

Sands Bereavement Support Book

The Use of Language

We acknowledge that some of you may have had more than one baby who died at the same time but for ease of reading, throughout this book, we use the term “baby” rather than “babies” to apply to both an individual baby and to more than one baby.

We do not know whether your baby was a boy or girl, and not all parents know the gender of their babies who died. Therefore, we will use the terms “they/them” rather than “his/her”.

When we use the term “mother”, we are usually referring to the person who is/was pregnant. We use the term “mother” because it is the word that is most easily and commonly understood. In doing so we understand that not all birth parents would define themselves as a mother.

We recognise that parents who identify as transgender males or people who do not identify with the gender binary who are the birth parent may not prefer the term “mother”. We also recognise that some surrogate birth parents choose not to identify as the mother. We refer to “mothers” rather than “women” as mothers may not always identify as women.

We also recognise the fact that there may be more than one mother involved. For example, for lesbian couples there will be the birth mother and her partner, or where surrogacy is being used, the birth mother and the mother/s who would be the legal guardian or parent.

For ease of reading, we use “partner” rather than “spouse or partner”. We use this in the context of heterosexual and same sex relationships, and where couples may or may not be married. We acknowledge that not all cultures think of spouses as partners.

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All information is correct at the time of going to print: June 2021.

Introduction

We are so sorry that your baby has died or that you have been told to expect that they may die soon. Few experiences can compare to the trauma and pain of losing a baby. Sands is available to provide support for as long as you need it and details of our bereavement support services are below.

You may have found out that your baby has already died and you could be waiting to give birth to them or perhaps your baby has died or is expected to die shortly in neonatal care. You could also have chosen to end a pregnancy for medical reasons or be expecting to do so soon. Whatever the circumstances, we recognise that this is an extremely sad and distressing time. We hope that you find the information in this book helpful both now and in the future.

You do not need to read this book in order. Each section is colour coded so you can easily find sections that are most relevant to you. If you would like to share a particular section with a relative, friend or an employer, you can download individual PDFs from our website. If you don't have access to a printer, you may like to ask for us to send you a printed PDF of a specific section. We have occasionally repeated information so that each section is complete for those who do not read the whole book.

There are various other organisations that you might find helpful. A list is available at www.sands.org.uk/usefullinks.

Table of Contents

Giving birth to your baby	1
Information and support for partners	11
Remembering your baby	19
Understanding why your baby died	27
Neonatal care and end of life	41
Ending a pregnancy for medical reasons (TFMR)	55
Saying goodbye to your baby	65
Supporting children	79
Physical and emotional challenges	89
Returning to work	97
Information and support for relatives and friends	105
The days, weeks and months ahead	117
Thinking about having another baby	123
About Sands	131
Online support and information	134

Giving birth to your baby

Waiting to give birth to a baby who has died is a traumatic and unexpected experience, and we hope that the information provided here helps you in making difficult decisions.

When your baby died

Your baby might have died before or during labour. If your baby has died before labour you will, in most cases, need to give birth. You may have been told that your baby is extremely unwell and not expected to live for more than a few hours or days.

Waiting to give birth is an incredibly difficult time. Whilst you are waiting you may have a huge range of thoughts and feelings racing through your head, you may feel completely numb, or anything in between. Even after your baby has died, as you change position, you might still feel the baby move in your womb and this could feel very unsettling for you.

You should be offered a private space to give birth away from other mothers and families. As it can be very hard to focus at this time, you may be encouraged to have a partner or someone else with you who can provide support and help you make difficult decisions.

How will your baby be born?

Unless there is a medical reason for you to have a caesarean section, doctors usually recommend that you give birth to your baby vaginally. This is usually medically safer for you and you are likely to make a quicker physical recovery.

The thought of going through labour and giving birth to a baby who has died can come as a huge shock to many parents. The midwife or nurse will ensure that you are well cared for during your labour and the birth, and you will have the opportunity to ask questions before your baby is born.

With time and support, most mothers adjust to the idea of going through labour. Although it may seem strange, many mothers who have been through this experience say that it feels right to have been able to go through labour and give birth to their baby. However, if you find the idea of labour too much to cope with, or if you have had a difficult birth or a caesarean in the past, do discuss this with the doctor who is looking after you.

How people refer to your baby

You might find that the health professionals caring for you, or even some family and friends, use technical definitions when talking about your baby without appreciating how this might make you feel. For example, if your baby died at 23 weeks of pregnancy, they might say that you had a “late miscarriage” rather than that your baby died. This could be because the requirements for registration are different, depending on when your baby died. It is important that you tell family, friends and hospital staff the language you prefer. They might know or have cared for other parents who use different language to describe a loss that happened at a similar time in pregnancy.

When will your baby be born?

If your health is at risk, the doctor will recommend that your labour is induced as soon as possible. If there are no medical reasons for delivering your baby straight away, the main decision is whether to have medication to start labour or wait for labour to start by itself.

You may not have to decide this straight away. You and your partner can discuss the different options with the staff. If you are a single parent, you may want to include a family member or close friend to help you think through your options and to support you when you are talking with the staff. You may also want to go home and take time to think about what you want to do.

Getting ready for labour

The staff will usually test your blood and urine, and possibly take vaginal swabs. Although these tests are important, it may not be possible at this stage to find out why your baby has died.



It is important to get support during labour. It can be helpful to have one or two labour partners to support you if possible. Having two labour partners will also let them support each other and let them take turns to have breaks. It is common for labour partners to feel helpless and to experience a range of conflicting feelings. Nevertheless, many labour partners have said that, although it was very difficult, it was important that they were there.

If your labour partner plans to take their car to hospital, then ask the staff about parking charges. Some hospitals may not charge, or have a reduced parking rate, for partners of mothers in labour.

If your labour is induced

The way that your labour is induced will depend on the stage of your pregnancy. You may be given medication to prepare your womb for the induction and this usually takes time to work. Some women go home during this time, with an appointment to come back to the hospital 24 to 48 hours later.

If you feel too distressed by the thought of going home, you may want to stay in hospital. The staff will usually try to organise this.

In hospital, your labour may be induced with tablets. These tablets may sometimes be combined with, or followed by, gel or pessaries that are inserted into your vagina. You may also need an intravenous drip containing medication to stimulate the contractions.

Once labour has started, most mothers give birth within 24 hours. The midwife or nurse caring for you should explain what to expect and how they will look after you. Some women decide to wait and see if their labour starts by itself.

If you have no medical problems and are considering waiting, you need to be aware of the following:

- If you wait more than 48 hours, you will be offered regular blood tests to check that your health isn't being negatively affected.
- If there are any worries about your health, or if your labour hasn't started after two or three weeks, the doctor will usually recommend that you have an induction.
- If there is delay before the birth, your baby's condition may deteriorate. If you want to have a post-mortem examination to try to find out why your baby died, this is less likely to provide

information. Your midwife will be able to explain what to expect. Some changes could include a change in a baby's skin tone, their skin becoming dry, or a change in their colour.

Where will your baby be born?

Most mothers decide to give birth in the hospital. However, if possible, some mothers may choose to have their baby at home. If you decide to go to the hospital, the place where your baby will be born will often depend on the policy of the hospital and on the stage your pregnancy has reached. In most hospitals, mothers are admitted to the labour ward or to another specialist unit if they have reached 20 weeks of pregnancy or longer.



The staff should explain where you will be cared for, where your baby will be born and what pain relief will be available. If you have a preference, do let the staff know. They might still be able to offer you certain aspects of your birth plan.

Going home before labour starts

Before you go home, the staff will give you the name and telephone number of a contact at the hospital. You can contact the staff at any time if you have any questions

or concerns. They will also tell you when to come back to the hospital and where to go. It is important that, as far as possible, you do not travel home alone. Shock and distress can affect people's judgment and ability to concentrate. It is especially important that you do not drive.

What to take into hospital

The hospital may give you a list of things to bring with you when you return. You may want to bring in something special for your baby to wear or to be wrapped in after the birth, and a camera or a smartphone to take photos. There are ideas for photos to take later in this book on page 22. You could also bring a soft toy or anything else you would like to place alongside your baby and maybe something in which to keep a lock of hair. All of these items will help you make memories of your baby and may become very precious to you in time.

I washed Alice, changed her, read to her, sung to her and took hundreds of photos and videos. I'm so glad we had this opportunity because these moments are my most cherished memories and they still get me through the darkest days of grief.


Clare

What to expect during labour

Different women can have different experiences of pain during labour. Some women feel pain more intensely if they feel afraid, shocked or distressed. An induced labour can be more painful than a labour that starts by itself. Inducing labour can also take a long time, especially if it is some time before your baby is due.

You may decide to use self-help techniques in the early stages of labour. For example, you might try relaxation, a warm bath, breathing awareness, massage, and different positions.

If you decide that you want additional help with pain relief, it is usually possible to change from one method of pain relief to another during labour.

 *How could they expect me to give birth and see my beautiful baby no longer alive?*

Nicky 

Most maternity and gynaecology units can offer strong pain-relieving medication such as diamorphine. This can be given either as an injection or through a drip in your arm. Some people find this type of pain relief helpful while others might not. Strong pain medication can reduce the pain and help you relax, but it may not take the pain away completely. It can make some people feel sick, drowsy or forgetful.

If the medication is given shortly before the birth, you may still feel drowsy when your baby is born. You may not remember as much about the birth.

Gas and air (also called Entonox) is available in both maternity and gynaecological units. You inhale it through a mouthpiece as soon as each contraction starts. It is very short acting and helps to take the edge off the pain, but doesn't remove it completely. It can make you feel a bit sick and sleepy and it can also be tiring to use it for a long time.

In most hospitals, an epidural is available only to women who are cared for on the labour ward. An epidural is a local anaesthetic injected into your lower back. The needle is then removed and a very fine flexible tube is left in place so that the anaesthetic can be topped up when it starts to wear off. This usually removes all the pain.

You may have an intravenous drip in your arm and your blood pressure will be checked frequently. You may need a catheter (a small tube inserted into your bladder) if you are unable to pass urine. You should be offered a chance to talk to a doctor who specialises in pain relief for labour.

Having a caesarean section

If you are critically ill, the priority will be to save your life. The safest and quickest way of doing this is through a caesarean section. If your baby is still alive, a caesarean may also help save them.

This situation can be very frightening for both parents. It can be particularly difficult for the partner, who can feel powerless and frightened. If there is time and you feel able, tell the staff if you have any particular wishes about your caring for or seeing your baby.

Except in an emergency, you will probably be offered a spinal or an epidural anaesthetic for a caesarean section. This is usually safer than a general anaesthetic, and recovery is often quicker. It also means that your partner, or someone else you have chosen, can be with you in the operating theatre and that you will be awake when the baby is born. However, there may sometimes be medical reasons for having a general anaesthetic.

What to expect when your baby is born

Knowing that your baby has died before birth will not necessarily prepare you for the silence that follows once they are born. The silence can be “loud” and this can be very distressing.



Once your baby is born and your condition is stable, you can begin to think about the choices you want to make. For example, you can think about whether you want to see and hold your baby and to have photographs taken. You may also want to create other memories such as hand and foot prints, or save a lock of your baby’s hair. You might have already started thinking about these decisions in the time before you gave birth.

If you are in a state of shock, or are feeling drowsy because of your medication, do not feel rushed into making decisions or feel that you cannot change your mind. Your baby will be cared for until you feel ready to make decisions. Later on, you might also have questions and want to understand more about what happened during labour. You may also find it helpful to go through the medical notes with the doctor or midwife.

Information and support for partners

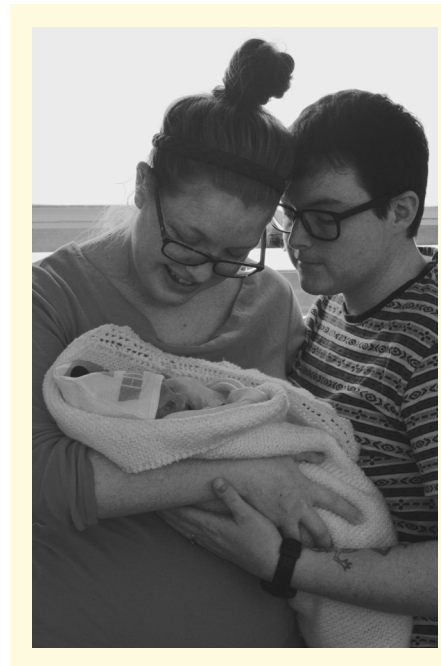
There is often the assumption that the birth mother is the primary griever when a couple experiences the death of a baby. Partners are often expected to assume a supportive role without adequate recognition of their own loss. This section is written primarily to support partners, whilst you are having to make difficult and unexpected decisions. For further support, please contact our Bereavement Support Services team, details of which are below.

This section is written for partners, including fathers in same-sex or heterosexual relationships and co-mothers. Adoptive parents might also find it useful.

Many of the other sections contain information that is relevant to both people in the couple. However, this section focusses more specifically on what a partner might need to know and how they might feel. In the case of adoptive parents, their support might be for the birth mother of the child that they are adopting.

Practical and emotional support

As a partner, you might be expected to take the lead role in telling family and friends, liaising with health professionals, making funeral arrangements and supporting the birth mother. This can feel overwhelming, particularly when you are also grieving for your baby. Consider asking for help when you can. You might like to speak with one or two close family members or friends and ask them to tell others. They can also answer questions on your behalf. You may prefer to send an email or text, or put some information on social media to more distant friends and relations, telling them about your baby, what has happened, and how you would like them to make contact and support you in the coming weeks and months.



If your baby died around their due date, people are usually eagerly awaiting your news and are enthusiastic to hear about the baby. If you phone family and friends you could start by saying, "I have some very sad news." This can help set the tone for the conversation and may reduce the number of inappropriate and upsetting questions. You can also set expectations about the length of the conversation, by saying, "I can only talk for a few minutes", at the beginning, which may help you end the call when it feels right for you.

If your baby died in neonatal care, people around you might have known of your baby's health problems, but they may still struggle to find the words.

Your family and friends may just not know what to say to you. As your news will be upsetting to other people, and perhaps even trigger difficult memories of their own, you might feel you want or have to support them, or apologise for upsetting them. It is important to remember that this is your experience of baby loss and you need to receive support at this time rather than provide it to your wider group of family and friends.

Try not to feel that you have to answer everyone's questions. Say only as much as you feel able. Later, you could follow up your calls or texts with emails providing more information and outlining any help you may need. You may want to ask people to help you look

after any other children you have and to support you in carrying out daily activities, such as cleaning and cooking. People are often keen to help and appreciate clear requests and boundaries. For example, you could say, "Please could you bring food around on Thursday and you are welcome to join us," or "If you don't mind, we are not really up to conversation or eating together, but having you bring over a meal would be lovely."



You could also ask people to help you talk with any other children you have about the death of their sibling. There is more information about this in the *Supporting Children* section.

You may want to tell people what you would like them to say on your behalf, including whether and how you want to be contacted in the first few days. For example, you might prefer for people to send cards, texts or emails rather than phone you.

These preferences can be communicated on your behalf. It is possible that you won't know what you need or would like people to say on your behalf. Please contact the Sands Helpline if you would like support thinking things through.

