



The
Compassionate
Friends

Grieving for Our Baby

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

Grieving for Our Baby

When we learn that we are to be parents, we are touched by wonder. A new life is created, and that life is unique to us.

As expectant mothers, we feel and see the changes in our bodies, as this little seed of hope grows. Today's technology lets us see our baby in the womb and look in awe at their form. The idea of impending parenthood is embedded in our lives and there is so much to look forward to.

Sadly, for some of us this dream of a perfect family future is shattered by the early death of our infant, perhaps still in the womb or shortly after birth. We are devastated and in shock. We may experience a sense of loneliness and isolation as we struggle to comprehend the depth of our loss. We suffer the extreme emotions of grief – shock, numbness, memory loss, anger and low self-confidence. We may feel as if we have somehow failed in our parental role.

The death of our baby

Our bond of love with our child started when we knew we were pregnant. Love cannot be measured by the number of weeks or months of pregnancy. No matter when our baby died, we are still bereaved.

If our baby died as a result of **miscarriage** or was **stillborn**, we have had no relationship outside the womb. Perhaps there were signs that something was wrong: the pregnancy might have been high risk or we might have noticed a sudden change that worried us. We may have learned that our baby was no longer alive and that our pregnancy could have no happy outcome. For some this may have ended with a clinical procedure, whilst others may have endured the process of giving birth.

It can be very hard to mourn someone you have only known as part of yourself – felt as a kick, bump or flutter. There is the loss of imagined future happiness together, of what might have been. A dimension is missing because they have not yet had a separate existence.

Our baby may have been **born alive** but was too frail to survive beyond the first few weeks of life. We may have known from the outset that the probability of their survival was minimal, but we clung on to hope. We may have spent agonising days in intensive care as they struggled to live and breathe. Sometimes their treatment meant that we could not hold them in our arms as we naturally wanted to do. The medical equipment keeping them alive became a barrier to our physical relationship; it seemed as though we became onlookers rather than parents. We lurched from hope to despair as we watched their struggle, feeling helpless because we could not affect the outcome. We had no time to welcome our child into the world before we had to confront the inevitability of their death. This nightmarish situation had no predictable duration. When we have other children to consider, we felt torn, worrying about them but knowing the time with our baby was limited and precious.

Some of us had a **multiple birth**, perhaps after lengthy IVF treatment. It is devastating when one baby survives and their brothers and sisters do not. How can we celebrate the safe birth of our child and simultaneously mourn their siblings? We are confused. Once we return home with our surviving baby, we may find that people almost ignore our loss. They may think – or even say – that we should be thankful we have at least one.

If our baby was born and diagnosed with a **life-limiting illness**, we would have known that our time together would be short. We knew that our baby would die but not now, not yet! We may have watched as they became weaker and frailer, yet the death was still a terrible shock, an unacceptable fact that we could not change; we clung on to hopes of a miraculous cure. Our minds may have processed the facts, but that does not mean our hearts comprehended, let alone accepted, the reality.

Cot death is a totally unexpected catastrophe. We are a new family unit, settling down into our new life. The shock is devastating. There is no obvious reason why our baby died, yet as parents we feel somehow responsible, shouldering guilt because of the death and our inability to prevent it. We torture ourselves, going over and over the last hours and worrying that we missed something, that we did something wrong. We feel it is our fault even when the professionals reassure us otherwise.

Deep down none of us accepts that our baby could die.

Coping with what happens next

Whatever the circumstances of our baby's death, our family is in a state of shock. We are numb with disbelief and denial. We will inevitably have contact with the medical services and whilst we will need to understand fully why our baby died, our shock can prevent us from asking questions or absorbing what we are told. Some decisions have to be made quickly: we may want to bring our other children to the hospital so that we can be together as a family in the hours after our baby's death. Hospitals should be sensitive to our emotional needs and recognise that we will need time to be a family, that these few hours are precious. If our baby died at home, we may wish to prolong our time together, holding our son or daughter close for as long as possible. After a sudden death there will be a post-mortem examination. This can be a source of conflict between head and heart – the need to know what went wrong but abhorrence at the thought of the procedure and the anguish that our baby is taken away from our care.

When a baby dies unexpectedly or after going home from hospital, there are certain formal procedures that must be followed to ensure that no one caused deliberate harm to the infant. The police may investigate the circumstances, and this can be very upsetting. Information gathered by the police will be passed on to the Coroner's Office (or the Procurator Fiscal in Scotland). Some officials will be understanding and tactful as they do their duty, but it still feels like an intrusion into our family tragedy. There is also the need to register our baby's existence and the trauma of registering both a birth and a death will always be remembered.

Our feelings

The loss will be individual for each member of the family. For mothers the intensity of the loss is made worse by biological factors. Our bodies may still be responding as if our baby was alive. It takes time to recover physically from giving birth and this healing is a cruel reminder of what we have lost. Our bodies may be in hormonal turmoil and our breasts ready to feed our baby. When we give birth by caesarean section, we are literally wounded and may still be feeling confused and surreal because of the anaesthetic. We may be kept in hospital in a maternity ward, surrounded by other mothers and babies, but feeling isolated and longing to go home.

