

# **Grief and Loss.**

## **A carers journey.**

### **Introduction**

Grief is a natural process of reaction and adjustment to loss and change. When we lose someone or something that is important to us, we grieve. There are many types of losses – loss of health, loss of employment, marital breakdown, divorce and death – and the reactions we have after a loss may be very different. It is natural to grieve the death of a loved one before, during and after the actual time of their passing. Every significant loss challenges us to find ways of coping.

### **Chronic illness and loss**

It is common for carers to have feelings of loss and grief as their life and the life of the person they care for, is changed due to a chronic illness. Like grieving after a death, adjusting to the changes that a chronic illness brings is a process. It can affect us in many different ways – emotionally, mentally, physically, and spiritually. There are two types of grief that may be experienced following a diagnosis of a chronic illness, these are:

#### **Ambiguous loss**

Ambiguous loss is the confusing feeling of interacting with someone who is not fully present mentally or socially, as often happens to family caregivers who are closely involved with a person living with dementia. A person may feel that they have lost a loved one even though their loved one is still present and in need of love and care. A carer may grieve their loved one's losses just as much as the person with the chronic illness is grieving their own losses.

#### **Anticipatory Grief**

Most people are familiar with the grief that occurs after a death, anticipatory grief is not often discussed. Anticipatory grief is the emotional pain and sadness that arises in advance of an expectant loss or death. It can start as soon as we become aware that death is a likelihood.

Though this is different than the grief that follows a death, anticipatory grief can carry many of the symptoms of regular grief – Tearfulness, anger, loneliness, anxiety and depression, guilt, desire to talk or withdraw, fear, fatigue, emotional numbness, poor concentration, forgetfulness.

Rather than death alone, this type of grief includes many losses, such as the loss of a companion, changing roles in the family, fear of financial changes, and the loss of dreams of what could be.

Both of these types of grief can be difficult for others and even yourself to recognise and acknowledge. Yet they are a normal response for some people where a family is supporting

a person with a chronic illness. Finding a friend or another loved one you can share your feelings openly with is extremely helpful, just as maintaining hope and preparing for death at the same time is difficult.

For more information for loss and grief when a family member has dementia see:

<https://hospicefoundation.ie/wp-content/uploads/2015/03/Alzheimers-society-of-Ireland-Loss-and-grief-when-a-family-member-has-dementia.pdf>

## Grief after a death

For most of us the death of someone close will be the biggest loss we face. Losing someone you love is painful and it can be even more painful if you have been a carer for that person. Your grieving process is to try to make sense of what has happened while learning to live your life without that person.

## The grief process

Grief is both a universal experience and a unique experience and it does not follow any set course or stages. You may experience a sense of shock and disbelief when somebody dies, even if you expected it. You may appear to be coping well but often feel detached and almost as if you are in a dream. This initial reaction is a protective device that allows you to shut down in some ways as you prepare for what lies ahead. As the reality comes into focus, so too does the pain of your loss.

You may experience all kinds of difficult and surprising emotions. You may feel confused, sad, angry and lonely. You may feel guilty and regretful about things you might have done or not done. You may also feel relief that the person's pain is over or that the difficult parts of caring are over. While these feelings can be frightening, they are normal reactions to loss.

At times, you may feel your loss and grief overwhelm you. You think about what happened, cry and want to talk about the person who has died. At other times, your energy is taken up with day-to-day events. How you grieve will depend on many things – the kind of person you are, the relationship you had with the person who died, and what support you have in your life.

Most people find that over time, and with the help of supportive family and friends, they find their way through grief. While they still may have low days or difficult days, their grief lessens and they can pick up the parts of their life they have put on hold.

### Remember:

- Grief is a process and it takes time
- Everyone's grief is different
- There is no right or wrong way to grieve
- Strong emotions and thoughts are part of grief

## The experience of grief

Bereavement can be painful and confusing. There is no right or wrong way to grieve. No two people will react in the same way, but these are some of the experiences you might have:

### Feelings

You may feel sad, numb, irritable, angry, relieved, guilty, lonely, depressed, frightened or helpless. There are no 'right' feelings and feelings come and go.

