

Saying goodbye to your baby

**For parents who have had
a late miscarriage, stillbirth
or neonatal death**





Fourth edition, Sands 2013

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We are grateful to the many parents who have contributed to this booklet.

Sands and the authors are pleased to acknowledge that the title of this booklet was originally used for Priscilla Alderson's booklet for Sands in 1985.

“There are no words to describe the utter devastation of walking empty armed out of the hospital. Of travelling home with the car seat you bought locked in the boot of the car because you can't bear to look at it. Of shutting the door to your baby's beautifully decorated bedroom and not opening it again for months.” Mum



We are very sorry that your baby has died. We hope this booklet will help you through the next few days, weeks and months. We have written it for all parents whose baby has died, including those who have had twins, triplets or more. It is based on what many hundreds of bereaved parents have told us that they needed to know.

We cannot be sure when you will receive this booklet or which sections will be useful to you at this very difficult time. We suggest that you read the sections that are important to you now and leave the rest until you are ready.

- ▶ If you have already left hospital and are reading this for the first time, some sections may not be relevant to you. But we hope that you will find the rest of the booklet useful.
- ▶ If your baby died in the neonatal unit, you may have started to do some of the things that we suggest here. Again, we hope that you will find the rest of the booklet useful.
- ▶ If your labour needs to be induced because your baby has died, you may also find it helpful to read our booklet *When a baby dies before labour begins*. This covers the things you may want to know, and the decisions you may be able to make about labour and about what happens when your baby is born.
- ▶ If your baby was born dead before 24 weeks of pregnancy, your feelings are very likely to be the same as those of parents whose baby was stillborn later in pregnancy. Some hospital staff may refer to the death of your baby as a “late miscarriage”. You may find this term very upsetting and rightly feel that it underestimates the significance of what has happened. However, it is used because the legal requirements for registration and funerals for these babies are different. We explain some of these differences in this booklet.

Contents

How you might feel	08
Emotional reactions	08
Physical reactions to grief	09
Telling family and friends	11
Creating memories	12
Naming your baby	13
Seeing and holding your baby	13
Washing and dressing your baby	15
Photographs	15
Other keepsakes	17
A ceremony for your baby	18
Hospital memorial books and services	18
Deciding about a post mortem	19
Discussing a hospital post mortem	20
Urgent funerals	22
Before the post mortem	22
Waiting for the results	22
A coroner’s/procurator fiscal’s post mortem	23
Taking your baby home	24
Deciding about a funeral	25
Organising and paying for a funeral	25

Choices about the funeral	26	Grandparents	41
A hospital funeral	26	Other people	42
Burial - things to consider	27	Rights and financial benefits	44
Certificates and registration	28	What are you entitled to?	44
If and when to register	28	Financial benefits	44
If your baby was born dead before 24 completed weeks	28	If your baby was born dead before 24 completed weeks	45
If your baby was stillborn after 24 completed weeks	29	If your baby was stillborn after 24 completed weeks	
If your baby was born alive at any stage and then died	30	OR if your baby was born alive and then died	46
Registering the baby's death	30	Follow-up appointments	47
Registering the baby's birth	31	Postnatal check-up appointment	47
Who can register a birth or a stillbirth?	32	Post mortem results appointment	47
Who can register a neonatal death?	32	Discussing the post mortem results	48
The register office	33	The weeks and months ahead	49
Urgent funerals	33	The longer term	50
If the death has been reported to the coroner/procurator fiscal	34	Remembering your baby	51
Leaving hospital	36	The Sands Garden	51
Care from your primary health team	36	Lights of Love services	52
Practicalities	36	Fundraising	52
More about grief and grieving	38	One day at a time	54
Coping with your feelings	38	How Sands can help	55
Grief and couples	39	Sands support resources	56
Children	41	Where to get more information about rights and benefits	57
		Useful addresses	58

How you might feel

Every parent's experience is individual, and every circumstance is different, but the death of a baby can bring a grief that is deeper and lasts much longer than most people realise. Many parents say they never knew it was possible to feel such sadness, and that their lives are turned completely upside down. You may experience all sorts of emotional and physical reactions following the death of your baby, some of which you may not expect.

Emotional reactions

Most parents feel shocked and numb, especially in the first few days after their baby's death. You may find it hard to take in what has happened, and also hard to understand and remember what people are saying. You may cry, even when you are not expecting to. Some parents wake up and find that they have been crying in their sleep. Some wake up feeling all right for a split second, and then remember what has happened.

"I remember the morning after my daughter died so clearly. I awoke and after barely a moment realised that she had gone. I sobbed and sobbed." Dad

Both parents can lose their confidence and self-esteem. Mothers in particular may feel guilty and blame themselves for their baby's death. Some may feel that they have let their baby, their partner or their family down.

