

# Cystic Fibrosis here for you

**Bereavement: losing a child  
of any age to cystic fibrosis**



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## Introduction

**“The reality is that we don’t forget, move on, and have closure, but rather we honour, we remember, and incorporate our deceased children and siblings into our lives in a new way. In fact, keeping memories of your loved one alive in your mind and heart is an important part of your healing journey.”**

Harriet Schiff, author of *The Bereaved Parent*

Being a parent is like nothing else in the world, and the bond with children is incomparable to other relationships; love, commitment, responsibility, guilt, fear and many other emotions can characterise parenthood. Identity and purpose can be inextricably linked with the role of a parent and so the loss of a child is not only a devastating personal loss but can also feel like a part of you has also died. Some people describe it as a physical loss of themselves; this may reflect emotional pain, but also a loss of identity as a mum, dad or carer.

The natural separation that happens between parents and their children as a child gets older is often, but not always, lessened by cystic fibrosis (CF). Poor health and the treatment burden associated with CF can mean that parents have a more active role in their child’s life into their adult years. The loss of their child can also mean a significant loss of their purpose and focus in daily life. In some cases a parent may have given up a career to be a full-time carer, so the gap in their life extends beyond their tremendous personal loss. Adapting to a new life and a new purpose can be very difficult.

## Grief

When a child dies, it goes against our sense of natural order. The sadness and grief can be overwhelming. This is the case whether your child dies in childhood or adulthood.

Grieving is often talked about as a process or a journey. And it is, but it's unique to you. The grief might not only be for the loss of your child but also for the loss of the milestones they might have reached and the future they might have had; it can feel desperately unfair and anger is a natural reaction to this life not fully lived. Sometimes people talk about the stages of grief, for example; starting with denial and moving into anger, depression and finally, acceptance. You may or may not relate to these stages or they could happen in a different order for you or not at all. Crucially, there is no right or wrong way to grieve.

However you feel, whether numb, sad, guilty, angry, scared, lonely, overwhelmed or empty, your feelings are 'normal'; it's how you are coping with your devastating loss. Everyone processes grief at different times; there is no limit on the time it takes to grieve so try not to compare your experiences with others who have been bereaved.

Sometimes people say that even many years after a death, something can happen that reignites their grief only for it to subside again.

As well as intense emotions, you might also feel the grief physically. Some people say they lose their appetite, can't sleep, can't concentrate or even think they see or hear their deceased loved one. People sometimes say they feel like they're 'going mad' – but it's not madness, it's your body and mind trying to come to terms with a new and very difficult reality.

When you're grieving it can feel like you won't ever feel 'normal' again; over time the overwhelming feelings associated with grief will decrease. It's important to remember that whilst these feelings diminish, life will always be different, and intense grief ending doesn't mean your son or daughter has been forgotten.

## Strategies for coping

Coping with your grief will take time. Your sense of loss may never leave you, but you'll reach a point where the intense, raw grief begins to lessen and you start to take part in 'life' again. Coping strategies will be different for everyone and finding out what works for you and your family is likely to involve a little bit of trial and error.

You may find it helpful to speak to and share your feelings with people you are comfortable with and ask for help if you need it. Take the pressure off yourself as much as possible. Your GP or staff from your CF team may be able to talk through any concerns you have. The Cystic Fibrosis Trust helpline is also available as a listening ear and the contact details are at the back of this booklet.

You might find online groups, perhaps even groups of bereaved parents, who will be likely to identify with some of the feelings and thoughts you have. Some churches or religious groups may also provide bereavement support. If you are returning to work following a bereavement, some workplaces also offer counselling or other assistance programmes for their employees. Your HR team should be able to advise you on this.

Try to look after yourself; eat and drink regularly even if you don't feel hungry, rest even if it's hard to sleep and try to get outside for fresh air. Some people find mindfulness exercises helpful when feelings become overwhelming. There are lots of mindfulness apps available for smartphones and tablets.

Although you can't escape grief, having distractions can help you get through difficult times. It can be really hard to see normal life going on around you when your world has been so drastically altered, particularly in the early days when your grief is likely to be so raw. Some distraction from this pain might help; going out for a walk with a friend or member of your family or meeting for a coffee. It won't fix your pain, but it may offer you some respite.

