

When your baby dies: a particular kind of grief

When a baby dies, the parents we support at Child Bereavement UK speak of a grief that has no comparison, a particular kind of grief. The new life they created was unique to them, as is their grief, and therefore no one else can feel what they feel. Families talk about the utter devastation, and a sense of loneliness and isolation, caused both by the loss and the fact that it is often not understood by others.

This information sheet includes input from parents, some feelings and thoughts that you might experience, some of the issues that you may be facing and what may help. We are grateful to the parents who helped shape this information sheet by generously sharing their experiences.

When a baby lives for only a short time, or dies before birth due to a miscarriage, stillbirth or the difficult decision to end a pregnancy, people can sometimes assume that a shortened life must mean a shorter and less intense grief. Nothing could be further from the truth. The intensity of love parents feel for their baby is not measurable in weeks and months of pregnancy, or in whether they lived after birth and for how long they lived, but in the emotional investment they have made in this child. A parent begins their relationship with their baby long before birth and will grieve not only for the baby, but for shattered hopes and dreams and the place their child would have had within the family.

"I was longing to give my baby his first bath, put a nappy on him, burp him, take him to the supermarket and show him off for the first time."
Clare, mother of Thomas who lived for one day.

Grieving for your baby

There is no right way to grieve the death of a baby. Everyone will do it their own way and in their own time, even within the same family. Grief means feeling and expressing all the emotions you have, whatever they might be. Emotions often involve a complicated mix of shock, anger, regret, love, guilt and sadness. You may also feel an emptiness or a sense of something being incomplete. For some parents, the grief is so intense that they think what they are feeling must be abnormal.

"I felt as though I was going out of my mind because I had never experienced such intense feelings before."
Pat, whose daughter was stillborn.

When a baby dies there are other cruel reminders of what has been lost. A birth mother's body will still respond as though her baby is alive. She will still experience the usual physical and emotional postnatal reactions but without the joy of a baby to hold and care for. This is particularly distressing and can be very hard to bear.

If possible, give yourself a place and time to grieve, to sit quietly and focus on your baby. You may find yourself trying to avoid your grief, by throwing yourself into work or other activities, or just keeping busy. People close to you may even encourage you to forget, but thinking about the baby who has died, and the way you feel, is an important part of your grieving process.

If you had a room with everything made ready, then going into that room may be very hard for you. In contrast, it may also be the place where you feel closest to your baby. Feeling the pain of your loss often brings a sense of the baby being near to you. There can be conflict between wanting to face tasks such as changing the room and feeling the need to keep your baby close. It can help to acknowledge this and let yourself move between these two different feelings. In time, you may feel more able to do the things you need to do with the room such as the hard task of packing away your baby's things. There's no 'right' time to do this - do it when you feel you're ready.

Searching for answers

Sometimes, no definite cause can be found for why a baby has died. For some parents this can be a relief. They take the view that if there is nothing wrong there can be no barriers to another pregnancy. For others, having no answer to the question "why?" creates immense distress.

"We still cannot accept why this has happened to our family – there seems no reason."

The mother of Josie, who died very suddenly at only a few weeks old.

Some parents blame themselves, or they feel they have failed their baby and failed as parents. Women may consider they have let down their partners and extended family because their body has not produced the baby that was so hoped for.

"I felt absolutely useless. Something that women do all over the world I couldn't manage."

Jane, whose son lived for a few days.

Even when there is an answer to why it has happened, this doesn't necessarily make it easier. Post-mortem results may provide an explanation that is logical but not always one that helps on an emotional level. Often there is conflict between our head and our heart. For some people, it may be too painful to even think about the logical or medical explanations.

Grieving parents can resent others who are pregnant, or experience mixed feelings towards family and friends who do have their babies. Although not easy, for some women having a cuddle with another baby can bring some comfort, but for many, it is an unbearable reminder of what they have lost. All they long for is their own baby and not someone else's.

