

# ***From Us To You***

## *When Your Baby Has Died*

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For parents who experience the death of their baby from causes relating to stillbirth or neonatal death



**From us to you, when your baby has died.**

Published by Sands (Qld) Inc.

02/05 Revised 09/12

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## ***When Your Baby Has Died.***

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**This booklet has been written for parents who have experienced the death of their baby from causes relating to stillbirth or neonatal death.**

### **Feelings**

Few people are prepared for the intensity and duration of grief that follows the tragedy of the death of their baby. Bereaved parents can experience a variety of emotions that they may never have felt before and can find this a very confusing and painful time and may feel overwhelmed. You may find yourself feeling some or all of the following feelings – shock, anger, guilt, resentment, despair, sadness and desolation. It can sometimes seem that you are on an emotional roller coaster over which you have little or no control. We would like to reassure you that whatever feelings you have concerning the death of your baby are ‘normal’ responses to a tragic experience.

### **Why did this happen? Why my baby?**

Between one and two babies in every hundred die before birth (stillbirth) or within a month of birth (neonatal death). Some die because they were born too early, or because of complications of prematurity. Others die because there was a serious abnormality or because the placenta was unable to meet the baby’s need for nourishment, and for many, the reasons may never be known. Life can sometimes be very unfair and there is no simple answer to these two important questions.

# Giving Birth

Some parents may discover that their baby has died before birth. Parent's reactions to this situation vary from wanting to deliver the baby immediately – preferably by caesarean, to a desire to wait for a day or two to come to terms with the death of their baby, to gather a support network around them. Even thinking about delivering your baby naturally and going through the pain of labour may seem just too hard but it may be something you can do for your baby and may have implications for future pregnancies. You will need to discuss with your health care professionals how and when your baby is to be born. The pain and discomfort normally felt after birth may seem greater because the cause of the pain has not been positive. Don't hesitate to request pain killers should you need to. Now is not a time for bravery.

## Your experience of parenthood

Although your baby has died you are as much a parent as any other parent. You may find that like other mothers your milk will come in. You can discuss the management of your milk supply with your doctor, midwife or the Australian Breastfeeding Association. You may feel that you would like to leave hospital earlier than normal and you need to be aware that going home early will not lessen the grief you are experiencing. We encourage you to stay as long as you need to be able to give yourselves time with your baby.

If you can hear the sound of babies crying and find this distressing, don't hesitate to ask the staff if you could be moved to a more appropriate location.

Some mothers find their post baby shape can cause hurt when unknowing people ask when the baby is due. Being aware of these situations may alleviate some of the hurt.

# Caring for your baby

Some people may feel that it could be easier to cope with their grief if they do not see and hold their baby; other parents feel that it is of benefit to the whole family to be able to parent your baby.

If you are apprehensive about seeing and holding your baby, ask your midwife to explain to you what to expect. Very often the reality of your baby's appearance is much easier to cope with than the imagined. If you decide not to see or hold your baby it is your right to change your mind right up until the baby's funeral or cremation.

Although it may seem frightening, seeing, holding and spending time with your baby can establish memories that you will truly treasure.

Many parents will bath and dress their baby and may stay in hospital to nurture and parent their baby over a number of days. If you choose to do this it may be beneficial for your baby to stay overnight in the hospital morgue – this will ensure that you can spend the time with your baby that you desire.

Some parents choose to have their baby home with them before the funeral or memorial service. Your health care professional or funeral director will be able to assist you with the details. The parents then find that they can spend time with the baby in the privacy of their home. Friends and family can also be invited to visit.

# Creating memories

When an older person dies we generally have many memories to help in the grieving process. These memories can be shared with family and friends. However, when your baby dies there may not be many tangible memories to reflect on. For this reason, we encourage you to create as many memories of your baby as possible. You do not have to do all of the following and you may find other memory creation methods that are more appropriate for you and your family. These ideas have come from other parents who have experienced the death of their baby.

- Naming your baby – this states your baby's place in the family – you might also like to have a baptism or naming ceremony.

- Seeing and holding your baby – bathing and dressing
- Photographs – you might like to ask a professional photographer to come and take photos of the whole family. If you have a digital camera, your photos can be burnt onto a disc for safekeeping. If you don't have a camera, a family member or friend may be able to help you out. It is important to remember that when taking photos the whole family is included – you might like to ask a staff member to help you. Be aware of lighting and background- using a blue background may help with features.
- Obtaining the hospital name bracelet, cot card, lock of hair, footprints, handprints and tape measure.
- Invite your family and close friends to the hospital to meet your baby and/or take your baby home for private farewells
- Choosing clothes for the baby to wear – some parents have more than one set that their baby has worn so they have a set the baby wore to keep with them and a set for the baby to wear for burial.
- Purchasing keepsakes for the baby's coffin
- Organising the baby's funeral – choosing the prayers, poems and readings and songs. You may like to decorate your baby's coffin and some parents make the coffin themselves. • Having a keepsake box – a special place to keep your memories
- Writing a letter or a poem for your baby
- Keeping a journal – some parents find that writing down their thoughts and feelings gives substance to their baby's life.
- Buying a special item for your baby such as a special bear, piece of jewellery
- If you have other children they may like to write a poem or letter for their sibling
- Video taping – this can be a wonderful way of creating memories of your baby and family.

