

Dementia and grief

When a loved one is diagnosed with dementia, it's common for caregivers to have feelings of loss and grief as their life is changed and the disease gradually takes hold. This is often called 'anticipatory grief' – it's normal and painful as you experience the inevitable decline and loss of the person you know and love.

Reactions which caregivers commonly experience include:

- **Disbelief and denial** – you might find yourself trying to normalise erratic behaviours or think they'll get better
- **Sadness** – at seeing the person lose their capabilities and independence, as well as sadness for your own loss of companionship and lifestyle
- **Anger, frustration and resentment** – both with the person and how the dementia has impacted your day to day life, your freedom and your planned future
- **Guilt and regrets** – about times when you are frustrated or lose your patience with the person or even have thoughts about everyone being better off if the person died
- **Confusion and conflict** – about trying to do all the caring yourself but knowing deep down it might be time to place the person in care because their needs are more than you can cope with
- **Isolation** – it can be hard to share how you really feel and you might find yourself putting on a brave face, not just for the person, but for family and friends as well, who try as they might, often don't understand just how hard it is to be in your shoes.
- **Helplessness** – having to watch the decline, the personality changes, the disorientation, the inability to hold a conversation, the lack of recognition of familiar faces – and know you can't do a thing about it.

 *Some days there won't be a song in your heart. Sing anyway.* 
Emory Austin

Looking after yourself can be easier said than done. Especially if you're tired, worn down and frightened for what the future will look like.

You need to face the truth that you are likely going through loss and grief – it's normal, it's not neat and easy, it's different for everyone and it's hard to know what it will be like from day to day – it's your unique story. You might be teary, you might be tough, you might be exhausted – it's all normal even though you might think this feels like you're not in control and going crazy.

Try to share your feelings with someone who understands – your doctor, a good friend, or contact an organisation like Dementia Australia which will know how to help you seek some support. They have specialist dementia knowledge, skills and experience in particular when it comes to the complex feelings of grief felt by loved ones, either before or after the person's death.

Speak up when friends ask if they can do anything to help – ask if they can sit with the person while you have your hair cut or allow yourself a treat like a massage or some quiet time in a coffee shop. It can be hard to ask friends to do some ironing, cook a meal or wash the car, but remember they want to feel good by helping you out.

Go easy on yourself – you're going through a tough time but remember going for a walk is like a tonic and so is remembering to eat something healthy each day and taking some 'me time' to restore your own energy. Writing in a journal is another helpful way to off load the weight of your feelings and your story.

 *You gain strength, courage, and confidence by every experience in which you really stop to look fear in the face. You must do the things which you think you cannot do.* 
Eleanor Roosevelt