

Support services

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Support services

Overview

Introduction

In Australia a broad range of services and programs are available to assist people with dementia and their carers and family. This section provides a brief overview of the key national projects and contacts for getting in touch with the right programs and services.

Some of the support services may be most useful at the time of diagnosis. For example, the Alzheimer's Australia branch in your state can provide information on understanding dementia and how to access counselling. Other services may be more useful in providing physical help with the day-to-day care of a person with dementia.

The national Home and Community Care (HACC) Program can assist with:

- Nursing care
- Allied health care
- Meals and other food services
- Housework
- Personal care tasks such as bathing
- Home modification and maintenance
- Transport
- Respite care
- Counselling, support, information and advocacy
- Assessment.

A range of services, including local councils and community health centres, provide HACC services.

Carers often need a break from caring and there are a range of respite services available. Respite care can be provided in a range of settings for varying periods of time to give family and carers a break:

- In-home respite involves someone coming to the home, usually for a few hours to look after the person with dementia
- Centre based respite is where the person with dementia goes to a centre for socialisation and support
- Residential respite is where the person stays overnight in a residential aged care facility, usually for a few weeks.

It is important for families and carers to seek assistance and ensure that they have support and adequate breaks. (Refer to *Caring for families and carers*). Financial support is also available to eligible carers through Centrelink.

The Aged Care Assessment Team (ACAT) is a national program that helps people work out what kind of care will best meet their needs. They complete a detailed assessment, in your home and discuss the type of services that are available, such as community care and respite. An assessment by an ACAT is required for eligibility to Community Aged Care Packages (CACPs), Extended Aged Care Packages (EACH), Extended Aged Care Packages – Dementia (EACH-D) and for residential aged care.

- Packages are individually planned and coordinated care provided to people who need the equivalent to residential care. A package aims to provide an alternative to residential care for people who want to remain at home
- Residential aged care includes low and high levels of care. These used to be referred to as nursing homes (high level) and hostels (low level).

The decision to use residential care is often difficult and a move into a residential facility can be stressful for the person with dementia and their family and friends. (Refer to *Transition to residential care*).

Further information on some of the support services available for people with dementia and their family or carers is listed below.

Summary

Living with dementia can be challenging and stressful at times for the person with dementia, their families and carers. There are services that provide practical and emotional support for each stage of the dementia journey. It is important to recognize that without support and assistance there is a risk of becoming worn down and unable to provide care. Getting help now, as well as planning for what you might need in the future, will ensure that you take care of yourself as well as your family and the person with dementia.

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Overview

Useful contacts

Support services

The following is a brief description of some organisations that provide information and help for people. This is not an exhaustive list as there are many organisations, some specific to particular regions and states that can also provide support and assistance. You can find out more about the services available for older people in your area by speaking to your doctor, contacting your state association of Alzheimer's Australia, or contacting your local council or community health centre. Alternatively, in the front of the telephone directory there is a page (The Age Page) that has information on services for older people.

Aged Care Assessment Team (ACAT) – Australia wide

Your doctor or local hospital can refer you to an ACAT. For further information:

www.health.gov.au/internet/wcms/publishing.nsf/Content/ageing-acat-assess.htm-copy2

☎ 1800 052 222 Commonwealth Carelink Centre

☎ 1800 500 853 Aged Care Information Line

Aged Care Standards and Accreditation Agency

This agency manages the residential aged care accreditation process using the national Accreditation Standards. The agency promotes high quality care and assists the industry to improve service quality through provision of information, education and training. The website provides access to recent accreditation reports for residential aged care services across Australia. For further information:

www.accreditation.org.au

☎ 1800 288 025

Alzheimer's Australia

Alzheimer's Australia is the national peak body representing the interests of people with dementia and their families and carers. They manage a range of national programs including support, counselling, training and education for both people with dementia, their carers as well as professionals working in the area of dementia. Each State and Territory of Australia has an Alzheimer's association.

