

About you: Feelings and adjusting to change

This help sheet describes some of the feelings you might experience following a diagnosis, as you adjust to changes that living with dementia will bring. It also suggests ways to recognise your emotions and share your feelings.

Your feelings when first getting a diagnosis

It is normal to feel a range of emotions after a dementia diagnosis. It is important to recognise your emotions and acknowledge how you are feeling. This will help you adjust to your diagnosis.

You may feel shock, anger, fear, loss, sadness, disbelief, denial, anxiety, isolation, embarrassment, frustration or a sense of relief.

People often ask themselves “Why me?” and “What does this mean?” You may feel shocked or distressed for a time, as you adjust to the information and make sense of the implications. These feelings usually diminish in time, as you understand what dementia is and find ways to adjust.

Alternatively, some people are relieved to have an explanation for memory loss or other symptoms they have been noticing. They can move on with life, knowing the reason for their symptoms and understanding what they are dealing with.

There are ways to help find a balance between allowing yourself to experience the sadness and frustration you may feel, and supporting yourself to feel happiness and pleasure.

Common feelings when adjusting to change

You may feel angry about the impact dementia is having on you: anger about the illness, memory loss, physical abilities or increased dependence on others. It is also natural to feel afraid of what the future may look like, and worry about how you might cope.

Frustration

Frustration is probably the most common feeling expressed by people living with dementia. It can be extremely frustrating searching for something you've misplaced, or having difficulties either remembering something or participating in activities or tasks independently.

Loss and sadness

It is natural to feel sad or upset. Sadness can feel overwhelming on some days as you adjust to changes in your abilities, skills or level of independence.

Sadness that persists for a long time without easing may indicate depression. It is important to talk with your doctor or a counsellor about ways of treating this. Sometimes medication can help in this situation.

Embarrassment

It can be embarrassing to forget a familiar face or not be able to find the right word to express yourself. Also, you may feel a loss of self-confidence, especially in social settings. In turn, you may feel angry or frustrated.

Look after yourself

Everyone has their own way of expressing feelings. The important thing is to find ways to support yourself when you feel emotional.

Allow yourself to feel what you are feeling, no matter what it is. If you deny your feelings and hope they will go away, it tends to do the opposite, and make them stronger.

- **Talk to a trusted family member or friend.** Sharing feelings often helps to understand and reduce them.
- **Talk with a counsellor.** Free, confidential professional counselling support is available from Dementia Australia. Counselling can help you gain a better understanding of the impact of dementia and help you find ways to respond to your emotions.
- **Join a support group.** Meet with other people who are living with dementia, where you can share and discuss your feelings and experiences.
- **Cry.** Tears can be therapeutic because they release feel-good chemicals in the body.
- **Laugh.** Laughter also releases feel-good chemicals in the body, so finding opportunities to laugh can be empowering.
- **Keep a journal.** Some people find it helpful to record and express feelings privately. Writing stories down or making audio recordings of them can help to clarify and understand your feelings.
- **Enjoy activities.** Doing something you enjoy can be a big help if you are feeling down. Catch up with a friend or play a sport as much as you can.
- **Plan activities to express your feelings.** You could try music, aromatherapy, art, dance or gentle exercise.
- **Explore spirituality.** It is important to keep enjoying anything that gives meaning to your life or a sense of pleasure. This may be through religious activities, meditation, appreciating art, enjoying a sunset, walking along the beach, or spending time with family.

- **Let some things go.** There may be times when changes to memory and thinking really frustrate you. Consider if it is worth feeling frustrated and stressed. Try letting it go and focusing on something else.
- **Be kind and patient with yourself.** You are experiencing changes that are not your fault and are part of adjusting to living with dementia. You may need more time to do or remember things, so try to be patient with yourself.

Additional reading and resources

- Dementia Australia national library
Visit: dementia.org.au/library
- Dementia Australia support
Visit: dementia.org.au/support
- Dementia Australia education
Visit: dementia.org.au/education

Further information

Dementia Australia offers support, information, education and counselling.

National Dementia Helpline: 1800 100 500

For language assistance: 131 450

Visit our website: dementia.org.au