

MEMORY CONCERNS AND BEYOND

New England and Northwest NSW



Where to go for help?

Information and support services for people living with memory loss and dementia, their carers and family.

**Access to phone numbers
listed in this booklet:**

If you have a hearing or speech impairment call **1800 555 677** and ask for the phone number you want to call.







If you need an interpreter (free service) call **131 450** and ask for the phone number you want to call. It is important to know that people living with dementia often revert to their birth language.



The New England Dementia Partnership acknowledges the traditional custodians of the land on which we walk upon today as the First People of this country.

We pay respect to their continuing culture and the contribution they make to the life of this region.

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WHAT IS DEMENTIA?

Dementia is **not** a normal part of ageing. Dementia is a disease of the brain that can affect memory, thinking and behaviour, and how someone performs everyday tasks.

The symptoms of dementia can be caused by different diseases, including Alzheimer's disease, vascular dementia, dementia with Lewy Bodies, frontotemporal dementia, or alcohol-related dementia.

Dementia gradually affects a person's ability to carry out daily activities, such as driving, shopping, getting dressed, going places, and managing money. Over time, it can be difficult for a person living with dementia to live by themselves.

When should I seek help?

Memory loss and changes to someone's thinking or behaviour can be caused by various conditions, including vitamin deficiency, hormone deficiency, infection or medications – the changes may not be caused by dementia.

If the changes are being caused by dementia, finding out early can help a person living with dementia, their carer and family:

- Understand what is happening and why
- Make timely decisions about planning for the future
- Access support and services to help them stay living independently at home

If you are concerned about yourself or someone you know who is experiencing symptoms of memory loss or confusion, it's important to have a conversation with your doctor.



What happens next?

If you are experiencing symptoms, such as memory loss and confusion, your doctor may order tests. The tests may include blood tests and a brain scan. You may also be asked some questions to check your memory, and be asked to write or draw on a piece of paper.

You may be referred to a memory investigation service, where staff have specialised skills and experience in assessing memory loss and dementia. As part of their assessment, they may spend one or two hours with you, your carer and family, to ask all the questions needed.

You could also be referred to other specialist clinicians such as a neuropsychologist, geriatrician, psychogeriatrician (old age psychiatrist), or a neurologist for further assessment and diagnosis.

What else do I need to know?

Your doctor can also refer you to allied health services, if you need them – such as:

- Aboriginal health worker
- Audiologist
- Chiropractor
- Diabetes educator
- Dietitian
- Exercise physiologist
- Occupational therapist
- Osteopath
- Physiotherapist
- Podiatrist
- Psychologist
- Social worker
- Speech therapist

It is recommended you have a regular doctor and local pharmacy.

WHERE CAN I GET INFORMATION?

If you have been diagnosed with dementia, it's important to know where to access information, to help you and your carer:

- Understand the symptoms and progression of the disease
- Understand strategies that can be put in place to support your changing needs and behaviours
- Be informed about useful services and resources

Knowing where to find information and answers can also help carers to:

- Develop skills to care for the person living with dementia while looking after themselves
- Know where to meet and spend time with others who are having similar experiences

**Dementia Australia
National Dementia Helpline
1800 100 500**

Mon-Fri from 9am to 5pm

A free, confidential service that provides support and access to counsellors who can help the person living with dementia, their carers and family manage the impact of dementia. The Helpline



also provides information about dementia and support services in your area, and has a list of local education opportunities.

The website has brochures, help sheets, videos, a lending library, and resources, including resources designed specifically for the **Aboriginal and Torres Strait Islander** (*Your Story Matters*), **Culturally and Linguistically Diverse (CALD)**, and **LGBTIQ** communities.

dementia.org.au

The website also contains useful apps for tablets and mobile phones, such as the Dementia Friendly Home app, which provides carers and family with ideas for the home, and the BrainyApp to help everyone keep their brain healthy.



Younger Onset Dementia (YOD)

There are services designed specifically for people under 65 years diagnosed with dementia. These services provide information, support, counselling and referral to other services that can help. For further information call the **National Dementia Helpline** on **1800 100 500** or visit **dementia.org.au**

Changes in behaviour

Sometimes dementia can cause changes in a person's behaviour which may be upsetting for their carer and family. Changes can also occur due to an underlying illness, pain or discomfort. It's important to always discuss any concerns or behavioural changes with your doctor.

