



Support Pathways  
for People with  
**Younger  
Onset  
Dementia**

Referral and Service Options



dementia  
australia™

## Acknowledgements

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Appreciation also goes to the people with Younger Onset Dementia and their family members who contributed to the development of the resource.

Dementia Australia respectfully acknowledges the Traditional Owners of the land throughout Australia and their continuing connection to country. We pay respect to Elders both past and present and extend that respect to all Aboriginal and Torres Strait Islander people who have made a contribution to our organisation.

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## Foreword

Younger onset dementia is the term used to describe people under the age of 65 years who have been diagnosed with a type of dementia. There is estimated to be more than 25,000 people living in Australia with younger onset dementia and these people often face various challenges.

People under the age of 65 years are often still working and they may be the family's only breadwinner. Many are raising dependent children and some are also caring for an elderly relative. People with younger onset dementia have numerous decisions to make and a range of service options to consider as their dementia progresses. They frequently report not knowing what services are available nor knowing how to access those services.

Dementia Australia – formerly Alzheimer's Australia NSW – was funded by the NSW Family and Community Services; Ageing, Disability and Home Care to develop the "Support Pathways for People with younger onset dementia: Referral and Service Options".

This is a comprehensive guide to health, social, community, legal services and resources which could be useful for people with younger onset dementia.

The guide is divided into sections making it easier for people to locate the service they are after. It is equally useful for people with younger onset dementia, their families and carers and for members of the health and service professions.

People with younger onset dementia can now be assisted through the Australian National Disability Insurance Scheme. It is an important time for people with younger onset dementia to know what services and supports are available to them. This booklet is a reference point for locating and choosing helpful and meaningful support services.



**1**

**WHAT IS  
DEMENTIA?**

# WHAT IS DEMENTIA?

Dementia describes a collection of symptoms that are caused by disorders affecting the brain. It is not one specific disease. Dementia affects thinking, behaviour and the ability to perform everyday tasks. Brain function is affected enough to interfere with the person's normal social or working life. The hallmark of dementia is the inability to carry out everyday activities as a consequence of diminished cognitive ability.

Doctors diagnose dementia if two or more cognitive functions are significantly impaired. The cognitive functions affected can include memory, language skills, understanding information, spatial skills, judgement and attention. People with dementia may have difficulty solving problems and controlling their emotions. They may also experience personality changes. The exact symptoms experienced by a person with dementia depend on the areas of the brain that are damaged by the disease causing the dementia.

## What is Younger Onset Dementia?

The term 'younger onset dementia' is usually used to describe any form of dementia diagnosed in people under the age of 65. Dementia in younger people is much less common than dementia occurring after the age of 65, and has been diagnosed in people in their 50s, 40s and even in their 30s. For this reason it can be difficult to diagnose and its incidence in the community is still not clear.

## Types of Dementia

### Alzheimer's disease

Alzheimer's disease is the most common form of dementia, accounting for around two-thirds of cases. It causes a gradual decline in cognitive abilities, often beginning with memory loss.

Alzheimer's disease is characterised by two abnormalities in the brain – amyloid plaques and neurofibrillary tangles. The plaques are abnormal clumps of a protein called beta amyloid. The tangles are bundles of twisted filaments made up of a protein called tau. Plaques and tangles stop communication between nerve cells and cause them to die.

For more information about Alzheimer's disease see the Help Sheet on About Dementia: Alzheimer's disease.

[www.dementia.org.au/files/helpsheets/Helpsheet-AboutDementia13-AlzheimersDisease\\_english.pdf](http://www.dementia.org.au/files/helpsheets/Helpsheet-AboutDementia13-AlzheimersDisease_english.pdf)

### Frontotemporal dementia

Frontotemporal dementia involves progressive damage to the frontal and/or temporal lobes of the brain. Symptoms often begin when people are in their 50s or 60s and sometimes earlier.

There are two main presentations of frontotemporal dementia – frontal (involving behavioural symptoms and personality changes) and temporal (involving language impairments). However, the two often overlap.

People with frontotemporal dementia can have difficulties maintaining socially appropriate behaviour because the frontal lobes of the brain control judgement and social behaviour. They may seem rude, neglect normal responsibilities, be compulsive or repetitive, be aggressive, show a lack of inhibition or act impulsively.

There are two main forms of the temporal or language variant of frontotemporal dementia. Semantic dementia involves a gradual loss of the meaning of words, problems finding words and remembering people's names, and difficulties understanding language, and progressive non-fluent aphasia, which is less common and affects the ability to speak fluently.

For more information, see the Help Sheet on About Dementia: Frontotemporal dementia:

[www.dementia.org.au/files/helpsheets/Helpsheet-AboutDementia17-FrontotemporalDementia\\_english.pdf](http://www.dementia.org.au/files/helpsheets/Helpsheet-AboutDementia17-FrontotemporalDementia_english.pdf)

or visit the Frontier research group website [www.neura.edu.au](http://www.neura.edu.au)

### Vascular dementia

Vascular dementia is cognitive impairment caused by damage to the blood vessels in the brain. It can be caused by a single stroke, or by several mini-strokes occurring over time. These mini-strokes are also called transient ischaemic attacks (TIAs). Vascular dementia is diagnosed when there is evidence of blood vessel disease in the brain and impaired cognitive function



that interferes with daily living. The symptoms of vascular dementia can begin suddenly after a stroke, or may begin gradually as blood vessel disease worsens. The symptoms vary depending on the location and size of brain damage. It may affect just one or a few specific cognitive functions.

Vascular dementia may appear similar to Alzheimer's disease, and a mixture of Alzheimer's disease and vascular dementia is common.

For more information see the Help Sheet on Dementia Australia About Dementia: Vascular Dementia:

[www.dementia.org.au/files/helpsheets/Helpsheet-AboutDementia16-VascularDementia\\_english.pdf](http://www.dementia.org.au/files/helpsheets/Helpsheet-AboutDementia16-VascularDementia_english.pdf)

### **Lewy body disease**

Lewy body disease is characterised by the presence of Lewy bodies in the brain. Lewy bodies are abnormal clumps of the protein alpha-synuclein that develop inside nerve cells. These abnormalities occur in specific areas of the brain, causing changes in movement, thinking and behaviour.

People with Lewy body disease may experience large fluctuations in attention and thinking. They can go from almost normal performance to severe confusion within short periods. Visual hallucinations are also a common symptom.

### **Three overlapping disorders can be included with Lewy body disease:**

- Dementia with Lewy bodies
- Parkinson's disease
- Parkinson's disease dementia

When movement symptoms appear first, Parkinson's disease is often diagnosed. As Parkinson's disease progresses most people develop dementia. When cognitive symptoms appear first, this is diagnosed as dementia with Lewy bodies.

Lewy body disease sometimes co-occurs with Alzheimer's disease and/or Vascular dementia.

For more information, see the Dementia Australia Help Sheets on Lewy body disease:

[www.dementia.org.au/files/helpsheets/Helpsheet-AboutDementia20-LewyBodyDisease\\_english.pdf](http://www.dementia.org.au/files/helpsheets/Helpsheet-AboutDementia20-LewyBodyDisease_english.pdf)

### **Who gets Dementia?**

Dementia can happen to anybody, but the risk increases with age. Most people with dementia are older, but it is important to remember that not all older people get dementia. It is not a normal part of ageing but is caused by brain disease. People under the age of 65 years can develop dementia and this is called 'younger onset dementia'.

### **What are the early signs of dementia?**

The early signs of dementia can be very subtle and vague and may not be immediately obvious. Some common symptoms may include:

- Progressive and frequent memory loss
- Confusion
- Personality change
- Apathy and withdrawal
- Loss of ability to perform everyday tasks

### **Is Dementia inherited?**

Most forms of dementia are not inherited although genetics can play a part. This is common in younger onset dementia. If you have a family history of dementia and would like to know more you can discuss this with your GP or specialist.