"It was my responsibility to nurture my son through the first nine months of his life and to see him safely into this world. And even if you don't smoke, didn't drink, took all the multivitamins advised...that guilt is still there. It was my responsibility and I failed." Mum

Anger is a common reaction to loss. You may be angry with yourself, with your partner, with your baby, with God, or with the health professionals who cared for you or your baby. You may also be angry with parents who have healthy babies. When your own life has fallen apart, it can be very difficult to accept that, for most people, life is going on as usual.

Parents who lose one of twins or triplets often face conflicting emotions: grief for the baby who has died, as well as hopes and fears for a vulnerable new baby or babies. This is especially hard to deal with.

"It was really hard and confusing – grieving for our beautiful baby son and at the same time feeling so relieved and delighted to have his twin – our wonderful baby daughter." Mum

Physical reactions to grief

Many bereaved parents have physical reactions to grief. These can feel very similar to intense fear. You may have palpitations or chest pains. You may feel a heavy weight on your chest or find yourself sighing a lot. You may feel sick and have diarrhoea; you may have a lump in your throat or butterflies in your stomach. You may not feel like eating anything, or you may find that you can't stop eating. You may feel exhausted but find it difficult to sleep. Your sleep may also be disturbed by very vivid dreams or nightmares.

If your baby spent time in the neonatal unit, you may have had to cope with a roller-coaster of emotions as his or her condition changed. You may also have had the stress of travelling long distances to and from home to get to the unit. You may be physically as well as emotionally drained.

Telling family and friends

Bereaved parents often say that their arms literally ache for the baby they were expecting to hold and care for. Some mothers still feel their baby kicking inside them, others hear their baby crying. You may search for things without being quite sure what you are looking for. It may feel comforting to curl up, or you may find yourself rocking back and forth with grief. All these reactions are common and normal.

"I had thought that terms like 'your arms aching to hold him' belonged in trashy romance novels. But they are true. Your arms do ache. Your chest does feel as if a huge stone has settled on it. Your heart does break into a million pieces. It's the loneliest feeling in the world." Mum

Even though her baby has died, a mother's body will react in just the same way as it does when she has a live baby. She will have the usual vaginal blood loss (lochia) that follows birth, and her breasts may start to produce milk. These physical reminders of the baby can be both painful and distressing. Waiting for the milk supply to subside naturally may be slow and very uncomfortable. The mother's GP can prescribe medication to suppress the milk supply and ease the breast pain.

Many mothers also get afterpains as the uterus (womb) contracts back to its normal size. Some mothers have painful stitches or a caesarean scar and will need pain relief. In addition to their grief, many mothers get the normal postnatal blues a few days after the birth.

One of the loneliest and most painful tasks, which often falls to partners, is to phone or text family members and friends to break the sad news. Breaking bad news is always hard, and it's especially difficult when you are shocked and distressed.

"Then we had to tell our family. How on earth can you tell your loved ones such awful news?" Mum

There may be a few people whom you want to phone or text straight away. But others can probably wait for a bit. If you phone family and friends, you could start by saying, "I am afraid I have some bad news". This can help to set the tone and may reduce the number of inappropriate and upsetting questions. If your baby died around the due date, people are usually eagerly awaiting your news and are ready with questions about the baby's sex, name and weight. They will be shocked and may find it hard to take in what has happened. If your baby has died before labour has begun, some may even ask if the doctors are sure.

Family members and friends are unlikely to know what to say. Some parents say that they end up supporting the people who they feel should be supporting them.

Try not to feel that you have to answer everyone's questions. Only say as much as you feel able to. Later, you could follow up your calls or texts with an email giving more information about what has happened. This can give people time to compose a more thoughtful response.

"For more distant people and my business contacts I did send emails. Amazingly, because people have 'time' to be shocked and compose a reply, some of the most touching comments came from these emails." Dad

If you can't face breaking the news yourself, you could ask someone else to do it for you. You may want to tell this person what you would like them to say, including whether and how you want other people to contact you in the first few days. For example, you might prefer people to send cards, texts or emails rather than phone.

Creating memories

When someone we love has died, we often share memories and stories of them with other people. We may treasure certain objects that remind us of them and of the times we had together.

When your baby has died around the time of birth, you may have only a few memories of him or her. You may also have very few keepsakes. Hospital staff now offer parents opportunities to create memories of their baby and to collect keepsakes that will help them to remember their baby. Although you may feel unsure about doing this, many parents have told us how precious photos and other items can be, especially in the years to come. Having keepsakes to share with family members and friends may also help them to understand what the death of your baby means to you.

The staff caring for you will suggest a range of things you could do. Take time to think about what is right for you. If, for any reason, you don't want to do what they suggest, please tell them. You may also have other ideas about what you want to do. If your baby died in the neonatal unit, you may have had time to start doing some of the things that we mention here.

