

Parents hope the birth of their baby will be a happy experience: one when people show a joyous affection towards their newborn and congratulate them on their new family member. Tragically, this is not the case for everyone. About 1 in 100 pregnancies end in stillbirth or newborn death.

Even with family and friends around me I felt so alone, like I was the only person in the world this had ever happened to.

-Emily

In Australia a stillborn baby is defined as one showing no signs of life at birth at or after 20 weeks' gestation or weighing 400 grams or more. Sometime medical professionals may say that a baby had died "in utero" – which means it dies in the uterus or womb.

The first 28 days of a baby's life are known as the neonatal period. When a baby is born alive but dies within this time, health professionals may use the term 'neonatal death'. Sometimes it is also referred to as newborn death.

There are several causes of stillbirth and newborn death including congenital abnormalities, prematurity, problems with the cord or placenta, fetal growth restriction, underlying maternal medical issues, and sadly, many baby deaths have no explanation at all.

Whatever circumstances surround the death of your baby, hearing that your baby has, or will die is incredibly distressing. Having to give birth to your baby knowing the tragic outcome that awaits is an experience no one could ever be adequately prepared for. Those parents who experience newborn death can also find the neonatal intensive care setting and the decisions regarding medical interventions needed for their child to bring great pain and anguish on top of the feelings of grief that occur when their baby has died

# It is natural to experience some of the feelings and reactions associated with significant loss such as:

- Shock
- Loneliness
- Feeling numb or empty
- Sadness
- Crying
- Frustration and irritability
- Anger

- Denial
- Guilt and self-blame
- Confusion
- Acceptance
- Relief
- Jealousy on seeing pregnant women or babies



<sup>66</sup> My baby was perfect, perfect in every way except she wasn't breathing. I was both thrilled to see her and devastated she wouldn't be coming home with us all at once. It was such a confusing time.<sup>27</sup>

- Rachel

# **Common questions**

# Putting on a brave face to console your partner may be Should we tell people what has happened?

Telling family and friends about the death of your baby is very hard and although it might seem too difficult to contemplate, inviting your close family and friends in to see you and your baby is often a good idea. It can make it easier for family and friends to understand your grief and pain as it makes the baby real tothem, too. It can also help to have people to remember your baby in the coming years.

For some families, though, this is an intensely private time. You do not have to have visitors and speak to others if you don't want to. If you have other children, it is strongly encouraged that you let them meet their baby brother or sister too. They need to be able to see and ask questions and it will help them understand what has happened so they can begin to grieve.

#### Should I see my baby?

In many instances there will be the opportunity for you to see and hold your baby. You may also be able to dress and bathe your baby. Your medical staff will ask if you would like to see your child if this is possible.

If you are unsure about if you wish to see your baby or worried about what your baby may look like you can ask your midwife to describe how your baby looks first, or ask to look at his or her hands and feet first. If you decide not to see your baby, you can ask for photos to be taken so you can look in the future when you feel ready. Whilst it might not feel right to do it now, most

bereaved families tell us that at some point they want to seetheir baby so having the photos may be important in the future.

# Are there government processes I need to complete?

You will need to register the birth and death of your baby. The hospital will assist in this process.

You may be entitled to either the 18 weeks of paid parental leave or to the stillborn baby payment. It is worthwhile contacting Centrelink to determine your eligibility.

# How will I cope with grief?

Women often feel confused or distressed by the sense of having no real control over their body. Many feel as if their body has betrayed them or feel guilt that somehow through their thoughts or actions they caused this to occur.

Physically, grief can be an intense experience. Parents may experience insomnia, tummy upsets, loss of appetite, headaches and anxiety. Mothers have described an intense physical craving to hold their baby, like their arms are aching.

Grief is a journey and there will be terrible days and more bearable days. Some people say that grief only comes where there is great love. Over time you will find a way to manage your grief and as hard as the experience is, know you are not alone.

# What will happen to my relationship?

The grief of pregnancy and infant loss can bring couples together, but it can also cause significant strain in relationships, particularly when parents express their grief in different ways and at different times. Try to accept these differences and support each other. If you feel you would benefit from additional help in supporting your relationship see 'Where to go for help' at the end of this fact sheet.