### Physical

Grief can also affect you physically. You may find that your attention and concentration are poor or that you become absent-minded. You may feel more tired than usual, yet find it hard to sleep. Your appetite may change and energy levels may be low.

Other grief and stress reactions which are often experienced include nausea, lowered immunity, headaches and tightness in your throat or chest.

### Thoughts

You might find you spend a lot of time thinking about your loss and the events leading up to it. It is normal to spend time thinking about 'if onlys' and how things might have been different. Many people find they think a lot about why it happened.

Although you know the person has died, you may 'forget' briefly, particularly when you wake up. These thoughts may overwhelm or frighten you, but they are a normal reaction to grief.

### Social changes

You may find you need time alone or you may feel a need to tell the story of your loss many times over. You may find you seek out people who can understand your need to talk and distance yourself from people who are uncomfortable with this. You may be surprised at who can support you and who cannot. You may miss the people who helped care for the person who died and miss the routine in your life, your home help coming in, going to a day centre or visiting a nursing home.

## Experience of former carers

While each former carer's journey is unique, we are beginning to get a picture of what the journey is like for many. As a former carer you may experience many losses after the death. Some losses and experiences include:

- the loss of your identity as a carer and your caring role,
- the loss of the close bond you may have had with the person you cared for,
- the loss of the relationships with the network of healthcare professionals,
- the loss of carer-related financial supports, and
- difficulties returning to the workforce.

## The grieving family

When someone dies, it not only causes major grief for you as an individual, it also affects how your family functions. Each family grieves in its own way, just as each person grieves in their own way. No one can ever replace the person who died, but with time and good communication most families adjust to the loss and find new ways to function together.

### As your family grieves, remember

- Everyone grieves differently. Allow each member to grieve in their own way.
- Try to talk openly with other family members. Let them know how you feel and listen to what they have to say. Expect that others will have different opinions and points of view.
- When somebody dies, the family is changed and everyone has to adjust to those changes. This can be very difficult, but most families find their own way through it.
- It can help to talk to someone outside the family if your family is having particular difficulties.

For more information on the grieving family: <https://hospicefoundation.ie/wp-content/uploads/2012/08/00298-07-IHF-The-Grieving-Family-V4.pdf>

## How long does grieving take?

There is no set time for grieving. Grieving can be a lifetime process, with some feelings coming back many times. You may find that you feel a 'dip' around important dates such as anniversaries and birthdays.

You will find that your grief is less intense and eases over time. That does not mean that you are over your grief but that you are finding a way to re-engage in life without the person who died.

## What can help?

### Accept your feelings

Know that it is common to feel conflicting emotions. Relief is often mentioned as a feeling expressed by carers. Allow yourself to notice and accept any feelings of relief. Acknowledging feelings of relief is not disloyal – the person who has died was still loved and valued by you.

### Be kind to yourself

Try to rest, eat well and keep some structure to your day. Try to express your feelings with a good friend or write them down.

### **Be informed**

Consider reading about, or talking to, other people who were carers. While no two experiences are the same, you may share something in common. Seek out accurate information about grief and loss.

### **Asking for and accepting help**

Ask for and accept support, both emotional and practical, from friends and family.

### **Talk to someone you trust about your feelings**

This can be a good friend, another carer, an understanding professional, or supportive members of your family. The important thing is that you feel safe and accepted.

### **Know that people may not understand your grief**

People may have different ideas or expectations about bereavement. If you were caring for the person or the person you cared for was ill for a long time some people may think you have had time to come to terms with the loss. Your grief is your grief; not everyone may understand the complexity of your role as a carer and the toll it took.

### **Combat feelings of isolation and loneliness**

Over time, try to develop some new routines. You may find you have gaps in your day, particularly if you were a carer, and so may risk becoming isolated. Arrange to meet friends to do something enjoyable. Stay involved in activities you enjoy and consider new hobbies.

