	
	been comfortable doing. e.g. lighting candles at Church	
	Diverse community	4
	Lack of services and costs involved	6
	Awareness	3
Activities/	Dementia-friendly signage and way fairing around the town	7
	centres. Coloured signs that can be followed	
	Dementia-Friendly Businesses or Place much like "Neighbour Watch" initiative.	2, 8, 9
	"Sit and Chat " chairs in the Parks, Shopping Centres and other Open Spaces encouraging people to chat to the person next to them.	4, 8
<del> </del>	"Dementia Bus"	4, 6, 7
_	Dementia Australia accreditation for local businesses	9
<del>-</del>	Tips to improve living space:	7
	Colour contrast	
	Noise	
	Strategies to assist:	3
	Showering	-
	Re-orienteering	

	Empowerment	DFH Plan Objective
Strengths	People who want to make a difference	1, 4, 6, 9
	Existing Dementia-Friendly program	3, 6
Challenges	Lack of understanding of rights	1
	Community Grants applications are too complex it restricts the opportunity	9
	More men's activities	2, 4, 6
	Being treated with fear by others in the community	1, 3, 4, 9
	Interacting in the Community businesses	9
Activities/	Provide choices on everyday activities	2, 4, 6
Suggestions	Provide options in activities	2, 4, 6
	Community grants to be more accessible	9
	Simplify grant application processes	9
	Inform people of rights	1
	Knowledge of abuse rights	1
	Consultation for Dementia sufferers and their carers	1
	Do not treat Dementia sufferers any differently from others in	3
	the Community.	
	Easy to follow signage, shopping centres and other	8
	Community space which will assist all ages of the community	
	e.g. St Ives Shopping Centre;	
	- Coloured signage	
	- Non slip surfaces	
	- Insulated for noise	
	- Lots of seating	
	Inform of volunteering opportunities or programs to be involved in	5
	People with Dementia network to share information	1
	ABC – Early onset segment	1, 3
	Raising awareness among businesses	9
	NOTE : Blue Mountains had trial with businesses to interact	9
	with people with disability. DARE Disability Services	
	Springwood	
	Community Directory that is accessible and simple to use	2, 3
	Referral Pathways are defined to access relevant support	2
	Future planning – wills, advance care and pensions	2, 6

	Education and Skills	DFH Plan Objective
Strengths	Existing Networks	2, 5
	Carer Support Groups	2, 4, 6
	Carers Coffee	2, 4, 6
	Local providers with local knowledge and education	2, 6
	Existing resources for carers	2, 3, 4, 6
Challenges	Need for carers to be educated in what to expect with the	1, 2, 3, 4, 6
	progression of Dementia	
	How to have business allocate finance and time to "MAKE IT HAPPEN"	9
	More education and skills	2, 3, 4, 5
	Training for staff in front line situations like the reception at Doctors surgery, around Dementia	3
	Education into remote areas	3
	Supporting organisations to keep people involved	1, 6, 9
	Keep existing networks	6
	Rotary, Probus and other organisations	2, 4
	Disseminating or sharing information	6
Activities/	Businesses becoming aware of alternative responses	2, 5, 6, 9
Suggestions	Workshop on "How To" courses for access to services and overcome previous barriers	2, 3, 8
	Promote more training	3
	Availability of carer support groups online and face to face.	2, 4, 6
	Community funding made available	6, 9
	Self-education	3
	Navigation support on internet	1, 2, 3
	Council free on line coursers and tools	1, 2, 3
	Booklet	2
	Hospitality Staff Training as well as raising their tolerance and knowledge	3, 9
	"Silent" od Dementia focused day	2, 3
	Bringing local Dementia groups together to arrange a trial run for local business to expose their staff to Dementia patients.	2, 3 3, 9
	Promote and spread to be national campaign and training tool.	
	Tap into existing trusted services	2, 3, 4, 6
	Hub or central network to access information for Dementia	2, 3, 4, 6
	Trusted and Accessible	2, 4, 6
	Dementia Aware providers	3, 6, 9
	Easy access to information and resources	2, 4, 6

# **Hawkesbury Carer Support Group**

When:

26 July, 2019: 10am – 11am Anglicare Education Precinct, Richmond Where:

Who: 4 attendees

Comments/Suggestions	DFH Plan Objective
Frustrated with continence aid supplier ceasing to stock our product. I don't know where else to get the one that he will wear	2, 6
I don't have the internet, so I can't look things up. I learnt about Anglicare's services from the hospital referral	1, 2, 4, 6
People with dementia don't look like there's anything wrong with them	3
I have to shower mum, so I regulate her routines	3
Routines and prompting are essential to support him each day	3, 4
Mum has been having dreams about dying	3, 6
My biggest worry is who will care for him if I can't	2, 4, 6
Mum is not suitable for the day program because it's too loud for her. She doesn't relax	3, 6, 9
Mum goes out to a friend's place once per week	4
Shop keeper are ignorant to what it means to have dementia	3, 9 2, 4
As a carer, I have made a lot of new friends through networking and coming to carer groups	2, 4
We had a really good cabdriver in the Hawkesbury once. He was calm and patient. I don't know how to contact him now.	2, 4, 9
People are scared of people with dementia and make assumptions about it	3
I have never heard my mum say she has dementia. She just says 'I'll be in the nut house soon'	1, 3, 6
I'm in the process of getting a new bathroom, getting quote because the waitlist for services to do it is too long	1, 6
We like to use local providers however their books are closed e.g. Peppercorn	1, 6, 7, 9
It was hard because mum wouldn't sleep in a bed	3, 4, 6, 8
If I am not happy with services, I don't like to tell them	1
Coming to this group was the best thing because of the friends that I have made	2, 4, 6
I would like to better understand how to access private services	2, 6
People tend not to look at or talk to my husband when we are out in public – they talk to me.	3, 9
Its good just to have that person [service provider] to talk to	2, 4, 6
GP's don't know enough. They make assumptions "he's just getting old' when I was trying to explain the changes that I had noticed	3, 6
Scared to acknowledge dementia	3
Respite is hard to get in the Hawkesbury, had to use respite in Bathurst	1, 2, 6
It was hard when he was diagnosed as we didn't know anyone who was or had gone through this	2, 4, 6
Lots of fear in using respite	3, 6
Had to go to Katoomba for a dementia specific [respite] bed	1, 2, 6
We need a home for people living with dementia	1, 2, 4, 6
Meals and nurses were fantastic at Hawkesbury Living	2, 4, 6
My husband has passed now, but I'm still confused by the whole thing	2, 4, 6
Anglicare are about to get the EDIE program [Educational Dementia Immersive Experience]	2, 3, 6
Everyone with dementia is different and they experience it differently	3
Being told by the doctors that I needed to put him in a nursing home – I wasn't ready for that.	1, 2, 3, 4, 6

# Appendix E: Dementia-Friendly Surveys

# **Dementia-Friendly Survey Distribution**

**When:** 28/06/2019 – 01/08/2019 **Where:** Available online using Survey

Monkey and distributed in print

#### Responses

- 23 people living with dementia or a carer of a person with dementia
- 52 small businesses and organisations

#### Distribution:

- Dementia Australia
- Fitzgerald Aged Care Facility
- Anglicare
- Health and Leisure to You
- Nepean Blue Mountains Primary Health Network
- Atkinson Turner Community Services
- Wendys Home Services
- Nova Employment Services
- Hawkesbury Living
- Richmond Market Place
- Curves North Richmond
- Windsor Market Place
- Chamber of Commerce
- Riverview Shopping Centre
- Crown Plaza Hawkesbury
- Windsor RSL
- Richmond Club
- Rotary
- Hawkesbury City Council Dementia Working Group
- Hawkesbury City Council
- Macdonald Valley Association
- Lynwood Country Club
- Crown Plaza Hawkesbury
- Hawkesbury Leisure and Learning Centre
- Lime and Coconut Café
- Windsor Post Office
- Blooms Chemist Windsor
- Hawkesbury Local Area Command
- Platform Youth Services
- Peppercorn Services Inc.
- Uniting
- The Women's Cottage
- Australia Resource Centre for PTSD
- Your Town
- TAFE NSW
- St John of God Community Health
- Health Care Australia
- Hawkesbury Community Services
- Hawkesbury Valley Baptist Church
- Flourish Australia

- Richmond Community Services Inc.
- Western Sydney Community Care Forum
- Samaritans
- Street Med
- Aftercare
- Hawkesbury Community Outreach Services
- YMCA Hawkesbury
- Be&Co
- Australian Unity
- Hills Nursing
- Strong Nation
- Aged Care Assessment Service (RAS)
- Western Sydney Community Legal Centre
- Family planning NSW
- Tedd Noffs Foundation
- Quovus
- Hawkesbury early childhood intervention service
- Settlement Services International
- Support Choices Australia
- Wentworth Housing
- Salvation Army
- Parramatta Mission
- Just Better Care
- Butts Worth Engineering
- Ability Options
- Bligh Park Community Services
- North Richmond Community Centre
- Evolve Housing
- One80tc
- Northcott
- MacDonald Valley Association

# Survey Responses: people living with dementia or a carer of a person with dementia

Hawkesbury City Council surveyed 23 residents regarding their experience of living with dementia or being a carer for a person with Dementia.

