

DEMENTIA FRIENDLY

NOOSA COMMUNITY MEMORY SUPPORT PACK

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dementia
friendly
communities

NOOSA *Care*
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INTRODUCTION

Dementia describes a number of conditions that can affect the way people think, act and perform everyday tasks. The effects are gradual, often taking place over months or years.

A diagnosis of dementia can be overwhelming. Obtaining accurate information and support will help you understand what to expect and make plans for the future. We hope the information and resources provided in this pack, along with the *Dementia Priority Checklist* will give you and your family direction during the early stages after diagnosis.

NoosaCare's Dementia Friendly Advisory Board

DEMENTIA FRIENDLY COMMUNITIES

Currently, around 70 per cent of people with dementia live in the community and 44 per cent of them live alone. This is expected to grow as the prevalence of dementia in Australia is projected to increase to almost 1.1 million by 2058.

Our Noosa community recognises that it is every individual's right to continue to live their lives as they choose, to participate in community activities they enjoy and to be empowered, supported and included in these activities. We will continue to foster our Dementia Friendly Noosa towards supporting our locals who live with dementia and their carers.

“Losing the ability to communicate is one of the most frustrating challenges for a person living with dementia. As the illness slowly progresses, their ability to communicate becomes more difficult. A dementia-friendly community is a place where people living with dementia are supported to continue living their lives with purpose and meaning.

As a community we must educate ourselves to ensure the communication lines remain open for all. Let's continue to evolve our incredible community to an inclusive dementia friendly Noosa”.

Cassandra Whadcoat, R.N.

NoosaCare's Memory Support Community

EARLY SIGNS OF DEMENTIA

The early signs of dementia can be very subtle and are unique to each person. While we all forget things from time to time, memory loss associated with dementia is very different. You may be experiencing difficulties recalling important information, following a conversation or writing a letter. It is natural to feel confused, worried and anxious about the changes you are experiencing. Talking to someone about it, is the first step.

Warning signs of early stage dementia may include one or more of the following:

1. Memory loss that disrupts daily life
2. Repetitive behaviour
3. Difficulty performing familiar tasks
4. Social isolation
5. Confusion about time and place
6. Problems with abstract thinking
7. Loss of initiative
8. Poor or decreased judgement
9. Language problems
10. Behavioural, personality and mood changes

For more information, call the National Dementia Helpline (1800 100 500).

QUICK COMMUNICATION TIPS FOR FAMILIES AND FRIENDS

Dementia can affect a person's ability to process information, reason, communicate and learn. In this reference guide we have suggested some simple things **YOUR FAMILY AND FRIENDS** can do to help keep conversations flowing naturally.

- D** Demonstrate understanding and empathy
- E** Eliminate background noise and distractions
- M** Maintain eye contact and open relaxed body language (smile)
- E** Enter their reality, don't try to bring them into yours
- N** **Never** overwhelm with too much information, focus on one question or instruction at a time
- T** Tone and pitch of your voice is important, avoid speaking sharply or raising your voice
- I** Initiate support when a person is sad or confused, validate their feelings, don't argue or dismiss
- A** Allow the person plenty of time to respond, it may take them longer to process the information

DEMENTIA PRIORITY CHECKLIST

The Dementia Priority Checklist has been developed to assist you and your family navigate through some challenging first steps after a diagnosis of dementia. Further information, important phone numbers as well as links to online resources and forms are provided throughout this document.

We hope you find the list below practical and helpful:

- ☐ ***Learn as much as you can about dementia so that you can find your own unique approach to managing changes associated with dementia.***
- ☐ ***Talk to your family and friends about your diagnosis and how they can help you.***
- ☐ ***If you live alone, talk to family and friends about assigning someone as your emergency contact/support person.***
- ☐ ***Contact MyAgedCare to discuss support options and to arrange an ACAT assessment.***
- ☐ ***Ensure legal, health and financial plans are in place. Do some health, legal and financial short and long-term planning. As a start, complete an Advanced Health Directive (AHD) or Statement of Choices and an Enduring Power of Attorney (EPOA). Learn about the financial support and services available to you through MyAgedCare.***
- ☐ ***Research local resources that you may require in the future i.e. in-home care, respite services or residential aged care facilities.***
- ☐ ***Create a wellness plan that incorporates staying social and active in your community, maintaining a healthy diet, counselling and support.***

LEARN - EDUCATION AND SUPPORT

Dementia affects people in different ways and each person will find their own approach to managing changes associated with dementia. Learning about the disease can help you and your loved ones understand what changes to expect, make plans for the future and improve your quality of life.

