The
Compassionate
Friends

Grieving for our child who had disabilities or complex needs

A nationwide organisation of bereaved parents and their families offering support after a child dies.

Grieving for our child who had disabilities or complex needs

To lose a child is the greatest pain a parent can endure. Those of us whose child had a disability will have already faced challenges in our parenting. Our dreams for our child’s future may have been shattered as we realised the implications of their condition.

We have had to come to terms with the effect that their limitations and special needs had on them and the rest of the family, and developed appropriate attitudes, responsibilities and skills in our roles as carers. Even if they had a life-limiting condition, we might still have felt unprepared for their death. We loved our children just the way that they were, and their absence from our lives is hard to bear.

(In this leaflet we are discussing issues particularly related to the death of a child, of any age, who had disabilities or complex needs. You may also find it helpful to read it alongside The Compassionate Friends [TCF] leaflet, When our child has died of a long-term illness. Alternatively, the leaflet Grieving for our child who experienced mental health problems may be appropriate in your circumstances.)

Our loss

> *“As a parent of a disabled child you become an expert on what is wrong with them and the things you have to do for them to have as normal a life as possible. You learn all you can to give your child the best in any situation. Their death leaves a massive gap.”*

To be bereaved of a much-loved child is heart-breaking. We may have had a child with learning difficulties, physical disabilities, mental health issues, neurodiversity, multiple health problems, a lifelong disability, complex needs, or a disability following an injury or illness. We may have been grieving already, in some respects. We have already experienced the pain of watching our child deteriorate in health. They may even have made progress in their health on occasion. Now it can feel like this has been so cruelly snatched away from us.

There may have been uncertainty in the lead up to our child's death. It might have appeared likely or it might have been unexpected. Whether or not it was anticipated, it still might have come as a complete shock. We may have the sense that there was never enough time to say our goodbyes and create precious memories.

The death of our child is an unspeakable, agonising loss with many layers.

If we have been bereaved of our only child, our pain at the loss of our parenting role may be intense. We have been bereaved not only of our child, but also perhaps of hopes and dreams for the future. This is a massive loss to deal with.

For those of us who bereaved of a younger child, we may find that we are also grieving for their shortened lifespan. Surely life could have held more for them?

For those of us who have lost an older child, we will also be grieving their shortened life and the limitations they faced in that life. We may grieve for their unfulfilled hopes, such as not being able to have a partner and family of their own, or we may be grieving their absence alongside their partner and children.

In spite of what others may have thought, our child was leading a full life, within their personal limitations. We knew that their successes may have looked different to other children's successes. We had different criteria. Their health and happiness were our prime concern, and we worked hard towards them gaining as much independence as was possible. We were glad to see any progress that they made, even if it might have taken them longer to acquire new skills or develop in other ways.

We may find some comfort in remembering what brought them happiness. Managing to smile or sit up unaided might have been an achievement, or perhaps our child was able to attend school or eventually work independently. However big or small their achievements, whether it took a short or long time to achieve them, they are still special to us and worth celebrating. We may have photos of these moments, or we could choose to write about them, and so help preserve these precious memories.

The changes brought about by our child's death

> *"My child was autistic. They had all sorts of rituals and routines to deal with daily life, and our day was structured around them. Now they have died, all of those things are gone, and life seems so aimless."*

Depending on our child's particular needs, we may find that the entire structure of our life has now changed, and we must find a new normality in the future.

We might have spent more time than most parents caring for our child on an everyday basis, perhaps even into their adult years. This closeness makes their death very difficult to bear. Now there are so many hours to fill when we were once so busy. We may have come to know health, social workers and other support staff as friends through our regular visits to hospitals, clinics and day centres, and we now find ourselves without their support in our grief. The years of caring will have taken their toll on us physically and emotionally, and many of us now face our bereavement following years of worry.