For further information:

☎ 1800 100 500

www.alzheimers.org.au

Australian Government Department of Health and Ageing website

This website provides an overview of the various aged care programs funded by the Australian Government:

www.agedcareaustralia.gov.au

Carers Australia

There is a Carers Association in each State and Territory of Australia and their aim is to advocate for and support the needs, views and concerns of carers. They offer a range of services and support such as counselling, carer support groups, respite coordination and information. For further information:

www.carersaustralia.com.au

☎ 1800 242 636

Centrelink

Provides financial support for eligible carers, including the Carer Allowance and Carer Payment. A resource booklet is available that describes the eligibility criteria and how to access these payments:

Centrelink. (2006). *Caring for someone? A guide to your options and our services:*

Australian Government. www.centrelink.gov.au [Publications > A-Z Publications directory > C]

For further information:

www.centrelink.gov.au

☎ 13 2717

Cognitive, Dementia, and Memory Service (CDAMS)

CDAMS is a service available in Victoria that provides expert clinical diagnosis for people who are experiencing memory loss or changes in their thinking. CDAMS can provide information on how to manage with day-to-day issues, planning for the future and general education, support and information. Speak to your doctor about a referral to your local CDAMS. For further information:

www.health.vic.gov.au/subacute/cdams.pdf

Commonwealth Carelink Centres

Commonwealth Carelink Centres provide free and confidential information on community aged care, disability and other support services available. There are 65 centers located throughout Australia, so that information and support can be provided

in person or by telephone. Commonwealth Carelink Centres can help people find out about support services, costs involved, assessment processes and eligibility criteria.

For further information:

www9.health.gov.au/ccsd

☎ 1800 052 222

Commonwealth Carer Respite Centres

Commonwealth Carer Respite Centres help people with dementia and their families and carers to plan for respite and other support needs. There are over 80 centres throughout Australia and they can help to organise emergency or planned respite as well as financial assistance for short term or emergency respite. For further information:

www.health.gov.au/internet/wcms/Publishing.nsf/Content/ageing-carers-respcent.htm

☎ 1800 059 059

Council on the Ageing (COTA)

COTA is Australia's leading seniors' organisation, with individual members and seniors organisation members in all states and territories. It is an independent consumer organisation that aims to protect and promote the wellbeing of older people.

For further information:

www.cota.org.au

☎ 1800 182 324

Dementia Behavior Management Advisory Service (DBMAS)

These Australian Government funded services were established while the Dementia Resource Guide was in development. These services will be provided within each state and territory to provide clinical support, advice and assistance to families, carers and staff providing care to people with dementia when behaviour impacts on care. To find out more about these services, contact Alzheimer's Australia (listed above).

Rights of Older People website


This website provides links to the various State and Territory age and disability advocacy services. Also refer to the *Quality of Life* section of this Guide and refer to *Human Rights and Dignity* where contact details for each State and Territory advocacy service are provided.

www.sa.agedrights.asn.au/rights/home.html

Veterans' Home Care

The Department of Veteran's Affairs runs the Veterans' Home Care (VHC) program. The program provides a wide range of low level home care services designed to enable veterans and war widows/widowers to maintain health and wellbeing and live independently in their homes. For further information:

www.dva.gov.au/health/homecare/mainvhc.htm

 1300 550 450

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Transition to residential care

Introduction

One of the most difficult changes that people living with dementia may face is the decision to move into residential care. This is often a distressing and confusing time for both the person with dementia and their family and carers. For some families and carers there may be disagreement about whether the person with dementia requires residential care or which facility is most suitable. For some individuals the prospect of moving to a new home may be frightening and they may not understand or agree with their need for extra support. This time of change is often described as an emotional roller coaster and it is normal to experience the extremes of emotion from guilt and sadness to relief. However, it is important to remember that the decision to move to residential care is about supporting the needs of the person with dementia.

Prior to moving to a residential facility, it is important to consider whether the person with dementia, and their families and carers, can be supported to continue to live at home. There are a number of community packaged care options, such as CACPs (Community Aged Care Packages) and EACH-D (Extended Aged Care at Home Dementia), which have been developed to help frail aged and/or people with dementia to safely remain at home with support services. This may include assistance with personal or domestic care, nursing or home-based respite. Community packaged care options are flexible and are administered by a case manager through an approved service provider. (Refer to *Support services*).

There are a number of steps that need to be completed before the person with dementia can receive a community care package or move into residential care. However, there are people and organisations that can support families and carers during this process. The first step is for the person with dementia to be assessed and approved for care by a member from the Aged Care Assessment Team (ACAT). The assessment determines the type and level of care the person with dementia is eligible for. The ACAT worker can also provide information on the most appropriate residential facilities. (Refer to *Support services*).

Following the decision to move into residential care, there are strategies and resources that can help carers, both practically and emotionally, during this time of change. Understanding what to look for in a facility can increase your confidence in making a decision. Checklists that assess factors such as staff attitude, layout of the facility and activity programs are useful. Talking to people who have experience and knowledge of the service system, such as a social worker can also provide information in selecting a good residential facility. Your doctor, ACAT worker or local community health service can advise you how to access a social worker. Remember, it is important to acknowledge your feelings during this time and consider seeking support from others who have had a similar experience.