One rare form of Alzheimer's disease is passed from generation to generation. This is called Familial Alzheimer's disease (FAD). If a parent has a mutated gene that causes FAD, each child has a 50% chance of inheriting it. The presence of the gene means that the person will eventually develop Alzheimer's disease, usually in their 40s or 50s. This form of Alzheimer's disease affects an extremely small number of people – probably no more than 100 at any given time among the whole population of Australia.

For more information refer to: Dementia Australia help sheet on Genetics of Dementia:

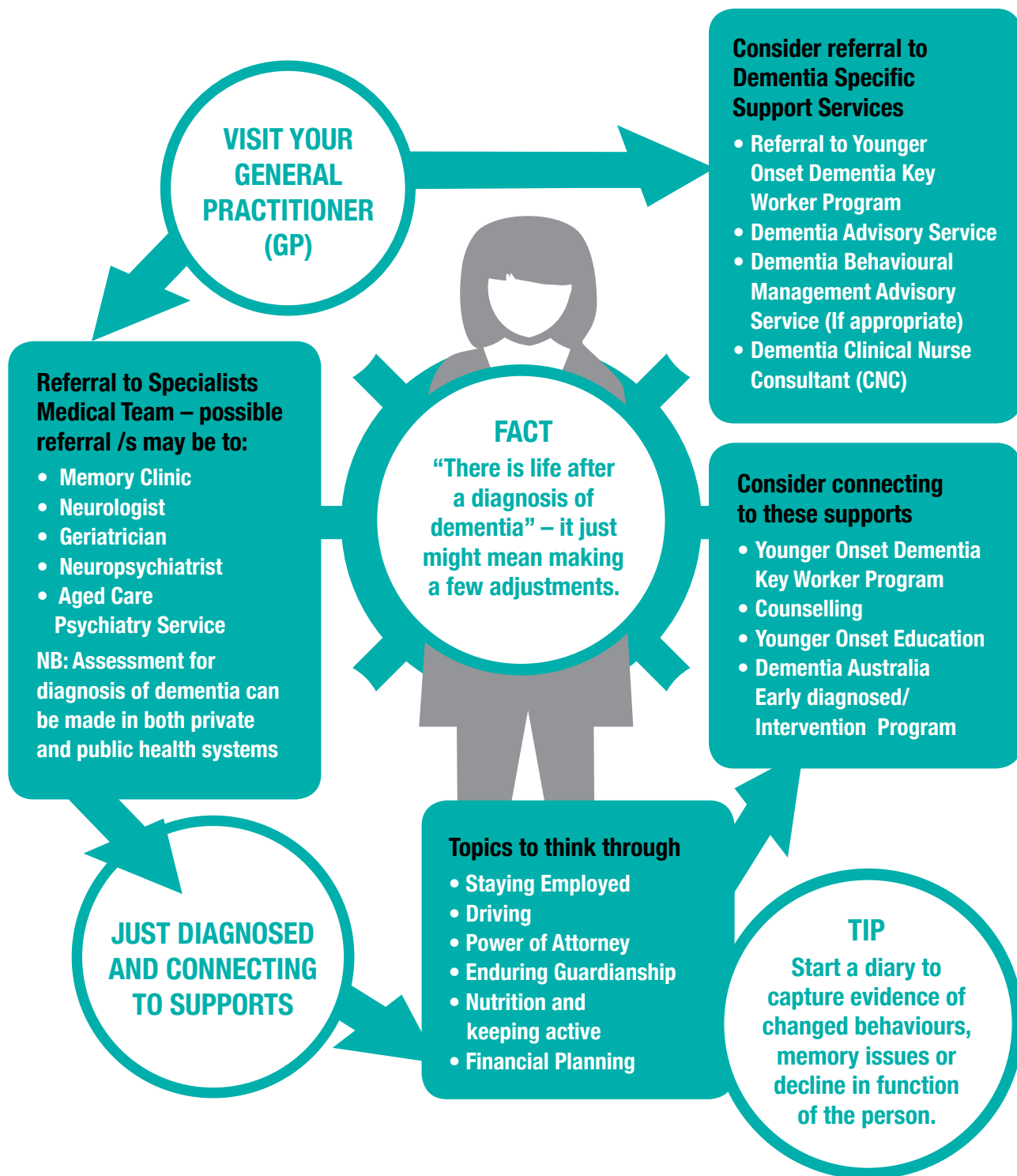
[www.dementia.org.au/files/helpsheets/Helpsheet-AboutDementia10-GeneticsOfDementia\\_english.pdf](http://www.dementia.org.au/files/helpsheets/Helpsheet-AboutDementia10-GeneticsOfDementia_english.pdf)



**2**

**COULD IT BE  
YOUNGER ONSET  
DEMENTIA?**

# SEEKING DIAGNOSIS



Younger onset dementia is the term given when dementia is diagnosed in people under the age of 65. Problems with thinking, mood, memory, behaviours, and language are some of the symptoms that people may recognise in themselves, or in a partner, relative or friend. Assessment from a General Practitioner and a referral to a specialist such as a Neurologist, Neuropsychiatrist, Psychogeriatrician or Geriatrician is often needed.

## Useful links to services that provide support

### Dementia Australia: National Dementia Helpline 1800 100 500

A free telephone information and support service is available across Australia. Trained professionals can answer your questions about dementia and provide guidance in pathways to services to address your needs and concerns.  
[www.dementia.org.au](http://www.dementia.org.au)

### Dementia Australia Services:

#### Younger Onset Dementia Key Worker Program

Key Workers act as a key point of contact for a person diagnosed with younger onset dementia and their support person. The program provides individualised information, support and advice, and helps consumers engage effectively with services appropriate to their needs.

[www.dementia.org.au/services/younger-onset-dementia-key-worker-program](http://www.dementia.org.au/services/younger-onset-dementia-key-worker-program)

#### Counselling

Speaking confidentially with a professional counsellor can help with understanding and coping with a diagnosis of younger onset dementia.

[www.dementia.org.au/services/younger-onset-dementia-key-worker-program](http://www.dementia.org.au/services/younger-onset-dementia-key-worker-program)

#### Living with Dementia Program

A group program for people living with early stage dementia and their support person. It provides the opportunity to meet and talk with others in a similar situation and to learn strategies for living well with dementia.

[www.dementia.org.au/support/in-your-region/nsw/living-with-dementia-program](http://www.dementia.org.au/support/in-your-region/nsw/living-with-dementia-program)

#### Better Life Program

A personal coaching program available via phone or video chat to help build confidence and skills for achieving personal health and wellbeing goals.

[www.dementia.org.au/support/in-your-region/nsw/better-life-program](http://www.dementia.org.au/support/in-your-region/nsw/better-life-program)

#### Safely Home Program

Supports people living with dementia to walk safely by the wearing of a personalised stainless steel bracelet that provides rapid and accurate identification. This program is a joint partnership between Dementia Australia and the Missing Persons Unit of the NSW Police.

[www.dementia.org.au/support/in-your-region/nsw/safely-home](http://www.dementia.org.au/support/in-your-region/nsw/safely-home)

#### Library and Information Service

The library offers a comprehensive and diverse range of dementia related books and multi-media resources. The library also publishes an online blog and e-mail library newsletter that informs readers about new information resources and links to podcasts, vodcasts and resources available.

[www.alzheimersnswlibrary.blogspot.com.au/](http://www.alzheimersnswlibrary.blogspot.com.au/)

# COULD IT BE YOUNGER ONSET DEMENTIA?

## **Younger Onset Dementia Blog**

A website where people with younger onset dementia can connect with others:

[www.youngersonsetdementiaandme.blogspot.com.au/](http://www.youngersonsetdementiaandme.blogspot.com.au/)

To view all of the services provided by Dementia Australia:

<https://www.dementia.org.au/services/programs>

Keep up to date with the latest news and research, resources and information about dementia on Dementia Daily:

[www.dementia.org.au/support/in-your-region/NSW](http://www.dementia.org.au/support/in-your-region/NSW)

Dementia Australia Help sheets provide advice, common sense approaches and practical strategies on the issues most commonly raised about dementia:

[www.dementia.org.au/help-sheets](http://www.dementia.org.au/help-sheets)

## **Dementia Advisory Services NSW**

Dementia Advisors are located throughout NSW and provide individualised information, support and advice for living with dementia. They can help consumers link with local community and health services appropriate to their needs.

