



coping with grief, loss and change

Not always there with you ...but always there for you



Coping with feelings of grief, loss and change

When caring for someone, feelings of grief, loss and change can be experienced in a number of ways. Often grief is seen as a direct reaction to a death but there is also another sense of grief that can come from a sense of loss while someone is still living. This grief is often seen when caring for someone with a chronic illness. Chronic illness, and particularly any illness that impairs a person's mental health and cognitive ability, may cause you to experience feelings of grief, loss and change. This fact sheet, takes a closer look at these feeling and ways of recognising, coping and managing them.

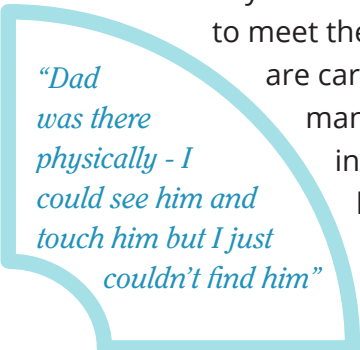
Over time, with most chronic illnesses, there are changes in a person's abilities. Whether it is someone living with Parkinson's Disease who can no longer button a shirt, or someone coping with diabetes who has to follow a special diet, or someone with Alzheimer's Disease who can't remember who you are. As a result of these type of progressive, debilitating and chronic illnesses you may

find that you are continually having to adjust

to meet the needs of the person you

are caring for. You may experience

many kinds of losses: loss of independence, loss of control, loss of the future as it had been imagined; loss of financial security, of the relationship as it once was, loss of

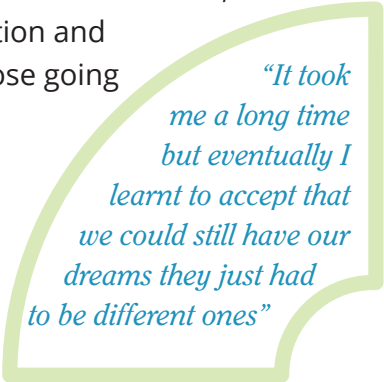


“Dad was there physically - I could see him and touch him but I just couldn't find him”

freedom, sleep, and family harmony; loss of someone to share chores and other tasks with, or simply the loss of someone to talk things over with. The person you care for also has to adjust to many of the same losses, but also—loss of dignity, mobility, a carefully planned future or retirement, a loss of roles that were played, or the loss of a sense of worth (all depending on what disability is associated with the illness).

It is easy to ignore these losses and just keep doing the things that need to be done. However, these losses lead to grief, and grief can lead to sadness, depression, anger, guilt, sleeplessness and other physical and emotional problems. It is important to identify your losses, identify your feelings, and let yourself grieve for the changes that have happened in your life. When you can do this, you may find that your feelings will less often erupt as angry outbursts weighed down by guilt, or creep over you as depression and a sense of hopelessness. Instead, they can more easily be expressed as a shared loss of something treasured—which family and friends close to the situation can also share and understand, leading to deeper communication and stronger relationships with those going through the loss with you.

Writing in a diary can help you to name and express your feelings about these losses. You can also use the diary to record positive things,



“It took me a long time but eventually I learnt to accept that we could still have our dreams they just had to be different ones”

writing them down can help you to identify and hold onto them. Relaxation exercises or attending a support group (or simply talking with a friend or counsellor), or creating a routine can help you to let go of the intensity of the feelings so that you can grieve but also heal.



*“It does
make such
a difference
talking to people
who have been
there and
done it.”*

Ambiguous loss

This can be experienced when someone is still “there” in the physical sense but also not “there”. The person you care for may be presenting in a very unaccustomed way both mentally but also through their personality traits. This is mainly experienced when someone has a cognitive impairment from dementia, a traumatic brain injury or a stroke.

Ambiguous loss can also be experienced when someone has “moments of lucidity,” for example, when he/she is clear and makes sense for a short period of time and then becomes “lost” again. This can be very difficult to manage and understand. It can be hard to come to terms with the fact that these are brief moments in time. These periods of lucidity and confusion can often lead to feelings of anger, frustration and disappointment and ultimately renewed grief. It is important to remember that these feelings are normal and part of the process of loss and grieving.

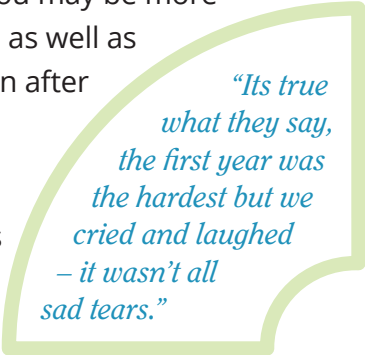
Anticipatory grief

If you have been caring for someone for a long period of time, you may find that you start to grieve the loss of the person's "former self" long before they die. Experiencing loss on a daily basis, as well as anticipating the loss at the end of life, knowing what is coming, can be just as painful as the loss associated with a death. Carers often express feeling guilt or shame for "wishing it were over" or thinking of their loved one as already "gone" (particularly when someone has a cognitive impairment). It is important to recognize these feelings as normal. Ultimately, these feelings are a way of allowing you to prepare emotionally for the inevitable. Preparing for the death of a loved one can allow family members to contemplate and clear unresolved issues, make end of life plans for funeral and burial, and experience their pain in stages. Sometimes, when someone has grieved a death over a long period, there is less grief when the person dies; sometimes there is more pain when a person dies.