The respondents surveyed indicated:

- 55% men and 45% women completed the survey
- 39% live within the rural areas and 61% in residential areas of the Hawkesbury
- 74% were carers completing the survey on behalf of the person living with dementia and 9% were completed by a person living Dementia
- 30% of respondents were under the age of 60
- 20% non-Australian
- 55% of people living with dementia live with family or living with a Carer.

#### The survey data showed:

- 45% of people go out most days and their main outings are shopping, attending medical and health care appointments and going to cafes and restaurants
- 73% of residents advised that support from family and friends is the greatest assistance when doing things around the community
- 57% people advised that feeling welcome also assists them when out and about in the community
- 50% of people find that difficulty with physical mobility makes it more difficult for them to do things in the community
- 45% of people have concerns around becoming confused or being a burden to others
- 65% of people advised that they wish they had more social contact with people in the community.

Who is completing this survey?	
I am a carer/friend/family member completing the survey on behalf of a person living with dementia	17
I am a carer/friend/family member completing the survey on behalf of myself	4
I am a person living with dementia	2
Other (please specify)	0
Answered	23
Skipped	0

Which town do you live in?	
Richmond	6
I do not live in the Hawkesbury Local Government Area	4
North Richmond	3
Bligh Park	2
Kurmond	1
Kurrajong	1
South Windsor	1
Windsor	1
Wisemans Ferry	1
Answered	20
Skipped	3

What is your age?		
18 or younger	0%	0
19 - 29 years old	0%	0
30 - 39 years old	0%	0
40 - 49 years old	5%	1
50 - 59 years old	30%	6
60 - 69 years old	15%	3
70 - 79 years old	10%	2
80 - 89 years old	20%	4
90 - 99 years old	20%	4
100 or older	0%	0
	Answered	20
	Skipped	3

What do you identify as?		
A woman	45%	9
A man	55%	11
	Answered	20
	Skipped	3

What is your cultural background?		
Australian	80%	16
Swiss	5%	1
British	5%	1
Dutch	5%	1
Anglo Indian	5%	1
	Answered	20
	Skipped	3

How do you typically live?		
I live on my own	25%	5
I live with my family/carer	55%	11
I live with someone who is not my carer	5%	1
I live in a care home	15%	3
Other (please specify)	0%	0
	Answered	20
	Skipped	3

How often do you get out of the house?		Responses
I go out most days	45%	9
I go out every couple of days	35%	7
I go out a few times a month	10%	2
I go out less than once a month	5%	1
Other (please specify)  • He doesn't	5%	1
	Answered	20
	Skipped	3

What do you do when out in the Hawkesbury? (select all that apply)		
Shop	72.73%	16
Attend medical and health care appointments e.g. GP, physiotherapy, podiatry	72.73%	16
Eat Out, cafes, restaurants	59.09%	13
Visit parks	45.45%	10
Run errands e.g. banking, post office	40.91%	9
Movies, Concerts, theatre or other performances	27.27%	6
Play sport or do a physically activity such a bowls, tennis	22.73%	5
Gardening	13.64%	3
Attend place/s of worship e.g. church, mosque, temple	13.64%	3
Museum or art gallery	13.64%	3
Dancing, music	9.09%	2
Hobby group e.g. wood work, sewing, paper craft, hobbies group	9.09%	2
Library	9.09%	2
Play cards or board games	4.55%	1
Community Groups such as Probus, Lions, Senior Citizens, Men's group	4.55%	1
Don't do anything in my local area	0.00%	0
Other (please specify)  Work  Walking around on the veranda  go for drive  he doesn't go out. Stays at home and watches TV  Visit family  assist with community action groups for the benefit of our community needs  Visit Granddaughter	31.82%	7
	Answered	22
	Skipped	1

What helps you to do things in the community?		
Support from family and friends	71.43%	15
Feeling welcome	57.14%	12
Support from business e.g. friendly and helpful staff	47.62%	10
Support from Services e.g. disability or aged care support	38.10%	8
Good physical accessibility	28.57%	6
Access to respite as needed	23.81%	5
Signs to help me find my way around	19.05%	4
Public transport	14.29%	3
Other (please specify)	9.52%	2
<ul> <li>do not need help</li> <li>Mum visits her sister and goes to the local shop</li> </ul>		
	Answered	21
	Skipped	2