[www.adhc.nsw.gov.au/individuals/caring\\_for\\_someone/caring\\_for\\_a\\_person\\_with\\_dementia/dementia\\_advisory\\_services](http://www.adhc.nsw.gov.au/individuals/caring_for_someone/caring_for_a_person_with_dementia/dementia_advisory_services)

## **Dementia Behaviour Management Advisory Service (DBMAS) 1800 699 799**

Provides individualised assessment and advice on strategies and interventions for people supporting someone with dementia who is experiencing behaviours and psychological symptoms associated with dementia.

[www.dementia.com.au/](http://www.dementia.com.au/)

## **Behaviour Assessment Management Service – NSW Health**

A specialised health service providing interventions for people with more severe and persistent behavioural and psychological symptoms associated with dementia and/or mental illness.

[www.nslhd.health.nsw.gov.au/Services/Directory/Pages/BAMS.aspx](http://www.nslhd.health.nsw.gov.au/Services/Directory/Pages/BAMS.aspx)

## **Younger Onset Dementia resources**

Information about younger onset dementia, why a correct diagnosis is important, and the differing needs of people with younger onset dementia.

[www.dementia.org.au/about-dementia/what-is-younger-onset-dementia](http://www.dementia.org.au/about-dementia/what-is-younger-onset-dementia)

## **Younger Onset Dementia and Me**

A website where people with younger onset dementia can connect with others in a similar situation, gather and share information and helpful suggestions.

[www.youngersonsetdementiaandme.blogspot.com.au](http://www.youngersonsetdementiaandme.blogspot.com.au)

## **Pathways to a diagnosis of Younger Onset Dementia**

Because dementia is usually associated with old age, doctors may be less likely to diagnose it in a younger person. It is important that younger onset dementia is diagnosed as early as possible so that the process of getting access to treatment and the right support can commence.

## **Website for General Practitioners**

As GPs are usually the first point for concerns about cognitive or behavioural changes, they would make a referral to a memory clinic or other specialist for a more comprehensive assessment.

Detect Early is a website developed by Dementia Australia for GP's, providing cognitive screening tools, and dementia information and education resources.

[www.detectearly.org.au](http://www.detectearly.org.au)

## Support for diagnosing younger onset dementia in a person with an Intellectual or Developmental Disability

The presentation of dementia in people with an intellectual disability may be subtle and go unrecognised. Specialist assessment is often required to assist the General Practitioner and Specialist with diagnosis and ongoing management.

### Clinics that provide assessment and consultancy for consumers with an intellectual or developmental disability:

The NSW Developmental Disability Health Unit (DDHU) – 02-9808-9287

A specialist clinic for adolescents and adults with a developmental disability, providing a consultancy service and working in conjunction with the person's general practitioner.

### Department of Developmental Disability Neuropsychiatry 3DN Clinic Prince of Wales Hospital Sydney. Phone: 02 9931 9160

Referrals to the Clinic are only accepted from specialists currently working with a person who has an intellectual or developmental disability. The Clinic provides assessment and consultancy in relation to neuropsychiatric symptoms that could be associated with younger onset dementia.

[www.3dn.unsw.edu.au/clinics](http://www.3dn.unsw.edu.au/clinics)

## Counselling

Speaking confidentially with a dementia trained professional counsellor can help with understanding and coping with a diagnosis of younger onset dementia.

### Dementia Australia 1800 100 500

Dementia Australia provides free professional counselling. Sessions are available face to face, by phone and over the internet.

[www.dementia.org.au/support/in-your-region/NSW](http://www.dementia.org.au/support/in-your-region/NSW)

### Beyond Blue 1300 224 636

A 24 hour telephone support service providing individual support, information and advice for people experiencing anxiety or depression. "online" chat is available.

[www.beyondblue.org.au/get-support/get-immediate-support](http://www.beyondblue.org.au/get-support/get-immediate-support)

### Lifeline 13 11 14

A 24 hour crisis support and suicide prevention service available by phone or via an "online" chat with a trained crisis support worker.

[www.lifeline.org.au/](http://www.lifeline.org.au/)

## Genetic testing

Because inherited forms of dementia are very rare, genetic testing is not relevant for most families affected by dementia. For those affected by a familial dementia which usually affects younger people under the age of 65 years, genetic testing is available. The decision to undergo genetic testing for familial dementia is very complex and the advantages and disadvantages should be carefully considered.

### Genetics of Dementia – Help Sheet Dementia Australia

This Help Sheet discusses the role of genetics in dementia and genetic testing;

[www.dementia.org.au/files/helpsheets/Helpsheet-AboutDementia10-GeneticsOfDementia\\_english.pdf](http://www.dementia.org.au/files/helpsheets/Helpsheet-AboutDementia10-GeneticsOfDementia_english.pdf)

### Genetic Counselling and Testing Services

Services are available in NSW. Provides an individual or family with information and support regarding health concerns which run in their family.

[www.genetics.edu.au/genetic-services/](http://www.genetics.edu.au/genetic-services/)

### Genetic Alliance Australia

This organisation provides information and peer support for individuals and families affected by rare genetic conditions.

[www.geneticalliance.org.au/](http://www.geneticalliance.org.au/)

# COULD IT BE YOUNGER ONSET DEMENTIA?

## **NSW Government Centre for Genetics Education:**

General information for consumers and health professionals about genetic health issues, genetic counselling and understanding of genetic testing. Lists genetic testing services available in NSW:

[www.genetics.edu.au/](http://www.genetics.edu.au/)

## **Information about Health and Community Services**

### **Health Direct Australia – 1800 022 222**

Provides health information and advice online and over the phone, and helps you to find local health services.

[www.healthdirect.gov.au](http://www.healthdirect.gov.au)

### **Aboriginal Health Services Support**

To locate an Aboriginal Health Service in NSW:

[www.health.nsw.gov.au/aboriginal/Pages/contact.aspx](http://www.health.nsw.gov.au/aboriginal/Pages/contact.aspx)

### **National Health Services Directory:**

A comprehensive directory of health services including general practice, pharmacy, hospital and allied health services such as physiotherapy, occupational therapy, psychology.

[www.healthdirect.gov.au](http://www.healthdirect.gov.au)

### **Commonwealth Department of Social Services**

Provides programs and services, benefits and payments to support families and children, people with a disability, people with mental illness, seniors and carers, carers.

[www.dss.gov.au/](http://www.dss.gov.au/)

### **Mental Health Line 1800 011 511**

Provides advice, support and referrals to local mental health services for people living with a mental health and their families.

## **Transcultural Mental Health Centre – 1800 648 911**

Provides support and information for people from culturally and linguistically diverse (CALD) who have a mental health condition or are looking after someone with a mental health condition. Lists bilingual workers and translation services.



# 3

## NEWLY DIAGNOSED. WHAT DOES YOUNGER ONSET DEMENTIA MEAN?



# NEWLY DIAGNOSED. WHAT DOES YOUNGER ONSET DEMENTIA MEAN?

Support to understand a diagnosis of younger onset dementia is important for the person with dementia and their family and supporters.

There will be questions about what will happen in the future and how to manage day to day, as well as planning ahead. It is a good time to enlist support of others, and to make legal and financial plans, such as wills, Power of Attorney and Enduring Guardianship. Appointing an alternative decision maker while the person with dementia has capacity to do so, is crucial.

There may also be questions about how to remain in the work force, secure Centrelink benefits, advice about driving, and how to stay connected and keep active in the community. The links below may be of assistance to you.

## Talking about Dementia

Sometimes people find it difficult to talk about dementia as it is sometimes surrounded by fear and misunderstanding. To raise awareness and alleviate misunderstandings, it is important to talk openly with people and share experiences.