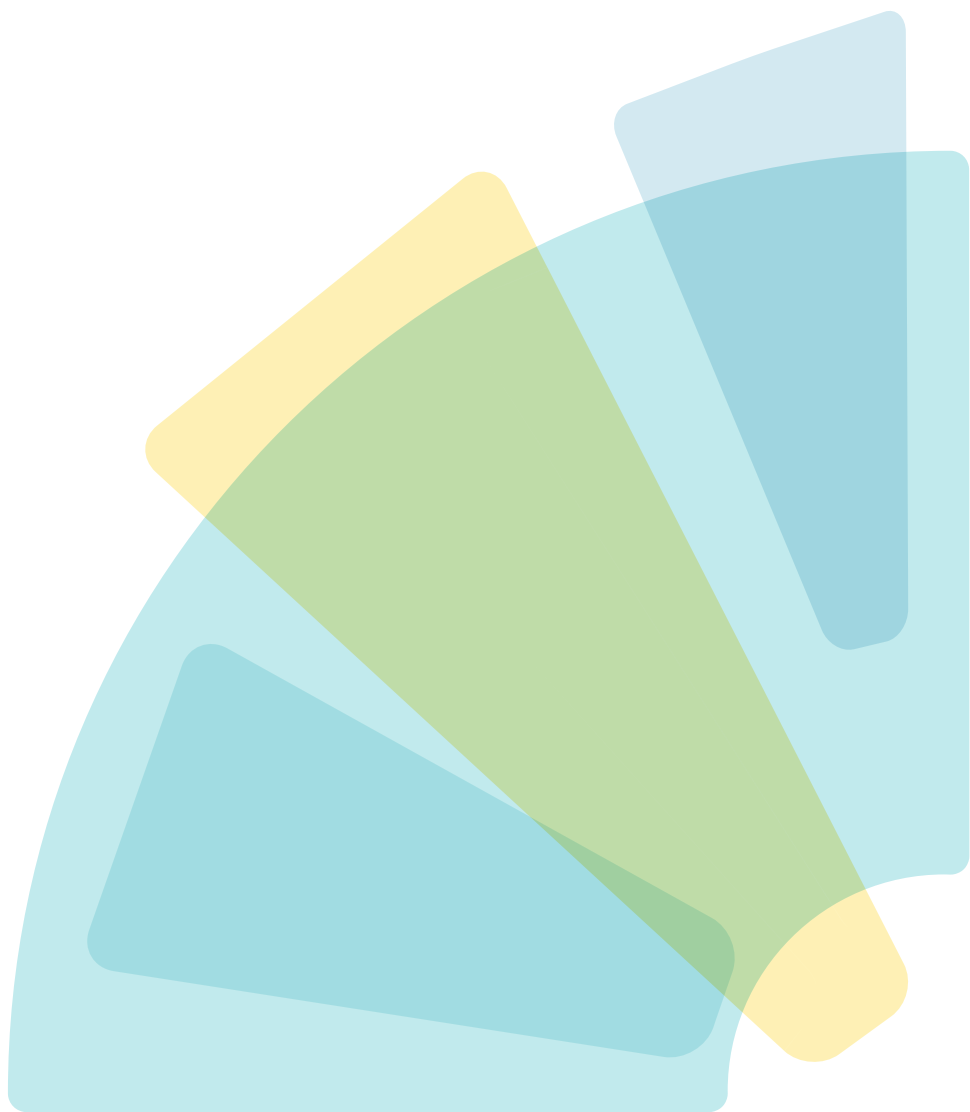
Tips that may help you

- ▶ Try not to bottle up your emotions: talk about your feelings. This may be with a professional, (eg your GP or support worker), other carers (eg via a carers support group), a friend or family member.
- ▶ Try to make time for yourself each day. This could be relaxing, walking outside, a hand massage or chatting to friends.

- ▶ Consider your own needs. If you feel that you need a break to help you cope, speak to someone about arranging this.
- ▶ Try to focus on the positives, for example things that you and the person you care for can still do together, or other interests you have.
- ▶ If you're feeling low or anxious, or are very tired or not sleeping, speak to your GP. It's important to look after your own physical and mental health.
- ▶ Try to avoid making any major decisions in the early months, you may still be feeling shocked or vulnerable.
- ▶ Take some time to reflect and come to terms with your situation, but try not to isolate yourself.
- ▶ Even though you may generally be coping, there may be times when you feel particularly sad or upset, this is normal.
- ▶ If you find events such as anniversaries or birthdays upsetting, ask for support from friends or family.
- ▶ Stay in touch with your GP. You may be more vulnerable to physical illness, as well as anxiety, stress and depression after bereavement.
- ▶ Speak to Borders Carers Centre about free workshops in "Coping with feelings of loss and change."



*"It's true
what they say,
the first year was
the hardest but we
cried and laughed
– it wasn't all
sad tears."*



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