Life, Loss, Hope: Surviving the death of your baby

A book to support parents who are grieving the death of their baby

Written by Sally Heppleston
edited by Rebecca Gill

for Sands Australia
Acknowledgements

This booklet was written in consultation with parents whose babies have died. Sands is grateful to these families for the courage and generosity they have shown through sharing their stories and providing feedback.

Sands Australia thanks Sands South Australia for allowing “My Empty Arms” to form the basis of this book. Thank you also to Professor David Ellwood and Dr Dominic Wilkinson, for their help in the development of this resource.

Disclaimer

In this book we describe common experiences after the death of an expected baby. Information and suggestions in this book are guided by our experience in helping families affected by this distressing event.

Sands acknowledges that values and beliefs surrounding death vary across cultures, religions and personal backgrounds. Reactions to the death of a baby are unique. Some responses may not be included in this booklet, while some of the offered suggestions may not suit everyone. However, Sands offers information and support without judgement.

Professionals have reviewed the information contained in this booklet. It is provided in good will, as a public service.

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Should you have further questions or concerns, Sands can assist – please refer to the ‘About Sands’ section at the back of this booklet.

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'For LB’

I wanted to be your mother more than you could know, to bring you into the world and watch you grow. The promise of you brought happiness and joy, but we were to lose you, our only little boy.

My heart was broken, I cried with despair, you being taken just didn’t seem fair. Gone was your future as our growing son, and broken was the promise of me being your Mum.

– Leah Sahb
About this book

*Life, Loss, Hope: Surviving the death of your baby* has been written to support parents who are grieving the death of their baby. It has been written by those who have also had their baby die.

If your baby has died through miscarriage, ectopic pregnancy, stillbirth, newborn death or termination for medical reasons, you may feel devastated and alone. Your initial reactions may be of shock, disbelief and denial: “it cannot be happening to me.” You may feel overwhelmed by the need to make some important decisions within a short period of time.

This booklet aims to give you some practical advice to consider when you are faced with those difficult decisions. While nothing will completely ease your pain and sorrow, we sincerely hope that you will find some comfort in these words, making your pain and confusion easier to bear.

This booklet is intended for all parents whose baby has died, but some information is more relevant for parents whose baby has died after the twentieth week of pregnancy. If your baby died earlier in the pregnancy, you may also find the Sands booklet ‘Early Pregnancy Loss’ to be helpful.

Some of you may be facing the last few days or hours of your baby’s life. You may be trying to pack a lifetime of memories into a few precious moments, and you may be overwhelmed by the knowledge that soon your baby will die. The chapter ‘Palliative care for your baby’ provides information about medical care for babies whose time is short. Through your disbelief and confusion, the chapter ‘Creating memories’ offers some positive suggestions for the special time you have left with your baby.

This book also features a memorial roll of the names of many babies, gone too soon. They are the babies of many parents who have used the services of Sands over the past 30 years. If you would like the name of your baby (or babies) acknowledged in future editions of this book, please email memorialroll@sands.org.au

*In this booklet, we often use the word ‘baby’ although we acknowledge you may have had multiple babies who have died, whether as part of a multiple pregnancy or previous pregnancy losses. Sometimes the words we use might not fit your particular circumstance – we hope you will understand. If you would like individualised support, please call our national bereavement support line on 1300 0 sands (1300 072 637) – see the back of this booklet for more details.*
Foreword

I am deeply sorry for your loss, but commend you for opening this booklet and reaching out to Sands. Within the pages of this booklet you will find information that can guide you through the grief. Compassion and empathy underlie its message.

Sands is a community-focused organisation that places a high value on quality non-judgemental bereavement care. True to the ethos of Sands, this book has been written by bereaved parents.

This Sands booklet is intended for all parents whose baby has died, as well as those parents facing the last precious moments of their baby's life. It is my wish that the booklet and the Sands community can help you find the hope to honour the short life of your baby and keep his or her place in your family forever.

I discovered Sands after my three miscarriages in 1982 and 1983, and I am extremely fortunate to have done so. I found solace in the words and wisdom of other parents who had experienced the same feelings and grief as I was feeling. Sands gave me the courage to grieve and then to try again. The legacy of that support continues, for I have been involved in Sands for 30 years; first to seek support, and later to give something back in thanks.

I am proud of the work carried out by all Sands volunteers across Australia. The peer-support model of bereavement care strikes a chord with those who have the misfortune of losing a baby, whether that happens in the early weeks of pregnancy or several weeks after birth. A nurturing community of sympathy and understanding develops when parents help other parents through grief and sadness.

Sands parent supporters are specially trained volunteers who have had the experience of losing a baby. Through their personal experience and their Sands training, their support helps reassure bereaved parents that there is always a helping hand extended in their direction. The help that is shared is ongoing, for as long or short a time as is needed.

Sands is ready to help you through this difficult time. It is my hope this book will encourage you to reach out further. It is an important contribution to a new suite of information resources developed by Sands. For that, I would like to thank those who helped produce this resource – Sally Heppleston for writing the document, Rebecca Gill for editing it, Sands South Australia for allowing its booklet ‘My Empty Arms’ as the basis and the Sands Australia National Council delegates for their regular feedback.

I sincerely hope you find the advice in this book useful and practical so that, when it comes to making the difficult decisions, you are well-informed and able to do so. Sands encourages you to acknowledge your baby’s life, however short, and your role as his or her parent now and into the future.

Please remember: you are not alone.

Christine Carroll
Chair, Sands Australia National Council
If you are reading this foreword it is possibly because you are one of thousands of Australian mothers who experience the tragedy of pregnancy loss through miscarriage, termination, stillbirth or neonatal death each year. Or you might be a partner, close family member, or friend who is trying to work out how to help at this sad time. You could also be one of the many health professionals who are involved each year in caring for families who are experiencing the most profound grief that comes from losing a baby, either before or after birth. For each one of you there will be something you can find within these pages, which helps in some small way.

This booklet has been written to provide some additional help and resources to the many people who are touched each year by the tragic loss of a baby at all stages of pregnancy, although it is more relevant to those whose loss is after the twentieth week. It has been written by parents who have personally experienced this devastating outcome of pregnancy. The advice is based, to a large extent, on real life and is practical, compassionate and caring, and delivered in a non-judgemental way. There is no right way to behave when faced with the death of a baby, and no correct way to grieve.

But amongst the practical advice about autopsy and funerals are some important messages about dealing with friends and family, ways to help to remember your loved one in the months and years ahead, and how to understand the long journey of grief.

For mothers and fathers, the advice about how the genders differ in their reaction to loss and their different ways of grieving is invaluable, and may help couples to avoid the additional burden of conflict and relationship breakdown. The practical suggestions about the next pregnancy will answer a lot of the questions that inevitably start to appear over the next months and years after a loss.

Sands is an organisation which has helped countless families over many years. This is an important and well-written resource that adds to the tools available to assist grieving mothers, fathers and families, as well as those who are trying to care for them. I congratulate the authors and all who have helped to put this together, and hope that it helps all who read it to deal with one of life’s all-too-common sad events.

David A. Ellwood
Chair, International Stillbirth Alliance
Past-President Australian & New Zealand Stillbirth Alliance
Introduction

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, your baby has died or is going to die very soon. This is an intensely painful life event for a parent. The future you had planned has been turned on its head, and you are now being forced to adjust to a life without the baby you expected. Making sense of what has occurred is challenging and upsetting.

Every parent reacts differently to the death of their baby. Newly bereaved parents generally experience a wide range of emotions. Grief is a natural journey and can be embraced in a healthy way.

Society often underestimates the profound grief that can be felt by parents whose baby has died before, during or soon after birth. This book aims to help bereaved parents navigate the feelings and situations they may face over the coming weeks, months or years.

Sands offers help through its parent supporters – volunteers who have experienced the loss of their baby and are using their understanding to help others through their journey. Talking freely with parent supporters who have lived through the experience can help to reassure bereaved parents that they are not alone and their reactions are normal.

Sands is incredibly sorry for your loss; we hope this is the first of many times you hear this.

“A Sands parent supporter came to visit me in hospital and talked about the time she spent with her baby and how she treasured those memories. She gave me two very precious things: the courage to spend time with our baby and the hope that we could keep on going.” – Kelly

Why do babies die?