## Talk to Children

Children may be aware of the changes in the person with dementia so it's important to have open communication with them. Whether the children are living in or out of the home it is important to include them in family planning and decisions wherever possible. Sometimes family counselling may be of benefit to everyone.

## Living well with Younger Onset Dementia

There are many positive things that can be done to live well with dementia. The following programs and websites provide information and practical tips on living well with dementia.

### Living with Dementia Program

A group program for people living with early stage dementia and their support person, providing the opportunity to meet and talk with others in a similar situation and to learn strategies for living well with dementia.

[www.dementia.org.au/support/in-your-region/NSW](http://www.dementia.org.au/support/in-your-region/NSW)

### Living Well with Dementia – on-line Portal

A website for people with dementia that provides information about lifestyle changes that can lead to better health and well being.

[www.livingwellwithdementia.org.au/](http://www.livingwellwithdementia.org.au/)

### Education and Training for Families and Carers

Dementia Australia provides a range of education programs to assist families and friends caring for a person with dementia. Sessions are conducted in groups to provide opportunities for meeting others who share a similar experience. Topics include the nature of dementia, understanding dementia, emotional impact and stress management, effective communication and activities, understanding and responding to changes in behaviour.

[www.dementia.org.au/education-and-training/nsw](http://www.dementia.org.au/education-and-training/nsw)

### Online Dementia Education

For people with dementia, family and health professionals

[www.dementialearning.org.au](http://www.dementialearning.org.au)

### Dementia Training Study Centres – E-learning

Dementia specific education and training for the health and aged care sector. E-learning courses and videos on younger onset dementia.

[www.dtsc.com.au/elearning/elearning-modules/](http://www.dtsc.com.au/elearning/elearning-modules/)

### The Frontotemporal Dementia (FTD) - E-learning Toolkit

An online toolkit covering topics relevant to a diagnosis of frontotemporal dementia and management strategies.

[www.ecdc.org.au/ftd-toolkit.htm](http://www.ecdc.org.au/ftd-toolkit.htm)

### National Younger Onset Dementia Key Worker Program

Provides individualised information and support to improve the quality of life for people with younger onset dementia.

[www.dementia.org.au/services/younger-onset-dementia-key-worker-program](http://www.dementia.org.au/services/younger-onset-dementia-key-worker-program)

# NEWLY DIAGNOSED. WHAT DOES YOUNGER ONSET DEMENTIA MEAN?

## Support and Counselling for Carers

### **Dementia Australia 1800 100 500**

Speaking confidentially with a professional counsellor can help with understanding and coping with a diagnosis of younger onset dementia. Phone, online and face-to-face sessions are available. Provides links to carer support programs and groups across NSW.

[www.dementia.org.au/support/in-your-region/NSW](http://www.dementia.org.au/support/in-your-region/NSW)

### **National Carer Gateway 1800 422 737**

An online and phone service that provides practical information and resources to support carers. Helps carers connect to local services.

[www.carergateway.gov.au/](http://www.carergateway.gov.au/)

### **Carers NSW 1800 242 636**

Provides individual and group counselling to help deal with issues related to the carer role and links to carers support groups and programs.

[www.carersnsw.org.au/](http://www.carersnsw.org.au/)

### **Transcultural Mental Health Carers' Program**

For carers from culturally and linguistically diverse (CALD) backgrounds supporting someone with a mental health condition. Provides language specific support groups across Sydney metropolitan area and Wollongong and links to bilingual mental health professionals speaking over 65 languages.

[www.health.nsw.gov.au/lhd/pages/default.aspx](http://www.health.nsw.gov.au/lhd/pages/default.aspx)

## Relationships Australia

Offers information, advice, counselling and mediation services that can assist individuals, couples and families to improve their relationships. Lists Family Relationship Centres across Australia.

[www.relationships.org.au/](http://www.relationships.org.au/)

## Younger Carers

### **Younger Carers NSW – 1800 242 636**

Provides support programs for people aged 25 years and under who are in a supporting role. Young carers can be connected with other young carers.

[www.youngcarersnsw.org.au/](http://www.youngcarersnsw.org.au/)

[www.youngcarers.net.au/](http://www.youngcarers.net.au/)

### **Headspace**

Support for a young person 12-25 years with issues affecting their well-being, covering mental health, physical health, work and study support and alcohol and other drug services. Confidential online and telephone support is available.

[www.headspace.org.au/](http://www.headspace.org.au/)

### **Younger Onset Dementia and Me Blog**

A website where people with younger onset dementia can connect with others in a similar situation, gather and share information and helpful suggestions.

[www.youngersonsetdementiaandme.blogspot.com.au](http://www.youngersonsetdementiaandme.blogspot.com.au)

## Younger Children

### **Kids Helpline: 1800 55 1800**

A free, 24/7 phone and online counselling service for young people aged 5-25 years, providing practical help and emotional support.

[www.kidshelpline.com.au](http://www.kidshelpline.com.au)

### **The Association for Frontotemporal Degeneration (AFTD) Kids and Teens website**

A website specifically for kids and teens who have a parent with frontotemporal degeneration (FTD). Provides information about FTD, how it impacts on families, ways to cope, and stories shared by kids and teens themselves.

[www.aftdkidsandteens.org/](http://www.aftdkidsandteens.org/)

# NEWLY DIAGNOSED. WHAT DOES YOUNGER ONSET DEMENTIA MEAN?

## Older parent Carers

Information for carers aged 60 years and over (or 45 or over if an Aboriginal person or a Torres Strait Islander) who are supporting a child with a disability or long term illness. Includes topics such as planning ahead, guardianship arrangements, taking a break, support networks and accommodation support.

## Taking a Break

Taking a break and having some respite from caring is a realistic and important thing to do. Respite offers carers a chance to restore their energy and find time for important things like catching up with friends, having a rest, attending to business, or taking a holiday.

## Finding Respite

There are several different types of respite services including in-home respite and out of home respite and emergency respite.

[www.adhc.nsw.gov.au/sp/delivering\\_disability\\_services/respite](http://www.adhc.nsw.gov.au/sp/delivering_disability_services/respite)

## Commonwealth Respite and Carelink Program 1800 052 222

Provides information about respite options and other support services for carers in their local area. Can assist carers to access short term and emergency respite.

## Emergency respite for carers

Emergency and crisis short-term respite care may be available to assist families and carers with unplanned or emergency situations.

Commonwealth Respite and Carelink Centre – 1800 052 222.

[www.carersnsw.org.au/advice/time-for-yourself/about-respite/#Section1](http://www.carersnsw.org.au/advice/time-for-yourself/about-respite/#Section1)

## Wills, Power of Attorney, Enduring Guardianship and Advance Care directives

Planning ahead for the future is important. Advance planning enables individuals with dementia to make their wishes about medical care, financial and living arrangements known.

The following links provide information and practical guidance for people with younger onset dementia, families and health professionals:

### Start2talk

Information and assistance with making a will, powers of attorney, and enduring guardianship. Branches located throughout NSW can provide financial management services (appointed by a Court or Tribunal).

[www.dementia.org.au/planning-ahead](http://www.dementia.org.au/planning-ahead)

### Advanced Care Planning

Advance care planning involves talking about your values and the type of health care you would want to receive if you became seriously ill or injured and were unable to say what you want.

### Legal Aid NSW

Provides information on making a will, planning ahead, appointing financial and lifestyle decision makers, and links to legal advice and assistance

[www.legalaid.nsw.gov.au/what-we-do/services](http://www.legalaid.nsw.gov.au/what-we-do/services)

### NSW Trustee & Guardian

Information and assistance with making a will, powers of attorney, and enduring guardianship. Branches located throughout NSW can provide financial management services (appointed by a Court or Tribunal).

[www.tag.nsw.gov.au/](http://www.tag.nsw.gov.au/)

## **NSW Civil and Administrative Tribunal (NCAT) 1300 006 228**

The Tribunal works across a broad and diverse range of matters, from tenancy issues and building works, to decisions on guardianship and administrative review of government decisions. The Guardianship Division determines applications about people with a decision making disability and who may require a legally appointed substitute decision maker.

