



treasured babies

A booklet by and for parents whose baby
is stillborn or dies soon after birth

sids^{and}**kids**[®]

All those months

By Margaret Cordukes

Your little heart beating so strong
All those months
Is silent.

Your little arms and legs
Moving so vigorously
Are still.

Milk falling from your mother's breasts
Will never nourish you.
Your eyes will never sparkle
Your little voice forever silent

Your mother holds you in her arms,
Timidly kisses your soft, smooth cheek
Caresses your tiny fingers
And whispers your name with tears

She dreams of holding you
Of watching you smile and grow
Her love is always with you
Though you will never know.

(used with permission)

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Introduction

The death of a loved one is hard to understand at any time but, for many, the loss of a baby is incomprehensible. Yet this loss is experienced by one in every hundred families. For those families, the stillbirth or death of their newborn is something that will affect them, and their families, for the rest of their lives.

With the loss of their baby, many parents feel the loss of their hopes, dreams and plans for the future. Following the death of your baby you may be left shocked and devastated, having thought that this would never happen to you. Suddenly your expectations for the future are shattered. Your feelings are likely to be intense as you search for reasons why your baby died. To feel sad, empty and bewildered at this time is understandable. These feelings are all part of grief and are common responses to loss. During the days, weeks and months that follow, you may often feel alone in your grief.

To help you approach this period, SIDS and Kids has prepared the following booklet. Written from the collective experiences of parents whose babies have been stillborn or died in the newborn period, it shows that while every parent's experience of their loss is different, the impact of grief is similarly great.

*"I waited so long for you and then in such a short time you were gone.
Such a tiny life, such a huge impact."*



A Stillborn Baby

In Australia a stillborn baby is defined as one with no sign of life at birth and is of at least 20 weeks gestation or, if the gestation age is unknown, 400 grams birth weight. However, definitions may vary from state to state.

When health professionals discuss a baby who has been stillborn, they sometimes use the medical term 'foetus' when referring to the baby. They may also refer to the baby having died 'in-utero', that is, within the uterus or womb. Sometimes they may describe a stillborn baby as a stillbirth.

A Baby Who Dies in the First Twenty-eight Days of Life...

The first 28 days of a baby's life are known as the neo-natal period. When a baby is born alive but dies within this time, health professionals may use the term 'neonatal death'.

Your rights and responsibilities

The birth of a stillborn baby or of a baby who dies in the early neonatal period must be registered with the Registry of Births, Deaths and Marriages and a certificate of birth is issued if the required fee is paid. As with any death, the baby's body must be buried, cremated or placed in a mausoleum.

Mothers of stillborn babies are still entitled to claim the Centrelink Maternity Allowance. You may also be able to claim further benefits if the baby was born live, but dies shortly after. Check with your local Centrelink for further information.

Receiving the news

Your baby may have died before or during labour, or in the weeks following birth. When the baby's death has occurred before labour commences, many parents have told of the overwhelming distress they felt as they watched the ultrasound show their lifeless baby. For others, being told during labour that their baby will be born dead brings a sense of helplessness and disbelief. Some speak of their pain and anguish as they watched over their baby in a neonatal intensive care unit.

Sometimes, the person who tells you that your baby has died or will die is someone you have never met. You may have found out that your baby died during pregnancy at a routine visit to your doctor or clinic and then had the death confirmed by ultrasound. Some women say they felt something was 'not right' before their baby's death was confirmed.

Your baby may have been born prematurely and died soon after birth or perhaps lived for a number of weeks or months in a neonatal intensive care unit. You may have been told soon after delivery that unexpectedly, your baby had been born with a medical condition or abnormality. During this time your baby may have been transferred to another hospital for specialist treatment.

The shock and turmoil that often occurs after finding out that your baby has died or will die can be overwhelming. Many decisions will need to be made in the days and weeks following. Parents have often found it valuable to take their time in making these decisions.

"As soon as he was born he had to be taken to the intensive care unit. I saw his little face and touched his warm skin for just a few moments."

Some Reasons

Finding out the cause of your baby's death may be of great importance to you. The reason may already be known at the time of birth or death, but for many parents the cause of the baby's death may not be known until after a post-mortem examination (see Post-mortem Examination).

However in some cases, post-mortem and other medical investigations do not reveal the cause of the baby's death.