Dementia Support Australia
1800 699 799

24 hours

Dementia Support Australia provides over the phone advice on how to manage and respond to changes in behaviour. Staff can also refer carers and family to other support services that can help.

dementia.com.au

National Disability Insurance Scheme (NDIS)
1800 800 110

Mon-Fri from 8am to 8pm

The NDIS provides access to support services for **people aged under 65 years**, including those diagnosed with Younger Onset Dementia. These services can help you manage at home, access health services, or get you out and about. Visit **ndis.gov.au** for further information or speak to your doctor.

WHERE CAN I GET SUPPORT?

Family and friends, church groups, men's and women's groups, and sporting clubs are places where you may find support. However, there are also support groups that are just for people living with dementia and carers.

Dementia support groups are for people living with dementia. The groups provide a supported, social environment with activities and outings. The groups also provide respite for carers, so they can go shopping, go to appointments, play golf, learn a new skill, or catch up with friends.

Carer support groups provide an opportunity for carers to meet others going through similar experiences. Groups may also have guest speakers who can provide expert information on a range of topics.

You can get information about dementia and carer support groups, including when and where they occur, by calling the **National Dementia Helpline** on **1800 100 500**.

New England Northwest

There are a number of dementia and carer groups in the New England Northwest, run by various organisations, including:

- **Armidale Dementia Carer Support**
The Home Nursing Group
1300 698 693
- **Glen Innes Carer Support Life Choices**
(02) 6730 2500
- **Inverell Dementia Carer and Support Services**
Inverell Home Support
(02) 6722 5888
- **Manilla Carer Support HNE Local Health District**
Community Health
(02) 6785 4116
- **Narrabri Dementia Carer Support**
Narrabri Community Health
(02) 6799 2800
- **Tamworth Dementia Carer Support**
Dementia Australia
0427 669 836
- **Walcha Dementia Carer Support**
Walcha Community Care
(02) 6774 2471

Support for carers

Caring for someone can be rewarding, however there can also be challenges. Carers may need to learn to balance looking after themselves while caring for someone else.

If you are a carer, seeking support from family and friends, and sharing your concerns with other carers is important. However, there may be times when you need to talk to a trained professional, who:

- Will understand how you are feeling
- Can help you to find solutions
- Can suggest services to support you and the person you are caring for

**National Australia
Carer Gateway**
1800 422 737

Mon-Fri from 8am to 6pm

The Carer Gateway is a national phone service and website that provides advice, information, resources, and links to support services. The website includes an interactive service finder to help locate the nearest carer support services.

carergateway.gov.au

Carers NSW Australia
1800 242 636

Mon-Fri from 9am to 5pm

Carers NSW provides information, support and counselling to help improve the health, wellbeing, resilience and financial security of carers.

carersnsw.org.au

Young Carers
1800 242 636

Mon-Fri from 9am to 5pm

Young Carers provides support for those under 25 years who are looking after someone in their family, taking them to appointments and/or doing the shopping or cooking. The website has stories from other carers, tips, resources and education scholarships.

youngcarers.net.au



HOW CAN I GET HELP?

If you need help at home, help caring for yourself, or want to know more about respite or residential care, the best place to start is **My Aged Care**.

When you call **My Aged Care**, the staff will ask you some questions so that they can work out what you need and what is the most appropriate next step for you.

If you require general support, **My Aged Care** can refer you to a suitable service at the time of the call. Otherwise, they can arrange for someone to visit you in your home, to work out what services are best for you.

My Aged Care
1800 200 422

Mon-Fri from 8am to 8pm
Saturday from 10am to 2pm

My Aged Care is a one-stop shop for anyone wanting access to services for people aged 65 years or older, or Aboriginal and Torres Strait Islander people who are 50 years or older.

My Aged Care provides information and advice about:

- How the aged care system works
- Types of services that are available, including help at home, respite care and residential care
- How to access services
- Eligibility criteria for services
- Fee estimators and the cost of services

The My Aged Care website allows you to search for services located near your home.

myagedcare.gov.au





Help at home

If you are able to manage but need some assistance with day-to-day tasks, or if you are a carer or family member and need help to look after a person living with dementia, you may be eligible for **help at home** through **My Aged Care**.