What makes it more difficult for you to do these things?		
Difficulties with physical mobility	50%	10
Decreasing physical health	45%	9
Worry about becoming confused	45%	9
Not wanting to be a burden to others	45%	9
Worry about getting lost	40%	8
Lack of confidence	30%	6
Waiting for services	30%	6
Lack of support from support services	20%	4
No knowing where to get support	20%	4
Financial concerns	20%	4
Lack of companionship	20%	4
Feeling unwelcome	15%	3
Difficult Service system to work out	15%	3
Lack of Respite services	15%	3
Concerns with community service providers	15%	3
Lack of transport	10%	2
Lack of support from businesses	5%	1
The things I enjoy are not available	5%	1
Other (please specify)	25%	5
Not trusting of service		
<ul> <li>leaving the person with dementia behind, as I am a carer</li> </ul>		
Mum only visits her sister and the local shops		
Difficulty leaving my husband alone		
<ul> <li>None of these relate. Activity only ceased due to physical health of my parents</li> </ul>		
	Skipped	3
	Answere d	20

Are there things that keep you from going out and doing things like sho eating out that you previously did?	pping, errand	s and
Concern about getting lost or confused	83.33%	15
I prefer to stay at home	52.63%	10
Difficulty communicating with staff at stores, cafes, banks	60.00%	9
People seem to feel awkward or tense around me when I go out because of my diagnosis	44.44%	8
People seem to feel awkward or tense around me when I go out because my family member's diagnosis	35.29%	6
Not enough support from family, friends or carers to assist me to do those things	28.57%	4
No appropriate services available nearby	20.00%	3
Other health problems keep me from going out	16.67%	2
Other (please specify)  Mum only visits her sister and the local shops  Consistency and routine is paramount. Even if the slightest thing is different it throws them. e.g. changing the position of particular groceries in the supermarket		3
•	Answered	20
	Skipped	3

Do you wish you had more social contact with people in the community?				
Yes	65%	13		
Unsure	25%	5		
No	10%	2		
	Answered	20		
	Skipped	3		

What do you think could be done to make the Hawkesbury a more dementia-frien community?	ndly
Comments/Suggestions	DFH Plan Objective
Richmond / Windsor needs to have a specific centre established. Currently the centre that my spouse attends has to be set up daily for the group as it is a shared facility.	2, 4, 6
Educate people on dementia and make them familiar with the disease so they can feel more at ease with the people living with dementia. Especially also around helping out with supports for carers and families. Offer more events that specifically include also younger onset dementia sufferers, who are still in the age of working life.	2, 3, 4, 5
People need to understand the disease more. I may not be able to work out change or how to use my card, or even directions to a place. But i can still do things and I am not stupid.	1, 3
Knowledge and acceptance by the community that this can and is a young persons disease also	3
Unsure as my mum won't go anywhere	8
More respite rooms available for carers and their husband/wife	2, 6
The wider community needs to be educated to understand that dementia affects young people (ie under 65 yrs) as well as older people AND that the diagnosis often comes a long time before we become bed bound and non-communicative. So, because of this people with dementia are often struggling with communication and simple tasks on a busy world where speech is fast, patience lacking and it feels like too much is happening even in relatively quiet places. If services and shops etc could be understanding that and go/speak slower, have quiet spaces for those who need it, and signage was simpler (less decorative so letters could be identified) it would help a lot	2, 3, 9
Education on dementia including workshops for carers	3
More public awareness of dementia & its affects	3, 2
Can't think	1
More care providers and support for all, especially those without family close by.	2, 4, 6
Awareness for customer service staff of how to recognise and deal with customers with dementia.	3
Support when I get confused Do things during the day not night.	2, 4, 6, 9
After hours support	4
Education on dementia and the need for patience when dealing with them. They take a long time to analyse and make decisions when they are out, even making payment confuses them.	3, 8
More Awareness	3
Make the Community more Dementia-Friendly	1, 2, 3, 4, 5, 6, 7, 8, 9

# Survey Responses: businesses, organisations and service providers

Hawkesbury City Council surveyed 51 businesses and organisations regarding their experience of working with and interacting with people with dementia.