Going home can be the moment when reality confronts us – entering a nursery that we lovingly made ready for our baby can be especially difficult. On returning to the hospital for a medical check-up, we are sometimes treated as if this episode of our lives is closed, when for us our grieving has only just begun. This would be a good opportunity to ask questions or to arrange an appointment with the consultant to discuss any unresolved issues around our baby's death. Suggestions may be made about how soon it is advisable to "try again" which can sound like the ultimate disloyalty to our son or daughter – because we know that we cannot simply replace them.

We may be experiencing strong emotions of grief, anger and despair and sometimes we direct these feelings at others as we need to place blame even when there is none. As the mother, we may feel that we have let our partner down because our body has failed to produce the child we longed for, or we may feel inadequate for not being able to keep our

baby alive. It is possible that we may feel resentful and jealous of other mothers and distance ourselves from them. Some bereaved parents continue to get baby-related mail. Maybe a good friend can be called upon to arrange for this sort of post to be cancelled.

As the father or partner, we will share some of these emotions but may face different problems. As well as witnessing the pain and anguish of our baby's mother, we feel our own. We may truly appreciate our baby and recognise our love for him or her only at or after birth, and then feel angry at what has happened. We feel helpless, desperate to make things right and yet this is beyond our control. It may have fallen to us to contact family and friends, and now we have to relay terrible news. We may find that the focus is on our partner and yet we need support too. Many practical arrangements will be down to us, and we also have to care for any other children.

If we are a lone parent, we may be dealing with the emotional and practical consequences of the death of our baby without much support. (For more on this, please see the TCF Leaflet: *The Bereaved Lone Parent*.)

It is important to us when our baby has died that we have evidence that this short life did happen. Photographs are incredibly precious – whether they are scans, snaps taken on phones or high-quality pictures captured on camera. We may want to keep a memory book or box and include other precious items such as a lock of hair, or the hospital wrist band with our baby's name on it. We will all have special things that are vital to us to keep. These affirm that our child existed and is part of the fabric of our family.

Eventually, decisions will need to be made about all the items we had prepared for our baby, such as nursery equipment and clothing. However, we should not feel pressured and can take whatever time we need.

The Compassionate Friends (TCF) produces a series of leaflets on topics related to the loss of a child of any age that may be helpful for us. For support following stillbirth or neonatal death specifically, we may like to contact SANDS, the Stillbirth and Neonatal Death Charity: www.sands.org.uk

Our baby's siblings

Telling our other children that their brother or sister has died is an enormous and delicate task. They may surprise us with their honest responses and questions. We now know that even very young children feel loss, and their close attachment to us means that they experience grief even when they do not yet have the vocabulary to talk about it. With twins it is apparent that the surviving twin, who had only known their sibling in the womb, can acknowledge feeling incomplete in later life, as if a part of them is missing.

It helps, where possible, to spend some time together with our deceased baby. One of the worst things for surviving children is feeling left out or excluded and not understanding what is going on.

The TCF leaflet *Our Surviving Children* discusses how children of different ages understand death and how we can help them.

Grandparents

Grandparents will most likely be profoundly affected by the death of their grandchild. The chance to get to know the little one has gone. It is against the natural order when the young die and the old live on. Many grandparents wish that they had died so that the baby could live. They have the added pain of seeing their children and other grandchildren grieving and in such distress.

The way forward

Hopefully, we are not alone and have someone to support us. Whether we have a partner or not, we need people who will acknowledge the depth of our loss.

We are fortunate if some of our friends and relatives try to support and understand us in our loss. We may find that support comes from unexpected quarters and it is not unusual for new friendships to be forged through the mutual understanding of shared loss. It is not uncommon to find that established friendships falter as people struggle to know what to say to us, and they may even avoid us.

With the best of intentions, things can be said that sound very insensitive. Unfortunately, some of us will be hurt by well-meaning comments such as "it is probably for the best" or "never mind, you can try again." References to our baby being in heaven may hurt us. However, others instinctively say and do the right things. Most of the comments we find hurtful are said out of ignorance; there is a genuine wish to help without knowing how. It is possible that we ourselves have not made appropriate responses to grieving parents in the past.

It is difficult to remember how we thought and felt before the devastating loss of our baby.

At some time in the future some of us may have another child. Our feelings during any future pregnancy will be complicated by our previous loss. Fear that this baby too will die may cause us to be over-anxious and afraid to acknowledge the expected birth. Even when our baby is born strong and healthy, we may find it hard to overcome the sad memories and to bond with our child as we would wish. Hopefully these feelings will pass quickly, and we can all enjoy our new family life. We will never see our new baby as a replacement, whatever others might unthinkingly say to us. We love and celebrate each child in their own right.

We will always love our baby. We can keep photographs and mementoes and share them with other children and family members, so that the baby who died is recognised, named and spoken about. If we succeed in integrating the memories of this present time of loss and suffering into our family history, it will be easier for new members of the family to feel the continuity, even though their sibling died before they were born.

Looking back, we may have regrets and wish we had done some things differently. It is important not to be too hard on ourselves – we did the best we could at the time in such dreadful circumstances. We need our baby to have a place in our family, and for any brothers and sisters to know about their sibling. We all wish our child could have lived a long and happy life. That was not to be, yet our baby gave us the experience of unconditional love and that loving memory will be a part of us for ever, no matter how short their life span.

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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