



Better Caring  
Better Outcomes

## Grief and Loss

*THIS FACT SHEET discusses the many losses associated with chronic conditions that challenge people with these conditions, their families and their carers. It describes the grief they can cause, emotional reactions that occur such as anxiety and depression, and presents ways to cope.*

Grief is the emotional pain that we feel when we lose something or someone we value. It is a natural and normal reaction. Death is one such loss, but illness also brings the experience of loss for the person with the condition and for their carer. There is no single way to grieve, no clear set of “steps” in a grieving process.

Friends often don't know how best to support you and grief can sometimes stretch relationships to breaking point. The most important thing is that people are allowed (and allow themselves) to grieve in their own way, in their own time.

### For the Carer and Family

Families almost always experience grief over the loss of the life they had before. Grief may be felt over the changes in the person you care for or in confronting their imminent death. Many carers feel they can't admit, even to themselves, how terrible they feel.

**Diagnosis:** The diagnosis often brings shock and confusion. You may be so focussed on the person that you have little time for your own feelings or reactions. Your relationship with the person may be changing, and your own needs may be neglected.

**Too close for comfort:** A carer looking after a parent may find their roles reversed – carer becomes parent – which can be awkward and difficult to come to terms with on both sides. Caring for a spouse often means taking over their responsibilities in the relationship. In both cases, you may be losing your greatest source of comfort and support.

Carers speak of loss in many ways:

- > Loss of the person you once knew, the things you did together, sharing good times.
- > Lack of intimacy and closeness.
- > Loss of independence, freedom, time for yourself, pursuing things you enjoyed, and employment.
- > Loss of communication and mutual support.
- > Losing a sense of normality and future, loss of dreams, goals and plans.
- > Loss of predictability, control, and financial security.
- > Loss of religious faith.

**Feeling stuck:** Each small setback can trigger grief. Where the condition is clearly progressive, you may feel you can't start to move on until the person's death, yet even to think like that opens up more grief and guilt. It can be a very drawn-out process.

### For the Person with the Condition

Your own grief will be paralleled in the person you are caring for. Consider some of the losses they are dealing with: loss of the ability to move about easily, to work, to play, perhaps even the ability to communicate.

There is loss of their authority and place in the family, loss of decision-making abilities, family security and predictability, loss of self-esteem, religious faith, privacy and dignity.

When we are well, we have a sense of invulnerability that somehow the bad things in life will pass us by. Chronic or progressive illness shatters this sense

and brings grief that anticipates losses yet to come – loss of control, of family support and the fear of further illness and of becoming a burden. For those with an inherited condition, there may be the added fear that their children may face the same experience.

## Feelings and Reactions

People react in many different ways and at different times. It's important to remember that these are all *normal reactions* to serious loss. You are not falling apart, cracking up or failing to cope.

**Feelings:** Feelings like these listed below may come over you in waves, often without warning. They are part of the process of adjusting to the changes.

- > Denial and shock – “Not us/me!” , it hasn't happened, it can't be true.
- > Anger and resentment – “Why us/me?” It's someone else's fault, blame the doctor, blame God.
- > You may feel sorrow, numb, miserable and many other negative emotions.
- > Guilt – at your anger, because you couldn't prevent the illness, because it didn't happen to you or because you no longer feel the same about the person.
- > Despair at the words “no cure” .
- > Depression, sadness, sorrow, helplessness hopelessness - feeling you can't cope, it's not worth it, there's nothing to live for, a continued grief with no end in sight.
- > Anxiety or panic – over the intensity of your feelings, about your future, about the present.
- > Self-doubt and blame – a sense of inadequacy, insecurity, “I'm doing a rotten job” , “It's my fault” .

**Reactions:** These feelings may cause people to behave and react in all sorts of ways. Each person's response is unique, but carers have described:

- > Tension, crying, fatigue, exhaustion.
- > Sleeping problems.
- > Changed eating habits.
- > Poor concentration and memory, loss of motivation, difficulty making decisions.
- > Poor health – headaches, stomach aches, indigestion.

- > Refusing help and withdrawing from social outings.

## Managing Grief

Ignoring grief won't make it go away, but there are certain approaches that might help you to find a path through it and to adjust to your losses.

**Recognise your feelings:** Become aware of the feelings you have and learn to recognise why you have those feelings. Keep a diary if necessary.

