



North West Neonatal Palliative Care Family Support



**This document has been produced in partnership with the Northwest
Paediatric Palliative Care Network**



Emotional and Psychological Support

When your baby dies – a particular sort of grief

When a baby dies, the parents Child Bereavement UK 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. 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.

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. 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. 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 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 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.

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, it’s 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."

Saying goodbye to your baby

After the death of a much longed for baby or child, thinking about what to do next can feel completely overwhelming. Whether your baby or child died at home or in hospital, you do have options. Every parent reacts differently and how each decides to say goodbye to their son or daughter will vary. There is no right or wrong way - it is a very personal decision. Knowing that you have choices will hopefully help you to feel that any decisions made, or arrangements planned, were the right ones for you and for your baby.

Some parents choose to say goodbye to their baby by having them at home for a time before the funeral. In most cases this should be possible, even when a post mortem examination has been performed. If your child has died in hospital and you wish to take them home yourself you should be given a form by the hospital staff that confirms your child's body has been released to you. Alternatively you can ask for help with this from the funeral director who can bring your child home for you should this be your preference.

The funeral

Although arranging a funeral can be painful and distressing, it is an important step in saying goodbye. It can be helpful to take a few days to decide what is right for you as a family as your first reaction may not be your final choice. You can choose to have a burial or cremation, a religious or non-religious service, in a church, at the graveside, in your home or anywhere else appropriate. There is no requirement for a religious minister to be involved. When a baby dies in hospital, the hospital can make the arrangements for you if you feel unable to do this yourself. It is helpful to find out what sort of funeral the hospital would provide. If you wish to use the services of a funeral director, it can be a good idea to contact several for an estimate of the costs involved, or to ask a friend to do this on your behalf. Many funeral directors will not charge for their basic funeral service for a baby or a child. However, if you wish to have a burial, there will be a cost associated with purchasing a grave, which can be quite expensive in some areas. Should you wish to carry out the entirety of the funeral yourself, independent of a funeral director, the Cemetery and Crematorium Department of your local authority should be able to provide you with advice and guidance. If there are other children in the family, to help them feel included in this important event, try to involve them in discussions about the funeral. They might like to contribute a favourite song, poem or reading. Provided they are prepared for what they will see and hear, if they are offered the option to

attend the funeral or a special goodbye, most find it helpful. You may want to ask another adult who

is close to the children to help support them if they choose to come to the funeral.

Helping yourself through grief

However overwhelming your feelings of grief, you will find ways of moving forward and coming to terms with what has happened, says experienced counsellor Julia Samuel. Go gently with yourself. Grief is a messy, exhausting and relentless business, but it is survivable. As human beings we have infinite resources within ourselves to heal and move forward, if we only allow ourselves the time to express the pain first.

Talking helps

It is helpful to talk, both to family and friends. And you may find that you need to repeat and repeat the events of the death in order to make some sense of what has happened. Often it is those closest to us, our relations, with whom we have most difficulty communicating when someone dies. This can leave you feeling misunderstood, unrecognised, hurt and angry. You may be able to help your family support you by being explicit about what you would like and what is missing. In families that have histories of poor communication, you may just have to accept that you will not be able to change things and acknowledge that, on the whole, the intentions are good, even if the expression of them is poor. Find other people outside the family to give you the support you need.

Ways to avoid isolation

Grief can be very isolating. Finding out information through books and videos, or joining a support group, can help you realise you are not the only one and that what you are feeling, painful as it may be, is normal. Writing a journal can be a cathartic way of expressing feelings on your own. It is also helpful to have a record for you to look back on the process of your grieving. Accept that you may not be able to function as effectively as you normally do. You may be tired, have a poor memory, and find it difficult to concentrate, or feel that nothing is important. Ask for support from friends, make a note of those things that you worry you will forget, and set yourself one achievable task a day. We grieve in our bodies as well as our hearts and minds so exercise, even a gentle walk, can help release some of the physical tensions. Massage can also be releasing and healing when the pain inside feels jagged, like a physical wound. One of the most difficult aspects of grieving is the feeling

of being out of control. Try putting some structure into your day by, for instance, doing essential chores in the morning, exercise in the afternoon. Give yourself a break from the pain. Plan treats or

diversions, like seeing a film that will distract you for a few hours.

Wait before you act

You may have a strong desire to remove all the objects - photographs, clothes and so on – associated with the baby because you hurt so much every time you look at them. It is not a good idea to throw anything away until your feelings are less intense. Then you will be able to decide more rationally what you would like to keep.

Returning to work

When you go back to work, find ways of supporting yourself. Perhaps you could ask a work colleague to accompany you to the office on the first day. Let people know whether you want to talk about what has happened or not. You can change your mind once you have been back for a while. Make sure that people know as much about the death as you want them to know, so you do not feel they are whispering behind your back. Ideally, you should go back to work gradually, working just mornings initially or a few days a week. Do not expect to be able to perform at your usual capacity; try to take on manageable, short-term tasks: big projects can seem overwhelming. Work can be a useful distraction from grieving, but you are unlikely to be able to switch off completely. Give yourself short breaks in the day to go for walks and have moments of peace, or a time for a few tears. There are no rules in grief. These guidelines may be useful to you, they may not. You are your best guide. Listen to yourself; learn what works for you and what drives you crazy. Accept that what helps initially may not do so after a few months. Whatever happens, be kind to yourself, give yourself time to heal and trust that, although it may initially seem impossible, there is light at the end of the tunnel.

Further Information Sheets are available at:

www.childbereavementuk.org/publications/information-sheets/

