

Living with dementia



For people living with dementia

alzheimer'swa
the dementia experts

alzheimerswa.org.au








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Living well with dementia

Dementia is not just a biological condition; it is a human experience.

A diagnosis of dementia does not have to mean the end to an active and engaged life.

The progressive nature of dementia means there are many challenges throughout the journey, however it is possible to continue to have an engaged and fulfilling life, and be connected to family, friends and the community.

Alzheimer's WA advocates for people living with dementia and promotes a focus on a person's abilities, rather than the impacts dementia can have. Although the impacts of dementia are progressive and need to be considered, they do not have to consume the whole of a person's life.

Similarly, negative stigma associated with dementia can influence other's perceptions, but this should not determine how a person with dementia lives their life.

Providing yourself with information and knowledge that supports wellbeing is the key to living well with dementia.

Alzheimer's WA membership

Become a member of Alzheimer's WA to receive information about dementia and the support available to you. Membership is free. Complete a membership form online at alzheimerswa.org.au/membership

Importance of staying connected

Staying connected to social networks, friends and your local community is vital to your wellbeing. Unfortunately, isolation is one of the most common experiences for people living with dementia. Many people report friends and some family members withdraw from social contact soon after being told of a person's diagnosis.

Sometimes people will distance themselves because of fear or stigma associated with dementia. This often results in feelings of disconnection and loneliness in a person with dementia. Staying connected to others is very important to all of us and can help maintain and enhance your wellbeing and quality of life.

How to retain your connections and build new ones

- » Communicate openly with family and friends right from the start
 - » Sharing your experiences will help others to understand what you are going through
 - » The more you can share your experiences the more likely other people will be able to relate to you
- » Express your need for connection as some people may not realise you are feeling isolated
- » Have conversations with friends about the realities of life with dementia and the impact it has
- » Link into supportive community groups that will offer new relationships
- » Start a hobby or nurture an interest that will connect you with others.



Accepting support

No one should have to do everything on their own. Although retaining independence and ability is important, recognising the areas of your life where you could accept some support can result in a better quality of life.

Dementia is a progressive disease, which means over time a person may lose their ability to complete everyday tasks and require more support.

Accepting support can trigger feelings of loss of independence and can be quite confronting for some people, especially those who have been strongly independent throughout their adult life. However, accepting support will enable you to have more time to focus on the things that matter to you.

Alzheimer's WA provides a wide range of supports including those listed below.

Types of support

Support in and out of the home

- » Information and education sessions (such as Adjusting to Change)
- » Social engagement
- » Personal care
- » Day to day activities (cooking, cleaning, gardening)
- » Shopping
- » Clinical care and medication management
- » Transport.

Friendship groups and social clubs

- » Walking group
- » Men's Shed
- » Coffee and chat

- » Volunteering group
- » Memory cafés.

Therapy and health services

- » Occupational therapy: Practical strategies and equipment to support changes relating to your cognition, daily living tasks and behaviour patterns
- » Social work: Counselling, assistance with legal documents and other matters.

Respite: short term day and overnight

Respite can be in your home or another location such as one of our dementia specialist Houses. Respite can be especially important in the future if your partner or carer needs to go to hospital or away unexpectedly, and you need someone to support you during this time.

Dementia specialist Houses

Our three Houses are located across Western Australia:

- » Mary Chester House, Shenton Park: Day and overnight respite
- » Ella's House, Mandurah: Day respite
- » Hawthorn House, Albany: Day and overnight respite.

To find out more call 1300 66 77 88, email support@alzheimerswa.org.au or visit alzheimerswa.org.au

Processing the diagnosis

A diagnosis of dementia can bring substantial change and adjustment for you and your family. You may face many changes emotionally, psychologically, physiologically and environmentally.

It may be that some dreams and goals of the future are no longer possible. This can be a big adjustment to make, particularly if you have worked towards those goals for a long time.

Change can lead to feelings of grief and loss, which is a normal response.

In order to accept the loss and change occurring it is important to allow yourself time to grieve. Take one day at a time and try not to isolate yourself.

There is no right or wrong way to grieve; it is a journey and a process of healing.

Common responses to grief

Emotional response

Crying, anxiousness, restlessness, anger, stress, exhaustion, confusion, shame, guilt, loneliness, withdrawal, blame, lack of motivation and enjoyment in life, feelings of hopelessness, denial and shock.

Physical response

Headaches, sleeplessness, lack of appetite or overeating, poor motivation, loss of interest in previously loved or enjoyed activities.

What can help

Grief uses a lot of energy so make sure you restore that energy with:

- » A healthy diet
- » Regular exercise
- » Lots of sleep
- » Doing things that you enjoy.

It is also important to consider:

- » Keeping a journal of your thoughts
- » Accepting help from others
- » Sharing your feelings with others
- » Seeking professional support.

Don't give up on your plans for the future. Having goals to work towards and plans to look forward to is important for everyone, including people living with dementia.