In an age of such wonderful medical advances, it remains a sad reality that babies still die. When it happens to you, it can be a shock to learn just how often it does occur, and that there are many reasons why and how they die. You are probably feeling tremendously alone, but rest assured that you are not. Many parents have walked this road before you, and there is help at hand to get you through these dark times.

Most parents have a strong need to know why their baby died, what caused the pregnancy to end so abruptly and whether it will happen again. Searching for answers is natural and a normal part of trying to come to terms with the death of your baby. You may feel angry and frustrated by the answers you do or do not receive. You may also feel guilty or responsible. This is normal and those feelings should not be ignored, but slowly and gently worked through. You may also be replaying what happened, over and over again in your mind. Ask as many questions and talk as much as you need. This is an important part of trying to comprehend and process your loss. Do not hesitate to talk to your doctors and midwives.

Unfortunately the answers aren’t always obvious or satisfactory, or there may be no real explanation for what happened at all. An autopsy (or post mortem) may help you and your doctor answer some of these questions. It could also help you plan future pregnancies if you decide to go on to have another baby.
Some facts

**Miscarriage** refers to the spontaneous end of pregnancy in the early months (before 20 weeks gestation). About one in five confirmed pregnancies end in miscarriage. After a miscarriage, a short operation called a dilation and curettage (D&C) may be performed to empty the mother’s uterus of any tissue remaining from the pregnancy. This is not necessary if all of the tissue passes naturally.

**Ectopic pregnancy** occurs when the fertilised egg implants itself outside of the uterus. A majority of ectopic pregnancies occur in the fallopian tube, but they can also happen in other sites such as the ovaries, abdomen or cervix. In most cases, the fallopian tube will rupture early in the pregnancy (at about 5 or 6 weeks) and will need to be removed surgically, leaving one remaining tube. Some ectopic pregnancies can be managed medically (i.e. non-surgically). Future pregnancies are still possible.

**Medical termination** is performed when there is known to be an abnormality in the developing baby which is either incompatible with life or would result in a serious disability. Occasionally parents may be advised to end a pregnancy because of risks to the mother’s health. The mother usually undergoes an induction of labour and vaginal birth, although in some cases up to 18 weeks gestation, the termination can be performed by dilation and evacuation (D&E) if the pregnancy has progressed further.

**Stillbirth** refers to the death of a baby after 20 weeks gestation before birth.

**Neonatal (or newborn) death** occurs when the child is born alive but dies within the first 28 days of life. About 1 in 100 pregnancies end either in stillbirth, or in a neonatal death.

**Autopsy and investigations**

After a medical termination, stillbirth or newborn death, you may request, or your doctor may recommend, an autopsy. This procedure involves an internal and external examination of your baby’s body. While this may be distressing, it can provide you with some much needed answers or clues as to what happened and can help work out if you will have similar problems in future pregnancies. Sometimes, unfortunately, an autopsy may not offer an adequate medical explanation for the death of your baby.

On rare occasions, the death of a baby after birth may be referred to the Coroner. Your doctor will tell you if this is likely to happen to your baby. In this case, an investigation (which generally includes an autopsy) will be conducted by the Coroner. In such cases, the concerns of parents are generally taken into account. Laws relating to coronial investigations may vary from state to state, but your doctor should be able to advise you of the procedures in your state.

After a miscarriage when the baby is fully formed, an autopsy or other tests can be carried out to check for other problems such as infection or chromosomal abnormalities. In this case it may be possible to determine the sex of the baby if you didn’t already know.

Following a D&C or very early miscarriage where the baby is not fully formed, it is unlikely that any investigations can be carried out other than to confirm that the pregnancy occurred. Some tests are possible, but unfortunately most of these are quite expensive and not very useful – so your obstetrician may advise against them. Miscarriage occurs quite frequently and there is often no
obvious cause. Doctors usually don’t recommend specialised testing for the cause of a miscarriage unless a woman has experienced at least three miscarriages.

Your obstetrician, paediatrician or midwife will be able to answer any questions you have and should provide you with information regarding autopsies. Take your time to consider the options and think of any questions you may have for your carers before you make your decision. You may choose a limited examination or opt for only the placenta to be examined. Your obstetrician, paediatrician or midwife should explain all procedures and obtain your written consent before any tests are carried out.

Your obstetrician may also suggest that you and your partner undergo blood tests. These may be helpful in detecting any fertility problems and may provide information to help plan future pregnancies.

When trying to come to terms with the death of a baby, many parents say it helps to have some answers as to what went wrong or why the baby died. Unfortunately it is not always possible to find definitive answers. Parents may have many unanswered questions, leaving them feeling frustrated and helpless.

If you find yourself in this situation, don’t be afraid to approach your obstetrician or midwife as often as you feel necessary. You may find it helpful to talk over what happened, to try and make it clear in your mind. This may not necessarily provide answers but can play an important role in trying to comprehend and process the death of your baby. Talking is healthy and a normal part of the grieving process.

**Palliative care for your baby**

If your baby has a condition that means he/she may die before or soon after birth, one option can be to continue the pregnancy with a plan for palliative care for the baby. Palliative care plans are designed to ensure that your baby is comfortable and that their short life is as good as possible. This means providing special care for the baby while avoiding medical treatments that would not be helpful, or might hurt the baby and separate them from you. Your treating team will be able to give you advice regarding palliative care for you and your baby.

A palliative care plan should include the following:

- A coordinated and well-communicated medical plan that supports yours and your baby’s needs from both inside the womb, and after they are born.
- The supply of relevant and comprehensive information about your baby’s diagnosis.
- Development of a birth plan which takes into account your wishes for medical and other care at the time of the birth of your baby.
- Help in finding suitable bereavement assistance and support for you and your family. You will need extra support in the lead up to your baby’s birth.
- Help in creating memories and mementoes of your baby for you to keep.
- Assistance with funeral plans.
Medical staff are integral to palliative care. Most parents will find sensitive and supportive carers in such situations. Your caregivers should respond to your questions in a timely and appropriate manner, and be respectful of your cultural and religious values.

Sometimes, hospital staff may not meet your expectations. Perhaps they seem unsympathetic to your circumstances, or that they do not respect your decisions. If you feel this is the case, you have the right to ask for another staff member. If this is too confronting, others may be able to act on your behalf (such as your obstetrician or midwife).

For more information about palliative care options for babies with life-limiting conditions, visit the web-based handbook Caring Decisions (www.rch.org.au/caringdecisions). Developed by Australian medical professionals, it is written especially for parents facing end of life decisions for their seriously ill newborn infant or child. It provides support to help parents work through difficult decisions towards the end of a child's life. Other helpful resources to visit include the Perinatal Palliative Care website (www.pnpc.org.au) or the US-based Perinatal Hospice and Palliative Care website (www.perinatalhospice.org).

Creating memories

Sometimes, in order to process what has happened, you have to come to terms with and acknowledge that it actually happened. If you try to pretend it never happened and avoid any contact with your baby, you may be left with deep regrets in the future.

We respect your right to make your own decisions but also offer the following thoughts and suggestions from our own experiences and those of other families whose babies have died.

Naming your baby

If you have not already selected a name for your baby, it could help you both to choose a name to give your son or daughter. Your baby is a real person and a part of your family. It may feel easier to include and acknowledge your baby with your family and friends if you can call them by their name. You may choose the name you thought you would use before you found out your baby died, or you may choose another name altogether. The decision is up to you and your partner.

Seeing and holding your baby

Studies have shown that parents who are able to see and hold their baby are potentially able to begin their grieving process sooner than those who do not. It helps parents to realise that their baby was a real person. In previous generations, parents were rarely given a choice and they were discouraged from holding and seeing their babies. The babies were taken away by well-meaning medical staff who thought it would do the mother more harm than good to see the baby. Thankfully today, times have changed and most people who have a baby die value the precious time they were able to spend holding their baby.

