

# *A resource for people living with Dementia their families and carers*



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Baptcare

MISSION

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This resource provides information about dementia, including the causes and symptoms, how it is diagnosed, treatment and non-medical approaches, and what people living with dementia can do to live well. It also looks at planning for the future and what support and services are available for people living with dementia and carers, such as residential care and end of life matters. *January 2018*

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## About dementia

**Dementia occurs when the brain is affected by a disease, such as Alzheimer's disease or a series of strokes. It is the term used to describe the symptoms of a large group of illnesses which cause a progressive decline in the person's functioning. It is not a normal part of ageing.**

Dementia affects each person differently and can result in a wide range of symptoms including problems with memory, difficulties with thinking, concentration, problem-solving, language or social skills. People may become confused or struggle with how they perceive things. Dementia can also cause changes in mood or emotions and can affect how a person behaves.

Dementia is a progressive disease, which means symptoms gradually get worse over time. How quickly it progresses varies greatly from person to person. Dementia is caused by physical changes in the brain and as it progresses, the brain changes, leading to damage and gradual death of brain cells. These changes are often small to start with, but can become severe enough to affect daily life. However, many people living with dementia lead active and fulfilling lives for many years.

Dementia can happen to anybody and is most common in people aged 65 years and over, but it can also affect younger people.

Dementia can sometimes be hereditary, but it is quite rare. While dementia cannot yet be prevented or cured, evidence suggests that people can reduce the risk of getting dementia by adopting healthy lifestyles.

The latest data shows that in 2017 there were more than 413,000 Australians living with dementia. By 2025, the number of people living with dementia is expected to increase to around 536,000 and without a medical breakthrough; this number is expected to be almost 1,101,000 by 2056. In 2016, there was an estimated 26,000 people living with Younger Onset Dementia, expected to rise to around 30,000 people by 2025 and 42,300 people by 2056.

For detailed description of dementia, its symptoms; changes over time; the causes; who gets it; types of dementia and their early symptoms read *Dementia Australia – The Dementia Guide for people living with dementia, their families and carers*. Available at:

**[dementia.org.au/files/VIC/documents/Alzheimers-Australia-Vic-Dementia-Guide-Web.pdf](https://dementia.org.au/files/VIC/documents/Alzheimers-Australia-Vic-Dementia-Guide-Web.pdf)**

Dementia Australia also publishes various resources, in different languages, that provide advice, common sense approaches and practical strategies on the issues most commonly raised about dementia. These resources are available from: **[dementia.org.au/resources](https://dementia.org.au/resources)**

## About diagnosis

Dementia can be difficult to diagnose, as a number of conditions can result in similar symptoms to dementia. For that reason, a thorough medical examination by a GP must take place so all other possible causes can be ruled out before a diagnosis of dementia is given. Assessment by a specialist in the area is then the best way to diagnose some form of dementia.

Dementia in younger people is not expected and for this reason it is frequently late in being diagnosed. Obtaining a diagnosis early is critical, as this allows for early planning, the early introduction of support services and medical follow-up, care and possible treatment.

After being diagnosed with dementia, people are likely to experience a number of different emotions including anger, fear, shock, disbelief, denial, a sense of loss or even relief at being given an explanation for the symptoms being experienced. These are all common reactions to a diagnosis. Talking about this with others can help. It is important for newly diagnosed people living with dementia not to feel they are on their own. The symptoms associated with dementia can be more difficult to accept and manage in a younger person. Knowing it is a rapidly deteriorating, aggressive and life-ending disease is difficult.

If you are person who is newly diagnosed with dementia or you are a family member and you are interested to know more about how dementia is diagnosed, feelings after diagnosis and dealing with those feelings, sharing the diagnosis, and responses to a person's diagnosis read: *Dementia Australia – The Dementia Guide for people living with dementia, their families and carers*. Available at: [dementia.org.au/files/VIC/documents/Alzheimers-Australia-Vic-Dementia-Guide-Web.pdf](https://dementia.org.au/files/VIC/documents/Alzheimers-Australia-Vic-Dementia-Guide-Web.pdf)

## About treatments and non-drug approaches

There is no known cure for dementia, but there are drugs and other therapies that can help with some of the symptoms. With the right combination, many people live well with dementia for many years. Developing a strong relationship with your GP is an important step in managing your illness.

