

Navigating dementia support



alzheimer'swa
the dementia experts

alzheimerswa.org.au








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Navigating dementia support

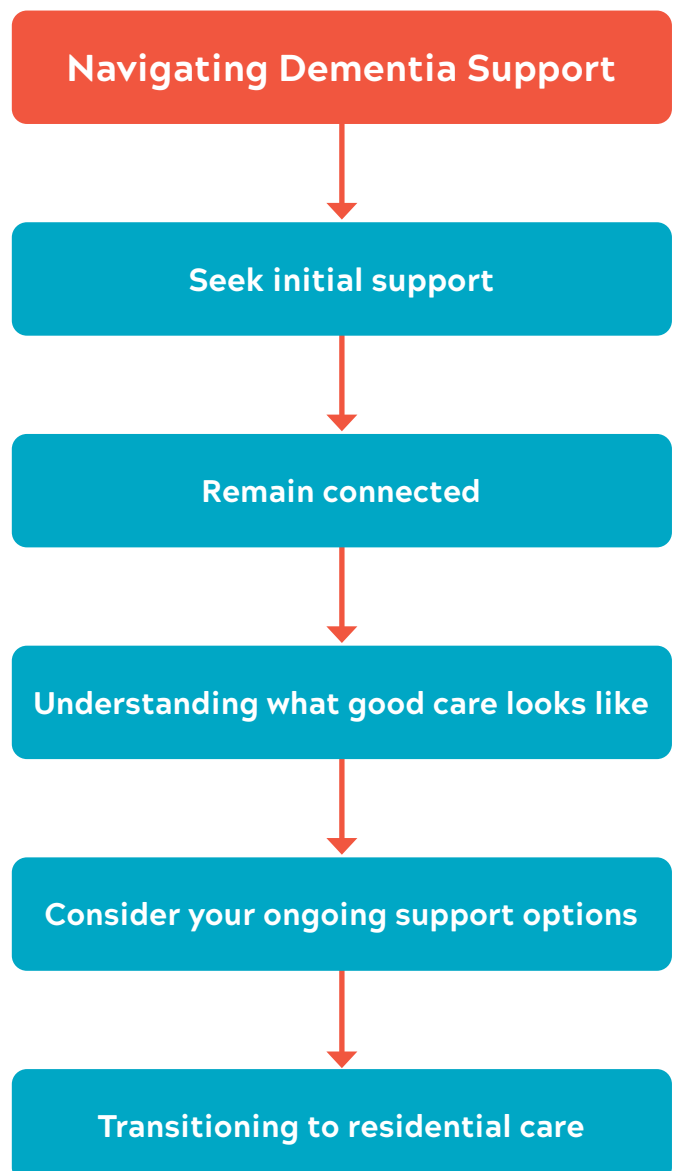
Understanding the different types of support that are available for a person living with dementia, and their carer, can be overwhelming.

Entering into or receiving support can also be a confronting experience if a person living with dementia or their carer is not prepared beforehand.

There are a lot of support services available for people living with dementia. Once diagnosed, it is important to find the support that is right for you.

Alzheimer's WA recommends you seek some support initially to fully understand your options during your dementia journey.

Our Dementia Advisory Service and Adjusting to Change program are available for people who have recently been diagnosed with dementia, as well as their primary support person.



Help at home

Many people are able to access services to assist at home. This can be privately funded, or you may be eligible for government subsidies.

If you are over 65, you may be eligible for support through the Commonwealth Home Support Program or a home care package. Contact My Aged Care to arrange an assessment.

If you are under 65 you may be eligible for support through the National Disability Insurance Scheme (NDIS). Contact NDIS to find out more.

Contact My Aged Care on 1800 200 422 or visit myagedcare.gov.au

Contact NDIS on 1800 800 110 or visit ndis.gov.au

Commonwealth Home Support Programme

The Commonwealth Home Support Programme provides entry-level support for people over the age of 65 who need help to stay at home.

Alzheimer's WA can provide services through the Commonwealth Home Support Programme. Please call 1300 66 77 88 or visit alzheimerswa.org.au/commonwealth-home-support-program for more information.

Home care packages

If you need more than entry-level support, a home care package can provide you with help to stay at home.