Facing death when you should be welcoming a new life is tragic and heartbreaking. You may also be afraid of seeing your baby and scared of being overwhelmed by your emotions when you hold your baby for the first time. Both of these reactions are understandable and normal. These feelings are an important part of the experience of meeting your baby and the very beginning of the grieving and healing process.
Hospital staff will, in most cases, encourage you to see and hold your baby, and they will be able to give you a good indication of what your baby may look like so you are in some way prepared. By seeing and holding your baby, you will not have to wonder about what they looked like. Even if there is some abnormality, your imagination is usually far worse than the reality and you will be able to see past any imperfections. It can be of great comfort in later years to know you saw and held your baby. If you are nervous about seeing your baby and are worried about how you will react, you may feel more prepared if you see a photo of the baby first. However, this decision is up to you. You do not have to see or hold your baby if you do not want to.

“When the midwives asked me, just before I gave birth to Alice, if I wanted to hold her – I initially said no. I was terrified of what her body might look like. But the image in my head was far worse than reality, and once she slipped out of me, my mothering instinct kicked in. I practically snatched her from the midwives and pulled her up onto my chest. I’ll never regret those first moments after birth where I got to see her face and take in all of her perfect little features. In those moments, I was able to look past her death.” – Kate

**Spending time with your baby**

The opportunity to create memories of your baby is very brief. Although painful now, hopefully you will look back on this time as special and precious. Try to treasure every moment you have with your baby, as you can never get it back. You don’t want to be left with any lingering regrets.

There is generally no need to rush your time in the hospital. The baby can stay with you as long as you choose. Even if you decide you want the baby taken out of your room, there is usually no reason that the baby can’t be returned to you later on. An autopsy does have to take place within a certain timeframe – check with the staff if you have agreed to an autopsy.

There may also be special cool cots for the baby to stay near you for longer without affecting the ability to do an autopsy. Your baby may need to spend some time during your hospital stay in the hospital’s morgue. Speak to your caregivers about this, as they will be able to advise on what is necessary for your baby’s body.

“We kept baby Lucas in with us overnight. While it was not long enough – as no amount of time could possibly have been long enough, when we hoped to raise him for the rest of our lives – we treasure those special moments spent with him. We’re glad we didn’t rush home as soon as Allie was up and about again after the birth.” – Trevor

When spending time with your baby, you may find it comforting to do some of the things you always dreamed of doing. This might include:

- Cuddling your baby
- Sleeping snuggled up to your baby
- Bathing your baby
- Massaging and caressing your baby’s body
- Taking time to examine your baby’s features - hair, feet and hands
- Dressing your baby in a special outfit
• Using a special bunny rug in your baby's cot
• Putting a special teddy or soft toy in your baby's cot
• Creating ‘atmosphere’ in the room by playing special music, dimming the lights, burning essential oils (if permitted in the hospital)
• Reading stories to them
• Taking your baby for a walk outside
• Taking your baby home with you before the funeral
• Inviting family and close friends to come in and meet your baby.

You may find it helpful to record everything you do with your baby in a journal as well as taking photos and video.

If you would like to do some of these things with your baby but find it too difficult or painful, ask other family members or friends to be involved. Grandparents, your siblings and your other children might like the opportunity to spend time with the baby. Like you, they have looked forward to the baby’s arrival and may also feel the need to spend time bonding with your baby. Later, you may find comfort in the fact that others met your baby and shared your experience.

“I’m so glad we had our immediate family come in and meet our baby Rose. The day after her birth the hospital arranged a small blessing ceremony for us, and it was so touching that they could all be there for that, to help us say goodbye.” – Rachel

There is no denying that being with your baby who has died is extremely painful and probably one of the most difficult things you will ever have to do. Don’t be afraid of the pain and heartache you are experiencing. Your baby has been and will always be an important part of your life. Your feelings are justified and normal.

Photos of your baby

Most maternity hospitals will be able to take photos of your baby for you, if this is something you would like.

This is strongly encouraged, as you may be thankful to have photos in the future should you decide to look at them or share them with others, when the hurt is a little easier to bear. Most parents do not regret having photos taken of their babies, but many parents who do not have photos wish they did. You will never get a second chance to capture these precious memories.

You may also like to take photos of you with the baby or of the baby with other family members, including your other children or friends. If the baby is a twin you should consider taking photos of the babies together, even if one of the twins survived. Although this will be painful to do, you will be creating special memories of the baby and the time you spent together.

The hospital will usually take some photos for you but you may feel these are not enough. Most parents who have been through similar experiences would suggest that you take as many photos as possible, as you will never have another opportunity.
Videoing your time with your baby is also a wonderful way of capturing the precious time you spend with your baby. Later you may find comfort in surrounding yourself with these treasured memories. It is natural to want to hold on to the memories of your baby, so do not fear that you are being morbid, even if anyone suggests you are. Having these tangible memories is healthy and an important part of grieving.

A volunteer photographic organisation called Heartfelt can also be contacted to take professional photos of your baby, free of charge. Heartfelt are a group of professional photographers, most of whom have been touched by the death of a baby in some way, who will come at a moment’s notice to take photographs of your very ill, premature or stillborn baby. If this is something you would like to consider, ask one of your caregivers, a family member or friend to contact them for you, at any time of day or night. Heartfelt photographers service most areas of Australia, including remote areas and will come at any time of day.

“We simply do not like to think about where our grief would be now if we didn't have our Heartfelt photos. We got many photos ourselves, but none as touching as the ones they took for us. Those photos are a true and irreplaceable gift.” – Dominique

Ensure you make copies of all of the photos and videos you have of your baby, both hard copies and digital, and store them with friends or family.

**Mementos and keepsakes**

There are many things you may wish to keep in memory of your baby. Anything that evokes a special memory of your baby is worth writing down, taking a photo of or keeping. Talk to the midwives or nurses involved so they can help you. They may have some suggestions or the hospital might offer other special keepsakes.

Just as you would compile an album for a live baby, you may like to use these mementos to compile an album for your baby who has died. You may even find it therapeutic to make, decorate or buy a special box in which to keep your mementos. Although this idea may be impossible or too painful to think about at the moment, it is something to consider in the future.

You may decide you never want to look at these mementos again, but it can be reassuring to know they are there if you change your mind, or if someone else wants to see them.

If you decide to put an album together for your baby, it may be upsetting to look through it at first. Eventually, as the intense pain eases, your baby's album and keepsakes may be a great source of comfort.

The following is a list of items that other parents have kept as mementos of their baby:

- Ultrasound photos
- Pregnancy records
- A lock of the baby's hair
- Footprints and handprints
- Family photos with the baby including your other children and your extended family and friends
- Bunny rugs or quilts used for your baby in hospital (speak with the staff if you would like these as a keepsake)
- Moulds of the baby's feet and hands (some hospitals or the funeral directors may be able to organise this for you)
- Identification bracelet
- Name and birth detail cards or cot cards
- A diary of the birth experience and your time with the baby, recording things such as the names of those who looked after you
- A letter or poem written for your baby
- A list of the visitors and phone calls you received
- Certificates, including baptism, birth and/or death certificates
- Letters or cards you received
- Photos of, or dried flowers from, any flowers you receive.

You may also like to create more symbolic mementos for your baby. These can be especially useful if you have experienced a miscarriage or never had the opportunity to see your baby:

- Use your baby’s star sign, birth stone or flowers to help create a memento, for example a ring or pendant with your baby’s birth stone in it
- Select a special song or piece of music that will always be their song
- Choose a place for a special plant in your garden
- Find an ornament such as a cherub, angel or teddy bear to remind you of your baby
- Donate to a charity in memory of your baby
- Get a small tattoo in honour of your baby.

The options are only limited by your imagination. Anything that is significant to you or helps you think about your baby can become a special keepsake.

“After Josie was born the midwives took a lock of her hair and hand and footprints and recorded them all in a little book for us. They also gave us a special quilt that we kept in her cot for the night we spent with her in hospital, so these became our first keepsakes of our time spent with her. To this day they are amongst our most treasured items, the sort of things we’d run back inside for if our house was burning down.” – Emily
Keeping a journal

Keeping a journal of your grief journey can be a very useful way of expressing your thoughts and feelings during this difficult time. Writing or recording your thoughts can be very beneficial for those who have suffered through the death of a baby. You are not confined to writing though. You may choose any medium, such as making a video of your thoughts and feelings.