Naming your baby

Many parents decide to name their baby. This gives the baby his or her own unique identity and can make it easier to talk about him or her. Some parents decide not to give their baby a name; some continue to use a nickname that they used during the pregnancy.

When a baby is extremely premature or has died some time before the birth, it can be very hard for the staff to determine the baby's sex straight away. This is a difficult situation for everyone and especially for the parents. You can deal with it in several ways: you may prefer to wait until the sex can be confirmed by a specialist or at a post mortem before you choose a name; if you decide not to have a post mortem, you could decide the sex for yourself; or you could choose a name that is suitable for a boy or a girl.

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 he or she died. If your baby died before or during the birth, the midwife or nurse will usually ask if you would like to see and perhaps hold him or her.

Many parents find the idea of seeing and holding their baby strange and a bit frightening, especially if they haven't seen a dead person before. But for many parents, the time they spend with their baby becomes their most precious memory and an experience that they wouldn't have missed for the world. If you want to see your baby and no one has suggested it, just ask the staff caring for you.

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 tell you what your baby looks like when he or she is born. Or you could ask to see a photo first. You could also ask the midwife or nurse to wrap or wash and dress your baby before you see him or her. If your baby has a visible abnormality, usually he or she can be carefully wrapped or dressed so that the abnormality is not obvious.

However, if your baby died quite a long time before the birth, his or her appearance may have deteriorated. This is often difficult to predict. In this case the midwife or nurse will discuss this with you when your baby is born. If you are not sure if you want to see your baby, you could see just his or her hand or foot.

Some parents decide not to see their baby. Or one partner wants to see the baby while the other does not. This is a very individual decision and neither of you should be under any pressure to see your baby if you don't want to. The most important thing is for each person to decide what feels right for them.

If you decided not to see your baby but have now changed your mind, just tell the staff caring for you if you are still in hospital. If you are at home, ring the labour ward or the contact number you were given before leaving the hospital. The staff can then arrange for you to see your baby. This will usually be in the mortuary in a special room for relatives. Bear in mind that your baby's appearance will change with time.

Washing and dressing your baby

Depending on your baby's size and condition, you may want to wash and dress him or her yourself. Or you could ask the midwife or nurse to do this for you.

You may want to bring something from home for your baby to wear. If your baby is very small or premature, the hospital will usually be able to supply suitable clothing: most units keep a stock of very small clothes. If your baby's condition makes dressing difficult, the midwife or nurse can wrap him or her in a tiny blanket or something similar.

"I brushed his hair and put him in the new cardigan I had bought him. I got to do all the things I'd looked forward to doing, it was my chance to show him all the love I had." Mum

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 use your mobile phone to take pictures, remember to download them as soon as possible in case you lose your phone. If you use a camera with a film, it's important not to send the film by post to be developed in case it gets lost.

If you are not sure that you want photos, the midwife or nurse may ask if he or she can take some and keep them in the mother's hospital notes. Hospitals are now encouraged to store keepsakes such as photos for parents, but not all hospitals do this. If this is what you want, it's important to check that the staff will do this for you. Otherwise, you could ask them to put your keepsakes in a sealed envelope for you to take home and store in case you change your mind in the future.

Other keepsakes

If the hospital does store keepsakes, you, the mother, can ask for them at a later date if you decide that you do want them. Again, this is a very personal choice. If for any reason you don't want any photos taken, just say so.

"I decided that it would be better to have a photo I might never look at than to want a photo that I do not have." Dad

If you do want photos, you may also want some of you or your partner with your baby, or of all three of you together. Some parents include other family members; for example, their other children and the baby's grandparents. Some take photos of their baby's hands or feet, or of their own hands holding the baby's hand or foot. Take as much time as you need to get all the photographs that you may want.

If your baby was one of twins or triplets, you may want photos of the babies together. This may be especially important if there is a surviving twin or triplet. In the future, when they are old enough to understand that they had a twin, or that they were one of triplets, this photo may be very helpful.

The keepsakes you can collect depend on the stage your pregnancy had reached. They may include, for example, a scan picture, your baby's cord clamp, a name band, a copy of a section of the monitor trace showing your baby's heart rate before or during labour, or a cot card. Some parents keep the blanket their baby was wrapped in at birth, or an identical set of the clothes they dressed their baby in. You might like to keep a lock of hair if your baby has some. You might also like to ask the midwife or nurse if he or she can take your baby's handprints and footprints for you.

Some hospitals offer parents a memory booklet in which they can record personal details about their baby and put keepsakes such as handprints, footprints and photos. You may also like to make your own memory booklet.