- Some parents take photographs, put them to music and create a PowerPoint style of presentation for the funeral and own memories..

## **What is a Post Mortem or Autopsy?**

Your health carer may ask for consent to your baby undergoing a Post Mortem or Autopsy. A post mortem is a surgical procedure that is carried out by a pathologist. Incisions are made in such a way as to minimise any disfigurement. The incisions are surgically repaired as with any operation. Your doctor or midwife can explain the procedure in greater detail. You may also ask to speak to the pathologist who is going to do the autopsy – both before and after the procedure. Sands has also produced a pamphlet – “Explaining Autopsy – Information for Parents When Your Baby Has Died” This pamphlet will also give you the information you need to make your decision.

## **Why should we have an Autopsy?**

It is important to discuss any issues of an autopsy with your doctor. An examination of this type of your baby may help uncover the reasons for his or her death and may also uncover the presence or absence of underlying abnormalities and whether genetic problems are indicated. An autopsy may also help to further medical research.

However, it is important to remember that sometimes, even after an autopsy no reason is found for your baby’s death and no further information can be obtained other than what is already known.

The decision to give consent for an autopsy is a very personal one that only you and your partner can make and you need to ensure that you have all the information you need to make the right decision for your family.

Will I be able to see my baby after a Post Mortem?

If you wish to see and hold your baby after the autopsy it will be helpful to discuss this with the pathologist or the health care professional who has asked you for permission. Many parents need to see their baby again after the post mortem and before the funeral.

# How Do I Arrange My Baby's Funeral?

In Queensland if your baby is born at 20 weeks gestation or weighs 400 grams it is a legal requirement to arrange a funeral. It is also possible to hold a funeral or memorial service for a baby who is born before 20 weeks gestation. In this case your social worker, chaplain, funeral director or Sands will be able to offer suggestions.

The type of service you arrange for your baby will play an important part in your grief journey. The decisions that you make are very personal and ones that only you and your partner can decide on. It is important to remember that there is no haste to arrange your baby's funeral – this ceremony will replace all of the ceremonies your baby would have had so take all the time you need.

If you have other children they may like to be included in their siblings funeral. They may like to do a drawing or write a letter or poem to their brother or sister. Some children may like to decorate the coffin and place trinkets inside. Even very young children will have an understanding that something dramatic has happened in their world and a funeral can give them an opportunity to express their feelings.

There are many options available when deciding on the format of the funeral. You don't need to seek a traditional funeral, which may be more suited to an adult. You may like to have the funeral in your home, a park, at sunrise or sunset. You may like to have your baby in a bassinet during the service rather than a coffin or nurse your baby throughout the service and place your baby in the coffin at the conclusion of the ceremony. On the way to the cemetery or crematorium you and your partner may like to have your baby between you in the coffin on the seat of the car.

**“ I had no idea so many other people had walked this journey”**

**Majella**

Some parents also take the option of taking their baby home with them for a time before the funeral. This can allow them an opportunity to parent their baby and to introduce the baby to family and friends. Your funeral director and health care worker will be able to assist you with this option.

Your baby belongs to you, not the hospital or the funeral home and if you wish to dress your baby yourself, bath the baby again before the funeral, make your own coffin it is your right to do so.

Some parents choose a cremation rather than a burial and may express concern over what to do with their baby's ashes. Many parents keep their baby's ashes in their home, some will spread them in a place that is special to the family, and others may inter them at a crematorium. Once again, there is no haste to make a decision.

Many parents have expressed the thought that they felt very supported by their family and friends who attended their baby's funeral. Inviting people to your baby's funeral can give you an opportunity to demonstrate the impact this tiny baby has had on your lives.