- Writing can help clarify your thoughts and feelings when you feel confused.
- Writing helps to release your emotions, particularly if you feel that no-one understands or wants to listen. Tapping away on a computer or scribbling thoughts on paper can be a healthy way of relieving anger and frustration.
- Write to your baby. Say all the things you never got the opportunity to say. Write of your love for them, your heartbreak and emptiness. Tell them of all the plans you had for them.
- Keeping a journal of times, events and people involved with your baby can be helpful. While your thoughts are clear and fresh in your mind now, it is best to jot them down as you will be grateful for this in the future when your memories of the time spent with your baby start to fade.
- Keeping a journal of the time following the death of your baby can be one of the first steps in the healing process. You will be able to see how you have grown and changed and how far you have come in your grief. If you record your journal you may even hear the changes in your voice as you move along the path of grief.

Try to also record the happy memories of the time spent with your baby, especially the pregnancy. Although this might be difficult at the moment, later you might find it comforting to recall the times that brought you joy. Looking back on these treasured memories can also help when thinking about a new pregnancy. Keep note of things such as:

- Your feelings when you found out you were pregnant
- Your feelings about yourself and the baby as the pregnancy progressed
- The first time you felt the baby kick, if the pregnancy progressed that far
- How you prepared for the arrival of your baby
- Significant events throughout the pregnancy
- Your feelings after the birth, when you discovered the baby’s gender, individual features and likenesses.
**Involving others**

Although it might seem too difficult to contemplate at the moment, inviting your family and close friends in to see you and the baby is often a good idea. These people have shared the anticipation and excitement as you've waited for your baby to arrive. Some of them also probably had their own hopes and dreams for the baby and are now grieving and hurting for you, too.

Your family and friends may find it easier to understand your grief and pain if they see the baby, which makes the baby real to them. They may feel more able to talk openly and honestly with you if they have shared in your experiences. They may also be grateful to have had the opportunity to say their own goodbyes to the baby. For some families, though, this is a very private time. You do not have to have visitors or speak to other people if you do not want to.

Involving your other children, if you have any, is also strongly encouraged. They need to see the baby and to be able to ask questions. They will also grieve and need to understand what has happened. Children are honest and open about death, which is both healthy and refreshing. Their responses should be nurtured and encouraged. However on some occasions, you may find it difficult to deal with them, especially during your darkest times. Try not to feel guilty about this, but enlist the help of your other family and friends, encouraging them to also be honest with the children. Speak to your children's teachers if they are in school or pre-school/kindergarten so they are on the same page as you are when it comes to discussing the death of their sibling. They will also be able to keep an eye out for any behavioural problems, which can arise after a trauma in a family.

**Religious beliefs**

Ceremonies for naming the baby, blessing or baptising the baby can be very meaningful and therapeutic for parents and families. This is a matter of personal choice: you may like to discuss this with your priest or religious leader, or a member of the hospital's pastoral care team. Even if you are not religious, they may be able to organise a naming ceremony for you, to acknowledge your baby as part of your family.

Speak with the staff for assistance with any arrangements if you would like a ceremony performed whilst in the hospital. This is usually straightforward to organise.

**Birth announcement**

It’s a joyful tradition to announce the arrival of a baby. However, when this news is sad, you may no longer feel it is appropriate. Although your family and friends will probably already know, a notice of your baby’s birth in the newspaper is a public acknowledgement of your baby. By placing a notice in the paper you are giving other people a chance to express their sorrow, sympathy and concern for you and your family.

What you decide to print is very personal. You may choose a simple announcement or you may want to include a personal comment or verse. A printed birth notice can also become one of the keepsakes you have to remind you of your baby.

Though it can seem impersonal, you may feel the need to let a lot of people know at the same time about your baby's birth, to stop the dreaded and sometimes unavoidable ‘Chinese whispers’. A
text message or email can be a quick and easy way to inform friends and family who might not immediately find out, about your baby. Ask someone close to you to do this for you, if you don’t feel up to it yourself. You may also wish to deactivate your social media accounts if you find they are too distressing for you to visit after the death of your baby. A friend or family member could also post a note for you, letting everyone know of your sad news.

After you have sent your messages, you may find it easier to keep your phone and your computer turned off for a period of time. Though you will likely receive many replies, you may not yet be ready to read them. You may also be disappointed by those who do not reply. It is best to spend this time with your partner bonding with your baby, as this time will be precious and fleeting.

Social networking can become a minefield for recently bereaved parents, as it is so often a place where people share happy and joyous news, especially pregnancy announcements and births. You may find you need to have some time out from these aspects of your “online” life to cushion yourself from further hurt. When the time feels right, ease yourself back into your online social networking circles.

“The first thing I did when I got home from hospital after finding out my baby had died in utero was remove myself from all of my online social communities. I just couldn’t bear to be a part of it all anymore. My friends were all waiting to hear my happy news, given they knew I was in labour and they knew I was overdue. Not to mention, nearly every other female friend I have is either pregnant or already has a baby of her own. I just couldn’t face that aspect of my life anymore.” – Emma

On the other hand, social networking may be a valuable way to connect with other bereaved parents. So while you might find some of your real life friendships failing in the wake of your loss, don’t discount the new friendships that may come your way as a result of your baby dying. No one will understand your grief and your pain like another parent who has had a baby die, and you may be both comforted and shocked to know just how many of them are out there.

**Birth Registration**

The guidelines for registering a baby’s birth and death can seem complicated. The following general guidelines will assist you, but we recommend discussing your situation with your hospital social worker, midwife or obstetrician.

- Any baby stillborn after the 20th week must be registered.
- A baby who has died before the 20th week of pregnancy cannot be registered.
- If the gestation period of the stillborn baby is unknown, and he/she weighs at least 400 grams, the birth must be registered.
- If the gestation of a baby born with no signs of life is unknown, and he/she weighs less than 400 grams, the birth cannot be registered.
- Legislation concerning the registration of babies from pregnancies which have been terminated for medical reasons is not currently uniform in Australia (i.e. it varies between states and territories). Ask your carers about your own situation.
If you have any uncertainties or questions that hospital staff cannot answer, you can also contact Births, Deaths and Marriages in your state or territory.

A Birth Certificate or the Birth and Death Certificate (after a newborn death) may also be obtained from the Registrar of Births, Deaths and Marriages (in circumstances where they are registrable under legislation).

**Funeral arrangements**

In the midst of the deep hurt you are experiencing there are important decisions to be made about your baby’s funeral. Funerals are a very personal event. The hospital social worker can explain the legal requirements and funeral options. The hospital may also provide you with important information about organising funerals. Read this information carefully. You may also find it helpful to visit local cemeteries or talk with funeral directors before making any decisions. You can have your baby buried or cremated, and the choice is a very personal one.

Some hospitals still offer burials, often in combined graves in special sections of the cemetery, but this is now rare. If you miscarried, you might be able to make use of this option, but speak to your caregiver before you make any decisions about what you want to do with your baby’s remains.

**Why have a funeral?**

Some people will question why you are having a funeral for your baby. It is often assumed parents of a baby who has died will either not wish to attend or be too upset to have a funeral for their baby.

When an older person dies, we have a funeral for them, and no one would suggest otherwise. Even if your baby lived only for a short time or died prior to birth, he or she is still a part of your family.

A funeral service forms a very important part of the grieving process and provides an opportunity for the reality of your baby’s death to be recognised. They also give an appropriate time and place for parents, and their family and friends to express their love for the baby.

**How soon should the funeral take place?**

The funeral for your baby should not be rushed. Several days between the death and the funeral can be helpful. It can provide you with time for the reality of your situation to begin to sink in. You may also need to regain strength or recuperate from the birth. The extra time may also allow family or friends from interstate to attend. Finally, extra time may enable you to better plan the ceremony you want for your baby. However, some cultures require their dead to be buried within 24 hours, so if this is the case for you, make sure you have plenty of support around you to plan the ceremony for your baby.

**Who should attend the funeral?**

Whilst some may assume that only the parents should attend the baby’s funeral; this is not always the case. Asking your family and friends to attend your baby’s funeral might seem confronting, but in time you’ll appreciate all of the extra support you had around you on such a difficult day. It allows your extended support network to realise the depth of your loss and shows them the importance of their much-needed support during the first days of your grief. They too need to grieve and time to say goodbye to your baby.
Rather than being a burden, as some may suggest, having those who care for you at your baby’s funeral can be of great comfort, as they support you through this difficult time. However, some parents prefer a small, private funeral: remember it is your choice.

