

## Dementia - how it affects carers

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

### Common feelings experienced by carers

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

Some feelings commonly experienced by carers of people with dementia include distress, frustration, guilt, grief and loss, exhaustion, annoyance, frustration and anger.

### Guilt

It is quite common to feel guilty. This may include feeling guilty for the way the person with dementia was treated in the past, guilty at feeling embarrassment from the person's odd behaviour, guilty for losing your temper or guilty for not wanting the responsibility of caring. If the person with dementia goes into hospital or residential care, carers may feel guilty that they have not kept them at home for longer, even though everything that could be done has been done. You may feel guilty about past promises, such as 'I'll always look after you', which cannot be met.

### Grief and loss

Grief is an emotional response to loss. The loss could be the loss of a relationship, moving house, loss of good health, divorce or death. If someone close to us develops dementia, we are faced with the loss of the person we used to know and the loss of a relationship. People caring for partners are also likely to experience grief at the loss of the future that was planned together. Grief is a very individual feeling and people will feel grief differently at different times.

### Anger

It is natural to feel frustrated and angry. You may be angry at having to be the caregiver, angry with others who do not seem to be helping out, angry at the person with dementia for difficult behaviour, and angry at support services. Sometimes you may 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 that you are losing control, it may help to discuss your feelings with your doctor or an Alzheimer's Australia counsellor.

### Things you can try

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

- **Feel the pain** – allow yourself to really feel what you are feeling, no matter what that is. Denying the feelings only intensifies and prolongs the pain.
- **Cry** – tears can be a therapeutic tool. Let them cleanse and relieve the pain inside.
- **Talk** – share the pain. Sharing grief diminishes it. It is important to talk about feelings, even at the most difficult times. 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 or other thoughts and feelings.
- **Let go** – try not to 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 to find comfort. For many carers, there can be comfort in rituals, including prayer, meditation or other activities.
- **Hold off** – tread carefully before making decisions. Thoroughly explore all options before you make any major steps. Remember that you may be very vulnerable at times.
- **Be kind to yourself** – be patient with your feelings. Find a balance between the happy and sad person, the angry and peaceful, 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 to honour the happy times that used to be shared with the person you are caring for.

## Take a break

Try to make sure that you get adequate breaks from caregiving so that you do not become worn down. Ask other family members and friends for help. Day care centres, in-home respite and regular residential respite are available to provide a much-needed break, so that you can continue in your role.

## Support groups

There are a large number of local support groups throughout Australia. Many people find enormous comfort and practical assistance from attending these meetings with others who know what it is like to care for, and live with, a person with dementia.

Carer support groups bring together carers, relatives and friends of people with dementia, under the guidance of a group facilitator. This is usually a health care professional or someone with first-hand experience of caring for a family member. There is no charge for attendance.

## Where to get help

- Your doctor
- Your local council
- Your local community health service
- Carers Victoria Tel. 1800 242 636
- National Dementia Helpline Tel. 1800 100 500
- Dementia Behaviour Management Advisory Service (DBMAS) Tel. 1800 699 799 – for 24-hour telephone advice for carers and care workers
- Carer Respite Centres Tel. 1800 059 059
- Carer Resource Centres Tel. 1800 242 636
- Aged Care Assessment Services – contact your regional Department of Health office
- The Aged Care Information Line Tel. 1800 500 853
- *Carer Support Kit* – for information about the support and services that are available to carers, and offers practical assistance. A copy of the *Carer Support Kit* is available by phoning Carers Victoria.

## Things to remember

- Caring for someone with dementia can be rewarding but it can also be difficult, exhausting and lonely.
- Carers may experience feelings of guilt, grief, loss or anger.
- Take a break from caregiving to avoid becoming worn down.
- Support is available for carers and can provide comfort and practical assistance.

**This page has been produced in consultation with, and approved by:**

Alzheimer's Australia Victoria

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