Grieving together

When a baby dies, much of the concern tends to focus on the birth mother. This can be even more the case if she needed medical attention. Partners can be overlooked and are often asked how the mother is rather than how they might be feeling. It is important to remember that partners have a great deal to manage. Witnessing the person you love in distress whilst feeling helpless, and not being able to 'save' the baby you most desperately wanted, is extremely painful. You have to manage your own grief while supporting your partner who is experiencing the normal emotional and physical consequences of giving birth but without the much longed-for baby.

For some, keeping busy with practical arrangements is a welcome distraction and gives them a sense of doing something useful. Their grief is no less, they just have a different way of dealing with it. This can cause misunderstanding and tension, making it hard to maintain a loving relationship. It might help to remind yourself that you are both grieving for your baby but expressing it in different ways. If possible, find ways to share your grief whilst respecting that each of you needs your own space.

Telling other children

Siblings will have been looking forward to the new baby's arrival and will need a simple explanation as to why their baby brother or sister has sadly not lived. What you say depends on what feels right for you and the children. It is important that even if very young, they are told the truth but in words appropriate for their age and understanding. Do not be afraid to use the word "dead" or "died", even though this may feel harsh and upsetting for you to say. Using words such as "lost" might feel more gentle but they only confuse children who will take them literally, expecting something "lost" to be found.

In simple words, you could say something such as:

"When the baby was born, her heart stopped working and very sadly she died."

If your baby died early on in the pregnancy, young children will sense and be unsettled by your sadness and distress, wondering why you are upset. Again, in simple language, you could explain that:

"he was born too early before he was ready to breathe properly on his own. Because he could not breathe properly, the baby died."

These are only suggestions and it may help to talk it through with our Helpline on 0800 02 888 40. There are also further suggestions in our information sheet: *Explaining To Young Children That Someone Has Died*.

What might help

Everybody is different and will have their own ways of coping. What is helpful for one person may not be at all helpful for someone else. Below are some suggestions from parents we have supported. The organisations listed at the end of this information sheet offer various types of support: it is about finding what is right for you.

Finding someone to listen

Bereaved parents tell us that it is invaluable to talk to someone you trust and feel comfortable with, someone who will not be shocked by anything you say and who will not tell you what to do or how you should be feeling. Finding a good listener is not always easy and family and friends may not understand or find it too painful to listen.

"My mother came to visit but I could barely cope with my own grief without someone else off-loading their grief onto me as well".

"We have learnt a lot about people. Their reactions are not always positive but with time you filter out the unhelpful advice."
Sarah and Matt, whose son Tobi was stillborn.

The people around you want you to be OK. It can feel easier to pretend that you are, when the reality is very much the opposite. If this is the case, try not to suppress your natural instinct to grieve for your baby and find support somewhere else. Friends and family can respond in unexpected ways, and it may be the ones you least expect who turn out to be the good listeners and to whom you subsequently become close.

Bereavement support services or counselling offers one to one time with someone whose job it is to listen and has the training and experience to understand and support you. You can say exactly what you think or feel and know that you are not upsetting them in the same way as family and friends.

Our helpline and website has information on finding bereavement support in your local area.

Sharing experiences with other parents

You can share experiences by going to a group or talking on the phone to other people whose baby has died.

"When I met other parents, I felt for the first time that I wasn't the only person in the world to have felt like this. I was able to talk about what had happened without leaving bits out".

Child Bereavement UK runs groups for parents in some areas, or contact the charity Sands for support groups throughout the UK (see Resources section).

You can share your experience over the phone with other bereaved parents, by calling the free Child Death Helpline on 0800 282 986. This is available for anyone affected by the death of a child or baby of any age from pre-birth onwards. It is staffed by volunteers, all of whom are bereaved parents.

The charity The Compassionate Friends also offers support from other bereaved parents, siblings and grandparents to those bereaved of a child or children of any age and from any cause (see Resources section).

