SUPPORT FOR CARERS
A PRACTICAL GUIDE TO SERVICES FOR FAMILIES AND FRIENDS OF PEOPLE WITH DEMENTIA
TALKING ABOUT ALZHEIMER’S ACROSS AUSTRALIA FIGHTDEMENTIA.ORG.AU
ACKNOWLEDGEMENTS

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Further contributions to the development of this guide were made by members of Alzheimer’s Australia’s National Consumer Advisory Committee.

The purpose of this document is to provide general information only. Information has been gathered from a number of sources, including the Alzheimer’s Australia website and My Aged Care website. Information was current at the time of publishing but may be subject to change.

Alzheimer’s Australia respectfully acknowledges Aboriginal and Torres Strait Islander people as Traditional Custodians of their land, we also acknowledge both past and present Elders, and their continuing connection to country.
FOREWORD

Dementia is part of the life of more than 342,000 people living with dementia and their carers and families. The vast majority of people living with dementia in the community rely on a carer to support them and there are currently more than 200,000 Australians providing this unpaid informal care.

Caring is a role that brings joy, togetherness, personal growth and the reward of being able to help. It can also bring challenges, stress and strain.

The symptoms and a diagnosis of dementia bring change for people living with dementia and those close to them. Friends and family begin a new and challenging journey of their own. They have to try and cope with the emotional impact and implications of a diagnosis, come to terms with and manage the changes they see in their relative or friend, provide emotional and practical help on a daily basis, and make difficult decisions about treatment options, use of services, finances, and long term care. Some may have work, children and other family commitments to cope with as well.

This guide has been developed as a helping hand for carers and the loved ones they care for. As a carer I found it quite difficult to find what services were available at the different stages of the dementia journey, so the guide is put together in a roadmap format. This will help carers to access the services when they are needed and to help with future planning.

It has been made possible through the generous support of a carer and with the assistance of the Alzheimer’s Australia National Consumer Advisory Committee. They join me in hoping that the information within these pages help smooth the journey for you and your loved ones.

Judy Woolstencroft
Chair, Alzheimer’s Australia National Consumer Advisory Committee
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This guide has been developed to help family members and friends of someone living with dementia. It provides practical information about services to support care partners at different stages on the dementia pathway. The guide is designed to help you find out about services when they are needed, and to help you with future planning. We hope this guide will help you to:

- Think about how you are feeling and coping
- Think about what help you may need, both now and in the future
- Talk to others about the help you need
- Find out about support services that are available to help you.
WHY DO FAMILY MEMBERS AND FRIENDS NEED SUPPORT?

The caring role
As a family member or friend of someone living with dementia, you may provide a wide range of care, including:

- Supporting the person to continue their involvement in hobbies, activities and interests that they enjoyed before their diagnosis for as long as possible
- Working with a range of health care workers and support agencies to ensure the person’s physical, psychological and social needs are met
- Helping the person with daily activities, such as household chores, shopping, preparing meals, managing finances, appointments and taking medications
- Providing personal care, such as bathing, dressing and going to the toilet
- Supporting the person when they experience changes to their behaviour or psychological symptoms associated with dementia such as withdrawal, agitation, anxiety and/or night-time disturbances
- Helping the person with physical tasks, such as getting in and out of bed, or walking.

You may also have to support the person you are caring for to make difficult decisions about treatment options, use of services, finances, and long-term care. If it is possible, it is useful to document the wishes of the person with dementia early in the disease to ensure that if they are no longer able to express their wishes, you can make decisions on their behalf that reflect their views.

You may have work, children and other family commitments to cope with as well.

The impact of caring
Caring for a person with dementia can have both positive and negative effects. One the one hand, you may feel closer together as a family, experience personal growth such as feeling more capable and resilient, and enjoy the satisfaction that caring for someone can bring.

However, in some cases caring for a person with dementia can lead to significant strain, stress and depression. Research shows that family members and friends caring for someone with dementia may experience:

- A mixture of feelings, such as guilt, sadness, grief, frustration, anger, lack of control and worry
- Higher levels of stress and depression than non-carers
- Disruption of sleep, tiredness and exhaustion
- Deteriorating or poor physical health
- Reduction in social or recreational activities, or social isolation
- Taking time off from or giving up paid work
- Financial worries or problems.

How support services can help
There are many services available to support you. Some provide strategies and resources to help you cope with your caring responsibilities and best support the person with dementia. Others aim to provide a break from the demands of caring and to provide opportunities for social engagement for the person with dementia. All aim to support you in your important role as a carer.

The following sections will describe the support services that are available for family members and friends at each stage of the ‘dementia pathway’, and point you in the right direction for further information and advice.
## ROADMAP TO SERVICES

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SECTION 1: GETTING A DIAGNOSIS

An early diagnosis of dementia is vital. It can help you and the person you are supporting to:

- Understand and come to terms with the changes that are happening to them
- Make decisions about appropriate treatment options
- Find out about and access available support services
- Plan for the future.

**Signs of dementia**

Dementia is a term that is used to describe a wide range of symptoms that may include:

- Memory problems
- Difficulty thinking or concentrating
- Difficulty in carrying out familiar daily tasks
- Difficulty finding the right words or following a conversation
- Confusion about time or places
- Difficulty controlling emotions or changes in mood

Early symptoms depend on the type of dementia and can vary from person to person. If you are worried about a relative or friend’s memory or thinking, or if you think they may be beginning to show signs of dementia, you may want to talk to them about seeking advice from a medical professional.

Dementia is most common in older people but can also affect people at younger ages. It is important to get assistance for any symptoms of dementia regardless of age.

**Assessment and diagnosis**

If a family member or friend experiences symptoms of dementia, you and the person you are supporting should talk to your local family doctor or General Practitioner (GP) about your concerns. The symptoms you have been noticing might not be dementia at all, but another condition, such as an infection, thyroid problem, depression or side-effects of medication, or another medical condition which may be treatable. Only a qualified medical practitioner can determine what may be causing the symptoms.