If you have other children, you are encouraged to take them with you, if you feel they are up to it. Some people may be concerned if you decide to take them but remember that children grieve deeply and by excluding them, you may be doing them more harm than good. Instead of being ignored or left to struggle with the tragedy alone, their grief can be shared with you, and worked through together as a family. A friend or relative could be available at the service to help you with them, if need be.

**Things that may help you plan a funeral**

Planning for your baby’s funeral will be difficult and painful; however, being involved in the funeral arrangements can be an important part of processing the reality of your baby’s death. You may also find some comfort in being able to do something special for your baby. Individual details can make a funeral special and personal.

You will need to choose a funeral director or may wish to plan your own ceremony if you have needs that might not be accommodated in a funeral service. In planning the funeral, the funeral directors might have some suggestions or you might like to consider the following:

- The venue could be in a church or chapel, at the graveside, outside at a park, the beach or gardens, or in your own home or garden.

- The ceremony might include songs/music, prayers, poems, readings, a letter you have written to your baby, or lighting of candles.

- Surroundings or decorations could include flowers, candles, fairy lights and balloons, teddy bears, angels or cherubs, photos, background music and burning essential oils or incense.

- Pick out a special outfit for your baby to wear and give it to your funeral director, as well as some special mementos to put in the casket. These might include a family photo, a letter you have written to your baby, a blanket and/or a special toy, or your other children might want to draw a picture or write to the baby. You may also wish to keep duplicates or copies of anything you have included in the casket as keepsakes.

- Plan to have someone at the funeral to take photos or video for you (some funeral directors offer this service). If you were unable to have Heartfelt attend at the hospital to take photos of your baby, they may be able to attend the funeral.

Later on, you can plan the wording for a special plaque or gravestone for your child, but this does not need to be rushed. Take the time to carefully consider how you would like this permanent marker for your baby to look and speak to your cemetery about any requirements or restrictions.
**Consider your entitlements**

Australian Federal Government financial assistance to families changes from time to time. Centrelink is the department which currently administers financial assistance to bereaved parents. If your baby was stillborn or has died, you may be entitled to government payments – you should discuss your options with Centrelink or the hospital social worker. Many parents use these payments to pay for funeral and burial or cremation costs, although it may take some weeks for your application to be processed.

In many workplaces, employees have access to paid parental leave as a condition of employment. If your baby has died, you may still be eligible for this leave. Eligibility for leave usually depends on your employment award or contract and how long you have been employed. Discuss your individual situation with your employer.

**Dealing with others**

**Doctors and hospital staff**

Doctors and midwives now have a much greater awareness of ways they can support you when your baby dies, but remember that they are only human, and not all will have a bedside manner that will sit comfortably with you, especially during this time of great distress. Some of them, whether intentionally or not, may say things that upset you.

Should they seem disinterested or lack empathy, it may be their way of coping with your baby's death. They may have difficulty in finding the right words and may therefore say nothing, or they may feel helpless, angry, guilty or that they have somehow failed you.

It is important for you to be honest and open with your thoughts and tears, thereby giving them permission to do the same. When a baby dies, this is not only traumatic for you, but also upsetting for everyone involved with your care, both during the pregnancy and the birth.

**Your other children**

If you have other children you will need to explain to them what has happened to help them with their grief. Even if your children are too young to understand the finality of death, they will still be upset.

Don’t be afraid of involving your other children regardless of their age. Allow them to come into the hospital to see you and the baby. They might want to hold and cuddle their baby brother or sister. This is healthy and normal and should be encouraged. Children have vivid imaginations and being honest with them is extremely important for them to understand what has happened to the baby.

They will also seek answers. Tell them about the baby’s death simply and honestly. Don’t hide your tears. They will need to be reassured of your love and understanding with lots of cuddles and encouragement to help them express their thoughts. Like you, they will accept this baby as part of their family. Your children are unique individuals and will show their grief differently, just as we do.

“I’m so glad we had our older two come in to meet Harry. We had pictures of all of us taken together, and these will be the only photos we’ll ever get as a complete family unit. And every year since Harry died, our children have enjoyed having a cake for him on his birthday, and leaving flowers for him at his grave site.” – Ian
Family and friends

Your family and friends will want to help and comfort you, but may not know how. They may think they are helping you by not talking about your baby, but often the opposite is true.

Your parents have suffered a double hurt; their grandchild has died and they are hurting for their own child as well – you. Their grief will have an added layer.

Some people will simply be unaware of the intensity of your grief. They may make insensitive or cruel remarks such as ‘never mind, you can always have another baby’. Be honest with your feelings and don’t allow resentment to build up. If you disagree with someone’s remarks, tell them. You need to be able to talk about your baby, so take the initiative and tell everyone right from the start how you feel. Not talking creates an illusion that everything is OK. Staying quiet can deny the reality of your experience and your baby’s death.

However, sometimes you may find you simply have nothing to say, and that you don’t have the energy to talk, which is perfectly understandable and normal. If you find written material or a website that captures how you are feeling, you may wish to share these with your family and friends. They will most likely appreciate that you are helping them understand what you are going through. The Sands website has useful information aimed specifically at family and friends of bereaved parents, which you may like to suggest to them.

“I was very fragile emotionally. My best friend called the Sands support line and they talked to her about how she could support me.” – Jenny

The journey of grief

Sadly, parents of babies who die are placed on an unavoidable journey of grief. Dealing with the lost plans and hopes you may have had for your family is incredibly difficult.

You may be in shock, having expected the happy arrival of a healthy, crying baby. Instead your pregnancy may have ended early, abruptly and silently. Your emotional and physical pain may seem overwhelming, almost too great to bear. You may feel as though your heart has been ripped out, with every fibre in your body longing to hold your baby.

There are many different responses to the death of a baby. Depending on when and how your baby died, those feelings may vary in severity from feeling sad for a day or two to excruciating pain lasting for weeks, months or even years. You may feel like a completely different person with new priorities in life. Performing what were once simple daily activities may now be challenging and difficult to achieve. You may feel like you will never be happy again and that joy, laughter and happiness will never return to your life. These feelings are normal and to be expected for bereaved parents.

There is no right or wrong way to feel and whilst there are many common aspects to our grief, we all respond to the death of a baby differently. Whatever the gestation of your baby, there will be a ‘period of adjustment’ before you can return to any sense of normality. In many ways, your life will never be the same after your baby dies. You will learn to live with a new version of ‘normal’.

Parents’ feelings in response to the death of their baby are many and varied. The following is a list of some of the feelings and experiences that are common and normal to grieving parents:
• Shock, feeling numb
• Disbelief, difficulty comprehending the reality of the baby’s death
• Feeling terrible, but unable to cry
• Crying
• Feeling depressed
• Longing to hold the baby
• Repetitious dreams about the baby
• Aching arms and breasts
• Wondering ‘why’ or ‘if only’
• Wanting to talk, going over what has happened
• Wanting to withdraw from society
• Feelings of guilt, responsibility or failure
• Anger
• Jealousy of other families or pregnant women
• Feeling physically exhausted
• Forgetfulness, restlessness, inability to concentrate
• Anxiety
• Loss of confidence or the ability to make decisions
• Confusion
• Feeling isolated, alone
• Feeling as if you are losing your mind
• Feeling that life is not worth living
• Unable to sleep
• Loss of appetite
• Stomach pains
• Dizziness
• Lack of strength
• Irritability
• Headaches
• Loss of libido
If at any time any of these feelings are too much for you to handle or you are worried about how you are coping, you should seek professional help. At times, grief can lead to depression and your caregivers will know if you need any further assistance, medical or otherwise, in dealing with your grief. You can also contact Sands for extra support and information.

Not all of your feelings may be negative. Through the tears and heartbreak you may still find a sense of overwhelming love for your baby. You might still find pleasure in remembering the features of the baby, of having examined his or her feet and hands, facial features and hair colour. Like the painful feelings, these positive emotions are normal and healthy.