The respondents surveyed indicated:

- 75% of businesses advised that they operate across the entire Hawkesbury LGA
- 17% of businesses were retail and 62% were Family, Child, Aged and Disability care services
- 78 % of business identified that they have customers with dementia
- 86% advising that their business would benefit if they support people with dementia
- 48% of businesses feel their staff don't know how to support and communicate with someone
  with dementia
- 51% of businesses did not know where to go for resources to train their staff in supporting people with dementia
- 75% of businesses would consider learning how to better assist people with dementia, and 25% advised that they had already done so (No respondents said they would not consider learning how to better assist people with dementia)
- 82% of businesses would consider reviewing the physical environment and involving people with dementia in these changes

Which town/s do you operate in?		
I operate over the whole Hawkesbury Local Government Area	75.51%	37
Richmond	14.29%	7
Windsor	14.29%	7
Riverstone	10.20%	5
South Windsor	8.16%	4
Kurrajong	6.12%	3
Wilberforce	6.12%	3
Bilpin	4.08%	2
Blaxlands Ridge	4.08%	2
Bligh Park	4.08%	2
Bowen Mountain	4.08%	2
Colo	4.08%	2
Clarendon	4.08%	2
Colo Heights	4.08%	2
East Kurrajong	4.08%	2
Glossodia	4.08%	2
Kurmond	4.08%	2
Kurrajong Heights	4.08%	2
Mulgrave	4.08%	2
St Albans	4.08%	2
Vineyard	4.08%	2
Agnes Banks	2.04%	1
Ebenezer	2.04%	1
Freemans Reach	2.04%	1
Grose Vale	2.04%	1
Grose Wold	2.04%	1
Higher Macdonald	2.04%	1
Hobartville	2.04%	1

Which town/s do you operate in?		
Kurrajong Hills	2.04%	1
Maraylya	2.04%	1
McGraths Hill	2.04%	1
North Richmond	2.04%	1
Oakville	2.04%	1
Pitt Town	2.04%	1
Pitt Town Bottoms	2.04%	1
Richmond Lowlands	2.04%	1
Tennyson	2.04%	1
Upper Macdonald	2.04%	1
Webbs Creek	2.04%	1
Wheeny Creek	2.04%	1
Windsor Downs	2.04%	1
Wrights Creek	2.04%	1
Yarramundi	2.04%	1
Berambing	0.00%	0
Bucketty	0.00%	0
Cattai	0.00%	0
Central Macdonald	0.00%	0
Cornwallis	0.00%	0
Cumberland Reach	0.00%	0
Fernances	0.00%	0
Leets Vale	0.00%	0
Lower Macdonald	0.00%	0
Lower Portland	0.00%	0
Mellong	0.00%	0
Mogo Creek	0.00%	0
Mountain Lagoon	0.00%	0
Perrys Crossing	0.00%	0
Putty	0.00%	0
Sackville	0.00%	0
Scheyville	0.00%	0
Ten Mile Hollow	0.00%	0
The Devils Wilderness	0.00%	0
The Slopes	0.00%	0
Upper Colo	0.00%	0
Wisemans Ferry	0.00%	0
Womerah	0.00%	0
I do not operate in the Hawkesbury Local Government Area	0.00%	0
	Skipped	3
	Answered	49

Please indicate the type of organisation or business you op	perate	
Retail	12.00%	9
Aged Care Service Provider/Assessment	16.00%	12
Carer/Family/Children Services	14.67%	11
Disability Service Provider/Assessment	12.00%	9
Finance/Banking	6.67%	5
Government Services (Local, State and Federal)	6.67%	5
Health	5.33%	4
Food/beverage/hospitality	4.00%	3
Fitness	4.00%	3
Charity	4.00%	3
Club/Entertainment	2.67%	2
Tourism/Travel	2.67%	2
Animal services	2.67%	2
School/Education	1.33%	1
Transport	1.33%	1
Emergency Services	1.33%	1
Housing	1.33%	1
Creative Arts	1.33%	1
Pharmacy	0.00%	0
General Practitioner	0.00%	0
Trades people	0.00%	0
	Answered	51
	Skipped	1

How much do you agree /disagree with the following										
	Strong Agre		Agre	e	Neithe	r	Disagi	ee	Strong Disagr	
Our organisation/ business has customers with dementia	39.22%	20	39.22%	20	11.76%	6	3.92%	2	5.88%	3
Our organisation/ business will benefit if we support people with dementia	52.94%	27	33.33%	17	9.80%	5	1.96%	1	1.96%	1
Our staff know how to support people with dementia	25.49%	13	27.45%	14	33.33%	1 7	11.76 %	6	1.96%	1
Our staff know how to communicate with people with dementia	21.57%	11	31.37%	16	33.33%	1 7	11.76 %	6	1.96%	1
I know where to go for resources to train our staff in supporting people with dementia	23.53%	12	25.49%	13	9.80%	5	33.33	1 7	7.84%	4
		1		1				Ans	swered	5 1
								Ski	pped	1

