



The
Compassionate
Friends

A photograph of a garden with large green leaves and purple flowers. The flowers are in various stages of bloom, and the leaves are vibrant green. The background shows a stone wall.

Grieving for Our Disabled Child

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

Grieving for Our Disabled Child

To lose a child is the greatest pain a parent can endure. Those of us whose child had a physical impairment, learning disability or other condition that is seen as a disability – whether since birth or following an accident or illness – 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 love our children just the way they are, and their absence from our lives is hard to bear.

(In this leaflet we are discussing issues particularly related to the death of a disabled child. 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*.)

Our loss

The death of a much-loved child is heart-breaking. Some of us may have had a child living with learning difficulties, or a child with more physical disabilities. There also may be those of us with children who faced issues around their mental health, or multiple health issues. Due to the nature of the care our child needed, we may find that the entire structure of life has changed for us, and we must find a new normality in the future.

The age at which our child died will impact on our experience. For those of us who lost a younger child, we may find that we are also grieving for the loss of hopes and dreams we had for their future. For those of us who have lost an older child, we may find ourselves for not only grieving for their loss, but also what they brought to our lives over the years as they grew and developed into adults. They may have made progress in their health, and however small or big, it can feel like this has been so cruelly snatched away from us.

In spite of what others may have thought, our children were leading full lives, within the limits of their physical or mental abilities. We did not necessarily expect academic success or highly-paid jobs for them – unless, of course, these were realistic aims. We had different criteria. Their health and happiness were our prime concern, and we worked hard towards gaining some degree of independent living for them. We were glad to see any progress that they made, however long it may have taken for them to acquire new skills.

We may like to think of ways we could to remember any achievements our child made, and use this as a way of marking their memory. This could have been saying their first word, or getting their highest mark in an exam at school. However little or big the achievement was, whether it took a short or long time to achieve it, it is still special to us and so finding a way to treasure this forever can be of great comfort. We may have photos from these special occasions that we may gather, or we could decide to write about such occasions in a diary.

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 brother or sister. 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

problems. Our surviving children can sometimes feel guilty when they experience a feeling of relief that such constraints have gone, even though they loved their brother or sister dearly and, in many cases, helped to look after them. We must tell them that it is perfectly normal to have these mixed feelings after a bereavement, and they need not blame themselves. We should try to focus on the happy memories we have of their sibling's life, and their abilities rather than their disabilities.

A mixture of feelings

There still may have been a lot of uncertainty in the lead up to our child's death as to when it was likely to happen, but whether or not it was anticipated, it still can come as complete shock.

Many of us have experienced the pain of watching our child deteriorate in health. The memory of this can be just as painful as the death itself, and whether this was over a shorter or longer period time, it is likely to be equally as devastating. We may feel we never had enough time to say our goodbyes and create precious memories, or feel distressed that our child had to endure so much for a significant period of time.

On the other hand, we may look back on such experiences with great comfort and love; it may have brought our family closer together. We might feel a sense of ease that our child was well looked after and made to feel as comfortable as possible.

For some of us 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 that, even to ourselves. The years of caring will have taken their toll on us physically and emotionally and we may now be more free to lead a life with more options.

(Please see the TCF leaflet *When Our Child has Died of a Long Term Illness* for more on this topic.)

Some of us may take a lot of comfort in sharing our thoughts and feelings with our partner, and they may be the first people we turn to for support. On the other hand, we might find how we feel and choose to cope with the situation is very different to our partner's way. This may cause tension and conflict. We may benefit from reading TCF's *Grieving Couples* booklet.

For lone parents, it may feel like we have no one to share this pain with no one else who will understand 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. The idea of not having someone to support us with this can be equally difficult as coping with the emotional aspects. It can help to reach out to someone we trust for support, whether this is a family member or a friend. The TCF leaflet *The Bereaved Lone Parent* might also be good source of support for us.

The changes brought about by our child's death

Depending on our child's particular needs, we might have spent more time than usual caring for our child on an everyday basis, even throughout their adult years. After their death, there are all these hours to fill when we were once so busy. We have come to know health and social workers as friends through our regular visits to hospitals and clinics, and we find ourselves now without their support in our grief. Many of us are facing our bereavement at the end of years of worry, and we are already drained.

It is also times like this where it may really hit us just how much of our life we put on hold to care for our child. Friendships, relationships, careers or any other personal goals may have taken a backseat. And while it is something we'd do again and again, we may also see these as losses too. It is natural and understandable if we find ourselves questioning our role in life is now.

It can be an enormous relief to share such thoughts, whether we choose to reach out to our loved ones, or seek support from another source such as counselling or through The Compassionate Friends (TCF) forum, Facebook or groups. We may take comfort in writing down how we feel or reading about other peoples' experiences, and learning about how they coped. There are also those of us who may gain more from engaging in various activities to relieve tension, such as some form of art work or gentle exercise.