[www.ncat.nsw.gov.au/](http://www.ncat.nsw.gov.au/)

## **Staying connected with others**

Healthy relationships with family, friends and colleagues are important for everyone's well-being. The following links provide access to programs that provide opportunities to socialise, share experiences and stay connected with others.

## **Younger Onset Dementia and Me – blogspot**

A website where people with younger onset dementia can connect with others.

[www.youngeronsetdementiaandme.blogspot.com.au/](http://www.youngeronsetdementiaandme.blogspot.com.au/)

## **Social and Support Groups**

Provide a great opportunity for people to be able to share their experiences and skills with others while learning new ones.

For information about dementia café groups and their location, contact Dementia Australia: National Dementia Helpline 1800 100 500

## **Dementia Cafés**

Cafe groups provide the opportunity to meet with others in a local community setting.

For information about café groups and their location, contact Dementia Australia: National Dementia Helpline 1800 100 500

## **Ability Links NSW**

Helps people with a disability aged 9 to 64 years to access support and services in their local community.

[www.adhc.nsw.gov.au/individuals/inclusion\\_and\\_participation/ability\\_links\\_nsw](http://www.adhc.nsw.gov.au/individuals/inclusion_and_participation/ability_links_nsw)

## **Assistive Technology**

Assistive technology and equipment options can help people remain independent and improve quality of life by making home, workplace and recreational activities easier and safer. The Independent Living Centre provides information about products, services and resources, including an online product search.

The Independent Living Centre 1300 885 886

[www.ilcaustralia.org.au/](http://www.ilcaustralia.org.au/)

## **Employment**

When someone has been diagnosed with younger onset dementia they may still be in full time employment at the time of diagnosis. The following services can assist with continuing to work and plan for the future.

### **Jobs in Jeopardy**

Provides assistance for people at risk of losing their job due to illness, injury or disability. Jobs in Jeopardy helps investigate ways to maintain employment.

[www.humanservices.gov.au/individuals/services/centrelink/job-jeopardy-assistance](http://www.humanservices.gov.au/individuals/services/centrelink/job-jeopardy-assistance)

### **Job Access 1800 464 800**

A website and telephone information service that provides advice on disability employment related matters. It offers help and workplace solutions for people with a disability and their employers.

[www.jobaccess.gov.au/](http://www.jobaccess.gov.au/)

### **Disability Employment Services**

Can help people with a disability, injury or health condition get ready to look for a job, find a job and keep a job. Disability Employment Services are delivered by a network of organisations around Australia.

For more information contact

Job Access 1800 464 800

[www.jobaccess.gov.au/](http://www.jobaccess.gov.au/)

To find your local Disability Employment Services provider visit Australian Job Search

[www.jobsearch.gov.au/serviceproviders](http://www.jobsearch.gov.au/serviceproviders)

# NEWLY DIAGNOSED. WHAT DOES YOUNGER ONSET DEMENTIA MEAN?

## **Supported Wage System – Australian Government**

When people are unable to find or keep a job at full wage rates due to the effect of disability on their workplace productivity, the Supported Wage System supports employment opportunities through a process that allows employers to pay a productivity-based wage.

[www.jobs.gov.au/supported-wage-system](http://www.jobs.gov.au/supported-wage-system)

## **Employment Assistance Fund**

Employers may be eligible for financial help from the Australian Government for equipment, modifications and services to support employees with a disability.

[www.jobs.gov.au/employment-assistance-fund](http://www.jobs.gov.au/employment-assistance-fund)

## **Accessing Benefits**

### **Accessing Superannuation**

There are several circumstances in which a person with dementia can apply to access the money in their superannuation fund early.

For further information regarding accessing your superannuation early:

[www.humanservices.gov.au/individuals/services/centrelink/early-release-superannuation](http://www.humanservices.gov.au/individuals/services/centrelink/early-release-superannuation)

Phone 1300 131 060 (Early Release of Superannuation Benefits Program)

### **Accessing Australian Government Payments and Services**

Individuals may be eligible for payments and services if unable to work or limited in the amount of work they are able to do as a result of having younger onset dementia.

[www.humanservices.gov.au/individuals/subjects/payments-people-living-illness-injury-or-disability](http://www.humanservices.gov.au/individuals/subjects/payments-people-living-illness-injury-or-disability)

### **Carer Payment and Carer Allowance**

Income supplement payments provided to carers who provide daily care for someone with a disability or a medical condition.

[www.humanservices.gov.au/individuals/subjects/payments-carers](http://www.humanservices.gov.au/individuals/subjects/payments-carers)

## **Financial Information Service 132 300**

This Australian Government service can help assist an individual make current and future financial decisions.

[www.humanservices.gov.au/individuals/services/financial-information-service](http://www.humanservices.gov.au/individuals/services/financial-information-service)

## **Driving**

Conditions such as dementia mean that the decision to stop driving needs to be planned for and made much earlier than expected.

The following links provide information about licensing requirements, and guidance for making what can be a really difficult transition from driver to non-driver as smooth as possible.

<https://www.dementia.org.au/resources/dementia-and-driving>

[www.dementia.org.au/resources/dementia-and-driving-nsw](http://www.dementia.org.au/resources/dementia-and-driving-nsw)

## **Alternative Transport Options**

The Staying on the Move with Dementia resource provides information on alternative transport options and how to access them when a person can no longer drive.

[www.dementia.org.au/resources/dementia-and-driving#alternatives](http://www.dementia.org.au/resources/dementia-and-driving#alternatives)

# 4

## WELLBEING AND LIVING WITH DEMENTIA



# WELLBEING AND LIVING WITH DEMENTIA

A diagnosis of dementia can be life changing for both the person diagnosed and those close to them. Staying connected, maintaining interests and activities, and independence is important for health, wellbeing and quality of life. Support is available from a variety of government programs and non-government services.

## Getting Connected

It is important to stay socially involved. Consider participating in local and online programs and services that provide the opportunity to meet other people with younger onset dementia and their families and friends.

## Staying Active

Physical activity can help to maintain alertness, concentration, attention and memory. It may also reduce stress and anxiety, and improve mood. Getting out and about can be supported by applying for a companion card that will assist with the financial costs of keeping active such as going to events.

## Adapting your home

A well designed environment can help maintain abilities. Having properly fitted smoke alarms, non-slip mats, and clutter free rooms, including bench tops can assist in making a home safe. Lighting should be even throughout to reduce the occurrence of shadows that can be perceived as objects.

For more information visit Dementia Enabling Environments:

[www.enablingenvironments.com.au](http://www.enablingenvironments.com.au)

## Employment

Many younger people with a diagnosis of dementia are still in the work force. It is up to the person to notify their employer of their diagnosis. For many people it will depend on the extent to which symptoms affect their ability to do their job, the pace at which symptoms are progressing, and the support that may be required of the employer.

For more assistance with employment and disability rights contact:

[www.dementia.org.au](http://www.dementia.org.au)

Job Access call 1800 464 800 or visit [www.jobaccess.gov.au](http://www.jobaccess.gov.au)

The Australian Human Rights Commission website [www.humanrights.gov.au](http://www.humanrights.gov.au)

## Staying connected with community

### Ability Links

Helps people with a disability aged 9 to 64 years access support to develop networks in their communities.

[https://www.adhc.nsw.gov.au/individuals/inclusion\\_and\\_participation](https://www.adhc.nsw.gov.au/individuals/inclusion_and_participation)

### Meeting others with Younger Onset Dementia:

#### Online Dementia Forum

This online forum provides a place where younger people with dementia, their families, carers and friends can gather and share information.

[www.talkdementia.org.au](http://www.talkdementia.org.au)

#### Younger Onset Dementia and Me – Blogspot

A website where people with younger onset dementia can connect with others.

