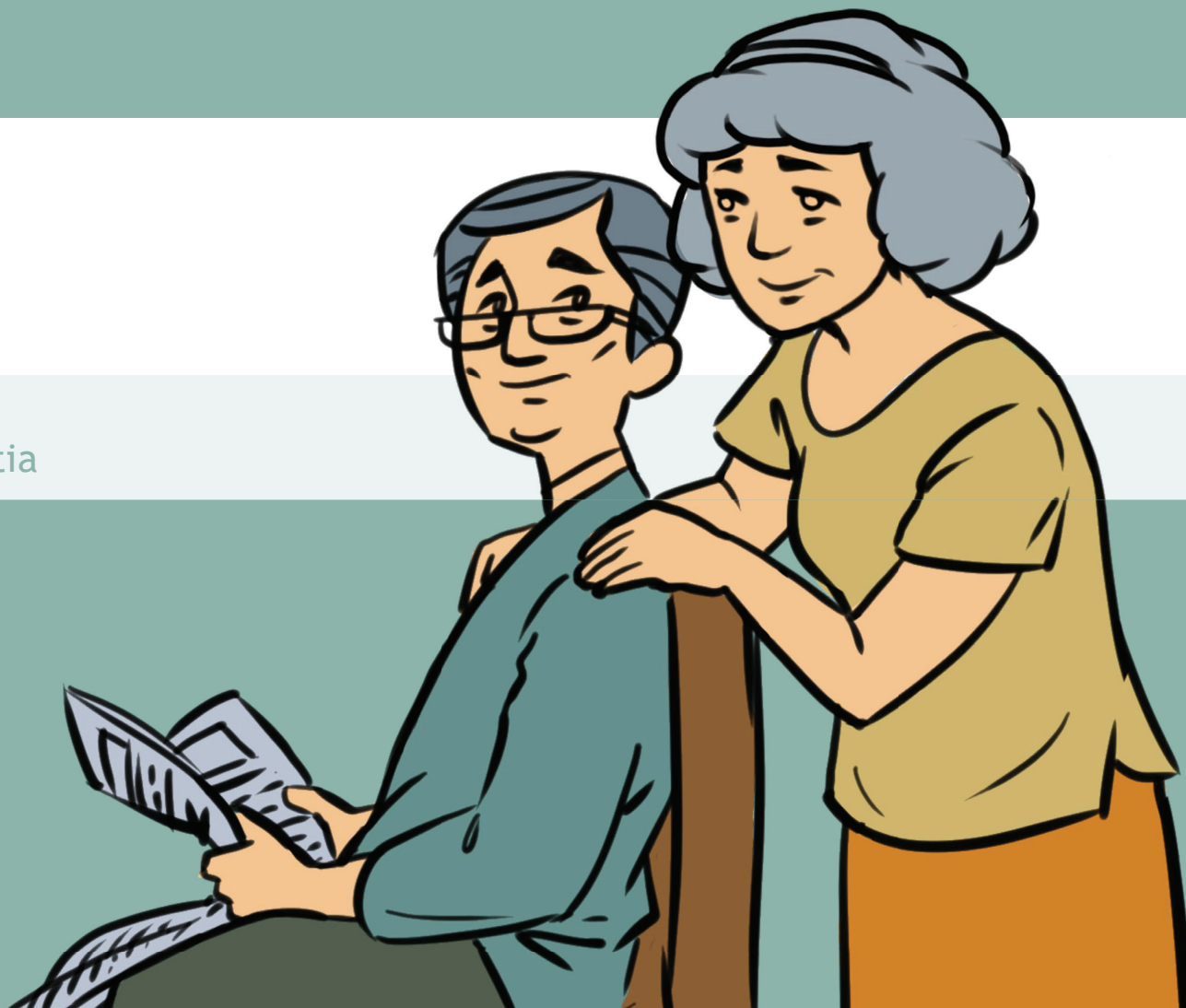


Australian version

iSupport For Dementia

Training and support manual
for carers of people with dementia



iSupport For Dementia

Training and support manual
for carers of people with dementia

Copied from the online iSupport for Dementia program www.iSupportForDementia.org, Version 1.0, World Health Organization, Copyright (2018). Adapted with permission of WHO. This programme has been adapted into the Australian social context and is not endorsed by the World Health Organization.

iSupport for dementia. Training and support manual for carers of people with dementia

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The World Health Organization (WHO) developed iSupport for Dementia, a comprehensive online dementia education and skill training programme for informal carers of people living with dementia [1]. This programme has been adapted into the Australian social context [2]. Flinders University funded the research activities leading to the current version of Australian iSupport for Dementia. The research team members who contributed to the adaptation of the WHO iSupport for Dementia programme and to the new learning module in the programme entitled 'My engagement in consumer directed care' are:

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MODULE

6

MY ENGAGEMENT IN CONSUMER-DIRECTED CARE

- Unit 1. Making informed choices in dementia care
- Unit 2. Services that are available for younger onset dementia
- Unit 3. Carer support
- Unit 4. Dementia Behaviour Management Advisory Service
- Unit 5. Home care packages
- Unit 6. Relinquishing the carer role

Unit 1. Making informed choices in dementia care

Why is this unit important?

On the completion of this learning unit, you will be familiar with services available for the person you care for and yourself or know how to make an inquiry about services. You will be able to make choice in dementia care.

How will this unit help me?

This learning unit will help you to understand that there are lots of services available that offer education and support for people with dementia like the person you care for, as well as for those who care for someone with dementia.

What will I learn?

- An overview of what services may be of interest for the person you care for
- An understanding of what Consumer Directed Care is
- Basic information of how you can select services so you and the person you care for remain in charge
- Where to go for more information.

Independent Living

Independent Living is designed to promote safe living and can assist you to make choices and find solutions to everyday problems so that you have some reassurance that the person you care for can continue to live in their home for as long as possible.

Guides to tasks and useful tips and solutions for issues an individual may encounter throughout their home are available.

There are many aids and equipment available to make living easier for both you and the person you care for, sometimes they are referred to as assistive equipment or technology - they are generally simple and easy to use.

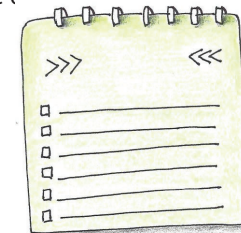
The **Independent Living Centre's Advisory Service** can assist in choosing relevant products and are situated in all states and territories. The national information line is available on 1300 885 886 (<https://ilcaustralia.org.au>)

- The government offer other services for carer support that may be an option. To find out these services, please contact the **Carer Gateway** www.carergateway.gov.au or call 1800 422 737 Monday to Friday, 8am to 6pm.

Dementia Australia early intervention program

Dementia Australia provides programs that offer information and support through small group-based activities with others in similar situations. It can be very valuable to listen and learn from others as well as share questions that you and the person you care for may have.

You can get more information on the Living with Dementia program by calling the National Dementia Helpline on 1800 100 500 or website www.dementia.org.au



Let's look at an Example

Maddie and Paul have been married for 30 years. Paul has recently been diagnosed with dementia. Maddie and Paul have lots of questions and concerns about the future. Paul until just recently ran his own business and was a problem solver. Now he is confused and unsure that he can get any pleasure from life. Maddie is worried that she may not be able to manage situations as Paul becomes more dependent. Both Maddie and Paul know they want to make the best of their time together and remain as independent as possible for as long as possible.

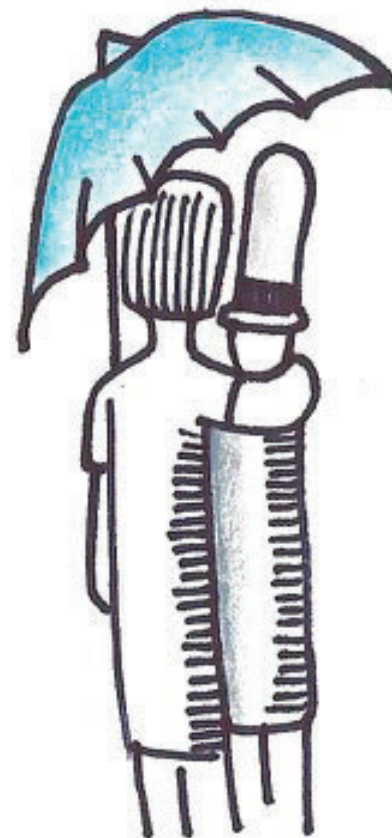
Check your understanding



What advice would be good for Maddie and Paul at this time? What would you think is the right response for Maddie and Paul?

Pick all the responses you think are appropriate.

- ☐ Go to the library and look up treating dementia.
- ☐ Start planning to move to a nursing home.
- ☐ Join the Dementia Australia 'Living with dementia' early intervention program to get information and support through sharing your experiences with a small group of others in a similar situation.
- ☐ Ask the local council and/or talk with MyAgedCare about what services they have to help people with dementia.