There are a number of programs and resources that you may find helpful:

Dementia Australia delivers national dementia programs and services including:

- The National Dementia Helpline
- Early intervention programs such as Living with Memory Loss
- The National Younger Onset Dementia Key Worker program
- Dementia and Memory Community Centres
- Counselling
- Carer education and support groups
- Public awareness activities and a national resources program.

National Dementia Helpline is available Monday to Friday, 9.00am – 5.00pm. Phone 1800 100 500. For more information, visit Dementia Australia www.dementia.org.au

The Dementia Australia Library provides free resources for people with dementia, their carers, friends and family. The collection includes books, magazines, DVDs and CD's, covering a range of subjects. 24 hour access to e-books and audio books can be accessed through <https://dementia-e-library.overdrive.com/>

Email library@dementia.org.au for more information.

Alzheimer's Queensland offers a range of services including in-home support and physiotherapy, education, nursing homes, training and much more. Alzheimer's Queensland Help Line 1800 639 331 Free call, 24 hours.

Carers Queensland supports carers and offers counselling, education, support groups and social events. The monthly Dementia Family Carer Support Group is held on the first Wednesday of each month from 10am - 12 noon, at 1/10 Wrigley St, Maroochydore. Phone (07) 5451 1882. www.carersqld.asn.au

The Wicking Dementia Research and Education Centre is an integrated dementia centre, seeking to improve the lives of people with dementia and their carers. Based at the University of Tasmania, the centre offers free, online MOOCS courses (Massive Open Online Courses): Understanding Dementia and Preventing Dementia. Information and enquiries, call 1800 982 600, email wicking.enquiries@utas.edu.au or visit <http://www.utas.edu.au/wicking>

GET REGULAR MEDICAL CARE

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It is important to find an understanding doctor who can guide you through the formal diagnosis process as well as provide ongoing support and understanding for you and your family. A good way to find a doctor with an interest in aged care is to talk to your family pharmacist.

Plan regular visits to your doctor to check your general health and wellbeing as they will be responsible for coordinating your care, enabling access to further assessment, support services and liaison with your pharmacist. Your doctor will be able to refer you to various specialists if required, such as Geriatricians, allied health professionals, community nursing, support services and complementary practitioners. You may find it helpful to bring a family member or friend to your appointment in order to better understand the disease and treatment. A trusted friend or family member can remember something that you missed or can act as your scribe and take notes for you.

Make a list of questions to ask your doctor, here are a few examples:

1. What type of dementia do I have?
2. Are there any medications that could help?
3. What support can I access?
4. Can I continue to drive?
5. How fast is the progression?
6. Where can I get support?
7. Is this illness hereditary?
8. Ask about diet & nutritional support including caloric and vitamin supplements. This is vitally important to maintaining brain-cognitive and bone-mobility health.
9. Depression is very often associated with the dementia process and left untreated can accelerate the symptoms and impairment. If you have concerns please talk to your doctor.

LOOKING AFTER YOU

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Although there is no single preventative treatment, creating a wellness plan that includes good nutrition as well as physical, mental and social activities can help slow the progression of dementia. Some days may be better than others. Be kind to yourself. Do the things you enjoy and focus on what you can do.

TALK - share your feelings and concerns with family and friends. Support from family and friends can be very beneficial in creating purpose and pleasure when things become difficult.

STAY CONNECTED IN THE COMMUNITY – Continue to enjoy visits and outings with family and friends. Maintaining a healthy social life is important for general health and wellbeing.

STAY ACTIVE - Physical activities such as walking, swimming and gardening stimulates your brain, strengthens your heart and reduces stress and anxiety.

NUTRITION – Eat a well-balanced diet including fruits, vegetables, whole grain products and vitamin supplements to support the health of your brain and body.

MENTAL HEALTH – Speak to your family and doctor if you are experiencing depression or increased anxiety.

