Caring for someone with a life-limiting illness





Bereavement – caring doesn't stop when a life ends

Bereavement refers to the process of learning to live your life again without the person physically being in your life. They remain part of your life but in a different way. This will be different for each person. Grief doesn't end, it just changes over time.

You may feel a range of emotions when someone you care for dies. These can range from devastation at the loss, to relief that the person is no longer suffering, and everything in between. These are natural grief responses. This information has been developed in partnership with carers who have experienced loss. Here, they share their experiences and describe what helped them through their grief.

Emotions

- It's very overwhelming, no matter how prepared you are
- I felt a loss of purpose
- I felt so guilty when I wasn't there when she died
- My mental health was affected and I became depressed at times
- I felt very stressed and anxious

- I found it difficult when they took the equipment away and services stopped visiting
- I felt overwhelmed when in busy places such as shopping centres as I had been so physically isolated while caring
- Something you see or hear can trigger your emotions. Some music can do this.

Behaviours

- It was hard for me to step out of the house as I hadn't done this much when I was caring
- I became very forgetful
- I cried a lot
- Everything just stopped. I had no routine and I felt alone
- Re-establishing life can be hard. A big hole was left.

Other responses

- Friends may want to help but don't know how
- Friends or family may not want you to share your feelings with them, which is very difficult. Often they mention another person who is struggling instead
- Friends don't want to talk about it after a while. They don't bring it up as they don't want to upset you.

What helps

- I had a good friend to talk to and that really helped
- You need to talk about it. A good support group or network helps
- I found it helpful to write about my feelings of grief and loss
- Find a bereavement counsellor who you can talk to somewhere you don't have to pretend that you are ok
- Let others know what is helpful to you and what is not
- Let your emotions out physically. Scream into a pillow. Cry when you need to. Listen to music
- Find things you can focus your time on and make yourself go out and do them
- Try some sport. Do regular exercise like going for a run or walk
- Acknowledge feelings, don't ignore them.
- Do things that honour their life or remind you of them. Visit a special place, look at photos, watch videos, or create a memorial at home with photos or a plaque
- Read books about how other people experience loss and grief
- Sometimes it's ok to just stay in bed when you are feeling down
- In time, you will rediscover a new life.

"Death ends a life, not a relationship."

Mitch Albom Tuesdays with Morrie

Further support

- Your local Palliative Care Service Bereavement Counselling team
- Your GP who can refer you to local bereavement counselling services
- Carer Gateway 1800 422 737 or www.carergateway.gov.au
- **Griefline** free, telephone counselling services – 1300 845 745 or www.griefline.org.au
- NALAG free loss and grief support to those who are grieving – 02 6882 9222 or www.nalag.org.au/griefsupport
- Kids Helpline free telephone and online counselling service for young people aged 5 to 25 – 1800 551 800 or www.kidshelpline.com.au

Carers NSW thanks the many carers involved in the development of this information for sharing their experiences and suggestions for the benefit of other carers.