Check your understanding



- ✗ **Go to the library and look up treating dementia.**
While this response may provide information about dementia as a disease it will not assist Paul and Maddie to make practical plans for their future.
- ✗ **Start planning to move to a nursing home.**
This is not the best response. There are many ways that Paul and Maddie can be supported to stay independent in their own home and enjoy a full range of meaningful experience and activities. An aged care home (sometimes known as a nursing home) is for older people who can no longer live at home and need 24 hour ongoing help with everyday tasks or health care.

- ✓ **Join the Dementia Australia 'Living with dementia' early intervention program to get information and support through sharing your experiences with a small group of others in a similar situation.**
This is a good response. Dementia Australia states 'Research shows this type of program can reduce the sense of isolation, distress and depression and increase the self-esteem of people with or caring for someone with dementia, increase knowledge of local services and gain positive perceptions of dementia'.
- ✓ **Ask the local council and/or talk with MyAgedCare about what services they have to help people with dementia.**
This may be a useful suggestion. Many local councils offer services to support people in the local area. Whilst councils have a role, it is not their role to provide expert advice and support for dementia. Think about this choice when you and the person you care for have made a decision about your needs.

Engaging in meaningful activities

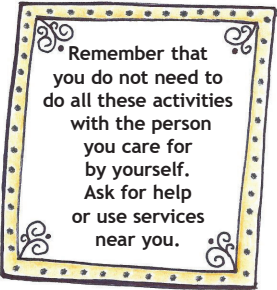
Keeping the person you care for interested and engaged in activities by focusing on what the person can do, even when the illness is quite advanced, is very important. Make sure the activities are of interest to the person and fit in with the person's preferences and abilities and the person you care for can cope with them physically. How much time you can devote to activities will depend on your personal circumstances.

Activities do not need to be complicated. In fact, some of the best ways of helping the person you care for remain active are to keep the person involved in the day-to-day tasks in and around the home.

Let's look at Maddie and Paul again

Maddie and Paul have been to some information sessions about living with and caring for someone with dementia. They have agreed that independence is very important for both of them and want to do things that will support this both now and in the future.

What advice would be good for Maddie and Paul at this time?



Check your understanding



What do you think is the right response for Maddie and Paul?

Pick all the responses you think are appropriate.

- ☐ Advise Maddie to get Foxtel connected so that Paul can watch the TV all day.
- ☐ Advise Maddie and Paul to make a list of everyday of activities so that they become a routine and structured part of the day.
- ☐ Advise Paul that he needs to join the local library so he can occupy his time by reading books.
- ☐ Advise Maddie and Paul to arrange for Paul to have coffee with his neighbour who has been his friend for many years.
- ☐ Advise Maddie and Paul to join a local community care social programs.

Check your understanding

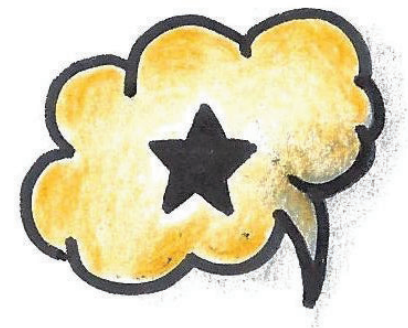


✗ **Advise Maddie to get Foxtel connected so that Paul can watch the TV all day.**

This is not a good response. While watching TV can be relaxing and enjoyable it is not something that is healthy to do all day. It also won't support Paul to maintain independence and may lead to boredom and behavioural problems. It will be more useful to look at activities around the home that encourages daily activities such as getting dressed and washed, setting the table, helping to do the dishes, simple gardening etc. Encouraging everyday activities for as long as possible will help the person hold on to skills and encourage independence. This will also allow the person to feel able to contribute and know that the help is valued.

✓ **Advise Maddie and Paul to make a list of everyday of activities so that they become a routine and structured part of the day.**

This is an excellent response. Keeping to a routine is very important: planning activities which can be part of a regular routine will help to structure the day. If the person living with dementia has always looked at the morning paper over breakfast continue this habit for as long as possible. Plan tasks and activities which you can do together, but also plan activities that the person you care for can do by the person as it will allow you some time to yourself.



Check your understanding (Continued)



✗

Advise Paul that he needs to join the local library so he can occupy his time by reading books.

This may not be the best response if it is not something Paul has always done or expressed an interest in doing. Introducing new activities must be carefully considered. Is it something the person living with dementia is able to do and enjoy? Is it safe for them to do? Consider how Paul would get to the library and could he do this by himself? Introducing new activities may be a cause of anxiety for the person living with dementia unless they enjoy the activity and are supported and guided in the activity.

✓

Advise Maddie and Paul to arrange for Paul to have coffee with his neighbour who has been his friend for many years.

This is a good response. Engaging family and friends in activities is a good way of providing variety in a day for the person living with dementia and also provides the carer with some time to themselves. Many friends and families are keen to know how they can help and is something that values the relationships Paul has developed. A regular meeting over coffee (or similar) is an excellent activity for everyone involved and can quite easily be organised to meet Paul's abilities.

✓

Advise Maddie and Paul to join a local community care social programs.

This is a good response. Local councils or ethnical communities have social programs that suit older people. Many of these programs can be tailored to promote peoples physical and emotional wellbeing and provide opportunities for people to build friendships, be confident and learn new skills. Local councils or ethnical communities can also provide information on other local services that are available.

Tip



Dementia Australia has a range of programs to support men and women living with dementia to engage in meaningful activities. The program may differ across regions and provides a safe environment to improve the quality of life. For more information call Dementia Australia on 1800 100 500 or visit the website (www.dementia.org.au).

Tip for respite care in an emergency



Emergency respite care

When emergency respite care is needed, call your local Commonwealth Respite and Carelink Centre on:

- 1800 052 222 during business hours
- 1800 059 059 outside business hours

Emergency respite care can be community-based or in an aged care home.



Respite care

Respite care is when the person you care for is looked after by someone else. Respite care is designed to give carers a break from their caring role and can be arranged for planned breaks, regular breaks or in an emergency. Respite can be from family or friends or from a formal respite care service and is provided for a short period time (<https://www.myagedcare.gov.au/>).

There are different types of formal respite care depending on your needs, eligibility and what services are available in the area:

- community based respite care
- residential respite care (short stays in aged care homes).

Government supported community-based respite care is on a needs assessment and can be provided in the home for a few hours, in a day centre that provides structured activities or overnight in a community home.

Access to community-based respite care requires an assessment with a Regional Assessment Service (RAS) and involves a series of questions about the needs of the person you care for. If you are assessed as eligible for respite services, then a support plan is determined. The support plan must take into account the needs and goals of the person you care for and you as the carer.

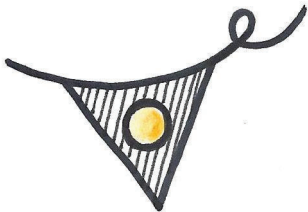
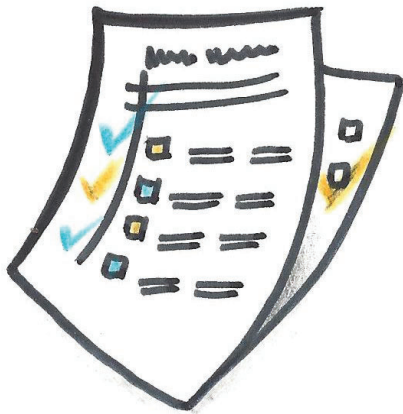
For more information call My Aged Care on 1800 200 422.

Respite Care

Let's look at an example for Maddie and Paul

Paul has been living with dementia now for over 3 years and Maddie has continued to provide for his care needs. Paul has a structured routine that he responds well to and is comfortable in familiar environments.

Maddie and Paul's daughter, Michelle, is expecting their first grandchild. Michelle lives in another state and, as her partner is away from home working quite often, Michelle has asked Maddie to help her once the baby is born. This would mean leaving Paul alone and Maddie does not think this is safe.



Check your understanding



What do you think is the right response for Maddie and Paul?

Pick all the responses you think are appropriate.

- ☐ Despite Maddie and Paul wanting to help their daughter, Maddie should tell Michelle she can't help her because she has to look after Paul.
- ☐ Maddie should go and take Paul with her.
- ☐ Maddie and Paul should see if respite services are offered in Paul's home as well as centre based/cottage respite that can provide him with the support he needs in a familiar environment whilst Maddie is away.

Check your understanding



What advice would be good for Maddie and Paul at this time?

- ✗ **Despite Maddie and Paul wanting to help their daughter, Maddie should tell Michelle she can't help her because she has to look after Paul.**

This is not the best response as it leaves Michelle with no help despite the family wanting to be there. It may make them all feel inadequate and unsupported.