Some hospitals offer parents a memory box to store their keepsakes in. You could also make your own memory box, or buy one from our shop. The Sands Always Loved Never Forgotten memory boxes contain, among other things, two small teddy bears, one that could stay with your baby and the other for you to keep.

As well as the keepsakes mentioned above, you may want to keep other things, such as photos of the flowers you have received, poems, condolence letters, emails and cards, and anything else that helps you to remember your baby. If you have a funeral for your baby, you may want to keep photos of the flowers, the order of service, or any readings or poems you have used.

Deciding about a post mortem

A ceremony for your baby

Depending on your beliefs, you may want to have a baby blessing or other ceremony. You may want to invite family members to join you. You may want to ask someone to lead the ceremony, for example, someone from your religious community, a member of the hospital chaplaincy team, a friend or relative, a humanist funeral celebrant or an independent funeral celebrant.

Most hospitals now have representatives of different faiths on their chaplaincy team. Members of the team spend much of their time listening and offering support. You don't have to want a ceremony or be religious to talk to a member of the chaplaincy team. If you would like to see a hospital chaplain, or to ask them to contact a member of your own faith to visit you, tell your midwife or nurse.

Hospital memorial books and services

Many hospitals have a memorial book for babies who have died. In some hospitals, parents' inscriptions are written in the book by a calligrapher and the relevant page is opened on the baby's anniversary. In other hospitals, parents write their own messages. Some families write about their babies; others write poems, draw pictures or stick in photos. The memorial book is usually kept in the maternity unit, the neonatal unit or the hospital chapel, so that parents can return to view it or to add to it whenever they want to. If you haven't been told about a memorial book, you could ask the staff if there is one and where it's kept.

Many hospitals hold an annual memorial service for babies who have died that year. Some services are open to all parents whenever their baby died. Services are usually non-denominational: parents of all faiths and none are welcome.

A post mortem examination of your baby's body and of the placenta (afterbirth) may help to find out why your baby has died. Research suggests that post mortems find new and often significant information about the cause of a baby's death in 60 to 80% of cases. A post mortem may also discover whether there was a problem that could affect any future pregnancies. Even if, as sometimes happens, a post mortem does not find a clear reason for your baby's death, it may rule out some possible causes. Post mortems may also contribute to important research into why babies die, and so help prevent more deaths in the future.

A senior doctor, midwife or nurse will discuss with you whether you want a post mortem examination. Unless your baby died after birth and the cause of death is not known, a post mortem can only be done if you give your consent (called authorisation in Scotland). This is called a hospital or consented post mortem. (For a coroner's/procurator fiscal's post mortem see page 23.)

It can be difficult to decide whether to have a post mortem. Many parents urgently want to find out the reasons for their baby's death. Others are unsure, or want their baby to be left in peace. Some refuse a post mortem for religious reasons, while others agree in spite of religious teaching because they need to find out why their baby died. If you think you might want a post mortem but have questions or worries, the person who discusses the post mortem with you should be able to answer them for you. Please say if you have any special wishes or concerns.

If you are sure that you don't want a post mortem, please say so. However some parents change their minds when they have had time to think, so staff may ask you a second time.

Discussing a hospital post mortem

The person who discusses the post mortem with you will explain what is involved, discuss the possible benefits and what may be discovered, tell you how long it will take, and explain the choices you can make. He or she will go through the consent (or authorisation) form with you and answer any questions you have. Whatever you decide, you can be confident that the staff will take great care of your baby at all times.

If you don't want a full post mortem, you could decide to have a limited examination. For example, you can have only certain organs examined, only skin samples or blood tests, or only an external examination of your baby. However, a limited examination will not usually give you as much information as a full post mortem: the person who discusses the post mortem with you can explain how much information each kind of examination is likely to provide. Genetic testing – testing the baby's DNA – will be recommended if the doctors think it will give useful information, but it can only be done if you give consent.

A post mortem is usually done by a perinatal pathologist, a specialist in the post mortem examination of premature and newborn babies. To get the most useful results, it should be done within 2 to 3 days of the death. Not all hospitals have a perinatal pathologist, so your baby might have to be sent to another hospital for the post mortem. This might delay the funeral. The person who discusses the post mortem with you will be able to tell you where the post mortem would be done and how long it would be before your baby is returned. Your baby would be taken there and back by a funeral director or by special transport organised by the hospital.

Very rarely, a pathologist may recommend keeping one or more organs for longer, to enable a much more detailed examination that will provide important new information, or to discuss the diagnosis with another specialist. In this case, it is sometimes necessary to keep the organ for a few weeks. This can only be done if you agree.

If you consent to a post mortem, your baby will be dressed or wrapped in a blanket afterwards just as he or she was before the post mortem. You can usually see and hold your baby again after a post mortem if you want to. Although his or her appearance will have changed because of the time that has passed since the death, the marks of the post mortem will not be visible when your baby is dressed or wrapped. However, if your baby was very premature, or if he or she died some time before birth and the body is very fragile, you might be advised to say goodbye to your baby for the last time before the post mortem.

