UNDERSTAND ALZHEIMER’S
SUPPORT AUSTRALIA

DEMENTIA
INFORMATION SUPPORT CONTACTS

IN VICTORIA
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Alzheimer’s Australia Vic Inc  ABN 14 671 840 186   ARBN 106 766 769
This information booklet has been written for people with all forms of dementia, their families and carers.

Much is still to be learned about dementia, but we do know that support and assistance can greatly benefit all people who are affected by the condition.

It is important to know about dementia, and how to get help. This booklet will provide a starting point with information about dementia, services and resources that are available to assist you.

Just as Alzheimer’s disease and other dementias affect people differently, the support needs of people with dementia, their families and carers will vary over time. The information in this booklet will be useful at different times. We encourage you to share it with family and friends and keep it for future reference.

Further information is available by calling Alzheimer’s Australia Vic on 1800 100 500 or visit fightdementia.org.au/vic
What is dementia?
Dementia is the term used to describe the symptoms of a large group of illnesses which cause a progressive decline in a person’s functioning. It is a broad term which describes a loss of memory, intellect, social skills and what would be considered normal emotional reactions. For a long time, the person may look healthy, but on the inside their brain is not working properly.

There are a number of different forms of dementia. The best known is Alzheimer’s disease, which is also the most common. Alzheimer’s disease is a progressive disease that damages the brain and affects how it functions.

Other forms of dementia include Lewy body disease, vascular dementia and frontotemporal dementia, as well as other more rare conditions.

Most of these conditions begin gradually and the person’s abilities deteriorate over time. They may experience early changes that are not severe enough to be called dementia. This is called ‘mild cognitive impairment’. Sometimes, changes in memory and thinking can occur for other reasons, so not everyone with mild cognitive impairment goes on to develop dementia.

Memory loss
One of the main symptoms of Alzheimer’s disease is memory loss. We all forget things from time to time, but the loss of memory with Alzheimer’s dementia is different. It is persistent and progressive, not just occasional. It may affect the ability to continue to work, or carry out familiar tasks. It may mean having difficulty finding the way home. Eventually it may mean forgetting how to dress or how to bathe.
An example of normal forgetfulness is walking into the kitchen and forgetting what you went in there for, or misplacing the car keys.

A person with dementia, however, may find the car keys but forget what they are used for.

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<th>Description</th>
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<th>Older Person</th>
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<tr>
<td>Events</td>
<td>May forget part or all of an event</td>
<td>Memory may sometimes be vague</td>
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<td>Words or names for things or objects</td>
<td>Progressively forgets</td>
<td>Sometimes may forget; words or names are on the tip of the tongue</td>
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<td>Written and verbal directions</td>
<td>Increasingly unable to follow</td>
<td>Able to follow</td>
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<td>Stories on TV, in books or movies</td>
<td>Progressively loses ability to follow</td>
<td>Able to follow</td>
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<td>Stored knowledge</td>
<td>Over time loses known information such as historical or political information</td>
<td>Although recall may be slower, information is essentially retained</td>
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<tr>
<td>Everyday skills such as dressing and cooking</td>
<td>Progressively loses capacity to perform tasks</td>
<td>Retains ability, unless physically impaired</td>
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Who gets dementia?
Dementia can happen to anybody, but the risk increases with age. Most people with dementia are older than 65, but it is important to remember that most older people do not get dementia. It is not a normal part of ageing, but is caused by brain disease. Rarely, people under the age of 65 years develop dementia and this is called ‘younger onset dementia’.

Can dementia be inherited?
There are a few very rare forms of inherited dementia, where a specific gene mutation is known to cause the disease. In most cases of dementia however, these genes are not involved, and the dementia is not inherited. People with a family history of dementia do have a slightly increased risk of developing the disease themselves. However, even if several members of the same family are affected, this does not usually mean the dementia is inherited.

Progression of dementia
The situation for every person with dementia is unique. Their abilities may change from day to day, or even within the same day. What is certain though is that the person’s abilities will deteriorate, sometimes rapidly, and in other cases more slowly, over a number of years.