Your doctor will talk to you both about the symptoms and may conduct a number of screening tests and assessments. They may also refer the person to a medical specialist such as a neurologist, geriatrician or psychiatrist for further assessment and diagnosis.

You may want to provide your doctor with information about how to best communicate with a person with dementia such as the Alzheimer’s Australia Talk to Me document (https://fightdementia.org.au/sites/default/files/TalkToMe_Brochure_FoldedDL_HR.pdf)

If you feel that your doctor is not addressing your concerns you should seek a second opinion or request a referral for additional testing.

**What support is available**

If you are concerned about the possibility of a family member or friend having dementia, as well as your family doctor, you may find it helpful to talk to an organisation, such as Alzheimer’s Australia or Carers Australia that provides information, counselling and support specifically for carers of people with dementia or for carers in general.
Information and education

In the early stages of supporting a person with dementia, carers often find it useful to get further information about the condition and what it means to support a person with dementia. Both Carers Australia and Alzheimer’s Australia provide different support services which may be useful in the early stages of support. Structured programs, led by qualified professionals, can provide you with:

- Knowledge about dementia, its symptoms, progression and changing care needs
- Skills training to support you in the caring role
- An opportunity to meet other people going through similar experiences
- Information and advice about available resources and services.

Alzheimer’s Australia currently provides two specialised education programs for people with dementia and their family carers: Family Carer Education, and the Living with Dementia series. Both provide people in the early stages of dementia, along with their families and carers, with information, advice and peer support to help them to come to terms with their condition and plan for the future.

Counselling and Psychotherapy

Talking to a qualified professional can help some people come to terms with a diagnosis of dementia, talk about concerns that are upsetting them, and help with symptoms of stress, anxiety and depression. These services are provided by a qualified professional and can be provided face-to-face, over the telephone or online.

A counsellor will listen to your concerns in a non-judgemental and supportive way. They will talk to you about your problems and help identify solutions to help you.

A psychologist will help you identify and understand your thoughts, feelings and behaviours and develop strategies to help you cope. For example, cognitive behaviour therapy (CBT) is a type of psychotherapy that helps people to change negative thoughts and behaviours, to improve how they feel.

Support groups

Many people find it beneficial to meet with others, who are going through a similar experience, through a support group. There are many different types of support groups available. Some support groups are specifically for people caring for someone with dementia, such as those run by Alzheimer’s Australia. Others are for carers more generally. They can be led by professionals, volunteers or by carers themselves. All provide the opportunity to share and discuss your experiences and feelings with others living in your local area.

Younger onset dementia

Younger onset dementia refers to people under the age of 65 who have been diagnosed with dementia. The Younger Onset Dementia Key Worker Program is delivered by Alzheimer’s Australia, and provides a single point of contact for younger people with dementia and their family carers, helping with access to services and providing support such as information, advice and counselling.
Who to contact

Support organisations, helplines, counselling and support services:

**National Dementia Helpline: 1800 100 500**
Alzheimer’s Australia runs this helpline and provides a range of services to support people with dementia and their families and friends, including telephone information and support, education and training programs, and a free counselling service. They can also put you in touch with local support groups. For further information please see: fightdementia.org.au or phone: 1800 100 500

**Carers Australia: 1800 242 636**
Carers Australia provides specialist services including counselling, advice and information for carers of a family member with any condition. For further information please see: www.carersaustralia.com.au or phone: 1800 242 636

**Commonwealth Respite and Carelink Centres: 1800 052 222**
Carelink Centres are located throughout Australia and help carers access information and training courses, such as the Dementia Education and Training for Carers Program. They may also organise appropriate respite for the person with dementia to enable the carer to attend the course.

**My Aged Care: 1800 200 422**
My Aged Care provides information and advice about how to access aged care services, including eligibility, assessment, finding local services to meet your needs, and costs.

**My Aged Care is now the key entry point to the Australian aged care system.**
For further information please see: www.myagedcare.gov.au or phone: 1800 200 422

**Young Carers: 1800 55 1800**
Young Carers provides information, support or counselling for carers under 18 years old and caring for a family member with any condition.
For further information please see: www.youngcarers.net.au or phone: 1800 242 636

**Counselling and psychotherapy:**

**Australian Counselling Association: 1300 784 333**
The ACA is a national association of qualified and registered counsellors and psychotherapists in Australia and has a Find a Counsellor service.
For further information please see: www.theaca.net.au or phone: 1300 784 333
**Australian Psychological Society: 1800 333 497**

The APS has a Find a Psychologist service (online, telephone and email referral) that allows you to find a qualified psychologist in your area.

For further information please see: [www.psychology.org.au](http://www.psychology.org.au) or phone: **1800 333 497**

**Psychotherapy and Counselling Federation of Australia: 03 94863077**

The Psychotherapy and Counselling Federation of Australia also has a Find a Therapist service.

For further information please see: [www.pacfa.org.au](http://www.pacfa.org.au) or phone: **03 94863077**

**Lifeline Australia: 13 11 14**

Lifeline Australia provides help to anyone experiencing a personal crisis, with online, phone and face-to-face crisis support and suicide prevention services.

For further information please see: [www.lifeline.org.au](http://www.lifeline.org.au) or phone: **13 11 14**

**In an Emergency:**

**Emergency help: 000**

If you or someone you are caring for is seriously injured or in need of urgent medical help phone the emergency services: **000**

For emergency respite support phone: **1800 059 059**
SECTION 2: PLANNING FOR THE FUTURE

People with dementia and their family carers often have to make difficult decisions about treatment options, use of services, finances and long term care. You should talk to the person you are caring for about their wishes, both for now and for the future, whilst they are still able to make decisions. There are a number of support services that can help you both with this.