### **Remember that grief comes and goes**

Even though you may be coping quite well most of the time, there may be times when you feel particularly sad or upset. You may be reminded of the person who has died by something you see or hear, or on certain significant days like anniversaries or birthdays. This can bring on a surge of grief.

This does not mean that you are not making progress; this is simply the normal process of grieving. Your life has been changed forever by the person's death, but you may find strength within yourself you didn't know you had.

### **Remember**

Death ends a life, not a relationship. The person who died can still be important in your life. Try to find meaningful ways to keep a connection to them, such as telling stories about them, looking at photos of them and including their name in your conversations.

For more information on understanding grief: <https://hospicefoundation.ie/wp-content/uploads/2012/08/00298-01-IHF-Understanding-GriefV4.pdf>

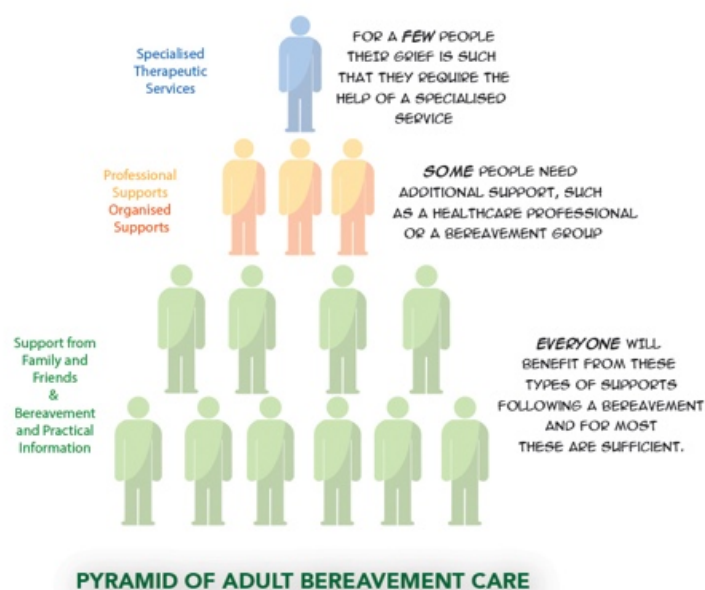
## **When to look for extra help?**

Grief and loss are normal life experiences and the best help and support often comes from people who care about you, like friends and relatives. Talking about what has happened,

and about the person who died, can help you to come to terms with their death and to cope with the feelings you have.

You might find it helpful to meet other former carers who have been bereaved, and attend a bereavement support group or avail of one-to-one support in your locality. It may help you to talk to people outside of family and friends or to get extra information. An experienced therapist can help you work through intense emotions and overcome obstacles to your grieving.

The pyramid of bereavement care outlines the different levels of support people may need after the death of someone close (See figure 1). Visit Care Alliance for a list of bereavement supports available.



**Figure 1: Pyramid of Adult Bereavement Care**

Designed by Medical Illustration Unit, St James Hospital, Dublin (printed with permission)

### It is a good idea to talk to your doctor if:

- You are worried about how you are coping,
- Your grief is intense and unrelenting and you feel your physical or emotional wellbeing is at risk, and
- you have serious and persistent thoughts or plans to end your own life or feel prolonged agitation, depression, guilt or despair.

A very small number of people get stuck in their grief and your GP can identify supports that can help, such as professional counselling. An experienced therapist can help you work through intense emotions and overcome obstacles to your grieving.

For more information see:

<https://www.carealliance.ie/userfiles/file/The%20Way%20Ahead%20Web%20SP.pdf>

## When someone you care about is bereaved

Grieving does not follow any set of stages. Bereaved people are likely to have some days when they feel they are doing quite well and other days when they may feel overwhelmed by their loss.

The needs of a bereaved person are often quite simple – they may need some emotional support, a listening ear, a shared cup of tea. They may also need some practical help – someone to answer the phone or pick the children up from school.

