

Australian version

iSupport For Dementia

Training and support manual
for carers of people with dementia



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.

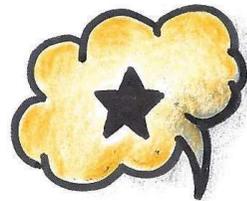
People with younger onset dementia are more likely to be diagnosed with rarer forms of dementia.

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

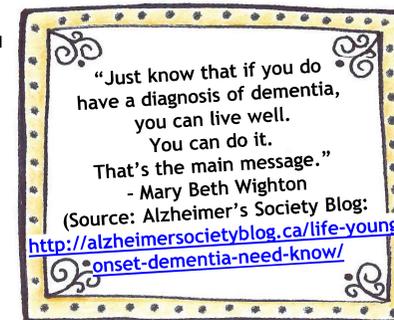
A diagnosis of dementia at a younger age is likely to affect income and financial commitments. This is something that the person you care for and you as a carer need to discuss.

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.

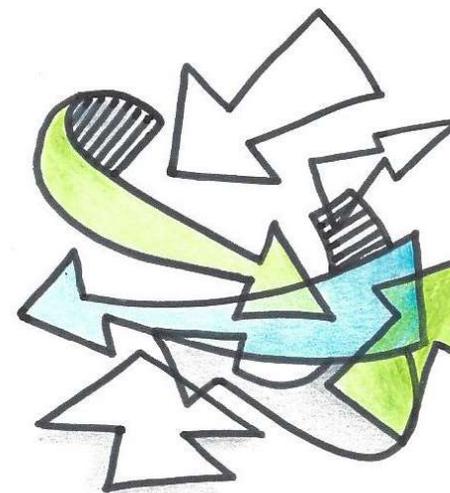
Maintaining a positive outlook

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!