- ✗ **Maddie should go and take Paul with her.**

This is not the best response. Paul is settled in his home and has structured routines in a familiar environment that make him feel safe and independent. Moving Paul from this may make him anxious and Maddie may not be able to give her daughter all the time she needs.

- ✓ **Maddie and Paul should see if respite services are offered in Paul's home as well as centre based/cottage respite that can provide him with the support he needs in a familiar environment whilst Maddie is away.**

This is the correct response. An assessment for respite services will consider what support Paul needs to remain safe and well. Maddie could also ask family and friends to help for a short time. Michelle will have her mother to support her after the birth of her first baby.

Let's review what you have learned

- Planned activities are an important part of living well with dementia.
- Activities and connection with other people with dementia will assist well-being.
- There are many types of activities that are simple to do and will help the person living with dementia maintain their confidence, skills and independence.
- Assistive technologies are available to make things easier for the person living with dementia.
- Maintaining or developing social networks is important for the well-being of the person with dementia and for the person caring for them.
- Dementia Australia has very useful information to support Australians who are living with dementia or for people providing care for people living with dementia.
- Local councils and respite services offer a range of services that can support independent living and social connectedness.
- Respite services are available if needed including in an emergency situation.

Where to go for more information

It's never too early or too late to talk about the care the person you care for needs or the support you need as a carer. Talking about getting some extra help doesn't mean you are not doing well in your role as a carer.

- **My Aged Care** www.myagedcare.gov.au phone 1800 200 422 will help you work out the steps you need to take.
- **Dementia Australia** delivers national dementia programs and services funded by the Commonwealth phone 1800 100 500
- **Independent Living Centres Australia** has information about products and services to help people remain independent and improve their quality of life. Call 1300 885 886.

RELATED LEARNING UNITS

- Module 1 Unit 1 Introduction to dementia
- Module 2 Unit 4 Involving others
- Module 3 Unit 3 Thinking differently



You finished this unit, well done!

Unit 2. Services that are available for younger onset dementia

Why is this unit important?

Younger onset dementia accounts for up to 8% of all dementia cases. A dementia diagnosis is difficult for anyone but comes with unique challenges when symptoms of dementia start before the age of 65. This learning unit will focus on some of the considerations and needs of people living with younger onset dementia.

How will this unit help me?

This learning unit will help you to understand specific matters for people with younger onset dementia and services that are available to offer education and support for people like the person you care for, as well as for those who care for someone with younger onset dementia.

What will I learn?

- An overview of what younger onset dementia is
- Basic information on considerations and services that may be suitable for the person you care for
- Where to go for more information.

What is Younger Onset dementia?

When symptoms of dementia start before the age of 65, we use the term younger onset dementia. Dementia is 'younger onset' when it affects people of working age, usually between 30 and 65 years old. It is also referred to as 'early onset' or 'working-age' dementia.

People with younger onset dementia are more likely to be diagnosed with rarer forms of dementia.

www.healthdirect.gov.au/younger-onset-dementia



Special Considerations

People with younger onset dementia are often still working at the time of diagnosis, are physically fit and may have children at home. It is likely that working and financial commitments are key matters that need to be worked through. A lot of social programs and services are designed for people with dementia are aimed at older people and people with younger onset dementia may not be of interest. But there are many services that could be helpful for a person with younger onset dementia that one might not even consider.



Working

Is the person you care for still working? Many people with younger onset dementia are still able to work after they have been diagnosed with dementia. the person you care for should talk to the person employer about modifying the person's job. For example, shorter days or a change in responsibilities. It is advisable that the person you care for discusses with their employer what to communicate to other staff so that everyone feels informed and supported. If the person you care for needs to stop working, ensure you get advice about employer benefits and leave entitlements.

Financial Considerations

A diagnosis of dementia at a younger age is likely to affect income and financial commitments. This is something that the person you care for and you as a carer need to discuss.

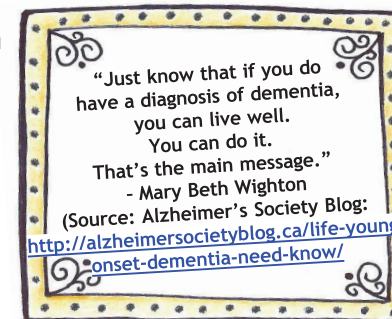
It is useful to think about how to effectively plan the financial future and deal with the financial losses incurred due to loss of income. Also consider what the person you care for and you as a carer may be entitled to from Centrelink -

www.humanservices.gov.au/individuals/centrelink . The person you care for should also consider getting information regarding access to superannuation benefits when they are no longer able to work.

Legal Considerations

It is important that the person you care for considers the legal implications of dementia. Younger people living with dementia may not have appointed a Power of Attorney, written a will or considered an Advance Care Directive.

In the early stages of dementia, it is still possible to attend to these matters and have their wishes considered.



Children

Does the person you care for have children that are still living at home? A diagnosis of dementia affects both the person and the entire family, this is even greater when the family includes younger people. Younger people may experience emotional trauma of their own when told a parent has younger onset dementia. For younger people this may include grief and loss and psychological distress. A 'whole family' approach is best considered, where the needs of younger people and their parents are respected and responded to appropriately. It is advisable that you and the person you care for seek the help of services trained in dementia assistance in approaching family matters.

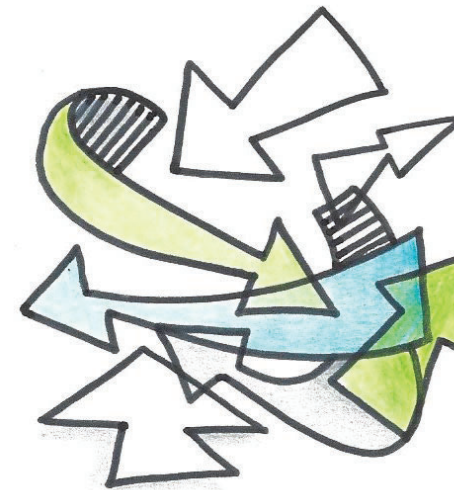
Maintaining a positive outlook

Many younger people with dementia and their family members speak of the importance of trying to maintain a positive outlook on life. Changed physical abilities and general health may mean that changes to lifestyle may need to be considered. Staying engaged in the community is extremely important for people with younger onset dementia.

Practical Help



Dementia Australia offers support, information and referral services and counselling. The National Dementia Helpline on 1800 100 500 can be contacted anywhere in Australia. Dementia Australia can put people with younger onset dementia, their carers and family in touch with support groups. The Dementia Australia website www.dementia.org.au also has a range of resources to assist people with younger onset dementia (www.dementia.org.au)



Let's look at an example

Ken is 57 years old and was diagnosed with dementia 3 years ago. It was a shock for Ken, his wife, Christine, and their 2 daughters who were living at home and still at school. At the time of his diagnosis, Ken was very confused and did not understand why he had been affected and at times became very angry. What advice do you think would have helped Ken when he was first diagnosed?



Check your understanding



What would you think is the right response for Ken?

Pick all the responses you think are appropriate.

- ☐ Ken should retire from work and join a dementia club for older Australians run through his local council.
- ☐ Start planning to move to a nursing home.
- ☐ Join the Dementia Australia 'Living with dementia' early intervention program to get information and support through sharing experiences with a small group of others in a similar situation.
- ☐ Ask the local council what services they have to help people with dementia.

Check your understanding



✗ **Ken should retire from work and join a dementia club for older Australians run through his local council.**
This is not a good response as it does not help Ken to understand and accept his diagnosis of early onset dementia and will not assist Ken and Christine to make practical plans for their future. Ken also probably needs help and support of other people living with younger onset dementia.

✗ **Start planning to move to a nursing home.**
This is not a good option. There are many ways that Ken and Christine can be supported to stay independent in their own home and enjoy a full range of meaningful experience and activities. An aged care home (sometimes known as a nursing home) is for older people who can no longer live at home and need 24 hour ongoing help with everyday tasks or health care.

✓ **Join the Dementia Australia 'Living with dementia' early intervention program to get information and support through sharing experiences with a small group of others in a similar situation.**

This is a good response. The detail of the program is available via:
<https://www.dementia.org.au/support/living-with-dementia>. The program helps reduce the sense of isolation, distress and depression and increase the self-esteem of people with or caring for someone with dementia, increase knowledge of local services and gain positive perceptions of dementia.

✓ **Ask the local council what services they have to help people with dementia.**

This may be a useful suggestion. Many local councils offer services to support people in the local area. Whilst councils have a role, it is not their role to provide expert advice and support about dementia. Think about this choice when you and the person you care for have made a decision about your needs.

Let's review what you have learned

- Planned activities are an important part of living well with dementia.
- Activities and connection with other people with dementia will assist well-being.
- There are many types of activities that are simple to do and will help the person living with dementia maintain their confidence, skills and independence.
- Assistive technologies are available to make things easier for the person living with dementia.
- Maintaining or developing social networks is important for the well-being of the person with dementia and for the person caring for them.
- Dementia Australia has very useful information to support Australians who are living with dementia or for people providing care for people living with dementia.
- Local councils offer a range of services that can support independent living and social connectedness.
- Respite services are available if needed including in an emergency situation.