Financial advice and planning

Financial advice and counselling

It can be useful to get independent financial advice when thinking about future financial issues. There are a number of government services and resources that can help you obtain appropriate financial advice.

For basic information on managing your finances, the Department of Human Services has a free Financial Information Service. This confidential service can help you make informed decisions about investment and financial issues for your current and future needs.

If you’re experiencing financial difficulties you can get help from a financial counsellor. A financial counsellor can help you negotiate with your creditors if you have debts, organise your finances and create a budget. You can find a financial counsellor near you using the MoneySmart website or you can contact the Department of Social Services. Please see the Who to contact page at the end of this section for further details.

Financial assistance

The following payments are available if you provide daily care to someone with severe disability or a medical condition or someone who is frail aged:

- **Carer Payment** provides financial support to people who are unable to work in substantial paid employment because they provide full time daily care to someone with severe disability or medical condition, or to someone who is frail aged.
- **Carer Allowance** is a fortnightly income supplement for parents or carers providing additional daily care and attention to an adult or dependent child with disability or a medical condition, or to someone who is frail aged. Carer Allowance is not income and assets tested, is not taxable and can be paid in addition to wages, Carer Payment or any other income support payment.
- **Carer Supplement** is an annual lump sum payment to help you with the costs of caring for a person with disability or a medical condition if you are receiving Carer Payment or Carer Allowance.

For more information on carer benefits please see: [www.humanservices.gov.au](http://www.humanservices.gov.au)

Superannuation

People with dementia and their families may want to consider whether it is possible to access their superannuation to assist with costs associated with caring for dementia. Alzheimer’s Australia has developed a document with information about what options are available for accessing superannuation which can be found here: [https://fightdementia.org.au/sites/default/files/NATIONAL/documents/superannuation-and-dementia.pdf](https://fightdementia.org.au/sites/default/files/NATIONAL/documents/superannuation-and-dementia.pdf)
Legal rights and planning

If you have dementia, the law protects your right to:

- Make your own decisions and be involved in any decisions that affect you
- Get support in making decisions about the future that you are finding difficult to make
- Put plans in place in case you are unable to make decisions in the future
- Appoint someone you trust to make decisions in your best interests if you can’t.

For family carers, it is important to discuss these issues with the person you are caring for at an early stage. Some decisions can only be made by someone with the legal authority to do so. This may mean that if the person with dementia no longer has the capacity to make decisions you may need to organise a power of attorney or apply for guardianship or administration rights.

Power of attorney

A power of attorney is a legal document that gives the nominated person (the attorney) the power to act on a person’s behalf and manage their affairs when they are unable to do so. This may include the power to make decisions about financial and legal affairs, decisions about lifestyle (including where the person with dementia will live) and what medical or health treatment they should receive.

Guardianship and administration rights

Depending on the types of decisions that need to be made, a carer may sometimes need to apply for guardianship or administration rights. A guardian is a legally appointed substitute decision maker who may make decisions, such as where a person should live, as well as give their consent to medical, dental and health care services generally. An administrator acts as a financial manager and looks after a person’s property and finances.

Alzheimer’s Australia will be publishing a Legal Rights booklet targeted towards people with dementia and their families, which will be freely available on fightdementia.org.au

The rules in each state and territory are different so you will need contact the relevant authority where you live, or your legal advisor, for details on powers of attorney, enduring powers of attorney, enduring guardians and administrators. A contact list for each state and territory authority can be found at: http://www.myagedcare.gov.au/financial-and-legal/powers-attorney-enduring-powers-attorney-and-enduring-guardians


Driving

A person diagnosed with dementia may not need to stop driving straight away. However, as the dementia progresses, the person will need to stop driving at some point.

All drivers are required by law to tell their local licensing authority of any medical condition that might affect their ability to drive safely such as dementia. Once notified, the licensing authority will ask that the driver’s doctor makes an initial assessment of the driver’s medical fitness. After this, a formal driving assessment may be required. Based on the results of these assessments the licensing authority will decide if the person can continue to drive.

If the person with dementia can continue to drive they will be issued a conditional licence. Conditional
licences are valid for a maximum of 12 months; after that the driver will be reassessed. Sometimes restrictions are also placed on the licence holder. These restrictions might be that the person can only drive close to home, at certain times, or below certain speed limits.

If a person with dementia continues to drive and they have not notified their licensing authority, or if they continue to drive after their licence has been cancelled or suspended, there can be serious consequences. If the driver is in a crash they could be charged with driving offences or be sued. In addition their insurance company may not provide cover.

The decision to stop driving is a difficult one and it is essential to consider what alternative arrangements can be put in place to support the person with dementia to continue to be independent for as long as possible and have safe and reliable transport to places they would like to go. Some jurisdictions have arrangements to support transportation for people who are unable to drive due to a disability such as dementia such as taxi vouchers.

**Employment**

If the person with dementia is still working when diagnosed, they will need to consider how dementia will affect their working life and consider what changes may be needed in the future. They can get support and advice from a range of places including:

- Family doctor or medical specialist
- Trade union or professional body
- Alzheimer’s Australia
- Legal and financial advisors
- A counsellor
- Anti-discrimination advocates

Any person who has a disability, mental health or medical condition (including dementia) which impacts on their work is eligible for reasonable support and disability services such as auxiliary aids that provides assistance to a person with a disability to alleviate the effect of the disability. (Disability Discrimination Act (1992))

For example, some employers may be willing to offer a person with dementia different job responsibilities or to provide additional support such as memory aids or reduced workloads to enable the person with dementia to continue employment for a period of time. Depending on the symptoms of dementia and the employment position in some cases the person with dementia will not be able to continue in employment.