## **Your Grief Journey**

Each person will grieve in a way that is intrinsic to him or her and each parent will need to walk his or her own grief journey. Experiencing the death of your baby is a tragedy and grieving this loss is hard. The emotions you may feel can sometimes be overwhelming and you may feel that you are "going crazy". Some parents feel responsible for the death of their baby. They may feel that negative feelings towards the baby, eating the wrong food, having a glass of wine contributed to the baby's death. It is very unlikely that anything you thought or did contributed to the death of your baby and it may be helpful to talk these feelings

through with your health care professional. As a mother, you may feel that your body has let you and your baby down and need reassurance that you did all you could for your baby. To outsiders these thoughts may seem silly but to parents they are very real. You may find yourself reacting to the death of your baby in ways that you find difficult to understand. Some parents are so overwhelmed by their grief that for a time they may withdraw from everyday life.

Many parents find themselves at different times very angry – at God, the doctor, hospital, themselves and even with their baby for leaving them.

The physical aspects of grief may take parents by surprise. Some of these aspects could be – fatigue, listlessness, dizziness, anxiety, heavy chest, noise sensitivity, appetite and sleep disturbances. You may feel the need to take deep sighs. You may also experience phantom kicks and hear a baby crying, have aching breast or arms and you may also physically ache to hold your baby. Not all parents experience all of these feelings but they are a normal part of grief and a response by your body to the death of your baby. They will occur less and less as time goes on and you start to integrate your baby's death into your lives.

## **Especially for Fathers**

As a father, the bond you have with your baby may not be the same as your partners, particularly after an early pregnancy loss. Some men may try to protect their partners from things that they think may hurt them. Other fathers may experience a sense of powerlessness because they were not able to protect their baby or comfort their partner. Fathers can also sometimes be a buffer between medical staff and their partners, and often find they have to interpret a range of medical information for the whole family. While you are dealing with all of this, you may

also be juggling home and work commitments. Very often people will ask how your partner is not recognising that as a father, you too have experienced your baby's death. You may feel that you have to be strong for everyone and may not allow yourself to cry or express your feelings. It is important that you feel comfortable expressing your feelings. Men will very often do this differently to women. Fathers may like to gather some mates around and go and have a drink together. Others may do something really vigorous such as a game of squash or washing the car.

Although as a couple, you grieve individually you share the same experience and it is important to share your feelings and talk with each other. It can be a very difficult time – accepting your partners tears, sadness, mood swings. You may need to be extra patient with each other.

## Especially for Couples

The following are some suggestions that other bereaved parents have found useful –

- Bereaved parents need to be aware that friends and family are unlikely to understand the full impact and the intensity of the pain of their grief after the death of their baby.
- The bereaved parents should consult each other in all decisions concerning their baby. They may need to be more aware of communicating effectively with each other, show respect for each others feelings and emotions.
- Bereaved mums and dads should try to have quality time together with their baby before having to cope with outside pressures.
- They should tell each other that they love each other and their baby.

The death of their baby can sometimes lead to changes in a couples' intimate relationship. A good sexual relationship may enrich communication between bereaved parents by becoming an expressing of affection and mutual support. Challenges may occur if the parents are concerned about another pregnancy. Along with other physical grief symptoms, a loss of interest in sex or an increase in interest can be a normal reaction during your grief journey.

## **Explaining Death to Your Children**

The death of your baby is part of your family life and if you have other children, you will need to explain to them what has happened to your baby. Parents usually find that their other children can be as upset as they are about their sibling dying. They will not have the brother or sister they expected.

Even very young children will be affected by the death of their sibling – they may have little understanding of the situation but will respond to the mood of their parents and other people around them. They may need extra reassurance that you still love them to make them feel secure.

You will need to explain to your children at their own maturity level what has happened. It is important that you use clear language so they are in no doubt that their baby has died and will not be coming back. As children grow older and mature they may need further explanations appropriate to their age and maturity level.

Children are not small adults and their response to grief is going to be very different to yours. Some children start misbehaving or behave like a baby. They may seem not to care and may need privacy to express their feelings.

It is important that your children are included in the memory creation and funeral of their sibling. They will cherish these memories as they grow older and if not included may question later why they weren't able to participate.

As parents, you may find it physically and emotionally difficult to parent your children at this time. Grief can be a very physically and emotionally draining experience and it might be wise to ask for help from family and friends with parenting issues. Some parents become very protective of their surviving children, preoccupied with death and fearful for the safety of their family. Other parents may find it very difficult to be with their other children. Once again, these feelings are all a normal part of the grief process.

## Family and Friends

Most people who have not experienced the death of a baby usually cannot understand the depth and intensity of the bereaved parents grief. Most family and friends want to support the bereaved family but may not know exactly what to do and you may find that you have to be direct in letting them know about the support you need.

Inviting family and friends to meet your baby and attend the funeral can sometimes ensure an increased level of support as this group of people gain some insight into your journey. Some people may not be comfortable with this and may need encouragement from you. Some family and friends may also feel awkward talking about your baby, feeling that if they mention your baby you will be upset. You may need to give them permission to talk about your baby and reassure them that you are upset already and talking about your baby gives you comfort.

