Looking after families and carers

Taking care of yourself

This Help Sheet discusses the importance of families and carers looking after themselves while they are caring for someone with dementia. It discusses some ways to manage stress and to ensure that support is there so that you can continue in your caring role.

The physical and emotional demands of caring for someone with dementia can be high. As the amount of care needed increases, more time and energy will be needed from you. It is important that you take care of yourself or these demands will wear you down.

If you are worn down, caring will become even more difficult and it will not be easy to continue balancing your needs with those of your family and the person with dementia. You need support and assistance to care for someone with dementia.

Remember

You are not alone

There are a large number of carer support groups throughout Australia. Many people find comfort and practical assistance by attending these meetings with others who know what it is like to care for a person with dementia. Support groups bring together families, carers and friends of people with dementia under the guidance of a group facilitator. The facilitator is usually a health professional or someone with first-hand experience of caring for a person with dementia. Contact the National Dementia Helpine for further information.

Managing stress

Everyone has different ways to manage stress. Managing stress improves your well-being and may positively impact on your caring role, so it can be useful to learn some better ways to deal with it. The Dementia Australia library can assist you in selecting appropriate material on different ways to manage stress. Browse the catalogue online dementialibrary.org.au and contact the nearest library to ask about borrowing and other library services, or call the National Dementia Helpline on 1800 100 500.

What to try

- A consistent schedule can make life a little easier when living with a person with dementia
- It often helps to remember that the person with dementia is not being difficult on purpose, but that their emotions and behaviours are affected by dementia
- Learning as much as possible about dementia and encouraging friends and relatives to do so as well can be helpful
- It is important to talk things over with family, friends and other people in a similar situation
- Look after yourself by looking after your diet, get regular exercise and maintain your social contacts and lifestyle
- Be realistic about what you can expect of yourself, and recognise that taking care of yourself is better for everybody

Getting out and about

It is very important to continue with activities that you enjoy. Some people say that they feel guilty when they leave the house, or enjoy an activity without the person with dementia. However families and carers have the right to follow their own interests outside their caring role. In fact, it is essential that they do. Someone who has regular breaks will be a better carer.

If you are having trouble coping with feelings of guilt about getting out and about, it may be a good idea to talk these feelings over with a supportive friend or relative, or a counsellor at Dementia Australia.

National Dementia Helpline 1800 100 500
dementia.org.au

This help sheet is funded by the Australian Government
Asking for help

Taking care of yourself means asking for assistance now, as well as planning ahead for what help you may need in the future. Help often, but not always, comes from relatives, friends and neighbours. Seeking outside help is important for people. Doctors, psychologists and counsellors all have experience helping people who are caring for others.

What to try

• Make it an aim to share the care of the person with dementia
• Don’t hesitate to ask for help
• Suggest specific ways that friends and family can help, such as bringing a meal or helping with the housework or shopping
• Organise regular breaks for yourself. A friend or relative may be able to care for the person with dementia on a regular basis so that you can have a few free hours. Find out about respite options in your local area
• Use the services of Dementia Australia and other support organisations

Friends and relatives

Caring for someone with dementia can be made more difficult by a lack of understanding from other people. Helping friends and relatives understand what is happening will make your job easier.

What to try

• Provide information about dementia. Useful material is available from Dementia Australia, much of it in community languages as well as English
• Explain that outwardly a person with dementia may look fine, but that they have an illness, which although devastating, is not contagious
• Accept that some friends may drift away
• Ask visitors to come for short times and not too many at once
• Suggest activities for the visit such as going for a walk, bringing a simple project to do together or looking at a photo album
• Prepare visitors for any problems with communication, and suggest ways that they might deal with these

Who can help?

The Australian Government has established My Aged Care as a national online and phone service to help you find out about aged care services, and what services may be able to help you and how. By calling 1800 200 422 or visiting myagedcare.gov.au information is provided about types of services, how to access, and the costs. This also includes information about whether you require an assessment to access services either at home or in an aged care home, and what type of assessment and by whom.

Comprehensive assessments are completed by an Aged Care Assessment Team (ACAT or ACAS in Victoria) if you have more complex aged care needs and wish to access government funded services. Contact details for your nearest ACAT are available by calling 1800 200 422 or visiting myagedcare.gov.au.

If you are considering respite services start by calling your local Commonwealth Respite and CareLink Centre (CRCC) on 1800 052 222 who can provide information on respite services to suit you. CRCC can also assist with emergency respite and if needed outside business hours call 1800 059 059.

If you need help finding the right advice, services and support you can call the Carer Gateway on 1800 422 737 or view online information at carergateway.gov.au. Carer services in each state and territory are provided by Carers Australia, carersaustralia.com.au will link you to the service in your area or call 1800 242 636.

The Dementia Behaviour Management Advisory Service (DBMAS) is a national free 24 hour helpline service for clients living with dementia, family carers and health professionals which provides information and support regarding the behavioural and psychological changes caused by dementia. These changes can reduce the quality of life and can be distressing for both the person and the carer. Call 1800 699 799 or online at dbmas.org.au

FURTHER INFORMATION

Dementia Australia offers support, information, education and counselling. Contact the National Dementia Helpline on 1800 100 500, or visit our website at dementia.org.au

For language assistance phone the Translating and Interpreting Service on 131 450