

MEMORY PROBLEMS

Information for people with
dementia and their carers



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Getting a diagnosis

Dementia is not a specific disease. It's an overall term that describes a wide range of symptoms associated with a decline in memory, intellectual function, personality and behaviour reducing a person's ability to perform everyday activities. There are many types of dementia with Alzheimer's disease being the most common. Early diagnosis is important. It can help you and the person:

- understand what is happening and why;
- make timely decisions about planning for the future, such as participate in decisions about care, living options, financial and legal matters;
- access and benefit from care and support services, making it easier for you and your family to manage in the future.

If you are concerned about yourself or someone you know experiencing symptoms of memory loss or confusion it is important to have a conversation with your GP about your concerns. A range of tests will be conducted, which can include a thorough medical history, and blood tests to rule out other causes to determine whether or not dementia is a possible cause.

Specialists such as Geriatricians, psycho geriatricians or neurologists may be referred to for further assessment and diagnosis or you may request these referrals for any additional assessment.

The Northern Sydney area has Memory Clinics located in local hospitals and private specialists which can be accessed for this (via a GP referral).

If a diagnosis of dementia is made it is helpful to access Information and Education about dementia. Supporting a person with dementia can be a positive experience if those around them:

- understand the symptoms and progression so that strategies can be put in place to address changing needs;
- develop coping skills in a caring role;
- meet others who are caring for someone with dementia;
- have relevant information about useful services and resources.

Dementia Helpline has a list of local education opportunities and counselling available 1800 100 500

Counselling by a qualified professional can assist to cope with the range of feelings and emotions that you may experience.

The first step in following up on symptoms is finding a doctor you feel comfortable with and ensure regular appointment are available. Your GP will oversee the diagnostic and referral process.

Younger onset dementia

- Under 65
- Diagnosed with dementia

Apply for the National Disability Insurance Scheme (NDIS) to have selected supports funded for life.

Call the NDIS 1800 800 110 to enrol.

You may also want to access younger onset dementia services in your community:

Support groups for you and loved ones;

Local younger onset dementia services;

Community Social Support eg. café groups, art and dementia programs;

Contact the National Dementia Helpline on 1800 100 500 for Younger Onset Dementia support.

What to expect at each stage of dementia

People with dementia differ in the patterns of problems they have, and the speed with which their abilities deteriorate.

A person with dementia's abilities may change from day to day, or even within the same day. What is certain is that the person's abilities will deteriorate; this may happen rapidly in a period of a few months or slowly over a number of years.

Very mild decline

- Minor memory problems; or
- Misplacing things around the home.
- This could be normal age related memory loss.
- **Dementia** is unlikely to be detected by your doctor or loved ones and memory tests often come back clear.

Mild Decline (Mild Cognitive Impairment - MCI)

- Friends and family members may begin to notice memory and cognitive problems.
- Problems finding the right words during a conversation, remembering people's names, planning and organising. Performance on memory and cognitive tests are affected and your doctor will be able to detect impaired cognitive function.
- You may be offered medication by your doctor.

Moderate decline

- Further decline may noticed by you, your friends and family.
- You may or may not be aware of any memory problems.
- Difficulty with simple maths may result in an inability to manage finance and pay bills.
- You may have difficulties recalling simple details about yourself such as your phone number or where you live.
- You may have difficulty dressing appropriately but may bath and toilet independently.
- Increasing memory loss of the detail of your past life.

Severe decline

- Significant memory and organisational issues may be present most of the day.
- Family members remain familiar and some detail about your past, especially childhood and youth can be recalled. Constant supervision and support services may be required to provide community care.
- As organisation or awareness of environment decreases, major personality changes and potential behaviours of concern may appear at this time.
- Assistance with activities of daily living such as toileting and bathing is required.
- You may be unable to recognise faces except closest friends and relatives.
- Wandering and loss of bowel and bladder control are likely to occur.

Very severe decline

- Dementia is a terminal illness, therefore you can expect total loss of the ability to respond to the environment or communicate.
- Some people may still be able to speak words and phrases, but lack knowledge of their meaning
- Assistance with all activities of daily living is required.
- In the final stages of dementia. The ability to swallow is ultimately lost.

Note: Some abilities remain, although many are lost as the disease progresses. The person still keeps their sense of touch and hearing, and their ability to respond to emotion.

Support for carers

The Carer Support Service Northern Sydney Local Health District is a free service to Carers, providing information, education and guidance on how to access services; short term emotional support; and assistance to navigate the Health and community care sector (this publication is provided by that service)

There are various avenues of support that Carers find useful, from support groups to education sessions or community events. In our region the Dementia cafés have been popular, Carers and their relative/friend are able to meet up with other couples on a regular basis for a coffee and chat.

Support groups can be beneficial for Carers to meet others who are going through similar experiences. There is a number of carer support groups located throughout the Northern Sydney area. Information about where and when they occur can be accessed from the

Carer Support Service NSLHD

Phone 9462 9488

www.nscarersupport.com.au

Information packs with help sheets about caring for someone with dementia and going to hospital for a person with dementia can be accessed via the public hospital displays of information or contact the Carer Support Service. Dementia Australia also has a wide range of information and fact sheets on their website www.fightdementia.org.au

Counselling can help carers in working through feelings and emotions which can add stress and anxiety for those supporting a person with dementia.

Dementia Australia provides face to face or phone counselling services. Or speak to your GP for a referral to a Psychologist.



National Carer Gateway

Phone 1800 422 737

Mon-Fri 8am-6pm

www.carergateway.gov.au

Access to counselling (internet/phone/face to face)

Access to emergency respite

Access to information – however you are encouraged to contact local Carer Support Services

National Dementia Helpline:

Phone 1800 100 500

CCNB Northern Sydney Dementia Advisory Service

Phone 1300 002 262

Northern Sydney Dementia Advisory service provides advice and assistance to people with dementia and their families as well as education sessions.

