

Cystic Fibrosis here for you

**Losing someone to cystic fibrosis:
coping with bereavement**



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Introduction

“There are no happy endings, endings are the saddest part, so give me a happy middle and a very happy start.” (anon)

Coping with the death of someone close can be one of the hardest things you'll ever have to deal with. Grieving is often talked about as a process or journey. And it is, but it's unique to you. 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 or not at all for you. Crucially, there is no right or wrong way to grieve.

Whatever you feel, whether numb, sad, guilty, relieved, angry, scared, lonely, overwhelmed or empty, is 'normal', it's how you are coping with your devastating loss. As well as coping with loss, people who've been bereaved often have worries and regrets about how they dealt with their loved one's final days; berating themselves for not realising that death was imminent or wishing that they'd had conversations about the end of life or said important things to their loved one. These anxieties are common. Try not to dwell on such regrets; often conversations don't take place because the person who is ill doesn't want to have that discussion.

When you're grieving it can feel like you won't ever feel 'normal' again; there's no set time for how long it takes to grieve. Bereavement specialists suggest that the most intense grief may last for around a year, but it can be more or less. Sometimes people say that even many years after a death, something can happen that reignites their grief only for it to subside again. Everyone processes grief at different times, so try not to compare your experiences with others who've been bereaved.

'Time heals' is a common phrase of condolence; rather than healing, perhaps it's more accurate to say that most people find that their grief becomes less raw over time and they learn to cope with feelings of loss. It's important to remember a change in the intensity of your grief is natural and doesn't mean your loved one is forgotten or any less missed.

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.



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– Andy

Coping with grief

“Jacqui was so special and lived her life to the full each day, and she took me with her. I did things and travelled to places I would never have dreamed of if it hadn’t been for Jacqui. We had 30 fantastic years together and I miss her desperately, but I wouldn’t change it. Jacqui died in October 2016. I’m surviving, I have an inner strength thanks to Jacqui.” – Andy

Grief is unique for everyone and even if you’ve experienced grief before, you might find it feels different depending on the nature of your loss. Everyone will cope in their own way but there are some things to bear in mind that might help you. Firstly, speaking about how you’re feeling can help; family members, friends, your GP or staff from your CF team could provide a listening ear. Try not to bottle things up inside; share how you’re feeling.

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“I had very valuable support from the CF team, but I also found speaking to a local priest – who didn’t know my brothers – useful and less painful in a way.” – Dom

“I want to talk about Becky and acknowledge her life and death. And I really want others to do the same. She touched so many people’s lives very positively and I want to keep that alive.” – Alasdair

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. If there are people around you that could help with practical jobs such as cooking or childcare, don’t be afraid to ask, it could help ease some pressure for you.

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 own 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.

“I found social media very helpful both whilst Becky was ill and after her death. I felt really supported by all the messages I received and also found it helpful as a way of sharing information. I also found writing about Becky and her death therapeutic, I’ve done this through a public blog and through social media although I think any writing helps get everything into perspective.”

– Alasdair



“Everyone copes differently, personally I found comfort in writing it all down. I found it therapeutic, but that’s just my way.” – Andy

Feeling guilty about moving on with life after a bereavement, particularly with enjoyable activities such as holidays or social activities, is a common feeling. But life will go on around you and at some point, when you feel ready, you’ll step back into this world.

Some people find that actively keeping memories alive can be therapeutic. Memory boxes can be created by a person before death; sometimes parents do this for their children. However, families can also create memory boxes after their loved one has died. The box could contain anything that is meaningful to you and your family; photos, children’s drawings or personal belongings (perfume for example). The process of creating the box can, for some people, feel positive. The memory box is a lasting keepsake for family and friends, giving a physical focus to their memories.

Significant anniversaries, such as a loved one’s birthday, can be challenging for family and friends but they can also provide a focus to come together and remember the person who has died. This may involve looking

through a memory box, releasing balloons, lighting candles or visiting a special place; there is no right or wrong, do whatever works for you and your family. The Compassionate Friends website (www.tcf.org.uk) has ideas for coping with anniversaries, which you might find useful. There is no right or wrong way to deal with anniversaries, and some people and families might prefer not to draw attention to the date.

Social media can be useful if you find the idea of a digital memorial comforting. Staying in touch and talking about your loved one on Facebook or other sites is, for some people, therapeutic.

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Some family members find it helpful to chat with someone from the CF team who cared for their loved one. CF teams can't usually offer bereavement counselling or ongoing support, but may be able to help answer any remaining queries you have about their death or just provide an informal, listening ear.

“Becky and I went on holiday not long before she died. I did worry that perhaps if we hadn't gone then she wouldn't have got the infection and wouldn't have died. I spoke to Becky's CF doctor about this. He was very clear that it wouldn't have made any difference and that it was a great thing that we went while we still could. Hearing that was very reassuring.” – Alasdair

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.

Family grief

It's likely that others in your family or friendship groups are also grieving for the loss of your loved one. You will all cope in different ways and at different speeds. Families sometimes struggle with these dynamics, feeling that certain individuals are grieving too little or too much. The intensity of emotion for everyone can affect family dynamics and cause tension. Keeping communication open by sharing how you all feel and what support you need can help the family to come together and cope with their shared loss.



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Bereaved siblings with cystic fibrosis

If you have CF and you've lost a sibling to CF, the grief can be particularly difficult. Not only are you coping with the loss of your sibling but their death may also heighten fears for your own future. Some siblings have said that this also brings a sense of pressure to stay well so as not to burden parents with further worry. Siblings with CF have also spoken about survival guilt associated with the loss of their brother or sister. This loss can create a range of complex feelings. Do speak to your CF team or GP for further support.

“There were four of us born with CF in my family, myself and 3 brothers. My brothers all died some time ago, the last in 1997. I definitely experienced survivor guilt and it remained for a long time. It's hard to reconcile what's happened; processing the grief but also thinking about your own situation.” – Dom

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) have a leaflet called 'When our grandchild dies', which you may find helpful.

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.

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 loved one died in a way that wasn't in line with their wishes, died unexpectedly or you had unresolved issues with the person who has died.

Cruse have good information on complicated grief
www.cruse.org.uk

Getting help

If you are struggling to cope or feel overwhelmed by grief, ask for help either via your GP or contact professional bereavement support (Cruse, for example). Links for further support are available below.

- **The Compassionate Friends** website offers a range of supportive leaflets and other information resources: 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
- **MIND** provide advice to anyone experiencing a mental health problem. Their helpline offers information about support available for mental health problems, including bereavement and addiction issues. You can call 0300 123 3393 or visit www.mind.org.uk
- **Widowed and Young (WAY)** is a national charity providing peer to peer support for men and women age 50 and under, who have been bereaved: www.widowedandyoung.org.uk
- **The Cystic Fibrosis Trust helpline**, whilst 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
- **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 services at www.samaritans.org



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