My Aged Care may refer you for a home visit with either the **Regional Assessment Service (RAS)**, or the **Aged Care Assessment Team (ACAT)**.

During the home visit, you will be asked questions so that the assessor can work out which services you may be eligible for. The assessor will then assist in linking you to services in your local area.

Some services have a waiting period and for these services you will be added to the **National Queue**, until a service becomes

available. While you wait, the assessor will ensure that appropriate, temporary services are able to help you.

When a service becomes available in your local area, you will need to choose the **provider** you would like to provide those services.

The **provider** will work with you to decide what help would best suit your personal needs. This information will be written into your **personal care plan** by the provider, and you will be given a copy of the plan.

If you can afford to do so, you will be asked to contribute to the cost of **help at home**, respite and residential care. The fees you are asked to pay will depend on your income and assets, as assessed by **Centrelink** or **Department of Veteran Affairs**.



What services can I access in my home?

Help at home is also known as either the **Commonwealth Home Support** or **Home Care Packages Program**.

These services are available to support you to continue to live independently within your own home and to remain socially active. The services also support carers and families to continue to care for someone living with dementia. If you want to know more about **help at home**, contact **My Aged Care**.

Help at home services may include:

- **Domestic assistance** – help with cleaning, clothes washing, shopping
- **Health services** – services such as counselling, dietetics, occupational therapy, physiotherapy, and podiatry
- **Home maintenance** – minor repairs and general maintenance
- **Home modification** – installation of safety aids such as ramps, rails and alarms
- **Nursing care** – assistance with medications and wound dressings
- **Personal care** – assistance with showering and dressing
- **Social support** – group support and activities in the community
- **Transport** – helping you get to appointments, go shopping, and get out and about

Respite care

Respite services can support someone living with dementia while their carer attends to everyday tasks (like shopping), goes to appointments or takes a short break. It also provides carers with an opportunity to care for themselves.

While respite care can be provided **in the home**, there are **day respite centres** which provide a safe, supported environment in the community. Day respite is a good opportunity for people living with dementia to get to know other people, be involved in activities, or go on outings.

Respite can also be arranged for **overnight or over a weekend**, either in the home, a cottage-style respite centre, or in a care facility. Some residential care facilities can offer respite for up to 63 days per year.



Respite care is available by contacting **My Aged Care** to arrange for an assessment.

Emergency Respite Care Commonwealth Respite & Carelink Centre

Phone: 1800 052 222

After hours: 1800 059 059

Commonwealth Respite and Carelink Centres provide information on local carer support, community services and respite care. The service is free and confidential, and the staff can assist with access to emergency and other respite services.



PLANNING AHEAD

Dementia affects everyone differently. However, sooner or later the person living with dementia will need support to make decisions about their health, day-to-day living, finances and legal matters.

Planning ahead is very important. This ensures that important decisions are made while the person is able to make those decisions for themselves, and make their wishes known.

NSW Planning Ahead Tools 1300 887 529

Business hours

Provides information and advice for future legal, health and financial decisions. Planning Ahead also provides access to documents such as a Will or

Advance Care Plan, for anyone living in NSW. The website contains useful information, such as who to call when someone dies, and how to plan for a funeral.

planningaheadtools.com.au

start2talk National Dementia Helpline 1800 100 500

Mon-Fri from 9am to 5pm

Provides practical assistance with planning ahead by providing resources, tools and the information you need to make decisions and put them into action. The information is for anyone living in Australia.

start2talk.org.au

Legal matters

A **Will** is a legal document that sets out who will inherit your assets, money and property when you die. If you die without a Will, your assets will be divided up according to a formula set by the Government. This may not be in line with what you would have wanted. It is also a slow and complicated process, which is stressful for family members.

Enduring power of attorney is a legal document which gives a designated person the power to act on your behalf regarding **legal and financial decisions**, if you are unable to do so for yourself. This differs from a **power of attorney**, where the appointment ceases if you are no longer able to make decisions for yourself.

Enduring guardianship is a legal document which allows a designated person to make decisions on your behalf regarding **lifestyle**, should you be unable to make these decisions for yourself. These decisions may include where you will live and what medical or health treatment you should receive.