How people refer to your baby

You might find that the health professionals caring for you, or even some family and friends, use technical definitions when

talking about your baby without realising how these definitions might make you feel. For example, if your baby died at 23 weeks of pregnancy, they might say that you had a "late miscarriage" rather than that your baby died. This could be because the requirements for registration are different, depending on when your baby died. However, it is important that you tell family, friends and professionals what language you prefer. They might know other parents who use different language to describe a loss that occurred at a similar time in pregnancy.

When people hear the word miscarriage I don't think they realise that we had gone through a traumatic 48 hour labour, held his body, made decisions about his body, and organised our son's funeral. I now describe Altair as having been stillborn as I want people to know that he was born. That he was here.

Shema

Individual grief

The stress on couples when a baby dies can be huge. It is very difficult to give support and understanding to someone else when you are so sad and in need of support yourself. Grief is very individual, and the way that it comes and goes means that, often, you and your partner may not feel or need the same things at the same time. You may also have different ways of expressing and dealing with your feelings.

Sometimes couples find it hard if their grief patterns do not match and one partner may feel that the other is not grieving as much or in the same way. This can put a strain on your relationship. Some partners put their grief on hold for a while and concentrate on supporting their partner or the birth mother. Their grief may

emerge weeks, or even months, after their baby's death. Some partners may find it hard to open up having kept things in for so long. Sands is here to support you when you feel ready.

Whether your grief is immediate or delayed, there will probably be times when your whole existence seems to be taken up with grief. Because grief can come in waves, you may also find that you can cope well for hours or even days. Some parents feel guilty about this and worry that they are being disloyal to their baby, but this doesn't mean that you have forgotten or no longer care about your baby. It's quite common to have periods of calm and normality between waves of acute sadness.

Special occasions

Special days such as Mothers' Day, Fathers' Day, and family gatherings are times when parents often feel renewed sadness. Festivals such as Christmas, Diwali, Eid or Hanukkah, where celebrations focus on family, may be hard. The build-up to the anniversary of your baby's death or due date may feel especially painful. You and your partner/family might want to plan a day off together so that you can do something special to remember your baby.



Baby-related mail

Reminders such as baby-related mail or adverts on social media can also be a source of distress. If, at the start of your pregnancy, you signed up to any baby clubs or for any mailings, you can cancel these subscriptions or ask someone to do this for you. You can also reduce the amount of baby-related mailings by contacting the Baby Mailing Preference Service.

When couples have separated

Many couples find it helpful to grieve together and to remember their baby as a shared experience. However, if you have separated from your partner during the pregnancy or after your baby died, you may not have the option of sharing your grief with each other.



If you feel able, you could make joint decisions and arrangements and, if you have other children together, working together to support them may also be helpful, so they receive consistent care and information about the baby and what has happened. There is more information on talking to children later in the book on page 51.

Grieving on your own can be especially difficult and you may need additional support from family and friends, or to seek professional support.

You may find that crying and talking about your baby are good ways of releasing feelings and you may want to tell your story over and over again or find it helpful to write down what happened and how you feel day by day. Not being able to share your experience with the other parent of the baby can feel isolating, even if there are other people to support you. Think about how you need to express your grief and what support you might need. Sands can provide you with your own memory box if this is what you would like.

Talking to others

You may find it helpful to talk to other partners who have had similar experiences, or to an understanding relative or friend. You can also use the Sands Online Community or contact Sands Helpline for information and support. The Helpline can also put you in touch with your nearest Sands support group. There are also football teams in some areas for bereaved fathers and other male family members to get together and express their grief through sport. You can learn more about Sands United at www.sands.org.uk/sandsunited.



Remembering your baby

When a baby dies, there are few happy memories to help process the grief that parents and other family members experience. This section discusses various ways in which you can make memories of the time that you have together and honour the memory of your baby.

Memory boxes

Memory boxes can help you capture the time that you had with your baby. The box is a special place for keepsakes to remember your baby by. It could include photos, a special baby-grow, a blanket your baby was wrapped in, cards that you might receive, a lock of hair, or a hand or foot print. There is space in Sands memory boxes for you to place items of your own in the box, both immediately and over the years, on anniversaries and other significant occasions.

In addition to the opportunity to add your own items to the box, Sands memory boxes already contain a handmade blanket, two teddy bears, and other items that you might like to read or use. Parents often give their baby one of the teddy bears and take the other home as a keepsake.

Hospital staff often offer parents opportunities to create memories of their baby by collecting keepsakes. Although you may feel unsure about doing this, many parents have told us how precious and important this can be, especially in the years to come. Having items to show and share with family members and friends may also help them to understand how much your baby means to you and help you start conversations about your baby.

Sands memory boxes are created specifically for those whose babies are stillborn or have died soon after birth. For babies born very early

it may not always be possible to take hand and foot prints or to have a lock of hair, but you may still like to have a box for other memories.

Memory boxes can help you acknowledge your grief and talk about your baby with other people. If you are not given a memory box in hospital, please ask staff for one, or contact us and we can send you one. Some hospitals also stock memory boxes from other charities.

The memory box that the hospital provided, with support from Sands, was the only thing that kept us grounded during the long sleepless nights and dark days.

Amanda and Dan

Taking photographs

The midwife or nurse caring for you will usually offer to take photos of your baby. You can also take your own photos. If you are not sure, the midwife or nurse might ask if they can take some to keep with the mother's hospital notes. You will be able to access these at a later time. You could also have photos taken and ask that these are put in a sealed envelope for you to take home to open if and when you feel ready.

Although it may feel uncomfortable, you may like to take photographs of just your baby or of all of you as a family. Some parents like to have photographs of their baby's hands or feet. If your baby was a twin or a multiple and their siblings are alive, you might like to take pictures of them together. It is important that what you choose to do feels right for you. We have included some ideas of photos you might like to take on the next page.

These photo suggestions were made by Esther, a bereaved mum, who felt that at the time her baby died, she couldn't think about the kind of photos to take, how to take them or who to ask, because everything was such a blur. These are examples of the photos she wishes she had taken.



Credit: @hannahbphotography

Memorial books

All crematoria and many cemeteries and hospitals have a memorial book; often called a Book of Remembrance. You could have your baby's name entered into one of these books. Some crematoria and cemeteries ask for a small charge to arrange this. We have many ideas and opportunities to remember your baby via Sands events and also virtual online spaces, such as our tribute pages www.sands.org.uk/always-loved-tributes.



Ongoing keepsakes

In addition to the keepsakes you collect soon after your baby has died, there may be other items that could form valuable keepsakes in the future. Among other things, these could include poems, letters, emails, cards and jewellery. If you had an order of service for the funeral, you could include that as well.

Attending events

Attending remembrance events can be a meaningful way of honouring your baby's memory alongside other bereaved families and a helpful part of your grief journey. Sharing this time with other families might help you feel less isolated in your grief.

Sands holds two types of remembrance events every year. The Sands Family Day and Service of Remembrance and Hope is held in June at the Sands Garden in the National Memorial Arboretum in Staffordshire. Lights of Love is normally held on the first Friday of December in London. There are also various regional and local remembrance and Lights of Love events held across the UK. You can find out more about these events on our website. You may also want to create your own event, such as a family picnic or a walk, in memory of your baby each year.



Baby Loss Awareness Week is held every year between 9-15 October and ends with the international Wave of Light at 7pm on 15 October for parents to remember their baby at the same time as others across the world. More information is available at www.babyloss-awareness.org.

More permanent memorials

Some parents decide to plant trees in a woodland in memory of their baby. You can dedicate a single tree or larger area of woodland in your baby's name in Woodland Trust (www.woodlandtrust.org.uk) sites across the UK. This will give you somewhere special to visit for years to come. The Woodland Trust also offers benches and marker posts in some locations, which can be inscribed with your own message.

The Sands Garden is one of over 350 gardens within the National Memorial Arboretum and is dedicated to the memory of all babies who have died. At the heart of the garden is a beautiful Portland stone sculpture of a baby, created by the respected sculptor John Roberts. The Sands Garden is a place where you can spend quiet reflective time during our annual event, or on your own, at other times in the year. You can dedicate a small stone in memory of your baby. There are also other Sands gardens around the UK and you can contact the Sands Helpline to find out if there is one near you.



You may also be able to have a commemorative plaque at a cemetery or crematorium. There will usually be a charge for this and there may be restrictions about where the plaque can be placed. Many crematoria and cemeteries have a special section set aside for memorials to babies and very young children.

Understanding why your baby died



Finding out why your baby died

Because many baby deaths are unexpected, it may not immediately be known what caused a baby to die. Medical staff will need to carry out different types of reviews and investigations to get a clearer understanding of what happened.

Medical staff can use the following ways to get more information about why your baby died.

- A **post-mortem** which is a medical investigation of your baby's body.
- A **placental examination** (the placenta is the organ that provides nutrients and oxygen to the baby in the womb).
- A **hospital review** of the care you and your baby received during pregnancy and birth. This is done by the hospital who cared for you and your baby.
- A **hospital investigation** of the care you and your baby received during pregnancy and birth. This is carried out by the hospital you were cared for.
- An **independent investigation** of the care you and your baby received during pregnancy and birth. This is carried out by an organisation which is independent from the hospital.

The post-mortem and placental investigation look for physical or medical reasons why your baby died. Whereas hospital reviews, hospital investigations and independent investigations look at the care the hospital gave to you throughout pregnancy, birth, labour and (if relevant) the care they gave your baby after your baby was born. Reviews and investigations look to see if there was a problem that the hospital should have noticed earlier that might have prevented your baby from dying.

The hospital will also look at the quality of your bereavement care although this will not add information to the understanding of why

your baby died. A review of your bereavement care is to ensure you received compassionate care after your baby died that was right for you and your family.

Sadly, in some cases, even after these investigations and reviews, the cause of your baby's death may remain unclear. This is because there is still a lot that we don't understand about why some babies die, and more research needs to be done.

This booklet explains the investigations and reviews in more detail.

Post-mortem investigation

A post-mortem (also called an autopsy) is an examination to help understand the medical reason why your baby died. You will be asked whether you would like a post-mortem performed for your baby. It can be very hard to think about a post-mortem investigation for your baby. The choice of having a post-mortem is very personal. Only you can decide what to do.

A healthcare professional who knows about the post-mortem process will talk with you about your options for having one for your baby and can answer any questions you have. They will explain the different types of post-mortems and ask you to decide what level of post-mortem you are comfortable consenting to for your baby. A post-mortem will not take place without your consent unless it is ordered by a coroner (or Procurator Fiscal in Scotland). It is not common for this to happen.

If you consent to a post-mortem, you will still be able to see your baby in the hospital until the time of the post-mortem. If you want to take your baby home before the post-mortem, ask the team looking after you if this is possible and how you can be supported.

Placental examination

There should be an examination of your placenta. This can happen whether or not there is a post-mortem examination of your baby. The placenta connected you to your baby in the womb. Examining the placenta can give extremely valuable information about why your baby died. During the examination, samples of the placenta are taken for study under a microscope. You might hear this referred to as placental histology.

Hospitals do not have to ask for your consent to examine your placenta, but should they inform you about it. If you don't want an examination of your placenta to take place, you should tell the staff caring for you.



What might a post-mortem investigation tell you?

Here are a few examples of why a post-mortem might be useful:

- Even if the hospital already believe they know the cause of your baby's death, a post-mortem might be able to confirm this.
- It might change a diagnosis of why your baby died.
- It may find conditions that have not been diagnosed before.
- It can exclude some common causes of death, such as medical problems with your baby, infections or issues related to your baby being growth restricted.
- It can help assess the chances of problems happening again in a future pregnancy.
- It can help provide information about any genetic conditions.

Different levels of post-mortem

If you consent to a post-mortem, the perinatal pathologist (the doctor who performs the post-mortem) will assess what level of post-mortem will give the most helpful information for understanding what may have caused your baby's death.

There are various levels of post-mortem

- Full post-mortem
- Focussed post-mortem, which involves fewer, targeted investigations than a full post-mortem but can often answer specific questions
- External post-mortem, which looks at the outside of the baby's body, along with some imaging techniques
- Minimally invasive post-mortem which uses a range of imaging techniques and in some cases a keyhole surgery examination

¹ "Consent" is the legal term used in England, Wales and Northern Ireland.
"Authorisation" is the legal term used in Scotland. For simplicity, we will use "consent".

Staff, especially the person taking consent, will talk through the different options with you and answer any questions you have. The different kinds of post-mortem are also described in the consent form you have to sign if you give consent.

The pathologist will never perform a post-mortem beyond the level you have consented to. But their expert assessment may lead them to judge that a less invasive post-mortem gives the maximum amount of information and that further investigations are not necessary. This means that even if you consented for your baby to receive a full post-mortem, occasionally this might not happen.

Will my baby be kept safe if they have a post-mortem?

If you consent to a post-mortem investigation, hospital staff will first take your baby to a mortuary. Keepsakes such as soft toys and blankets can stay with your baby, and your baby will be well looked after and treated with respect.

Your baby might need to be transported to a different hospital where a specialist pathologist is based. If this applies in your location, you should be told about this by the person taking your consent. If this happens, your key contact at the hospital (this might be your bereavement midwife) can keep you informed about where your baby is and how long it will take.

Once the post-mortem has been completed, you can see your baby again if you wish. Some parents choose to say goodbye to their baby before the post-mortem.

It was upsetting to think someone we didn't know would operate on our baby, but it felt like we owed it to him to understand what had happened.

Bereaved mother

When should a post-mortem take place?

A post-mortem usually provides the most information if carried out within a few days of your baby's death. If you would like a post-mortem for your baby and you need to hold the funeral within 24 or 48 hours, tell the staff at the hospital, as they can help the body to be returned as quickly as possible.

Once you have consented to a post-mortem investigation, you can change your mind and withdraw consent. However, there is a limited window in which you can do so. The person taking consent should make clear to you how much time you have to do this, and who to contact if you do.

The post-mortem showed that there was something wrong with my placenta and it had stopped working. This means the amniotic fluid wasn't being produced and the baby wasn't gaining weight.

Sophie

Does a post-mortem investigation include taking tissue samples?

Most post-mortems include taking tiny samples of tissue for further examination, for instance under a microscope. You will be asked what you want to happen to any tissue samples that are taken, as part of the consent process. Whatever you choose will be respected.

Does a post-mortem investigation include genetic testing?

With your consent, as part of a post-mortem investigation, a blood sample may be taken, which is sent to test for conditions in your baby's DNA. Genetic testing may be especially useful if your baby had a condition relating to how cells in their body were formed or if the doctors think that you or your partner carry a genetic disorder. If you think you may have another baby in the future, genetic testing may be particularly useful for assessing the risk of the same thing happening again.

When a post-mortem is ordered by a coroner/ procurator fiscal

If your baby died after birth and the cause of death is unclear, the doctor looking after your baby must, by law, refer the case to a coroner (in England, Wales and Northern Ireland) or a procurator fiscal (in Scotland). The coroner/procurator fiscal will decide how to proceed and whether they will carry out an investigation.

If the coroner/procurator fiscal decides to investigate, they might order a post-mortem to understand more about the cause of the death. If this happens, they do not need your consent to do a post-mortem. However, this does not happen very often. If this does happen, you should be kept informed by the coroner/procurator fiscal's office.

