When our child has died from a terminal illness

A nationwide organisation of bereaved parents and their families
WHEN OUR CHILD HAS DIED FROM A TERMINAL ILLNESS

We all expect that our children will live long, healthy and happy lives; it is our instinct as parents to want the best for them and to do all that we can to make this happen. So when we discover that one of our children has a life-threatening illness, we enter 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 enjoyed carefree years of good health for their child, with the illness and eventual diagnosis coming as a dreadful shock. Either way, we learn 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 tiny part of us began to grieve when we had 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 focus all our energies on the fight ahead. The lives of all our immediate family are changed, as the sick child and his/her illness and treatment take centre stage. This can be a very
hard time for siblings as we struggle to remember their needs, and to make them feel that they too are loved and cherished. Parents have to tread a difficult path between optimism and realism: we want so much to tell our children, parents, other relations and friends that all will be well, but we know in our hearts that it may not be so. Some of us are told that our child is suffering from an irreversible degenerative illness, and it seems that we have no hope of halting their slow decline. We may have to watch their regression into dependency, their developmental milestones lost one by one, and even their personality enveloped by the encroaching illness. We can do nothing but care for them, try to make their lives as comfortable and stimulating as possible, and enjoy the time we have together.

Many terminal illnesses bring an emotional roller-coaster 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. There may be difficult decisions to be made, which can produce conflict within the family. If our children are older, they will have more influence over the course of their treatment, and their views may not coincide with our wishes for their continued survival. We experience deep despair and wonder how much longer we can carry on, yet we know that we have no choice.

When our children are adult, the problems are different. We still want to "parent" them, but we must accept their right to confidentiality and control over their treatment. We may wish to play a more central role than is permitted to us. When our child has a partner, s/he will be the prime carer - sometimes so preoccupied with responsibility that there is not sufficient time or energy to keep us informed or involved as much as we would wish. We can feel marginalised and disregarded.
Whatever the circumstances, we carry the burden of realisation that our child may die, while still hanging on to the slightest hope that there could be a miraculous recovery.

**When hope fades**
There comes a time when death becomes inevitable. Many of us are able to play our part in looking after our child during their final palliative care, whether at home or in a hospice or hospital, and later treasure the memories that we have. We have watched over them as they loosened their ties with this world, and, perhaps, accepted at some level that their suffering should come to an end. Increasingly, research tells us that children are more aware that they are dying than they have words to say. Even so our final goodbye to our child is hard to bear: death is always a shock, even when expected.

We have to find ways of preparing our other children for the imminent death of their brother or sister, to help them say goodbye, and to cope with their feelings. They may be angry and uncomprehending, thinking that we or the doctors are "letting my sister die", that we could have done something about it if we had tried harder. We may have reassured them in the past that their brother **would** get better, and that the doctors **could** help, only to have them feel that we have deceived them. It is important to create time for them to express openly how they feel and think - but we are all worn out and grief-stricken, and do not always have the energy for this. It is so hard to tell, perhaps frail, grandparents that their much-loved grandchild will die before them. They may have given us and our children amazing support throughout the struggle with the illness; for that battle to be lost feels like failure. They will often say, "I should have died instead."

**The early days of grieving**
When our child has died, our world is turned upside down, just
as it was when we first heard the diagnosis. Caring for our child has been the focus of our lives, and suddenly we are left with a great void. There is the funeral to plan, and many people have to be told that our child has died, but the intense, ever-present concern about keeping our child alive is removed. For some of us this time is made worse because we are now cut off from the support networks surrounding the illness and treatment which have sustained us. 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 the family has to find a way to cope with a life without their beloved child.

We also 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 Compassionate Friends' (TCF) leaflets Grief of the newly bereaved and Grieving couples talk about this in more detail. 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.

When our only child has died, these thoughts may be overwhelming: our role as parents has been stripped from us, and we feel that a part of our own existence has been destroyed. Nothing has meaning anymore, and we feel 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 which 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.

We know that 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.

Helping our children
We will have tried to include our other children in the care of our sick child, and to have made sure that we explained things to them. We took them to visit the hospital or hospice, and prepared them for the time when their brother or sister died. We must understand that children do not see things in the same way as adults, and they may well have thoughts and fears that are quite hidden from us. The TCF leaflet Our surviving children looks at how they are likely to think about death at different ages, and has practical suggestions for caring for them as they grieve. However, children who have been part of a family where a child is terminally ill have additional needs, because of the experiences they have been
through. Family life has been different, perhaps for years, or even for as long as they can remember.

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.
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 of our minds. 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 can 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. TCF leaflet *Back to work* discusses this work issue more fully.

We need to be kind to ourselves, to create time to be with our partner, 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 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.

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 need to 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, 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. For, whatever our circumstances, we are still our child's parents.

The Compassionate Friends
Communication with other bereaved parents through TCF will reassure us that our experiences are part of grief; the turmoil is normal. This may be by telephone, letter, or e-mail; on a one-to-one basis with a local contact; or at TCF local meetings. TCF has an active website with a "chat room". Over thirty leaflets are produced and in great demand - especially by the newly bereaved, who feel they are alone in their suffering. There is a TCF Postal Library for those with a greater reading appetite, and a quarterly journal, Compassion, written by and for bereaved parents. There are specific groups for parents who have now become childless, and for those whose child has died through murder or suicide. There are TCF contacts for grandparents and siblings.

The support, comfort and understanding gained through talking to someone else who has experienced the devastating
death of their child is profound, and the help each receives from the other plays a very important part in living with grief, carrying our children with us in our hearts and minds.

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**Where can I go from here?**

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 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, private Facebook groups, and support forum where bereaved parents can ‘talk’ online. A quarterly journal, Compassion, is also produced, containing articles and poems written by our members about their own experiences. Those who wish for further reading can borrow from our Postal Library.

For general enquiries, and details of how to become a member of TCF, please contact the office (details overleaf).
The Compassionate Friends

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