What can be done to help?
At present there is no cure for dementia. However, medications have been found to help some of the symptoms for some people. Your doctor will be able to provide advice about these.

Support is available for the person with dementia and their family, friends and carers. This support can make a positive difference to managing dementia.
What are the early signs?
Because the diseases that cause dementia develop gradually, the early signs may be very subtle and vague, and not immediately obvious. Early symptoms also depend on the type of dementia and vary a great deal from person to person.

Common early symptoms include:

- Memory problems, particularly remembering recent events
- Increasing confusion
- Reduced concentration
- Personality or behaviour changes
- Apathy and withdrawal or depression
- Loss of ability to do everyday tasks

Sometimes people fail to recognise that these symptoms indicate that something is wrong. They may mistakenly assume that such behaviour is a normal part of ageing. Or symptoms may develop gradually and go unnoticed for a long time. Sometimes people may be reluctant to act even when they know something is wrong.

Remember that many conditions have symptoms similar to dementia, so it is important not to assume that someone has dementia just because some of the symptoms are present. Strokes, depression, alcoholism, infections, hormone disorders, nutritional deficiencies and brain tumours can all cause dementia-like symptoms. Many of these conditions can be treated, so it is very important to seek medical advice if at all concerned.

Only a medical practitioner can diagnose dementia. If a diagnosis has been made, it is helpful to find out about dementia and the support that is available to help you manage.
**WARNING SIGNS**

- Memory loss that affects day-to-day function
- Difficulty performing familiar tasks
- Confusion about time and place
- Problems with language
- Problems with abstract thinking
- Poor or decreased judgement
- Problems misplacing things
- Changes in personality or behaviour
- A loss of initiative

*Based on information from Alzheimer’s Association USA*
Alzheimer’s Australia Vic was established to assist people with dementia, their families and carers. It does this by providing a range of services across Victoria to support people with dementia, their families and carers throughout the course of the illness.

To find out about the services closest to you call the National Dementia Helpline.

National Dementia Helpline 1800 100 500

The National Dementia Helpline is a telephone information, counselling and support service that is available across Australia, and is an Australian Government initiative. The Helpline is staffed by trained and experienced volunteer advisors. Many of the advisors have personal experience in dementia care.

National Dementia Helpline counsellors and advisors provide:

- Understanding and support
- Counselling
- Practical information and advice
- Up-to-date written material about dementia
- Information about other services
- Details of the full range of services provided by Alzheimer’s Australia

Dementia Help Sheets

A large number of Help Sheets are available free of charge for people with dementia, their families and carers. These Help Sheets provide specific information across a range of areas including:

- About dementia
- Caring for someone with dementia
- Looking after families and carers
- Residential care and dementia
- Changed behaviours and dementia
- Young people and dementia
- Younger onset dementia
- Information for people with dementia

For copies of the Help Sheets visit fightdementia.org.au or contact the National Dementia Helpline on 1800 100 500. Selected Help Sheets are available in 30 community languages.
Information and education

Information sessions

Regular information sessions are conducted for families, carers and people with dementia who want to learn more about dementia and the services available in their community. These sessions are free of charge.

Practical education programs for families and carers

A range of information and support workshops are available for families and carers which provide useful information and practical suggestions for caring. These programs are delivered by professionals with experience in dementia care. They are held regularly across Victoria and are free of charge. Information about dates and times of programs can be obtained by contacting the National Dementia Helpline on 1800 100 500 or by visiting fightdementia.org.au/vic

Counselling and individual support

Professional staff are located across Victoria to provide individual support and practical advice to people with dementia, their families and carers. Counselling may involve:

- Identifying strategies for managing and living with dementia
- Dealing with changed behaviours
- Planning for the future
- Dealing with feelings of stress
- Resolving conflicts within families
- Helping to obtain an appropriate service or practical assistance

The service is confidential, sensitive and free of charge.

Support for people with early stage dementia

When a diagnosis of dementia is confirmed, people in the early stages can benefit greatly by receiving information, practical advice and emotional support. This can help with adjusting to living with the illness and planning for the future.

Individual or family counselling is available. Provided by professional staff, it is confidential, sensitive and free of charge.