How long should it take to get the results of the post-mortem?

The post-mortem report may not be ready for several months and sometimes may take longer. The results of the post-mortem are often included in the letter the hospital sends which summarises the findings of the hospital review. The hospital review is sometimes referred to as the PMRT. This review will be explained in the next section about reviews and investigations. But delays to the post-mortem report might mean that it isn't ready in time to be included in the hospital report letter. In this case, the post-mortem report will be sent to your doctor at the hospital where your baby died. You should be offered face-to-face time with your doctor to talk through the report so you can understand everything it says and can ask questions.

Get in touch with the hospital and ask what is happening if you find you are waiting a long time. Sands have template letters available on our website to help you write to your hospital when your post-mortem report is delayed.

The senior health professional who talks with you about consenting for post-mortem can explain fully the differences in the types of examination, and will give you written information to take away to help you think about your choices.

Reviews and investigations of care: A hospital review

A hospital review of care is carried out for all babies who die before or shortly after birth from 22 weeks gestation onward. Its purpose is to understand why they died. This review is carried out using the Perinatal Mortality Review Tool (known as the PMRT). This is a part of standard NHS care.

Before you leave the hospital, staff should tell you about next steps and offer you the chance to ask any questions or express any feelings or thoughts you might have. Your questions are important and you and other family members have the right to be involved in this process. You should be supported to be part of the process so that the review answers any questions you have.

To support you in doing this, the hospital should provide you with a named member of staff sometimes called a 'key contact' or 'key worker'. The key contact is the link between you, the review process, and the review team. They should support you while you are in hospital as well as once you return home. Often this 'key contact' is your bereavement midwife.

Once you have returned home, your key contact will:

- Invite you to ask questions or express any concerns about your or your baby's care for staff reviewing your care to address.
- Give choices about how you might contribute to the review, either in person, online, via telephone, or email.

The hospital will hold a review meeting of different professionals from the hospital. The review meeting is not open for parents to attend but you can ask for your key contact to be there to advocate for you during the review. The staff carrying out the review should

be from different medical specialties (for example someone from midwifery, obstetrics and/or neonatology). At the hospital review meeting they will:

- Discuss your care in detail to understand what happened and why your baby died.
- Address any questions/concerns you raised.
- Look at medical records and test results, including a post-mortem if you had one.
- Look at the guidance staff followed to ensure you and your baby received appropriate, safe and personalised care.

The review may also provide the hospital with information that can help change the way staff work when they look after those who are pregnant and their babies.



Keeping you informed during a review

It can take many weeks to gather all the information needed for a hospital review. This may feel like a long time to wait, and if you would like to meet with a senior doctor before the review takes place, you can arrange this through your key contact. However, they will most likely not be able to give you any answers yet.

Once the review is completed, the findings of the report should be summarised in a letter by a senior member of staff and shared with you either in a face-to-face meeting or a video call. They should also send this letter to you in the post. If you don't receive it, ask your key contact for it to be sent to you.

If the review finds that your care did not follow local or national guidelines, or that more could have been done to prevent your baby from dying, staff should be open and honest with you about this. They might also open a further investigation into your care called a Patient Safety Incident Investigation or PSII. These investigations are referred to as Serious Adverse Event Reviews (SAER) in Scotland, and a Serious Adverse Incident Investigation (SAII) in Northern Ireland).

For more information about the PMRT hospital review process, go to: <https://www.sands.org.uk/reviews-and-investigations>

Hospital and independent investigations of your care

Sometimes the hospital is aware that more could have been done to prevent a baby from dying. When this happens, they will start an urgent investigation called a Patient Safety Incident Investigation (PSII) in England and Wales, a Serious Adverse Incident Review (SAER) in Scotland, or a Serious Adverse Incident Investigation (SAII) in Northern Ireland.

In some cases, the hospital might not know right away that there was a mistake made during your care. In these cases, it's usually the PMRT 'grading of care' which highlights that the care fell below the expected standard.

These investigations run in parallel with the PMRT and the information gathered during the PMRT review is used to complete some parts of the hospital investigation. Hospital investigations might include written statements from the staff who were involved in the incident to get a better understanding of the circumstances which allowed mistakes to happen.

If the internal hospital investigation finds that mistakes did happen with your care, they should be open and honest with you about this.

Independent investigations

In England, there is another organisation which is independent of the NHS which reviews certain baby deaths. This organisation is called the Maternity and Neonatal Safety Investigation or MNSI (formerly known as the Healthcare Safety Investigation Branch or HSIB). They only carry out investigations for babies who were born full-term (after 37 weeks of pregnancy) and who were alive at the start of labour, but who died during labour or shortly after birth. Parents need to give their consent for these investigations to take place because the MNSI will look over the medical record of the mother and baby (if baby was born alive) to see if there were any mistakes in the delivery of care.

Just like hospital reviews and investigations, parents are invited to be involved in the review, to ask any questions, and voice any concerns they might have about their care. If an MNSI investigation is carried out, there will still be a PMRT review and the findings of

the MNSI investigation will inform the PMRT. You will have separate contacts for both the MNSI and the PMRT.

For more information, go to: <https://www.mnsi.org.uk/for-families/>

Feelings around reviews and investigations

It can be difficult to go through a review and discuss details of why your baby died. You may find that some days you are keen to know what happened but feel anxious as you approach the time when the results will be shared with you. You may worry about hearing details or medical facts that are hard to understand or you may feel angry with those who cared for you. It can be particularly hard if results from reports and any post-mortem don't provide all the answers you hoped for. While you are waiting for the results of the review or investigation it may feel like your life is on hold. All these feelings are really normal, and it is important that you look after yourself during this time. If the hospital is taking a very long time to finish the review, or to let you know the report results, you can find template letters on our website which can help you write a letter to your maternity unit or hospital Trust. These templates and further information about reviews and investigations can be found here:

<https://www.sands.org.uk/reviews-and-investigations>

Our Helpline and other support channels are here to support you before, during and after this process has taken place.

Support: [sands.org.uk/support-you](https://www.sands.org.uk/support-you)

Neonatal care and end of life

Neonatal death is when a baby dies within the first 28 days after birth. This applies to babies born at any stage of pregnancy who show signs of life and then sadly die. Some babies live for minutes, others for hours and some for days/weeks. However long a baby lives, it is devastating for the parents, family and friends.

You may have been aware of the risk of your baby arriving too early, maybe as a result of a medical condition that made you unwell or that meant your baby would be safer outside the womb. Because babies are not fully developed until around 37 weeks gestation, it is more risky to deliver a baby early, when their bodies are not ready to cope without help. Many complications can cause a premature baby to die and the risk of complications or your baby dying increases the earlier in pregnancy they are born.

Medical care for premature babies

Doctors may have talked to you about your baby's chances of survival and about the care they may receive after birth.

An examination will be done when your baby is born, which will enable the team caring for your baby to know how poorly they are and whether they are going to be able to give your baby a good chance of survival. The team will look at their gestation, their weight, if their heart is beating at delivery and other factors. Based on this information, the doctors will be able to talk to you about your baby's condition, the risks for your baby and what your hopes and expectations are for their care.

You can ask questions and you can revisit discussions with the team caring for your baby if there is anything that you have not understood, or as things change. This information will likely be

challenging for you and there may be difficult decisions to be made. You may be asked if you want the medical team to try to resuscitate your baby or not.

In some cases, babies will not be considered able to survive even with medical care, so the decision will have been to allow for parents to spend time with them without any medical intervention. If this was the case for you, it may have been difficult to know that your baby was unwell and important to hold on to the time you had together, which can be very valuable over the years to come.

The NICU setting

If your baby spent time in the Neonatal Intensive Care Unit (NICU) you probably visited alone or with your partner. The setting can be a difficult one for parents, who may at times feel unsure of what to do or where to place themselves in such a busy and delicate space. The range of equipment used to care for babies, the constant sound of machines and hospital staff moving about may have left you feeling confused, uncomfortable or helpless. It is normal to have bitter-sweet memories of this time, even if it was the only opportunity you had of seeing your baby while he or she was alive.

Even if your baby was not fully awake when you visited them, it is important to remember that a parent's scent and the sound of their voice is unique and babies are known to respond to this. Even if you could not interact, your presence will have been sensed by your baby.

Care for your baby at the NICU

During the time your baby was in the NICU, they may have had to receive medicines into their bloodstream, been connected to a ventilator or received UV-light treatment for a condition called jaundice. This may have meant you could not hold them or touch them because they were connected to different types of equipment

or because your baby's condition may have been too unstable. You may have been allowed to perform some tasks along with the nurses caring for your baby, which can in time help you to remember how you were part of giving them the best possible chance. If you could not help because they were too ill, it can also help to remember that it takes a lot to trust others with the care of your baby and that holding back on your wish to hold them to enable professionals to care for them is a way of showing your affection as a parent too.

Depending on the care that your baby needs and the care the hospital can offer them, it may be necessary to transfer your baby to another NICU. Before your baby is transferred, the team caring for them will discuss the options with you. A specialist neonatal team will accompany your baby during the journey. If you are well enough, you may be able to go in the ambulance with your baby. If you are not well enough, your partner or another family member can go with your baby. Being separated from your baby can be very hard, but the team caring for them will update you as soon as they can. You may have to stay where you are until you are well enough to leave hospital, or if you are needing longer term care, you may be able to transfer to the hospital where your baby is if there is a bed for you and if your condition allows for this to happen.

If you were unwell after delivery

Sometimes the birth parent of a baby is not fully recovered after the birth and can't visit the NICU to meet and spend time with a baby. This can be because you had a condition that led to the early labour that meant you had to wait for your health to be stable, or it could be that a surgical delivery meant you had to wait until the anaesthetic wore off. There are a number of reasons why it may not have been possible for you to be the first to meet your baby in the delivery room or NICU.

If your baby's other parent or your birth partner was able to, they may have visited the NICU and taken photos of your baby to show you. This can be a wonderful way to share the job of being parents after your baby is born. It can mean a lot to the parent who did not give birth, so hopefully it can become part of the many good memories you have of your baby's arrival.

Spending time at the NICU

Your baby may have spent long enough in a neonatal setting to have had a routine of care. As a parent, you may have been involved in changing or feeding them or may have had other tasks like expressing milk.



Whilst your baby is in neonatal care, you may have feelings of helplessness or be unsure how you can be a parent to such a delicate baby, but there are things that you can do for and with your baby. Some of these may need the assistance of the team caring for your baby and will depend on your baby's condition. You can read books and sing to your baby, enabling them to hear the familiar voices that they have heard in the womb. You may want to use bonding squares to enable your baby to smell your scent,

this can be beneficial for babies who cannot be picked up. If you cannot pick up your baby, you may be able to 'comfort hold' them, which has been shown to help your baby to feel secure and relaxed when in their incubator. If you are unsure about any of the things that you may want to do with your baby, ask a member of the team for support.

You may want to be involved in changing your baby's nappy, feeding them or changing their clothes. You may also be expressing your milk for feeding your baby, which can take up a lot of your time and feel as though you are away from your baby for long periods.

Not having spent time with your baby can be difficult

It is normal to have strong feelings if your baby died before you could visit them or you visited when you were not fully recovered. Perhaps you wonder what it may have been like if you had been able to see them for longer or when you felt better and could do more. If the hospital had restrictions on visits, it may be that you didn't spend long at the unit or that both parents could not visit at the same time. You may wonder if your baby missed you or was lonely, but it is important to remember staff at the NICU treat all babies with care, often singing and talking to them as well as meeting their medical needs. Research tells us that babies get used to the sound of their parents' voice while in the womb, so it is important to think of the journey you shared together as they grew, before being born.

When a baby is born early, it can be difficult to predict how long they will live or if their condition will change suddenly, so you may wish you'd had more information from doctors to understand how to manage the time you had with your baby. Doctors caring for your baby will keep you updated on changes in your baby's condition as and when these happen. However, with premature babies, their condition can decline suddenly which can be a shock when your baby has been doing well. This sudden decline could happen for

a number of reasons, perhaps as a result of an internal bleed, an infection, breathing difficulties or their body being unable to cope with things that full term babies manage more easily. If you have questions about your baby's condition or care, ask the team caring for you and your baby, and someone will be able to talk to you about this. If you do not feel able to ask these questions yourself, or you may be finding it difficult to retain the information given to you, you may want to ask a trusted family member or friend to advocate for you.

Whatever the circumstances, if you feel you could not have enough time with your baby because of how you or they were coping physically or as a result of the NICU restrictions, it is ok to feel that you'd have liked to do things differently. Talking to your partner, close friends or other bereaved parents about the things you wish you had done may help you to explore how you feel. There are also ways to help you to add to the story and make new memories, for example by taking part in a memorial service; remembering you are still your baby's parent and can continue to show them how much you love them in the public and private things you do.

Withdrawing life support and end of life care

Withdrawing life support means that a baby who is ill will no longer be assisted by equipment and medication and will not survive on their own. This can happen because of sudden changes to a baby's condition or because they do not get better after receiving treatment. Doctors may have told you your baby was unlikely to survive because of very serious medical problems, or would have had to cope with serious disabilities after being born early. Being told that your baby won't live is possibly the hardest moment for parents and will very likely be a time you remember with extreme emotions for quite some time.

You may feel that you are not ready to make a decision about withdrawing life support, and you may disagree with medical staff,

or even your partner about it. Getting as many facts as possible can help give you more confidence that you are making the best decision for your baby. Don't be afraid to ask lots of questions, or the same questions multiple times – and keep asking until you really feel you understand the situation. The doctors, nurses and other support staff caring for your baby can be invaluable at such a crucial time, with their knowledge and experience to be able to answer the questions that you have. It can be helpful to write your questions down, so that you can remember to ask them when you have the opportunity.

You don't have to face this alone. Talk to the people you are closest to – your partner, family and friends. You may also want to have friends and relatives near you and your baby at this time. If you have a religious or spiritual adviser, you may want to talk with them, or you can ask to speak with the hospital chaplain.

Although parents usually find this to be an immensely sad part of a family's story, you may also think of this moment as a time when you could make a decision alongside your medical team which felt kinder and took your baby's long-term wellbeing and quality of life into consideration. For whatever reason this occurs, it is important to remember you acted with your baby's interest at heart and out of love for them.

End of life care is the time doctors and nurses spend helping to make your baby comfortable after stopping the medicines and equipment which were keeping them alive. Your baby may have been moved away from the NICU to a special room which was quieter, perhaps with a little time for you to have bathed, changed or dressed them in clothes you chose. You may have the option of moving to a children's hospice or taking your baby home with community nursing support, depending on the expectations of your baby's health.

Nurses will administer pain relief and take off any equipment which connected your baby to a ventilator or small tubes through which they received medication, allowing you to hold them if you feel you would like to. After your baby being in an incubator, this can be a very special moment, and may be the first time you hold your baby without anything in the way, spending time alone as a family and sharing songs, stories or simply time together.

Although you will have been making memories with your baby through the time they have been in NICU, there may be other memories or keepsakes that you would like to take home with you.