Where to go for more information

It's never too early or too late to talk about the care the person needs or the support you need as a carer. Talking about getting some extra help doesn't mean you are not doing well in your role as a carer.

- **Dementia Australia** delivers national dementia programs and services funded by the Commonwealth phone 1800 100 500
- **Younger Onset Dementia Association Inc** provides a range of information for members <https://www.dementia.org.au/support/young-onset-dementia>

RELATED LEARNING UNITS

- Module 1 Unit 1 Introduction to dementia
- Module 2 Unit 4 Involving others
- Module 3 Unit 3 Thinking differently





You finished this unit, well done!

Unit 3. Carer Support

Why is this unit important?

Carers play a central role in caring for, and supporting, people like the person you care for who are living with dementia in Australia. Your involvement as a carer for the person you care for enhances the person's ability to access and engage with a range of services and live as independently as possible.

How will this unit help me?

This learning unit will summarise how your role as a carer is important to provide support to the person. The learning unit will provide you with some advice for caring for yourself and accessing support when you need it.

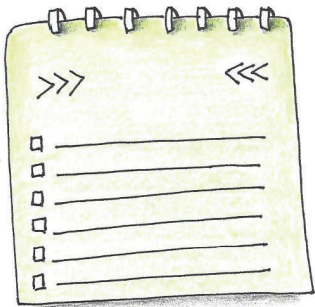
This learning unit provides:

- An overview of your legal rights and responsibilities
- Ways to ensure you look after yourself
- Services that are available to support you and the person you care for remain in charge
- Where to go for more information.

What is a carer?

A carer is anyone who looks after a friend or family member who can't cope alone due to illness or disability. You may not recognise yourself as a carer, but if you are helping someone you love to live a safe and healthy life at home then you are a carer. Being a carer is very rewarding, but it can also be demanding and sometimes it may be overwhelming.

To ensure you can provide the support and care that you want for the person you care for it is very important that you look after yourself including recognising that you may need some practical and emotional support. Please contact Dementia Australia (1800 100 500 or <https://www.dementia.org.au/> and/or Carers Australia (Phone: 1800 422 737 or www.carersaustralia.com) to find support that you want.



Legal considerations of being a carer

There are a number of legal and policy frameworks which recognise the important role of people in caring and supporting roles. The Australian Government has created an Act to increase recognition and awareness of carers. Most states and territories also have legislation that sets out your rights as a carer.

It's important to know your legal rights when you are an unpaid carer which include:

- being recognised by health providers as a contributor to the health of the person being cared for
- being heard and treated with respect
- using services to support the person you care for without discrimination
- being able to comment on services provided to the person being cared for
- acting in the best interests of the person being cared for.

Your involvement as a decision maker in aspects of the daily life of the person you care for will be dependent on [His/her] capacity to make decisions. You could be appointed as a nominee to discuss matters with Centrelink for example or be formally appointed as a Power of Attorney to manage the person you care for's financial affairs. Advance Care Directives can also ensure that the person with dementia has their wishes considered and you may be appointed by them as a Substitute Decision Maker when they no longer have a capacity to make decisions about medical and welfare matters concerning them. (www.carergateway.gov.au)

Let's look at an example

Antonio and Maria have been married for 40 years. Maria has always been happy to let Antonio manage their affairs. Antonio has recently been diagnosed as having the early signs and symptoms of dementia and they are now considering what they need to do to manage their affairs in the future.

What do you think is the best advice to give Antonio and Maria?

Check your understanding



What do you think are the right responses for Antonio and Maria?

- ☐ Maria must immediately start making all the decisions for Antonio in regards to his health care.
- ☐ Antonio and Maria should start managing their affairs together so that Antonio can show Maria what to do.
- ☐ Antonio should immediately stop managing their affairs and leave it to Maria.
- ☐ Antonio and Maria should seek advice about Advanced Care Directives and Enduring Powers of Attorney.

Check your understanding



- ✗ **Maria must immediately start making all the decisions for Antonio in regards to his health care.**

This is not a good response. Whilst Maria may have Antonio's best interests, Antonio is probably still able to make decisions for himself. Antonio and Maria should understand that as the disease progresses, Antonio's ability to make decisions will change. Maria will still need to offer options and give Antonio the chance to make decisions on his own, whether they are simple day to day decisions, or decisions about their future care and support. There may be a time when Maria will need to make decisions for Antonio, but with appropriate planning in the early stages of dementia Antonio should express his wishes for the future so the Maria knows how to best support him.

- ✓ **Antonio and Maria should start managing their affairs together so that Antonio can show Maria what to do.**

This is a good response as it provides both Maria and Antonio with the opportunity to ensure they can continue to successfully manage their affairs. It will provide assurance to Antonio that things will be looked after. It provides Maria with a chance to learn about managing their affairs while Antonio is still able to help her.

- ✗ **Antonio should immediately stop managing their affairs and leave it to Maria.**

This is not the best response. Living with dementia does not mean that you must immediately stop making decisions or managing affairs. However, it is wise that plans are discussed and made for the future when Antonio needs help to manage finances and legal matters.

- ✓ **Antonio and Maria should seek advice about Advanced Care Directives and Enduring Powers of Attorney.**

This is a good response as it will ensure arrangements are in place for when they may be needed. Advance Care Directives allow individuals to let others know what their wishes are if they are unable to make these decisions themselves and to know the wishes will be respected. Enduring Power of Attorney provides legal authorisation to act on behalf of someone in legal and financial matters after the person granting it loses capacity to manage their own affairs.

Supporting carers

Carers play an important role in dementia care. As a carer you may feel isolated or lonely because you are busy caring. Sharing your experiences with someone you trust - family, friends, neighbours, other carers or health workers - can help.

To help you in your role as a carer, you might consider:

- applying for Australian Government financial support, such as the Carer Payment and Carer Allowance
- respite care inside the home or outside
- asking other family members or friends of the person to help you on a regular or informal basis
- joining a local support group for carers.

There are also a wide range of services and organisations that can support you in your role as a carer for the person you care for. A great place to start for support and services is the Carer Gateway which is a national online and phone service that provides practical information and resources to support carers. You can contact them on free call: 1800 422 737 for support and advice Monday to Friday 8am to 6pm. (www.carergateway.gov.au)

Let's look at an example with Antonio and Maria.

It's now 5 years since Antonio was diagnosed with dementia. Maria is finding she needs to support Antonio with everyday activities more often than before. Maria feels like she has no time to herself and worries that Antonio may need more help than she can give him. Maria feels if she asks for help it may look like she is failing in her caring role.

Check your understanding



What do you think are the right responses for Maria?

- ☐ Tell Maria to just get on with it and look after Antonio.
- ☐ Tell Maria to get her son to leave his job and come back from living overseas to help her and Antonio.
- ☐ Tell Maria to call My Aged Care to get information about her role as a carer.
- ☐ Tell Maria to get a hobby to distract her from her caring role.
- ☐ Give Maria the number to call the Carer Gateway for further information about her role as a carer and what support is available to her and Antonio.

Check your understanding



- ✗ **Tell Maria to just get on with it and look after Antonio.**
This is not a good answer as it does not provide help for Maria and may make her feel more isolated and worried.
- ✗ **Tell Maria to get her son to leave his job and come back from living overseas to help her and Antonio.**
This is not a good response. It is not a practical option. Maria should, however, share her concerns with her son and they might look at options together to help Maria.
- ✓ **Tell Maria to call My Aged Care to get information about her role as a carer.**
This is a good response. My Aged Care provides a central place to get information about services available to help. My Aged Care will give Maria some contacts to call for further assessment or assistance and suggest some services that may help her.

- ✗ **Tell Maria to get a hobby to distract her from her caring role.**
This may help a little but it will only be suitable if Maria feels she has time to get a new hobby. Maria may benefit more from talking to people who are in the same situation as she is. Maria can get advice and talk with people about things they have in common and maybe even get tips to make her caring role easier.
- ✓ **Give Maria the number to call the Carer Gateway for further information about her role as a carer and what support is available to her and Antonio.**
This is a good response. The Carer Gateway will be able to give Maria the contact details of services in her local area. Maria will be able to share and talk to other people to support her or advise her about services she can access.



Where to go for more information

It's never too early or too late to talk about the care the person needs or the support you need as a carer. Talking about getting some extra help doesn't mean you are not doing well in your role as a carer.

My Aged Care www.myagedcare.gov.au phone 1800 200 422 will help you work out the steps you need to take.

A few of these useful contacts and resources that My Aged Care recommend are listed below.

- **Carer Gateway** 1800 422 737

A national online and phone service that provides practical information and resources to support carers.

