

About this handout

This handout is aimed at the key supporters of a person who has been experiencing some difficulties with thinking and memory. Most carers or supporters are typically a spouse, partner, or adult child, though you may also be a close friend.

It covers:

- Adjustment to the changes in your relative or friend
- Common day-to daychallenges you may experience
- How you can help yourself
- When you should seek further help and support
- Some places to get information and support
- Information box: Tips for managing 'carer' stress.

Supporting someone

with thinking and memory difficulties

Adjusting to the changes in your relative or friend

As a close relative, it is likely that you were among the first to notice subtle thinking and memory difficulties in your relative or friend. You may have been worried for some time (sometimes several years) before discussing your concern with another relative and/ or other health professionals.

When a doctor confirms your suspicions that your relative is experiencing some 'real' memory and thinking difficulties, you may feel one or a combination of the following:

A sense of relief

You are not imagining things. You may feel happy to locate some new information on how to best help your relative manage their difficulties. You may be hopeful that some medical treatments might be available.

Confusion, worry and a loss of certainty

You may be wondering what the news means. Your doctor may have suggested that your relative is at an increased risk of developing dementia in the future, but can't be certain what will happen. You may feel very anxious and uncertain about what to expect. You may wish that the diagnosis was a bit clearer to help you and your relative plan your future.

Not 100% convinced

In some cases, you may feel that the doctor has exaggerated the problem or simply 'got it wrong'. You may think that stress, depression or illness is the 'real' reason for many of the difficulties that your relative or friend is experiencing.

A sense of sadness or loss

You may feel sad about the changes that your relative is experiencing. You may also be feeling sad about the way that your relationship with your relative is changing. For example, you don't seem to talk as much as you used to.

Guilt

You may feel guilty, particularly if you have been getting frustrated with your relative from time to time. You may also feel guilty and worry about how you will cope.

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Common day-to-day challenges

The nature of the concerns you experience will depend on the nature of your relative's memory and thinking difficulties. Some common stressors include:

Repetitive questioning or forgetfulness

You may find it frustrating if your relative is very forgetful. You may need to be the person who acts as the 'memory bank' for much of the time.

Indecisiveness

Your relative may be more indecisive and dependent on you to make decisions (e.g., about medical care). This may be upsetting and you may feel a little resentful about taking on this role; you may miss your relative's more independent style.

Increased defensiveness

Your relative may be very defensive about their difficulties. They might deny them or become angry if someone complains that they have a problem. You may be unsure about how to cope with this as you may worry that they will become depressed if they start acknowledging their problems.

Reduced initiation of activities

You may have noticed that your relative or friend no longer initiates housework, social activities or financial tasks the way they used to. You may find yourself prompting your relative or taking over some of their previous roles. You may worry that their difficulties will worsen further if they do not remain active.

Any pre-existing problems may make it even harder to cope with the new situation. These can include:

Multiple responsibilities and busy lifestyles

If you are already coping with other responsibilities — with work, children or partners — then dealing with newly emerging difficulties (often with a parent) can be especially hard. You may find it difficult to balance all the competing demands and you may find yourself becoming very stressed or anxious, with too much to do.

Pre-existing medical / physical problems

In some cases, either you or your relative may already be coping with other medical problems prior to developing difficulties with thinking or memory. These difficulties may already be stressful and difficult for you both to manage.

Relationship problems

Any relationship problem with your relative or friend that existed prior to the development of thinking and memory difficulties may make things very difficult. You may feel as if your relative is sometimes intentionally doing things to upset you. You may feel ambivalent about doing more things to help your relative or friend.

Conflict within the family

Sometimes there is disagreement within a family about how to best help the person with thinking and memory difficulties. This can be difficult for you, particularly when other family members or friends live a long way away and may not be aware of all the changes that have occured.

When you should seek help

It is important that professionals and community services are available to assist you to cope with the challenges of supporting your relative.

You should seek help if you:

- Find it difficult to think of ideas on how best to support your relative or to adjust to the changes in your lives
- Are feeling overwhelmed by the stressors in your life
- Feel very isolated and find it difficult to talk to friends or family about your relative's thinking and memory difficulties
- Experience very low mood (e.g., feeling unhappy, being irritable or having difficulty sleeping) or anxiety (e.g., constant worrying and having difficulty relaxing) and not getting any better over time.

Several different types of professional may be able to help you. A useful first point of call is often your family doctor (GP) who can refer you to a range of services that may be of use. These could include:

- Support groups for people who, like you, are looking after someone with thinking and memory difficulties.
- Activity groups your relative may enjoy that are run in your local community. These could include council-run activities groups: Men's Shed groups, senior citizens' clubs and so forth. Participating in more activities may assist your relative to be more active and encourage you to take some time out.
- Seeing a psychologist, psychiatrist, counsellor or other mental health professional on a one-on-one basis may be of assistance.
- Educate other family members about the difficulties your relative is experiencing. Try to keep communication open and avoid conflict. Ask them for support and assistance.
- **Share** your concerns with friends in your local community clubs or church group.
- Try to be sensitive to your relative's feelings on this issue. If there are some people who your relative would be reluctant to tell about his/ her problems try to respect his/ her wishes. If necessary, seek out people who are not related to or involved with your relative.





Tips for managing 'carer' stress

Try to stay focused on a positive problem solving approach BUT don't set unrealistic expectations

- Don't be too hard on yourself if occasionally you get frustrated with your relative due to the changes caused by their thinking and memory difficulties. You are human. If you find yourself having outbursts or getting angry on a daily basis – seek help. Consider seeing a psychologist or counsellor or talk to a good friend.
- Don't expect to provide support for your relative all the time. Instead, remember that you need help too. It is important to take time out and to continue spending time with people who are supportive and positive in your life.

Learn to take time out and use relaxation techniques

- Both you and your relative need to take time out of your day to relax and think.
 For example, spend time in a garden.
- Consider taking up activities such as Yoga, Pilates or Tai chi, either together or separately.
- Consider learning some new relaxation techniques. You can read about them from books or CDs, attend some local classes or learn from a professional such as a psychologist.

Take care of yourself

- Get regular exercise, eat healthy food and maintain a healthy weight.
- Try to do more things that you enjoy (such as socialising, walking on the beach or playing music) and fewer of the things you don't.
- Seek out social support.



Further information and support

Dementia Australia

(www.dementia.org.au) provides support for people who have been diagnosed with dementia. It has also developed a set of information materials called "Your Brain Matters", designed to inform all Australians about ways to reduce their risk of developing dementia. It also runs support groups and information evenings for people and their relatives with mild thinking and memory difficulties (without a diagnosis of dementia).

Australian Psychological Society

(www.psychology.org.au) has developed some resources about coping with depression and anxiety. You can also find a psychologist by using its website.

Beyondblue

(www.beyondblue.org.au, phone: 1300 22 46 36) provides a range of support services and information for people, including older adults, suffering from depression, anxiety and related disorders. It also provides information about how to locate psychiatrists or other mental health practitioners such as psychologists to provide support.

Carers Australia

(www.carersaustralia.com.au, phone: 1800 242 646) aims to improve the lives of carers. It provides important services like counselling, advice, advocacy, education and training. It also promotes the recognition of carers to governments, businesses and the wider public.

Carers Gateway

(www.carersgateway.gov.au; phone 1800 422 737) is a government-funded organisation which provides practical support and advice, counseling and referral to other support services for carers.

My Aged Care

(www.myagedcare.gov.au; phone: 1800 200 422) is a starting point to access all Australian Government-funded aged care services. The phone line and website can help older Australians, their families and carers to get the help and support they need.