Although more than half of all stillborn babies will have an unexplained cause of death, some babies are stillborn because of congenital abnormalities.

Of the babies who die in the newborn period, more than half have been of less than 2000 grams birth weight. Some babies are born too early to survive, and others may have congenital abnormalities of the heart, circulatory or gastro-intestinal systems. Chromosomal abnormalities and complications of the placenta and cord can also result in the death of the newborn infant.

Concerns or questions you may have regarding the cause of your baby's death can be discussed with your obstetrician, neonatologist, midwife, geneticist or genetic counsellor.



Losing a baby before or during labour

When told that their baby will be stillborn, many women describe the pain of knowing that the unborn baby they are carrying has died. It can be very lonely and frightening to anticipate and prepare for the birth of a baby that has died.

What will happen?

If your baby dies before labour has begun, your doctor may recommend that labour be induced, that the baby be born by caesarean section or that labour commence naturally. These recommendations may be made for particular medical reasons.

You may find it valuable to take some time to make decisions about how your baby will be born. This may involve changing the place and type of delivery you had anticipated, as the plans you had made for your baby's birth may now be unsuitable.

Before your baby is born you may wish to talk about involving family and friends as support people during your labour. The use of traditional aids to labour like music, hot packs, massage and breathing techniques may still be very valuable, as will the love and support of those around you. If you are unsure about the labour your midwives and doctor will be able to provide information, support and assistance at this time.

The birth of a stillborn baby

The staff caring for you during your labour will be able to answer questions about the progress of labour and provide emotional support for you and your partner. They will also be able to discuss and plan with you the moments following your baby's birth and your first contact with your baby.

It may be worth discussing your expectations with your midwives or doctor. The size and appearance of your baby will depend on the length of your pregnancy and any medical condition the baby may have. Factors like skin tone, texture and the colour of your baby's lips can vary, and depending on the amount of time between death and birth, your baby's skin may have begun to blister and peel in a process called maceration. Asking your doctor to explain how your baby may look and feel immediately after birth will help your expectations to match reality.

“Although I was told my baby would be born dead, it was only when I saw her so lifeless that I began to understand that she really had died”

When your baby dies after birth

The knowledge that your newborn baby is critically ill is a tremendous shock. Your lives are thrown into turmoil as your expectation of taking home a healthy newborn baby is shattered. If your baby has been born too early, you may be faced with watching helplessly as your tiny baby struggles for life. In some cases, your newborn baby may be transferred for intensive care either locally or hundreds of kilometres away, as health professionals work to save your baby's life.

During this time you and your family will see unfamiliar people and places, with some families becoming separated by distance or work commitments. Some mothers are unable to be with their baby immediately following delivery due to their own medical condition. If your baby has been transferred, it may be days before you are reunited. Disruptions to family life occur as you and your partner focus on your critically ill baby.

“I had to stay in hospital while my baby son was flown to the city for intensive care. I desperately wanted to be with him.”

Caring for your baby in Neonatal Intensive Care

Your baby may live for hours, days or weeks in a neonatal intensive care unit. This time may be the only opportunity to be together as a family, to get to know your baby. It can be difficult for you and your partner to have contact with your baby because of the presence of other people, the baby’s condition and the medical equipment in use.

When twins or triplets are born prematurely or with a serious medical condition, one or more babies may be in the neonatal intensive care unit at the same time. In this situation, it may be difficult to deal with the conflict of having two very ill babies, or trying to care for one who is ill and another who is well.

“He looked so sick that I was scared to touch him.”

With guidance and support it is often possible for you and your partner to share in caring for your baby. You may be able to assist in washing and changing your baby and you may be able to bottle, tube or breastfeed your baby. If actively caring for your baby is not possible you may be given opportunities just to touch and hold your baby and you might like to take photographs or videos. You may want to let family, friends and other children become close to your baby. Sometimes just placing a special item close to your baby is enough.

Deciding to withdraw life support

When your baby's death seems inevitable the attending doctor may offer you the opportunity to withdraw life supportive treatment. This may be one of the most difficult decisions you and your partner will ever have to make. You may feel abandoned, as everyone around you appears to give up hope for your baby's life. You may also find that the removal of life supporting treatment brings a sad relief.

It can be valuable for you to spend time discussing the withdrawal of life supporting treatment with family members, health professionals and the hospital social worker.