As your dementia progresses, you may rely on medical experts such as geriatricians, neurologists, psychiatrists, social workers, counsellors, dieticians, occupational therapists, psychologists, and the local pharmacist.

You can also benefit from staying active, doing things you enjoy and keeping in touch with people. Some other non-drug approaches and activities include counselling or cognitive behavioural therapies. Reminiscence therapy, which involves talking about things from the past, using prompts such as photos or music can also be helpful. Staying mentally active, for instance doing word puzzles or discussing current affairs, is important, as is remaining socially connected and continuing to be engaged in enjoyable activities.

Baptcare provides various in-home and out-of-home care services to support the independence of people living with dementia.

These services can support people living with dementia to live more comfortably and confidently; stay part of the community and near the places that they know.

Baptcare acknowledges the work of Dementia Australia and in giving permission to use the material they developed in this resource. Dementia Australia provides information and support for people, of all ages, living with all forms of dementia, their families and carers. To contact Dementia Australia, call 1800 100 500 or visit: [www.dementia.org.au](http://www.dementia.org.au).

Some of these services include:

Service	Examples of this service
Supporting your independence	Personal care, home care, meal preparation and community inclusion (shopping, transport, etc.)
Keeping you in touch with others	Getting to appointments, respite care and transport assistance
Supporting your family	Diversional therapy and active sleepover
Support your health and wellbeing	Allied health and nursing, medication assistance
Support, consult and plan service	Care management
Help you live with memory loss and dementia	Nursing, personal care, diversional therapy.
Support your recovery at home	Nursing, allied health and personal care

Baptcare’s registered nurses monitor and support the health and wellbeing of people living with dementia in their own home, while its diversional therapists provide one-on-one guidance to help build meaningful connections and reduce the isolation, loneliness or anxiety that relates to ageing at home. Diversional therapists take time to understand the life experiences and interests that make each person unique. They create tailored leisure opportunities, activities and strategies to support a better quality of life.

For detailed information on drug and non-drug treatments for dementia visit *Dementia Australia – The Dementia Guide for people living with dementia, their families and carers*. Available at: [dementia.org.au/files/VIC/documents/Alzheimers-Australia-Vic-Dementia-Guide-Web.pdf](http://dementia.org.au/files/VIC/documents/Alzheimers-Australia-Vic-Dementia-Guide-Web.pdf)

For more information on personal care, nursing services and diversional therapy see *Baptcare’s Living with memory loss or dementia*. Available from: [baptcare.org.au/services/home-help/helping-you-live-with-memory-loss-and-dementia](http://baptcare.org.au/services/home-help/helping-you-live-with-memory-loss-and-dementia), or contact the Baptcare Customer Enquiry Centre by calling 13 22 78.

## About living well

If a person has been diagnosed with dementia, there is a number of things they can do that will help them live as well as possible. To help them cope with memory problems they could try using a large diary, while important items, such as keys or glasses, could be kept together in the same place.

To make home safer and create an environment that maximises the wellbeing of people living with dementia at home and increases their participation in activities, remove things that are easy to trip over and install smoke alarms, improve lighting, reduce clutter and remove potential hazards. They could also get automatic timers for plugs, lights and heaters.