You will be given options to make memories, which may include taking photographs, bathing/dressing your baby and introducing your baby to siblings and/or other family members. You may want time to consider what is right for your baby and you. If you say no initially, the team caring for you may ask again at a later time, as thoughts and feelings can change, especially when you may be overwhelmed with what is happening to you and your baby.

Your neonatal unit may have given you a 'journey box' or 'memory box' so that you have a place to keep special reminders. If you haven't been given a box, please contact the Sands helpline and we can arrange for one to be sent out to you.

Many parents gather keepsakes of their baby's time in hospital, starting when they are first born or admitted. These items can be very important memories for you in the future even if you do not want to look at them immediately. Here are some items that parents often save:

- Hospital bracelet
- Cot card
- Photographs of you, your baby and family together
- A hat or other special clothing
- Your baby's cord clamp
- A record of your baby's weight and measurements over their time in NICU
- The blanket that your baby has been wrapped in
- Handprints and footprints
- Cardiac monitor sticker or syringe
- Cards and letters from family and friends
- A diary, poems or notes that you make whilst on the neonatal unit

Doing these small but positive things may help you to cope with the feelings of stress and grief that can overwhelm parents at this time. Memories are precious for parents and so are the moments that you have with your baby, even though these moments may be difficult in the neonatal setting. Having keepsakes to share with family members and friends may also help them to understand what the death of your baby means to you.

After your baby has died, you may want to hold them and spend some time with them. Some parents feel unsure about seeing or holding their baby after they have died, or need time to decide. Whatever decisions you make about seeing and holding your baby and the memories that you make with them, are right for you at that time.

Everyone will feel differently and there is no right or wrong way to grieve or to remember your baby.

If you decide you do not want to see your baby again after they have died, you will be informed where they will be moved to and you can ask to see your baby if you change your mind. There may be time limits on seeing your baby, for example if there is a post-mortem or medical investigation.

Grandparents, siblings and people close to you

Your baby may have been well enough to have visitors at the hospital, so perhaps older siblings and grandparents were able to meet them before you had to say goodbye. This may have happened when they were well, or when they were given a short time to live. If people close to you were able to see your baby in hospital, the memories they have made of your baby's time with you will be something you can look back on together.

It may be that your baby could not have visitors, so the people closest to you could not meet your baby. You may find that the hopes and expectations that people had before the birth are what brings you together. Photos of your baby in the NICU and the items you may have brought home after you left the hospital can bring that part of their story to siblings and other family members.

If your baby died at the NICU, family members may find it difficult to know what to say or ask, but you can share whichever aspects of your baby's time in hospital feel important to you. This could be how often you helped with their care, expressed milk, the friendships you made with others at the unit or a religious ritual you carried out before or after your baby died.

Children who visited their sibling at the NICU may need extra support to understand what happened, but may value their involvement in

their baby brother or sister's short life all the more. Talking about how special it was to their baby sister or brother to have them close by will help them feel involved at a time when you may be working through your own feelings. For more ideas around supporting siblings please see our website (<https://www.sands.org.uk/support-you/how-we-offer-support/support-siblings>).

Leaving the Neonatal Unit

You may have spent a long time at the neonatal unit or only a few days or hours. Either way, your baby's story will have touched many people there.

It is normal to feel strongly about leaving that setting and you may want to say goodbye to the staff and parents you spent time with, even if you only had brief exchanges. Their kindness to your family is something you may want to look back on over the years.

Some parents wish to take their baby home to allow time for the family to grieve quietly and privately. Parents can often take their baby home directly from the ward (with relevant paperwork), but this may be affected if a post-mortem is required and your baby will have to come home once the post-mortem is completed. You can choose to take your baby home yourself in your car in your arms, in a Moses basket or car seat. Alternatively, you can arrange for a funeral director to collect your baby from the hospital and bring them home for you. You can decide how long you would like your baby to be at home with you. Some parents have their baby at home the night before their funeral, but for others, they feel a longer period of time is needed. In this time your baby's skin will change and this can be distressing and upsetting. Your funeral director will be able to give you guidance on keeping your baby cool, particularly if the weather is hot when your baby is at home.

There is no legal requirement for a funeral to be held, but when a baby is born after 24 weeks, or is born alive at an earlier stage of pregnancy and later dies, the law does state that they should be cremated or buried. You will be provided with a death certificate for your baby, but you will need to make an appointment to register your baby's birth at the Registrar's Office. The team caring for you at the hospital will be able to give you information on organising a burial or cremation for your baby and may be able to put you in touch with a local funeral director, or you can contact a funeral director yourself.



Taking your baby's items will be an important part of leaving so take time to think of what matters to you: it can be a difficult time but your partner, family or friends can help you to make it better by preparing in advance. While it may be difficult to leave, you may want to take time to plan the end of your time at the NICU by arranging for a small gift to the people who looked after your baby. Alternatively, you might think of staying in contact and asking for the name of staff who helped you and send a card later on.

In time you may want to have a birth reflections appointment with a member of the team who delivered or cared for your baby. They will be able to talk with you about your baby's care and may be able to give you more information about the aspects that you may have forgotten when so much was happening.



Ending a pregnancy for medical reasons (TFMR)

TFMR/TOPFA definition

Termination for Medical Reasons' or TFMR is also referred to as TOPFA (Termination of Pregnancy for Fetal Anomaly). TFMR includes a number of different medical interventions that result in a pregnancy being ended. The reasons for ending the pregnancy may be a diagnosis relating to the baby or a diagnosis relating to the parent.

TFMR can be a frightening and isolating experience and many parents who have been in touch with us have questioned whether bereavement support is available to them because of the particular circumstances of their loss. Please know that our support is here for you.

Receiving an antenatal diagnosis

Receiving the news that there are serious issues relating to your pregnancy will probably be unexpected and is likely to leave you in a state of shock. You may also experience feelings of sadness, guilt, and grief when coming to a decision about how to proceed.

In a state of shock and distress, you will have had to decide whether to continue the pregnancy or not. This is an immensely difficult decision for many parents and one that no-one should make without support.

This chapter is aimed at helping you through your loss and to support you as you journey through the emotions this can bring. If you have not yet decided what to do after a diagnosis, you can research your options through <https://www.arc-uk.org/> Antenatal Results and Choices (ARC) | Support for Parents and Professionals (arc-uk.org)

Screening tests and diagnostic tests

The health of you and your baby can be checked during your pregnancy using screening tests and diagnostic tests. It can be helpful to understand the difference between the two types of tests.

- Screening tests are used to detect if a condition has a high probability of being present.
- Diagnostic tests will detect if the condition is actually present.

Making a decision

Ending a pregnancy for medical reasons is a complex and challenging situation. This may evoke many difficult feelings for you including grief, loneliness and guilt. It may also be difficult to know who to discuss this with and you may fear judgement from the people close to you, as well as the pressure of limited time to consider and react. Sands is here to support you along with other organisations such as ARC, which has long experience in supporting parents through decision making. <https://www.arc-uk.org/for-parents/>

You may need to wait for test results that confirm which condition is affecting your baby or how it has impacted their health so far. You may also feel under pressure from other factors affecting you throughout your pregnancy, or you may simply feel that you need a resolution at what can be an immensely distressing time. The factors influencing your decision will be unique to you and your baby, and whatever they may be they are valid, as are your concerns and worries. For some parents external opinions can often influence their emotions and they are left navigating intrusive thoughts and feelings such as guilt and shame. We are here to listen and help you talk about the difficult emotions that can sometimes be a part of a traumatic response to TFMR for so many parents experiencing this

type of loss. At Sands we acknowledge that your baby is much loved and that making a decision to terminate for medical reasons is sometimes the only way that feels compassionate and appropriate for you, your baby and family.



Navigating Emotions after TFMR

There is no right or wrong way to feel about your own personal TFMR journey. For some rationalising the decision of compassionately ending a pregnancy for medical reasons will be straightforward: understanding that their baby's quality of life and prospects would be poor allows them to make a decision of TFMR with little doubt. For others, deciding what to do after a diagnosis may not be so clear, and navigating this decision may come with mixed feelings and emotions. Your experience of TFMR is personal to you: sometimes grief may present as sadness, guilt and isolation, at other times

parents may feel angry or unable to accept their decision to terminate for medical reasons. You may possibly find that you feel all of these emotions at different times, as moving between emotions can be a common response to grief and loss. Parents we speak to often mention how isolated they have felt after experiencing TFMR, often minimising their own feelings of grief and sadness. Please know our helpline and other support channels are here for you to explore your experience of loss and how your grief impacts you.

Bereavement Support

More and more parents are experiencing baby loss through TFMR due to the advancement in diagnostic tests and scans, and our community and bereavement support service understand how difficult this is. Our helpline and other support channels are available for you to talk through how you have experienced TFMR and to explore how this has left you feeling.

The differing circumstances of baby loss through TFMR can often leave parents questioning what options are available to them when making funeral arrangements and saying goodbye to their baby. Please read through our bereavement support book and think about ways you would like to honour your baby. The memory making and saying goodbye sections of the book may be helpful to reflect on how you would like to create memories of your baby and also saying goodbye.

How or if you are able to hold and spend time with your baby may also be affected by what gestation your baby is or your method of termination. If you are unable to meet your baby, it doesn't mean you can't create memories. Our community can provide support and comfort to you when you are thinking of alternative ways to remember your baby. This can be such an important part of the grieving process and may provide you with an opportunity

and space to grieve your baby and remember them. If you are given the chance to meet your baby, it is very normal to feel anxious about how your baby may look when they are born. Talking about this with your midwife or nurse to understand what to expect or the bereavement support services team at Sands about how you feel can be helpful.

Relationships and Grief

Here at Sands we understand that loss can impact us all in different ways due to the individual ways we all grieve. Many parents we speak to describe how the loss of a baby can create challenges within a relationship due to the different way each partner grieves. Parents can sometimes have different thoughts and feelings around the decision to TFMR. Yours and their feelings and thoughts may change as you navigate the loss of your baby too.

This can sometimes result in relationships feeling fraught. Some parents find comfort in talking about their baby and their experience whereas others may find they are distancing themselves away from those around them and they may avoid thinking about their loss as a way to manage their grief.

You may feel anger towards yourself and others after experiencing the loss of a baby. With TFMR, feelings can also be affected by the decision process taken to end the pregnancy; it can take time for you and those around you to adjust. There is no right or wrong way to grieve, though it can be helpful to reflect on ways that help you to communicate your wants and needs to each other as you process your grief, finding channels of support that feel comfortable to you when you need it most. Sands are here to support everyone impacted by the loss of a baby.

Siblings

As you navigate the loss of your baby you may find that you are supporting others in your family, and if you have other children supporting your baby's siblings. This can be a difficult task to undertake when your own grief may be very painful and consuming.

Sands' children's activity books are a helpful way to encourage children to process their own grief and the loss of a baby, recognising that children understand and deal with loss in different ways at different stages of their own life. They can also enable you to develop age-appropriate ways of remembering your baby together. This can be helpful when building a connection and continued bond for the whole family.

Family and Friends

Our support book has a section for family and friends that can also be helpful. Family members and friends often want to help bereaved parents but are unsure of the best way to do so. Our support is here for them too. Speaking to someone impartial and confidential can be useful for anyone who is affected by loss. Our helpline provides that safe space for you and your family and friends to speak to someone honestly and frankly about any difficulties they are feeling.

Sharing your Story

Telling others what has happened can be one of the hardest things to do after your baby dies. This can be made even harder if your baby has died as a result of a TFMR, which may leave you feeling judged or that you feel you have to explain your situation to others at a time when you are vulnerable and in distress. Some people feel remorseful about having to bring sad news to their family and friends. Others may worry about their news adding to existing problems or being a burden.

It is also important to remember that your own emotions, wellbeing and thoughts are valid, and that you understand your situation and what is best for you and your baby. Others may form and share opinions based on their own values and experiences, but this does not mean that their opinions are correct and they may not fully understand your personal experience. In those situations it can be helpful to think about your own boundaries and needs and how you can protect yourself from unwanted opinions.

Pregnancy loss through TFMR may activate intense, confusing and painful feelings for you. It can be helpful to think ahead about how you want to tell others about your loss. This may include finding a sentence to explain what's happened which you are comfortable using in situations when you may feel vulnerable. It can be especially important to think about how much or how little to share if you feel your situation may not be fully understood by other people. You may not want to be drawn into conversations about your loss that could be difficult especially if others question your position or options.

Social media and the press can sometimes present unkind and minimising attitudes towards families who have suffered this type of loss, so prioritising your own wellbeing by choosing who and what you connect with is a vital part of helping yourself through this.

Cultural and religious considerations

Ending a pregnancy for medical reasons is a difficult and traumatic experience for most parents. It can be particularly complicated if it seems to go against cultural or religious beliefs you are connected to.

Every culture and the individuals within them have their own beliefs around baby loss and what it means to families, how that loss is understood by your community, and what you as parents need to feel supported. No two experiences of loss are the same, so it is

important to voice your own feelings and ask for what you need. With grief, our identity and our relationships with ourselves and others can often be challenged. It can be helpful to talk this through with someone impartial and unconnected to your life.

If you have a religious faith, you may find that you question it in challenging situations like that of ending a pregnancy. You may wonder why this is happening to you, rebel or feel dissatisfied with your life in ways that go against the beliefs you held up to this point. It can be helpful to remember that the feelings you are experiencing are valid. You may also find it important to find someone within your faith community who can help to guide you through this time. You will need to identify someone you trust and feel comfortable with, if they are to support you through your feelings and help you to find your own way of relating to your faith after what has happened.

Accessing support in this way can also be helpful if you are able to use it to navigate and acknowledge your loss through a connection with your beliefs. Whether you have a religious faith or not, it is important to have opportunities to grieve in a way that is helpful to you.

Accessing Support

Sands is here to support you and your family after a termination of pregnancy for medical reasons for as long as you need us. There is no judgement made about anyone who has ended a pregnancy. Our support channels, volunteer support groups and online spaces welcome parents who want to share their experiences irrespective of the reasons for their baby's death.

With the rise and improvement of medical intervention and prenatal diagnostics, more and more families have found themselves in the painful position of accepting TFMR as a part of their pregnancy

journey. While you may find that many families you talk to have experienced a stillbirth, neonatal death or other type of loss, there are also many families affected by TFMR in the Sands community. Connecting with others can show you that you have far more in common than you expected aside from the nature of your loss.

We can support you as you journey through the grief you may experience after losing your baby. Here at Sands, we have many options for you to choose from and these may feel more helpful at different times in your journey. Our support options include our Helpline, peer support such as our local group meetings, Sands United Football teams, online support groups, online community and Facebook group. You can use any or all these options, whatever works best for you.



Saying goodbye to your baby

No parent expects to arrange a funeral for their baby. While this is a very hard thing to do, many parents have said that doing special things to “say goodbye” was a way of honouring their baby, including others in their baby’s life and helped them to move forward through their grief. This section talks about seeing and naming your baby, registering their death and arranging their funeral.

Seeing and holding your baby



If your baby lived for a short while, or was admitted to a neonatal unit, you may have held and cuddled your baby before they died. You may have provided skin-to-skin care and spent time next to their incubator reading stories to them and, if you are the birth mother, you might have expressed your milk for them.