No matter what your feelings, they may be so intense they scare you. Those around you may be concerned that you are wallowing in sadness or not coping. Your feelings are normal. Your very precious baby has died and you have every right to hurt and grieve for your baby. Try not to be afraid of your feelings or when everything seems dark and empty. Your grief will ebb and flow and you will not immediately begin to feel better after the death. Some days will be worse than others and in many ways, grief is like a roller coaster. Take the time you need to grieve, and roll with the good and bad days. Grieving is hard work; it is painful, exhausting and consuming. Grief is a normal, natural process that takes a long time to work through. It is not linear, and there are also no shortcuts.

Don’t expect to get over the death of your baby in a few days or even a few weeks, even though well-meaning people may seem to expect it of you. You simply cannot carry on as normal when your baby has died. The death of your baby will forever be a marker in your life, a reference point for when everything changed.

Gradually you will be able to function again and start doing some of the things you previously enjoyed doing, although it is almost impossible to imagine this will ever be the case. There is no time frame in which you should “get over it” and “move on”. In fact, you never have to get over it or move on, but you have to learn to live with your “new normal”. In time your heart and mind will slowly adjust to the reality that your baby has died and you will be able to integrate this fact into your life. There will always be times when you think of your baby and what might have been. Given time, your memories of your baby may be coloured with warmth and love rather than bitterness and sadness.

**When one baby dies, but another survives**

It is well recognised that babies from a multiple pregnancy are at higher risk of stillbirth or newborn death. One or more of your babies may die, but one or more may survive. For many parents going through a multiple pregnancy, one or more of the babies may also end up in intensive care. Sometimes one baby is well enough to go home when the other or others are not. Sometimes one baby dies very soon after birth, while the other or others fight for life, only to later die as well.

These situations are a time of complex and conflicting emotions, and you need to find a way to balance your joy and sadness and your hope and despair. You will feel torn between two worlds.

As you start a new life with your surviving baby, and grieve the loss of your baby or babies who have died – you will feel mixed and intense emotions. You will also need to deal with practical matters, such as a funeral. Sadly, having a living baby does not take away the pain of having one or more of your babies die.

One of the most difficult things about this situation is that friends and family often focus their attention on your baby who survived. You may feel like you are not being given the care and sympathy you need
and that some are turning their back on your devastating loss. This may be because people don’t want to upset you, or because they do not understand what you are going through. Few people realise the overwhelming grief you will be feeling for the baby or babies who died.

While it may be hard, try to let others know how you are feeling. Encourage them to help you mourn the loss of your baby, while still celebrating the life of your surviving baby.

“When one of my twin boys Joseph died, people said, ‘Aren’t you lucky you have Tristan?’ But nobody acknowledged Joseph; nobody said his name out loud. It felt like they were trying to push him away. But I had to grieve for my son. I loved Tristan, but I hurt so much for the child I lost.” – Margo

“When I first found out I was pregnant with twins, I was so scared. Those feelings eventually changed into excitement. But still, when Aiden died, I felt so guilty – like he died because I hadn’t wanted him enough. I then worried about not being able to bond with Sarah. And when I fell in love with her, I worried that she would die too. Those acute fears have gone now. But still, whenever Sarah reaches a milestone, like her first day of kinder, I also think of Aiden.” – Megan

Couples

Partners often grieve differently. Many couples find their relationship goes through a testing time as they begin, in their own way, to express their grief and sorrow. It is important to accept and respect your partner’s way of grieving as many couples will grieve differently and may find it difficult to grieve openly for fear of hurting one another.

You may also find that as your grief ebbs and flows, your partner’s grief takes a different path. When one of you is struggling the other may seem to have a better handle on things. Try to be tolerant of one another, accept your differences and be honest with each other about your needs. Give one another space to grieve openly and in your own way.

“It was a struggle to get by each day but I wanted to be strong to help Kathryn. There were times when we cried together, times when she was upset and I was able to comfort her and then times when I would break down and she would be there for me.” – Lance

You may find it helpful to talk with other couples, both separately and together, in order to try to understand one another. Alternatively, it may be beneficial for you to attend professional counselling together to help you with your grief. There are also books available that may help in trying to better understand your partner’s grief. Sands can be of assistance.

Fathers

You may feel helpless, having witnessed your partner go through extreme physical and emotional pain. You may also feel frustrated and angry that you were not able to protect both mother and baby from harm.

“I felt a lot of anger. I expected to be the protector of my child, and as a man, I expected to be in control. The sense of helplessness and the lack of control completely overwhelmed me. I flew off the handle a couple of times, which wasn’t like me.” – Chad
It may seem as if no one realises this baby was your child, too. You might be putting on a brave face to be strong for your partner, believing it is a sign of weakness to cry and openly express your emotions. You may also be overlooked by medical staff who direct information at the mother and not you and feel unsupported by family and friends who ask after the mother and not you. You may feel torn, having to care for your partner and other children, then having to return to work before you feel ready.

Out of love and concern, you may try to protect your partner from any further hurt by not discussing the baby and what has happened, believing that talking will cause her more pain. Often, the opposite is true. Not talking about the baby and what has happened can only cause more problems in the future.

Regardless of the gestation of the baby you will probably be experiencing feelings of grief, loss and possibly frustration and anger. Allow yourself the time to grieve as your feelings are valid and normal. Try to find a way in which you can comfortably express your feelings. Physical activity can be a good source of release, particularly for feelings of frustration and anger. If you know of other fathers who have been through the loss of a baby, seek them out as they may appreciate having someone to talk to. Even if you get together and don’t talk about the baby, the shared knowledge that you have both been through something heartbreaking can be of comfort.

**Mothers**

Try to be patient and give yourself time to recover physically and emotionally. Your hormones will take time to settle and return to normal. Discuss any recovery concerns you have with your doctor or nursing staff.

At times, your whole body will ache for your baby. You may feel robbed of self-esteem, feeling that you have failed as a woman and a mother. You may think your body has let your baby down. You might lack self-confidence, and completing simple daily tasks may be difficult. These are natural reactions to your baby’s death. Many women take comfort in talking and sharing their experiences. Express your feelings and share your grief with as many others as you feel comfortable and with those who can give you the most help. Use the internet and ask Sands to put you in touch with other women who have been through similar experiences. This will help you realise your feelings are normal and that you’re not alone.

“I was hungry for information and I searched the net for other parents’ stories. A Sands parent supporter came to visit me in hospital and that also helped.” – Anne

During the initial shock, most mothers will have a very real reminder that they have had a baby when their milk comes in. Mothers will respond to this situation differently. 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 some ways of relieving the symptoms. Frozen or cold cabbage leaves or cold compresses help to relieve the pain and heat. Wearing firm fitting bras or binding your breasts can also help. Avoid stimulating your breasts as this increases your milk supply. Talk to your midwives and doctor for any other suggestions for suppressing the milk or dealing with the discomfort. Or, contact your local representative of the Australian Breastfeeding Association. Some hospitals also now accept donor milk for other sick or premature babies. If this is something you would like to consider, speak to one of your midwives. Some mothers feel donating their milk is something positive that can stem from the most tragic of situations. Writing in your journal about how producing milk is making you feel can also be helpful.
**Going home**

Whatever the gestation of your baby, going home without them will be difficult. You will still be recovering physically from the birth, and your hormones will not have settled down. Your body and mind will know that you have had a baby, but there will be no baby to hold or nourish. Your partner may have to return to work before either of you are ready.

You have spent many months preparing for the arrival of the baby, and adjusting to the reality that the baby is no longer with you will take time. You have to get used to the idea of no longer being pregnant, and if the baby died before full term, you will have to “count down” the remaining weeks, knowing you don’t have the happy ending you had looked forward to. You may feel lost and confused, not knowing what to do with yourself. Be aware of the shock and pain you experience during this time.

Take your time and approach new situations when you are ready and feel strong enough. Your experience is unique and you have a right to recover in your own way and in your own time. There is no timeline to grief.

There are a number of situations and firsts that can be difficult to face. It is worth being prepared for these:

- **Going into the baby’s room.** You may have a fully furnished room with rocking chair, cot, mobile and change table. Some parents choose to pack these things away while others like to keep everything out, finding some comfort sitting in the room with the baby’s things. Some parents find it too painful to go in the room, choosing to close the door for a period of time. Well-meaning family or friends may try to encourage you to pack everything away or want to do this for you thinking ‘out of sight, out of mind’ is best. The choice is yours. There is no right or wrong approach; do what you need to when you are ready.

