

Grief and coping with loss

If someone close to you develops dementia you are likely to experience feelings of grief and bereavement as the illness progresses, not just in the period after their death. It may help to know that such feelings are normal and that other people experience similar reactions. Feelings are neither right nor wrong.

- *Loss of the future you had planned together*
- *Loss of their companionship, support or special understanding.*
- *Loss of finances or a lifestyle which you once took for granted.*

There are so many small changes that occur along the way when caring for someone with dementia that it is difficult for many carers to deal with their feelings. You may adapt and come to terms with one stage of the person's illness only to find that their behaviour alters or their abilities decline further and your grieving starts all over again.

Sense of loss

The sense of loss is one of the most powerful feelings that carers can experience. Depending on your relationship with the person and your individual circumstances you may grieve for the:

- Loss of the person you once knew
- Loss of the future you had planned together
- Loss of the relationship you once enjoyed
- Loss of their companionship, support or special understanding.
- Loss of your own freedom to work or to pursue other activities.
- Loss of finances or a lifestyle which you once took for granted.



Ref. brucefong.files.wordpress.com



Ref. advance-counseling-denver-boulder.com

Restrictions

However much you wish to go on caring you are bound to feel resentful at times at the restrictions placed on your own life. You may also feel unhappy that things have not turned out as you had hoped.

- Consider your own needs. Taking regular breaks away from caring can keep you in touch with the outside world and raise your moral.
- Make time for yourself each day. Just relaxing with a cup of tea or having a good chat on the phone will help you recharge your batteries and cope with your own emotions.
- Cultural dictates might have placed you in the position of carer although you had other aspirations for your life e.g. a daughter-in-law caring for a mother-in-law.

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Up and down process

Grieving is an up and down process. In the earlier stages, you may swing between despair and wild optimism that a cure will soon be found. Some people even deny that anything is wrong with the person and try to suppress their feelings.

Later, when you have accepted the situation, you may find that there are periods when you can cope well and make the best of things. At other times, you may feel overwhelmed by sadness or anger or you may simply feel numb.

Many carers are shocked to find that they sometimes wish that the person were dead.

Such feelings are a normal part of grieving. It is important to realize that you are under a great deal of stress and that you seek emotional support for yourself.

Please contact the DEMENTIA SA Office

Support | Awareness | Education | Counseling | Training | Resource centre | Advocacy
info@dementiasa.org or support@dementiasa.org www.dementiasa.org

National Helpline 0860 MEMORY / 0860 636 679

What can help?

- Talk about your feelings to an understanding professional, to other carers, to a trusted friend or to supportive members of your family. Don't bottle your feelings up.
- Relieve tension through crying, or shout or punch a cushion. However, make sure that the person you are caring for is safe and out of earshot or you may distress them.
- Try to persuade friends to drop in for a chat or to phone you regularly.
- Make sure that you see your GP, Clinic or Community Health Centre if you are feeling low or anxious or if you are very tired and unable to sleep. It is important to try and prevent your normal feelings of sadness from slipping into depression, which is much harder to deal with.
- Complete unfinished business and deal with emotional baggage.
- Turn to your own personal spirituality/faith.
- Accept the knowledge that you deserve to have your own needs met.

Long term care

If the person goes into long-term care you may grieve at another change in your relationship.

- The relief, which you might feel initially, may be replaced by feelings of loss and grief, and mixed up with guilt, which can last for a surprisingly long time. You may miss the person's presence. You may experience feelings of emptiness and feel very tired, both physically and emotionally.
- Try to take it easy until you feel your energy levels rise again.
- Giving a structure to your day which includes visits to your loved one/ person with dementia may help you get through the difficult early months.
- Don't fall into the trap of building your life around visiting the person in their new home.

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Towards the end

In the final stages of dementia the person may be unable to recognize you or communicate with you. This can be very painful. Although the relationship seems very nearly over, you are unable to mourn fully because the person is still alive.

Holding the person's hand or sitting with your arm around them may be comforting for both of you. It might also help you to recognize that you have done all that you could. Accept what is beyond your control.

When the person dies

Some people find that they grieve so much during the course of the illness that they have no strong feelings left when the person dies. Other people experience a range of overwhelming reactions at different times.

These may include:

- Numbness, as though their feelings are frozen
 - Inability to accept the situation
- Shock and pain, even if the death has been expected for a long time
 - Relief, both for the person with dementia and themselves
 - Anger and resentment about what has happened
- Guilt over some small incident which happened in the past
 - Sadness
 - Feelings of isolation
 - Fear of a future alone

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Carers should be prepared for the fact that it may take them a long time to come to terms with the person's death. Caring will probably have been a full-time job for a long time and when it ends it will leave a void.

- Try to avoid making any major decisions in the early months if you are still feeling shocked and vulnerable.
- Accept that, even though you may generally be coping, there may be times when you feel particularly sad or upset.
- Events such as anniversaries or birthdays are often distressing. If so, ask friends and family for support.
- Stay in close touch with your GP, Clinic or Community Health Centre and your support group. You are likely to be more vulnerable to physical illness as well as to anxiety or depression following bereavement.

Getting back on your feet

Although you may feel very tired after someone dies or goes into long-term care, the time will come when you are ready to re-establish your own life and move forward.

You may feel very vulnerable at first and find it difficult to take decisions, make polite conversation or cope with social gatherings, don't give up. Your confidence will gradually return. Take things slowly and make sure that you have plenty of support from family and friends, professionals and other former carers. Learn to dream, hope and live again.

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