Alzheimer's WA is a home care package provider. Please call 1300 66 77 88 or visit alzheimerswa.org.au/home-care-packages for more information.

National Disability Insurance Scheme (NDIS)

The NDIS can help a person living with younger onset dementia to access social support, support with daily tasks, therapy and specialist support, and assistive equipment.

Alzheimer's WA can provide services through the NDIS. Please call 1300 66 77 88 or visit alzheimerswa.org.au/our-services/ndis for more information.

Services available

A number of services are available including:

- » Respite
- » Cleaning
- » Personal care
- » Meals and food preparation
- » Transport
- » Shopping
- » Gardening
- » Social support
- » Therapy and health services: such as occupational therapy and social work.

Respite care

Respite services provide temporary care that is beneficial for both a person living with dementia and their carer, and aim to enhance wellbeing. Respite care can be a great way for a person living with dementia to have a new experience, meet new people, or enjoy a change to their normal environment. Respite care can also give carers some time for themselves, which is equally important.

Different types of respite care

- » **Respite in the home:** A support worker comes to the house either occasionally or regularly to provide care for the person with dementia. Together they may undertake an activity such as going for a walk or to the shop. They may cook, garden, play cards or do another enjoyable activity. A carer will often make other plans during this time.
- » **Respite outside the home:** Services are provided in the community, in a range of settings including day centres. A person with dementia can meet new people and enjoy a range of activities. A carer will often make other plans during this time.
- » **Overnight respite:** The person with dementia is able to stay overnight in a day centre or hospital setting. The stay may be for one night, several nights or several weeks, depending on individual requirements. This option is often used if the person's regular carer needs to have a break, go to hospital or on a holiday. Overnight respite is also available in a person's home.

Using respite care for the first time

First time respite can be difficult for both the person with dementia and for their carer. People often have mixed feelings around seeking out and accepting respite care; including guilt, worry and relief. However, respite can be an enjoyable experience for everyone.

Tips on using respite care:

- » Involve the person living with dementia in a discussion about respite care, and any decision making such as choosing a location
- » Be flexible as it may take several weeks to establish a new routine
- » Respite services will always try to match a support worker to a person based on their individual interests and preferences
- » Create a personal profile book to help support workers become familiar with the person and build rapport
- » Build relationships with the support worker/s
- » Keep respite coordinators up to date with any changes to the person's needs
- » Try introducing the person to respite slowly at first. A person with dementia may need time to adjust to unfamiliar people or environments. If they are joining a day club start with attending for morning tea, then half days, then once they feel more comfortable try staying for a full day.

What does good care look and feel like

- » Staff are respectful
- » You have regular support workers so relationships can be established
- » Support workers are not rushing to their next client
- » You know what time your service will be provided
- » Service provision is consistent
- » Support workers make an effort to get to know you as a person
- » Support workers talk to the person living with dementia - not about them in front of them
- » The service provider listens openly to any concerns you have about service delivery and makes attempts to alter these to better suit your unique needs
- » Support workers have a good understanding of dementia
- » Support workers look beyond the symptoms of the disease and connect with the person
- » Support workers do not use labelling language or stigmatise the person by making generalisations about dementia and the person's experience.

Alzheimer's WA can provide you with a range of respite services.

Please call 1300 66 77 88 or visit alzheimerswa.org.au/our-services for more information.

Support groups help you stay connected

Support groups can provide caring support for a person living with dementia while encouraging them to participate in regular activity.

Support groups for people living with dementia

- » Walking or other exercise groups
- » Men's shed
- » Coffee and conversation
- » Volunteering in the community.

Support groups for carers

Support groups are also available for carers. Carer support groups provide carers with information about dementia, an opportunity to meet other carers, and to discuss the impact of dementia on their lives in a supportive environment.

Alzheimer's WA offers a number of support groups for people living with dementia and their carers.

Please call 1300 66 77 88 or visit alzheimerswa.org.au/our-services for more information.

Deciding on residential care

A good residential care home will have person-centred principles as their underlying philosophy. These principles should be evident in the way staff approach their work and each other, the way staff are cared for by the organisation, and in the surrounding environment. A person-centred philosophy is all about the approach and includes everyone in the care environment.