Take one day at a time and try not to isolate yourself. Time on your own is important, however be mindful of staying connected to your family and friends.

Safety and independence

Making your own choices in life is very important for a sense of control, self-worth and self-esteem. It also helps to maintain independence for as long as possible.

However, as dementia progresses it may become more difficult to do things you are used to doing yourself.

There is a large range of assistive products available to purchase that can assist you to complete everyday tasks and maintain your independence.

Assistive products and technology

Every day living

Items such as:

- » One touch radios
- » Easy to use universal TV remotes
- » Simple to use mobile phones
- » Safety irons
- » Easy pour kettles
- » Shower chairs.

Prompts and reminders

Items such as:

- » Bluetooth trackers for important items
- » Whistle key finder
- » Orientation signs
- » Easy to read clocks
- » Timers and reminders
- » Medication packs.

Safety

Items such as:

- » Sensor lights
- » Flood detectors
- » Phone locating apps
- » GPS phones, watches, pendants
- » Emergency ID pendants, bracelets.

Assistive technology sheets are available to download from alzheimerswa.org.au (search 'assistive technology' help sheets).

Apps

There are a number of apps available to download on your smart phone that can be useful.



Accessing support

Practical considerations

Receiving a diagnosis of dementia may prompt you to take the necessary steps to ensure your future life is as enabling as possible.

Things to consider:

- » Find out if you are eligible for government funded services
- » Financial and legal planning
- » Investigate in-home supports available in your area (see page 3).

Early planning can also include goals you would like to achieve, holidays you would like to take, or other things you would like to see or do in your lifetime.

This kind of planning helps your future be self-determined. It can help you to maintain and even enhance your quality of life and state of wellbeing. It may also help you to stay at home and active within your local community for as long as possible.

Accessing Government funded services

Support if you are over 65

A person who is over 65 at the time of their dementia diagnosis may be eligible for Australian Government funded services through My Aged Care including Commonwealth Home Support and home care packages.

My Aged Care: myagedcare.gov.au

Support if you are under 65

A person who is under 65 at the time of their dementia diagnosis may be eligible for Australian Government funded services via the National Disability Insurance Scheme (NDIS).

NDIS: ndis.gov.au

Need more help?

For information and advice call us on **1300 66 77 88**.

Financial and legal considerations

You should be included in discussions regarding your future and support.

Often a person with dementia is left out of their own life planning because of the assumption they will not understand or have anything to contribute. The earlier you start this planning, the more you can be a part of the process.

Legal documents can only be completed and signed by you if you are deemed to have full legal capacity. Although the onset of dementia does not mean you lose legal capacity, it can reduce a person's legal capacity as the disease progresses. This is why it is important to consider completing these legal documents as early as possible after a diagnosis.

For more information visit:

- » Enduring Power of Attorney or Guardianship, Advance Health Directive: publicadvocate.wa.gov.au
- » Advance care planning: palliativecarewa.asn.au
- » Wills: publictrustee.wa.gov.au

Things to consider

Financial planning: May cover topics such as retirement, superannuation, mortgages and pension eligibility; life and health insurance; and the needs of others who are financially dependent on you.

Enduring Power of Attorney: A legal document that enables you to appoint a person, or persons, to make financial and property decisions on your behalf when you become legally incapable of making those decisions.

Enduring Power of Guardianship: A legal document that enables you to appoint a person, or persons, to make personal, lifestyle and treatment decisions on your behalf when you become legally incapable of making those decisions.

Advance Health Directive: A legal document that enables you to make decisions now about the medical treatment you would want, or not want, when you become legally incapable of making those decisions.

Creating or updating a Will: A legal document that describes how you wish your assets to be distributed upon your death. A Will allows you to choose an Executor who will be responsible for making sure your wishes are met.

Tips:

- » Family meetings and discussions can help you explain your wishes to others, and this can help to reduce confusion in the future
- » Discuss your decisions regarding enduring appointments with the person, or persons, you have nominated
- » Let loved ones know of any legal documents (such as a Will or any enduring appointments) you have completed, and their location.

Validating and acknowledging death

It is important to acknowledge the inevitability of death - it is a part of everyone's life.

A person living with dementia may think about death more often after a diagnosis. It is important to have opportunities to discuss your thoughts and feelings about death and dying.

Talking about death can help family and friends process their own thoughts and feelings as well.

If you have particular wishes or beliefs, these should be recorded in a safe place and communicated to close family members.

It can help to talk to a counsellor about any concerns you may have.







OUR VISION

A world where people with dementia and their families are supported and valued on their dementia journey.

OUR PHILOSOPHY

Dementia is a lived human experience rather than just a biological condition. We therefore embrace and support a holistic, person-centred approach that respects the individuality and the experience of those living with dementia.

OUR PURPOSE






To improve the lived experience of those on the dementia journey through our advocacy, leadership, innovation, education, partnerships and holistic, person-centred care and support, and to support the pursuit of risk reduction, treatment and cure for dementia.

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