If your baby died before or during the birth, the midwife or nurse will usually ask if you would like to see and

hold them. If you want to see your baby and no one has suggested it, ask the staff caring for you.

Some parents feel it is important to see their baby regardless of their size, condition or the stage at which they died. Some parents may find the idea of seeing and holding their baby strange and a bit frightening, especially if they haven’t previously seen anyone who has died.

For many parents, the time they spend with their baby becomes very precious memories in the months and years afterwards.

If you are not sure about seeing your baby, or are anxious about how your baby will look, you could ask the midwife or nurse to show you a photo. If your baby has a visible anomaly, you can ask your midwife or nurse to describe your baby. You can also ask for your baby to be washed and dressed before you see them.

If your baby died quite a long time before the birth, their appearance and colour may have changed. These changes are difficult to predict and may influence whether or not you wish to see your baby. You could ask the midwife or nurse to describe your baby for you first. If you choose not to see your baby, you may decide that you want to see just part of them, such as their hand or foot.

If you initially decided not to see your baby, or were too unwell to see them, you will have the option of seeing them afterwards. You can contact the hospital and let them know that you would like to see your baby. You can ask to see your baby more than once or to take them home.

It is important to remember that you do not have to make the same decision as your partner. Each parent needs to do what is right for them.

Naming your baby

Many parents decide to name their baby, giving the baby their own identity and making it easier to talk about them. Some parents continue to use a nickname that they used during the pregnancy. If a baby is extremely premature or has died some time before they were born, it can be hard to determine their gender and you might like to choose a name that fits either gender.

You do not have to name your baby if this does not feel right for you.

Washing and dressing your baby

You may want to wash and/or dress your baby, or you could ask the midwife or nurse to help you. For many parents, bathing and dressing their baby is a special opportunity to care for their baby and form treasured memories.

You could bring something from home for your baby to wear. If your baby is very small, the hospital may be able to supply suitable clothing. Many units have a stock of very small clothes. You may also be able to order very small clothing online at www.littlebabyandco.com. If your baby's condition makes dressing them difficult, you might want to wrap them in a blanket or something similar. If it is helpful, you can ask a midwife or a funeral director to help you do this.

Deciding on a funeral for your baby

If your baby died before birth and had not reached 24 weeks of pregnancy, you won't be able to register their birth officially. You may, however, request a special certificate from Sands.

If your baby was stillborn at 24 weeks or later, or died after birth, you are legally required to have a burial or cremation for them, although not necessarily a funeral. Your baby's stillbirth, or birth and death, must be registered by the local registrar of births and deaths. The hospital staff will tell you how and where to register. The registrar will give you a certificate that you will need for the burial or cremation.

Although there is no legal requirement to have a funeral, this could be an opportunity to say goodbye to your baby in the presence of your family and friends. If you prefer for the hospital to arrange the funeral, you might need to let them know before you are discharged to go home. Some hospitals can arrange funerals only for those babies who died before birth. Most funeral directors will offer a funeral free of charge for babies.

Before the funeral

Some parents feel they want to take their baby home before the funeral. Unless a coroner or procurator fiscal has ordered a post-mortem examination, this is usually possible.

If you would like to take your baby home, or out of the hospital environment to a place which has special meaning for you, feel free to discuss this with a midwife or nurse. Many hospitals give parents a form to take with them to confirm their right to take their baby's body out of the hospital. You may like to take your baby for a walk or to meet any other siblings, family or friends.

The staff should also give you information about keeping your baby as cool as possible. Some hospitals, children's hospices and funeral directors have cold cots (also known as cuddle cots) which can help to keep your baby cool and stop their body from deteriorating. You may be able to borrow one for your baby.

If your baby remains in hospital, they are likely to be kept in the hospital or maternity unit mortuary. You will be able to visit your baby although this might feel more difficult than the time you spent with them on the ward. Your baby might be in a Chapel of Rest or a room by the mortuary that is for both adults, children and babies who have died and this might feel more difficult for you.

If the hospital is arranging the funeral, the staff will tell you when to bring your baby back or when to take them to the funeral director. If you are arranging the funeral yourself, you will have the option of keeping your baby at home with you until the funeral takes place. We have resources for funerals on the Sands website.

Preparing your baby for the funeral

You may want to wash and dress your baby for the funeral. If your baby has had a post-mortem examination, ask the hospital staff to tell you what to expect. For example, they can describe where any stitch lines might be and make other suggestions for handling your baby. Any stitch lines will be covered when the baby is dressed and wrapped. Alternatively, you could ask the hospital staff or the funeral director to help you.



Depending on your baby's size and condition, you may want them to be dressed in a particular outfit or wrapped in a special blanket. You may also want to put special items into your baby's coffin, such as a soft toy, photos, a letter or a poem. Some parents keep an identical outfit, blanket, toy, letter or poem as a keepsake. Any other children within or close to your family may like to draw a picture or write a letter. However, if you have decided to have your baby cremated, you should ask the funeral director or crematorium what you can put in the coffin with your baby.

If your baby was in neonatal intensive care, they might not have worn any clothes. Many babies wear only a nappy when they are in an incubator so this might be the first time that you will be dressing your baby.

Accompanying your baby's coffin to the funeral ceremony

If your baby is at the funeral home or the hospital, you can ask the funeral director to take them to the venue of the funeral. If you do not want a hearse, you could ask that your baby be transported in an ordinary car. Some funeral directors have cars that are adapted to carry a small coffin and have space for the family.

You will also have the option of collecting your baby and taking them to the ceremony yourself. If you are using a taxi, make sure that they agree in advance to transport a coffin. If your baby is at home, you can take them directly to the funeral.

The ceremony

If you are arranging the funeral yourself, you will need to think about the type of ceremony you would like. For some bereaved parents, their baby's funeral will be the first funeral they have had to think about, and for some it will be the first they have ever had to attend. Couples sometimes find that they want different things and need time to reach decisions. You may also want time to discuss your choices with family members and close friends. If you have had twins or more babies from a multiple birth who have died, you may want them to share a coffin and a funeral.

If you have older children, you may want to include them in planning your baby's funeral. Likewise, if you have a baby who is in hospital, you might like to wait until they recover and take them to their sibling's funeral. It is important that you make a decision that feels right for you at the time.

If you need to arrange a funeral very quickly for religious or other reasons, please tell the hospital staff. They will advise you about urgent registration so that you can see if this is a possibility.

Funerals arranged by the hospital

If the hospital offers to arrange your baby's funeral, there may not be as many choices as you would have if you make your own arrangements.

Hospital funeral ceremonies for babies are usually led by one of the hospital chaplains. Most hospitals hold a shared funeral ceremony at regular intervals for all the babies who have died within a certain period of time. Some hospitals might be able to organise an individual ceremony for your baby if that is what you prefer.

Shared funeral ceremonies are usually non-denominational and suitable for those of faith and of no faith as well. Parents, and anyone else they want to invite, are usually welcome to attend. The ceremony may be held in a hospital chapel, crematorium or cemetery chapel. You could ask the hospital chaplain if it is possible to include a poem, a reading, or music that has meaning for you. You might also like to take some flowers with you. The hospital can arrange a funeral for your baby even if you don't feel able to attend.

If the hospital offers you an individual funeral, you can choose a hospital chaplain or another religious leader to lead the ceremony. If there is no religious leader of your own faith, the hospital might be able to recommend someone. You might instead choose a non-religious leader.

Some hospitals offer both burials and cremations. In areas where the cost of graves is very high, hospitals may offer only cremation, or burial in a shared grave.

Burials

Burials arranged by the hospital are often in a shared grave. Although many babies are buried together, they will still be in their own coffins. Some hospitals offer parents the option of an

individual grave as well. Individual graves are most commonly offered to parents of those babies who died after birth or who died at a later stage in pregnancy. Similarly, individual cremations are often reserved for those babies who died after birth or at a later stage in pregnancy.

Many cemeteries have a special area for babies' graves. Most cemeteries have restrictions about what can be placed on or around a grave and it is usually not possible to put a headstone or memorial on a shared grave. You may be able to make your own arrangements for a plaque somewhere else in the cemetery. Although the hospital would be arranging the funeral, you can contact the cemetery directly to ask about memorial options.

Cremations

One of the key questions for parents who have opted for a cremation is whether they will receive their baby's ashes. This could depend on:

- Whether or not you have opted for an individual or joint cremation: ashes are available for individual cremations only. For shared cremations, all the ashes will be buried or scattered together in a special place in the crematorium grounds.
- The size of your baby: if your baby is very small, the amount of ashes might be very little. Some ashes usually get absorbed in the cremation chamber. This means that there might be no ashes left.
- The facilities at the crematorium: some crematoria have special facilities to protect ashes even for babies who are very small. You can enquire in advance to help you choose the right crematorium.

The ashes will contain remains of any items that are cremated with your baby inside the coffin. Any items that are placed on top of the coffin may be removed before the coffin is placed in the cremation chamber.

You may choose to scatter or bury your baby's ashes somewhere special to you, a favourite walk or woodland. If you choose to bury or scatter your baby's ashes in a crematorium, they may have regulations about what you can place near the area where the ashes are buried or scattered. You may, however, be able to have a plaque placed somewhere else in the crematorium gardens.

“ At his funeral I wore a blue dress. I didn't want anyone wearing black. When his tiny coffin was taken out of the car I heard a collective intake of breath from our families. In that moment, for them it became real.

Gemma ”

Funerals arranged by funeral directors

If you have chosen not to have the hospital arrange a funeral for your baby, you could contact a funeral director to assist you. A few crematoria will accept cremations through funeral directors only. The hospital staff may be able to give you the contact details of local funeral directors who specialise in funerals for babies.

You can also find information in the Good Funeral Guide www.goodfuneralguide.co.uk or the National Association of Funeral Directors (NAFD) website at www.nafd.org.uk.

It is important to make sure that the funeral director you choose is a member of a professional body such as the NAFD. The funeral director will ask you to sign a form allowing them to collect your baby from the hospital mortuary and they can usually organise the other paperwork that is required.

Forms you will need

If you are making funeral arrangements without the help of a funeral director in England, Wales or Northern Ireland, staff at the crematorium will give you copies of the forms you need to complete. Forms are no longer needed in Scotland.

In England and Wales, if your baby died after 24 completed weeks of pregnancy, or after birth but before 24 weeks, you will need a cremation form that is signed by a registered doctor. Your midwife or doctor can give you more information.

In Northern Ireland, if your baby died after 24 completed weeks of pregnancy, or after birth but before 24 weeks, you will need a cremation form and a confirmatory medical certificate form. Again, your midwife or doctor can give you more information.

If your baby needs a post-mortem examination, you will need to wait until this is completed before you can hold the funeral. If a referral has been made to the coroner or procurator fiscal (in Scotland), there may be a slightly longer delay before the funeral can be held. The coroner's or procurator fiscal's officer will explain what will happen and provide expected timescales for returning your baby to you.

If your baby died before birth and had not completed 24 weeks (legally described as a "late miscarriage"), their death cannot be officially registered. Although it is not an official document, Sands can provide a certificate for you to keep as an acknowledgement of your baby.

The funeral director, crematorium or cemetery will usually need a form or letter from the hospital or your GP to confirm that your baby died before birth before 24 completed weeks of pregnancy. A burial or cremation can then be arranged.

The service

Just as with adult funerals, you can choose the type of service you would like to have, including an order of service, readings, music and flowers, and let people know what colours you would like them to wear to the funeral. You may like to have a small gathering after the service.

If you choose not to have flowers at the funeral, you might like to request donations instead to a charity of your choice. Sands has funeral envelopes and other resources available if you would like. You may choose to hold the funeral service at an external public venue or you may prefer a more intimate space such as your home or your garden. If you are looking for a reading for the service, you can browse some readings and funeral resources at www.sands.org.uk/funeralresources.



Some parents ask a friend or relative to take photographs. It is important to let them know exactly what you want them to do and especially if there are any times during the service that you want them to avoid taking photographs. Photos can provide you with precious mementoes and remind you of the people who came to honour your baby and to support you. These photos may also be helpful for young siblings as they grow older, or as a way of starting a conversation with them about their brother or sister.

If you want photos or a video of the funeral ceremony itself, check first with the person leading the funeral, the funeral director and any staff involved in the funeral. It is usually possible as long as the funeral is only for your baby and is not shared with others.

After the funeral - cremations

If your baby was cremated, and it is possible to collect the ashes, you will have time to decide what to do with them.

There are various options for burying, immersing or scattering your baby's ashes:

- The crematorium could bury or scatter the ashes in a special place in the crematorium grounds. The crematorium will have regulations about this.
- You could choose to scatter the ashes in a place that is special to you such as a woodland or in your own garden, though before you decide, consider whether you might move home in the future.
- You could choose to scatter or immerse them in water as long as the urn you use is biodegradable. You might like to scatter flowers or petals as well. Phone your Local Environment Agency office to make sure that the site you are thinking of falls within their guidance.
- If you want to keep the ashes, you could store them in an urn or another container of your choosing. There are also frames that have a compartment at the back to hold ashes behind the photograph.

- You could also choose to have jewellery made from ashes.

After the funeral - burials

- It could take at least six months before you will be able to set a headstone for your baby.
- There may be restrictions on what you can place on and around your baby's grave. Please contact the cemetery for more information.



Supporting children

The death of a baby at any time can be a major bereavement for the whole family. It will have an impact on children who were expecting to have a new brother, sister, niece, nephew, or cousin, or a surviving child of a multiple birth, and also on brothers and sisters born after a baby has died. Children in the wider family, children of close friends, and friends at school may also be affected.

This section considers ways in which to share the news of the baby's death with their siblings and other children who may have known or known about your baby. This section is written for parents but could also be useful for relatives, friends and other people, including nursery and school teachers who are able to provide support.

Breaking sad news

Telling anyone that a baby has died can be difficult. Telling children may be especially challenging as it can be hard to work out the right amount of information to provide them with and to explain it in a way that works for their age and ability. It can also be difficult to offer reassurance to children about a situation that cannot be changed. If you do not feel able to tell your children what has happened, you may be able to ask a close family member or friend to tell them for you or help you to tell them. For example, this person could help explain what has happened and explain why you are sad. The person could also explain why they, rather than you, may need to look after them.

If your baby died on a neonatal unit, there may be a counsellor, psychologist or play therapist who could help you with this.

When deciding what to tell your children, it is natural to feel anxious and protective towards them. It is important to consider their age and their ability to understand. Try not to let any possible fear that they might get upset determine what you tell them. It is important for children to know that it is okay to cry and that they might see you crying as well. When talking with your children, you might like to start by telling them what happened, without including too much detail. You could also say, "We are sad because our baby has died. When someone dies, it means that we won't be able to see them again." You can then be led by their questions. You might like to include the baby's name if you have one and the gender if this is known. Let your children know that they can come back to you to ask questions at other times. They may accept your simple explanation and immediately change the subject, or carry on with their previous activity. This is very normal.

Young children who visited the baby in neonatal intensive care might have believed that the baby would get better and go home. They could be confused and distressed as to why this has not happened. It is likely that their own lives were disrupted as their parents spent long periods of time with the baby in hospital. They might also have started to develop their own relationship with the baby. It is important to encourage them to talk about how they are feeling and to explain to them why the baby died.