- **Facing friends and attending social functions.** You may find it too difficult to be at events where you know there will be other babies, especially those that are around the same age as your baby should be or pregnant women, who through no fault of their own, can often trigger a huge emotional response from you. If you think an event will be too hard to attend, save yourself the stress and stay home.

- **The first shopping trip, hairdressers appointment and/or having to tell people who last saw you pregnant.** Your memories of the last time you were at these places will no doubt be happy, and you will know when the time is right when you are up to visiting these places again. There is no hurry.

- **Listening to hurtful comments or difficult questions from people who knew you were pregnant.** Sadly you can’t always avoid situations like this, and while people often have your best interests at heart, it is worth keeping in mind that at some point on your journey through grief, someone will inevitably upset you, whether they meant it or not.

- **Taking your other children to school.** Being around other mothers, especially if they also have babies with them or are pregnant can be hard, so ask for help if you can until you feel ready to join your existing parenting circles again.
• Returning to work. There is certainly no rush. You will most likely still be eligible for a period of either paid or unpaid maternity leave. Speak with your employer and take all the time you need to make a huge decision such as this. If you didn’t plan on returning to work after you had your baby, this will most likely be an incredibly difficult decision for you, as practically speaking you may need to, at least for the short term, until you decide if you’re ready to try for another baby.

• Reaching the baby’s due date, if your baby died before full term. This date will be difficult for you, no matter which way you look at it. You have been counting down to this date since you first found out you were pregnant. Make sure you have lots of support around you in the lead up to this day, and on the day itself, as you will most likely need it.

• Christmas, Easter and other significant religious and cultural dates. These significant dates on our calendar are often tough when we first face them without our babies. You have probably been daydreaming about days such as these and how you would incorporate your new family member in to these special family events. Try to find a way to make the day special for you, even though your situation is not what you thought it would be. If you don’t feel up to facing celebrations with your family as you usually do, then take a step back and know that the people who truly care about you will most likely understand.

• Mother’s Day and Father’s Day. If you have other children, these days will certainly be bittersweet, because while you will be missing and grieving for your baby who died, you will still be celebrating with your other children who will no doubt be smothering you with affection. If it was your first baby who died, these might be incredibly painful days for you, as you come to grips with not only having lost your baby, but the fact that you have no one to parent or care for on that day. Of course you are still a parent, but on these days the pain might be more acute.

• The baby’s first birthday or the anniversary of their death. The first 12 months of grieving are generally the most intense, with a huge build up to the first anniversary and birthday. The build up to the day or days itself can often be worse. Surround yourself with people who can care for your emotional needs at this incredibly difficult time.

• Baby’s milestones. Seeing other babies crawling, walking and talking at the same time your baby would have been. While you will no doubt be happy for family members or friends who had babies around the same time you did, it will still be difficult for you to see babies progressing through their first milestones, while all you can do is imagine what it would have been like for your baby.

“I felt so bereft and empty when I got home, but I found some comfort and solace, strangely enough, in the nursery I meticulously planned for her for all of those months. It was where I felt closest to her.” – Tamara

You may feel very isolated, alone and confused facing each day without your baby. Perhaps now is the time to get in touch with Sands or the people you know who will be able to support you. Sands volunteers have all been through a similar experience. They will reassure you that your feelings are normal and offer you support to get through this time. Speaking with other parents who understand is very comforting and reassuring when those around you can’t help you in the way you need them to. Sands volunteers will also be able to offer you some practical tips on how to survive the first few months, when the grief is most intense.
“After I had been home a few days I felt so alone. I called the Sands number I was given in hospital. The person I spoke to understood what I was feeling and talked to me about my baby Gregory. It was really helpful to talk to someone who had had a similar experience.” – Jenny

**Another pregnancy**

After some time has passed, you may feel ready to think about having another baby. This is not uncommon and does not mean you are moving on from your baby who died.

You may find deciding when and if to have another baby incredibly difficult and confusing. No doubt, you will be given advice from well-meaning family and friends as to if and when you should have another baby. Thoughts about your baby who has died and a possible new pregnancy can be confusing and conflicting. You may also feel upset because you know there can be no replacement for your baby who died.

Some parents choose to wait until they are through their initial period of mourning, often a year, while others decide to get pregnant immediately. It is a very personal decision and all parents approach the situation differently.

“I couldn’t bear the thought of being pregnant again immediately, the grief was too physical and I didn’t think I had the energy to do it again, at least not immediately. We decided to wait until Joseph would have been one, and then a few more months until the next Christmas had passed before we tried again. If Joseph had lived, that might have been the time we’d waited anyway.” – Michelle

If the baby you lost was your first, you may feel more desperate to be pregnant sooner, feeling that you lost not only your baby, but your status as a parent. Your partner may also have different ideas, so together you need to discuss what will be best for your family. Try not to push your views onto your partner if they are different from yours. You are the only ones who can determine what is best for your situation.

“Emily was our first, and I desperately wanted to be pregnant again right away. I did not want to wait one month, let alone six. In the end, it took us six months to conceive again, but those six months were without doubt the darkest months of my life and the grief was only intensified by my need to be pregnant again and feeling shattered every month that passed and it didn’t happen. As it turned out, James, our third baby, ended up being born the day before Emily’s third birthday, which was also the exact anniversary of the day Emily died in utero. So we do now have one very happy and one very sad occasion, side by side, just three years apart. And do you know, it’s ok.” – Margaret

When considering a new pregnancy some things to think about may be:

- Your doctor may have some advice about the time your body needs to recover physically from the pregnancy. Give your body the time it needs and discuss an appropriate time frame with your doctor.
- You may feel the need to wait until you are through the initial intense period of mourning in order to be able to cope with the anticipation and anxiety of a new pregnancy.
• Time may help but it will not completely relieve your grief. You may therefore find time irrelevant when considering a new baby.

• Getting through certain stages of a new pregnancy may be difficult particularly if they fall at similar times of year. These might include the baby’s birth date and due date. It is worth considering this when planning a new pregnancy.

• Choosing a model of care. You may wish to change doctors, midwives or hospitals for your next pregnancy. This is perfectly natural and you should not feel guilty. It is important for you to have peace of mind and confidence in those who will be caring for you. You need to be able to discuss any problems or worries you have during your new pregnancy. However, some parents find they have a deeper bond with the professionals who were there for them through their pregnancy and the death of their baby. Parents often appreciate the extra sensitivity and understanding this bond can offer them, and choose the same team to follow them through a new pregnancy.

Any decision to use permanent birth control should be postponed until you are sure you do not want another child.

If you become pregnant again, you will naturally be anxious about the outcome. You may find your feelings confusing and overwhelming. Such feelings are very normal. They include:

• Difficulty bonding with the new baby throughout the pregnancy

• Having trouble being positive and believing you will deliver a live, healthy baby

• Not feeling excited or happy about the pregnancy

• Overwhelming fear

• Internal contradictions – you can’t wait to see and hold this baby, yet are too scared to believe everything will be all right

• Feelings of “déjà vu”

• Not wanting to plan ahead

• Planning what to do if this baby also dies.

“I just wished someone had a crystal ball, so they could tell me everything was going to be ok. I wanted guarantees, I wanted assurances, but I knew no one could give them to me, and that was incredibly frightening. In my local Sands group there were a couple of mothers who had had healthy babies after their loss and they understood how I was feeling – that really helped.” – Hannah

Ways of dealing with a new pregnancy:

• Expect to feel some degree of anxiety, perhaps up to the time of the previous baby’s birth or death or for the entire pregnancy. This is to be expected, considering what you have been through.
• Your family and friends may hope and expect a new baby will make you happy again. Talk to them about how you feel and let them know how they can help you.

• Your other children will also be worried during your next pregnancy and will need your love and encouragement to help ease their fears.

• Finding out the gender and naming the new baby may help you to bond with the baby before the birth, or if you found out the gender of your previous baby, you may like to keep the gender a surprise until birth this time, so there is a difference between the two pregnancies.

• Write a letter to your carers to be filed in your notes expressing your fears and concerns so they can better understand and support you.