The Living with Dementia program provides opportunities for both people with early stage dementia and family members to get information and talk through issues in a group program. Sessions are held separately for people with dementia, and jointly with their
families, generally meeting weekly for six sessions. Ongoing support is also available to provide social contact and further educational opportunities.

**Support for people with Younger Onset Dementia**

A range of specialist services are available for those under the age of 65, including a network of key workers who can assist you in a variety of ways. For more information contact the National Dementia Helpline on 1800 100 500.

**Memory Lane Cafés**

Alzheimer’s Australia Vic has been successfully running Memory Lane Cafés for more than 10 years. The café events provide an opportunity for people with dementia and their family members to enjoy time together in the company of people in a similar situation to themselves.

The cafés are a great place to meet other people, share experiences, learn about a range of services that can provide support and have a good time in a friendly and relaxed atmosphere.

Many people begin to attend the café in the early stages of dementia; however, people at various stages of progression attend the cafés.

Our café programs are available in 8 locations around Victoria.

**Community awareness**

To increase community awareness about living with dementia, professional staff and trained volunteers are available to speak to organisations and interested groups of people.

**Website**

For the latest information about our services, current information about dementia, Dementia Help Sheets, and links to other useful sites, visit fightdementia.org.au/vic

**Library**

Visitors are welcome to drop in to our library (no appointment is necessary) at 100 Riversdale Road, Hawthorn, between 9.00am – 5.00pm Monday to Friday (except public holidays) and an advisor or counsellor will be able to assist.

The library holds an extensive collection of books, brochures, journals, and DVDs about dementia. Dedicated computers are available for browsing the internet and online resources, with experienced staff to assist. Everyone is welcome to visit and use the facilities of the library, however, membership to Alzheimer’s Australia Vic is required if items are borrowed.
Regional areas

Alzheimer’s Australia Vic has ten regional sites ensuring people living in rural locations have access to information and support services in their local area.

For further information, contact the National Dementia Helpline on 1800 100 500.

Diversity services

Alzheimer’s Australia Vic is committed to meet the language and cultural needs of all members of the community. Alzheimer’s Australia Vic provides culturally responsive and inclusive services to diverse communities including people from Culturally and Linguistically Diverse (CALD) backgrounds, Aboriginal and Torres Strait Islanders (ATSI), Gay, Lesbian, Bisexual, Transgender, Intersex (GLBTI) people, and people who are homeless or at risk of homelessness.

Dementia information is translated into 30 community languages. Interpreters are used across all services, including counselling. Our National Dementia Helpline provides information, support and referrals for all diverse target groups in any area that may provide assistance.

If you or someone you know has difficulty communicating in English, please call the Translating and Interpreting Service (TIS) on 131 450 and ask to speak with the National Dementia Helpline on 1800 100 500.

Keeping in touch with Alzheimer’s Australia Vic - become a member

Becoming a member of Alzheimer’s Australia Vic is the best way to keep informed of the latest news on services, support, research, treatments and other developments.

Members receive our newsletter, are able to borrow from the library and are entitled to reduced rates for some events, education courses and workshops.

To become a member contact Alzheimer’s Australia Vic by telephone or download the membership form from fightdementia.org.au/vic
In addition to the services provided by Alzheimer’s Australia Vic, there are many other services available. Some of the services will be useful when seeking a diagnosis and in the period immediately after a diagnosis of dementia has been made. Others will be more useful with the day-to-day management of dementia.

**Family Doctor**

Only a medical practitioner can make a diagnosis of dementia. The family doctor is often the first person that people talk to about their concerns. They may assess for dementia and may refer the person to a specialist. The family doctor will most likely be the key health professional providing on-going health care for both the person with dementia and their family member.

**Specialists**

The family doctor may refer people with dementia to a specialist for particular testing or treatment, particularly at the stage where a diagnosis is being made.

Relevant specialists may include:

- **Geriatrician** - a doctor who specialises in the care of older people.
- **Psychiatrist** - a doctor who specialises in mental disorders.
- **Psychogeriatrician** - a doctor who specialises in mental disorders affecting older people.
- **Neurologist** - a doctor who specialises in conditions that affect the brain and the nervous system.
- **Neuropsychologist** - a psychologist who specialises in conditions that affect the brain and how they affect people’s day-to-day functioning.

