

FEELINGS

This Help Sheet discusses some of the feelings that families and carers of people with dementia often experience. These may include feelings of guilt, grief, loss or anger.

Caring for someone with dementia can be very rewarding. It can also be difficult, exhausting, lonely, and at times, overwhelming. You may have to deal with many different feelings as the needs of the person with dementia change over time.

You may experience a range of very different and often extreme feelings. This is particularly difficult because as dementia gradually causes the person's abilities and personality to change the nature of your relationship will also change. There is no simple way to deal with these feelings, but it may help to know that the complex and changeable emotions you feel are completely normal.

Your feelings

Some of the most common feelings experienced by families and carers are guilt, grief and loss and anger.

Guilt

It is quite common to feel guilty – guilty for the way the person with dementia was treated in the past, guilty at feeling embarrassed by their odd behaviour, guilty for lost tempers or guilty for not wanting the responsibility of caring for a person with dementia, and more.

If the person with dementia goes into hospital or residential care you may feel guilty that you have not kept them at home for longer, even though everything that could be done has been done. It is common to feel guilty about past promises such as "I'll always look after you", when this cannot be met.

Grief and Loss

Grief is an emotional response to loss. This could be the loss of a relationship, moving home, the loss of good health, divorce or death. If someone close develops dementia, we are faced with the loss of the person we used to know and the loss of a relationship we previously had. People caring for partners may experience grief at the loss of the future that they planned to share together.

Grief is a very individual feeling and people will feel grief differently at different times. It will not always become easier with the passing of time.

Anger

It is natural to feel frustrated and angry – angry at having to be a carer, angry with others who do not seem to be helping out, angry at the person with dementia for their difficult behaviours and angry at support services.

Sometimes you may even feel like shaking, pushing or hitting the person with dementia. Feelings of distress, frustration, guilt, exhaustion and annoyance are quite normal. However if you feel like this or that you could lose control, it is important to remove yourself from the situation and discuss your feelings with someone such as your doctor or an Alzheimer's Australia counsellor. Discussions with doctors and counsellors are confidential. Call the National Dementia Helpline on **1800 100 500** or the Carer Advisory and Counselling Service on **1800 242 636** for further information about counselling and carer support.

What to try

You may find some of the following ideas helpful when dealing with feelings of guilt, loss and anger:

- **Feel the pain**

Allow yourself to really feel what you are feeling, no matter what that is. Denying the feelings only intensifies whatever feelings you are experiencing

- **Cry**

Tears can be therapeutic. Let them cleanse and relieve the sadness inside

- **Talk**

Share your feelings. It is important to talk about how you feel even at the most difficult times. Sharing grief will help diminish it. It can be helpful to talk to a person outside the family, such as a counsellor

- **Keep a journal**

A journal is a private place where anything can be written including unfulfilled wishes, guilt, anger and any other thoughts and feelings

- **Let go**

Don't be engulfed by bitterness. Resentment is a heavy load and can only continue the hurt. If there is a source of anger, try to resolve it

- **Find comfort**

Different people have different ways of finding comfort. For many there is comfort in rituals, whether prayer, meditation or other activities

- **Hold off**

Be wary of making hasty decisions. Thoroughly explore all options before making major steps. You can be vulnerable at times

- **Be kind to yourself**

Be patient with your feelings. Finding a balance between the happy and sad person, the angry and peaceful person, and the guilty and glad self. Have patience with yourself

- **Learn to laugh again**

Rediscover your sense of humour. Finding joy in life can be one way of honouring the happy times that can continue to be shared

Remember

Try to make sure that you get adequate breaks from caring so that you do not get worn down. Ask relatives and friends for help.

Contact support services to see how you can get regular breaks. Help and further information can be obtained from:

- The National Dementia Helpline on **1800 100 500** or visit **fightdementia.org.au**
- The Carer Advisory and Counselling Service on **1800 242 636** or visit **carersaustralia.com.au**
- Carer Gateway on **1800 422 737** (not mobile phones) or visit **carergateway.gov.au**
- Commonwealth Respite and Carelink Centres provide free and confidential information on local carer support, disability and community services. Centres are located throughout Australia and you can contact your nearest Centre by phoning **1800 052 222** (free call except from mobile phones)
- My Aged Care on **1800 200 422** (not mobile phones) or visit **myagedcare.gov.au**

Support groups

Alzheimer's Australia can link people to a large number of support groups throughout Australia. Many people find comfort and practical assistance by attending these meetings with others who know what it is like to care for a person with dementia. Support groups bring together families, carers and friends of people with dementia under the guidance of a group facilitator. The facilitator is usually a health professional or someone with firsthand experience of caring for a person with dementia.

'It helps to know you're not alone... listening to how others deal with similar problems.....it makes me feel much better to know that there are other people with a similar caring role'

FURTHER INFORMATION

Alzheimer's Australia offers support, information, education and counselling. Contact the National Dementia Helpline on **1800 100 500**, or visit our website at **fightdementia.org.au**



Interpreter

For language assistance phone the Translating and Interpreting Service on **131 450**