#### What about my other children?

Children's reactions will vary according to their age and level of knowledge and understanding of the pregnancy. For children who knew about the pregnancy try to provide a simple and honest explanation of what has happened. They may need time to deal with their emotions and behavioural changes are also common during this time. A child who is too young to understand what has happened will react to parents' sadness and distress. They will need comfort and reassurance. Rednose's fact sheet 'Children and Grief' goes into this topic in more detail.option to work fewer hours.



#### What about work?

It's unlikely you'll feel well enough to go back to work straight after the loss of your baby. Give yourself time to recuperate. Even when you feel physically OK, you will still need time to recover emotionally. Your doctor should be able to provide you with a medical certificate that gives you enough time but if you feel you need longer don't be afraid to ask.

If you feel concerned about returning to work, speak to your employer. Open communication can help them understand what you're going through and how to accommodate your needs. You should also consider how they can help you communicate to others in the workplace what has happened. Do you want them to make an announcement on your behalf? Would you like the to ask people not to discuss it with you in the first week? Would you prefer to tell people yourself?

### When to consider another pregnancy?

Thinking about trying to conceive after losing a baby can be overwhelming. Some parents desperately want to try again but are terrified of experiencing another loss. Others need more time to adjust to their loss before looking to the future.

It's important to discuss your feelings with your partner and decide how you both feel about another pregnancy. Red Nose has additional resources to support you if you are considering another pregnancy.

The nurse kept talking like he was going to die. I can see now she was trying to prepare us but at the time it was so frustrating, we only wanted positive thoughts around him.

- Nick

# Things you might be unprepared for

#### Lactation

During the initial shock, some mothers will have a very real reminder that they have had a baby when their milk comes in. Some feel reassured by the proof they had a baby while others can feel it is a cruel reminder. The start of lactation can also be physically uncomfortable and in some cases extremely painful.

You may be very tender and leaking milk. 'Letting down' milk can be easily triggered, and you may find this upsetting, given you have no baby to nourish. There are options to stop lactation –including medication – which you can discuss with your doctor. Alternatively, you may like to consider donating your milk to a milk bank if there is one near you or using your milk to create a piece of jewellery to remember your baby.

# Neonatal intensive care and deciding to withdraw life support

Having a critically ill baby is incredibly stressful. In many cases your baby will need to be transferred to intensive care. You may not be able to see your baby straight away. When you do see your baby, it can be a shock to watch them fight for life surrounded by strangers and amongst so much medical equipment. NICU staff will offer every opportunity they can for you to touch, hold, or care for your baby. You might worry about hurting your baby or making things worse, but your medical team will guide you.

Sadly, many parents face the decision of whether to withdraw life support for their baby when they are unlikely to recover. Parents who've been there say this is the most difficult decision they have ever had to make. Inviting family or friends to meet your baby, taking the time to make memories with your baby, or observing special religious rituals can help make these final moments with your baby special. You will have the opportunity to hold your baby, free from medical equipment, after their life support has been withdrawn. For many parents this is the first time they've held their baby and it can be a very special, intimate time that will be forever remembered.





# **Autopsy and coronial processes**

It's natural to want to know how or why your baby died and if it could happen again in the future, however you may feel reluctant to allow a post-mortem or autopsy. Some parents worry their baby will not be treated with care and respect. Others fear their baby may look or feel different afterwards, or that it means they will have less time with their baby. You can consent to a full or limited autopsy. This is an emotional decision, but remember it is the greatest chance you have to understand why your baby has died. Medical staff can help reassure you about what happens during and after an autopsy. Rest assured that you will be able to see and hold your baby afterwards if you would like.

In some rare circumstances a post-mortem examination is a legal requirement that can be ordered by a court. Be prepared that it can take a very long time to get the results of an autopsy and that there is a chance you won't get the answers you are seeking.

# **Funeral arrangements**

In the midst of the deep pain you are experiencing there are important decisions you will need to make about your baby's funeral. A hospital social worker can explain any legal requirements and help guide your planning of your baby's funeral. Arranging a funeral will be difficult and painful; however, most parents say they find comfort in being able to do something special to express their love for their baby. If you are feeling overwhelmed, it can help to have assistance from family, but it is important to make sure they understand your wishes and that you make the important decisions as this will form part of your lifelong memories about your baby.

Leaving the hospital without our baby was the hardest thing I have ever done. I will never be the same. 99

- Alicia

Choosing to leave my wife and go with the baby who was being flown to intensive care was hard but telling her that the baby had died was even harder.

I kept hoping the doctors got it wrong and that I would hear my baby crv. 99

- Mel