Many people living with dementia can continue to live on their own during the early stages of the disease, by making simple adjustments, taking extra safety precautions and calling on support from families, friends and others. You can find out more by visiting *Dementia Australia – The Dementia Guide for people living with dementia, their families and carers*. Available at: [vic.dementia.org.au/files/VIC/documents/Alzheimers-Australia-Vic-Dementia-Guide-Web.pdf](http://vic.dementia.org.au/files/VIC/documents/Alzheimers-Australia-Vic-Dementia-Guide-Web.pdf)

## Planning for the future

Following diagnosis, it is important for people living with dementia to devote some time to making sure their financial and other affairs are in order. There are things they can do to manage their money easier. An Enduring Power of Attorney will allow someone else, nominated by the person living with dementia, to make decisions about matters relating to finances. An Enduring Power of Attorney can also be appointed for other matters, including making medical decisions on their behalf, once they no longer have the capacity to do so.

Now is the time to plan ahead and talk to others about the future. If the person is able, try to do this as soon as they can. To have a say in their future care, they can set up a care plan. Bapcare's support, consultation and planning services are available across Melbourne and Victoria, as well as Tasmania to help people living with dementia and their family to deal with complex care needs or changing circumstances.

Our Care Consultants can help create effective care plans and coordinate multiple aged care services. The care plan will document the current needs and aspirations of people living with dementia and help them achieve those goals.

## Support and services for people living with dementia

There is a wide range of social care and support services that exist to help people living with dementia live as well as possible, throughout the various stages of their condition. While some services are free, people living with dementia may have to contribute to the cost of others, depending on their income and savings.

The key point of contact to access dementia services is **My Aged Care**, **Dementia Australia VIC**; the **Dementia Behaviour Management Advisory Service (DBMAS)**; **Local Government Victoria**; GPs and home care agencies, such as **Bapcare**, can also offer valuable support.

## Support for carers

Much of the day-to-day care for people living with dementia is provided by family carers. These are people who are often themselves older, or who regularly have multiple commitments to jobs and family. They play a vital role in the lives of people living with dementia living in the community, particularly when the condition has progressed beyond the early stages. Caring for someone with dementia places a large burden on carers and reduces their physical and emotional wellbeing. Caring can also be very rewarding.

Carers often go through a wide range of emotions, including loss, guilt and anger. They may also experience grief for the loss of the person their family member previously was, their hopes and dreams for the future, and their prior relationship. They may also have positive feelings, such as a sense of fulfilment from being able to support their family member with dementia.

Information and advice is available to support carers in their role. Sources of support for carers include family and friends, health professionals, carer support groups, and organisations such as **Dementia Australia VIC** and **Carers Victoria**.

There are practical tips that can make caring for someone with dementia a little easier. For example, encourage the person to keep doing what they can to retain their independence. When communicating, make eye contact, listen carefully, be aware of your body language and tone of voice, and make sure you speak clearly.

Carers may find changes in the person's behaviour difficult to cope with. This might include aggression, repetitive behaviour or agitation. Keep in mind that they are not doing these things deliberately, and try not to take it personally. They may be confused, in pain or trying to tell you something, for example that they are bored or frustrated.

## Residential care

Making the decision to explore residential care options can be difficult for you (the person living with dementia), your family and friends.

Many decisions go into identifying when you should enter a residential care facility and finding the right place. You should be involved in the decision-making process as much as possible.

Family carers should ask themselves whether the care needed by their family member is beyond their ability to provide, whether the residential care facility provides everything the person might need and whether they will be able to remain in contact easily.

If you are considering moving into a government funded aged care home, you will first need an assessment from an Aged Care Assessment Service (ACAS). You can find an ACAS service from **Victoria ACAS Contacts**.

The best way to find a place that suits your needs is to visit a few different homes. Before you visit any aged care homes, it is a good idea to make a checklist of the types of care you need and the things that are important to you in a home. The ACAS assessment should list your care needs. Many considerations must be taken into account, including location and accessibility, the friendliness, competence, and ability of staff to inform succinctly and recognise the turmoil family members are undergoing, access to medical care, cleanliness, space, ambiance, a dementia-friendly environment, good quality meals, and social and recreational activities.

Baptcare's ten accredited aged care communities offer a warm welcome to people living with dementia as residents and their families. Residents receive quality 24/7 care and compassionate support from our understanding, nursing-led staff.