As a family carer, you may also find it difficult to continue working whilst caring for someone with dementia. Before you make any final decisions about leaving work you need to find out about:

- Superannuation policy and entitlements
- Any sick leave or long service leave entitlements
- Disability or sickness benefits
- Any income protection insurance or other insurances that may have a disability component
- Any government benefits for which they might be eligible after leaving work

Please see the above section on financial assistance for further information.
Advance care planning

Advance care planning (sometimes called a ‘living will’) helps the person with dementia to make plans for their future medical treatment and care needs. An advance care plan may include:

- An Advance (Health or Care) Directive (or other similar document)
- An enduring power of attorney (or other similar document)
- A letter to the person who will be responsible for decision making
- An entry in the person’s medical record
- Instructions for family members, doctors and other health care workers.

Advance care planning encourages the person with dementia to reflect on what is important to them in life and what their preferences are. It explains how they want to be cared for when they reach a point where they cannot communicate or lose the ability to make decisions about their medical care. By creating a plan in advance, doctors and family members can understand how the person would like to be cared for. For family members and friends, it will help you to make informed decisions on behalf of the person with dementia, because they have explained their wishes in advance.

Alzheimer’s Australia, with support from J.O. & J.R. Wicking Trust and Bupa Care Services have developed a website that provides information on planning ahead for people with dementia and their family carers: http://start2talk.org.au/

Each state and territory has different names for the legal documents you can use to create an advance care plan. These can be obtained, along with general information on advance care planning, from Advance Care Planning Australia (Respecting Patient Choices): http://advancecareplanning.org.au/
Who to contact

**General advice and information**

**National Dementia Helpline: 1800 100 500**

Alzheimer’s Australia runs this helpline and provides a range of services to support people with dementia and their families and friends, including telephone information and support, education and training programs, and a free counselling service. For further information please phone: **1800 100 500**

**Carers Australia: 1800 242 636**

Carers Australia provides a Carers Advisory Service, with information and advice about carer supports and services, as well as counselling services for carers of a family member with any condition.

For further information please see: [www.carersaustralia.com.au](http://www.carersaustralia.com.au) or phone: **1800 242 636**

**Financial advice and assistance**

**Department of Human Services: 132 717**

Information about financial assistance, benefits and services if you provide care to someone who has a disability, illness or is frail aged.

For further information please see: [www.humanservices.gov.au](http://www.humanservices.gov.au) or phone: **132 717**

**My Aged Care: 1800 200 422**

My Aged Care provides information and advice about how to access aged care services, including eligibility, assessment, finding local services to meet your needs, and costs.

My Aged Care is now the key entry point to the Australian aged care system.

For further information please see: [www.myagedcare.gov.au](http://www.myagedcare.gov.au) or phone: **1800 200 422**

**Money Smart:**

For financial information, advice or to find a financial advisor in your area please see: [www.moneysmart.gov.au](http://www.moneysmart.gov.au)
Legal support and assistance

My Aged Care: 1800 200 422


Driving and dementia

Licensing authorities

Please contact the licensing authority for your state or territory. Contact details can be found on the Australian Government website:

Working and dementia

JobAccess: 1800 464 800

JobAccess helps people with disability, employers, service providers and the community to access information about services, financial assistance and workplace solutions.

For further information phone: 1800 464 800 or see: www.jobaccess.gov.au

Advance care planning

Alzheimer’s Australia: 1800 100 500

Alzheimer’s Australia have a website for information and advice about planning ahead for people with dementia and their family members: www.start2talk.org.au

Advance Care Planning Australia

For information on advance care planning and contacts in your area please see: www.advancecareplanning.org.au/advance-care-planning/for-everyone
SECTION 3: HELP TO LIVE AT HOME

Most people with dementia and their families prefer that the person with dementia remain living at home for as long as possible, but you may need help to do this. There are a number of services available to support family members and friends caring for someone with dementia living in the community. These can be provided by the federal government, the states and territories, not-for-profit or private organisations. Whilst some services are available across all of Australia, others may differ depending on where you live.

Getting advice and an assessment

My Aged Care Gateway

My Aged Care Gateway is now the key entry point for older people, their families and carers to access the aged care system across Australia. You should contact the service if you need information and advice about:

- How the aged care system works
- The different types of aged care services that are available (including home, community and residential aged care)
- Eligibility for services
- Assessment for the Commonwealth Home Support Programme or Home Care Packages
- Accessing local services to meet your needs
- The cost of aged care services, including fee estimators.

Depending on your needs, the My Aged Care contact centre staff may:

- Discuss the needs of the person you are caring for and the appropriate next steps for you
- Provide you with information about aged care
- Refer the person you are supporting for a home support assessment conducted by the Regional Assessment Service (RAS) or a comprehensive assessment conducted by an Aged Care Assessment Team (ACAT, or ACAS in Victoria)

Regional Assessment Service (RAS)

Under the Commonwealth Home Support Programme, you may require a home support assessment conducted by the Regional Assessment Service (RAS) to find out exactly what help you will need at home. Together, you will be able to work out what sort of help and how much you need, and what it might cost.

Aged Care Assessment Team (ACAT)

An ACAT assessment (or ACAS in Victoria) is recommended for those who have more complex aged care needs and want to:

- Access aged care services through any level of Home Care Package
- Receive services through transition care
- Receive respite care in a residential aged care home (sometimes known as nursing home)
- Move into a residential aged care home.

An ACAT assessment involves meeting with a member of the ACAT team, such as a doctor, nurse, social worker or other health professional, to assess the care needs of the person you are supporting. They will talk to you both about how well you are managing in your day-to-day life. They will help identify the right services for your needs and work out what level of care you require. The team might also put you in touch with organisations in your local area that can deliver the services you need.
What support is available

There are a number of government programs to assist older people who require assistance living at home. The My Aged Care Contact Centre will assist you in getting an appropriate assessment which will determine which program the person with dementia is eligible for. In many cases people start out accessing a lower level of support such as the Commonwealth Home Support Programme but will eventually require more support over time. If you believe the person with dementia requires additional support, you can request a reassessment of their needs through My Aged Care.