When a person with dementia moves into residential care, the role of families and carers may change. The level of involvement that families and carers choose to have will depend on their specific needs and desires and those of the person with dementia. Some people may choose to become involved in practical day-to-day tasks such as assisting with meals while others may become involved in social activities at the facility. It is also normal for families and carers to take time out to rest and focus on their own health and wellbeing. There are no rules about how much involvement families and carers should have when the person with dementia moves into residential care. (Refer to *Caring for families and carers*).

Recommendations

- Explore community based care options, such as a package of support services, as a first step before considering moving into a residential facility
- Learn all you can about the services available to people with dementia, and the process for accessing these services. Your doctor, local ACAT or state Alzheimer's association can provide a great deal of information and advice
- Acknowledge your feelings during this difficult time and understand they are normal. Talk to a family member, friend or a counsellor
- Consider the best way to communicate the move into residential care to the person with dementia
- Allow the person with dementia time to adjust to changes. For example, following a move to residential care, the person with dementia will need to adjust to a new home and new routine, just as families and carers will need to adjust to a change in their role and routine
- Although the caring role may change following the move into a residential facility, your new role is equally important and may involve educating staff about the history, needs and preferences of the person with dementia
- Seek support from friends, family and others who have experience with dementia. Carer support groups can continue to provide both practical and emotional assistance following the move into residential care
- Consider your needs following the move into residential care. For example, how often would you like to visit the person with dementia? How much free time will you have? Are there new hobbies you would like to try or old ones you would like to take up again?
- The person with dementia may feel unsettled following a move into residential care. It is important to provide reassurance, seek advice from the staff at the facility and be consistent in any strategies to address changed behaviours.

Summary

The person with dementia and their family and carers will experience many changes, both physical and emotional, throughout their journey. Although the transition to residential care is a stressful time, preparing for this change can help the person to feel safe and in control. It is normal to experience many emotions when the person with dementia moves into a residential facility. Discussing feelings and seeking support from friends, family or a counsellor can help during this time of change.

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Transition to residential care

Personal story – Jan



The whole family felt devastated when it came time for Mum to go and live in a residential care facility. She had Vascular dementia and had been living on her own, in her home, for the five years since Dad had died. During that time she had coped well but now it was clear she needed more help and couldn't be left alone any longer.

The family were devastated for different reasons. Jan, the eldest daughter who lived closest to Mum in Melbourne, felt bad that she could not give her all the care she needed and was sad to see Mum leaving the family home. Phil, her brother, lived in Perth, and didn't see Mum very often. He was devastated that his mother was being 'dumped in an old folks home' (as he put it) and didn't see why his sister Debra, who was single and lived in Sydney couldn't move back home with Mum. He thought that Mum wasn't 'as bad as Jan said'. And Debra felt guilty that she didn't want to move back home, and angry that her brother felt she should when he was not prepared to do it himself. She wondered how it would affect their future relationship.

But it was clear that it was not safe for Mum to live alone any more. As the condition progressed Mum had started doing things that were becoming dangerous. Burning the toast, forgetting to turn off the gas and once she had tried to heat the electric kettle on the gas stove. On that occasion Jan had been there and had quickly turned off the gas before any damage was done. Mum had lost her memory of how to use things and could only remember how she had used them when she was younger.

And there were other things too. The family had been very happy when they had organised meals to be delivered to her, only to be shocked later when Jan found several unopened containers when had they looked in her kitchen. Mum didn't know the deliveries contained food.

It was difficult to know sometimes whether Mum really knew what was going on. She had told Jan that her home helper had not been for a couple of weeks, but when Jan rang to check she found the helper hadn't missed a session. Mum had simply not remembered that she had been there. That made them worry about other things that might happen, or people she might let into the house without remembering.







It made much more sense for Mum to live where she would have the help and support she needed. A residential facility would provide an environment where Mum could be safe and have company. She would have her meals served and that would improve her nutrition. Mum was fairly thin and frail and didn't go outside much, but in the residential facility she could join in exercise and other activities and walk along their paved garden paths. Nutrition and exercise would help with her strength and balance and mean that she was less likely to fall and injure herself. Her medication of eight prescription medicines would be supervised and if there was an emergency, trained staff would be able to assist her and call the family.









It all made sense, but it had been such a difficult decision to make. When Jan talked with Mum about it, she didn't seem to mind the idea but Jan couldn't be sure whether she really understood. Everyone just wanted Mum to be happy.