- **Commonwealth Respite and Carelink Centres** 1800 052 222

These centres can help link carers to a wide range of aged care services to help at home and in the community.

- **Carers Australia** 1800 242 636

The peak national body representing carers. Carers Australia provides information, support, education, training and counselling.

- **Carer support groups** 1800 200 422

Carer support groups are sometimes organised around specific conditions. Call for information about these groups in your area.



- **Independent Living Centres** 1300 885 886

Resource centres that display a range of products and equipment to assist with day-to-day living activities. You and the person you care for can try out products on display and talk to the centre's occupational therapists. Staff at these centres are trained to match products and services to your requirements and can help you locate suppliers of special-needs equipment.

- **Young Carers** 1800 242 636

An initiative of Carers Australia, Young Carers provides information and support groups targeted specifically to the needs of young carers.

- **Dementia Australia** 1800 100 500

- **Dementia Support Australia** 1800 699 799

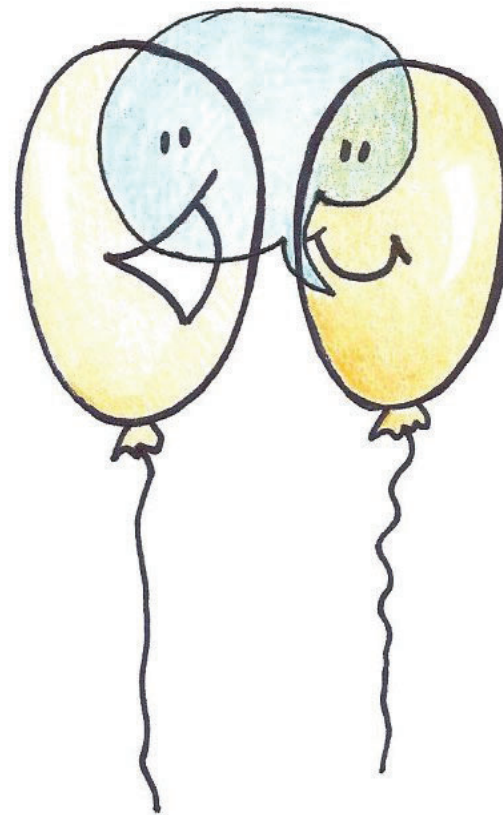
- **Dementia Behaviour Management Advisory Service (DBMAS)** 1800 699 799

Let's review what you have learned

- Being a carer is rewarding but can also be stressful at times - having someone to talk to and get advice is very important.
- As a carer you have legal rights and responsibilities.
- It is important to plan ahead so you understand what the person you care for wishes are for future care.
- There are a range of services to support you in your caring role.
- Maintaining or developing social networks is important for you as a carer.

RELATED LEARNING UNITS

- Module 1 Unit 1 Introduction to dementia
- Module 2 Unit 4 Involving others
- Module 3 Unit 3 Thinking differently





You finished this unit, well done!

Unit 4. Dementia Behaviour Management Advisory Service

Why is this unit important?

This learning unit will summarise what support is available if the person you care for has behaviours that have changed and you cannot manage them on your own.

How will this unit help me?

If you are concerned that the person you care for is experiencing behaviours that are not usual for them or they can't describe why they are behaving in a certain way or you are confused and perhaps even fearful of the behavior, then this learning unit will explain services available to help you and the person you care for.

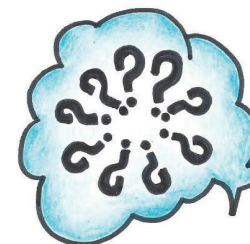
This learning unit provides:

- An overview of changes in behaviour
- Ways to ensure you look after yourself
- Services that are available to support you and the person you care for
- Where to go for more information.

What is a changed behaviour?

People with dementia, like the person you care for, can have changed behaviours. These behaviours affect them, but can also be difficult for carers, like you.

People living with dementia may find communicating their needs increasingly difficult. Changed behaviours can represent a form of communication as the person living with dementia tries to express what they are feeling. In Module 5 we discussed behaviour changes that may include aggression, depression, anxiety, delusions and hallucinations, suspicions, repetitive behaviour, sexual behaviour, wandering, restlessness and poor judgement. These behaviours are caused by damage to the brain and are not something your relative can control or prevent.

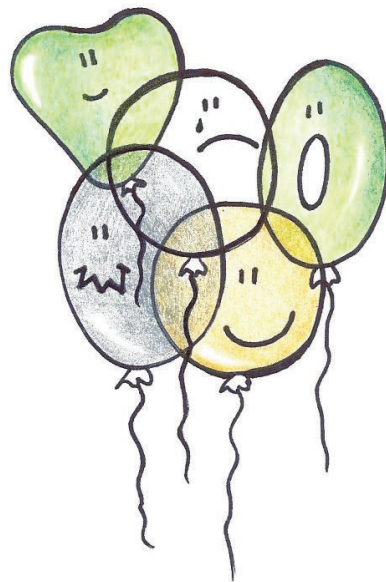


Tip

The key to managing changed behaviours is to accept them with compassion and a no blame attitude.

Support is available

If the person you care for is experiencing one or more of these behaviours or any other behaviours, you may feel caring for the person has become more difficult. This is a time when many carers will need help and support both for themselves and the person being cared for.

**Dementia Australia**

Dementia Australia is a national peak body for people, of all ages, living with all forms of dementia, their families and carers. Dementia Australia operates a helpline number 1800 100 500 from 9.00am to 5.00pm Monday to Friday (excluding public holidays) and a message service is available after hours to request a call back. The Dementia Australia web site also provides information and resources to support people living with dementia and their carers.

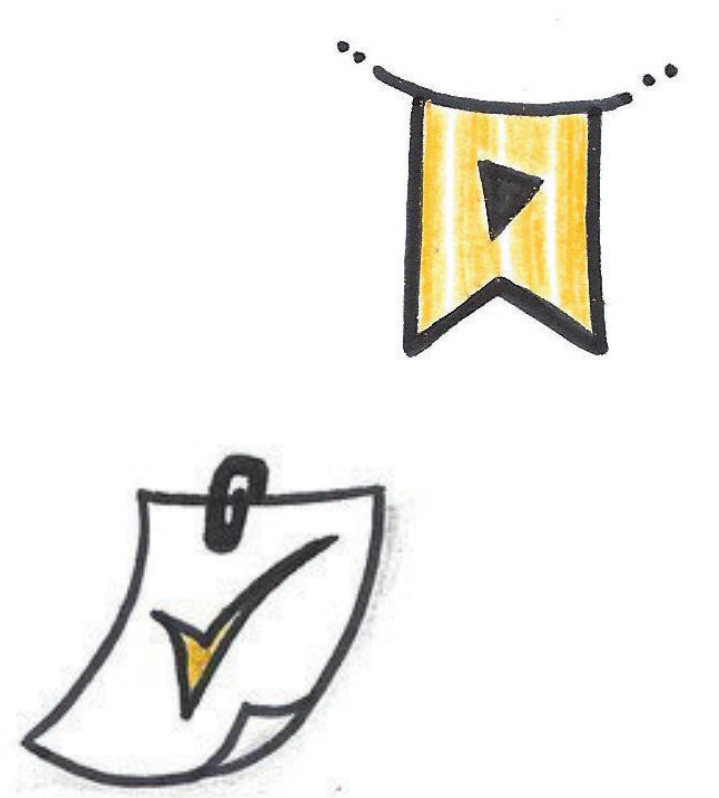
The website address is www.dementia.org.au and states they provide free confidential phone, email and support service for:

- information about dementia and memory loss
- information on how you may be able to reduce the risk of getting dementia
- information about government support services
- information about services in your area
- emotional support to help you manage the impact of dementia.

Lets do an exercise

Think about the services that Dementia Australia can support you with and answer True or False to the following questions.

Check your understanding	
<i>True or False?</i>	
<input type="checkbox"/>	I can talk to someone from Dementia Australia at anytime.
<input type="checkbox"/>	I can ask Dementia Australia for help with showering and dressing.
<input type="checkbox"/>	I can call Dementia Australia if I need some support about coping in my caring role.
<input type="checkbox"/>	I can call Dementia Australia to find out about services to help me.
<input type="checkbox"/>	The dementia help line is a free service.



Check your understanding



- ✗ **I can talk to someone from Dementia Australia at anytime.**
Dementia Australia operates a helpline number 1800 100 500 from 9.00am to 5.00pm Monday to Friday (excluding public holidays) you can ring after hours and leave a message, and someone will call you back the next day.
- ✗ **I can ask Dementia Australia for help with showering and dressing.**
Dementia Australia can provide you with information about services that might be useful for you, but they do not provide in home care services.
- ✓ • • **I can call Dementia Australia if I need some support about coping in my caring role.**
Dementia Australia provides a counselling service for people with dementia, their families and friends and have a range of fact sheets on common dementia topics that may help.
- ✓ **I can call Dementia Australia to find out about services to help me.**
Dementia Australia can provide information about services in your area.
- ✓ **The dementia help line is a free service.**
The dementia helpline is a free confidential support service. If you are calling from a mobile phone there may be a cost for the call.