If you consent to a post mortem, you should be offered a copy of the completed consent or authorisation form to keep. If not, you may want to ask for a copy. If you have already left the hospital, you, the mother, can write to the hospital and ask for a copy to be sent to you.

Urgent funerals

If, for religious reasons, you need to hold the funeral within 24 or 48 hours, please tell the person who discusses the post mortem with you straight away. He or she will speak to the pathologist to see if it could be completed in time. An urgent post mortem is not usually possible at weekends or bank holidays. It may also not be possible if your baby would need to be transferred to another hospital for the post mortem (see also page 19).

Before the post mortem

Before a post mortem, some parents dress or wrap their baby in a special blanket, or place a small cuddly toy with him or her. The staff should ensure that these items stay with your baby and are returned with him or her.

"I was so relieved to find that she was dressed in the same clothes and hat that she had been in when we'd last seen her. It's so comforting to know that people had taken such good care of her." Mum

Waiting for the results

You should be given an appointment to discuss the post mortem results. Many parents find this waiting period very stressful.

The full results are usually available within 8 to 12 weeks, but may sometimes take longer if special tests are done on tissue samples. However, the funeral can be held as soon as the main post mortem examination has been completed. There is no need to wait for the full results. (See also Post mortem results on page 47).

A coroner's/procurator fiscal's post mortem

If your baby died after birth and the cause of death is not clear, the doctor looking after your baby must, by law, refer the case to a coroner (in England, Wales and Northern Ireland) or to a procurator fiscal (in Scotland). He or she may order a post mortem. This is called a coroner's or procurator fiscal's post mortem and you do not have the right to refuse. The coroner's/procurator fiscal's officer will contact you to explain why the post mortem was ordered and what will happen. If you need an urgent funeral (see page 33) it is important to tell the officer, though it may not be possible to do the post mortem immediately.

The complete post mortem report with all the test results may not be ready for several weeks. However, once the main post mortem is complete, the coroner/procurator fiscal will usually issue a document allowing you to register your baby's death (see page 28) and to hold the funeral. He or she will also inform the registrar that registration can go ahead.

The coroner's/procurator fiscal's officer will give you the final results of the post mortem when it is completed. You may also want to make an appointment with the neonatologist who looked after your baby to get a fuller explanation of the results and discuss any implications.

For more information about post mortems see our booklet *Deciding about a post mortem: Information for parents*.

Taking your baby home

Some parents decide to take their baby out of the hospital for a short while. They may take their baby home or to a place that has special meaning for them. There is no legal reason why you should not do this (unless a coroner or procurator fiscal has ordered a post mortem, see page 23).

If you would like to take your baby out of the hospital, tell the 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. The staff should also give you information about keeping your baby as cool as possible.

If you are going to have a post mortem, you will need to bring your baby back to the hospital fairly quickly; a post mortem will provide more information if it's done as soon after death as possible.

If the hospital is arranging the funeral, the staff will tell you when to bring your baby back or to take him or her directly to the funeral director. If you are arranging the funeral yourself, you can keep your baby at home until the funeral takes place. However, we suggest that you ask the hospital staff or the funeral director for advice about how, and for how long, to keep your baby at home.

Deciding about a funeral

If your baby was stillborn after 24 completed weeks of pregnancy, or was born alive at any stage of pregnancy and then died, he or she must, by law, be formally buried or cremated. Before this can take place, your baby's birth and death or stillbirth must be registered. The staff will tell you how to register. (See also page 29)

If your baby was born dead before 24 weeks (a "late miscarriage"), he or she cannot be registered (see page 28) but you can still arrange a funeral, though this is not required by law.

A funeral can be religious or non-religious, traditional, or a ceremony of your own design. Take your time to think about how you would like to say goodbye to your baby and what would be right for you.

Organising and paying for a funeral

Note: Arrangements in Northern Ireland may be different from those described in the rest of this section. Your midwife or nurse will explain them to you.

Many, but not all hospitals, in England, Scotland and Wales offer to arrange a funeral for a baby. This may be free of charge or there may be a fee. The choices you can make if you have a hospital funeral may sometimes be more limited than if you arrange the funeral yourself: the midwife or nurse looking after you will explain the choices you can make. See page 26 for more about hospital funerals.

Some parents arrange and pay for their baby's funeral themselves. Most funeral directors charge a reduced rate for a baby's funeral. The hospital staff may be able to give you the contact details of local funeral directors and tell you if any specialise in funerals for babies.

Alternatively you, or a relative or friend, could call local funeral directors to find out about the services they offer and the fees they would charge.