You may be worried that you might do or say the wrong thing. Remember, you do not need any particular skills or training to be supportive. More important than who you are, is how you are in the company of the grieving person. Often the best help that you can offer is your company and a willingness to listen and accept how they feel. There a

### **Support at the time of the death:**

- Try to attend the removal or funeral if this is appropriate.
- Take the time to make contact either by writing or by phone. A personal note that expresses your condolences and mentions any fond memories you have of the person who died can be very comforting.
- Express your sympathy in a simple way. Avoid clichés such as ‘it was for the best’, or ‘life goes on’ as they may give offence. Phrases such as ‘I’m so sorry’ or ‘you are in my thoughts’ are better. There are no words that will take away the pain.
- Make a brief visit and offer your practical help.
- Don’t avoid a bereaved person out of embarrassment or a fear of upsetting them. They may believe you don’t care enough to sympathise with them.
- Try not to tell them that you know how they feel; you can never truly know how someone else feels.
- Your own losses may be triggered when you talk to a bereaved person, but try not to recount stories of your own, or other people’s losses.

### **Support as time goes by:**

- Don’t assume they are ‘over it’ or have enough help.
- If you are unsure how to help, just ask.
- Don’t avoid mentioning the person who has died. Most bereaved people welcome the chance to talk. You do not lessen grief by avoiding the subject.
- Don’t offer advice on how they should feel, act or get on with their lives. Allow them space to make their own decisions.

- Try not to make vague offers of help such as ‘Call me if you need anything’. Bereaved people may find it hard to reach out and ask for that help. Make specific offers of help – cook dinner, cut the grass, go for a walk with them.
- Don’t feel offended if they refuse your offer of help or turn to someone else for comfort.
- Try to remember special occasions such as birthdays and anniversaries.
- Finally, mind yourself. Supporting a bereaved person is hard work. Know your own limits and only offer to do what you can reasonably do.

For more information on how to support someone who is grieving:

<https://hospicefoundation.ie/wp-content/uploads/2012/08/00298-02-IHF-Someone-you-care-about-is-bereaved-V4.pdf>

## Grieving in exceptional times

COVID-19 restrictions is impacting on how people are experiencing dying, death and bereavement. The nature of the illness is that it comes on relatively suddenly, family may be unable to spend time with the person who is ill prior to their death, they may not be there at the time of the death, due to current restrictions some of the ways we mark our grief is not possible and being physically close to people outside our household.

This is a very uncertain and upsetting time for us all. However, we can support ourselves and each other in managing our grief in new ways during this time. The following resources from the Irish Hospice Foundation offer advice and suggestions from planning a funeral in the current climate to acknowledging and coping with grief in isolation.

See: <https://hospicefoundation.ie/covid19careandinform/support-and-advice-on-grief-and-loss/>

## Source material and further readings

Bereaved.ie (under the auspices of the Bereavement Education and Resource Centre, Irish Hospice Foundation) have a wide range of online bereavement resources (including leaflets and videos). These resources cover loss from different types of deaths (e.g. death by suicide) and the loss of different relationships (e.g. death of a partner, death of a child etc)

Website: <https://hospicefoundation.ie/bereavement-2-2/bereavement-resources/bereavement-leaflets/>

Carers Alliance Ireland developed an information booklet for former carers in collaboration with a wide range of stakeholders. Website:

[https://www.carersweek.ie/userfiles/file/The%20Way%20Ahead%202020%20SP\(2\).pdf](https://www.carersweek.ie/userfiles/file/The%20Way%20Ahead%202020%20SP(2).pdf)

The Alzheimer’s Society of Ireland in collaboration with the Irish Hospice Foundation have developed three leaflets for families and carers coping with dementia. Loss and grief when a



family member dies with dementia. Website: <https://hospicefoundation.ie/bereavement-2-2/bereavement-resources/bereavement-leaflets/>

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