It may also be important for you to have your baby blessed or baptised before the withdrawal of life supporting treatment. You may choose to do this yourself or invite a close family member, a member of the hospital staff or a celebrant of the family's faith to conduct the ceremony.

Choosing whether or not to be present as life supporting treatment is withdrawn is a very personal decision. The length of your baby's life after support is withdrawn can vary widely. Your baby may be brought to you once intervention has ceased. In some cases your baby may live for hours, days and even weeks after life supporting treatment has been withdrawn.

Staff often provide a private room where you and your family can be alone with your baby. Sometimes you may be able to take your baby home for his or her final days. Letting medical staff understand your needs and expectations at this crucial time is the best way to ensure your final moments with your child are as you wish.

“I always thought he’d pull through. I was shattered when the doctor suggested we discuss the removal of life support as I realised maybe he would die.”

Some of the following suggestions may be helpful as you decide how to spend your baby’s final days.

Making the most of your time together

Spending time with your baby after death is a very personal, individual choice, and whatever you choose it is important to do only what is right for you. Spending time together may give you the opportunity to express your feelings for your baby and help you understand the reality of your baby's death. However, you may choose not to do this.

Usually when family members or close friends die there are many memories of time spent together, which serve as a comfort for those who grieve for them. When you lose a baby, there are often very few memories of time together. You may wish to spend time with your baby to create these memories, naming him or her and doing for your baby some of the things you may have done in life.

It's alright to be unsure

You may be anxious about how your baby will look after death. You may feel scared and worried about seeing, touching and holding your baby. You may be concerned about any medical condition or abnormality your baby may have or the presence of incisions from a surgical procedure. Many parents experience these fears when their baby dies.

It can be helpful for health professionals to describe your baby's appearance to you. They may also be able to provide a photograph of the baby. Sometimes you may feel unable to see your baby at a particular time, but may wish to do so hours or days later.

“The utter sense of powerlessness that I felt while holding my beautiful little son and watching him die was crushing.”



What happens after death

You may find that with the support and guidance of hospital staff, family and friends are able to spend time with your baby, once the turmoil of the labour ward or neonatal intensive care unit is over.

While staying in hospital, staff should be able to arrange for you to see your baby as often as you wish. The time you spend with your baby may occur over several hours or days.

Until the burial or cremation (see Funeral, Burial and Cremation), your baby's body will be kept at the hospital or at a funeral home. It is possible for you to spend time with your baby at either of these places.

In situations where a post-mortem is legally required, you may not be able to touch and hold your baby until after this has been completed. Also, some medical tubing may have to be left in place.

Being with your baby

During the time spent with your baby, you might like to look carefully at your baby's features, observing likenesses to other family members. Although you may feel nervous about any abnormalities or skin changes, these issues become less significant as you spend time getting to know your baby, absorbing everything you can about your daughter or son.

Some hospitals are able to provide accommodation for you and your partner away from the nursery, where you may spend time with your baby. If you have other children you may choose to involve them as well as family and friends.

During this time you may choose to take photographs, collect a lock of your baby's hair, have ink prints or plaster moulds made of your baby's hands and

feet, or draw a tracing of your baby's body. You may find comfort in bathing, sponging and dressing your baby in clothes specially bought or made. Some hospitals are able to provide a pram so that you can walk with your baby in the hospital grounds. You may even choose to take your baby home. The hospital social worker may be able to arrange this for you.

However you spend the time you have with your baby, this precious time is an opportunity to talk to your baby, saying things that would otherwise have been left unsaid. Or you may prefer just to look and create memories.

“Born too early he died, and I am left with the sad, warm memory of his skin against mine”

Post-Mortem Examination

It is often difficult to grasp that decisions about your baby's body must be made soon after death. Having to comprehend and discuss a post-mortem examination of your baby's body may seem too painful to endure. At the same time, you may be aware that a post-mortem may provide vital information that will help you come to understand the reasons for your baby's death.

In some cases the post-mortem examination of your baby's body is a legal requirement. This may occur when a baby who is born alive dies suddenly of an unknown cause; or dies within twenty-four hours of an anaesthetic; or dies an unnatural or unusual death. In these situations a post-mortem can be done even without your permission.

When a baby is stillborn or dies in the newborn period, you may be asked to give permission for a post-mortem examination of your baby's body. Unless

the examination is legally required, a post-mortem cannot be done without the signed consent of you or your partner.