Commonwealth Home Support Programme

The Commonwealth Home Support Programme is an entry level home help program funded by the Australian Government. It is for older people who are able to live at home with some assistance and who do not as yet need higher levels of support.

Services provided may include:

- Social support – social activities in a community-based group setting
- Transport – helps people get out and about for shopping or appointments.
- Domestic assistance – household jobs like cleaning, clothes washing and ironing
- Personal care – help with bathing or showering, dressing, hair care and going to the toilet
- Home maintenance – minor general repair and care of your house or yard, for example, changing light bulbs or replacing tap washers
- Home modification – minor installation of safety aids such as alarms, ramps and support rails in your home
- Nursing care – a qualified nurse comes to your home and may, for example, dress a wound or provide continence advice
- Meals – help with shopping, preparing and storing food in your home, and delivering meals to your home
- Allied Health support services – occupational therapy, podiatry, dietician, physiotherapy etc. for people having particular health problems, for example with their speech or walking, or needing help with ongoing problems resulting from an accident or illness.
- Respite care.

To receive these services, the person you are caring for will need an assessment by the Regional Assessment Service (RAS). Please see the previous section on Getting advice and an assessment for more information.

The Australian Government funds the Commonwealth Home Support Programme service providers so they can deliver affordable services. There will be a fee for each service and the amount you contribute depends on your income and the type and number of services you require. What you pay is discussed and agreed upon between you and the service provider. The rate is set before you receive the relevant services.

Home Care Packages Programme

If the person you are caring for has more complex needs, a Home Care Package may be more appropriate. This program offers similar services to the Commonwealth Home Support Programme, but the services are coordinated and tailored to meet your specific needs. Services provided in a Home Care Package may include:
• Personal services – such as help with showering or bathing, dressing, toileting and mobility
• Support services – such as help with washing and ironing, house cleaning, gardening, basic home maintenance, home modifications related to your care needs, and transport to help you do shopping, visit your doctor or attend social activities
• Clinical care – such as nursing and other health support including physiotherapy, dietitian and hearing and vision services
• Nutrition, hydration, meal preparation and diet – such as assistance with preparing meals, special dietary needs, using eating utensils and assistance with actual feeding if needed
• Management of skin integrity - including providing bandages, dressings and skin emollients
• Continence management - including assessment for and assistance in using continence aids and appliances and managing continence
• Mobility and dexterity - including providing walkers, walking frames, walking sticks, mechanical devices for lifting, bed rails, slide sheets, pressure relieving mattresses and assistance with the use of these aids
• Telehealth, video conferencing and digital technology (including remote monitoring) where appropriate, to increase access to timely and appropriate care
• Assistive technology, such as aids and equipment (particularly those that assist a person to perform daily living tasks), as well as devices that assist mobility, communication and personal safety.

There are four levels of Home Care Packages that are allocated depending on the support needs of the person.

• Level 1 supports people with basic care needs
• Level 2 supports people with low-level care needs
• Level 3 supports people with intermediate care needs
• Level 4 supports people with high-level care needs.

At each level there is a supplement available for people with dementia which recognises the additional costs in providing care and service to people with dementia.

To receive a Home Care Package, the person you are caring for will need an assessment by an Aged Care Assessment Team or Service (ACAT or ACAS). Please see the previous section on Getting advice and an assessment for more information.

From 1 July 2015, all Home Care Packages will be provided on a Consumer Directed Care (CDC) basis. This means that you and the person you are caring for will get more say in the care and services you access, how it is delivered and who delivers it to you. This will be discussed at your initial assessment or your next care plan review. You can get more information about CDC and what it means for you at Home Care Today http://www.homecaretoday.org.au.

**Costs for Home Care Packages**

**Basic fee**

Everyone taking up a Home Care Package can be asked by their service provider to pay a basic fee.
Income-tested care fee

Depending on your income, you may be asked by your service provider to contribute more to the cost of care. This extra amount is known as an income-tested care fee, and is based on an assessment of your financial situation. Please note that if you are a member of a couple, half of your combined income is considered in determining your income-tested care fee, regardless of which partner earns the income. The assessment does not include the value of your home or any other assets.

My Aged Care provides a home care fee estimator to help you estimate what costs your Home Care Package provider may ask you to pay. http://www.myagedcare.gov.au/personal-stories/aged-care-fee-estimators

Dementia Behaviour Management Advisory Service (DBMAS)

The Dementia Behaviour Management Advisory Services is a nationwide network of services funded by the Australian Government. You may wish to contact DBMAS if you need support caring for someone with dementia who is demonstrating behavioural and psychological symptoms of dementia (also known as BPSD), such as agitation, aggression, social and sexual disinhibition, verbal outbursts, delusions, hallucinations, and anxiety. These symptoms can be caused by changes to the brain due to the dementia or may be due to a range of physical or social needs not being met (such as the person being in pain or bored). DBMAS can assist in assessing the person with dementia and providing support in responding to these symptoms.

DBMAS services include

- Assessment of the person with dementia
- Clinical support, information and advice (face to face and via telephone or email)
- Care planning, case conferences and short term case management
- Education and training.

Family carers can contact the service on 1800 699 799 at any time of the day or night. Situations will be assessed free of charge and appropriate referrals to other support services can also be made if necessary.

Respite care services

Respite care is designed to give you a break from your caring responsibilities for a period of time as well as providing important opportunities for social engagement for the person with dementia. The type of respite you use will depend on both your own needs and the needs of the person you are caring for at the time of booking. This may vary from a few hours to a few weeks at a time. Although experiences vary, those who use respite tend to report high levels of satisfaction with the services received.

