

Caring for a person living with dementia: The lived experience



For carers

alzheimer'swa
the dementia experts

alzheimerswa.org.au








Contents

Living well with dementia1	Grief in a person living with dementia6
Alzheimer's WA membership1	Experiencing grief as a carer6
The human experience of dementia2	Accessing support7
Importance of staying connected3	Practical considerations.....7
Accepting support4	Accessing Government funded services.....7
Types of support4	Financial and legal considerations..8
Processing the diagnosis5	Validating and acknowledging death ..9
Common responses to grief5	
What can help5	

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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 nature of dementia means there are many challenges throughout the journey, however it is possible to live well with dementia and to be engaged in a fulfilling life, connected to family, friends and 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.

Stigma and negative perceptions associated with dementia can influence other's perceptions, but this should not determine how a person with dementia lives their life. Where possible, continue to include the person with dementia in activities they enjoy.

Providing yourself with information and knowledge that supports wellbeing is the key to supporting a person to live 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

The human experience of dementia

The human experience of dementia will be different for each person, however there may be some common experiences which are explained in the following table.

Challenge	Human Experience
Language: difficulty with word finding, verbal communication, comprehension	Frustration at difficulty in communicating. Impact of other people's perceptions of someone with difficulty verbally communicating.
Processing information	Being outpaced. Things happening too fast around the person or information being delivered too quickly. Being unable to keep up can result in confusion and frustration. Often results in the person being seen to have more disabilities than are actually present.
Reasoning	Not always able to make sense of external situations, to problem solve or understand other people's perceptions. Can create feelings of anxiety and distress.
Memory	Can lose associations with people and places and parts of their life story. Can result in fear, sadness and frustration.
Recognition	Unsure of objects, people, places. Can feel lost or disconnected to others, isolation and loneliness. A reduced sense of security or sense of belonging, not recognising oneself.
Planning and organising	Frustration, reduced sense of autonomy, feelings of loss of control, being reliant on others, others not knowing where line is between supporting and doing for, future goals hindered, something to look forward to is altered.
Visuospatial awareness	Feeling frightened, unsteady and unbalanced on feet, cautious, irritated, destabilised and dizzy, fearful of the environment, might need to be close to others, use others as a guide, follow others for sense of security, misjudge distance and location of objects, compromised independence.
Disorientation to time and place	Changed routine, waking in the night, confusion in familiar and unfamiliar surroundings. Can experience fear and anxiety.

Importance of staying connected

Staying connected to social networks, friends and the local community is vital to the wellbeing of both carers and people living with dementia. 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 from a person living with dementia because of fear or stigma associated with the diagnosis. This often results in feelings of disconnection and loneliness in a person living with dementia and their carer. Staying connected to others is very important to all people and can help maintain and enhance wellbeing and quality of life.

How to retain connections and build new ones

- » Communicate openly with family and friends right from the start
 - » Sharing experiences helps others to understand what you are both going through
 - » The more you can share your experiences the more likely other people will be able to relate to you and the person you are caring for
- » Express your need for connection, as some people may not realise you are both 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, for you and the person you are caring for.

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 in a person living with dementia and can be quite confronting for some people, especially those who have been strongly independent throughout their adult life. However, accepting support will enable both of 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

Information and education sessions

- » Carer support groups
- » For both the person living with dementia and their carer
- » For family and friends.

Support in and out of the home

- » 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 a person's cognition, daily living tasks and behaviour patterns
- » Social work: Counselling, assistance with legal documents.

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 you need to go to hospital or away unexpectedly.

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 the person living with dementia, and their family. A person living with dementia will face many changes emotionally, psychologically, physiologically, environmentally and experientially.

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.

Grief in a person living with dementia

Expressing grief can be complicated for a person with dementia, due to the varying impacts of the disease.

If communication pathways are affected it can be very difficult for a person to express how they are feeling. This can lead to feelings of isolation, loneliness and frustration and can further impact on their grief process.

Grief is often overlooked in people with dementia. This typically happens when feelings associated with grief are expressed by the person, yet seen as a symptom of the dementia, rather than a human response to grief.

Being aware and open to what a person is expressing will help them through their journey. Try to avoid diverting a person away from their feelings.

Experiencing grief as a carer

Feelings of grief and loss are a normal part of your journey as a carer of a person living with dementia. Feelings of grief and loss can be experienced with the loss of the way life was, adapting to change, losing a job, changes in friendships, changes in close relationships and an imagined future that might not come to be.

It is important to acknowledge your new reality and understand how you are feeling. Acknowledge what it is you have lost, but also remember what you still have. Fears associated with myths and stigmas of dementia can exacerbate feelings of grief and loss. Talking with someone who understands dementia in a holistic person-centred way can be helpful. The support of a qualified counsellor can be a great help.



Accessing support

Practical considerations

If your partner or loved one has received a diagnosis of dementia you may wish to consider the following:

- » Find out if you or your loved one are eligible for government funded services
- » Financial and legal planning
- » Investigate in-home supports available in your area (see page 4).

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 with your loved one while you still can.

This kind of planning can help to maintain and even enhance the quality of life and state of wellbeing for a person with dementia. It may also help them to stay at home and active within the 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

A person with dementia should be included in all discussions regarding their 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 they can be a part of the process.

Things to consider

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

Enduring Power of Attorney: A legal document appointing someone to make financial and property decisions when a person becomes legally incapable of making those decisions.

Enduring Power of Guardianship: A legal document appointing someone to make personal, lifestyle and treatment decisions when a person becomes legally incapable of making those decisions.

Advance Health Directive: A legal document outlining the medical treatment a person would want, or not want, when they become legally incapable of making those decisions.

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

Legal documents can only be completed and signed by a person who is deemed to have full legal capacity. Although the onset of dementia does not mean a person loses 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.

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

Tips:

- » Family meetings and discussions can help you explain your loved one's wishes to others, and this can help to reduce confusion in the future
- » Discuss decisions regarding enduring appointments with the person, or persons, who have been 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 they have opportunities to discuss their thoughts and feelings about death and dying.

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

Make sure you ask a person living with dementia whether they have particular wishes or beliefs regarding their own death. These wishes should be recorded, respected and communicated to family and friends at the appropriate time.

When a person living with dementia loses someone close

After a person dies it is common to feel a variety of emotions. These may include:

- » Sadness
- » Loss
- » Guilt
- » Grief
- » Numbness
- » Anger
- » Disappointment
- » Loneliness.

A person living with dementia can still feel grief and loss if a person close to them dies. Talk to and acknowledge the emotions of a person living with dementia if they have someone close to them die. Ignoring a person's feelings about death only suppresses those feelings, it does not make them disappear.

It is important to consider the person's reality and not enforce our own views. For example, a person with dementia may talk about family members as if they are still living, when in fact they have passed away. It is not always necessary to discourage this.

When a person living with dementia passes away: a carer's perspective

As a carer of a person living with dementia you may have experienced a range of emotions during your loved one's dementia journey. When your loved one passes it is normal to feel:

- » Sadness
- » Loss
- » Guilt
- » Grief
- » Numbness
- » Anger
- » Disappointment
- » Loneliness.

It is also quite normal to feel relief. We suggest talking to a counsellor to access support through this time.



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.

CONTACT US

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