If you are on a low income and your baby was stillborn or was born alive and then died, you may be able to get a Funeral Expenses payment from the Social Fund to help towards the costs. See page 57 for where to get advice about benefits.

Choices about the funeral

Whichever sort of funeral you decide on, there are always choices that you can make. For example, and depending on your baby's size and condition, you may want your baby to be dressed in a particular outfit or wrapped in a special blanket. You may also want to ask the funeral director to put special items into your baby's coffin, such as a soft toy, a letter or a poem. Some parents keep an identical outfit, a blanket, a toy, a letter or a poem as a keepsake.

However, if you choose cremation you should ask the funeral director what can be put in the coffin with your baby. This is because there are strict health and safety rules about emissions from crematoria.

A hospital funeral

Your midwife or nurse can explain what your options are, and what the hospital offers. Some hospitals offer an individual funeral service for each baby. In this case you can choose the kind of service you want, who will lead it, and how you want to participate. In other hospitals, the hospital chaplain usually leads a non-denominational funeral service for several babies at the same time. You can usually attend if you want to.

The staff caring for you can discuss with you other ways in which you can participate. Take time to think about what you would like.

Some hospitals offer either burial or cremation. In areas where the cost of burial sites is very high, hospitals may offer only cremation. However, some will arrange for a baby to be buried if this is a religious requirement.

You don't have to decide what you want straightaway. However, in some hospitals the staff will need to know what you have decided before you go home.

Burial – things to consider

If your baby has a hospital burial, he or she may share a grave with other babies. In some local authority cemeteries, shared graves are in a special area set aside for babies. Some cemeteries use lockable grave covers to protect a shared grave until it's full and the ground can be filled in. You can ask the midwife or nurse if lockable grave covers are used at the local cemetery.

If your baby is in a shared grave, you will probably not be able to place any kind of memorial on the grave itself. Some cemeteries have a separate section in another area of the cemetery for memorials or memorial plaques. Some have rules about the type of memorials that are allowed. You may want to ask about this. Most cemeteries have a book of remembrance and you can arrange for your baby's name to be entered.

Although this is not relevant at present, you should bear in mind that it is usually not possible to move a body from a shared grave. This may be important if, later on, you might want to re-bury your baby with another family member, for example, a grandparent.

Certificates and registration

If and when to register

If your baby was born dead before 24 completed weeks of pregnancy

Although it is sometimes not possible to ensure that there are ashes after the cremation of a very small baby, some crematoria go to great lengths to try to ensure that there are ashes, however few.

In hospital funerals at some crematoria, several babies may be cremated together. This means that even if there are any ashes they cannot be returned to the parents. However parents should be told where the ashes will be buried or scattered.

Ashes that remain after a single baby is cremated should always be offered to the parents. The parents can then decide if they want the crematorium to bury or scatter the ashes, or if they would prefer to bury or scatter them themselves, perhaps in a place that is special to them.

If you are considering a cremation, you may want to find out if the local crematorium staff do their best to produce ashes. If the hospital is arranging the funeral, you can ask the midwife or nurse about this. If you are arranging the funeral yourself, you can ask the funeral director or contact the crematorium yourself. If the crematorium states that there will not be any ashes and you would like to have some, you might want to consider finding another crematorium. Alternatively you could choose burial instead.

Many crematoria have a special area for memorials for babies who have died. Most have rules about what can be placed there. You may want to find out about these in advance so you can think about what you want. Crematoria also have a book of remembrance and you can arrange for your baby's name to be entered.

If your baby was stillborn after 24 completed weeks of pregnancy

You need to register your baby's stillbirth within 6 weeks in England and Wales, and within 3 weeks in Scotland. In Northern Ireland, you don't have to register a stillbirth but you can if you want to, as long as it is within one year of the birth. (See also Who can register a birth or a stillbirth? on page 32.)

You don't have to enter a name for your baby in the register, but you cannot add a name or change the name you have given after you have registered.

The hospital will give you a Medical Certificate of Stillbirth to take to the registrar. The registrar will keep the Medical Certificate (you may want to make a copy before you go to the register office) and will give you a Certificate of Registration of Stillbirth. This simply confirms that the stillbirth has been registered – there is no charge. If you want a full Certificate of Stillbirth, which is a certified copy of the complete entry in the register with names and other details, this will cost £4 per copy (price in 2013).

The registrar will also give you a form to permit burial or cremation. You should give this to the funeral director or, if the hospital is arranging the funeral, to the hospital.

If your baby was born alive at any stage of pregnancy and then died

You need to register your baby's death within 5 days in England, Wales and Northern Ireland, and 8 days in Scotland. If the death has been reported to the coroner or procurator fiscal, the process is slightly different (see page 30). The hospital staff or the coroner's/procurator fiscal's officer will advise you.

