



The
Compassionate
Friends

When Our Child has Died of a Long Term Illness

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

When Our Child has Died of a Long Term Illness

We all wish that our children will live long, healthy and happy lives; as parents we want the best for them and to do all that we can to make this happen. It is an immense shock to discover that our child has a life-threatening illness, whether it is cancer or any other condition.

We find ourselves thrust into a new and frightening world, where we are not in control; we are forced to see them suffer pain and distress; and, ultimately, we are powerless in our struggle to keep them alive. When they die, we are worn down by the battle with their illness and have few resources left to sustain us in our journey through grief and loss.

When did it all begin?

Some of us knew from the birth, or soon after, that our child was suffering from a terminal illness, and that our time together as a family was likely to be limited. Others of us enjoyed carefree years of good health for our child, with the illness and eventual diagnosis coming as a dreadful shock. Either way, we learned to structure our lives around the fact that the unthinkable could happen - our child might die before us.

Most of us, looking back, feel that a part of us began to grieve when we received the initial diagnosis. As we prepared to fight for our child's life, we realised for the first time that death

was something that might happen to our child, our family, and we began to live under the shadow of that knowledge.

Grieving, fighting and hoping

After the initial feelings of shock, disbelief and anger, we invested our energies on the fight ahead. During our child's illness we will have had to adapt our own lives, routines and home spaces, and the care of our child will have taken centre stage. If we have other children, this will have also been a hard time for them, and we will have had to remember their needs as well.

Many terminal illnesses bring an emotional rollercoaster of hope and fear: surgery or drug therapy may bring remission, a welcome period of normality and expectancy that the worst is past, only to have our hopes dashed as symptoms return with renewed intensity. We may have experienced deep despair.

If our child was an adult, we may have had to accept their right to confidentiality and control over their treatment. If they had a partner, s/he may have been the prime carer, and we might not have been as present as much as we might have wished.

The early days of grieving

When our child died, our world was turned upside down, just as it was when we first heard the diagnosis. Death is always a shock, even when expected -- a time when all hope has finally been snatched away and we must begin to face a future without our child. Caring for our child has been the focus of our lives, and suddenly we are left with a great void.

Often one of the hardest things to adjust to is the loss of structure and purpose to each day, which was until now built around the needs of our sick child. It is difficult to re-enter the world of those everyday practicalities which seem to dominate the lives of “normal” families, and which now seem so trivial in the face of our tragic loss.

Perhaps it should feel that we have more time on our hands now that the intense, ever-present concern about saving our child is over, but the fight to save them will have taken every ounce of emotional strength. This, along with our emptiness and fear for the future, can make it almost impossible to face the tasks of daily living, as well as those resulting from our child's death, such as memorial arrangements, and so on.

Sometimes the care of a child with a long-term illness or disability has not only defined our lives, but being with other parent-carers has also provided our support network and social circle. When we are no longer a carer, we may lose this support. We may feel that we no longer qualify to join in social events and outings, or that other parents find it difficult to deal with us, knowing that they may be facing a similar outcome at some point. This is perhaps the reason why this time is made worse for some of us. We may now find ourselves cut off from the support networks surrounding the illness and treatment that have sustained us.

If our child was in a hospice, we may discover that many hospices continue to be involved with families through the early weeks and months of bereavement, recognising how big a part they have played in the life of the family during the illness. Inevitably, though, beds are filled with other sick children, and our family has to find a way to cope with a life without our beloved child.

If our child died at home then any specialist equipment is collected, along with unused medications or dressings. As the daily stream of visitors ends, our feelings of loss and isolation can be increased.

The death of our child may also have affected us financially if we were in receipt of benefits, as these may stop if we are no longer officially a carer. We may even have to consider moving home if we are in rented accommodation and the size of our home or number of bedrooms is now considered excessive. All of these changes can be frightening and add to the uncertainty we may be feeling as we face our changed future.

We should not be afraid to ask for help from family and friends at these times. The Compassionate Friends (TCF) can also be a great source of support via the telephone helpline. Chatting with other bereaved parents on the online forum or Facebook pages can be very strengthening as we realise that we are not alone in what we are facing.

Within our close family relationships, we may discover, perhaps for the first time, that each of us grieves differently; we may have been united in fighting the illness, but coming to terms with the death of our child is a different sort of journey. The TCF leaflets *Grief of the Newly Bereaved* and *Grieving Couples* talk about this in more detail.

If we are single parents coping with our child's illness and death, we may feel that we have to bear our grief alone, even when family and friends offer help. We may also carry painful memories of difficulties with our child's other parent during treatment, or of arguments over access that have reopened old wounds. Perhaps there has been a welcomed

element of sharing throughout the illness which, when it is withdrawn after the death, causes additional sadness. (See the TCF leaflet *The Bereaved Lone Parent* for more on this.)

When our only child has died, we may feel our role as parents has been stripped from us, and that a part of our own existence has been destroyed. Nothing has meaning any more, and we feel deep despair and a loss of identity as a parent and carer. (See the TCF leaflet *Childless Parents* for more on this subject.)