(Dementia.org.au, 2018)



Support is Available (Continued)

Dementia Support Australia (DSA) provides the Dementia Behaviour Management Advisory Service (DBMAS). This is a free service supported by funding from the Australian Government. The helpline service operates 24 hours a day, every day of the year and can provide advice to assist you when needed. DBMAS can also assist with short term case management. This means trained staff may be able to provide you and the person you care for with advice based on your individual case. The Dementia Support Australia website has a range of resources and information to help you understand and respond better to behaviours. This includes tools that may help you to identify the triggers that can cause the changed behaviours the person you care for may have that cause you concern.

The contact details for Dementia Support Australia and DBMAS services is 1800 699 799 or website www.dementia.com.au.



Let's look at an example

Jill has been living with dementia following a series of strokes over the last 5 years. Jim, her husband, has been providing care for her at home and their daughter, Karen, helps as she is able. Jill has been experiencing changed behaviours and gets very anxious when Karen visits and Jill will not let Karen touch her. Last week Jill hit Karen as she tried to help her put a cardigan on. Karen and Jim are both very upset by these actions and don't know what to do.

What do you think would help Jill, Jim and Karen?

Check your understanding



What do you think would help Jill, Jim and Karen?

- ☐ Karen should stop visiting as it seems to upset everyone.
- ☐ Jim should tell Jill that her behaviour is wrong.
- ☐ Jim and Karen should get some advice from DBMAS.

Check your understanding



- ✗ **Karen should stop visiting as it seems to upset everyone.**

This is not a good response. Karen will not get to visit with her mother and father, and she will not be able to help Jim provide care for Jill. It is important to understand Jill cannot help how she is, and Karen and Jim should not take this personally or let it upset them. Instead, they should try to work out what may be the trigger for the behaviour, and they should recognise help is available to support them.
- ✗ **Jim should tell Jill that her behaviour is wrong.**

This is not the best response. Jill cannot help the behaviour, she is not doing it on purpose and trying to tell them that it is wrong, and blaming is not likely to help. Karen and Jim need to remain calm and see if there is a need that Jill is trying to express. If Jill is angry, it is best to give her some time and space.
- ✓ **Jim and Karen should get some advice from DBMAS.**

This is a good response. DBMAS can provide carers with information, advice and short term case management to help Jill and her family.



Let's review what you have learned

- There are a range of services to support you in your caring role.

Dementia Australia provides the national Dementia Helpline for anyone that needs help to understand dementia and services that can support you in your area.

- Dementia Services Australia provides the Dementia Behaviour Management Advisory Service (DBMAS). DBMAS can be contacted 24 hours a day, every day of the year.
- Maintaining or developing social networks is important for you as a carer.



RELATED LEARNING UNITS

- Module 1 Unit 3 Using memory aids in your care activities
- Module 5 Unit 2 Aggression
- Module 5 Unit 3 Changes in mood or interest
- Module 5 Unit 5 Delusions and hallucinations
- Module 1 Unit 4 How to respond to repetitive behaviour
- Module 5 Unit 6 Walking and getting lost
- Module 5 Unit 7 Changed judgement



You finished this unit, well done!

Unit 5. Home Care Packages

Why is this unit important?

The Australian Government provides a taxpayer funded subsidy towards a package of care that helps you as a carer and the person living with dementia to live at home for as long as possible. To use this service to benefit the person you care for and yourself you need to understand how it works.

How will this unit help me?

This Unit will summarise how Home Care Packages work and how you can utilise them to improve your role as a carer and provide support to the person you care for.

This learning unit provides:

- An overview of what Home Care is
- Australian government subsidy and eligibility
- An understanding of what Consumer Directed Care is
- Basic information of how you can select services so you and the person you care for remain in charge
- Your rights as a user of Home Care packages
- Where to go for more information.

What is a Home Care Package

The Home Care Package program is government subsidised and provides support for older people who want to stay living at home. There are four different levels of care according to the person's support needs. Each level receives a different amount of funding. This money can be used to buy hours of care and other support that suits your needs.

The four levels of support are:

- Home Care Level 1 - basic care needs
- Home Care Level 2 - low level care needs
- Home Care Level 3 - intermediate care needs
- Home Care Level 4 - high care needs.

Individuals approved for a Home Care Package are placed on a national queue until a package becomes available and is assigned to them.

(www.myagedcare.gov.au)

Let's look at an example

Mandy has been looking after her 86 year old mother, Barb, who has been living with dementia for over 8 years. Mandy now lives with her mother to provide the support she needs. Lately Mandy has been feeling like she has no time to herself, and Barb needs more and more help. Barb has recently been assigned a Home Care Package and Mandy wants to make the most of this for her mother and herself.

What advice would be good for Mandy and Barb?



The government offer other services for carer support that may be an option. To discuss particular needs, contact the Carer Gateway - www.carergateway.gov.au or call 1800 422 737 Monday to Friday, 8am to 6pm.

Tip

Check your understanding



What would you think is the right response for Mandy and Barb?

Pick all the responses you think are appropriate.

- ☐ Access the My Aged Care website and register for an assessment. Use the My Aged Care Researching Home Care Providers - Considerations and Checklist.
- ☐ Wait for a provider to contact Barb in relation to her Home Care Package.
- ☐ Determine the services Mandy and Barb may be interested in having as part of a Home Care Package to discuss with the service provider and ensure the services can be provided where and when Barb and Mandy decide they need them.
- ☐ Mandy should use her savings to cover the costs of services beyond the package budget provided.
- ☐ Use the services only offered by the service provider.
- ☐ Work with the selected service provider to identify care needs and enter into a Home Care Agreement.

Check your understanding



- ✓ **Access the My Aged Care website and register for an assessment. Use the My Aged Care Researching Home Care Providers - Considerations and Checklist.**
This is where arrangements for an assessment are made and a good start. The checklist provides a list of things to think about and to compare when selecting a provider once they have been assigned a home care package.
- ✗ **Wait for a provider to contact Barb in relation to her Home Care Package.**
It is the role of the person living with dementia or carer to make initial contact with a service provider. Service providers should not contact you.

- ✓ **Determine the services Mandy and Barb may be interested in having as part of a Home Care Package to discuss with the service provider and ensure the services can be provided where and when Barb and Mandy decide they need them.**
This is a good response as it means the services will be tailored to Barb and Mandy's needs. Remember - consider what is important and then find out if providers can meet special requirements.
- ✗ **Mandy should use her savings to cover the costs of services beyond the package budget provided..**
This is not the best response as Mandy may have been saving for something specific. Barb may need to contribute to the cost of her care if the needs are more than her budget allows. Mandy should first ask the provider to review the care plan with them to see if all the services are required. Mandy can also ask for Barbs needs to be reassessed by the Aged Care Assessment Team for a higher (or lower) level home care package or other support services.

Check your understanding (Continued)



- ✗ **Use the services only offered by the service provider.**
This may not be the correct response. Barb and Mandy must have a say in the types of care and services they receive as well as who delivers those services. Barb and Mandy should discuss their preferences with potential providers to understand how they can make that happen.

- ✓ **Work with the selected service provider to identify care needs and enter into a Home Care Agreement.**
This is correct. The Home Care Agreement is a legal agreement that details what your package will provide, who will provide the services and how much the services will cost including administration fees, as well as fees associated with ceasing service with a provider. It is important to remember that you and the provider are entering into a Home Care Agreement as equal partners.

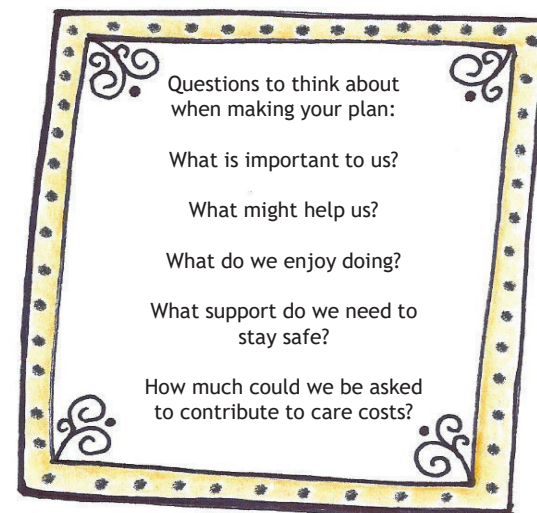


What things can a Home Care Package help with?

A care package can help support the person you care for and you to meet care needs. It can be good to have people help give the care that you may not be able to for whatever reason. Care needs are identified by a member of the Aged Care Assessment Team (ACAT) depending on your level of need. During the care planning process, the assessors will help determine what needs are not already being met by other supports.