The former National Respite for Carers Program is now part of the Commonwealth Home Support Programme and offers respite in the following settings:

- In-home respite - a person working as a carer who comes to your home so that you can go out for a few hours, or they may take the person you are caring for out for a few hours to give you a break. In-home respite can happen during the day or overnight.
• **Centre-based day respite** - this usually takes place at a day centre, and provides the person you are caring for with structured activities, group activities or small group outings. Day respite often runs from 10am to 3pm and may include transport to and from the centre-based day respite centre.

• **Overnight or weekend respite** - overnight care may be provided in a variety of settings. These include a respite house (‘cottage-style’ respite) or the home of a host family.

• **Community access respite** - community access respite provides the person you are caring for with social activities.

• **Consumer Directed Respite Care** - Consumer Directed Respite Care (CDRC) packages can give the person receiving care and you a greater say and more control over the design and delivery of respite services provided to you. This means with your support the person receiving care can make choices about:
  - The types of respite services
  - How they are delivered
  - When they are delivered
  - Who will deliver them.

**Residential respite care** (offering short stays in a residential aged care home) is available if you need a longer break, for example to go on holiday, or as an emergency if you become ill. **Commonwealth Respite and Carelink Centres (CRCC)** will continue to co-ordinate residential respite care, until 30 June 2017.

Costs for respite care may vary depending on your circumstances and the kind of help you need. Costs can vary depending on the type of service, from an hourly rate for in-home respite to a sessional fee for a morning or afternoon in a day care centre. Any fees and eligibility for subsidy will be discussed and agreed upon with your service provider before you receive the relevant services. If you receive respite care in an aged care home, different fees will apply.

**After-hospital care (transition care)**

Transition care provides short term care for older people who have been in hospital and who need more help and time to recover. The aim is to help the person return to home rather than considering early admission to a residential care home. Transition care may be provided in the person's own home, in an aged care home, or in a separate wing of a hospital. Transition care services may include:

- Low-intensity therapy such as physiotherapy
- Access to a social worker
- Nursing support for clinical care such as wound care
- Personal care.

**You can only access transition care directly from hospital.** The person you are caring for will need an assessment by the Aged Care Assessment Team or Service.
Who to contact

Support for living at home:

National Dementia Helpline: 1800 100 500

Alzheimer’s Australia runs this helpline and provides a range of services to support people with dementia and their families and friends, including telephone information and support, education and training programs, and a free counselling service. They can also put you in touch with local support groups.

For further information please see: fightdementia.org.au or phone: 1800 100 500

Carers Australia: 1800 242 636

Carers Australia provides a Carers Advisory Service, with information and advice about carer supports and services, as well as counselling services for carers of a family member with any condition. There are also services specifically for Young Carers, Aboriginal and Torres Strait Islander carers, and Culturally and linguistically diverse (CALD) carers.

For further information please see: www.carersaustralia.com.au or phone: 1800 242 636

Commonwealth Respite and Carelink Centres: 1800 052 222

Carelink Centres are located throughout Australia and can provide information about residential respite options in your local area.

If you need emergency respite care, phone your local Commonwealth Respite and Carelink Centre on 1800 052 222 during business hours or 1800 059 059 outside business hours.

My Aged Care: 1800 200 422

My Aged Care provides information and advice about how to access aged care services (home, community and residential care), including eligibility, assessment, finding local services to meet your needs, and costs.

My Aged Care is now the key entry point to the Australian aged care system.

For further information please see: www.myagedcare.gov.au or phone: 1800 200 422

Dementia Behaviour Management Advisory Service (DBMAS): 1800 699 799

DBMAS provides clinical support for people caring for someone with dementia who is demonstrating behavioural and psychological symptoms of dementia (BPSD) which are impacting on their care.

For further information please see: www.dbmas.org.au or phone: 1800 699 799
Home Care Today

This national service aims to support consumers accessing home care by providing information, resources and peer supports that focus on providing the tools to make the most of the benefits and opportunities of Consumer Directed Care.

For further information please see:  http://www.homecaretoday.org.au/provider

In an Emergency:

Emergency help:  000

If you or someone you are caring for is seriously injured or in need of urgent medical help phone the emergency services: 000

Emergency respite: 1800 052 222 during business hours or 1800 059 059 outside business hours
Most people would prefer to receive care in their own home. Unfortunately this is not always possible. As care needs increase or if an informal carer is not available, residential care may be required to support a person with dementia. The majority of people in residential aged care have dementia and therefore most aged care facilities have some experience supporting residents with memory or thinking problems. Some facilities provide specialised dementia care and have staff who have received additional training on dementia.

Making a decision

Placing a relative with dementia into a residential aged care home can be a very difficult and stressful decision. This may be particularly true if the person with dementia is a long-term partner. Being prepared can help make this decision less stressful. Knowing about the types and costs of residential care beforehand can help you make the best decision, even if the decision has to be made quickly.

Before making your decision, you may wish to talk to:

- The person with dementia, if this discussion can take place while they are still capable of making their views known
- Your family doctor
- Other family members and friends
- Families and carers who have already been through the placement process
- A consumer organisation such as Alzheimer’s Australia or Carers Australia
- The My Aged Care contact centre.

It may be necessary to visit a number of residential aged care facilities to see if they will meet the needs of your relative. If possible, take a friend or family member with you on the visits. Alzheimer’s Australia has produced a checklist that may also help you with this process: https://fightdementia.org.au/sites/default/files/helpsheets/Helpsheet-ResidentialCare01-DecidingOnResidentialCare_english.pdf

Family members can sometimes experience feelings of guilt, depression or anxiety as a result of placing a family member in an aged care facility. If this occurs it is important to get support and/or counselling to assist during this transition. There are a range of organisations which can provide assistance during this time.

Assessment for residential care

If you’re thinking about moving your relative into an aged care home that is subsidised by the Australian Government, the first step is to organise an assessment with an Aged Care Assessment Team (ACAT, or ACAS in Victoria) via My Aged Care. An ACAT assessment usually involves a nurse, social worker or other health professional, who will determine the level of care needed by the person with dementia. The team will assess their needs and recommend appropriate types of residential care and provide details of facilities which may be suitable. Any concerns or issues that you may have can be discussed with the team.