[www.youngeronsetdementiaandme.blogspot.com.au/](http://www.youngeronsetdementiaandme.blogspot.com.au/)

#### Cafes, Social and Support Groups

Provide a great opportunity for people to be able to share their experiences and skills with others while learning new ones. For information on the range of groups available contact

Dementia Australia: National Dementia Helpline 1800 100 500

#### Café Groups

Provide a great opportunity for people to be able to share their experiences and skills with others while learning new ones. For information on the range of groups available contact

Dementia Australia: National Dementia Helpline 1800 100 500

Dementia Australia has developed a Community Café Toolkit for establishing a café group for people living with dementia.

[www.dementia.org.au/resources/community-cafe-toolkit](http://www.dementia.org.au/resources/community-cafe-toolkit)



## Leisure and Lifestyle Activities

### YMCA

Provides a suite of recreation, sports, health and leisure programs.

[www.ymcansw.org.au](http://www.ymcansw.org.au)

### Sport and Recreation NSW

Provides information and resources on ways to get active, links to physical activity programs, specific sports and organisations for people with a disability.

[www.sportandrecreation.nsw.gov.au/gettingactive](http://www.sportandrecreation.nsw.gov.au/gettingactive)

### Men's Sheds

Many communities operate Men's Sheds, providing a friendly environment for men to work on meaningful projects in the company of other men. To find a men's shed near you:

[www.dementia.org.au/resources/mens-shed-manual](http://www.dementia.org.au/resources/mens-shed-manual)

Dementia Australia has developed a Men's Shed Dementia Manual providing assistance in enabling a person with dementia to participate.

[www.fightdementia.org.au/about-dementia/resources/mens-shed-manual](http://www.fightdementia.org.au/about-dementia/resources/mens-shed-manual)

### Companion Card

The Companion Card allows a person's carer free entry into participating venues and events. The card is issued free of charge to people who have a disability and need support to engage in community based activities.

[www.nswcompanioncard.org.au](http://www.nswcompanioncard.org.au)

## Volunteering

Being a volunteer can build self-esteem and confidence and provide a way to learn or develop skills and interests, meet new people and broaden social connections.

[www.volunteering.com.au/](http://www.volunteering.com.au/)

## Dementia Friendly Communities

A dementia friendly community is a place where people living with dementia are supported to live a high quality life with meaning and purpose.

Dementia Australia has developed a number of practical resources for individuals and communities to use to help their local community to become dementia friendly.

<https://www.dementia.org.au/dementia-friendly-communities>

## Transport Assistance

### Taxi Transport Subsidy Scheme (TTSS)

Provides subsidised travel, allowing approved participants to travel by taxi up to half fare, up to a maximum of \$30 per trip. Your doctor or treating specialist will need to complete the application form.

[www.transport.nsw.gov.au/customers/taxis/ttss](http://www.transport.nsw.gov.au/customers/taxis/ttss)

### Community Transport NSW Providers list

Community Transport Services are contracted by Transport for NSW, to provide transport to people who have difficulty accessing regular public transport.

A list of providers can be found on the following website:

[www.transport.nsw.gov.au/operations/community-transport-operators](http://www.transport.nsw.gov.au/operations/community-transport-operators)

## Holidays and Travel

### Travelling

Thoughtful planning can ensure a successful travel experience.

Helpful suggestions:

[www.dementia.org.au/files/helpsheets/Helpsheet-CaringForSomeone08-Travelling\\_english.pdf](http://www.dementia.org.au/files/helpsheets/Helpsheet-CaringForSomeone08-Travelling_english.pdf)

[www.dementia.org.au/about-us/news-and-media/news/2016/travelling-with-dementia-how-to-make-the-most-of-your-holiday](http://www.dementia.org.au/about-us/news-and-media/news/2016/travelling-with-dementia-how-to-make-the-most-of-your-holiday)

## **Air Travel Companion**

A service that provides experienced nurses to act as a travel companion for people who are travelling alone internationally and require assistance to do so.

[www.airtravelcompanion.com.au/](http://www.airtravelcompanion.com.au/)

## **Community Care Assistance**

Community care services may support people to stay in their own home and to get out and about in your community. There are government subsidised services and there are private services available.

## **NDIS – National Disability Insurance Scheme**

This scheme is run by the Australian Government and provides individualised funding packages to eligible people living with a disability under the age of 65 years. The financial assistance enables eligible participants to obtain the supports they need.

[www.ndis.gov.au](http://www.ndis.gov.au)

## **My Aged Care 1800 200 422**

This provides information about services, how to access them, and referral for people who are 65 years and over and require supports.

<https://www.myagedcare.gov.au/help-home/home-care-packages>

## **Better Caring**

An online service where people who require in-home or community care support can custom search for private hire, independent nurses, care and support workers to suit individual needs.

[www.bettercaring.com.au](http://www.bettercaring.com.au)

## **Managing Medications**

The daily management of medication can be impaired by difficulties with vision, hearing, memory or cognitive function. There are services that can help.

## **Home Medicines Review (for those living alone)**

A program funded by the Australian Government and the Pharmacy Guild of Australia, where local GPs and Pharmacists work together to review and help individuals

manage medications at home.

[www.nps.org.au/topics/how-to-be-medicinewise/managing-your-medicines/home-medicine-review](http://www.nps.org.au/topics/how-to-be-medicinewise/managing-your-medicines/home-medicine-review)

## **eHealth Record**

Having an eHealth record is another way a person can be supported in medication management. My Health Record is a secure online summary of a person's health information. What goes into it, who has access to it, and who the information is shared with is determined by the individual. People often choose to share their eHealth record with their doctor and other specialists to ensure everyone has the most up to date information about a their medications.

[www.myhealthrecord.gov.au/internet/mhr/publishing.nsf/content/home/](http://www.myhealthrecord.gov.au/internet/mhr/publishing.nsf/content/home/)

## **Continence**

Continence concerns can be very distressing for the person with dementia and impact quality of life. For information about managing continence contact:

## **National Continence Help Line 1800 33 00 66**

Speak with a continence nurse advisor who can provide information and advice.

[www.continence.org.au/pages/national-continence-helpline.html](http://www.continence.org.au/pages/national-continence-helpline.html)

## **Continence products**

[www.continence.org.au/pages/product-providers.html](http://www.continence.org.au/pages/product-providers.html)

## **Relationships and Sexuality**

Dementia causes many changes in people's lives. This includes changes to intimate relationships. Dementia can affect sexual feelings, desires and needs of people with dementia and their partners.

## **Information Sheet – Sex and Intimate Relationships**

This information sheet developed by Alzheimer's Society England, explains how dementia can affect intimate relationships, and outlines some of the ways sexual behaviour can change. It highlights some practical issues and discusses forming new relationships and issues around consent.

[www.alzheimers.org.uk/downloads/download/1140/](http://www.alzheimers.org.uk/downloads/download/1140/)

## factsheet\_sex\_and\_intimate\_relationships

### Relationships Australia

Provides information and advice about relationship issues, and offers counselling and mediation services that can assist individuals, couples and families to improve their relationships. To find a Family Relationship Centre near you:

[www.relationships.org.au/](http://www.relationships.org.au/)

### Touching Base Inc.

Touching Base Inc. is a charitable organisation, based in Sydney operating since October 2000. Touching Base was developed out of the need to assist people with disability and sex workers to connect with each other.

[www.touchingbase.org/](http://www.touchingbase.org/)

### Spirituality and Wellbeing

Spirituality is an essential part of many people's lives and can help people cope with a diagnosis of dementia.

The Dementia Australia Library has a range of books and articles, many of them personal journey stories written by people living with dementia, that explore the role of spirituality in living positively with a diagnosis of dementia.

[www.dementia.org.au/library/nsw](http://www.dementia.org.au/library/nsw)

### Pastoral Care

Pastoral Care workers can provide spiritual and emotional support for the needs of people of all faiths and none. They work in parish settings, hospitals and residential care facilities.