• Make a plan with your caregivers for how to deal with the pregnancy and particular situations. This might help reassure you that you will be treated the way you want to be.

• Be wary of painful reminders from your previous pregnancy by anticipating any situations which might trigger strong emotions of when your baby died. If you decide to stay with the same doctor and hospital this may involve visiting certain rooms and areas that bring back memories of your baby who died.

• Keep a pregnancy journal, recording precious memories of the new baby and expressing your feelings and concerns.

• Contact Sands’ trained support workers who have all been through similar situations. They will offer support, encouragement and practical advice through a new pregnancy, as they will understand your feelings and fears.

“When the desire for another baby outweighed the fear of another loss, I knew we had to give it another shot. It was unfinished business; we had to bring a baby home from hospital.” – Georgia

Although there will be great relief, excitement and joy when your new baby is born, there will also be painful memories of your baby who died. When you are holding your new baby in your arms, the enormity of your previous loss may finally sink in. You may find yourself crying for the baby you don’t have while kissing and cuddling your new baby. This is common and natural.

Doubts about your ability to care for and even love your new baby are not uncommon. You may feel vulnerable, anxious or over-protective. Usually these feelings are short-lived but it is important to talk about your concerns with each other and your doctor. Just because you have had a baby die, it doesn’t mean you will avoid the common and normal demands of parenting a newborn, which is difficult at the best of times.

“I promised myself I would never complain about any living baby I was lucky enough to bring home, but I totally underestimated the demands of caring for a new baby. He seemed to cry 23 hours out of 24, and I felt so out of my depth when it came to caring for him. All I wanted was for him to live, I never stopped to think that it would actually be really hard work.” – Amy
Make sure you have lots of support around you when you bring your new baby home. You will need to adjust to the daily routines of caring for a new baby, and you will still have your grief to contend with, which may have been intensified by the birth of your newest baby.

After the birth of a new baby, some people may not understand why you can’t forget the baby who died. This may be very upsetting for you. No matter how many more children you have or how much time passes, you will always remember your baby who died. Treasure these memories and know that your love for your precious baby will never fade.

**Helping yourself**

Grief is overwhelming, all-consuming and exhausting work. The following are suggestions to help you through this difficult time:

- Give yourself permission to grieve. It is healthy to express your feelings and emotions, as bottling them up won’t help your future recovery.

- Indulge your feelings and embrace your thoughts and emotions. Sad and negative thoughts are normal to grieving. While you don’t have to wallow in sadness, try not to pretend these feelings don’t exist. You will have good days and bad days, so take both as they come.

- Set aside time to focus on and think about your baby, especially as significant dates arrive.

- Look after yourself physically, taking time out to put your own needs first. A gentle exercise regime will do wonders for your mind and body as you allow yourself to heal.

- Don’t be afraid of saying no to family and friends. It is reasonable to withdraw for a while until you feel strong enough to face certain situations and people.

- Keep your journal, using it as a tool to release emotions and to clarify your thoughts.

- Find one or two significant people who are willing to support you, to be with you in your grief, no matter what sort of a day you’re having.

Having a baby die is not only very traumatic but can also be a very isolating and lonely experience. Sometimes it will feel as though no one understands how you are feeling.

> “I felt the loneliest when I was not alone. For weeks the house was always busy and buzzing with people all just trying to help me, but no one around me seemed to have any idea of what I was going through. That made things even more isolating.” – Sally

Throughout this difficult time it is important that you get the support and help you need in order to be able to grieve healthily. Being with people who have been through similar experiences and can understand your feelings is extremely beneficial. This is where Sands can help.

> “After the death of my baby, it was a comfort to speak to someone who truly understood the depths of my grief – because they had been there before and come out the other side.” – Sarah
Other resources for support

Print resources

*Coping with grief*
Mal McKissock and Dianne McKissock, 2001 (Australia)
ABC Books
This excellent book outlines the grieving process and provides practical suggestions for reducing further suffering and bereavement.

*Our Babies Have Died*
Sands Victoria 2008 (Australia)
This is a collection of 37 stories written by bereaved parents in the hope that they will help others going through the grief of losing a child. These stories are at times heartbreaking, brave and sensitive.

*Pregnancy Loss: surviving miscarriage and stillbirth*
Zoe Taylor, 2010 (Australia)
A book of courage, hope and survival for people touched by all aspects of pregnancy loss, whether late or early.

*An Exact Replica of a Figment of My Imagination: A Memoir*
Elizabeth McCracken, 2010 (US)
“This is the happiest story in the world with the saddest ending,” Elizabeth McCracken writes in her hauntingly beautiful and often blunt memoir about the stillbirth of her firstborn son.

*Layla’s Story: A Memoir of Sex, Love, Loss and Longing*
Vanessa Gorman, 2005 (Australia)
An extraordinary account of the life of a 30-something both before and after the death of her firstborn daughter Lalya, just hours after she was born.

*They Were Still Born: Personal Stories about Stillbirth*
Edited by Janel Atlas, 2010 (US)
Atlas has written extensively about her daughter’s stillbirth and this book is a compilation of courageous accounts of stillbirth written by some brilliant writers.

*Still At Birth*
Caroline Sugden, 2011 (Australia)
A story about the deep loss, grief and survival after stillbirth, including a legal battle over her obstetric care.

*Life Touches Life: A Mother’s Story of Stillbirth and Healing*
Lorraine Ash, 2004 (US)
A mother’s memoir about the stillbirth of her first and only child.
A Mother’s Tears
Nicole Wyborn, 2011 (Australia)
Midwife Nicole loses two babies to miscarriage, then experiences a stillbirth as well.

Not Compatible With Life: A Diary of Keeping Daniel
Kylie Sheffield, 2008 (Australia)
A mother’s journey after learning her baby had a condition in utero that was not compatible with life.

A Kiss From An Angel
Stacey and Gavin O’Brien, 2005 (Australia)
A glimpse into the pain of a mother and father after the death of their firstborn son.

Empty Cradle, Broken Heart
Deborah L. Davis, Ph.D, 1996 (US)
Offers reassurance to parents who suffer from anger, guilt and despair after the death of their baby.

Empty arms: coping with miscarriage, stillbirth and infant death
Sherokee Ilse, 2008 (US)
A revised edition of this useful supplement, reinforcing and expanding on some of the issues presented in this book. Written by a parent.

When a baby dies: The experience of late miscarriage, stillbirth and neonatal death
Nancy Kohner and Alix Henley, 2001 (UK)
Produced in co-operation with Sands UK, this book presents the experience of perinatal loss from parents’ perspectives. It includes a 60-page appendix on medical explanations.

Wishes For Us, Wishes For You
Julie Pearce, 2010 (Australia)
A picture storybook for parents about love, loss and grief.

Telling children

Someone Came Before You
Pat Schwiebert, 2009 (US)
A gentle book with illustrations explaining the death of a baby to siblings.

Beginnings and Endings With Lifetimes in Between
Bryan Mellonie and Robert Ingpen, 2005 (Australia)
A beautifully illustrated book to help explain life and death to children.
Online resources

Stillbirth Foundation Australia
www.stillbirthfoundation.org.au

Australia and New Zealand Stillbirth Alliance
www.stillbirthalliance.org/anz

International Stillbirth Alliance
www.stillbirthalliance.org

Share: Pregnancy and Infant Loss Support Inc (US)
www.nationalshare.org

Heartfelt: Giving the Gift of Photographic Memories
www.heartfelt.org.au

To Write Their Names in the Sand
www.namesinthesand.blogspot.com
A memorial website set up by bereaved mother Carly Dudley. She writes the names of babies who have died in the sand at sunset on a Western Australia beach.

Glow in the Woods
www.glowinthewoods.com
A wonderful blog for parents of lost babies and potential of all kinds.

Stirrup Queens
www.stirrup-queens.com
An incredible blogroll for parents who have suffered infertility and all types of pregnancy and child loss.

Parenting/pregnancy websites with loss forums

www.babycentre.com.au
www.bellybelly.com.au
www.birth.com.au
www.bubhub.com.au
www.essentialbaby.com.au

Facebook also has many pages, both private and public, on pregnancy loss. Search and find one appropriate to you.