

# Memory Problems



Information for people with dementia and their carers

Version 6 - 11 April 2016

**Northern Sydney Local Health District  
Dementia Services Directory**



**Health**  
Northern Sydney  
Local Health District



# Getting a diagnosis

Dementia describes the progressive irreversible syndrome of impaired memory, intellectual function, personality and behaviour causing significant impairment in function. These symptoms are caused by disorders affecting the brain. There are many types of dementia with Alzheimer's disease being the most common.

## Information and education

Early diagnosis is important. It can help you and your carer:

- Understand what is happening and why
- Make timely decisions about planning for the future
- Access support and services

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. A range of tests may be conducted including a short screening test for memory, blood tests and a brain scan to rule out other causes. These investigations can be made to ascertain whether or not dementia is a possible cause.

You may be referred to specialists such as a geriatrician, psycho geriatrician or neurologist for further assessment and diagnosis.

**The Northern Sydney area has Memory Clinics located at several local hospitals: Hornsby, Royal North Shore, Ryde and Northern Beaches.**



This is also 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.

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

### Younger Onset Dementia (YOD)

Services are designed specifically for people **under 65 years** diagnosed with dementia. A **key worker** provides support information and referral to services.

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 more 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

National Dementia Helpline has a list of local education opportunities available.

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**> National Dementia Helpline  
1800 100 500**



## Support Groups

Support groups can be beneficial for carers to meet others going through similar experiences. There are a number of carer support groups located throughout the Northern Sydney area. Information about where and when they occur can be accessed from Alzheimer's Australia helpline and:

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- > **Northern Sydney Health Carer Support Services**  
**9462 9488**  
[nscarersupport.com.au](http://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 obtained from Carer Support Services.

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- > **Alzheimer's Australia Capital Support**  
[fightdementia.org.au](http://fightdementia.org.au)

A practical guide to services for families and friends of people with dementia can be found at:

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- > **National Dementia Helpline**  
**1800 100 500**  
[fightdementia.org.au/sites/default/files/NATIONAL/documents/Support-for-carers.pdf](http://fightdementia.org.au/sites/default/files/NATIONAL/documents/Support-for-carers.pdf)

Northern Sydney Local Health District Carer Support Service based in Northern Sydney provide information, education

and advice to assist carers. They can help you navigate the health, community health and community care systems to find the right service/s to assist you in your caring role. A very useful information booklet on caring for a person with dementia is available on request.

The Carer Support Service provides intensive carer support for complex care situations. The website provides information on available services.

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- > **Northern Sydney Local Health District Carer Support Service**  
**9462 9488**  
[carersupport.com.au](http://carersupport.com.au)

Northern Sydney Dementia Advisory Service is a service which provides advice and assistance to people with dementia and their families.

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- > **Northern Sydney Dementia Advisory Service**  
**9998 2900**

**Counselling** can assist in coping with the range of feelings and emotions that may increase stress and anxiety for those supporting a person with dementia. Alzheimer's Australia can provide both face to face as well as over the phone counselling.

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- > **Alzheimer's Australia**  
**1800 100 500**

## Help at Home

There are a number of supports and services to assist with keeping the person with dementia socially connected and assist you with caring for someone with dementia at home.

## 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
- How to access Residential Aged Care Facilities

A staff member will ascertain your needs over the phone and discuss with you the needs of the person you are caring for. They will advise on the most appropriate next steps and may refer you for a face to face comprehensive assessment with either the **Regional Assessment Service (RAS)** or **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. The phone line is operational Mon-Fri 8am-8pm and Saturday 10am-2pm and closed on public holidays.

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> **My Aged Care**  
**1800 200 422**  
[myagedcare.gov.au](https://myagedcare.gov.au)

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**.





## Service types available in Northern Sydney are:

**Social support** – Social activities in a community setting sometimes referred to as day center or social club. Social support can occur in the home or community and are available one on one.

**Transport** – helping you or the person you are caring for 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** – qualified nurse who comes to your home and may assist with medications, wound dressings

**Allied Health support** – Podiatry, dietician, physiotherapy and occupational therapy.

**Respite care** – having someone come to the home while the carer takes a break or the person with dementia attends a Day Center program. Respite 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. Some residential aged care facilities offer respite for up to 63 days per year.

**Dementia monitoring** – a drop in service for people living alone in the community with dementia to check their safety and well being.

**Local councils** are also a valuable source of local information on community services in your area.

## Home support services

If the person needs more intensive support and have complex needs then a home care package may be required. Contact **My Aged Care** web site and the Aged Care Assessment Team will visit and assess the person to ascertain the level of assistance required.