What does good care look and feel like

- » Individuals are enabled to participate as much as possible
- » You are welcomed to look through the home
- » Staff demonstrate respect for people currently living there
- » Staff introduce you to people living there and talk about it being their home
- » There is a feeling of engagement in the home
- » People who live there seem to be happy and content
- » There is a feeling of family and closeness in the social setting
- » Staff are not rushing or dismissive of people who live there
- » The environment supports a person with dementia to navigate and orientate themselves throughout the home (refer enablingenvironments.com.au/care-environments)
- » There is easy access to outside areas including gardens
- » Everyone is encouraged to have their own things in their rooms
- » Family and friends are encouraged to visit
- » There is meaningful activity: this means that individuals are actively engaged and involved in any activity that is happening and that these activities are meaningful and purposeful to those participating
- » There is flexibility with times for personal care tasks such as showering
- » The individual needs of the person are always considered
- » Staff have knowledge about dementia
- » Staff look beyond the symptoms of dementia and connect with the person
- » People with dementia are not labelled or stigmatised.

Transitioning into care

It is integral that the person living with dementia is included in the decision to enter residential care. Be open, honest and transparent with the person about what is happening. For a person to be able to adjust to change they need to be aware that it is happening.

Moving into a residential care home is a major event in a person's life and can be quite a difficult process for the person with dementia and their family.

It is common to experience guilt and concern over the decision to move a person into residential care, especially if the decision has been initiated by a family member and not the person living with dementia. If a person is used to having support at home this can help with the transition.

Take your time to make decisions about residential care.

Models of care

Different organisations, and residential care homes, adopt different models of care.

Before you visit a respite or residential care home, ask about their philosophy or model of care. This can be useful to know before visiting as you can then look for evidence of this philosophy in practice.

An example of a model of care is the Eden Alternative™. The Eden Alternative™, along with a person-centred approach, is the model adopted by Alzheimer's WA to support people living with dementia.

Person-centred approach

Dementia is just one part of a person. Understanding this is an important step on the pathway to a person-centred approach.

A person-centred approach has become popular as the underlying philosophy for dementia support and care across Australia, and in many other countries.

A person-centred approach requires the person with dementia to be at the centre of everything

that involves them and their life, with a focus not solely on their diagnosis but who they are as a person and their lived experience.

At its core, a person-centred approach is about connecting with others, building and maintaining relationships, embracing uniqueness and the expression of this, and providing a safe supportive environment with high levels of dignity and respect for those within that environment. It involves empathy, unconditional positive regard, and authenticity.

Central to a person-centred philosophy is the concept of personhood.

Personhood is sacred and unique and every person has an ethical status and should be treated with deep respect. Each person has value, we thus have an obligation to treat each other with deep respect; as ends and never means towards some other end.

Tom Kitwood,
Dementia Reconsidered



Eden Alternative™

Dr Bill Thomas is the founder of the Eden Alternative™. The focus of this model of care is to address what Dr Thomas describes as the bulk of suffering amongst the elderly. This suffering is explained as three plagues: loneliness, helplessness and boredom. The Eden Alternative model of care addresses these plagues by creating care environments that promote quality of life.

1. The three plagues of loneliness, helplessness and boredom account for the bulk of suffering among elders.
2. An elder centred community commits to creating a human habitat where life revolves around close and continued contact with plants, animals, and children. It is these relationships that provide the young and the old alike with a pathway to a life worth living.
3. Loving companionship is the antidote to loneliness. Elders deserve easy access to human and animal companionship.
4. An elder centred community creates opportunity to give as well as receive care. This is the antidote to helplessness.
5. An elder centred community infuses daily life with variety and spontaneity by creating an environment in which unexpected and unpredictable interactions and happenings can take place. This is the antidote to boredom.
6. Meaningless activity corrodes the human spirit. The opportunity to do things we find meaningful is essential to human health.
7. Medical treatment should be the servant of genuine human caring, never the master.
8. An elder centred community honours its elders by de-emphasising top-down bureaucratic authority, seeking instead to place the maximum possible decision making authority into the hands of the elders or into the hands of those closest to them.
9. Creating an elder centred community is a never ending process. Human growth must never be separated from human life.
10. Wise leadership is the lifeblood of any struggle against the three plagues. For it, there can be no substitute.

