

When your baby dies – a particular sort of grief

When a baby dies, the parents we support speak of a grief that has no comparison, a particular sort 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. This information sheet has been written with contributions from some of those families including Sarah and Matt whose son Tobi was stillborn. *"We have learnt a lot about people. Their reactions are not always positive but with time you filter out the unhelpful advice."* Families we support talk about the utter devastation, sense of loneliness and isolation, caused both by the loss and that it is often not understood by others.

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 equate to shortened 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 life after birth however short that might have been, 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 Fone, 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. For some parents, the grief is so intense they can think that 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 grieving, the emotions often involve a complicated mix of shock, anger, regret, love, guilt and sadness. The parents that we support talk about intense feelings of emptiness and a sense of something incomplete.

When a baby dies there are other cruel reminders of what has been lost. A 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.

Do your best to give yourself a place and time to grieve, to sit quietly and focus on your baby. You may find yourself trying to avoid it – 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 the grieving process.

Sometimes, no definite cause is discovered for a baby's death. 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, they feel they have failed their baby and failed as parents. Women may consider they have let down their husbands and extended family because their body has not produced the very much hoped for baby. This is often accompanied by a loss of confidence:

"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, it doesn't necessarily make it easier. Post-mortem results may provide an explanation that fits with logic but not always one that helps on an emotional level. Often there is conflict between our head and our heart. There are times when our heart can not even begin to contemplate what the head knows and makes sense of.

Grieving parents can resent others who are pregnant, or experience ambivalent 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.

If you had a room with everything made ready, then going into that room will 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 and there can be conflict between wanting to "get on" and wanting to keep your baby close. It can help to acknowledge this and let yourself move between the two states. In time, you may feel more able to do the things you need, or want, 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.

Grieving together

When a baby dies, much of the concern tends to focus on the mother. This can be even more the case if she required medical attention. Fathers can be overlooked and are often asked how the mother is rather than how they might be feeling. It is important to remember that they have a great deal to manage. For partners, 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. Fathers have to try to deal with their own grief while attempting to support a 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. Do your best to find ways to share your grief whilst respecting that each of you needs your own space. The Child Bereavement UK information sheet *Women, Men and Grief* has more information.

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 is dependent on what feels right for you and the children to whom you have to break the news. 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", even though this will feel rather harsh and will be 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 be aware and unsettled by your sadness and distress and will wonder why you are upset. Again, in simple language, you could explain their little brother or sister was "born too early before the baby was ready to breathe properly on its own. Because it could not breathe properly, the baby died."

These are only suggestions and more help can be obtained by calling Child Bereavement UK's 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 the families and parents we see all have their own way 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

The families we support 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"*. 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 to the situation and it may be the ones you least expect who turn out to be the good listeners and to whom you subsequently become close.

Counselling offers one to one time with someone whose job it is to listen and has the training and experience to understand. 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. Child Bereavement UK's helpline (0800 02 888 40) has information on finding a counsellor in your local area.

Sharing experiences with other parents

You can share experiences by going to a group to meet other families 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 parents groups in some areas, or contact SANDS at www.uk-sands.org for groups throughout the UK.

Some parents find that reading other people's stories, although sad, can be reassuring. Parents talk about the relief they feel when they realise that they are neither alone nor abnormal. Others find they do not have the strength, nor desire, to do this. For real life stories from families, visit www.childbereavementuk.org and follow the links under For Families.

You can share your experience over the telephone with others who have "been there", by calling the free Child Death Helpline on 0800 282986. 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.

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, going back brings back too many painful thoughts and feelings and is too difficult to contemplate.

Going to the grave

Some parents (although by no means all) can find themselves visiting their baby's grave, or place where the ashes are buried, on an almost daily basis. They find it somewhere to feel close to their baby. Tending and caring for the grave, taking flowers, leaving mementoes, or just sitting there, can bring some comfort. Many of the families we support keep their baby's ashes at home until they eventually feel ready to let them go and are then able 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 mementoes 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

This can be a daunting prospect for both a mother and father. The amount of leave people are given, or 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 a difficult one. 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 upset.

Try not to ask too much of yourself. 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. Child Bereavement UK has helpful leaflets for both employees and employers on returning to work after your baby has died. Visit www.childbereavementuk.org and follow the links to Information, reading and resources under For Families.

Resources and further reading

The following are available to order from Child Bereavement UK.

When your baby dies: a particular sort of grief. Printed booklet version. £1.00

Memory Folder

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

Farewell My Child

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. £5.00

Organisations

SANDS www.uk-sands.org

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

ARC www.arc-uk.org

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

The Miscarriage Association www.miscarriageassociation.org.uk

Support for couples whatever the circumstances of the miscarriage.