

Australian version

iSupport For Dementia

Training and support manual
for carers of people with dementia



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.

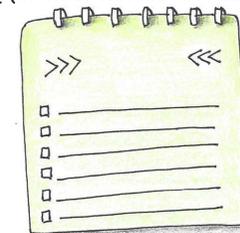
The **Independent Living Centre's Advisory Service** can assist in choosing relevant products and are situated in all states and territories. The national information line is available on 1300 885 886 (<https://ilcaustralia.org.au>)

- 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

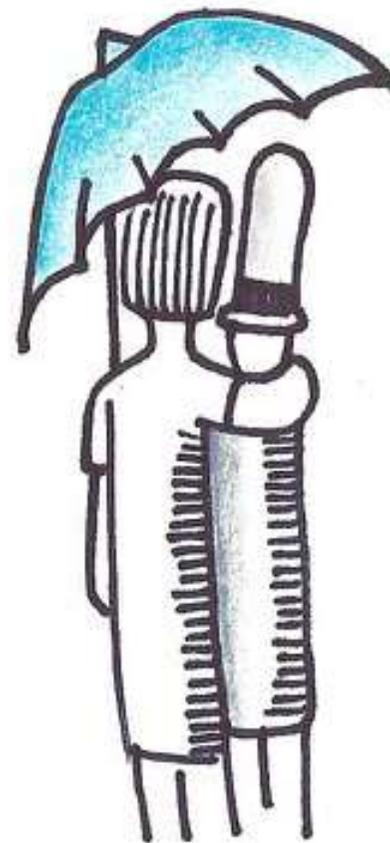
Maddie and Paul have been married for 30 years. Paul has recently been diagnosed with dementia. Maddie and Paul have lots of questions and concerns about the future. Paul until just recently ran his own business and was a problem solver. Now he is confused and unsure that he can get any pleasure from 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.

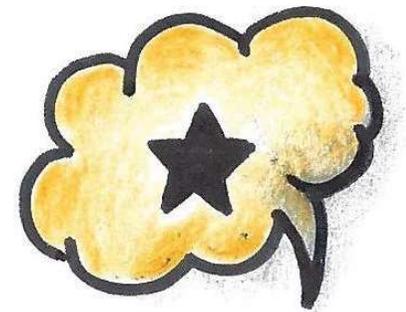
- Advise Maddie to get Foxtel connected so that Paul can watch the TV all day.
- Advise Maddie and Paul to make a list of everyday of activities so that they become a routine and structured part of the day.
- Advise Paul that he needs to join the local library so he can occupy his time by reading books.
- 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!