During a post-mortem, the baby's body is examined to reveal a possible cause of death. This examination very often includes a surgical procedure, which is performed by a pathologist, where incisions are made in the baby's body to enable examination of internal organs. Following the examination, the incisions are usually stitched.

When considering a post-mortem, or when a post-mortem is legally required, you may find it valuable to spend time discussing the examination with your doctor, midwife or hospital social worker. They can also provide information brochures about post-mortem.

The decision to consent to a post-mortem does not have to be made immediately following the baby's death.

Considerations about a post-mortem

You may consent to a post-mortem, hoping to find the cause of your baby's death. However, a post-mortem examination may or may not reveal this. You may also permit a post-mortem examination of your baby's body in the hope that medical knowledge can be gained. However, you may not want a post-mortem because of cultural or spiritual beliefs, or because you feel that your baby has been through enough invasive procedures prior to death.

In some instances, the cause of death will already be known when your baby dies, and a post-mortem examination will reveal no further information. Sometimes, when a possible cause of your baby's death has been identified, you may choose an alternative to a full post-mortem, such as a limited post-

mortem or an external examination only. Your doctor, midwife or hospital social worker will be able to provide you with more information about these options.

Following a post-mortem procedure, a verbal report of any preliminary findings will usually be made available to your doctor within twenty-four hours of the examination. The final results may take from six to eight weeks or sometimes even longer. To discuss any possible findings of the post-mortem, you usually need to make an appointment with your doctor, who may also be able to answer questions or provide information about your baby's death.

“I wanted to understand why my baby died and at the same time I didn't want anyone to touch her body.”

Seeing and holding your baby after a post-mortem

You are able to see and hold your baby following a post-mortem, although you may have concerns about how your baby's body will look. Often, the time following the post-mortem is the last opportunity you will have to spend time with your baby.

Medical and nursing staff will be able to accurately describe the position of the incisions on your baby's body. You may request that staff bring your baby to you dressed, so that the incisions are covered, or you may feel it is important to look at the incisions to see what has happened. That decision is entirely up to you.

You might like to use this time with your baby to take photographs and create other memories of your baby. You may also wish to give your other children,

family and friends the opportunity to spend some time with your baby before the funeral or memorial service.

Funeral, Burial and Cremation

It is a legal requirement that the body of a stillborn baby or a baby who dies in the newborn period be buried, cremated, placed in a mausoleum or a permanent resting place. To this end you may choose to create a personal or individual service to mark your baby's life in the form of a funeral or memorial service. Alternatively you may wish for the hospital to handle the arrangements.

Hospital Burials

Sometimes you may be asked if you would like the hospital to organise the baby's burial for you. When the hospital organises the baby's burial there is usually little or no cost to you. However, often you and family members cannot be present, and your baby may be buried in a grave with others. In this instance, you are usually not invited to place any type of plaque or memorial stone on your baby's grave.

Planning your own service

A funeral or memorial service can provide you with the opportunity to acknowledge your baby's life and death, and to say goodbye to your baby. Many parents describe their baby's funeral as a very special, personal occasion and take much care and time in planning the ceremony. There is usually no need to hurry to have the funeral.

You can arrange a service through a funeral director or you and your partner may decide to arrange the ceremony yourselves. While you are still trying to

comprehend that your baby has died, you may feel it is a burden to contact a funeral director and organise your own baby's funeral. You also may not know about the types of ceremonies available.

Your baby's funeral or memorial service can be held quite a number of days after your baby has died. You might choose to wait a week or more to allow time for recovery from a caesarean birth or other medical treatment, or to give you some extra days to rest after days or weeks spent in hospital with your baby. Waiting to hold the funeral may also provide an opportunity for family and friends to travel to be with you.

You may choose to plan a very small, private funeral attended only by immediate family members. Alternatively you may choose to involve extended family and friends. You may also wish to invite members of the staff who cared for you or your baby to attend your baby's funeral.

Sometimes, parents and family members write letters or poetry which they place in the baby's coffin, along with toys, mementos, drawings from the baby's brothers and sisters and other items of significance. You might like to select clothes to dress your baby in for the funeral. Other parents have been given lovingly knitted layettes made for tiny babies that have been provided by the hospital.

You can also hold your baby's funeral service in a chapel, at the baby's graveside, at home or at another special place. You may be comforted by having your family and friends with you to share readings of particular significance, special music or to speak of the hopes and dreams they had for the baby.