ALTERNATIVE HEALTH OPTIONS - You may consider working with a holistic practitioner for a complementary approach to your mainstream medical treatment.

KEEP YOUR BRAIN BUSY - Listen to music, read and challenge your brain with word puzzles and a range of other creative and artistic activities.

ASK FOR HELP – Call the National Dementia Helpline (1800 100 500), open 9.00am to 5.00pm Monday to Friday excluding public holidays.
www.dementia.org.au

PLAN FOR THE FUTURE

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During the early stages of dementia, it is important to document your wishes. As the disease progresses it will become increasingly difficult to make competent decisions. If you haven't already done so, commence legal, medical and financial planning for the future. Consider nominating a person or persons to make decisions on your behalf and organise an Advanced Health Directive (AHD) or Statement of Choices and Enduring Power of Attorney (EPOA) so that you are covered if you lose capacity.

The following will give you an overview of what steps to take in order to document your wishes and plan for the future:

- ☐ Visit your bank or accredited financial advisor for advice regarding bank accounts, insurance and superannuation. For spouses and other close family members, you may consider joint signatures to access financial accounts.
- ☐ An Enduring Power of Attorney (EPOA) allows people to choose someone to act on their behalf in legal, health and financial matters when they are no longer able to do so. It is important to make an Enduring Power of Attorney as soon as possible after diagnosis, while you have the capacity to do so. The form can be found here: www.qld.gov.au/law/legal-mediation-and-justice-of-the-peace/power-of-attorney-and-making-decisions-for-others/power-of-attorney

You can complete an Enduring Power of Attorney form yourself however, we recommend working through this with your solicitor who will be able to give you professional advice tailored to your circumstances.

PLAN FOR THE FUTURE

- ☐ Statement of Choices is an advance care planning (ACP) document used throughout Queensland. Dr Wendy Vidler, who has endorsed the memory support pack, recommends the Statement of Choices as the preferred Advance Care planning document. Form A should be completed by people with capacity to make their own decisions. Form B should be completed on behalf of someone who is either unable to make decisions on their own or requires help to do so. The Statement of Choices document provides clear advice about a person's wishes and health care choices.
- ☐ Visit www.metrosouth.health.qld.gov.au/acp/queensland-advance-care-planning-forms and enter your postcode. The document is uploaded to a national database which can be easily accessed by emergency departments and hospitals Australia-wide.
- ☐ An Advanced Health Directive (AHD), often called a living will, is a formal way to document your wishes and nominate a person to follow your instructions when you are no longer able to make decisions about your health and medical treatment. The AHD can record existing health conditions, allergies and other religious, spiritual or cultural beliefs that could affect your care. In addition, the document can include your decisions regarding life-sustaining measures and acceptable quality of life.
- ☐ We recommend printing out the AHD form and going through this with your general practitioner who is required to sign off on section five. Access the AHD form here: www.publications.qld.gov.au/dataset/power-of-attorney-and-advance-health-directive/resource/6a3af073-cdba-4b82-8de7-eabe65950c24
- ☐ The Queensland Government Advance Care Planning website can provide information regarding the Advanced Health Directive and Enduring Power of Attorney www.metrosouth.health.qld.gov.au/acp
- ☐ Complete an Asset and Income Assessment form in case you need to go into residential aged care at a later stage. The form can help providers determine applicable fees. www.humanservices.gov.au/individuals/forms/sa457
- ☐ We recommend you contact MyAgedCare as soon as possible to arrange an ACAT assessment as there is often a lengthy waitlist. Completing the ACAT assessment will give you the flexibility to know what government funded services are available to you. Phone 1800 200 422 Monday to Friday 8am - 8pm and Saturday 10am - 2pm or visit www.myagedcare.com.au
- ☐ Ensure you give copies of all your documents to family members as well as add them to your Memory Station.

(What is a Memory Station? Go to the Practical Tips section included in this pack).

LOCAL SERVICES AND SUPPORT

Receiving quality local service and support can make a positive difference to managing the daily challenges of living with dementia. This is the time to share what you are experiencing with your family and friends and ask for help with shopping, transport and appointments as needed.