Depending on the assessed care needs the types of services that may be useful include:

- Help with personal care such as bathing, showering, toileting, dressing and undressing
- Help with preparing some meals
- Help with equipment to manage care needs
- Nursing and other clinical services such as podiatry, occupational or physiotherapy services
- Transport and assistance with shopping, appointments and attending social activities
- General support such as washing, ironing and gardening
- Support to access meaningful therapy and activity related to dementia and support to undertake hobbies/interests
- Respite and time out for the carer.



Australian government subsidy and eligibility

Funding for home care packages are through the government and you need to contact My Aged Care services to start the process. The staff will ask you questions to help understand the person's care needs. The person you care for may also need to have a face-to-face assessment with a trained assessor. There is no cost for assessment, and it will help to determine eligibility to receive help at home services.

(www.myagedcare.gov.au)

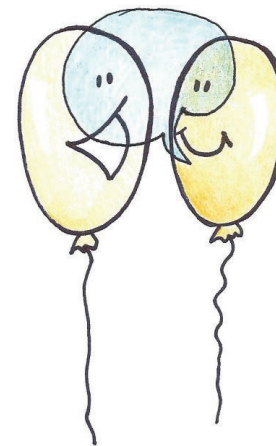
All people have to contribute to the cost of the home care package, including full pensioners. There is a means test, so some people have to contribute higher levels than others. This is assessed by Centrelink. If you are thinking about a Home Care Package for the person you care for, you first need to have their income assessed, as there may be a contribution they need to pay toward the care they receive. This fee is different for everyone because it is based on individual income.

You should do this as soon as possible. You can ask for an assessment before you start receiving care. Refer to the income assessment for home care packages area on the My Aged Care website for further information.

(www.myagedcare.gov.au)

Home care packages are made up of a budget that includes:

- The government subsidy (and eligible supplements)
- An income-tested care fee depending on the assessable income of the person with dementia
- Any other amount you have agreed to pay.



Knowing how much each service costs and what type of services you can receive lets you get the most out of your package. Ask the provider for the itemised cost of each service and be clear about the administration costs.

Tip

Once a package has been approved

Once there is approval you move to the national wait list. At a later date when it is your turn to receive a package you will receive a letter from My Aged Care indicating your package has been assigned. You should move immediately to enter into arrangements with a provider as the offer is time limited. It is up to you and the person you care for how you make the package work. Someone may choose to manage their services, choose to ask a Service Advisor to undertake these tasks on their behalf, or you may be provided with a list of possible service providers.

Use the questions and check list below to help you think about what services you may need and make sure you get the right provider:

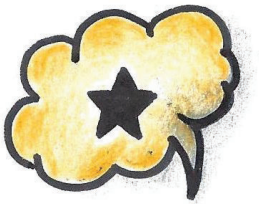
- Are Packages flexible and enable choice and control in the way they are provided? (see Consumer Directed Care)
- Are packages offered as coordinated support as well as direct services?
- How will I receive individual budgets and monthly statements ?

Activity



Tick the services you may want to ask about:

- ☐ General household cleaning
- ☐ Spring cleaning
- ☐ Personal care
- ☐ Meal preparation
- ☐ Meal delivery service
- ☐ Laundry service
- ☐ Assistance with shopping
- ☐ Transport services
- ☐ Social support
- ☐ Minor maintenance
- ☐ Minor renovations such as handrails, ramps
- ☐ Equipment.



An understanding of what Consumer Directed Care is

Consumer Directed Care is a term used to explain a way of providing services that allows you and the person you care for to make choices about the types of services and who will provide them. Under the Consumer Directed Care approach, you can shop around for the types of services you need and want, and choose who you want to provide those services. You can get the best price and make your funding go further.

How to use Consumer Directed Care to benefit the person you care for

Think outside the box when you are thinking about what would be the most useful for you and the person you care for. Consider some of the things you have looked at in this program that will support the person you care for. Maybe someone to help with a hobby or go for a walk. Maybe help with showering and dressing. Remember different people may be supporting you for different purposes, so the important thing is to consider what the person you care for wants or needs.



Let's look at an example.

Annie and Bob have been married for 37 years. Bob has had dementia for 3 years and recently had to spend some time in hospital for an infection. Up until recently Bob had managed to keep himself fairly well occupied if Annie made suggestions for things for him to do. Since he has come home, Bob seems very fragile and not interested in the things he used to do. He has trouble walking and just sits in his chair most of the day. Annie is worried about him and thinks he needs some company and things to do but she doesn't feel she can be there all the time. They have not yet had applied for a Home Care Package. What advice is best for Bob and Annie? What advice would you give to them?

Check your understanding



What advice is best for Bob and Annie?

You can pick more than one response.

- ☐ Annie should not worry and just let Bob be.
- ☐ Annie should consider options for a Home Care Package to provide support for Bob.
- ☐ Annie should wait and see if things get better.
- ☐ As soon as possible contact My Aged Care to find out about the support services that are available to help.

Check your understanding



✗ **Annie should not worry and just let Bob be.**

This is not a good answer as it does not provide help for Bob and may make him feel isolated and depressed.

✓ **Annie should consider options for a Home Care Package to provide support for Bob.**

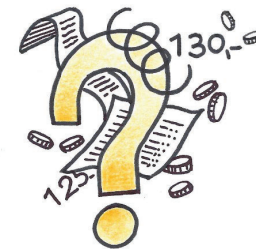
This is a good answer as it means Annie can get some support for Bob. It is good to start the aged care assessment process to support independence and get more help as she and Bob need it.

✗ **Annie should wait and see if things get better.**

This is not a good response. There are a number of steps that are needed to receive a Home Care Package and this takes time. In addition, once Bob has been assessed as eligible, he will be placed in a national priority queue for Home Care Packages and will be contacted when a suitable package becomes available.

✓ **As soon as possible contact My Aged Care to find out about the support services that are available to help.**

This is a good response. My Aged Care provides a central registration function and initial screening of people seeking government funded services. If the initial phone call determines there are care needs, the My Aged Care contact centre will refer you for a further assessment undertaken by your local Aged Care Assessment Team (ACAT) to determine the type of care needed and the level of Home Care Package required.



How to remain in charge

Once a provider is selected from the Approved Provider list they will receive and manage your Home Care Package.
The Home Care Agreement you sign with a provider will outline how to go about planning for services. The control over the funding use remains with the individual who it was provided to.

Activity



Use the tick box to ensure that you and the person you care for have agreed with the Service Provider:

- ☐ Choice in the care and services, how they are delivered and who delivers them
- ☐ Goals have been set
- ☐ The individual care plan is understood
- ☐ Involvement in managing the care package
- ☐ How the package is funded
- ☐ Monitoring and formal reviews.

Keep in mind



Note the Home Care Agreement you sign with a provider will outline how to go about planning for services. Also, under the legislation there are some exclusions, and it is important to not overstate expectations here.



If needs cannot be met within the Home Care Package budget, look at other options, including:

- being reassessed for eligibility for a higher level of package.
- if you can afford using your own money to purchase top up services.

If the person you care for's or your circumstances change the home care provider can change the care plan to suit your needs at anytime.

Tip

Knowing More: Your rights as a user of a Home Care Package

www.myagedcare.gov.au

The government has determined that older Australians have a right to be looked after properly, treated well and given high-quality care and services.

Service users must follow:

▫The Charter of Care Recipients' Rights and Responsibilities for Home Care (The Charter)

The Charter outlines consumers rights when receiving care, including the right to:

- be treated with respect
- be involved in deciding what care meets your needs
- have a written agreement covering everything you and your service provider have agreed to
- have your care and services reviewed
- privacy and confidentiality of your personal information
- be given information on how to make comments and/or complaints about your care and services
- have your fees determined in a way that is transparent, accessible and fair
- be given a copy of the Charter.

Consumer (user) responsibilities

The Charter also outlines your responsibilities when receiving care. This means you need to:

- respect the rights of care workers
- give enough information to the service provider so they can develop and deliver your care plan
- follow the terms and conditions of your written agreement
- allow safe and reasonable access for care workers at the times agreed in your care plan
- pay any fees outlined in your written agreement.

Home Care Standards

Under the Home Care Standards, service providers need to:

- give you information about your services
- speak with you about any changes to these services
- respect your privacy and dignity
- handle your concerns or complaints fairly and confidentially.

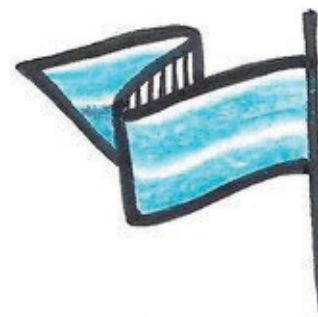
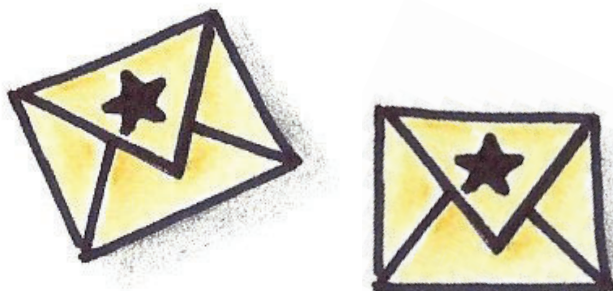
Where to go for more information

It's never too early or too late to talk about the care the person needs or the support you need as a carer. Talking about getting some extra help doesn't mean you are not doing well as a carer.