Please indicate whether you have done or would consider doing the following to move towards your organisation/business being Dementia-Friendly:								
	Have done consider doing		Have done		Have done		Would no conside doing	
Learning better to assist people with dementia	25.00%	13	75.00%	39	0.00%	0		
Committing to supporting people with dementia	37.25%	19	58.82%	30	3.92%	2		
Supporting staff in dementia awareness	25.49%	13	70.59%	36	3.92%	2		
Reviewing our physical environment	9.80%	5	82.35%	42	7.84%	4		
Reviewing information we provide to the community	9.80%	5	90.20%	46	0.00%	0		
Involving people with dementia in these changes	7.84%	4	82.35%	42	9.80%	5		
Planning to review our level of dementia-friendliness	9.80%	5	88.24%	45	1.96%	1		
Becoming recognised as a Dementia-Friendly organisation/business	13.73%	7	82.35%	42	3.92%	2		
					Answered	52		
					Skipped	0		

What do you think could be done to make the Hawkesbury a more Dementia-Friendly community?			
Comments/Suggestions	DFH Plan Objective		
Sensory gardens in parkland Training for Dementia-Friendly services Speaker in schools to talk about Dementia-Friendly approach to people sitting in the community	8 3, 4, 6, 8, 9 3		
Create more understanding and awareness	3		
Having a trained support person who could be booked to accompany dementia people into community for shopping activities etc.	4, 5, 6, 7		
Increase awareness in local business	3, 9		
Blanket free training in each district business	3, 9		
Information	2, 3,		
A master plan for emergency situations	2, 3, 4, 6, 7		
Training businesses to be more aware	3, 9		
Opportunity for carers and general community members to participate in information sessions to learn more about dementia and how this can increase the likelihood of it ultimately leading to a dementia-friendly community.	2, 3, 4		
Support for implementing the 'compassionate communities' project to assist people who are socially isolated - Council in partnership with PHN	2, 4, 6		
Awareness and respite support for carers	2, 4, 6		
More knowledge and education	3		
Education to community	3		
Education, inclusiveness, services	3, 4, 5, 6, 7, 8, 9		
Community Support Group	2, 4, 6		
Providing services such as music therapy for both carers and sufferers	2, 4, 6		
Education for everyone is essential. Essential oils would be good.	2, 3, 6, 9		
Free support for carers. More understanding	2, 3, 4		
Create a more accessible community. Simplify navigation of services	2, 6, 8		
Organise free sessions, workshops or support group for people with dementia	2, 3		
Unknown	-		

Comments/Suggestions	DFH Plan Objective
Advertise more	2
Area for them to be together in a safe activity based environment	6, 8
This has given me the idea of proving entertainment for people with dementia	2, 4, 9
Community Education, understanding how to access services and help when it is needed	2, 3
Access to animals as therapy	2, 4, 6
Assist the community by providing information to who come into the centre Advertise information in the Gazette Information and flyers	2
Consider all areas where carers require more assistance to meet the needs for carer and care recipient	2, 4, 5, 6, 7, 8, 9
More information for the community of available resources, advertising	2
I honestly don't know, except more understanding	3
More support services such as community social groups and respite services for carers.	4, 6
Increased community awareness - give people the skills of what to do. Reduce people's fear of getting it wrong.	2, 3
Provide hands on support at the coal face	4, 6
Making people aware that dementia patients still have something to offer.	3
Have people with the condition wear a "I am trying to live with a condition named Dementia" (personal experience of course tells me they may forget to put it on - perhaps they could wear a permanent bracelet). Easily identifiable by the public, in conjunction with a campaign of awareness. Have general public wear the badge to offer they are aware. We recognise visually impaired because they have either a guide dog or a cane we're offered their condition by a 'symbol'	3
More awareness and supporting a central hub for dementia services (something raised by Dr Ravi in the past).	2, 3, 5, 6, 8, 9
Raised awareness within the business and general community about living with dementia and how it can impact a person, how to respond and communicate.  Advertised dementia safe spaces - cafes, businesses, transport, shops, social settings.	2, 3, 9
Just lots of education and information	3