**Cognitive, Dementia and Memory Services (CDAMS)**

These are specialised diagnostic services that provide expert assessment and diagnosis to people with cognitive impairment causing confusion, memory loss, personality or behavioural changes. CDAMS can also offer general information and advice to anyone supporting a person with a cognitive impairment such as dementia.

CDAMS also refer people to appropriate services, working closely with the family doctor.

CDAMS are located throughout Victoria. To find the location and telephone number of your closest CDAMS call the National Dementia Helpline on 1800 100 500.
Aged Care Assessment Services (ACAS)

Aged Care Assessment Services provide an assessment and advisory service to people who are requiring additional support. These health professionals provide a thorough assessment of care needs and offer advice for future options. ACAS staff will visit the person in their home and provide guidance about the best care for the person with dementia. An assessment by this service is required to access a Community Aged Care Package or other care packages, and when residential placement or respite in a Commonwealth Government funded facility is being considered.

There are ACAS teams in both metropolitan and country Victoria. The doctor can refer the person with dementia to the service, or they can be contacted directly. The contact number for your closest ACAS can be found by calling the Aged Care Information Line on 1800 500 853, or visit agedcareaustralia.gov.au or commcarelink.health.gov.au

Aged Persons Mental Health Services

Aged Persons Mental Health Services are primarily for people with a long-standing mental illness who are now over 65 years of age, or who have developed functional illnesses such as depression and psychosis in later life. They also provide services for people with psychiatric or severe behavioural difficulties associated with organic disorders such as dementia.

Contact the National Dementia Helpline for more information on how to access aged persons assessment and treatment services. These specialist services provide community-based assessment, treatment, rehabilitation and case management for older people.

Dementia Behaviour Management Advisory Service (DBMAS)

DBMAS is an advice, assessment, intervention, education and specialised support service available 24 hours a day. DBMAS provides advice about managing behaviours of concern in people with dementia. Behaviours of concern may include (but are not limited to):

- agitation
- sleep disturbances
- resistance to care
- depressed mood, hallucinations and/or anxiety

DBMAS has been established to support carers and care workers of people with dementia who experience behaviours of concern that may impact on their care.

To find out more about DBMAS call 1800 699 799 (24 hours a day, 7 days a week) or call the National Dementia Helpline on 1800 100 500 (business hours).
**Nursing care**

Community nurses are available to assess care needs in a person’s home. They can help with home nursing, assistance with medication, advice and referral.

The Royal District Nursing Service (RDNS) provides this service for people living in the Melbourne metropolitan area and can be contacted on 1300 334 455 (24hours a day, 7 days a week) or by email getinfo@rdns.com.au, or contacting the National Dementia Helpline on 1800 100 500. In country Victoria, district nurses can be contacted by calling your local community health service or local hospital.

**Home support**

There are many services which help people live more comfortably in their own home by offering extra support. Some of the most commonly used services for people with dementia living at home include:

- Home help: this can provide assistance with housekeeping, shopping, paying bills and related tasks.
- Delivered meals: provides meals in the home.
- Personal care: assistance with bathing, dressing, toileting and other needs.

Home Care Packages: individualised packages of home care support funded by the Commonwealth Government. Dementia supplements are available across all levels of package, which range from low level care to high care needs.

For information about these and other services contact your local council or the National Dementia Helpline on 1800 100 500.

**Support groups**

Support groups are meetings of family members, friends or neighbours who are affected by dementia. They meet regularly at a local venue to share their experiences and support each other in working towards overcoming the problems and challenges they face as carers.

Support groups vary in size and some have special memberships such as for people with different cultural backgrounds and men’s groups.

Professional staff of Alzheimer’s Australia Vic are available to visit support groups to provide useful information and practical suggestions for living through the dementia journey.