Returning to the hospital

Going back to the hospital where your baby was born and died may be important for you. It can be an opportunity to clarify exactly what happened with staff who were there at the time. For others, such a visit brings back too many painful thoughts and feelings and is too difficult to contemplate.

Going to the grave or another special place

Some parents (although by no means all) can find themselves visiting their baby's grave, or place where the ashes were placed, on an almost daily basis. They find it somewhere to feel close to their baby. Tending and caring for the grave, taking flowers, leaving momentos, or just sitting there, can bring some comfort. Many families keep their baby's ashes at home until they eventually feel ready to decide on an appropriate place to put them.

Remembering

Remembering your baby, although it is painful, is also a way of acknowledging their life, however short, and their importance to you. When a baby dies at or before birth, there are fewer memories but this makes them even more precious. Some parents gather together everything they have to put into a memory box or memory book. If your baby died before birth you may have precious momentos and hospital appointment cards and scans. You can keep these in a special, private place or share them with friends and family - it is up to you.

If it is some time since your baby died, you may have few memories and very little information about what happened to him or her. This makes your grief no less intense and some callers to our helpline are grieving for babies who died, or were born too early, many years ago. It might be difficult to get in touch with your memories, but if you can begin to remember, you may be able to begin to grieve.

Going back to work

Returning to work can be a daunting prospect for both partners whose baby has died. The amount of leave people are able to take after a bereavement varies enormously. However much time off work you have had, you will still be grieving for your baby and the decision to go back to work can be difficult. You may be returning sooner than you would like to, for financial reasons. For others, returning to work is a positive step, providing some routine to the day and an environment not directly connected to the baby.

Try to meet with your manager to discuss how you would like your return handled and how best to let everyone know what has happened. It might help ease the transition if you arrange to go in for a short time before your actual start day to meet colleagues. This is a way to help overcome the hurdle of seeing everyone on your first day back, some of whom might be uncomfortable with what to say to you. Your employer only needs to have as much information as you want to give them, but it is important that they are aware.

You may be anxious about becoming tearful or emotional. This may well happen but if people know the reason why, this will help them to understand your distress. Be realistic about what you can manage at work and if you can, find quiet moments for a bit of peace, or time to shed a few tears if you need to.

We have further information on our website for employees and employers about returning to work.

Be kind to yourself

You will know best what works for you, at home, in your relationships, at work and in any support other people can offer you. If possible, find time for grieving as well as time for activities in everyday life that you feel you can manage and that are helpful for you.

Resources and further reading

All available from Child Bereavement UK unless otherwise stated.

Child Bereavement UK information sheets

How we grieve

Helping yourself through grief

Looking after yourself

Returning to work after the death of your baby or child: guidance for employees

Women, men and grief

When your baby dies: a particular kind of grief

Printed booklet version of this information sheet. £1.00

Memories folder

For families to keep important information about their baby including a card for hand and foot prints. £1.00

Farewell My Child

Book of stories from families with a wide range of experiences, from those whose babies have died to those who have lost adult children. Includes sections on coping with loss and where families may find support. £ 2.50

Organisations offering support

ARC (Antenatal Results and Choices)

www.arc-uk.org

Provides support and information to expectant and bereaved parents throughout and after the antenatal screening and testing process.

The Compassionate Friends

www.tcf.org.uk

Charity dedicated to the support and care of other bereaved parents, siblings, and grandparents who have experienced the death of a child or children.

The Child Death Helpline

0800 282 986 or 0808 800 6019

www.childdeathhelpline.org.uk

Helpline for anyone affected by the death of a child of any age, from pre-birth to adult, under any circumstances, however recently or long ago.

The Miscarriage Association

www.miscarriageassociation.org.uk

Support for couples whatever the circumstances of the miscarriage.

Sands (Stillbirth and neonatal death charity)

www.uk-sands.org

Support for anyone when a baby dies during pregnancy or shortly after birth. Runs groups throughout the UK.