We may eventually find ourselves thinking more about the future, and how we now may have more time for goals or personal interests we previously set aside. It is easier said than done, but it is important to try not to feel guilty about this. This does not diminish the love we have for our child.

If he or she was our only child, our feelings of loneliness may be amplified. It can feel like a double loss, as we haven't just lost our child but our role as a parent too.

(See TCF leaflets on *Living with Grief*, *A Mother's Grief*, *A Father's Grief* and *Childless Parents* for more on these topics.)

Other people's attitudes

Sadly, we live in a world where those with different abilities are not so readily valued in the community as their able-bodied peers, and are considered to make less of a contribution

to society. Families with disabled children are viewed with a mixture of pity and admiration for the way in which they manage their lives.

Some people find it hard to believe that we love our child as much as any parent does. This is reflected in the attitudes we encounter when we pass on the news of our bereavement. We hear comments such as, "It must be a relief to you now that your burden has gone," "You'll have plenty of time now to get on with your own life," and "It's all for the best – a blessing that s/he has died." We share none of these sentiments, and soon realise that often we are thought not to be deserving of the sympathy that is offered to those who have lost a "normal" child. This may make us very angry.

It may help us to anticipate such comments, which of course probably have well-meaning intentions, and think about how we could respond to them. For example, we may decide we want to use this as opportunity to share the positives of our experience raising our child, or let people know how much our child meant to us, and gently remind people that like any other parent going through this, we are finding this incredibly tough. There is no right or wrong in terms of how we choose or choose not to respond, though sometimes planning how we may react in advance can help us feel a bit more in control.

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 gain 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 everything we learnt to cope with future challenges.

We might now decide we want to use our own experience 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 have may have gained life-long friends from this, and given us some much needed hope and encouragement during our journey in supporting our child.

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. Alternatively, we may like to use blogging or vlogging as a way of reaching out to fellow grieving parents who have also lost a child with a disability, and reassure them that they're not alone.

Our surviving children

Older children may look back on their life with their sibling, and even though they love them, might feel as though there is a lot they missed out in life due to there being a lot of attention and focus on them.

Children of a younger age may look back on their experience and feel like they have had to grow up very fast in order to support their siblings, others may even feel an amplified sense of loss as living with their sibling and their disability has been all they've ever known.

These are just a few examples of the kind feelings different ages may bring, but of course everyone's experience is unique and individual.

(For more on this topic, see the TCF leaflet *Our Surviving Children*.)

For those of us who have surviving children living with a disability, whether or not it is the same condition our late child had, it can be a very worrying time for us. We may have lost confidence in our ability to look after them due to our child's death. We may also feel incredibly anxious for their future -- what if the same thing happens to them?

It is worth us remembering that while this is a natural way to feel, there can be a lot of things in our lives that are beyond our control however hard we try. Our child's death doesn't in any way reflect our abilities as parents, and though it is easier said than done, we must try not to let it knock our confidence if we have surviving children, whether they have a disability or not.

It might be an idea to write down the things we are proud of and pleased with about our experiences as parents, and look back at this if ever we are going through a difficult period.

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 enduring similar challenges. Alternatively, we may feel as though we can channel our experience with our late child into a positive. We may feel confident in using what we have learnt to guide and look after our future child or children.

Going forward

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.

Who are the Compassionate Friends?

The Compassionate Friends (TCF) was founded in 1969 by a hospital chaplain and a group of bereaved parents who recognised the lack of support and understanding they were receiving from those who had not suffered in this way. This leaflet aims to share the experiences of all of us bereaved parents and most especially those aspects which came upon us so suddenly and, sometimes, with no warning.

The reading of this leaflet may be your first real contact with TCF. We hope it has given you a little comfort, perhaps showing you that your pain and worries are shared by others. TCF publishes over 30 leaflets, on different aspects of grief which follow the death of a child. All of them are available at no charge to bereaved parents and siblings (but a small donation is, of course, always welcome).

If you would like to hear more about our work and access further support, you could ring our Helpline number on the back page of this leaflet, and you will be able to talk to one of our volunteers, all of them bereaved parents. He or she could give you the number of a Local Contact and details of any Local Group which may meet regularly in your area. You could also find out from them details of our occasional retreats, when a small number of bereaved parents meet and talk in peaceful surroundings. Most years there is a weekend gathering, to which all members are invited.

Our website at **www.tcf.org.uk** has more information about our services, how to join TCF as a donating member, private Facebook groups, and support forum where bereaved parents can 'talk' online. We also publish a quarterly journal, *Compassion*, containing articles and poems written by our members about their own experiences. And, if you would also like further reading, please contact our Library for details and recommendations of books on all aspects of bereavement.



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