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Transition to residential care

Recommended resources

Name of resource and where it is available	Brief description and type of resource	Target setting
<p>Alzheimer's Australia. (2005). <i>Help sheet 4.1: Deciding on residential care.</i> www.alzheimers.org.au [> Publications & resources > Helpsheets & update sheets > Residential care and dementia]</p> 	<p>Help sheet. Directed at families and carers who may be considering residential care. Provides a brief overview of the different levels of care available, assessment for placement and strategies for helping the person who has dementia to settle in to their new environment. Also includes a useful checklist for evaluating residential care facilities.</p>	
<p>Alzheimer's Australia. (2005). <i>Help sheet 4.2: Which residential facility?</i> www.alzheimers.org.au [> Publications & resources > Helpsheets & update sheets > Residential care and dementia]</p> 	<p>Help sheet. Directed at families and carers who may be considering residential care. Provides information about visiting residential facilities and includes a checklist for determining whether the facility is dementia friendly.</p>	
<p>Alzheimer's Australia. (2005). <i>Help sheet 4.3: Caring Partnerships.</i> www.alzheimers.org.au [> Publications & resources > Helpsheets & update sheets > Residential care and dementia]</p> 	<p>Help sheet. Targeted at families and carers of people with dementia after they have moved into residential care. Describes a partnership approach where the carers, families, person with dementia and facility staff work together to provide individualised care for the person with dementia. Provides a list of things that facility staff should be doing to involve families and carers in caring for the person with dementia. This list is also useful for residential care staff.</p>	

<p>Alzheimer's Australia. (2005). <i>Help sheet 4.4: Good care in a residential facility</i>. www.alzheimers.org.au [> Publications & resources > Helpsheets & update sheets > Residential care and dementia]</p> 	<p>Help sheet. Provides a brief overview of the important aspects of good care for people with dementia living in residential facilities, including the involvement of relatives and friends.</p>	
<p>Alzheimer's Australia. (2005). <i>Help sheet 4.5: Coping with placement</i>. www.alzheimers.org.au [> Publications & resources > Helpsheets & update sheets > Residential care and dementia]</p> 	<p>Help sheet. Provides an overview of strategies to assist in the adjustment to residential care placement for families and carers. Provides some practical ideas about what families and carers can do when they visit to help make the visit enjoyable.</p>	
<p>Alzheimer's Society. (2006). <i>Lesbian and gay network inclusion toolkit</i>. www.alzheimers.org.uk [> About dementia > Caring for a person with dementia > Gay carers]</p> 	<p>Kit. Discusses the experience of lesbian and gay people with dementia, and that of lesbian and gay carers. Includes information on choosing residential care facilities. Refers to United Kingdom legislation regarding legal issues and the recognition of same-sex relationships.</p>	
<p>Alzheimer's Australia. (2003). <i>Moving to residential care</i>. www.alzheimers.org.au [> Victoria > Publications]</p> 	<p>Kit. Provides suggestions on how to support the person with dementia during the transition from home to residential care. Consists of five help sheets: An introduction, Frequently Asked Questions (FAQs) about the move, FAQs about after the move, Caring after the move, and Getting support.</p>	

<p>Alzheimer's Scotland. (2005) <i>Letting go without giving up.</i> www.alzscot.org [> Information and support > Information about dementia]</p> 	<p>Booklet. Addresses the emotional impact of moving into residential care for both the person with dementia and families and carers. Also provides practical suggestions on how families and carers can stay involved.</p>	
<p>Alzheimer's Scotland. (2004) <i>Working with dementia: A handbook for care staff.</i> www.alzscot.org [> Information and support > Information about dementia]</p> 	<p>Booklet. Resource for residential aged care staff that encourages the reader to 'walk in the shoes' of the person with dementia and/or families and carers.</p>	
<p>Victorian Government DHS Rural and Regional Health & Aged Care Services (2002). <i>A guide for families and carers to the 'how, when, what and where' of residential care.</i> www.health.vic.gov.au [> Aged Care > Aged Care in Victoria > Publications & resources > Publications]</p> 	<p>Booklet. Useful resource for families and carers deciding whether to use residential care. It explains some of the common feelings associated with placing a relative in residential care, a checklist for choosing the right facility, a list explaining the differences between high and low residential care as well as Supported Residential Services (SRS). Developed by the Victorian government so some of the included forms may be specific to Victoria.</p>	

Symbol	Explanation
	Residential care setting
	General
	Light reading
	Medium level resource
	In depth, detailed resource
<u>Underlined text</u>	Refer to glossary for definition