

Common emotions at the end of their life

Caring for someone at the end of their life can be a very demanding and distressing experience. We know that approximately half of people caring for someone with an advanced disease report high levels of distress and that it impacts on their overall level of functioning. This fact sheet describes the common ways that distress can be experienced and gives some tips for managing distress. However, it is important that you talk with your GP or other health professional if you are experiencing high levels of distress.

Stress

Many carers experience stress. You may feel overwhelmed, exhausted, frustrated or angry, or guilty. You may feel like you lack choice over your caring responsibilities. Stress can come in many forms but feeling stressed for long periods of time is also called 'chronic stress'. Stress can result in physical changes in the body which if prolonged can result in stress related illnesses. High demands, lack of support and being isolated due to the caring role can all contribute to chronic stress.

What to do about feeling stressed

If you are experiencing chronic stress then you should see if you can reduce the demands on yourself by asking others (friends, family and the health care team) to do more. If you are caring at home, try and organise a break from caring by organising some 'respite' (this is where the person you are caring for has a short stay in hospital or an aged care facility). Alternatively, you may want to consider moving the person you are caring for permanently to an aged care facility, hospital or hospice/palliative care unit.

Also, try some self-management strategies such as:

- Make healthy changes to your lifestyle (improve your diet, increase your sleep, attempt some gentle daily exercise, and try and socialise with friend and family)

- Identify the signs of stress (physical tension, increased heartbeat, a short fuse) and monitor your own stress levels. Identify if there are any situations that increase your stress and try to minimise those situations. Take a break for 5 minutes when you feel like your stress levels are increasing. Try some deep breathing before you return to the situation.
- Accept things or situations that are out of your control. Try not to expend energy on things you cannot change. Focus on things that you do have control over and can change.
- Plan ahead. Seek information about what is likely to happen in the coming weeks and try and plan ahead to reduce the burden on yourself.

Anxiety

When you are caring for someone who is seriously ill, it makes sense that you would feel worried about them, panicky about all the things you need to do, and anxious about whether you would be able to cope if there was an emergency situation related to their illness. It is normal to feel some level of anxiety as a result of your situation. However, it is not helpful or healthy to be feeling high levels of anxiety for long periods of time. Anxiety is associated with lower quality of life, poor functioning, poor sleep and diet, and even poor physical health.

The signs of anxiety can include physical symptoms such as panic attacks, hot and cold flushes, racing heart, tightening in the chest, rapid breathing, restlessness, and feeling tense, wound-up and edgy. Psychological symptoms of anxiety include excessive fear, worry, thinking the worst, and obsessive thinking. Behaviour changes such as avoiding people or situations can also be a sign of anxiety.

What to do about feeling anxious

Firstly it can be helpful to seek support from your GP or other health professional. In addition, you can try some simple self-management strategies such as:

- Slow your breathing and concentrate on your in and out breaths
- Make health changes to your lifestyle (improve your diet, increasing your sleep, attempt some gentle daily exercise, and try and socialise with friend and family)
- Try and focus on the present moment
- Try meditation or progressive muscle relaxation (relaxing each of your muscle groups by tensing it, holding for 3 seconds, and then letting it go)
- Write all your worries down in a journal

Depression

Many people feel sad when they are caring for someone at the end of their life. However, depression is a term for when these sad feelings are more intense and last longer than usual. Depression means that you are sad, miserable or down most of the time and are not feeling interested in things or experiencing pleasure the way you usually would. You may have even lost your appetite, may be sleeping more or less than usual, and may have withdrawn from friends and family. You may be experiencing lots of negative thoughts about yourself and your situation and may feel like things will never get better.

What to do about feeling depressed

Taking time for relaxation, planning activities that you enjoy, socialising with friends and family, and looking after your health are all helpful ways to manage depression.

However, it is important that you seek help if you are depressed. Talk to your GP or other health professional about proven effective treatments for depression including talking therapies and medication. If you are having thoughts of harming yourself or others, then call Lifeline on **13 11 14**.

Grief

If you are caring for someone at the end of their life, then you are probably already experiencing grief. Grief is the natural response to loss. You may be grieving for the loss of the life you once had, or grieving for the loss of a shared future, or grieving for the loss of the person as they were before they were ill, or grieving in advance for the loss that you know is coming when the person you are caring for dies. Grief can be exhausting, both emotionally and physically. It can affect any aspect of your life and be expressed in many ways. Grief can leave you feeling sad, angry, anxious, shocked, regretful, relieved, overwhelmed, isolated, irritable or numb.

What to do about grief?

- Share your grief with others. Talk to friends and family
- Look after yourself physically (eat well, sleep, regular gentle exercise)
- Give yourself time and space to grieve
- Seek help through your GP, a grief counsellor, support group etc.

For more information on anxiety, depression and grief, please visit www.beyondblue.org.au.

CarerHelp is here when you need it.
www.carerhelp.com.au