We may also start to realise just how much of our life we put on hold to care for our child. Friendships, relationships, careers or any other personals goals may have taken a backseat. We may have become isolated due to our caring responsibilities. And while we were glad to focus on our child for all of that time, this is going to impact us going forward. It is natural to question what is now our role in life.

We may eventually find ourselves thinking more about the future and how to make use of the increased time on our hands. Perhaps we will start to think about how to pursue our goals, personal interests and wider social contact. Looking forward with hope and without guilt are good things, if we can manage them. The fact that we are now starting to live a different life does not diminish the love we continue to hold for our child.

Coping with a mixture of feelings

> *"Sometimes I feel in a muddle. I was sitting there crying for my child, missing them so very much, and then it struck me that I can finally go to Australia to visit my sister, something I had been unable to do all these years. This combination of grief and relief is hard to deal with, and sometimes I do feel guilty."*

Over the years, we might have been faced with difficult decisions, not only about what was best for our child, but also what was best for the rest of the family and what we were all capable of. We may have also struggled getting the support and care they needed. We might have wished to keep our child at home, but circumstances made this impossible, and our child may have gone to live in a supported facility or care home. Some of us look back at these decisions with regret, perhaps overlooking the actual circumstances of the time. We did the best we could. We loved our child and gave them the best care that could be provided, and sometimes this required other people's involvement.

Some of our feelings may be quite conflicted. For instance, it might come as a partial relief that our child is no longer suffering, or that our lives are no longer constrained by their needs. It can be very hard to admit this to ourselves. There may also be some relief in looking to the future, as we will no longer have to worry about who will look out for them when we are no longer able to do this ourselves due to age, infirmity or our own death.

If we have a partner, there will be some comfort in sharing our thoughts and feelings together, although they may be coping with our bereavement in quite different ways to ourselves.

For single parents, it may feel that no one else understands what we are going through. We may also feel overwhelmed with the multiple practical issues we have to sort out after our child's death.

It can be a great relief to share such thoughts, whether we choose to reach out to close friends or family, or seek support from other sources such as counselling or through The Compassionate Friends (TCF) Facebook pages, online or in-person groups. It may help to write down how we feel or to read about other people's experiences. We may also benefit from activities to relieve tension, such as creative work, exercise or relaxation.

Our surviving children

If we have other children, we have always had to reassure them that we did not love them less because we spent so much time caring for their sibling. Now the whole family has to make many adjustments to our loss. In the past, social activities may have been limited by the disabled child's needs. Like us, our surviving children may experience guilt when they feel relief that such constraints have gone, even though they loved their sibling dearly and, in many cases, helped to look after them.

Along with their grief and sadness, and perhaps unfounded guilt, there could be some resentment. Children may look back and feel as though they missed out due to their sibling's care needs. Some children may feel that they had to grow up very fast in order to support their sibling.

Depending on their age and level of maturity, it may be helpful to explain that it is perfectly normal to have these mixed feelings after a bereavement, and they need not feel bad about them. Focussing on happy memories, perhaps doing some craft or remembrance projects together, may help them.

Support for grieving children is provided by various charities, including:

Child Bereavement UK: **ChildBereavementUK.org**

Winston's Wish: **winstonswish.org**

Having surviving children living with a disability, whether or not it is the same condition as their sibling, can cause us great worry. We may be anxious for their future, feel a loss of confidence in our parenting abilities, or that there is too much out of our control. These feelings and fears, whether they are real or unfounded, need to be faced. We might need additional support to cope until we can get back up on our feet again. It may be worthwhile contacting our GP for advice, or a charity for this condition as they sometimes have ongoing support for parents.

Other people’s attitudes

Sadly, we live in a world where those with disabilities are not so readily valued in the community as their non-disabled peers, and are considered to make less of a contribution to society. Families with disabled children are often viewed with a mixture of pity and admiration for the way in which they manage their lives.