Dementia Support Australia

Phone 1800 699 799

Dementia Support Australia can offer 24 hour over the phone advice when there are complex behaviours that are stressful for a Carer to manage. They are not an emergency medical service but can help the Carer work out strategies and access appropriate medical care.

It is important to advise your GP if you are struggling with your family member's behaviour they are able to refer to appropriate medical services.

Help at home

There are a number of supports and services to assist you at home and to stay socially connected. It may be quicker, and more efficient to pay for services required through private arrangements, with many businesses now operating in this area. To access Government subsidised services and information

My Aged Care is the key entry point to access the aged care system across Australia. It also provides information and advice about

- How the Aged care system works
- Types of services that are available
- Eligibility criteria for services
- Local services
- Fee estimators and the cost of aged care services
- Assessment for entry to aged care services



A call centre operator will discuss your needs and the needs of the person caring for you over the phone. They will advise on the most appropriate next steps and may refer you to have a face to face comprehensive assessment with either the **Regional Assessment Service (RAS)** or the **Aged Care Assessment Team (ACAT)**. If you require more general support they can refer you to a suitable service at the time of the call. Consent for this support must come from the person needing the assistance. It is a good idea to nominate a representative to your Aged Care record, who can help you understand the services available.

My Aged Care

Phone 1800 200 422

Mon-Fri 8am – 8pm, and Saturday 10am – 2pm

If you have a hearing or speech impairment call 1800 555 677 and ask for 1800 200 422. If you need an interpreter call 131 450 and ask for 1800 200 422.

The website provides a wide range of information as well as access to service providers:

www.myagedcare.gov.au

Some of the types of services available are:

Social support – Social activities in a community based group setting sometimes referred to as day centre or social club. Some social support occurs in the home/community and is available one on one.

Transport – helping you get to appointments, shopping and getting out and about.

Domestic assistance – cleaning, clothes washing.

Personal care – assistance with showering and dressing.

Home maintenance – minor general repair and general maintenance of your home.

Home modification – installation of safety aids such as ramps, rails and alarms.

Nursing care – an Enrolled or Registered nurse can come to your home and can assist with chronic disease management, medications, wound care, continence assessment, respiratory monitoring, palliative care support.

Meals – delivering meals to the home or assistance with shopping for food and if necessary meal preparation

Respite care – having someone come to the home while the carer takes a break to ensure the person is safe. It can also be arranged for overnight or weekend either in the home or at a cottage style service with only a couple of residents in a home like setting.

Home Care Packages – if the person needs more intensive support and has complex needs then a Home Care Package may be required. The Aged Care Assessment Team is required to visit and assess you to ascertain the level of assistance required.

There are four levels of Home Care packages. You will be required to register with approved package providers and can choose which provider you wish to deliver your services. At your initial appointment with this provider you can determine what help would best suit your personal circumstances and a care plan will be developed based on this information.



Planning for the future

It can be useful to get financial advice for the future and in consultation with the person with dementia. It is wise to plan and make decisions early regarding treatment options and care options if needed.

There are a number of financial supports which may include carer allowances and carer payments that you may be eligible for. For more information regarding carer benefits please see www.humanservices.gov.au or contact your local Centrelink office for advice, Lifeline offer financial counselling 13 11 14

It is a good time to ensure that an Enduring Power of Attorney and Enduring Guardian is appointed while the person is still able to make these decisions for themselves.

Enduring Power of Attorney is a legal document which gives a designated person the power to act on behalf with regard to financial decisions for them if they are unable to do so for themselves.

Enduring Guardianship is a legal document which allows a designated person to make decisions on behalf of the person with regard to lifestyle decisions. These may include where the person will live and what medical or health treatment they should receive should they not be able to make these decisions for themselves.

These documents can be drawn up by a solicitor.

Advance Care Planning

Your GP will discuss with you and help you develop an Advance Care directive which outlines medical healthcare that meets your needs. A useful website is www.planningaheadtools.com.au

Palliative Care Services

The goal of palliative care is to alleviate any unpleasant symptoms being experienced by the person, whether at home, residential care or hospital. They provide specialised guidance, emotional and practical support to the family and friends.

Your GP or community nurse can assist you to access Palliative Care services at the right time. www.palliativecare.org.au

24hr Emergency Contact Numbers

Ambulance, Fire, Police	000
Dementia Support Australia	1800 699 799
Lifeline	13 11 14

Other useful numbers

National Dementia Helpline	1800 100 500
www.dementia.org.au	
Northern Sydney Dementia Advisory Service	9998 2900
www.ccnb.com.au/dementia-advisory-service	
Continence Helpline (available 8am–8pm Mon–Fri AEST)	1800 330 066
www.continence.org.au	
Centrelink	13 27 17
www.humanservices.gov.au	
My Aged Care	1800 200 422
www.myagedcare.gov.au	
NDIS	1800 800 110
www.ndis.gov.au	
National Carer Gateway	1800 422 737
www.carergateway.gov.au	
Aged Care Quality & Safety Commission	1800 951 822
www.agedcarequality.gov.au	
Aging & Disability Abuse Helpline	1800 628 221
www.ageingdisabilitycommission.nsw.gov.au	
Seniors Rights Service	1800 424 079
www.seniorsrightsservice.org.au	

For copies of this publication and other support for Carers, please contact:

Carer Support Service Northern Sydney LHD	02 9462 9488
www.nscarersupport.com.au	
www.facebook.com/NSLHDCarersupport	

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