Visit the Infoxchange Service Seeker website at serviceseeker.com.au for a list of groups.
**Carers Victoria**

Carers Victoria provides information about support services available for carers and how to access them. Carer Support Kits, available in a number of community languages, provide a range of practical information for carers. Kits can be obtained by contacting the Commonwealth Respite and Carelink Centres on 1800 052 222 or carersvic.org.au.

**Respite services**

Respite is another term for taking a break. Respite can give family members a break from caring and a chance for the person with dementia to take part in some social or recreational activities.

Respite care can be provided in local day activity centres. Some centres offer specialised activities for people with dementia. Day centres offer care for a few hours to five days a week. Some centres offer weekend or overnight care.

Another way to take a break is to have a person come to the house of the person with dementia to enable the family to do things outside the house, or to accompany the person with dementia to an activity they enjoy. This is often called in-home respite.

Respite can also be used to provide care in an emergency or arranged for a longer period of time in a residential facility.

Commonwealth Respite and Carelink Centres (CRCC) are information centres for older people, people with disabilities and those who provide care and services. Centres provide free and confidential information on community aged care, disability and other support services available locally and interstate. Contact your nearest CRCC by phoning 1800 052 222 (freecall) or visit commcarelink.health.gov.au
The family solicitor, Victoria Legal Aid and the Office of the Public Advocate can all provide advice on these legal matters.

The Office of the Public Advocate can be contacted on 1300 309 337 or visit publicadvocate.vic.gov.au

Planning ahead for financial and legal matters can make it much easier for everyone who is affected by dementia. By making plans early, the person with dementia can participate in decisions about how their financial and legal affairs will be managed in the future.

Enduring Power of Attorney (Financial)

An Enduring Power of Attorney (Financial) is a legal arrangement for another person to look after a person’s financial and legal affairs if they become unable to do so for themselves. A person can only sign an Enduring Power of Attorney (Financial) if they are legally competent at the time of signing.

Enduring Power of Attorney (Medical Treatment)

An Enduring Power of Attorney (Medical Treatment) is a legal document that enables a person to appoint another person to make medical decisions for them. Like an Enduring Power of Attorney (Financial) a person must be legally competent at the time of signing.

Enduring Power of Guardianship

This is a legal arrangement that enables a person to appoint another to be their guardian. This person will be able to make general health and lifestyle decisions, subject to any conditions set out in the legal document of
appointment. This document can only be signed by a legally competent person.

For more information contact the Office of the Public Advocate on 1300 309 337 or visit publicadvocate.vic.gov.au

**Guardianship and administration**

The Victorian Civil and Administrative Tribunal (VCAT) Guardianship List can appoint a person to make personal and lifestyle decisions for any adult who is unable to make decisions for themselves. This person is called a Guardian. They can also appoint an Administrator to take responsibility for managing a person’s finances. Often the person appointed to be a guardian or administrator is a relative.

**Wills**

A Will gives instructions as to how the estate of a deceased person should be distributed. A Will is only legal if the person making it understands its implications, so it is important that the person with dementia makes or updates their Will while they are still competent to sign.

**Financial support**

If you are a person with dementia, or you are caring full time for a person with dementia, you may be eligible for some Government benefits.

**Carer Payment and Carer Allowance**

These are income support payments for carers who, because of the demands of their caring role, are unable to support themselves through full participation in the work force. For more information visit any Centrelink office, phone 132 717 or visit centrelink.gov.au

**Disability Support Pension**

A person with dementia may be eligible for the Disability Support Pension if they are unable to work.

Other benefits include rent assistance, pharmaceutical allowance and mobility allowance.

For more information about any of the above benefits visit any Centrelink office, phone Centrelink 132 717 or visit centrelink.gov.au

**Benefits for Veterans**

The Department of Veterans’ Affairs provides a range of financial assistance and support services to veterans, war widows, their families and carers. For more information, contact the Department of Veterans’ Affairs on 133 254, or 1800 555 254 (rural areas only).
Commonwealth Funded Residential Care

Living at home may not always be possible and it may become necessary to consider residential placement. Before a person can enter a Commonwealth Government funded residential aged care facility they must be assessed by an Aged Care Assessment Service (ACAS), who will determine the level of care needed. The ACAS will provide information about finding suitable facilities. The family doctor and other carers may also provide useful information about residential placement.

