

Caring for someone with a life-limiting illness



Managing feelings – what can I expect to feel?

While each person is unique there are some common emotional reactions that carers often talk about. It is important to realise that other carers have similar feelings to you and that these are normal. Carers say knowing this helps them to understand their own feelings and reactions.

This information has been developed in partnership with carers who have shared their experiences and offered suggestions as to what may help.

Carers share the feelings they experienced

Sadness

- I struggled with feelings of grief and sadness. Grief is not neat. It's messy and it hurts
- Grief is unique and you may feel alone at times, but that's normal.

Exhaustion

- I felt exhausted and overwhelmed most of the time
- It was like being on an out of control train that you couldn't get off.

Fear

- I didn't know if I could care for him, but when the time came I just did it
- I worry about how they will die. Will I be able to manage? When will it happen? It's a very uncertain time. I am constantly on edge
- What if I get it wrong? I've never done this before.

Helplessness

- I felt helpless as I couldn't take away the suffering.

Isolation

- Friends and family don't understand what I am going through. I feel very alone and isolated
- Even those closest to you don't understand. Some friends and family stop contacting you.

Guilt

- I sometimes feel resentment, then I feel guilty for thinking this way
- I felt guilty for losing my temper. I was tired and did not do it intentionally
- I feel really guilty when I have thoughts about the future, when I don't have to care anymore.

Burden

- Caring is not something you choose. You do it because someone you care about needs it
- It creeps up on you, with more and more tasks being added as they deteriorate
- I felt the burden of complete responsibility for another person's wellbeing.

Love

- I felt glad I was caring and could be there
- It was an honour to be able to care for her. It was my expression of love
- We talked about what we meant to each other. This was a very special time.

Anticipatory grief

The feelings described above can be fuelled by your anticipation of the death of the person you are caring for. This is called anticipatory grief and it doesn't just affect our feelings. It affects our thoughts, our physical wellbeing and our relationships.

"Just knowing about anticipatory grief helped me to cope better. It helped me to understand what I was feeling and why."

Caring for someone at this time can provide an opportunity to talk about things that are important with the person you care for so that you have a better understanding of their wishes.

"Anticipatory grief helps us prepare for the loss of someone we love and the loss of a way of life."

Further information and support

- **Carer Gateway** – 1800 422 737 or www.carergateway.gov.au
- **Carers NSW** – www.carersnsw.org.au
- Talk to your **doctor**

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.



What can you do to help manage your feelings?

- Understand that you will have a range of emotions that can be overwhelming
- Be kind to yourself. Accept your thoughts and feelings without judging them. You may feel sad and you may feel happy at times, both of these feelings are ok
- Get support – find someone you can talk to who understands. It may be a friend, counsellor, psychologist or doctor
- Join a carer support group or talk to other carers who understand
- Read about others with similar experiences so you can better understand your own
- It's ok to be upset and cry
- Be informed and have a plan for care – try to prepare for what's ahead.