These are just some of the ways you can remember your baby. Your social worker or the medical staff in your hospital may be able to help with information and ideas for your baby’s funeral. SIDS and Kids also has a booklet called “Choices in arranging a child’s funeral” which gives further ideas and information. Contact 1300 308 307 to obtain a copy.

“Together, we dressed her for the funeral and our families came to say goodbye with us.”



Women's Health After Childbirth

Physical Wellbeing

After the birth of a stillborn baby or a baby who has died in the neonatal period, the physical needs of many women become overshadowed by the death of the baby.

After childbirth, women's bodies go through a process of change and recovery. You will experience vaginal bleeding, your breast milk will come in and your uterus will gradually return to normal size. You may also be recovering from procedures such as epidurals, episiotomies, caesareans or other medical conditions associated with pregnancy.

While trying to recover from childbirth, you may be spending time organising and attending the baby's funeral, with visitors, taking telephone calls and caring for other family members.

After the death of a baby it can be difficult for you to get adequate rest, eat regularly and generally be aware of your own needs.

Medical follow-up

Medical follow-up is important to ensure that your general state of health is good and your uterus has returned to normal. Your doctor, clinic or community nurse should carry out this follow-up within six weeks of your baby's birth.

At this visit many parents discuss their baby's birth and death with their doctor or midwife. You may want to prepare questions you wish to ask. It can be distressing for you to return to the doctor's surgery or clinic where you

had last been while you were pregnant. It may be possible to arrange an appointment when the surgery or clinic is not busy. You may find it helpful to ask a supportive person to go with you on this visit.

Medication

Give yourself time to recover both emotionally and physically. Medications can often prevent the expression of emotions and are usually unnecessary. Family and friends may be able to assist you with any tasks that seem too much.

Vaginal Bleeding

Vaginal bleeding usually continues for one to three weeks, gradually becoming lighter. It is advisable to use sanitary napkins (pads) at this time rather than tampons. You should seek medical advice if heavy bleeding occurs or if you experience strong pain.

Lactation

Women cannot control the hormones that stimulate the breasts to fill with milk. Within two to three days of your baby's birth your breasts will produce milk. Full breasts may leak following an embrace, hearing the cry of a baby or even after thinking of your baby who has died. The breasts can be very sensitive to touch and may be painful and uncomfortable. Production of milk is distressing for some mothers and comforting for others. You may feel that your milk is the last link you have to your baby.

Breast milk can be suppressed by avoiding stimulation of the breasts and wearing a firm bra both day and night. Painful breasts are often relieved by

taking warm showers, the application of chilled cabbage leaves and cold compresses, and using pillows for support. Small expressions of milk may be necessary to relieve discomfort and can gradually be reduced over time.

Breast milk can also be suppressed through the use of prescription drugs. Your doctor can explain the use of these medications. Tender lumps or red areas on your breasts may indicate a blocked duct. If this occurs seek medical advice through your doctor or clinic.

“My breasts were aching, my whole body was longing for my baby.”

Sexual intercourse

Your doctor or medical staff may suggest the period of time before your body will be physically ready to resume sexual intercourse. However, when you will be emotionally ready is an individual experience. Discuss your feelings with your partner so that the timing is appropriate for both of you. Concern and love for each other may be expressed in other ways until you feel you are ready for sexual intercourse.

Grief and Feelings of Loss

Our culture, beliefs and upbringing all influence the way we will express our grief. Families and individuals with a particular culture often have a wide range of attitudes or reactions. All individuals will have different needs, expectations and ways of experiencing and expressing their grief.

After your baby dies, many parents experience a range of responses including disbelief, anxiety, loneliness, sadness, guilt, despair and overwhelming confusion. Life may suddenly seem to be “out of control”. Physical reactions such as changes in appetite, sleeping difficulties, a general feeling of being unwell, fatigue and difficulty in concentrating may also be experienced. These are all part of grief and bereavement and are common responses to loss.

You and your partner

As individuals, you may find that your thoughts and reactions during bereavement are often different from those of your partner. It can be difficult for you to maintain effective communication in your relationship while you are experiencing feelings of grief and sadness. This is particularly so when one of you seems to be “getting on with life” and the other is continuing to express sadness. It can seem that one has forgotten and doesn’t care about the loss, or that the other is “not coping”.