Helping our children

Our surviving children need our time, love and attention. Their lives have been disrupted and deeply affected by their brother or sister's death, and we have to find ways to plan the future together. In these early days, that seems impossible to achieve. Once the funeral is over, we should try to arrange shared times. This might be with one parent doing something with just one child, to make them feel special.

Parents often try to grieve in private, thinking that their children have seen enough sadness. However, our surviving children need to see us weep, or weep with us, otherwise they may secretly wonder whether we were unaffected by the death of their sibling, and whether we would shed no tears for them if they were dead. Our shared sorrow also gives them "permission" to express their own feelings.

Sometimes our children have carried their own secret fears for a long time. They may have worried that they too were going to get sick; that something they did made their brother or sister ill; that we love our sick child more than them; or that they would be loved more if they were to become ill themselves.

They may have felt resentful or jealous, and now feel guilty. Perhaps, if we have been preoccupied and distressed, they may have been wary of sharing these thoughts with us, or they may be ashamed of “bad” feelings. If these issues can be discussed openly, it will help to prevent our children carrying these burdens through the rest of their childhood and beyond.

Young children do not understand the finality of death. If their brother or sister has been in hospital for a long time, nothing much for them has changed – except that we no longer visit the hospital. We have to try to understand their thoughts and fears, to recognise their need for repetition of the key facts about death, and to be brave enough to share our own grief with them. We must reassure them that it is all right to cry, and that while loving hugs do not take away the pain, they are better than weeping alone. We need to be aware that as perception of death changes with cognitive development, they will need new explanations at an age-appropriate level.

In some ways, it can be harder to share grief with our older teenage children; for them, friends will be very important, and we have to respect their choices. They will benefit from times when they visit friends and escape the atmosphere of sadness at home, but they also need to feel included within the embrace of a loving family.

Please see the TCF leaflet *Our Surviving Children* for more on this subject.

Caring for ourselves

While our child has been ill, we will have been juggling, both practically and emotionally, with the daily routines of the rest of the family, but with the overwhelming priority of keeping our sick child alive always in the forefront. Friends may have helped us to have short periods of time away from the caring, but these have been interludes. Now we must give ourselves time to mourn the death of our child, to reflect upon the past months and years, and give these life-altering experiences time to settle into the fabric of our being. It may seem less painful to launch ourselves into another frenzy of activity, perhaps fund-raising for a charity researching into our child's illness, or setting up a trust in his/her memory. These are important and valuable things to do, but they do not replace our need to face what has happened. For some of us, a return to work may give us a structure to our days. Others find the workplace too stressful to contemplate. The TCF leaflet *Back to Work* discusses this issue more fully.

We need to be kind to ourselves, to create time to be with those who love us, such as a partner, close family and/or friends, to nurture ourselves back to good health, to overcome exhaustion. The idea of enjoying a treat, or laughing at something, seems beyond imagining in the early days. We must catch and hold on to these fleeting moments of happiness when they appear, and not feel guilty that we can feel pleasure even though our child is dead. Each individual has to find her/his own way through the paths of grief. Often well-meaning friends are full of advice, wanting us to “get over it”, and become our old selves once more. We cannot return to a time when our child was alive and healthy, and so we are permanently changed.

We should also take the time we need to gather our thoughts about what has taken place. If we have any lingering concerns about the care of our child, we may want to speak with their health professional team. (TCF Factsheets on NHS Complaints provide some helpful guidance.)

Some of us must also face our fears concerning the possibility of our remaining children – or children yet to be born – suffering from the same condition. Such fears may not be groundless if there was a genetic component to our child's life-limiting illness. If we are in this difficult position, it can be advisable to seek professional advice and support, perhaps speaking with the specialist team that cared for our child in the first instance.

The future and the family

Our family has been fractured, divided by death, but it is still a family. Gradually we find ways of carrying our dead child with us into the future, even though their physical absence will always leave a void. If we have younger children, or if we have another child after the death, we can help them share in the re-telling of the family story so that it can develop as they grow older. By making memory books and photograph albums, or using digital resources (see the TCF Factsheet Digital Legacy for more on this), we can produce collections of words and pictures in remembrance of our children who have died, and share these with our family – especially at times of celebrations and anniversaries. All children enjoy hearing stories about the family in past years, and so our child can take a rightful place in our collective family history, and live on through subsequent generations. We should avoid the “silence trap”, that uneasy feeling that there is something that we do not talk about.

If we are in the tragic situation of having no surviving children, our lives and actions need to be witness to their life. Whatever our circumstances, we are still our child's parents; they live in our hearts and memories, and we always will hold them close.

The way forward

Our grieving will probably have intensified our awareness of each other and our sense of 'together yet alone'. Our lives do continue, and the insights into our relationship, that have been so painfully discovered as we grieve, may enrich our partnership in the years ahead. We are inevitably different people after the death of our child, but the need to remember our child and to share memories will always be there.

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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UK Helpline:

0345 123 2304

Northern Ireland Helpline:

0288 77 88 016

General Enquiries

0345 120 3785

E: info@tcf.org.uk

TCF Library

0345 120 3785

E: library@tcf.org.uk

www.tcf.org.uk

Founder: The Revd Canon Dr Simon Stephens OBE

President: The Countess Mountbatten of Burma