Some children might like to know about the funeral or ask where we go when we die. You might have religious beliefs that could influence your answers, or wish to provide more secular or neutral answers such as "Some people believe..." or "We don't know where people go". For young children, focus on what might happen at the funeral so that they know what to expect. Young children might need reassurance that the baby can't feel anything. Otherwise, they might find the idea of a burial or cremation frightening. You could say, "When people die, we bury them," or "When people die, we cremate them," and explain what this means.

One way to help younger children understand death and dying is to read them books for children that discuss these topics in an age-appropriate manner. The Sands online shop stocks various children's books that you can order, as does Winston's Wish. You can also check your local library for appropriate books.

Being open and honest with children

Even very young children usually sense when something is wrong. If they are not told what is happening, they may be frightened and imagine they are at fault for making you feel sad.

It is best to use direct language rather than words and phrases that also have other meanings. For example, telling a young child that the baby is sleeping could be confusing and worrying as they might not want to go to bed. Similarly, words such as "lost" or "gone" could lead them to think that they might also get lost or go away. These words could also lead to false hope such as thinking that the baby might wake up or be found. The child may worry about whether the same



could happen to them or to you. Similarly, saying that the baby was unwell might frighten the child when they are unwell.

Like adults, children of any age may experience a range of feelings; these may not come in any particular order or at any predictable time. Similar to those of adults, children's feelings may be complicated and conflicting.

Children sometimes have mixed feelings when a new brother or sister is expected. A child who felt jealous during the pregnancy might feel guilty after the death of their sibling. It can be helpful to try to reassure a child that the death was nobody's fault and that nothing they did or thought made the baby die.

Some children may feel angry towards the baby who died or towards their parents. Children may also fear that they or others close to them might die as well. They may be more upset than usual at being separated from their parents, especially if their mother is critically ill or has to stay in hospital.

As with adults, children, especially younger children, might find it difficult to express their feelings. Look for changes in behaviour, especially acts of going back to younger behaviours. For example, a child who is toilet-trained might want to wear nappies again or start wetting the bed. Children might become clingy or dependent. There might also be changes in eating and sleeping patterns, and there might be a tendency to fall sick. Maintaining a routine as far as possible is really helpful and giving lots of opportunity for children to ask questions.

It is common for children to express their feelings through play, drawing or painting. This can give you an idea of what your child is thinking and feeling as well as give them an opportunity to express how they feel. Consider what external support your child might need, either from relatives or friends, or through play therapy.

Professionals such as your child's health visitor, teachers, child minders and your health visitor, should be informed so that they can support your child accordingly. Winston's Wish and Child Bereavement UK specialise in supporting bereaved children and have various resources available through their websites.

Children will generally move through the broad stages of understanding as described below, but there can be a great deal of variation. If a child has already experienced the death of a family member or friend, or has a learning disability, this may affect their understanding and response. It is important to check their understanding even if they have been bereaved previously.

How do you explain to a 3 year old that his little sister has died? We sat him down on the couch between us. John tried to explain as best as he could. It affected him just as much as it affected us.

Claire

2-5 Years

Young children may be beginning to understand the concept of death, but do not realise that it is permanent. They may well need repeated explanations of what has happened, before moving on to other seemingly unrelated questions or conversations very quickly. You may find you feel anxious getting ready to tell them that the baby has died and their response is brief and then moves on to what might be for dinner, or if they can go back to playing. As their thinking is very much focussed on themselves and their world, they may need reassurance that nothing they did or said caused the

death. It is also important that children of this age have a chance to understand why the baby died, as they may otherwise create fantasies and stories which may be much more frightening. Children may also make the baby an imaginary friend. You may find this unsettling even though it is a common way for children to cope with their loss.

5-8 Years

Between the ages of 5 and 8 years, children begin to understand the difference between being dead and being alive, and between 7 and 8 years old they start to understand the permanence of death. Separation anxiety may increase or return at this point. They may not ask questions but may be very interested in what is happening and why, so giving them the opportunity and time to ask questions is important. They may "play" funerals or act out scenarios where a death occurs to help them process what is happening. This can be a good opportunity for you to gauge their understanding and concerns. Try to respond in a calm way, even if their responses may feel unsettling for you.

8-12 Years

The understanding of children at this age is closer to that of an adult, although they may find the abstract nature of faith or less concrete concepts hard to understand. Like younger children they will need specific questions answering and find detail important. They may become more anxious about their own mortality and those around them. It is important to listen to and acknowledge their concerns, and to put them in a realistic context.

It can help children to practise answering questions they may receive from other children, with information and language that they are comfortable using.

Teenagers

Anxiety about a young person's own mortality and that of those close to them continues at this age. This combined with a natural need for independence may be a struggle. Teenagers can respond by engaging in an increasing amount of risk-taking behaviour and becoming angry more easily. This can be very hard for parents at a time when they may be feeling more anxious and protective of their other children. Questioning the meaning of life is an important part of adolescence and bereavement can have a significant impact on this process. This can sometimes result in depression. Adolescents may find it easier to talk to friends or a trusted adult rather than their parents. It can help to think about who this might be and support the teenager via this person. Teenagers in step families can feel very conflicted about their place in the family and may need more reassurance than usual.



Telling the parents of other children

You may also want to tell the parents of younger children's close friends so that they understand if your child's behaviour or mood changes. If they have not discussed death with their own children before, they may need time to think about what to tell them.

Some parents may offer to help by inviting your child to play or have a meal. However, some parents may decide to keep their distance in order to

“protect” their own child from learning about death at a young age. This might feel painful for you and your child, and your child may need to be reassured that they have done nothing wrong.

Ways to involve children

There are different ways in which you could involve your children and help them feel part of what is happening around them. You could ask if your child would like to come to the hospital to see the baby and say goodbye. If you are going to be bringing your baby home, you could explain that this is so that the whole family can say goodbye together. Depending on your child's age, you might like to take them to the funeral and encourage them to participate in the service.

Many parents collect keepsakes of their baby, which can be stored in a memory box. Other children might want to add something of their own to the box. Depending on their age, they could do a drawing or painting, or write a poem or a letter. Some children might want to give the baby a cuddly toy, which could be placed in the coffin or kept in the memory box. Children might also want to help make a memory box for the family or to make one themselves. They might also like to have a photograph taken with the baby.

In the months following the funeral, you might like to take your children to visit their sibling's grave, or a special place where you scattered their ashes or planted memorial trees. Children may want to bring something special to leave on the baby's grave. Some places have restrictions about what can be placed on the grave. For example, they may not allow items such as balloons, soft toys, pictures or wind chimes. It's a good idea to find out in advance about any restrictions in order to avoid disappointing a child who wants to take a special item along with them.

Anniversaries, memorial services and family celebrations

Important dates, such as the anniversary of the date when the baby was born, died or was due to be born, or occasions traditionally celebrated with family, such as special holidays, can be especially sad for parents. It can be helpful to talk to children in advance about any dates on the calendar that might be more difficult than others, so that they are aware that you may be sad again for a while. Do not be surprised if important dates and the lead up to them, trigger feelings of grief for children too.

Holidays and other times when families gather together can be a time when the baby is especially missed. Family birthdays, and especially those of a surviving twin or multiple birth, can also be bitter-sweet. Some families do something special to remember their baby on these occasions, such as lighting a candle for the baby or choosing a special decoration together.

Many families mark birthdays, anniversaries or other special occasions by lighting a candle, baking a cake for the baby or visiting a special place, such as the baby's grave, the place they scattered their baby's ashes, or another place that has strong associations with the baby. If you celebrate Christmas, hanging a stocking for the baby or putting ornaments on the tree in their memory, might help other children. Children can be involved in any of these activities and this can provide comfort and ways to acknowledge the grief that is felt by the whole family.

You may want some time on your own whenever grief resurfaces. It might be helpful to explain to children why this is, rather than risk further upset and confusion at what might already be a time of heightened emotions.

Physical and emotional challenges

There are arguably few experiences that can compare to the trauma of losing a baby. As well as the various practical aspects that might occupy your time in the first few weeks, there will also be a significant physical and emotional impact on you and your family.

Physical challenges

If you are the birth mother, you will be recovering from the physical impact of the birth of your baby, just as you would if your baby was alive. Your body would have prepared itself for a live baby and not register that your baby has died. If you are experiencing any medical issues after the birth of your baby, it is vital that you receive any medical care that you need.

You might find that you are producing milk in preparation for breastfeeding. This can be very painful both physically and emotionally.

If your baby died in neonatal care, you might have already started breastfeeding either directly or by expressing your milk.

You could consider donating your milk to a milk bank. This can help those mothers whose babies were born very prematurely and who were therefore unable to produce milk. Someone from your healthcare team will be able to talk with you about milk donation. There is also information on the United Kingdom Association for Milk Banking (UKAMB) website www.ukamb.org. You can allow your body the time to stop producing milk naturally or, if you prefer, you can ask for medication to slow down milk production.

For all parents, grief can be exhausting. You may be physically as well as emotionally drained. You may be tired from the shock of finding out that your baby died, the decisions you have had to make, or the

labour. You may also have had the stress of travelling long distances to and from home to get to a neonatal unit or to appointments. Telling people that your baby has died might also have felt exhausting.

Other physical reactions could include a loss of appetite, inability to care for yourself, or difficulty sleeping. Where possible, ask family and friends to help you look after other children you might have and to help with day-to-day tasks such as shopping, cooking and cleaning.

If you have had twins or multiple babies, you might be faced with a situation where all of them have died, or one or more is alive. If the babies who are alive are also unwell and in neonatal care, you might be exhausted trying to focus on their needs while also grieving for the babies who have died. Sometimes, twins or multiples who are unwell might be in different specialist centres in different parts of the country. Visiting them, while managing the practical and emotional aspects of your grief, can be extremely difficult.

Sexual relationships

When grieving the death of a baby, people's feelings can also be very complicated and vary a great deal. These can have an impact on your physical health and influence physical contact with your partner. You might be associating sex with creating your baby, and this can cause anxiety about having sex. Try to accept your feelings rather than fight them and try to resist the pressure to be "strong".

Some people may not feel ready or able to have sex. Other people may find that it is comforting or reassuring to have sex. Grief can also lead to a loss of sexual desire for some people. Mothers particularly can also feel that their body has "let them down" and their self-esteem and self-worth is affected. There may be new scars and changes to the mother's body that are magnified by the loss of the baby.

When considering when to have sex, it is important that the mother has healed from any surgery, and that the cervix (neck of the womb) is closed again otherwise sex could lead to an infection. Oral sex, where the mother is the recipient, should also be avoided because there is a small but serious risk of air getting into the mother's bloodstream and this can be fatal.

Physical healing from birth usually takes approximately six weeks, but grief and bereavement and any kind of psychological impact can have an effect on physical responses. For example vaginal dryness and inability to have an erection are common physical responses to trauma. Sometimes physical closeness is enough whilst you heal.

Often, people wait until after the six week check-up before thinking about having sex again. Some people wait much longer. It is a complicated and distressing time so be patient with yourself and with each other. You may want to consider talking to your midwife or doctor about contraception options if this is relevant to you and your partner.

If you feel the need for professional support, you can contact the Sands Helpline or visit your GP for help accessing psychosexual counselling.

Emotional challenges

The emotional impact of baby loss is long lasting. You might feel shock, numbness, anger, resentment, sadness, emptiness, guilt, self-blame, loss of self-esteem, and many other emotions. While this can be difficult to accept, it is important to grieve for your loss and to do what you need to receive support. Some people may change the subject if your baby is mentioned, or unknowingly say insensitive or hurtful things. They may not know what to say or are frightened of causing more distress. Many bereaved parents say that some friends and acquaintances cross the road to avoid having to talk to them, or may stop talking to them completely. You might find it helpful to view this animation and to recommend it to family and friends so that they can support you:

<https://www.sands.org.uk/finding-words>

There are many ways to express grief. These vary from person to person and can also change over time. Being aware of what you need will help you grieve in a way that is right for you.

Many parents contact Sands for support. You can contact our Helpline, share your experiences with others on the online community, attend a local Sands support group and meet other local bereaved parents and family members, contact a Sands befriender, or download the Sands Bereavement Support App.

Sands support is available for as long as you need.

After we lost Rachel it became clear that I was struggling mentally. I did not sleep well, and had frightening flashbacks to the labour and the observation ward. Hearing new-borns crying would create a panic inside me that I needed to run from. The environment that I had been nursed in, and the fact that I had not been able to speak about the birth, created nightmares - both waking and sleeping.

Cheryl

It is possible that you might grieve both for the loss of the baby and for the loss of your own hopes and dreams. Until the 1980s, the death of a baby was often dismissed as unimportant and most parents did not receive much understanding or support. Parents were likely to have been told to forget about their baby, to have another, and to carry on as though nothing had happened.



However, even with sensitive and supportive care, the grief that follows a baby's death may remain for a long time.

It is normal to experience strong emotions of sadness and loss, but you may find that your grief lasts for longer than you expect. If you are still finding it hard to manage everyday life or to work after several months, you may want to seek professional help.

You can also make an appointment with your GP and explain how you are feeling. They can refer you for specialist help and support if needed. You may also like to seek counselling directly.

You may already know someone who has experienced the death of a baby or you may have had this experience previously. Comparing your grief to that of another parent, or to yourself during a different baby loss, may not be helpful as each bereavement is different and everyone grieves differently. You might, however, find it beneficial to talk about your experience.

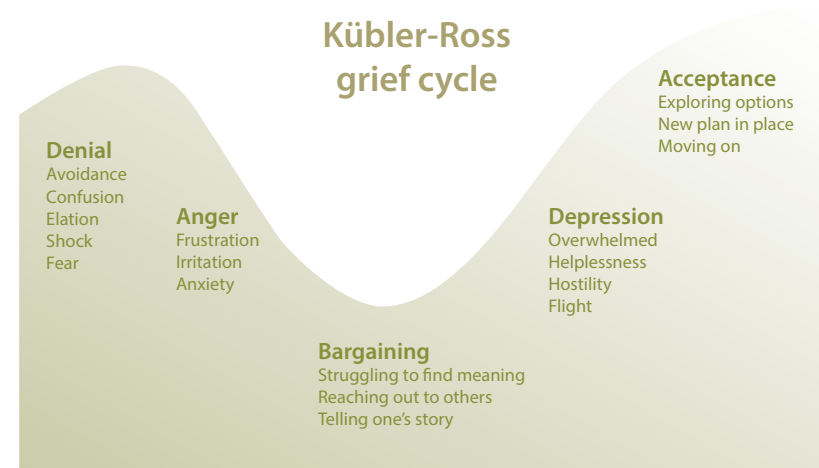
There are various theories of grief. We are including two of them here as these might help you understand and explore your grief

over time. At no time is there the expectation that you should be "fine" or feel "normal".

“ My husband had already returned to work which I think helped him stay focussed. My children had returned to school. I was on maternity leave but I had no baby to look after. I sank deeper and deeper into grief. When we found out Rebecca's death was due to complications this added so much guilt. It consumed me.