Your partner’s needs may be different to yours. Talking openly and honestly about your own feelings with your partner and listening to each other’s needs and expectations can be helpful. Just as sadness does not mean you are “not coping”, “getting on with life” does not mean that a person doesn’t care. You may just be experiencing grief differently. Often, your partner cannot be expected to meet all of your needs and it may be helpful to have others to talk to.

Coming Home

Often, couples who have experienced the death of their baby feel isolated and lonely. Telling others of your baby's death can be extremely difficult, and may cause much distress. After you return home, it can be hard to meet people who may be expecting good news about the birth of your baby. Going shopping, meeting neighbours in the street and taking other children to school can all seem overwhelming.

There may be times when you withdraw into yourself and lose interest in everything around you. It may take weeks or even months before you feel able to return to daily activities. It can also be painful for parents to discover that others around them are expecting babies. It can be difficult to see pregnant women at work or at the shopping centre, and you may find you avoid holding other people's babies for some time.

“I was inwardly screaming about how incredibly unfair life can be.”

When you are single

If you don't have a partner, you may experience difficulties in having your emotional and physical needs met. It is important to have someone with whom you can share your thoughts and feelings at this time. Reaching out to family members or just taking the time to see friends can be often be surprisingly helpful.

Anniversaries

Future events such as your expected date of delivery, the anniversary of your baby's birth and death, another pregnancy and significant family occasions

may be difficult for you. Planning for these occasions ahead of time, and accepting that they may be hard, can help.

Siblings

If you have other children their reactions to the loss of your baby will be individual and will be influenced by age, personality and the parental, cultural and religious influences present in their upbringing.

You may have concerns about your other children having contact with their baby brother or sister who is dying or has died. You may also worry about the effect on your other children both immediately and in later years.

Sometimes it can be difficult for you to involve your other children, particularly when the baby has been transferred to another hospital. Perhaps the mother's medical condition may prevent your whole family spending time together. You may choose not to involve your other children because you feel that this would not be appropriate. Whatever you choose, it is important for the family to do whatever they feel comfortable with.

Even if they didn't fully understand that you were pregnant, young children may become unusually clingy, easily upset and distressed. Older children may be aggressive, disruptive or unusually quiet. These are common grief reactions in children.

Involving your other children gives them the opportunity to know that the baby was real. Meeting their brother or sister can also demonstrate to your children that the baby is part of their family. A photo of your child or children with their baby brother or sister may become a treasured family memento.

Your own feelings of grief, sadness, hurt and confusion may make it difficult for you to provide the comfort and explanations that your children may need. Talking to your children openly about your baby and about how you feel may be helpful. Providing explanations suitable to their age, ability to understand and your family beliefs can also help. It is better to give simple, short, accurate explanations frequently rather than lengthy talks. Their questions will help you to understand their specific concerns. Be open to their questions, even if your answer is “I don’t know”.

“I wanted to protect my daughter and so did not let her meet her baby brother. Now, I wish we had done it differently.”



Remembering your baby

During the days, weeks, months and years following the death of your son or daughter, you may find some of the following acknowledgments of your baby to be comforting:

- Planting a shrub or tree in memory of your baby, perhaps one that flowers around the time of the birth date or another significant day.
- Keeping a journal or diary to write about your baby, about the hopes and dreams you had and the things you would have done together.
- Writing poetry or songs about your baby and about your own experience of loss.
- Drawing the image you have of your baby, or having an artist professionally draw your baby from a description or photograph.
- Sending cards, birth announcements or writing to family and friends letting them know what has happened.
- Choosing a piece of jewellery, e.g. a locket on a chain, a bracelet, a birthstone or ring engraved with your baby's name or initials.
- You may choose to have a tattoo or piercing to symbolise your child.
- Choosing a special painting, book or ornament to place in your home in memory of your baby.
- Placing a memorial to your baby in the personal notices section of the newspaper.
- Collecting any ultrasound pictures, medical reports and papers, arm bands, etc. from your hospital admission.

- Creating a name giving or memorial certificate, or applying for a copy of your baby's birth certificate, which can be displayed at home or kept in an album with other mementos.

Any of the above suggestions may be of use and there are no right or wrong ways to create memories of your baby.

“We have an album and I kept some of her clothes. They are precious reminders of my baby's life.”