You may find the following services and support networks listed below helpful:

- **Dementia Australia** provides a range of sensitive and flexible services to inform and support people living with dementia as well as their families and carers. Contact the National Dementia Helpline on 1800 100 500.
- **Noosa Community Support (NCS)** is a Noosa Council service offering centre-based day care, house cleaning, personal care, meal, shopping and transport assistance, minor home maintenance and much more. Phone (07) 5329 6175.
- **Sunshine Coast Dementia Network (SCDN)** provides information for people living with Dementia enabling them to make informed decisions, resolve issues and access services. Phone (07) 5476 0642 and mobile 0418 298 183.
- **Sunshine Coast Friendship Group** supports individuals living with dementia and their carers. Meetings are held on the last Wednesday of each month, 2.00 pm- 4.00pm at the Bosco Cafe, 22 Lacebark Street, Meridan Plains. Register through Dementia Australia on 1800 100 500.
- **The Adventure with Dementia** – first support group on the Sunshine Coast to provide activities for people living with Younger Onset Dementia. Participants are challenged within their capabilities to participate in a range of physical activities. Contact Bromilow Community Care on (07) 5445 5676.
- Access local in-home care packages, respite or permanent residential care support through **MyAgedCare**. Arrange an ACAT Assessment through **MyAgedCare** to access these services. Monday – Friday 8am – 8pm; Saturday 10am – 2pm. Phone 1800 200 422 or visit myagedcare.com.au
- **Aged and Disability Advocacy Australia (ADA)** has more than 25 years experience in supporting and improving the wellbeing of older people and people with disability. ADA Queensland can help manage difficulties with your Enduring Power of Attorney, Guardianship, administration arrangements, residential care, in-home or community care services. Call 1800 818 338 for information and advice. Office Hours are Monday to Friday, 9.30am – 4.00 pm.

HELP WITH DAILY TASKS

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Although you may feel uncomfortable asking for help with daily tasks, the additional support can actually help you maintain your independence while living in your own home.

- Ask family and friends to help you with transportation, cooking, mowing, paying bills or shopping. Alternatively, if unable to help due to work, location or other limitations, they could assist by arranging for a service provider to help with routine tasks.
- Use simple memory aids like a notepad, calendar on the wall or post-it-notes to remind yourself of tasks and a 7-day pillbox to keep medication organised.
- The following links provide access to information sheets to share with your family and friends:

www.dementia.org.au/files/helpsheets/Helpsheet-TipsToAssistSocialEngagement01-TipsForFriends_english.pdf

www.dementia.org.au/files/helpsheets/Helpsheet-TipsToAssistSocialEngagement06-TipsForCaringFromADistance_english.pdf

www.dementia.org.au/files/helpsheets/Helpsheet-TipsToAssistSocialEngagement02-TipsForVisiting_english.pdf

SAFETY AT HOME

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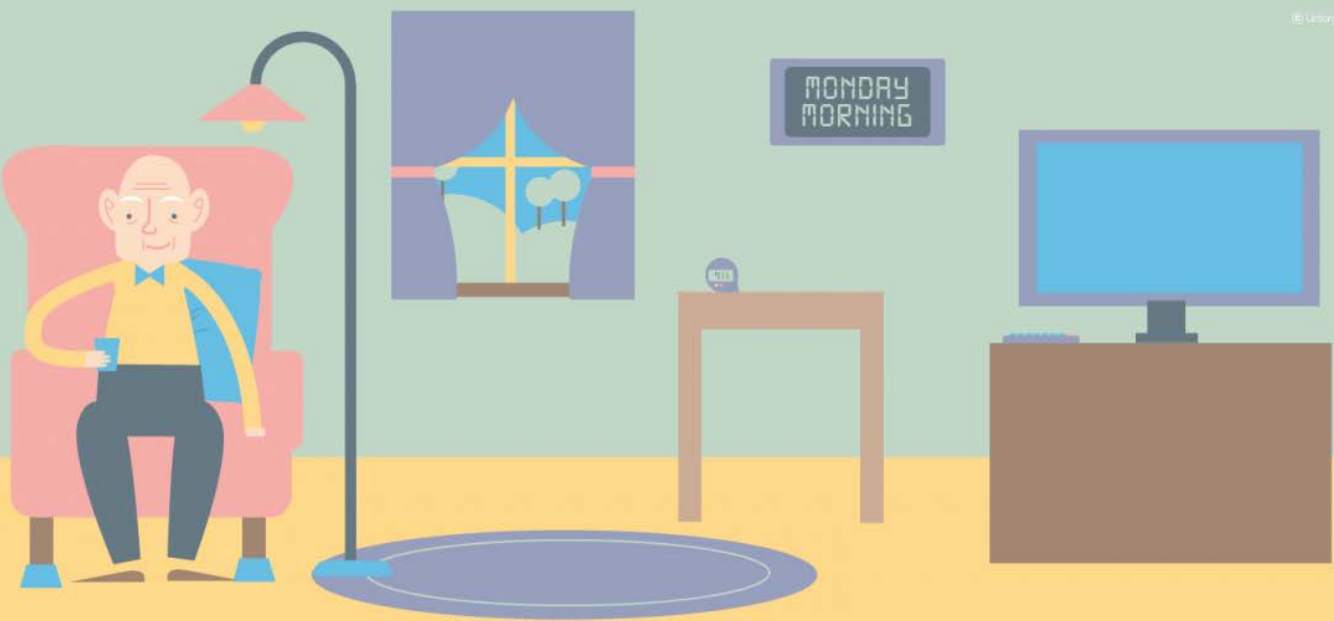
As your capabilities change, it is important to modify and adapt your home environment to minimise safety risks while keeping your surroundings comfortable and familiar. The following information will help you and your close family and friends get started:

Helpful safety tips for in and around the home can be found here:

<https://www.dementia.org.au/national/support-and-services/carers/safety-in-and-around-the-home>.

- **The Noosa Home Assist Secure** service provides free safety-related information, referrals and subsidised assistance to eligible clients unable to undertake or pay for critical maintenance services and home security.
- Home Assist Secure is a State Government funded program delivered through Noosa Council by **Noosa Community Support**. For information on eligibility and general enquiries contact Home Assist Secure on (07) 5329 6181.
- **Maroochy Home Maintenance and Care Association**, a not-for-profit organisation based at Kunda Park on the Sunshine Coast, funded by Federal and State Governments, offers home maintenance and modifications (minor and major) for frail/aged and/ or disabled clients throughout the Sunshine Coast and Gympie regions. For more information, please phone (07) 5476 6130.

PRACTICAL TIPS



HELPING YOUR MEMORY

Keeping to your usual routines can help reduce anxiety and stress. You may find it helpful to use a diary for appointments or make lists of regular outings as well as daily, weekly and monthly activities and tasks. Create notes to tell you what you have to do or how to do it. Place the lists or diary on the fridge or in your 'Memory Station' (see below) and give copies to your close family and friends.

MEMORY STATION

Create a 'Memory Station' in your house near the phone or wherever you need it most. Your Memory Station will be a place where you keep all your important items and documents in one place for easy access. Items that you may like to add to your Memory Station could include:

- **medications and prescriptions**
- **photos of family and friends labelled with names**
- **medical documents e.g. history, referrals**
- **doctor and specialist contact details**
- **important contacts including family, friends and emergency numbers**
- **financial & legal information**
- **bills**
- **any other important information you need to have on hand**

LOCAL TRANSPORT SERVICES

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As your needs and capabilities change, you may like to consider alternative transport options. To maintain your health, wellbeing and social connections, it is important to continue to visit family and friends while participating in regular outings and activities.

In addition to asking family, friends and carers to assist you with transport, you may like to consider using one of the following options:

- ☐ MyAgedCare Services – after completion of the ACAT assessment, you may be eligible for transport services. To check your eligibility, phone 1800 200 422 or visit <https://www.myagedcare.gov.au/>
- ☐ Suncoast Cabs - (07) 5441 8888 or 131 008 (local call)
- ☐ ComLink is a Queensland not-for-profit organisation providing transport and care services for a small fee. Phone 1300 761 011.
- ☐ You may be eligible for the Taxi Subsidy Scheme (TSS). This service is available for people who are unable to travel on public transport without the assistance of another person. Phone 1300 134 755



Every individual has the right to mobility and independence. Talk to your doctor if you are confused about driving or if family and friends are concerned.