Cost of residential care

There are four main components to the cost of residential care:

- Basic daily fee (day to day living costs)
- Means-tested care fee
- Accommodation fees
- Extra services fees
Basic daily fee

A basic daily fee is used to contribute towards your day-to-day living costs such as meals, cleaning, laundry, heating and cooling. Everyone entering an aged care home can be asked to pay this fee. From 20 September 2015 to 19 March 2016, the maximum basic daily fee for new residents (including respite residents) is up to $47.86 per day. This rate increases on 20 March and 20 September each year in line with changes to the Age Pension.

Means-tested care fee

This is an additional contribution towards the cost of care that some people may be required to pay depending on income and assets. The Department of Human Services will work out if you are required to pay this fee based on an assessment of your income and assets, and will advise you of the amount. If you are a member of a couple, half of your combined income and assets are considered in determining your means-tested care fee, regardless of which partner earns the income or owns the asset. There are annual and lifetime caps that apply to the means-tested care fee. Once these caps are reached, you cannot be asked to pay any more means-tested care fees.

Accommodation costs

This is for your accommodation in the home. Some people will have their accommodation costs met in full or in part by the Australian Government, while others will need to pay the accommodation price agreed with the aged care home. The Department of Human Services will advise which applies to you based on an assessment of your income and assets.

Fees for extra services or other additional care and services

Additional fees may apply if you choose a higher standard of accommodation or additional services. Aged care homes with dedicated extra service places are now required to publish their extra service fees on the My Aged Care website, their own website and in other relevant materials they provide to prospective residents.

You can use the Residential Care Fee Estimator to get an idea of the costs of Residential Care given your financial situation: http://www.myagedcare.gov.au/fee-estimator/residential-care

If you believe you will face financial hardship in paying your aged care costs, you can ask to be considered for financial hardship assistance. If you apply for financial hardship assistance, the value of your assets will be taken into account as part of the application process.

Quality of care

Carers are often concerned about whether the residential aged care facility will provide good care for the resident.

In Australia, residential aged care homes are required to be accredited to receive Australian Government subsidies. The Australian Aged Care Quality Agency assesses each facility against a set of legislated Accreditation Standards. This involves periodic full audits, as well as unannounced visits to monitor continuing compliance with standards.

The main elements of the accreditation process are:

- Self-assessment by the home against the Accreditation Standards
- Submission of an application for re-accreditation (with or without the self-assessment)
• Assessment by a team of registered aged care quality assessors at a site audit
• A decision about the home’s accreditation by a decision-maker (not part of the assessment team)
• Issue of an accreditation certificate
• Publication of the decision on this website
• Unannounced visits to monitor homes’ on-going performance

Although the facility that you will be using may be accredited, you may still have concerns about specific aspects of the care that the resident is receiving. If this is the case you should first talk to staff within the facility to see if you can resolve the concern. If this is not possible, you can make a complaint to the Aged Care Complaints Scheme which will be investigated. They can be reached on 1800 550 552.

If you need assistance in making a complaint, there are free Aged Care Advocacy services in each State and Territory. Advocates can provide professional, confidential assistance free of charge. They can help you to understand your rights and responsibilities, make complaints, advocate for change or refer you to other appropriate agencies. The National Aged Care Advocacy Line is 1800 700 600.
Who to contact

Residential aged care

My Aged Care: 1800 200 422

My Aged Care provides information and advice about how to access aged care services, including residential aged care and costs. My Aged Care is now the key entry point to the Australian aged care system.

For further information please see: www.myagedcare.gov.au or phone: 1800 200 422

Aged Care Complaints Scheme 1800 550 552

If you have concerns about the care someone is receiving it is important you raise your concerns. This can be done by phone or through the Aged Care Complaints Scheme website: https://agedcarecomplaints.govspace.gov.au/concern-2/#.Vg4Xw_4cTIU

National Advocacy Service 1800 700 600

This free confidential service can provide assistance to people who wish to make a complaint about an aged care service.
Whether the person you are caring for is living at home, in hospital or in residential aged care, they will need quality care at the end of life. Palliative care is specialised care and support that recognises the unique needs of the person with a terminal condition, as well as their family members and carers.

**What is palliative care**

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 that are causing their death. For family members and carers, palliative care concentrates on providing emotional and practical support before and through the death of the person.

**Personal comfort measures**

Palliative care concentrates on providing comfort in an active way. The following areas are all likely to need careful thought and attention:

- Positioning to promote comfort
- Mouth care
- Difficulty in breathing
- Skin care
- Bowel management
- Mobilisation
- Personal support
- Pain Management

**Symptom management**

Managing symptoms will depend on the stage of the illness and any other conditions that the person may be experiencing. Some symptoms that occur for people with terminal dementia may also require difficult decisions to be made. The focus should be on the key palliative care questions: How useful is the treatment for the person with dementia? What choice would best promote the comfort of the person with dementia? What kind of care would the person with dementia want?

**Pain**

There is strong evidence that pain is often not recognised or appropriately managed in people with dementia. It is important that there is an ongoing and systematic approach to recording, assessing and managing pain.

**Nutrition and hydration**

A reduced desire to eat and difficulties with eating and swallowing are a normal part of the disease process and are often key indicators that the person is moving towards the end of their life. There is no evidence to show that artificial nutrition or hydration has any benefits towards prolonging life or providing a peaceful death for a person with terminal dementia.