Facilities which provide long term care are usually grouped into those providing low level care and those providing high level care. Some facilities provide care for people with all levels of need.

Dementia specific units

These are small units designed specifically for people with dementia and can be classified either as hostel or nursing home depending on the level of care provided.

Supported residential services

Privately owned and funded, supported residential services provide accommodation and some personal assistance. As these services do not receive Commonwealth Government funding, an ACAS assessment is not required. However, the ACAS can provide an assessment and information about local supported residential services.

For more information about residential care contact
My Aged Care
1800 400 422
www.myagedcare.gov.au
Over time a person with dementia will require increasing support and care from family and friends. Often partners and children provide significant amounts of care on a daily basis as the dementia progresses.

Family and friends can play an important part in the lives of people affected by dementia. They provide valuable links to past experiences, and enable the person with dementia to continue to be a loved and valued member of the family and circle of friends.

Family and friends can also provide invaluable support to carers. Whilst studies confirm high rates of depression, anxiety and even physical illness in families where someone has dementia, support from others can reduce the impact of the disease.

Unfortunately, many people with dementia and their carers find that family and friends stay away from them after dementia has been diagnosed. Some people are frightened or embarrassed by dementia. Some are afraid of saying or doing the wrong thing.
Ways to help

Family and friends can support people affected by dementia in a variety of ways:

- Learning about dementia is always a good starting point. This includes understanding that while outwardly the person may look fine, they do have a condition that affects the brain. This is not contagious.
- Encouraging all involved to have a break or just a change of scenery.
- Being available for a chat from time to time.
- Bringing a meal, or helping with gardening or shopping.

Helping the person with dementia do the kind of things that they enjoyed doing before dementia was diagnosed can be helpful. Outings to the football, fishing, walks, or drives in the country are all activities that may still be enjoyed. Remember that many people with dementia do not enjoy crowds or noisy environments. Activities may need to be adapted but it is important to keep doing them for as long as possible. Enjoyment does not require memory, so it is important to remember that even if an outing is soon forgotten, it is still worthwhile.

Ask about specific ways you can help. Be aware that many people are reluctant to admit that they need help until the need becomes desperate.

Communicating

Losing the ability to communicate can be one of the most frustrating problems for people with dementia, and can also add to the difficulty of maintaining friendships for family and friends.

Remember that people retain their feeling and emotions even though they may not understand all that is being said. It is important to always maintain their dignity and self-esteem. Be flexible and always allow plenty of time for a response. Using touch to keep the person’s attention and to communicate feelings of worth and attention may be helpful.

It is important to talk in a gentle, matter of fact way and to keep sentences short, focusing on one idea at a time. Always allow plenty of time for what you have said to be understood. Silence provides time to think and respond.
You may find this useful to record any names, addresses and telephone numbers that you use regularly.

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GLOSSARY

ACAS  Aged Care Assessment Service
CDAMS  Cognitive, Dementia and Memory Service
EPA  Enduring Power of Attorney
HACC  Home and Community Care
OPA  Office of the Public Advocate
RDNS  Royal District Nursing Service
TIS  Translating and Interpreting Service
VCAT  Victorian Civil and Administrative Tribunal

USEFUL CONTACTS

National Dementia Helpline  1800 100 500
My Aged Care  1800 200 422
Carer Advisory and Counselling Service  1800 242 636
Dementia Behaviour Management Advisory Service  1800 699 799
Department of Veterans’ Affairs  133 254
1800 555 254 (rural only)
Commonwealth Department of Health and Ageing  1800 020 103
Centrelink  132 717
Office of the Public Advocate  1300 309 337
Translating and Interpreting Service  131 450
Commonwealth Respite and Carelink Centres  1800 052 222
For more information about
• diagnosing dementia
• living with dementia
• dementia research
• support services
• education and training

contact

NATIONAL DEMENTIA HELPLINE
1800 100 500

TRANSLATING AND INTERPRETING SERVICE
131 450

FIGHTDEMENTIA.ORG.AU/VIC

FIND US ON