Dementia Australia has an important role in ensuring that the issue of driving is appropriately and sensitively handled. Driving should not be challenged if drivers have the functional ability to do so without risking their own safety, safety of their passengers, other road users and pedestrians. More information can be found here: <https://www.dementia.org.au/resources/dementia-and-driving-qld>

INFORM GOVERNMENT ORGANISATIONS

- ☐ MyGov - for any changes or amendments to current services, please advise MyGov as soon as possible to avoid possible difficulties in the future. MyGov is a simple and secure way to access government services online with one login and one password. MyGov online, visit www.my.gov.au or phone MyGov helpdesk on 13 23 07 select option. The following government services can be linked to your MyGov account:
 - Centrelink
 - Department of Veteran's Affairs
 - Medicare
 - My Aged Care,
 - My Health Record and the
 - National Disability Insurance Scheme.
- ☐ Medicare Australia - on 132 011 or at www.medicareaustralia.gov.au
- ☐ Enduring Power of Attorney (EPOA) - your nominated Enduring Power of Attorney can update information on your behalf once you are unable to do so.

LOCAL AGED CARE FACILITIES

NoosaCare, Incorporated Carramar Residence in Tewantin 186 Cooroy-Noosa Road, Tewantin Phone: (07) 5449 8799	NoosaCare, Incorporated Kabara Residence in Cooroy 20 Topaz Street, Cooroy Phone (07) 5447 7355
Ozcare Noosa Heads Aged Care Facility 80 Cooyar Street, Noosa Heads Phone: 1800 692 273	Arcare Peregian Springs 33 Ridgeview Drive, Peregian Springs Phone: (07) 5351 2500
Japara Noosa Aged Care Home 119 Moorindil St, Tewantin Phone: (07) 5447 1840	Sapphire Noosa 3 Adensfield Ct, Cooroibah Phone (07) 5447 1832

PRIVATE HOME CARE SERVICES

Homecare Assistance Noosa/Tewantin

In-home care provides seniors with one-to-one assistance in the comfort of their own home, which enables them to live independently.

Phone (07) 5491 6888.

Home Instead Senior Care Sunshine Coast

Home Instead CAREGivers provide compassionate and reliable home care services, helping to keep seniors living happily, safely and independently in the comfort of their own home. Home Instead provide a free guide for carers and families that can be downloaded from their website www.homeinstead.com.au/resources/dementia.

Phone (07) 5443 3562.

NOOSA COMMUNITY – HOW CAN I HELP?

I'd like to help support people living with dementia but I don't have a lot of time. Is there anything I can do?

YES!

Become a dementia friend and notice how small acts of support make a big difference in the life of someone living with dementia. For more information, visit www.dementiafriendly.org.au

Here are a few more suggestions that can help people living with dementia.

- Learn about Dementia. Educating yourself as much as you can will help you understand and empathize with your loved ones, friends or community members. Find out more at the following sites run by Dementia Australia <https://www.dementia.org.au/> or www.dementiafriendly.org.au.
- Encourage your family, friends and employers to think about what life might be like for people with dementia. Talk to them about being aware of the symptoms of dementia and how a little support and understanding can make it possible for people to live well with dementia.
- Always use respect & dignity- focus on what the person living with dementia can do, not what they can't.
- Be a good listener with your ears, eyes and heart. Give them your full attention and take the lead from the person living with dementia.
- Help them maintain independence. By supporting them so they can do as much as they can for as long as possible. Why not pop in from time to time and ask if they need help with anything.
- Meet them in their now and speak to them in a warm and calm voice. Sometimes the conversation may not seem present and real to you – just accept it because it is for them and go with 'their flow'.

We hope that by reading this guide, people will have a better understanding of how living with dementia can affect everyday living at home and in the community. Although dementia is a progressive disease, it is often difficult to identify. People living with dementia, especially in the early stages, work very hard to mask their symptoms which can be exhausting and terrifying, especially in public. For most members of our community, just being aware is extremely supportive.



The Dementia Friendly Memory Support pack has been developed by NoosaCare's Dementia Friendly Community Advisory Board in partnership, and informed by people living with dementia, and their carers.

Enquiries

If you would like to speak to NoosaCare's Dementia Friendly Community Advisory Board, please call us on (07) 5449 8799.

Disclaimer

The information and statistics in this pack are provided as a guide only.

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