### Dental

Poor dental health can affect a person's comfort, appearance, eating, nutrition, behaviour and general health. Every person with dementia needs an individualised preventative approach to dental care:

[www.dementia.org.au/support-and-services/families-and-friends/personal-care/dental-care](http://www.dementia.org.au/support-and-services/families-and-friends/personal-care/dental-care)

### Allied Health

Allied health professionals can assist in optimising day-to-day quality of life and independence. They include exercise physiologists, physiotherapists, dieticians, occupational therapists, speech pathologists, psychologists, podiatrists, audiologists, chiropractors. A Medicare rebate is available for people who have a patient care plan drawn up by their GP. Some private health insurance companies offer rebates.

To find out more about what allied health professionals do and how to access their services:

<http://www.abc.net.au/health/consumerguides/stories/2005/10/15/1836929.htm>

### Community Health

Community Health Centres provide a range of health services and programs. To find your local Community Health Centre, click on your local health district website, followed by the "Community Health" option:

[www.health.nsw.gov.au/lhd/pages/default.aspx](http://www.health.nsw.gov.au/lhd/pages/default.aspx)

### Financial Security

#### Planning Ahead Tools

This NSW Government website provides information about power of attorney and how to appoint a power of attorney. This is a legal document and it is advisable to have a professional help tailor it to specific requirements.

<http://planningaheadtools.com.au/make-a-power-of-attorney/>

## **NSW Civil and Administrative Tribunal – Financial Management**

The Tribunal can appoint a manager to oversee the affairs of a person who no longer has the capacity to make financial decisions in operating bank accounts, paying bills, selling or buying property, and investing money. An application process applies.

[http://www.ncat.nsw.gov.au/Pages/guardianship/gt\\_matter\\_about/financial\\_management.aspx](http://www.ncat.nsw.gov.au/Pages/guardianship/gt_matter_about/financial_management.aspx)

## **Housing**

Assistance may be needed for maintaining or securing appropriate housing.

### **Housing NSW**

Housing NSW can provide assistance options including affordable housing, social housing, temporary and emergency accommodation, and private rental assistance.

### **Housing Accommodation support Initiative**

This service supports people with an existing mental illness who have been unable to secure and maintain tenancy.

### **Aboriginal Housing Office**

This service provides housing assistance to Aboriginal and Torres Strait Islander people.

[www.aho.nsw.gov.au](http://www.aho.nsw.gov.au)

Housing Contact Centre 1300 HOUSING

### **Link2home – 1800 152 152**

Link2home is a single, state-wide telephone service for homelessness enquiries in NSW. Link2home provides assistance to people who are homeless or at risk of homelessness by offering access to specialised support and accommodation services.

## **Home Modifications**

There are simple modifications that can be made to the home to develop a safe and enabling environment.

### **At Home with Dementia – A Manual**

This manual was developed for people with dementia and their carers. It provides strategies and suggestions for modifying the home environment.

<https://www.humanics-es.com/athomedementia.pdf>

## **Home Sa-fety**

For suggestions on safety in and around the home visit.

[www.dementia.org.au/national/support-and-services/carers/safety-in-and-around-the-home](http://www.dementia.org.au/national/support-and-services/carers/safety-in-and-around-the-home)

## **Home Modification Australia**

Provides a comprehensive service directory to help find services that can assist with home modifications such as occupational therapists that can assist with the design and planning around the home, builders, consultants, and professional trades people who are experienced in home modifications.

Search the Service Directory:

[www.homemods.info/service-directory](http://www.homemods.info/service-directory)

## **Enabling Environments – Virtual Information Centre**

This website provides practical tips, guides and resources to make home spaces, gardens, care environments and public buildings more enabling.

[www.enablingenvironments.com.au](http://www.enablingenvironments.com.au)

## Meals, nutrition and Shopping

It is important to ensure good nutrition, especially for people with dementia who live alone. Meal monitoring, shopping support and meal preparation services play an important role in supporting good nutrition.

### Nutrition – A Discussion Paper

[www.dementia.org.au/support-and-services/families-and-friends/personal-care/nutrition](http://www.dementia.org.au/support-and-services/families-and-friends/personal-care/nutrition)

### Meals on Wheels

This service provides nutritionally balanced meals prepared and delivered to the home. To find the location of a Meals on Wheels service near you:

[www.nswmealsonwheels.org.au/](http://www.nswmealsonwheels.org.au/)

### Shopping

Shopping may present new challenges for a person with dementia. Domestic help services can assist with shopping and most of the major grocery retailers offer online ordering of groceries and delivery into the home.

## Domestic Assistance

There are many organisations that provide assistance in the home for domestic duties such as cleaning and laundry. Some are government subsidised services and others are private services.

To access a personalised funding package to meet your specific needs, you will need to arrange an assessment through the NDIS.

### NDIS – National Disability Insurance Scheme

This scheme is run by the Australian Government and provides personalised funding packages to eligible people living with an ongoing disability who are under the age of 65 years. The financial assistance enables participants to obtain the supports they need to help them stay in their own home and to participate more fully in life.

[www.ndis.gov.au/](http://www.ndis.gov.au/)

### Veterans' Home Care Program

This scheme is run by the Australian Government and provides individualised funding packages to people living with disability under the age of 65 years. The financial assistance enables eligible participants to obtain the support they need.

To arrange an assessment call:

Veterans Home Care Assessment Agency  
1300 550 450

[www.dva.gov.au/health-and-wellbeing/home-and-care/veterans-home-care-vhc](http://www.dva.gov.au/health-and-wellbeing/home-and-care/veterans-home-care-vhc)

### Lawn, Garden and Home Maintenance

[www.jimsmowing.net](http://www.jimsmowing.net)



# 5

## PLANNING FOR RESIDENTIAL OR OTHER ACCOMMODATION

# PLANNING FOR RESIDENTIAL OR OTHER ACCOMMODATION

As dementia progresses a person will need more support. Assistance to remain at home can be obtained through National Disability Insurance Scheme (for eligible people aged under 65) or the My Aged Care gateway (for people aged 65 and over).

Moving into residential care or other accommodation is an option when a person is not longer able to live at home.

**Information on living the way you want is available on the Accommodation Support page.**

[www.dva.gov.au/health-and-wellbeing/home-and-care/veterans-home-care-vhc](http://www.dva.gov.au/health-and-wellbeing/home-and-care/veterans-home-care-vhc)

## Support to remain at home

### NDIS – National Disability Insurance Scheme

This scheme is run by the Australian Government and provides individualised funding packages to people living with disability under the age of 65 years. The financial assistance enables eligible participants to obtain the support needed to stay at home.

[www.ndis.gov.au](http://www.ndis.gov.au)

### Aboriginal Housing Office

This office provides housing assistance to Aboriginal and Torres Strait Islander people.

[www.aho.nsw.gov.au](http://www.aho.nsw.gov.au)

Housing Contact Centre 1300 HOUSING

## Homeless or at Risk of Homelessness

### Link2home 1800 152 152

Is a state-wide telephone service for homelessness enquiries in NSW, providing assistance by offering access to specialised support and accommodation services.

[www.facs.nsw.gov.au/about\\_us/news/2014/link2home](http://www.facs.nsw.gov.au/about_us/news/2014/link2home)

### Dementia Australia National Dementia Helpline 1800 100 500

Alzheimer's Australia has produced a DVD about Homelessness and Dementia:

[www.dementia.org.au/information/about-dementia](http://www.dementia.org.au/information/about-dementia)

## Moving into a Residential Facility

Making the decision to find an alternative to caring for a person with dementia at home can be one of the most difficult decisions that families and carers will make. Being prepared can help make this decision less stressful. Knowing about the services, government policies and costs of residential care beforehand can help make the best decision.

### Approval for Residential Care and Residential Respite

When moving into an aged care home that is subsidised by the Australian Government, or accessing residential respite, the first step is to organise a free assessment with an Aged Care Assessment Team (ACAT)

### Choosing a Residential Care Facility

When choosing a facility it is advisable to take time to consider how it will meet the needs of the person with dementia. The Aged Care Assessment Team (ACAT) can advise which type of accommodation is best. The following link provides guidance on choosing a residential facility:

[www.dementia.org.au/services/programs](http://www.dementia.org.au/services/programs)

### Steps to Take Before Moving into a Residential Facility

The Five steps to entry in an aged care home booklet gives an overview from assessing eligibility, finding an aged care home and living in an aged care home.