Advance Care Directive is a legal document which plans for future medical treatment and care needs. You can read more about this on the next page, under **Advance Care Planning**.

All of these documents can be drawn up by a solicitor, or can be drawn up and lodged with the Registrar of your local court house. These documents are also available on the **Planning Ahead Tools** and **start2talk** websites.



LawAccess NSW
1300 888 529

Business hours

Provides free telephone information, including location of nearest Legal Aid office or Community Legal Centre.

lawaccess.nsw.gov.au

Advance Care Planning

This is a process that helps you to plan for future medical treatment, so that anyone involved in your care, such as your doctor, your carer and your family, understand your wishes.

As part of this planning process, you may want to document your decisions about what treatment you wish to receive, if you are unable to make a decision for yourself and are experiencing a life-threatening illness or injury – this document is called an **Advance Care Directive**.

Whatever you decide, it is important to discuss your plan and any decisions with your carer and family, and your doctor.



Palliative care services

Many people want to spend the end of their life in their homes, with friends and family around them, rather than be transferred to a hospital. Palliative Care is a service that provides care and support to people that choose to die in their home.

The goal of palliative care is to reduce suffering and manage symptoms being experienced by someone at the end of their life, including pain. Palliative care also provides specialised guidance, emotional and practical support to the carer, family and friends.

If you want to access palliative care services, talk to your doctor.

Palliative Care Australia
(02) 6232 0700

Business hours

The Palliative Care Australia website provides information and resources, as well as a service directory, so that you can find a service near you.

palliativecare.org.au

Financial advice and support

Centrelink 13 27 17

Mon-Fri from 8am to 5pm

Centrelink provides financial support, including a carer's allowance, to anyone who is eligible. Centrelink also has financial counsellors that can assist with financial difficulties. A Centrelink assessment may be required if you are accessing help at home, respite care, or residential care.

humanservices.gov.au

Department of Veterans Affairs (DVA) 1800 555 254

If you or your partner has served in the Australian defence force, you may be eligible for financial support or benefits, household help, medical equipment, home or health care. A DVA assessment may be required if you are accessing help at home, respite care, or residential care.

dva.gov.au



Financial Information Service 13 23 00

Mon-Fri from 8am to 5pm

Provides free advice to help you understand your options, plan for retirement, and make informed decisions about your finances.

humanservices.gov.au

Money Smart

This website contains practical tips, a financial calculator, budget planner, planning for retirement, and information on how to avoid scams.

moneysmart.gov.au

Salvation Army Emergency Financial Assistance 1300 371 288

Mon-Fri from 9am to 5pm

Financial or material assistance, and support for people in crisis.

salvos.org.au

OTHER INFORMATION AND SUPPORT

NSW Elder Abuse Helpline 1800 628 221

Mon-Fri from 8:30am to 5pm

Provides information, support and referral for anyone who suspects, witnesses or experiences abuse. Elder abuse includes physical, psychological, emotional, sexual or financial abuse.

If it is an emergency call Triple Zero (000).

elderabusehelpline.com.au

Local Councils

Provide valuable, local information on community services in your area.

Older Persons Advocacy Network 1800 700 600

Mon-Fri from 9:30am to 4:30pm

Provides advocacy, expert advice and information for people who are unhappy with government funded home care, community care or residential care services.

opan.com.au

Seniors Rights Service 1800 424 079

Business hours

Provides free legal advice and assistance for older people.

seniorsrightsservice.org.au





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Health
Hunter New England
Local Health District



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EMERGENCY CONTACT NUMBERS - 24 HOUR

Ambulance, Fire, Police

Phone: Triple Zero (000)

Lifeline (crisis support)

Phone: 13 11 14

Dementia Support Australia (behaviour support)

Phone: 1800 699 799

CONTACT NUMBERS - BUSINESS HOURS

Dementia Australia – National Dementia Hotline

Phone: 1800 100 500

Emergency Respite Care

Business hours: 1800 052 222

After hours: 1800 059 059

My Aged Care

Phone: 1800 200 422

**National Disability Insurance Scheme
(Younger Onset Dementia)**

Phone: 1800 800 110

National Australia Carer Gateway

Phone: 1800 422 737