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 do all that we can to make this happen. However, not everything is within our control. 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. We are forced to see them suffer pain and distress. Ultimately, we are powerless in our struggle to keep them alive. When their life ends, we are worn down by the battle with their illness. We have few resources left to sustain us on 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 was likely to be limited. Others of us enjoyed years of our child's good health before illness and eventual diagnosis came 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. Even as we prepared to fight for our child's life, there came a point when we realised that they might die. 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 in the fight ahead. During our child's illness we will have had to adapt our own lives, routines and home spaces. The care of our child will have taken centre stage.

We exhausted ourselves by living in a continued state of hyper-anxiety. We may have been unable to eat or sleep properly for long periods, and might have needed medication to keep going. We may have spent long periods with them at the hospital. Perhaps we witnessed our child undergoing painful procedures. We may have nursed them right to the end, without ourselves having medical or nursing training. We may have become exhausted and traumatised, all while needing to maintain a cheerful, brave face for our child's sake.

There may have been intolerable strains within the rest of the family. If we have other children, this will have also been a hard time for them, and we will have had to take care of their needs as well.

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, they may have been the prime carer, and we might not have been present as much as we would have wished.

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 hopes dashed as symptoms return with renewed intensity. We may have experienced deep despair.

Our child's suffering may have been so severe that we found ourselves sometimes hoping and praying for the end to come. The fact that we thought this way is not surprising. We love our child and did not want them to suffer. Still, remembering our thoughts might leave us feeling confused. On similar lines, when the end finally came, we might have felt a degree of relief. Now we wonder, how could we have felt glad that our child had left us? Needless to say, these feelings would have quickly passed, replaced by intense sadness, pain and perhaps guilt.

The early days of grieving

The death of our child turned our world upside down, just as when we first received their 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 them has been the focus of our lives, and suddenly we are left with a great void.

It is not easy to adjust to 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 most households, and which now seem so trivial in the face of our tragic loss.

Now that the intense, ever-present concern about saving our child is over, we might have more time on our hands, 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 leave us struggling to face the tasks of daily living. This is on top of what must be taken care of in relation to our child's death, such as funeral arrangements, the return of medical equipment, 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. We may also fear that other parents will find it difficult to be in our company, knowing that they may be facing a similar outcome at some point.

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. We may soon find that this is no longer a place for us.

The end result is that we may soon feel adrift and alone, cut off from our usual support networks. In addition, as the initial stream of visitors ends, our feelings of loss and isolation can be increased.

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, in a support group – in person or online – or on Facebook pages can be comforting. We are not alone in what we are facing.

Coping with our changed circumstances

If our child died at home, their room, our living room, maybe the whole house, will have been transformed into a hospital-like space. Even when specialist equipment has been returned, this house will forever be the place where they suffered and spent their final weeks, days or moments. We may feel unable to continue living there. We may equally feel that we will never be able to leave.

We may worry about our child’s possessions and what to do with them. We might feel unable to change their room in any way, finding it a sanctuary in which to express our own grief. We might create a smaller special area in our home in which to place treasured possessions, so that they become part of our daily lives and keep the memories of our child ever present. At some point we might feel able to donate clothes or toys to a charity which has helped our child or with which we feel a deep connection. However, there is no need to feel that we must dispose of anything before we feel ready. It is better to wait, no matter how long, until we are as sure as we can be that we will have no regrets.

The death of our child may affect us financially. We may no longer be eligible for benefits such as Carer's Allowance or Disability Living Allowance. If we are living in rented accommodation, we might have to think about moving, as the size of our home or number of bedrooms could now be considered excessive. All of these changes can be stressful.

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.

If our child's death has left us childless, we may feel our role as parents has been stripped from us, and that a part of our own existence has been destroyed. Life may feel meaningless, and we could experience deep despair and a loss of identity as a parent and carer.

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. On the other hand, perhaps there was a welcome element of sharing throughout the illness which, when it is withdrawn after the death, causes additional sadness.

We might struggle to make sense of the outcome of our child's condition. If we have any lingering concerns about the care they received, we may want to speak with their healthcare team.

Helping our children

Our surviving children will need our time, love and attention. Their lives have been disrupted and deeply affected by their sibling'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 could 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 died. 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 sibling 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 sibling has been in hospital for a long time, to them it might seem as though the only change is 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 increasing maturity, new more appropriate explanations may be necessary.

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.

Whatever their ages, our children may be helped by support from professional counsellors to enable them to talk freely about their own feelings and find their own ways to mourn. (Organisations such as **Winston's Wish** are very helpful).

Caring for ourselves

While our child has been ill, we will have been juggling the daily routines of the rest of the household, but with our sick child's care taking priority. 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 take time to adjust to our loss.

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 their memory. These are important and valuable things to do, but they do not replace our need to grieve.

For some of us, a return to work may give us a structure to our days, whilst others may find going back to work too difficult.

We need to be kind to ourselves, to create time to be with those who love us, such as a partner, close family 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 has died.

Each individual has to find their 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. Yet we cannot return to a time when our child was alive and healthy, and so we are permanently changed.

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 element 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

Families come in many shapes and sizes. Our family might have consisted of simply our child and ourself, or we may have other children. We may have a partner. We may live in a “blended household” that includes stepchildren. Whatever our family has looked like up until this point, this has now changed. Our child is absent.

Their physical absence will always leave a void. For many of us, finding ways of carrying the memories of our child into the future becomes very important. By making memory books and photograph albums, or using digital resources, we can produce collections of words and pictures in remembrance of our deceased child. This is for our own benefit, but also to share with family and friends, so that they take a rightful place in our family history. We might also seek out other ways to honour their memories beyond the circle of our family and friends.

Children enjoy hearing stories about the family in past years. If we have other children, or if we have another child after the death, we can help them feel part of the re-telling of the family story so that it can develop as they grow older.

The future is not going to be what we expected. The illness or condition that took our child might leave us feeling angry or in despair. Yet we can find comfort in the memories of better times. We are parents - our children live in our hearts and memories, and we will always hold them close.

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*
- *Remembering our Child (Handbook and leaflet)*
- *Our Surviving Children*
- *Childless Parents*
- *Grieving Couples*
- *The Bereaved Lone Parent*
- *Back to Work*

TCF leaflets can be read and downloaded at this link:
www.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
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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
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Emma Swift
10.12.75 -22.11.22

In memory of my dear, kind, courageous
and compassionate daughter Emma,

“All things bright and beautiful”

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