Natasha

One theory, by Elisabeth Kübler-Ross, talks about the five stages of grief, namely denial, anger, bargaining, depression and acceptance. These stages do not necessarily happen one after the other; you might find yourself at any stage at any time, or perhaps experience a combination of any of these stages.



Lois Tonkin's model talks about "growing around your grief". The idea is that your grief remains intact and that your life grows around it.



The green represents the grief and the jar represents the growth of life around the grief. The grief of losing your baby initially takes up almost every part of you, but as time goes on, and with support, your grief does not diminish but other aspects of life grow around it, enabling you to find a new kind of normal.



Returning to work

Grief is very personal and everyone responds to it in a different way. This section explores some of the experiences which bereaved colleagues have shared with us, but your situation may be different.

Throughout this section the word 'manager' is used. This means a more senior person in your workplace who is directly responsible for you. Depending on where you work this could be a head of department, a commanding officer, or simply the person you call your 'boss'. If you are self-employed you may find it useful to read the practical advice in the Sands Bereavement in the Workplace guide and toolkit for managers [insert link](#) alongside the suggestions here.

Medium to large employers and organisations will have HR departments who can provide advice, and some workplaces also have dedicated employee assistance programmes, welfare officers, chaplains or others who can give support. If you are not sure whether this is the case where you work, you can ask your manager.

Telling your employer and colleagues

Pregnancy loss and baby loss is a very personal experience, and it is completely up to you what to share with colleagues. Your manager and HR department (if you have one) will need to know why you are off work, but beyond that you can share as many or as few details as feels comfortable.

Many bereaved colleagues find that it is helpful if others know what has happened, as they are more likely to behave in a sensitive manner and be able to offer support which otherwise they would not know was needed. However, other bereaved colleagues want and need more privacy.

There may be others in your workplace who have also experienced pregnancy loss and baby loss, but have never disclosed it.

Even if you are clear that you want your colleagues to know what has happened, you may be uncertain about how to share the news. If you do not want to do so yourself, you can ask your manager to tell other people on your behalf. There are template emails in the Sands Bereavement in the Workplace guide and toolkit for managers [insert link](#) which they may find helpful. Agree with your manager what information they should share, when they should share it, and who they should tell. For example, if you named your baby, you may want your colleagues to be told their name and be reassured that you would like them to use it. Similarly, if you do not want others to know, make sure that your manager knows this.

Being honest with yourself and your manager

The early stages of bereavement can be very challenging. Above all, be kind to yourself, but also be honest with yourself and your manager about the work you are able to do. They should not make assumptions about how you are feeling based on what happened to you, the length of the pregnancy, whether you have given birth or are a partner.

There may be times or dates which you find especially difficult, such as your baby's birthday, due date or anniversaries. The build up to these can also feel challenging. You may wish to take annual leave around these times to give yourself some space. The feelings which can surround these key dates are not a sign that your grief is getting 'worse', as it is normal to have many different emotions when bereaved, and to move between different emotions quickly.

You may need to attend medical appointments following your pregnancy. If a medical review or investigation is taking place to find out why your baby died, this can also be emotionally challenging.

If you tell your manager what is happening and when you need time off, they will be better able to understand and support. If you feel that you are not being supported well at work, your employer may find the Sands Bereavement in the Workplace guides for managers and colleagues useful. We also offer training for employers. Many managers are grateful to be given guidance, especially if they have not previously worked with colleagues who have experienced pregnancy loss and baby loss, but if you need support in communicating your needs to your manager or employer, the Sands Bereavement Support Services Team may be able to help you think through the best way of doing this.

When to return to work

Returning to work can bring up a range of different emotions: some bereaved colleagues look forward to getting back to work as a way of distracting themselves or representing a sense of 'normality', whereas others find the prospect very daunting.

Surveys show that:

- Women need up to 8 weeks off work following a miscarriage
- 10% of parents remain off work for 6 months following their baby's stillbirth
- 38% of mothers and 21% of partners reduce their working hours following their baby's stillbirth

So it is important that you take as much time off as you need. Many bereaved colleagues find a phased return to work or reduced hours helpful. A good employer will realise that it is best for everyone if you return when you are ready, that if you try to do too much too soon you will not work effectively, and that you may also need to take more time off in the longer term.

There are some occupations which may present additional challenges. These may include physical work when your body is recovering from giving birth or you are experiencing the tiredness which can come with grief, work which brings you into contact with situations which are emotionally draining or which mirror your experience of pregnancy or birth, working in healthcare or with young children, or work which requires you to travel and be separated from your partner or other family members. Again, it is important to be as honest as you can with your manager, and to explore different tasks which may be easier or more appropriate for you to do.

My return to work was completely my own decision and I felt it was the right time to try, on the basis that upon returning I might find that it was too soon and I would need some more time off.

Andrew

Some employers will offer you the minimum legal entitlements, but others will be more generous and flexible. There are slightly different entitlements across the different nations of the UK, and laws also change, so do check the latest information and ask your manager what leave, pay, benefits, and adjustments you are entitled to.

With so much to think about, you may find it difficult to remember details, so also ask your manager to put everything in writing for you so that you can look over what has been said, and take time to make decisions.

Workplace celebrations

It is important that you give yourself permission to 'opt out' of workplace celebrations which you find difficult. You may have colleagues who are pregnant or who have new babies, and who want to share their excitement. Social gatherings, especially at sensitive times such as Christmas, other religious festivals, or coinciding with anniversaries, may also be a challenge.



At the same time, if you feel isolated, either because you work remotely, or because your colleagues are trying to be thoughtful and are unsure whether or not to include you in conversations or activities, speak to your manager. Your manager should be checking in with you regularly when you return to work.

Your work space needs to feel safe for you. If you work at a desk you may choose to have a photograph, or something with your baby's name on it, so that they feel close to you. This may be particularly important if it is not something you can do at home. You may share a space with others who are apprehensive about seeing photographs. This could be for a variety of reasons. Some bereaved colleagues

prefer not to have anything on public display which feels private, or may not have a work space where this is possible, but there are other ways of keeping memories close, including wearing a special piece of jewellery, or carrying something personal to your baby in a pocket or wallet.

Showing emotions

Some bereaved colleagues worry that if they show their emotions, they are not being 'professional', but any good manager will want to support you as best they can. You may find it helpful to go into your workplace to see colleagues informally before you return to work, as this can help overcome any concerns you have about seeing them for the first time.

If you are concerned about crying in front of a colleague or manager, try to imagine how you would react if it was one of your colleagues who was bereaved and crying in front of you. You would want to support them, so remember that other people will want to support you. They may not always know the best way to do this, and sometimes they may get it wrong, but most people will be genuinely concerned, want to help, and happy to take the lead from you.



One of the emotions which can come with grief is a sense of guilt. You may feel guilty or as if you are letting colleagues down if you do not think you are doing your job properly, or if you are not as productive as you were previously. This is another reason why you and your manager need to discuss workload, responsibilities and hours, so that expectations are realistic and the work you are given does not put you or anyone else at risk. Even simple day to day tasks can sometimes feel overwhelming, so try to see each step you take as a positive achievement.



Information and support for relatives and friends

This section is written for grandparents, cousins, aunts and uncles, colleagues and friends of the parents. Each of you reading this might have had a different relationship with the baby and their family. We are very sorry that a baby who was important to you has died.

We know that this is a very sad and difficult time for the baby's parents, for you and for the whole family. It is important that you access support yourself if you need it and be aware of the impact that the death has had on you and those around you.

Grieving for the baby

The death of a baby at any time during pregnancy is a major bereavement for the baby's parents. However, how the death affects the wider family isn't often fully understood. Not everyone realises the need for other family members or close friends to grieve or to share their distress.

Some people change the subject if the baby is mentioned, or unknowingly say insensitive or hurtful things. Often they don't know what to say or are frightened of causing more distress. Many bereaved parents say that some friends and acquaintances cross the road to avoid having to talk to them, or stop talking to them altogether. You may find that some people do the same with you. You might find it helpful to view this animation: <https://www.sands.org.uk/finding-words>.

It is possible that you might grieve both for the loss of the baby and for the loss of your own hopes and dreams. You may also grieve for the parents too. It can be extremely upsetting to see someone close to you in distress and be unable to protect them or to take their pain away. If you are a relative, you may also experience difficult feelings

of guilt if the baby had a hereditary condition even though there was nothing anyone could have done to prevent it.

For some relatives and friends, the death of the baby might also bring back painful memories of their own experience of having had a baby who died. Until the 1980s, the death of a baby was often not recognised as traumatic and most parents did not receive much understanding or support. Parents were likely to have been told to forget about their baby, to have another, and to carry on as though nothing had happened. They may not have been allowed to see or hold their baby, or make any special memories. However, even with sensitive and supportive care, the grief that follows a baby's death remains and may be reawakened many years later.

It is normal to experience strong emotions of sadness and loss. You are welcome to access Sands support resources and the Sands Helpline. If you are finding it hard to manage everyday life or work, you may want to seek professional help. You can make an appointment with your GP and explain how you are feeling. They can refer you for specialist help and support if needed. You may also like to seek counselling directly. Please do get in touch with the Sands Bereavement team to help you with this.

Care from health professionals

Parents are usually offered a number of choices about how they would like to give birth, what they might want in terms of making memories and spending time with their baby. There are no right and wrong decisions and parents need to decide what is best for them. Depending on the situation you may also be invited to be involved. It is always important to try to take your cue from the parents rather than imposing your views or needs onto them.

Details about labour and giving birth are in the section *Giving birth to your baby*.

Seeing and holding the baby

If a baby is stillborn or has died shortly after birth, parents are asked if they would like to see and hold their baby. For many parents, the time they spend with their baby becomes a precious memory. Not all parents will decide to see their baby. The parents may ask you if you would like to see and hold the baby. If they do, and you feel this is something you would like to do, seeing the baby can give you precious memories to share with the parents in the future. It can also be helpful for parents if someone else has seen and perhaps held their baby. If the parents invite you to see or hold the baby, and you do not feel able to do so, it is important to let the parents know in as gentle a way as possible.



If the baby died in neonatal care, you might have already seen and held them while they were alive. You might have visited them in hospital and bought them presents. You might have seen them in an incubator with numerous tubes and in only a nappy. This might be the first time that you are seeing them clothed and without tubes.

Creating memories

Parents may want to create memories of their baby and, depending on what they decide, you may also want to ask about creating your own keepsakes.

If the parents decide to have photos taken, these photos may include some of the baby alone, with one or both parents, with brothers and sisters, or with you or other family members. You may want a photo to keep and perhaps display at home.

Remembering the baby

In addition to the grief of the parents, many family members and friends will feel waves of sadness when other children they know, who were born around the same time, start nursery or primary school, or begin to be independent. A living child's progress is inevitably a reminder of what might have been. You might want to acknowledge various anniversaries for yourself as well as share them with the baby's parents.

Offering support

Offering support can feel complicated. The extent to which you want or feel able to be involved, can be affected by your relationship with the baby's parents and how you have dealt with shared problems and grief in the past.

Some parents need time and privacy and want to work things out on their own. They may want to talk to you but they may also prefer to talk to someone else, or use one of Sands Bereavement Support Services.

It is important to listen to the parents to understand what support they need. Everyone grieves differently, so offering a form of help that might have been beneficial for you in the same situation might not be helpful for them.

If they refuse your offers of help or want to be alone, you may feel hurt or excluded. However, they need to do what feels right for them at the time. This does not mean that they will not value further efforts you may make to support them when they are ready. They may also be so distressed that they cannot appreciate your offers of help.

It can be difficult to find the right balance between being supportive and being intrusive. It can also be hard to show bereaved parents that you care without saddening them with your own grief, making them feel that they need to support you, or that your grief “overshadows” theirs. They may need to be reassured that you care about their baby and about them; however, it is important that they should not feel that they have to comfort you. The Sands Bereavement Support Services Team is available to support parents as well as other family members and friends.

Relationships can come under additional strain when there is a bereavement, and grief may make it harder than usual to see other people’s points of view and to accept different ways of doing things. It can be helpful to remember that remarks about how you think the parents are coping, or advice on how you think they should be grieving, can feel hurtful. Being there to listen is often the best form of support.

In addition to providing support to the parents, you might find that you grieve together. This could be helpful as long as each person is doing what they need at the time. It can be useful to allow time to grieve separately as well.

Getting support for yourself

It can be extremely hard to offer support under these circumstances if you do not have support for yourself. Having a safe place, where you can express your own grief and pain, can be very helpful. You may have your own friends you can contact. You could also contact Sands for support; our support services are available for parents, families and anyone else who has been affected by the death of a baby.

Using the baby’s name

If the parents have named the baby, and they would like people to use the baby’s name, it is important that you do this as well. Using the baby’s name is an important acknowledgement for many parents. You may also want to include the baby when talking about how many grandchildren, cousins, nieces or nephews you have, but ask what the parents would like you to do.

Supporting partners

You may notice that most people focus on supporting the birth mother and assume that her partner will be able to support her. People may not realise that parents who haven’t physically given birth may also be profoundly affected by the death of their baby; as a result, their needs and feelings may not be recognised. In addition to experiencing their own grief, partners are often also witnessing the birth mother’s pain and distress and may appreciate being asked how they are and having their own pain recognised.

It is often the partner who has the hard task of breaking the news of the baby’s death to family and friends and of coping with their shock and pain. If the couple already have children, they may also need to find a way of ensuring that the children are cared for and to explain to them what has happened. When the mother is ill, or if her life is in danger, her partner may also face additional fear and worry.

Adoptive parents and foster parents

Prospective adoptive parents and foster parents might be awaiting the arrival of a new baby. It is important to recognise the death of the baby as the death of their baby as well and to support them as they need. While they might not be actively involved in preparations for the funeral, or be making other practical decisions, they will have still experienced a loss. They may need to explore their own ways to mark the death of the baby and could benefit from support. You might like to help them by asking what they need.



Becoming parents through surrogacy and surrogate mothers

If the baby was born through surrogacy, one or both of the parents would be genetically related to the baby. Even though neither would have been pregnant with the baby, as intended parents, they would

have still experienced the death of their baby and need support. Surrogate mothers, i.e. those who are pregnant but do not intend to become parents through the pregnancy, may still need support after the death of the baby. Although they may not necessarily be genetically related to the baby, they may still need to grieve for the baby and face many of the same challenges as any birth mother would.

Relationships between couples

The death of a baby can place a huge amount of stress on a couple. It can be very difficult for couples to find mutual support in each other as they grieve, especially as they may not feel or need the same things at the same time. They may also find it hard to understand and sympathise with each other's reactions and behaviour.

If a bereaved couple feels angry and hurt by each other's behaviour, it can also be tempting to "take sides". However, it may be more helpful if you can try to support both parents.

Single parents

A single parent may never have had any support from their partner or may not have had a partner. Alternatively, their relationship may have broken down during the pregnancy or as a result of stress caused by their baby's death. They are likely to need a great deal of support from their family and friends and it is important to offer support if you feel able.

Younger parents

Young parents are also likely to need a great deal of practical help and support even if there are two parents involved. This may be very important if young friends are unable to provide the support

that the parents need or if they are not around.