Understanding wellbeing

It is important for a person living with dementia to feel good about their life just as it is for someone without dementia.

To reach a state of wellbeing there are certain components of our lives that need to be fulfilled. A diagnosis of dementia does not take away the relevance and importance of these or the need for them to be nurtured.

‘Wellbeing is not tied to what one can or cannot do - it should be possible to experience wellbeing regardless of one’s cognitive or functional capabilities.’

Dr Allen Power

What to do in times of reduced wellbeing

Sometimes all a person with dementia needs in times of distress or reduced wellbeing is acknowledgment, understanding and an empathic listener.

Be honest with a person about what you see and feel in the moment you are with them.

For example you might say:

- » ‘I can see you are distressed / upset / sad’
- » ‘I would like to understand what you are experiencing’
- » ‘I can see it is hard for you to communicate with me’
- » ‘I want you to know that I am here, right beside you and I see you’.

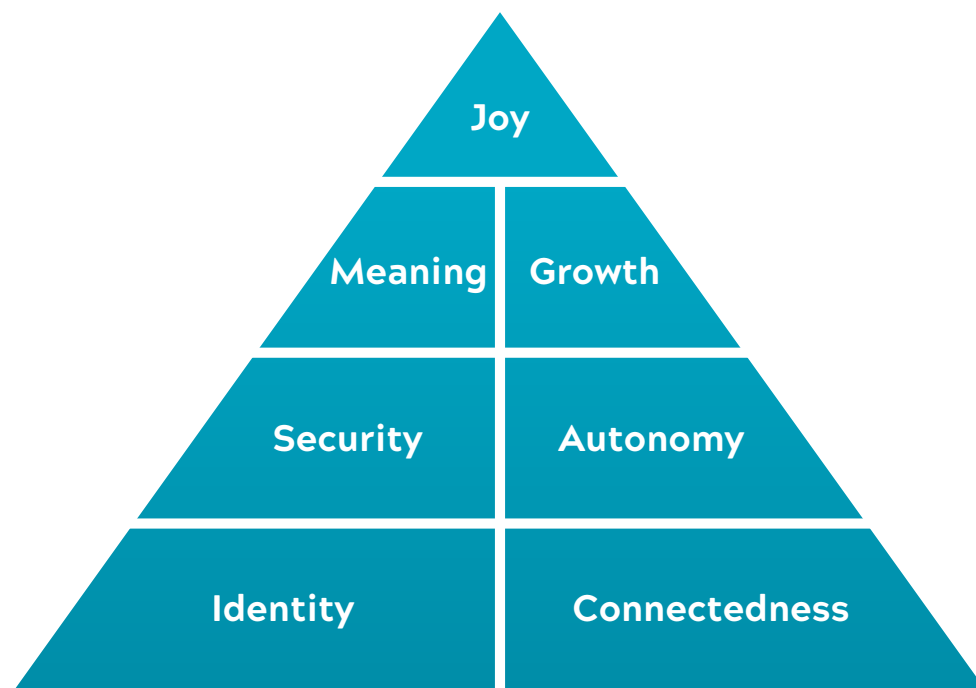
Open and honest communication is important and acknowledging real struggles and the feelings that are associated with this can help a person living with dementia.



Domains of Wellbeing™

The Domains of Wellbeing™ provide a simple guide to understanding some of the key components to wellbeing. Understanding these domains, how they affect you and contribute to your own personal wellbeing can help you understand the important effect they have on others.

Dr Allen Power is an international dementia expert, geriatrician, author, and educator. His pyramid version of the seven domains of wellbeing is adapted from a model developed by Dr Bill Thomas.



Domain	Definition
Identity	Who you are as a unique person, your values and life experiences.
Connectedness	Sense of belonging. Having close and meaningful relationships, links with others and the wider community.
Security	Sense of feeling safe: emotionally, psychologically, spiritually and physically.
Autonomy	Choice, self-determination and independence. Empowered to make own decisions.
Meaning	Purpose, value in life, contributes to self-esteem and reason for being.
Growth	Opportunities to grow and develop. Personal transformation and change.
Joy	Happiness, pleasure, contentment. Variety and spontaneity.



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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