Some people may not comprehend the depth of our grief. Even if some of us feel a degree of relief that our child is no longer suffering, our overwhelming sense is of the pain of our loss. Not everyone understands this. On occasion we may be on the receiving end of appropriate comments that can hurt deeply, especially if they imply there is anything positive in what has happened.

There is no right or wrong in terms of how we choose to respond to insensitive comments, although sometimes planning in advance how we may react can help us feel a bit more in control. We love our child dearly. They mean so much to us, and we miss them desperately. This is something we will want to keep expressing. Like any other bereaved parent, our grief is incredibly hard to bear.

Using our experience

Our months or years, however few or many, of looking after our child will have taught us a lot. It is likely we will have developed resilience, patience and an outgoing concern for others, as we gained awareness of the many challenges people living with these conditions face every day. We perhaps have found strengths we did not know we had until we were put in a situation where we needed them. We may feel empowered to use what we learnt to cope with future challenges, although it is perfectly normal to not feel this way when our grief is fresh.

Eventually we might decide we want to use our own experiences to help others. For example, we may choose to volunteer or fundraise for a charity that supports other children living with the same condition our child had.

It is likely we have met other families and children going through similar experiences. We may have gained life-long friends from this, and we may continue to share mutual hope and encouragement.

Some of us may like to write a blog or do a vlog about our experience supporting our child during their life in the hope that it possibly helps other people. We may eventually want to volunteer in some capacity with The Compassionate Friends to reach out to fellow grieving parents who have also lost a child with a disability, and reassure them that they're not alone.

Having more children in the future

The question of whether to have more children, if we have this possibility, is something we may find difficult to answer, particularly if our child's condition had a genetic cause.

We may fear the thought of watching another child endure similar challenges. Alternatively, we may feel as though we can channel our experience with our child into a positive. We may want to use what we have learnt to guide and look after our future child or children.

There are a range of possible sources of support to help us make a decision about having more children, including genetic counselling, a charity associated with the condition, other parents with children with the same condition, trusted friends or family, and our partner. Ultimately, however, this is a decision to make for ourselves. There is no "correct" answer here.

Going forward

> *"It has been a privilege and an honour to be the mum of a disabled child. My whole world has changed since she is gone from my sight, but I will have her in my heart always."*

Our child was an individual. Their sense of humour, their personality, their likes and dislikes, their hobbies and interests are all part of who they were. As we remember them, the limits of their condition or disabilities may fade in importance as we focus on other elements of their life. We can enjoy talking or writing about them, keeping a memory box, or honouring their memory in other ways.

Our children have taught us much. Their legacy includes all that we have learned about love, joy, patience, perseverance, courage and acceptance through them. We are proud to have been their parents, and we will carry them in our hearts for ever.

Further reading

The Compassionate Friends (TCF) have published a range of leaflets to support parents who have experienced the death of their child. The following titles could be helpful at this time:

- *Living with grief*
- *When our child has died of a long-term illness*
- *Grieving for a child who experienced mental health problems*
- *Our surviving children*
- *Handbook of ideas for remembering our child*
- *Coping with friends, family and social situations*

TCF leaflets can be read and downloaded at this link:
tcf.org.uk/leaflets

Printed copies are available from the office, free of charge for bereaved parents (see contact details on the back page).

The
Compassionate
Friends

Call our National Helpline
0345 123 2304
The helpline is open from 10am - 4pm and 7pm - 11pm every day.
Calls are always answered by a parent whose child has died.

Email our National Helpline
helpline@tcf.org.uk

For more information and support visit
tcf.org.uk

Find us on social media
@tcf.org.uk
@TCFcharityUK
@thecompassionatefriendsuk

General enquiries	TCF library
0345 120 3785	**0345 120 3785**
info@tcf.org.uk	**library@tcf.org.uk**

This leaflet is sponsored by Carol Maindonald.
In loving memory of Emma Elizabeth
my lovely smiley girl who is missed every day xxx

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