**Help yourself:** Adopt a problem-solving approach. What can you do to help deal with these feelings or to defuse them?

**Care for yourself:** It's essential that you take care of your own needs as well as those of the person you care for. Acknowledge to yourself that you are grieving – it's OK to grieve.

**Talk it out:** Find someone you can talk to, perhaps a friend who will listen without giving advice. Consider seeing a grief counsellor who can give you skilled help in dealing not only with your own grief, but with that of the person you care for.

**Find hope:** You need hope. With hope, there is a future. While one part of you needs to acknowledge the difficulties you face, there is always something to hope for, however small or large it may be – don't let anyone talk you out of it. It might be an event, it might be a relationship or the knowledge that this time, too, will pass.

Other strategies that carers have found helpful include:

- > Seeking respite care (see Fact Sheet: Respite and Residential Care).
- > Actively trying to maintain a positive state of mind.
- > Faith in a higher spirit or religion.
- > Treating yourself once in a while – to the movies, shopping with a friend, buying yourself something special.
- > Keeping informed, knowing what to expect in the future.
- > Avoiding isolation.
- > Holding on to a sense of humour.
- > Keeping a journal to write down fears, hopes, concerns, joys.

- > Joining a carers' support group.
- > Nurturing activities like yoga and tai chi.

## **Depression, Anxiety and Insecurity**

Anxiety and depression are common and understandable reactions in a person who has a serious and disabling condition or in someone caring for that family member.

Depression is more than the sadness we all feel at times. It may be an overwhelming feeling of blackness that persists and deepens over weeks and months. Depression saps motivation and energy.

Grief may look a bit like depression, and for some people, the two may merge if grief becomes a sense of chronic sadness and hopelessness.

**Symptoms of depression:** Typical symptoms of depression include difficulty sleeping, crying a lot, overwhelming tiredness, a general loss of interest, changes in eating patterns, poor concentration, forgetfulness and confusion, difficulty in getting going, slowed movements, and a sense of worthlessness and guilt.

**Affecting behaviour:** If you are depressed, you may begin to neglect yourself, avoid things that have brought you pleasure, even blame yourself for your situation. You may begin to resent and neglect the family member you are caring for and feel there is no end to the despair.

Depression and anxiety coupled with the insecurity of illness can make a person with a chronic condition very reluctant to be left alone, even from room to room. This can be very demanding on the family. Even small changes make some people anxious.

**Treatment:** Chronic depression needs to be treated professionally. Speak to your doctor about your feelings so he or she can recommend a course of treatment. Both medication and talking about your concerns with someone such as a psychologist can help to overcome the depression. Likewise, if you feel the person you are caring for is depressed, talk to your doctor about it. You can help by treating the person as normally as possible. Be chatty and positive, but show them that someone still cares.

## **Preparing for Death**

We all know we are going to die, yet in our society, we tend not to think about death or to prepare ourselves for it. Watching a person you love slowly approach death as they move, perhaps, from home to hostel to a nursing home, can therefore become a painful and confronting process for carers. But by thinking about how you might feel and doing some preparation, you can make this process a little easier.

**Acknowledging death:** For many people, the grief is there long in advance. It may start when the person is diagnosed, or before, and continue throughout their illness. Some people may begin grieving only after their family member dies.

**Grief is unique:** There are no rules about how to grieve – what you do, how long you are sad, when you stop crying – each of us deals with this in our own way. Do not expect those around you – family members or friends – to behave or feel as you do. We all react differently.

Just be yourself and allow yourself to grieve in your own time, in your own way, whether that is publicly or privately, but do grieve.

**Before or after death:** Talk about your thoughts, feelings and memories – it helps to sharpen memories, to remember the good times and the bad. Accept offers of support – this can help you to express your feelings, to reflect and to talk it out.

**Professional help:** If you can't seem to come to terms with the loss or if after several months you are not sleeping, not eating properly and are sad much of the time, seek professional help. A trained grief counsellor can make a difference.

**Moving on:** For many people, caring has defined their lives for so long that life beyond it can seem a challenge. There are usually decisions you can make and actions you can start that will help you move toward a new future. Try planning things you might do now, or in a few weeks, months or further down the track. These might include finding someone to help sort out a large house and financial affairs, thinking about friendships you would like to rekindle, looking into TAFE courses, volunteering, employment or community work, or planning a break.