Baptcare understands that moving to a residential aged care home brings a major upheaval to the lives of people living with dementia, their families and carers. To make the transition and stay at its aged care homes as beneficial as possible for people living with dementia, Baptcare has, over the past few years, embarked on a process of increasingly:

- a. building a dementia friendly environment where staff take a personalised approach to care
- b. designing aged care homes that exude a feeling of homeliness, where friends and family can drop in for a cup of coffee and a chat
- c. creating a physical environment where the delivery of support and care occurs is familiar, safe, small, and simple; and
- d. developing new approaches that enable residents with dementia to be active participants in daily life, of retaining personal control and maintaining relationships with family and friends.

An example of this new wave of approaching the care of people living with dementia differently is the Memory Support Unit at Wyndham Lodge in Werribee, established earlier in 2017. The Memory Support Unit is home to 15 people living with dementia who are unable to live in their own home even with relatively high levels of support and require care and accommodation in an aged care facility.

Baptcare has developed the Unit to provide a personalised approach to care by creating a home-like environment; where the residents are involved in individualised everyday activities; work routines are adapted according to their preferences; and care is provided with respect that upholds the dignity of the person, and retains the trust and confidence of family members.

Dementia Australia provides key contact details in its guide to people living with dementia, families and carers. It also identifies the things that people need to consider when looking at residential care options. These are available at: **[dementia.org.au/files/VIC/documents/Alzheimers-Australia-Vic-Dementia-Guide-Web.pdf](https://dementia.org.au/files/VIC/documents/Alzheimers-Australia-Vic-Dementia-Guide-Web.pdf)** (page 128)

If you have been diagnosed with dementia and need help, or if you are caring for someone who does, contact Baptcare's Customer Enquiry Centre on **13 22 78** or visit:

**[baptcare.org.au/services/aged-care-homes/about-our-residential-aged-care](https://baptcare.org.au/services/aged-care-homes/about-our-residential-aged-care)**

Our Customer Enquiry Centre and our website will help you understand the service options that are available to you and the process open to you to move to one of our nine aged care communities.

## End of life issues

As a person living with dementia approaches the end of their life, there are a number of issues that need to be considered. Due to advances in medicine, people are now far more likely to die in old age of chronic and degenerative diseases, including dementia. These changes to the way we die have required changes to the way a person is cared for at the end of their life. The changing prominence of diseases has shifted the focus from curing a disease to managing a person's illness and providing them comfort and pain relief during this time.

Whether the person with dementia is living at home, in hospital or in residential aged care, they will need quality care at the end of their life. Palliative care is specialised care and support that recognises the unique needs of a person with a terminal condition, as well as their family members and carers.

The goal of palliative care is to relieve the symptoms experienced by a person towards the end of their life, rather than on curing the condition or conditions causing their death. For family members and carers, palliative care concentrates on providing emotional and practical support at this time.

Baptcare witnesses and actively responds to the struggles and sufferings of people who are experiencing intolerable physical and/or existential pain at the end of life, due to serious or incurable conditions. Baptcare's response to end of life choices is informed by our commitment to protecting the dignity of people and delivering appropriate, compassionate and timely care, including continuous palliative sedation, information about other available supports, pastoral and spiritual care of the person and their love ones.

## References

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For more information please contact the Head of Research, Policy and Advocacy: Rachel Breman:  
Email: [rbreman@baptcare.org.au](mailto:rbreman@baptcare.org.au) | Phone: 03 9831 7361

Baptcare is a purpose driven organisation focused on delivering the best of care to people of all ages, cultures, beliefs and circumstances. Through our social enterprise model, we deliver better outcomes for more than 13,000 people in our community, combining the best commercial practice with a social heart. Baptcare has more than 2,000 dedicated staff across Victoria and Tasmania to deliver the best of care to people in Residential Aged Care, Retirement Living, In Home Care, Family and Children Services, Affordable Housing and Disability Services.



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For enquiries  
(13 22 78)

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a translator

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