You can register the birth when you register the death if you have not already done so (see page 32).

Registering the baby's death

The midwife or doctor will give you a Medical Certificate of Neonatal Death (for a baby who died within 28 days of birth) or a Medical Certificate of Death (after 28 days) to take to the registrar.

The registrar will keep the Medical Certificate (you may want to make a copy before you go to the register office) and will give you a Certificate of Registration of Death. He or she will also give you one or more certified copies of the complete entry in the register (called a Death Certificate). These cost £4 (in 2013) each.

The registrar will also give you a form to permit burial or cremation. You should give this to the funeral director or, if the hospital is arranging the funeral, to the hospital.

Please note that some of the details of the registration process may change in 2014. The hospital staff will tell you what to do. You can also go to www.gov.uk/register-stillbirth for up to date information.

Registering the baby's birth

You don't need a form from the hospital to register the birth. The hospital should have notified the register office automatically but you can register the birth even if the notification hasn't arrived yet. (See also *Who can register a birth or a stillbirth?* on page 32.)

The registrar will give you a short Certificate of Birth free of charge. This confirms that the birth has been registered. You don't have to enter a name for your baby in the register, but you cannot add a name or change the name you have given once you have registered.

If you want a full Certificate of Birth, which is a certified copy of the complete entry in the register with names and other details, this costs £4 (in 2013).

Who can register a birth or a stillbirth?

If you are married or in a civil partnership

- ▶ Either parent or both parents together can register the birth or stillbirth. Whoever registers, both parents' details will be included in the register.

If you are not married or in a civil partnership

- ▶ If the mother goes to the register office alone, only her details will usually be on the stillbirth or birth certificate.
- ▶ If you both want both your names in the register, both parents must usually go to the register office together.
- ▶ If you both want the father's name in the register, but one parent can't go to the register office, the father must sign a Statutory Declaration of Acknowledgement of Parentage in front of a magistrate or a solicitor who is a notary public. (Contact the register office for the name of a suitable person in your area.) The other parent must take the declaration to the registrar.
- ▶ If the mother cannot leave the hospital but wants to register the birth or stillbirth herself, and the time limit for registration is approaching, contact the local register office for advice.

Who can register a neonatal death?

The death can be registered by both parents or by just one parent, whether or not you are married or in a civil partnership. If neither parent is able to register the death, another relative, someone else who was present at the death, or a member of the hospital staff, can register the death.

The register office

The hospital staff will give you the papers you need to take with you. They will also tell you where the register office is, how to get there, the opening hours and the phone number.

It's a very good idea to phone the register office to make an appointment before you go. If the registrar knows that you are coming to register the death of your baby, they will usually try to ensure that you do not have to wait with parents and their new babies. You can also contact the register office if you have questions about anything to do with registration. If you find it hard to phone the register office yourself, you could ask someone to do it for you.

Note: You can go to any register office in the UK country in which your baby was born. But it's usually best to go to the office in the area where the baby was born as otherwise the necessary paperwork may take longer.

Urgent funerals

The stillbirth or death of your baby must usually be registered before the funeral can take place. However if for religious reasons you need to hold the funeral very quickly, most registrars will register – or will issue a certificate permitting burial – out of normal office hours if necessary. The hospital staff can give you the information you need to arrange urgent registration. You could also ask someone in your religious community about local arrangements for urgent funerals.

If the death has been reported to the coroner/ procurator fiscal

In this case you cannot register the death until the coroner/procurator fiscal gives permission. You can, however, register the birth in the normal way (see page 32).

If the coroner/procurator fiscal decides that no further investigation or post mortem is needed, they will inform the registrar. The hospital will give you the papers you need to register your baby's death and you can register in the normal way (see pages 32).

If the coroner/procurator fiscal orders a post mortem In this case the post mortem is required by law and you will not be asked for your consent, but you will be told when it will take place (see also page 19). Once the initial post mortem results are available, the coroner/procurator fiscal will usually decide that registration and the funeral can go ahead. He or she will issue a document allowing you to register the death and will inform the registrar.

If your baby will be cremated, the coroner/procurator fiscal will also issue the necessary legal document. If your baby will be buried, the registrar issues the legal document permitting burial. If you are using a funeral director, they can now collect your baby to prepare him or her for the funeral. If the hospital is arranging the funeral, they can collect your baby.

Occasionally, if the cause of death was not discovered during the main post mortem examination, additional tests are needed. The coroner/procurator fiscal will usually open and adjourn an inquiry. This is a short administrative procedure that enables you to register the death and hold the funeral. You do not usually need to attend the inquiry. The coroner/procurator fiscal will issue the paperwork you need for registration and will inform the registrar. He or she will also send the legal document for burial or cremation to the funeral director or to the hospital if the hospital is arranging the funeral.

