



## Grieving for our baby

A nationwide organisation of bereaved parents and their families



## 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. Expectant mothers feel and see the changes in their bodies, as this little seed of hope grows. Modern technology means that we can see our baby in the womb, look in awe at their form and the idea of impending parenthood is embedded in our lives. 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. We may experience a sense of loneliness and isolation as we struggle to comprehend the enormity 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.

If our baby dies as a result of miscarriage or a stillbirth, we have had no relationship outside the womb. Perhaps we will have had signs that something was wrong: the pregnancy might have been hazardous or we 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 ends with a clinical procedure whilst others endure the birthing process. However, our bond of love with our child started when we knew we were pregnant. Love cannot be measured by the weeks or months of pregnancy. We are hurt by well meaning comments such as "It is probably for the best". Hopefully we are not alone and have someone to support us. 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 be born alive but too frail to survive beyond the first weeks of life. We may know from the outset that the probability of their survival is minimal, but we cling to hope. We may spend agonising days in intensive care as they struggle to live and breathe. Often their treatment means that we cannot hold them in our arms as we naturally want to do. The medical equipment keeping them alive becomes a barrier to our physical relationship; we are

onlookers. We lurch from hope to despair as we watch their struggle but cannot affect the outcome. We have had no time to welcome our child into the world before we must confront the inevitability of their death. This nightmarish situation has no predictable duration. When we have other children to consider, we feel torn, worrying about them but knowing the time with our baby is limited and precious.

Some of us have 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 baby we may find that people almost ignore our loss, thinking – or even saying – that we should be thankful we have at least one.

If our baby is born and diagnosed with a life limiting illness, we will know that our time together is 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 is still a terrible shock, an unacceptable fact that we cannot change. Deep down none of us accepts that our baby could die; we cling on to hopes of a miraculous cure. Our minds may have processed the facts, but that does not mean our hearts have comprehended, let alone accepted, the reality.

When a baby dies unexpectedly or after going home from hospital, there are certain formal procedures 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.

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 we feel as parents somehow responsible, shouldering guilt because of the death and our inability to prevent it. We torture ourselves, going over and over the last hours worrying that we missed something, that we did something wrong. We feel it is our fault even when the professionals

reassure us otherwise.

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 him or her 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 anguish that our baby is taken away from our care.

The loss will be individual for each member of the family. For mothers the intensity of the loss is made worse by other 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 Caesarian 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 lovingly made ready can be especially difficult. On returning for a medical check up, we are sometimes treated as if this episode of our lives is closed, when for us our grieving has hardly begun. This is 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 – 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. We may feel that we have let our

partner down because our body has failed to produce our longed for baby, or inadequate for not being able to keep our child 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 and maybe a good friend can be called upon to get this sort of post cancelled. Decisions will need to be made about all the things made ready for our baby.

Fathers share some of these emotions but face different problems: as well as witnessing our partner's pain and anguish, we feel our own. As males, 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 their 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.

Telling any 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. (It is apparent that the surviving twin, who had only known their sibling in the womb, sometimes acknowledges feeling incomplete in later life, as if a part of them is missing.) It helps if we can spend time together, if possible with our dead child. One of the worst things for surviving children is feeling left out or excluded and not understanding what is going on. The Compassionate Friends (TCF) leaflet *Our surviving children* discusses how children of different ages understand death and how we can help them.

Grandparents will most likely be profoundly affected by the death of their grandchild. On the death of a baby 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. There is the added torment of seeing their children and other grandchildren in such distress.

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. Sometimes established friendships falter as people struggle to know what to say to us and maybe even avoid us. With the best of intentions, things can be said that sound very insensitive. It is not uncommon where a child with disabilities has died for the parent to be told, "It was better this way". For us how can it possibly be better for our child to be dead? Fortunately others instinctively say and do the right things for us. 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 bond with our child as we would wish. Hopefully these are feelings that 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 can keep photographs and mementoes and share them with other children and family members, so that the baby we have lost is recognised, named and talked 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. 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.

**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 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 forever, no matter how short their life span.**



### **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](http://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

**14 New King Street, Deptford, London SE8 3HS**

**Office 0345 120 3785      info@tcf.org.uk**

**www.tcf.org.uk**

**UK Helpline 0345 1 23 23 04**

Northern Ireland Helpline 0288 77 88 016

## **TCF Postal Library**

Tel: 0345 120 3785      Email: library@tcf.org.uk

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