My Aged Care www.myagedcare.gov.au phone 1800 200 422 will help you work out the steps you need to take.

RELATED LEARNING UNITS

- Module 1 Unit 1 Introduction to dementia
- Module 2 Unit 4 Involving others
- Module 3 Unit 3 Thinking differently



If you or the person you provide care for are concerned about the care or services, it is important that you discuss this with the service provider.

If, after this discussion, you do not believe the service provider is meeting their obligations for the Home Care Package you may want to contact the

- National Aged Care Advocacy

Program, www.opan.com.au or by calling 1800 700 600.

- Aged Care Complaints

Commissioner, www.agedcarecomplaints.gov.au or by calling 1800 550 552

Tip



You finished this unit, well done!

Unit 6. Activities and services to help carers relinquish their carer role

It is best for the carer if they start planning and putting things in place for themselves before giving up the caring role.

Why is this unit important?

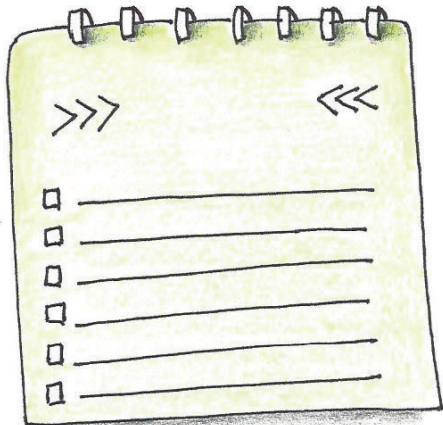
This Unit will summarise some of the emotions and feelings you may have if you can no longer provide some of the care that is needed for the person you care for. The Unit will outline activities and services that are available for carers to help when they have to give up or change their role as the carer.

How will this unit help me?

As a carer you have given a lot of time and emotion to care for the person. Your role as a carer may change as a result of circumstances and choices that have been made. This may be because the person you care for requires 24 hour care in a residential care facility, because of their death, or some of the care is provided by others. Whatever the reason for the change in your circumstances, it does not mean the end of the impact of caring. A sense of loss may be experienced, and it is normal that you will need to think about your own wellbeing and future.

This learning unit provides:

- What some of the feelings you may experience are
- Ways to ensure you look after yourself
- Services that are available to support you
- Where to go for more information.



Change in caring

Taking care of the person living with dementia has probably been your main focus for some time and now those responsibilities have changed or lessened, and you may be feeling a bit lost. Your daily routines have now changed, and you may feel a lack of purpose in your day. Now that you are not caring for the person it may be lonely. You may also feel relieved that the pressure has been taken away from you. This is very normal as caring for the person has been a big part of your life and you may have a lot of mixed feelings.

Support is available

It is helpful to talk about your feelings with someone. Family and friends are an obvious start, but for some people counselling and support services may better meet your individual needs.

If you feel so lost and like you are not managing, get help.

Lifeline

Lifeline is a national charity that can provide telephone counselling for people in a crisis situation. Any information you provide is confidential.

Lifeline can be contacted 24 hours a day, every day of the year on free call 13 11 14.

(lifeline.org.au)

Carers Australia

Carers Australia is the national peak body representing Australia's carers, and works with a network of state and territory Carers Associations.

Carer Australia can provide you with links to Carer Associations and supports in your area. Carers Australia offer counselling services provided by trained professionals.

For support services and advice call 1800 242 636 or visit website www.carersaustralia.com.au.

National Association for Loss and Grief Australia (NALAG)

The National Association for Loss and Grief Australia (NALAG) is a free service that can help you to work through issues such as loss, grief, bereavement and trauma. You can access NALAG's services by telephoning 02 6882 9222. Staff will register you over the phone and provide you with contact details of a centre or branch near you or access to the Grief Support Telephone Service.

Alternatively, you can access their website www.nalag.org.au.

Dementia Australia

Dementia Australia provide a range of resources to help carers understand their feelings and coping with loss. You can call Dementia Australia National Dementia Helpline 1800 100 500 or visit their website www.dementia.org.au.

Other sources

It may also be helpful for you to talk with your doctor or religious leader.

Everyone is different

Everyone responds to a change in or the end of their carer role differently.

Common reactions include feelings of:

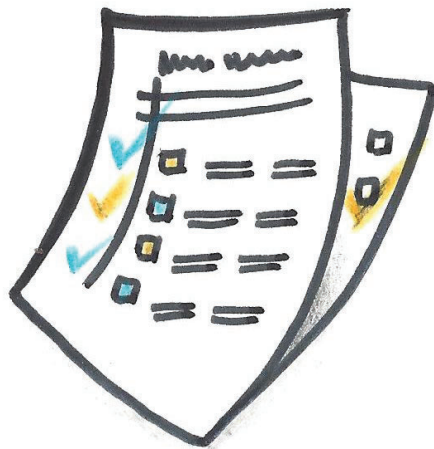
- sadness
- shock
- pain
- guilt
- relief
- resentment
- a loss of purpose.

Remember you have got to take care of yourself and get the support you need and deserve. If after a while you feel you're still not coping, you should talk to your doctor.

Let's look at an example.

With the support of the family and local doctor , Paul was admitted to an aged care facility. His wife, Maddie, had been caring for him at home but after a short illness Paul could no longer manage any of his own needs and Maddie was not strong enough to lift and help Paul move. The residential home is very nice, and Paul has settled really well, enjoying some of the different activities they are able to offer. Maddie tells their daughter she is physically and emotionally exhausted, but also feels lost now that she is no longer caring for Paul.

What advice would help Maddie?



Check your understanding



What advice would help Maddie?

You can choose more than one.

- ☐ Maddie must go on a holiday to get over her exhaustion.
- ☐ Maddie could talk to the staff at the residential aged care home to see how she can still contribute to Paul's care needs.
- ☐ Maddie should seek counselling to talk about her feelings.

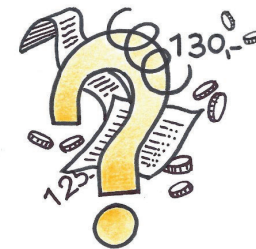
Check your understanding



- ✗ **Maddie must go on a holiday to get over her exhaustion.**
This may not be the best response at this time as Maddie needs some time to adjust. Maddie's feelings are quite normal, and it is probably best that she be encouraged to talk about them and have access to any support she may need. A holiday may be a good idea once Maddie is feeling more relaxed and better able to deal with the change.
- ✓ **Maddie could talk to the staff at the residential aged care home to see how she can still contribute to Paul's care needs.**
This is a good response. If Maddie still wants to help care for Paul, there are many things she can do. It is important to discuss this with the staff so that Maddie's role in caring can be planned and supported. For example, Maddie may want to help Paul with his lunch time meal or take him for short walks in the garden in the afternoons. Maddie will still feel involved and it will also help Paul.

- ✓ **Maddie should seek counselling to talk about her feelings.**

This may be a good response if Maddie still feels emotionally and physically exhausted after a few weeks. It is best Maddie be encouraged to talk to her friends and family about her feelings which are perfectly normal. It is a good idea to get professional help when the feelings start to overwhelm a person and affect their wellbeing.



Let's review what you have learned

- It may take some time to adjust to not having a caring role.
- It is normal to feel emotional for a little while.
- Take some time for yourself just to do things you enjoy, such as reading, going for a walk or seeing family/friends.
- If you feel isolated after many years of caring, you may need to get some further support.



Where to go for more information

Professional support for carers during their caring role and when it has changed can be found at:

- **Lifeline**
For people in a crisis situation. Lifeline can be contacted 24 hours a day, every day of the year on free call 13 11 14.
- **Carers Australia**
Carers Australia can provide you with links to Carer Associations supports in your area. Carers Australia offer counselling services provided by trained professionals. Call 1800 242 636.
- **Dementia Australia**
Dementia Australia provide a range of resources to help carers understand their feelings and coping with loss. You can call the Dementia Australia Helpline on 1800 100 500.



You finished this unit, well done!

Worldwide, carers of people with dementia should have access to information and support in order to effectively respond to, and manage, the physical, mental and social demands associated with caring for someone living with dementia. This iSupport manual has been developed to provide accessible, evidence-based training and information, tailored to carers' needs. It aims to improve knowledge and caregiving skills, such as carers' ability to cope with dementia symptoms and care for themselves.



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