Support

After your baby has died, understanding family members or close friends may provide valuable support. However there may be occasions when you feel particularly alone, and the support of other people who have experienced a similar loss may be helpful.

A hospital or community social worker, migrant health worker, bereavement counsellor, or bereavement support organisation such as SIDS and Kids may provide the support or assistance you need at these times.

Special Circumstances

You may find that special circumstances add to your feelings of grief. The loss of a previous baby, years of trying to conceive, or prenatal testing and a decision to end the pregnancy may also influence your responses. The loss of extended family through migration or other personal losses in your life may contribute to your grief. If the pregnancy was not planned, you may or may not have even come to terms with having a baby before he or she died.

Planning Another Pregnancy

Following the death of your baby, you may be keen to become pregnant again as soon as possible. You and your partner may feel that to have another baby as soon as possible will help to ease the pain of your loss. Alternatively, you may feel the need to wait for some time, so that you can work through your feelings about your baby who died and recover physically from pregnancy. In some cases pregnancy may not be possible or advisable. There's no "right" approach.

You and your partner may have differing views about subsequent pregnancy, causing strain in your relationship. Also, planning future pregnancies may involve medical or genetic investigations and counselling. Another pregnancy can also be a time of great anxiety. Emotional, cultural, religious and other considerations may influence you in making this decision.

Apart from medical and physical considerations, there is no right or wrong period of time to wait before trying again. Discuss your individual needs with your partner. Your doctor or clinic medical staff may suggest how long to wait before resuming sexual activity and before attempting to become pregnant again.

Some other considerations are listed below.

Your health professional

Do you feel that you could comfortably work together with your health professional through another pregnancy? Discuss any unresolved issues or concerns you may have with the health professional concerned; if you are not satisfied you may wish to seek other care.

Results of testing

You may need to consider the results of post-mortem, pathology or genetic investigations when contemplating another pregnancy. Discussions of these issues with your doctor may lead to consultation with a geneticist, genetic counsellor or other specialist.

Birth plan

You may want to consider discussing a birth plan with your health professional. This might include pre-pregnancy discussions about investigations, tests and also the frequency of visits during another pregnancy. You may also wish to talk about choosing a birth place with particular facilities, the type of birth you wish to have and plans for “What if something goes wrong...?”

Support

Supportive people around you will help you through the often anxious and stressful months of a subsequent pregnancy. Often these may include your extended family, friends, health professionals and others who have had a similar experience.

“I was so scared of losing another baby.”



How Others Can Help

Family and friends are often deeply distressed when someone close to them loses a baby. They may feel incredibly helpless and powerless and wonder what they can possibly do to make the family “feel better”. It is often distressing for family and friends that the people closest to them are going through an experience that no one has any control over or can prevent.

Following the death of your baby, you may find that your family and friends have added to your sadness through insensitive remarks and lack of understanding. At the same time the support of family and friends can be invaluable to bereaved parents. Indeed, the support a bereaved family has available from the people around them can greatly affect how a family will “get through” the months ahead.

It may be helpful if you obtain a copy of the SIDS and Kids booklet “To family and friends – you can make a difference.”

Hurtful comments and actions

You may feel hurt and upset at some things that well-meaning family and friends will say and do following your baby’s death. Some of these may include:

- Meeting or talking with you and not acknowledging your loss. For many parents it is important to have their loss recognised.
- Certain sayings that are offered as comfort can also be hurtful to you, such as “You’re young and fertile, you can always have another one”; “You’ve already got two healthy children, maybe this is for the best”; or “Put it behind you and get on with your life”. Whilst these statements may be well intended they often provide little or no comfort.

- Asking after the welfare of only one of you, either the man or the woman, can be hurtful. It is important to acknowledge that each of you may be grieving in your own way. The question “How are you, and how is?” demonstrates concern for both parents.
- Packing away the baby’s nursery or other reminders before you return home from hospital. This is usually done in the belief that it will help ease your pain if there are no reminders of the baby. However, it is often a lesser pain for you to have reminders of your baby around you and for you to pack away nursery and other items when you are ready.
- Rushing you, expecting that you will have recovered from your experience and be planning for the future in any particular amount of time is also unhelpful. Grieving is individual and you “move on” from your sadness when and how you are able to.