It is really important that young people are not judged for being pregnant and that it is not assumed that the pregnancy was a mistake. If the parents are still at school or in education, there may be student support services available. Sands is able to work with these services to ensure that support is offered in a sensitive way.

Funerals

If the parents have decided to have a funeral for the baby, you could offer to help them with organising it. They may need time to decide what will be right for them. This can be difficult, especially if there are different ways of doing things or differing religious beliefs in the family. You may be able to offer the parents support and time to make the decisions that feel right for them as well as help them explore the options available.

Helping around the house

In the early days and weeks after their baby dies, many bereaved parents find it extremely difficult to do everyday things, such as cooking, housework, shopping, sorting out bills, or walking the dog. Parents may find it helpful if you are able to offer to help with some of these types of things. However, parents may also need privacy sometimes, even if they want you to be around at other times. It may be helpful if you offer to leave after providing some help. On the other hand, if they need you to stay for a while and you have only limited time, it is best to let them know this early in the visit.

Clearing away baby things

Sometimes relatives and friends try to protect the parents from further pain by removing equipment and clothes that were bought for the baby. It is really important to check carefully as to whether this would actually be helpful. Many parents prefer to clear away

the baby's things themselves in their own time, even though it may be weeks or months before they feel able to do so. Doing this in stages might help them with the grieving process and it is very important not to rush the parents into getting rid of or donating things that they might have had ready for the baby.

Other pregnancies and births

Some bereaved parents find it distressing to be around expectant or new parents and babies. It can be very hard if another family member or friend is pregnant or has a healthy baby. It can also be difficult for the parents of a new baby; they may feel constrained and unable to celebrate their baby's arrival as they would like. It is important to recognise and acknowledge this and maybe give bereaved parents a private opportunity to meet a new baby when they are ready.

Other relatives and friends

You might find that the parents rely on other relatives and friends more than on you, and this might feel painful for you. Be aware of prioritising the parents' need for help over your own need to help. There can often be a rush to help initially but there will be a need for ongoing support for many months and years.

Other children

Even though babies and very young children might not understand what has happened, they are likely to be sensitive to the feelings of people around them. Their behaviour may change. For example, they may become clingy and dependent, and their eating and sleeping patterns may change.

This can be very hard for grieving parents who are already exhausted with grief. If it is possible for you to help with childcare, this could

help them have some time for themselves. Being looked after by a trusted relative or friend who loves them may also help children to feel cherished and important. However, it may be better for some children to remain in their own home and spend time with their parents and with you.

It is important that parents tell their children what has happened. What a child is told will often depend on the child's age and ability to understand, the questions they ask, and the parents' decisions. It can be helpful if you know what has been said and discussed with the children. It may also help if you try to use the same words and phrases, and avoid giving more information than the parents have agreed.

You may also notice that the parents change their approach to caring for their living children. For example, some parents may react by becoming very protective of their children. Other parents may "relax the rules". It is important to try to understand that the parents are doing the best they can in extremely difficult circumstances.

Fundraising in memory

Many friends, family and colleagues choose to raise money in memory of the baby and as a way of showing their support to the parents. From making a donation to organising a fundraising event, doing anything in memory can provide a real comfort to those who know that their donations are going to help others going through difficult times. There are loads of ways you can do something tangible in their memory. Do visit our website www.sands.org.uk/get-involved or contact our Supporter Care team on 0203 908 5525. You might like to talk to the baby's parents to make sure that they are happy for you to carry out any fundraising in memory of their baby.

The days, weeks and months ahead

When you find out that your baby has died, it may feel incomprehensible that you will ever feel differently and less in pain or broken than you do at that time. Saying goodbye and leaving hospital without your baby is possibly the hardest thing you'll ever have to do.

Sands is here to support you for as long as you need in the months and years ahead. Finding support from others who have found their way through losing a baby can offer hope and show that you will survive this. There are other parent stories on our website and social media.

The early days

In the first few weeks you may just take one step at a time, or accomplish one small task and that is enough. Many aspects of life will just feel like hurdles to overcome and you may not find any joy or positivity in anything. This is very normal.

Planning your baby's funeral and the build up to the day can be incredibly challenging and the Sands Bereavement Support Services Team are here to support you through this.

Important dates

Important dates, such as the anniversary of the date when your baby was born, died, their due date, or occasions traditionally celebrated with family, such as special holidays, can be especially hard. Mothers' Day and Fathers' Day can be especially difficult and our Helpline extends its hours on these days. Often the build up to the actual day is harder than the day itself and planning something specific can be really helpful.

If you have other children, it can be helpful to talk to them in advance about any dates on the calendar that might be more difficult than others, so they are aware that you may all feel sad again for a while. Do not be surprised if a child also shows signs that important dates, and the lead up to them, trigger feelings of grief for them too.

Holidays and other times when families gather together can be a time when the baby is especially missed. Family birthdays, and those of a surviving twin or multiple birth, can also be bitter-sweet. Some families do something special to remember their baby on these occasions, such as lighting a candle for the baby or choosing a special decoration together, having a picnic, or doing something they've always planned, but not managed to do. It's important that you do what feels right for you.



Many families mark birthdays, anniversaries or other special occasions by lighting a candle, baking a cake for the baby or visiting a special place, such as the baby's grave, the place they scattered their baby's ashes, or another place that has strong associations with the baby. If you celebrate Christmas, hanging a stocking for the baby or putting ornaments on the tree in their memory, might help other children.

Some parents buy a gift for the age their child would have been and donate it to a charity. Many families choose to raise funds for Sands by taking on a fundraising challenge, organising an event such as a sponsored memory walk or making a donation in memory of their baby. There are many ways you can do this and you can find out more at www.sands.org.uk/get-involved.

In memory

Sands has many In Memory opportunities to enable you to mark special days and see your baby's name recorded somewhere significant. Children can be involved in any of these activities and this can provide comfort and ways to acknowledge the grief that is felt by the whole family. You may also want some time on your own whenever grief resurfaces. It might be helpful to explain why this is, rather than risk further upset and confusion at what might already be a time of heightened emotions.

A Sands Always Loved tribute is a wonderful and lasting way to remember your baby. In partnership with the memorial website charity MuchLoved, we are able to provide you with a way of creating a tribute website in memory of your baby, which, if you wish, can also be used to raise funds for Sands. Your free online memorial dedicated to your precious baby can be shared with family and friends or kept completely private if you'd prefer.

An Always Loved tribute is a safe space to help you remember and reflect. You can create a beautiful, unique, personalised website in memory of your baby, where you can easily add and display a whole range of information and memorabilia, including stories, messages of condolence, pictures, music and video clips. You can also write an online journal.

Find out more at www.sands.org.uk/always-loved-tributes.



Over time

Your need for support may change over time as you begin to find a "new normal". You will never forget your baby and life will grow around your memories and grief will feel less all-consuming. Grief is not a straight line and you may move backwards and forwards through the process with bad days when you least expect them.

There are many ways you can remember your baby and Sands' website has examples of how people have turned their grief into another memory for their baby or another way of honouring them. What is important is that you give yourself the time and space you need to grieve and to move forward, which is different for everyone. You may undertake challenges or volunteer for a period of time and when you feel you need to step back it is not a sign of letting your baby go, or letting them down, but an important recognition of all that you have done and where you are now in your journey.

As with the early days of grief, you may find that you and those around you grieve in different ways and need different types of support or opportunities at different times. If you are worried about yourself and feeling that you are not coping, or have suddenly started to feel worse, please do reach out to the Sands Bereavement Support Services Team, or your GP or trusted health professional. Sudden changes in how you, or those closest to you, feel are signs that you may need more support. It can be harder to reach out at these times and feel that you "should" be coping, particularly if some time has passed, but grief is not a straight line or process and sometimes we need more help.



Thinking about having another baby

One of the questions that you might ask yourself after the death of a baby is whether you will ever be able to have another baby. Family and friends might try to cheer you up by encouraging you to think about this as an option. However, it is important to grieve in the way that you need for the baby who has died and to think about another baby if and when this is right for you.

Having another baby



If you do decide that having another baby is the right decision for you, it is best to wait until any medical issues have been resolved. These could include underlying conditions for the birth mother, illness during the previous pregnancy, or scars from the birth. You might also want to wait until the birth mother's six-week check-up before you try again. Your baby's post-mortem examination might also reveal specific problems so consider this information before trying for another baby.

You may want to consider talking to your midwife or doctor about contraception options if this is relevant to you and your partner. If you find that you or your partner is pregnant, it could feel very difficult to share the news of your pregnancy or allow yourself to get excited about having a baby. As with grief, you and your partner may not experience these feelings about a new pregnancy at the same time, which can be

challenging. Having had experience of loss, you will be aware in a very personal sense that not all pregnancies end happily. If you have other children, they might remember the time that their sibling died and, like you, be afraid that this might happen again.

You might find that your child re-visits conversations that were held at the time that their sibling died with further questions and feelings. It's important to see what the child remembers and try to fill in any gaps in their understanding if you can. If this feels too distressing for you, perhaps a family member or friend can help.

Antenatal care

Some parents choose to go back to the same maternity unit while others do not want to re-live the memories of their baby's death in the same place. If you do not have the choice to go to another hospital, and find the prospect of attending the same hospital too distressing, you can ask to be under the care of a different consultant and a different team of midwives from the ones you had previously. It is natural to want to be extra cautious and to feel very anxious. If there is anything about your pregnancy that is worrying you, it is essential to tell a member of your healthcare team. In addition to the usual antenatal clinics, some maternity units run special clinics or drop-in sessions for bereaved parents who are expecting another baby, where they understand the anxiety and pain of a new pregnancy and can provide extra reassurance and check-ups.

If you are the birth mother, you might feel especially anxious throughout and this can be particularly hard when you reach the point in your pregnancy when your previous baby died. You can ask for extra checks to help reassure you. Your notes should be marked with a special sticker or alert to indicate that you have had a baby who died. Sands provides special stickers or alerts to health professionals to use. This helps them be more aware that you might need extra care. If you go to antenatal classes, tell the

person facilitating the class that your previous baby died. They can then be sensitive to your needs and understand why you might have additional concerns to some of the other parents who attend the class.

Relating to the new baby

For most parents, planning a nursery and choosing clothes for a baby they are expecting is an exciting experience. When your previous baby has died, it can be difficult to feel confident enough to make preparations for the arrival of your baby. Again, you can speak to someone about your anxieties and maybe ask a family member or friend for practical help in putting together a hospital bag or going shopping for baby clothes and equipment with you. You may feel more comfortable to wait until after your baby is born before you make any extra preparations.

You might also feel afraid of loving the new baby or forming strong attachments until you are confident that the baby is alive and well. It is totally natural to have these fears. You might also find that you



are extremely protective of the new baby when they are born. Think about what you would like from your birth plan and what those caring for you need to know.

When you choose not to have another baby

Experiencing the death of a baby whom you dearly wanted and loved does not mean that you will automatically want to try to have another baby. Equally, you might decide not to have another baby straight away but decide to try to have one later. If you're feeling unsure, give yourself enough time and space to consider what is best for you. You may be unsure for a long time before you make a decision.

There may be both adults and children around you who will assume that you want to have another baby and this could feel painful for you. They might be grieving in their own way and feel that another baby would help their own grief. While this might be true for them, you are under no obligation to meet others' expectations, or to help others cope with their grief. You also do not have to find a reason such as ill health or infertility to explain why you are not trying to have another baby.

You may want to grieve for the baby who has died and how you feel as a parent towards that baby rather than thinking about any future parenting. You might also not want to experience any risks and complications that you had to experience with the baby who died, or any health problems that you might have developed as a result of being pregnant. In addition to these concerns, you might not want to risk future loss. The thought of future loss can feel very frightening.

If you do not want a baby but your partner does, try to resolve this as you would any other issue in your relationship. The death of a

baby can have a huge impact. It might be helpful to arrange couples therapy to help you talk through some of your feelings and the impact of the loss on your relationship.

For the partner who does want another baby, having this denied can feel like a further loss. For them, it can be important to find a way to say goodbye to the baby who has died but also to those babies they imagined they might have. If you have had IVF, there might be embryos remaining. Deciding not to have another baby can feel especially difficult and cause conflict as these embryos could be implanted. It might be possible to donate the embryos for use by other people or for research if you wish, however, this may still create feelings of loss that will need to be processed. Your IVF clinicians will be able to discuss options with you.

When it is not possible to have another baby

Not all parents will have the option of trying to have another baby.

We're too scared to try again. Too scared another loss would break us. It hurts. We'd love another child, not to replace the ones we've lost but because we feel our home isn't full yet. We've tried but the IVF hasn't worked. We're doing our best. For some of us a rainbow baby isn't coming.

Natalie

Sometimes there are medical or personal reasons why another pregnancy is not possible, such as the mother's health, age or the couple's relationship. Parents who had IVF may need to decide whether they are able to bear the emotional and financial costs of going through this process again.

In these situations, it is best to think about where to receive support. Attending a support group for parents who have experienced the death of a baby might be useful in many ways; however, there might also be parents who announce that they are expecting another baby. This can create feelings of jealousy, anger, or provoke a further sense of loss.

The grief of wanting another baby and knowing that this is not possible might compound the feelings of loss for the baby who has just died. Working on a one-to-one basis with a counsellor who can support you through this grief may be more helpful than attending a group. Some Sands groups have been set up specifically for those parents who are expecting another baby, thereby allowing other groups to support parents solely through their experience of loss. It is important to explore the right option for you. The Sands Bereavement Support Team are experienced in supporting parents in many different situations and our Online Community is an opportunity to share experiences and ideas with other parents in similar situations.

About Sands



We hope you have found the information in this book helpful. We would encourage you to use Sands for as long as you need. Our services are open to anyone affected by the death of a baby, no matter how recent or how long ago.

Our website also has a number of ways that you can help Sands make a real difference for bereaved families now and in the future. Visit www.sands.org.uk/get-involved.

About Sands

Sands is the leading stillbirth and neonatal death charity in the UK. Founded in 1978, Sands exists to reduce the number of babies dying and to ensure that anyone affected by the death of a baby receives the best possible care and support for as long as they need it wherever they are in the UK.

Sands strives to reduce the number of babies dying and to better understand the causes of baby deaths, working with governments and other organisations to drive change and raise awareness of the issues relating to baby loss.

Sands exists to support anyone affected by the death of a baby, before, during or shortly after birth. Sands provides bereavement support services at both a local and national level. These include the Sands Freephone helpline, mobile app, online community, family support packs, memory boxes and over 100 regional support groups run by trained befrienders.

Sands works to improve bereavement care available to parents and families, by offering a range of training programmes and resources and working in partnership with health care professionals, trusts and health boards.



Online support and information

For an easy read version of this book type this URL in to your browser:

[sands.org.uk EasyReadSupportBook](https://www.sands.org.uk/EasyReadSupportBook)

This support book is available in other languages

For all language options visit

<https://www.sands.org.uk/sands-bereavement-support-book> or scan the QR codes below



Polish



Simplified Chinese



English



Arabic



Portuguese



Urdu



Bengali



Punjabi



Ukranian



Welsh

Your notes

Your notes



Sands supports anyone affected by the death of a baby, works to improve bereavement care and funds research to save babies' lives.

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Sands Online Community

www.sands.community



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