**Antibiotics**

Decisions about antibiotics need to be taken in context and on an individual basis.
Who provides care

Care can be provided by a number of different health professionals including:

- General practitioners
- Specialist palliative care doctors and nurses
- Specialist doctors – oncologists, cardiologists, neurologists, respiratory physicians
- Nurses
- Allied health professionals – pharmacists, occupational therapists, physiotherapists
- Social workers
- Grief and bereavement counsellors
- Pastoral care workers

Planning palliative care

Palliative care in terminal dementia can be facilitated when both the person with dementia and their family members and friends have explored issues related to treatment and management in advance. It is also helpful to have discussions with health care staff about what support is available to assist with palliative care. For information about planning for the future and Advance Care Directives, please see the information in Section 2 of this guide.

Coping with end of life

When a person with dementia is dying or has died, their family members and friends often experience a range of feelings. You may grieve for the loss of that person, and for the relationship you once had. Even if you did not wish for the person to go on living with dementia you may still feel a sense of loss. Some people find that they have grieved so much during the course of the illness that they have no strong feelings left when the person dies. However these feelings may surface at a later time, sometimes quite unexpectedly.

If you would like to talk about your feelings or would like help coming to terms with your grief, you may find it useful to talk to a professional. For further information about counselling please phone the National Dementia Helpline on 1800 100 500, the Carer Advisory and Counselling Service on 1800 242 636 or see the contacts list below.
Who to contact

<table>
<thead>
<tr>
<th>Information and advice about palliative care</th>
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<tbody>
<tr>
<td><strong>Palliative Care Australia: 02 6232 4433</strong></td>
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<tr>
<td>For information about palliative care and services in your area please see: <a href="http://www.palliativecare.org.au">www.palliativecare.org.au</a></td>
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<td><strong>National Dementia Helpline: 1800 100 500</strong></td>
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<td>Alzheimer’s Australia runs this helpline and provides a range of services to support people with dementia and their families and friends, including telephone information and support, education and training programs, and a free counselling service. They can also put you in touch with local support groups. For further information please see: <a href="http://fightdementia.org.au">fightdementia.org.au</a> or phone: <strong>1800 100 500</strong></td>
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</tr>
<tr>
<td><strong>Carers Australia: 1800 242 636</strong></td>
</tr>
<tr>
<td>Carers Australia provides specialist services including counselling. For further information please see: <a href="http://www.carersaustralia.com.au">www.carersaustralia.com.au</a> or phone: <strong>1800 242 636</strong></td>
</tr>
<tr>
<td><strong>Australian Counselling Association: 1300 784 333</strong></td>
</tr>
<tr>
<td>The ACA is a national association of qualified and registered counsellors and psychotherapists in Australia and has a Find a Counsellor service. For further information please see: <a href="http://www.theaca.net.au">www.theaca.net.au</a> or phone: <strong>1300 784 333</strong></td>
</tr>
<tr>
<td><strong>Australian Psychological Society: 1800 333 497</strong></td>
</tr>
<tr>
<td>The APS has a Find a Psychologist service (online, telephone and email referral) that allows you to find a qualified psychologist in your area. For further information please see: <a href="http://www.psychology.org.au">www.psychology.org.au</a> or phone: <strong>1800 333 497</strong></td>
</tr>
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Psychotherapy and Counselling Federation of Australia: 03 94863077

The Psychotherapy and Counselling Federation of Australia also has a Find a Therapist service.

For further information please see: www.pacfa.org.au or phone: 03 94863077

Lifeline Australia: 13 11 14

Lifeline Australia provides help to anyone experiencing a personal crisis, with online, phone and face-to-face crisis support and suicide prevention services.

For further information please see: www.lifeline.org.au or phone: 13 11 14
APPENDIX 1: USEFUL GUIDES AND FACTSHEETS

Diagnosis
For detailed information about the early signs of dementia and seeking help from a doctor, download the Worried About Your Memory? booklet from the Alzheimer’s Australia website on https://fightdementia.org.au/sites/default/files/WAYM-booklet.pdf or call the National Dementia Helpline on 1800 100 500 to order a copy.

Information for family and friends

Diagnosing dementia

Information on dementia specific to Aboriginal and Torres Strait Islander people

https://fightdementia.org.au/sites/default/files/helpsheets/Helpsheet-AboriginalAndTorresStraitIslanderPeople02-DiagnosingDementia_english.pdf

https://fightdementia.org.au/sites/default/files/helpsheets/Helpsheet-AboriginalAndTorresStraitIslanderPeople03-InformationForFamilyAndFriends_english.pdf

https://fightdementia.org.au/sites/default/files/helpsheets/Helpsheet-AboriginalAndTorresStraitIslanderPeople04-MemoryChanges_english.pdf

https://fightdementia.org.au/sites/default/files/helpsheets/Helpsheet-AboriginalAndTorresStraitIslanderPeople05-AlzheimersDisease_english.pdf

Information on dementia for people from CALD backgrounds
Many of Alzheimer’s Australia’s help sheets and resources have been translated into different languages. A good place to start is https://fightdementia.org.au/about-dementia-and-memory-loss/help-sheets (you can select the relevant language)

Planning for the future

Capacity and decision making

Superannuation and dementia

Driving and dementia

Working and dementia

Advance care planning
Alzheimer’s Australia, with support from J.O. & J.R. Wicking Trust and Bupa Care Services have developed a website that provides information
and advice about planning ahead for people with dementia and their family members:
www.start2talk.org.au

For information on advance care planning and contacts in your area please see:

**Support for living at home**

**Taking care of yourself**


**Information for people who are balancing work and caring**


**Next Steps**


**Taking a break**


**Making the most of respite care**


**Getting the most out of respite care: a guide for carers of people with dementia**


**Residential care**


**Residential Care Fee Estimator:**


**Aged Care Complaints Scheme:**

https://agedcarecomplaints.govspace.gov.au/concern-2/#.VhB5VP4cTIU

**Palliative care**


Visit the Alzheimer’s Australia website for comprehensive information about dementia, care information, education, training and other services offered by member organisations.

Or for information and advice contact the National Dementia Helpline on

1800 100 500

The National Dementia Helpline is an Australian Government funded initiative.