It is understandable that at such a difficult time, sometimes people seek to escape or numb their grief in any way they can, and for some this means turning to drink, drugs or other addictive behaviours. Ultimately though, these things can be self-destructive for many people. It can help to seek professional support to cope with your grief, and we have provided some links to organisations that can help at the back of this leaflet.

## Complicated grief

While there isn't a 'normal' way to experience grief there is an expectation that regardless of how you cope with your grief, at some point you will be ready to return to usual activities; engaging with family/friends, work and hobbies for example. Complicated grief is when this doesn't happen and instead grief triggers mental health difficulties. This can be more likely to happen if your son or daughter died in a way that wasn't in line with their wishes, died unexpectedly or you had any unresolved issues with them.

Some parents also experience guilt following the death of their child and this can sometimes play into their feelings of grief. If you feel you may be experiencing mental health difficulties then it is important that you discuss these with your GP so that you can access the help you might need.

**Cruse has good information on complicated grief that you may find helpful [www.cruse.org.uk](http://www.cruse.org.uk)**

## Coping with other people

People sometimes find it hard to know what to say to someone who is grieving, and sometimes they avoid the subject or say nothing at all. Stories of people crossing the street to avoid a recently bereaved friend or colleague are, sadly, common. If this happens to you, or people treat you differently, it's likely that they are uncomfortable and don't know what to say rather than deliberately setting out to hurt your feelings. Inappropriate remarks or clichés such as 'time heals' can be difficult to hear but again are usually the result of people doing their best to console without really knowing what to say. You may wish to deal with people directly and make it clear if you want to speak about your loss or not, or you might feel more comfortable just letting those around you offer support in their own way.

Anxiety about returning to work and dealing with work colleagues after a bereavement is common; there can be concern about what work colleagues will or won't say regarding your loss. It can help to have a 'stock answer' if your colleagues express their condolences or you might be able to identify a trusted colleague who you could talk to at difficult times and who could support you in sharing any information you want other colleagues to be aware of.

## Grandparents

As a grandparent, you may feel a bit out in the cold or less entitled to grieve, even though your feelings of grief may be intense. Some grandparents find that they are grieving for the loss of their grandchild while also experiencing the emotions of watching their own child suffer. Coping with your own grief, while supporting your child and perhaps other grandchildren can be incredibly challenging. It's likely that everyone will grieve differently and have their own coping strategies, which can sometimes be the source of friction. Giving each other space to express feelings and respecting their ways of coping might help reduce any tensions.

Some grandparents feel that people around them might not appreciate the depth of their grief. It can help to share your feelings and concerns with a trusted friend or partner – guilt, anger, regret, shock and a sense of numbness are all common. As well as acknowledging and working through your feelings, it's important that you also look after yourself physically; rest and remember to eat and drink. Keeping yourself well physically and emotionally will help you to support your child in dealing with their loss.

It's legitimate to struggle and to ask for help. The Compassionate Friends ([www.tcf.org.uk](http://www.tcf.org.uk)) have a leaflet called 'When our grandchild dies', which you may find helpful.

## Getting help

- **The Compassionate Friends** website offers a range of supportive leaflets and other information resources: [www.tcf.org.uk](http://www.tcf.org.uk)
- **Cruse** is a well-known and respected charity providing bereavement support through their network of volunteers. You can find out more about their services here: [www.cruse.org.uk](http://www.cruse.org.uk)
- **Child Bereavement UK** supports families when a baby or child of any age dies or is dying, or when a child is facing bereavement. They offer a range of services including information resources and a helpline. Find out more about them here: [www.childbereavementuk.org](http://www.childbereavementuk.org) or call their helpline on 0800 02 888 40.
- **The Samaritans** offers a 24-hour helpline and can be contacted on 116 123. They are there for anyone needing emotional support. You can find out more about their service at [www.samaritans.org](http://www.samaritans.org)
- **The Cystic Fibrosis Trust helpline**, while not a dedicated bereavement support service, provides a listening ear service run by trained staff who understand cystic fibrosis. You can contact the helpline on 0300 373 1000 (Monday–Friday, 9am–5pm) or at [helpline@cysticfibrosis.org.uk](mailto:helpline@cysticfibrosis.org.uk).

# Cystic Fibrosis Trust

**[cysticfibrosis.org.uk](https://cysticfibrosis.org.uk)**

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