Helpful comments and actions

Sometimes family and friends don’t say anything because they don’t know what to say or they feel awkward and unsure. Family and friends can do many things to support and assist parents, including:

- Bereaved parents are sometimes reluctant to state their needs. Even given the opportunity to talk, they may not be willing to take the risk for fear of being hurt or embarrassed. However, listening and providing opportunities to talk openly with you will let them know that you care.
- Talk openly with the parents and let them know if you feel unsure about what to say or do.

- Visit in hospital or at home, acknowledging the family's experience and expressing your own feelings of sadness, disbelief and helplessness.
- Ask questions about the baby and how the parents are feeling.
- Talk of the baby by name, and of the hopes and dreams you had for the family as the parents of this baby.
- Read this and other books to learn about bereavement.
- Make or buy something in memory of the baby. Display it in your home, or give it to the parents.
- Offer practical help including housework, cooking, childcare etc.
- Visit the cemetery or place of memorial for the baby.
- Be available to listen to the parents, often to the same details over and over.
- Be sensitive to the sometimes unpredictable behaviour of bereaved parents.
- Understand that sometimes parents will want to be alone.
- Offer to accompany the parents as a support person to a support group meeting or on a follow-up visit to their health care provider.

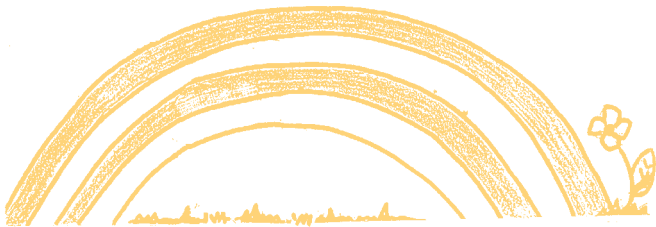
While assisting a bereaved family, a supporter needs to have someone who can be available for them to talk with. Along with the carer's own sadness, supporting others through bereavement may be physically tiring and emotionally draining.

“Friends and family were so helpful providing meals, childcare and comfort, which we will always remember and appreciate.”

Finally

You and your partner may find that you will be “forever changed” following the death of your baby. “Normal” will take on new meaning, as you find your way into the future without your baby. Many parents describe that while they feel they will never “get over” the death of their baby, they do come to find new purpose and meaning in life.

“I don’t believe that time heals, but that with the passage of time, we have found ways to adjust to our new reality. I’ll never, ever forget my baby. His memory is part of me.”



Glossary

Coronial Post-Mortem: A coronial post-mortem is a legal investigation into the cause of the baby's death.

Foetus: Medical term often used by health professionals when referring to a baby of a gestation age greater than six weeks until birth.

Gestation: The medical term for the duration of the pregnancy, from the first day of the last menstrual period through to the birth of the baby.

Miscarriage: A miscarriage occurs when the baby dies and the pregnancy ends prior to the twentieth week of gestation.

Neonatal death: The first twenty-eight days of a baby's life after birth is known as the neonatal period. When a baby who is born alive dies during this time, medical staff use the term "neonatal death".

Placenta: The oval, spongy structure in the uterus, which provides nourishment for the baby. The baby is attached to the placenta via the umbilical cord.

Post-mortem: This is a surgical procedure, which seeks to determine the cause of the baby's death. During post-mortem, incisions are made to enable examination of the baby's internal organs. In most cases, following the procedure the incisions are usually stitched.

Stillborn baby: In Australia a stillborn baby is generally defined as one who shows no signs of life at birth and is of at least 20 weeks gestation or, if the gestation age is unknown, 400 grams birth weight. However, definitions may vary from state to state.

Ultrasound: Sound waves are bounced off the internal organs and the reflected waves are used to construct an internal picture. An ultrasound can be performed abdominally or by using a vaginal probe.

Uterus: Pear-shaped muscle also called the womb in which a fertilised ovum (egg) embeds and grows.

Publications available from your local SIDS and Kids office

Choices in arranging a child's funeral

Always your child

To Family and friends – you can make a difference

Grandparent to Grandparent

Another baby? The decision is yours

Other publications and videos are available for parents, health professionals and others affected by the sudden and unexpected death of a child.



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SIDS and Kids Organisations

For more information, further reading materials or if you would like to talk to someone please contact the SIDS and Kids office in your area on 1300 308 307 or visit the SIDS and Kids website on www.sidsandkids.org.

What is
Part of us
For however long
Is us
And will
Forever be.

Unknown

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