You may find that people will offer support in various ways – meals cooked, groceries purchased, children looked after. It is your decision what to accept – support is good but you need to ensure that people are not taking over your lives. In the coming weeks and months your family and friends may not understand your need to talk about your baby and you may need to reassure them that by talking about your baby you are going through the grief journey in a very healthy way.

Grandparents are in a very unique position as they are grieving for a grandchild while having to stand by and watch their own child suffer. They may feel very helpless and some of the older generation may not be initially comfortable with talking about and meeting their new grandchild.

## Another pregnancy

An issue that most bereaved parents consider sometime is that of another pregnancy. Some parents feel an intense yearning for a new baby immediately whilst others may feel that it will be some time before they can even think about another baby. If there is a possibility of genetic factors being involved with the death of your baby, you may need to seek genetic counselling before any decision is made.

- If you do decide to have another baby, there are a few things that other bereaved parents have found helpful when they have been through a subsequent pregnancy. Physically, a woman's body needs several months to prepare for another pregnancy. It may be longer if the birth was complicated or your baby was born by caesarean section.
- Emotionally, you need time to mourn the death of your baby. No one will be able to tell you how long your grief journey will be. It cannot be shortened or lengthened. Some health care professionals recommend six – twelve months pass before parents fall pregnant. □ When planning another pregnancy, perhaps you need to ensure that the birth of the new baby doesn't fall on the anniversary of your baby who has died. Parents who experience another pregnancy when the dates coincide very often find the experience very emotionally challenging.

- It may also be difficult to make rational decisions while you are still experiencing intense feelings of grief. Despite the hope that another baby may ease your grief, you may find that sadness follows you into the next pregnancy and beyond.

Once you are pregnant, it is natural that you will worry about the baby. Some parents do not wish to return to the same doctor or hospital and if this is the case you will need to ensure that the new hospital and doctor have your obstetric history. You may find that you need to see your doctor more frequently because of your anxiety and developing a good relationship with your obstetrician or general practitioner is a wise idea. If you have other children, it is quite likely that they too will be anxious about the new pregnancy and may need extra reassurance.

The safe arrival of a new baby will bring great joy and relief, but it may also herald another period of mourning for your baby who has died. It is very normal to experience feelings such as these.

## **Taking care of yourself**

The experience of the death of your baby can be quite exhausting and you may find that you will need to take extra care of your physical and emotional wellbeing. You may need extra sleep, eating properly is important also.

No one else can know what you are feeling and you need to look after yourself first.

# Returning to Work

The thought of returning to work can be a painful reminder to parents of the magnitude of their loss. Some parents find that returning to work allows them time to focus on something other than their baby while others find it difficult to concentrate at work because they need to think about their baby. Before returning to work it may be a good idea to speak to a supervisor or manager about easing your way back to work on a part time basis for a time perhaps or talking about flexibility if you find that at a certain time you simply cannot manage and need time off. It may also be a good idea to go into your work place a day or two before your official return to work and have a casual morning tea to break the ice.

**“I am so glad we spent time with our son – holding him, loving him. Those memories will last forever. I had been scared to hold him at first but he was beautiful”**

Andrew

# Support Available

At Sands there are people who understand what it's like to grieve for a baby because they too have been through this experience. People have many different needs at this time and Sands is here to offer empathy, understanding and the opportunity to talk, listen and share experiences in a safe, non-judgmental and caring environment. Our services are available 24 hours a day, for anyone affected by the death of a baby.

We offer a wide range of support services including:

**Phone Support:** Bereaved parents, family members, health professionals and members of the wider community can talk in confidence to an experienced parent support volunteer.

**Phone 13 00 0 sands (13 000 72637).**

**Email Support:** Sometimes it can be easier to communicate by email than by phone. The [support@sandsgld.com](mailto:support@sandsgld.com) email puts you directly in touch with a trained Sands parent supporter.

**Support Groups:** Run by, and for, bereaved parents at a local level in many parts of Queensland. All support group meetings and contact details are listed on our website [www.sandsgld.com](http://www.sandsgld.com)

**Information & Resources:** We have a large range of resources including books, leaflets, videos and DVDs as well as library services.

**Sands Newsletter:** Provides information and support, and a link with other parents. Many find it especially helpful to read about the experiences of others.

**Booklets:** we have available a wide range of booklets that focus on specific topics including fathers' grief, supporting other children in the family, and some of the decisions you might need to make. Many of these are available on the Sands website, or copies can be mailed to you.

**Sands Membership:** You don't have to be a member of Sands to access these services but paying the small membership fee helps us continue to support bereaved families.



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