There are two types ( 1/2 low or 3/4 high) Commonwealth Home Care packages provided on a consumer directed care basis. After an assessment by ACAT and approval 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.



Sometimes there can be behaviours of concern. Carers may need advice on how to manage and respond to difficult situations. The DBMAS can offer 24 hour over the phone advice and can refer to other support services if necessary.

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**> Dementia Behaviour Management Service- DBMAS**  
**1800 699 799 (24 hrs)**

## Financial Advice

There are a number of financial supports including carer allowances and carer payments which you may be eligible to receive. For more information regarding carer benefits please visit your local Centrelink office

*A Centrelink Assessment is required if you are accessing a Commonwealth Home Support Package or residential care.*

If you are experiencing financial difficulties you can access assistance and advice from a financial counsellor through Lifeline or Centrelink.

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**> Centrelink**  
**13 27 17**  
[humanservices.gov.au](http://humanservices.gov.au)

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**> Lifeline**  
**13 11 14**

The National Australia Carer Gateway commenced in January 2016.

The purpose of the Carer Gateway is to provide information about the services and support available for people who care for someone with a disability, chronic illness, dementia, mental illness or who are frail aged.

Carer Gateway provides information for carers online and by phone from Monday to Friday between 8am and 6pm for information about services and support available.

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**> National Australia Carer Gateway**  
**1800 422 737**  
[carergateway.gov.au](http://carergateway.gov.au)

- Carers can visit the website to access information about caring and support services available to them.
- Service finder: Carer Gateway website has an interactive service finder to help carers locate their nearest carer support services.





## Legal matters

**Enduring power of attorney** is a legal document which gives a designated person the power to act on behalf of the person with regard to legal and financial decisions 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 or can be drawn up and lodged with the local Registrar of your local court house.

For more information contact The NSW Public Guardian. Information and support branch who can send out a guide to assist you.

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> **NSW Public Guardian**  
**8688 6070**  
[publicguardian.justice.nsw.gov.au](http://publicguardian.justice.nsw.gov.au)

## Planning for the future

Sometimes referred to as a “living will”, an **Advance Care Directive** helps the person with dementia to make plans for their future medical treatment and care needs:

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> [planningaheadtools.com.au](http://planningaheadtools.com.au)

A useful website that provides information on planning ahead for people with dementia and their carers is:

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> [start2talk.org.au](http://start2talk.org.au)

## Palliative care services

Many people choose to die in their homes with friends and family around them rather than be transferred to a hospital. The goal of palliative care is to alleviate any unpleasant symptoms being experienced by the person. They also provide specialised guidance, emotional and practical support to the family and friends.

Ask your community nurse or general practitioner how to access Palliative care services.

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> [palliativecareservices.org.au](http://palliativecareservices.org.au)

# What to expect at each stage of dementia

## Very mild decline

You may notice minor problems or start misplacing things around the home; this could be dismissed as normal age related memory loss. Memory tests and the disease are unlikely to be detected by your doctor or loved ones.

## Mild decline

Friends and family members may begin to notice memory and cognitive problems. You may notice problems with 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 is noticed by friends and family, you may or may not be aware of your memory problems. Difficulty with simple maths can result in an inability to manage finance and pay bills. Expect increasing short term memory loss and loss of details about your past life.

## Moderately severe decline

Significant confusion may be present most of the day, with an inability to recall simple details about yourself such as your own phone number or where you live. Some people will have difficulty dressing appropriately but can still bathe and toilet independently. Family members remain familiar and some detail about your past, especially childhood and youth can be recalled.

## Severe decline

Constant supervision and support services may be required to provide community care. As confusion or unawareness of environment and surroundings increases, major personality changes and potential behaviour's 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 recognize faces except closest friends and relatives, wandering and loss of bowel and bladder control are likely to occur.

## Very severe decline

Because dementia is a terminal illness, expect total loss of the ability to respond to the environment or communicate. While some may still be able to utter words and phrases, they have no insight and assistance with all activities of daily living is required. In the final stages of dementia, the ability to swallow is lost.

Acknowledgment of contributions from NSW Agency for Clinical Innovation, Sydney North Health Network, CCNB Ltd and Alzheimer's Australia NSW.

## 24 hour Emergency Contact Numbers

Ambulance, Fire, Police	000
DBMAS	1800 699 799
National Dementia Hotline	1800 100 500

### Business hours

Carer Support Service	9462 9488
Northern Sydney Dementia Advisory Service	9998 2900