[www.agedcare.health.gov.au/programs/residential-care/five-steps-to-entry-into-an-aged-care-home](http://www.agedcare.health.gov.au/programs/residential-care/five-steps-to-entry-into-an-aged-care-home)



## **Advocacy in residential Care**

Advocacy services may be able to help with concerns about the quality of the service being received in an aged care facility. The following services are free, confidential and independent.

National Aged Care Advocacy Line  
1800 700 600

[www.myagedcare.gov.au/how-make-complaint/advocacy-services](http://www.myagedcare.gov.au/how-make-complaint/advocacy-services)

## **The Aged-Care Rights Service (TARS)**

[www.agedrights.asn.au/nsw/](http://www.agedrights.asn.au/nsw/)

**Seniors Rights Service 1800 424 079**

[www.seniorsrightsservice.org.au](http://www.seniorsrightsservice.org.au)



# 6 FUTURE PLANS

Dementia is a progressive life limiting condition. A person's needs will increase and become more complex over time. Making adequate plans and decisions for end of life care is important. Some people with dementia remain at home, while others will need to access residential aged care.

## Tools to Help You Plan Ahead

Palliative Care NSW and Dementia Australia have produced two booklets to support people with dementia, their families and care professionals have important conversations about planning for the future and end of life care.

The Dementia Journey is a workbook and planning tool for people with dementia.

[www.palliativecarenewsw.org.au/site/wp-content/uploads/2011/07/PCNSW-Dementia-Workbook.pdf](http://www.palliativecarenewsw.org.au/site/wp-content/uploads/2011/07/PCNSW-Dementia-Workbook.pdf)

Asking Questions About Dementia Can Help is a booklet and kit for people with dementia, their families and carers.

[www.palliativecarenewsw.org.au/site/wp-content/uploads/2011/07/PCNSW-Asking-Questions-Booklet.pdf](http://www.palliativecarenewsw.org.au/site/wp-content/uploads/2011/07/PCNSW-Asking-Questions-Booklet.pdf)

## Palliative Care

Palliative care is specialised care support provided for someone with a terminal illness, which also involves care and support for family. Every person has different needs and it is often the need, which determines the care and support offered by service providers.

Palliative care can be offered by a number of different health professionals and the person's GP is often a main palliative care provider. Sometimes a person may need to be referred to a specialist palliative care service where a team of health professionals will work together to meet their needs. Palliative care can be provided in the person's home, in hospital or in a residential aged care facility.

For help and information about palliative care, ask your doctor or contact:

### Palliative Care NSW

Phone: 02 9206 2094

[www.palliativecarenewsw.org.au](http://www.palliativecarenewsw.org.au)

## Acute Hospital Care

There may be times when a person with dementia requires medical care in a hospital setting.

In some situations it is best for people with dementia to receive medical care within the home or within specialised residential care facilities.

People with dementia can be susceptible to delirium. Delirium is an acute medical condition that increases confusion and disruptions in thinking and behaviour. It can be caused by a urinary tract infection or other infection; uncontrolled pain; an adverse reaction to medication; or a "brain event" such as stroke.

It is important to find and treat the underlying cause.

To find a Clinical Nurse Consultant (CNC) specialising in dementia and delirium, please contact your local health district.

[www.health.nsw.gov.au/lhd/pages/default.aspx](http://www.health.nsw.gov.au/lhd/pages/default.aspx)

## Bereavement Support and Grief Counselling

Grief is the emotion we feel when an important relationship breaks down or ends. After a family member or friend dies it may be helpful to talk about the experience outside the immediate circle of family and friends. Bereavement counselling services can provide this support.

### Dementia Australia Counselling Service 1800 100 500

[palliativecarenewsw.org.au/new/get-equipped/resources/](http://palliativecarenewsw.org.au/new/get-equipped/resources/)

### Bereavement Care Centre 1300 654 556 [www.bereavementcare.com.au](http://www.bereavementcare.com.au)



# 7

## YOUNGER ONSET DEMENTIA IN OTHER DISORDERS



Whilst Alzheimer's disease is the most common form of dementia, there are many disorders and conditions that can cause dementia. Dementia can occur as a secondary result from having a neurodegenerative disorder such as Parkinson's disease, Huntington's disease, multiple sclerosis, motor neurone disease, AIDS/HIV, and can be associated with having an intellectual disability.

## **Information about Rarer Causes of Dementia:**

[www.dementia.org.au/files/helpsheets/Helpsheet-AboutDementia18-AlcoholRelatedDementiaAndWernickeKorsakoffSyndrome\\_english.pdf](http://www.dementia.org.au/files/helpsheets/Helpsheet-AboutDementia18-AlcoholRelatedDementiaAndWernickeKorsakoffSyndrome_english.pdf)

## **Information about alcohol-related dementia:**

[www.dementia.org.au/files/helpsheets/Helpsheet-AboutDementia19-HIVAssociatedDementia\\_english.pdf](http://www.dementia.org.au/files/helpsheets/Helpsheet-AboutDementia19-HIVAssociatedDementia_english.pdf)

## **Information about HIV Associated Dementia:**

[www.dementia.org.au/files/helpsheets/Helpsheet-AboutDementia19-HIVAssociatedDementia\\_english.pdf](http://www.dementia.org.au/files/helpsheets/Helpsheet-AboutDementia19-HIVAssociatedDementia_english.pdf)

## **Information about Down Syndrome and Dementia**

[www.dementia.org.au/files/helpsheets/Helpsheet-AboutDementia15-DownSyndromeAndAlzheimersDisease\\_english.pdf](http://www.dementia.org.au/files/helpsheets/Helpsheet-AboutDementia15-DownSyndromeAndAlzheimersDisease_english.pdf)

## **Living with Intellectual Disability and Dementia – a video resource**

[www.dementia.org.au/videos/living-with-intellectual-disability-and-dementia](http://www.dementia.org.au/videos/living-with-intellectual-disability-and-dementia)

Organisations providing information and support services for people with dementia who have other disorders and conditions:

### **Down Syndrome**

[www.downsyndromensw.org.au/](http://www.downsyndromensw.org.au/)

### **Parkinson's Disease**

[www.parkinsons.org.au/](http://www.parkinsons.org.au/)

### **Multiple Sclerosis**

[www.msaustralia.org.au/](http://www.msaustralia.org.au/)

### **Motor Neurone Disease**

[www.mndaust.asn.au/Home.aspx](http://www.mndaust.asn.au/Home.aspx)

### **Huntington's disease**

[www.huntingtonsnsw.org.au](http://www.huntingtonsnsw.org.au)

### **HIV/AIDS**

[www.acon.org.au](http://www.acon.org.au)

### **Alcohol-related dementia**

[www.arbias.org.au](http://www.arbias.org.au)

# CONTACT US

## Our Offices

### ADMINISTRATION

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**F:** 02 9805 1665

**E:** NSW.Admin@dementia.org.au

**W:** www.dementia.org.au

### NORTHERN NSW

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Port Macquarie:	02 6584 7444
Forster:	02 6554 5097
Coffs Harbour:	02 6651 7101
Central Coast:	02 9805 0100

### SYDNEY REGION

North Ryde:	02 9888 4268
St George/Sutherland:	02 9531 1928
Blacktown:	02 9805 0100

### SOUTHERN NSW

Bega Shire:	02 6492 6158
Eurobodalla Shire:	02 4474 3843
Cooma, Bombala & Snowy Mountains Shires:	02 6452 3961
Yass, Young, Goulburn, Queanbeyan, Harden, Moss Vale:	02 4869 5651
Wollongong:	02 9805 0100

### WESTERN NSW

Orange:	02 6369 7164
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### National Dementia Helpline

# 1800 100 500

This is an initiative of the Australian Government

Dementia Australia

**www.dementia.org.au**

ABN 27 109 607 472