If your baby died at home

Most babies who die in the early days of life do so because of extreme prematurity or other medical conditions. But if a baby has died unexpectedly or after going home from hospital, there are certain formal procedures to ensure that no one caused deliberate harm to the baby. You may be contacted by a police officer to be asked about the circumstances. This can be very upsetting but it is normal procedure. The information you give to the police officer will be passed to the coroner/procurator fiscal.

Leaving hospital

“There are no words to describe the utter devastation of walking empty-armed out of the hospital. Of travelling home with the car seat you bought locked in the boot of the car because you can’t bear to look at it. Of shutting the door to your baby’s beautifully decorated bedroom and not opening it again for months.” Mum

Care from your primary health team

Although most parents want to be at home, they often miss the contact they had with the hospital staff who cared for them or their baby. The hospital should tell your GP, community midwife and health visitor what has happened so that they can offer you continuing care and support once you are home.

All mothers need normal postnatal care. They may also need advice and help to deal with breast milk or painful stitches. Both you and your partner may need support and care as you come to terms with what has happened.

If you don’t hear from your GP, or from a midwife or health visitor within a few days of getting home, it’s a good idea to phone the surgery. Tell them what has happened and ask to see someone. Most GPs will arrange to see you at home if you don’t feel able to go to the surgery.

Practicalities

Getting back into the routines of daily life can be hard. Many parents feel exhausted. It may be very difficult to find the energy and motivation to do basic household tasks or to deal with letters and phone calls. Some parents find it hard to go out; others can’t bear to be at home.

Try to take things gently and don’t expect too much of yourself. You can only cope with so much each day. If friends and family want to help, you could ask them to bring round a ready-cooked meal or to do some household chores or shopping. You might want to ask someone to help with answering letters, to go for a walk with you, or to help with other practical tasks you can’t face just now.

Unfortunately, some bereaved parents receive baby-related mail and this can continue for months. Most hospitals try to ensure that parents don’t continue to receive mailings from the Bounty Club. If, at the start of your pregnancy, you signed up to any other baby clubs or to Emma’s Diary, you may need to cancel these yourself. You can also reduce the amount of baby-related mailings by contacting the Baby Mailing Preference Service (see page 59 for contact details).

If you have already bought baby clothes and equipment, you will need to decide what to do with them. Some parents decide very quickly, others wait several weeks or months before they feel ready. Well-meaning friends or relatives may offer to pack the baby things away. But many parents prefer to do this themselves and in their own time, even though it can be very painful and emotional. Some shops will take back unused baby clothes and equipment when a baby has died.

At some point you may have to think about going back to work. You may want to read our booklet *Returning to work after the death of your baby*.

More about grief and grieving

Coping with your feelings

At first you may feel that your whole existence is taken up with grief. You may also feel that life has no purpose now that the plans you made for your future with your baby have been swept away. It takes quite a long time for these feelings to begin to fade and for the grief to become less overwhelming.

You may find that crying and talking about your baby are good ways of releasing feelings. You may want to tell your story over and over again. You may find it helpful to write down what happened and how you feel day by day. You may want to draw or paint, write a poem, keep a diary, create a web page, set up a blog, or make a scrapbook.

Some parents find it hard to express their feelings or talk about their baby. However you grieve, it's important that it's not combined with things that are in themselves damaging, such as working round the clock or drinking too much.

Because grief can come in waves, you may sometimes find that you can cope perfectly normally for hours or even days. Some parents feel guilty about this and feel that they are being disloyal to their baby. But it doesn't mean that they have forgotten or don't care. It's quite normal to have periods of calm and normality between waves of acute sadness.

Grief and couples

Bereaved couples often feel cut off from each other. It's very hard to give support and understanding to someone else when you are in such need of support yourself. The way that grief comes and goes means that 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.

"The first few months were very hard. We seemed very separate and at times I wondered if we would ever get through this. But looking back now, I think it has made us stronger as a couple." Mum

For most mothers, the death of their baby is intensely physical as well as emotional. The baby that has been growing and moving inside her is suddenly gone. After the birth, her body still reacts as though she has a baby to care for. Mothers may also be more inclined than fathers to focus on and to express their feelings. They may cry and talk a lot about what has happened, how they feel, and how they coped that day.

Fathers may also cry and talk about their feelings, but some may be uncomfortable with frequent and open expressions of emotion. They may feel helpless and unsure what to say, or under pressure to express more emotion than they feel able to. Some fathers say that there are times when they simply want to "switch off", "close down", or get away for a bit.

Many fathers say that they put their feelings on hold for some time and get through by focusing on supporting the mother and planning for the future. Other people often assume that men will be strong and just keep going. Fathers are also usually expected to return to work very soon after the death of their baby, and this too may lead some men to ignore their grief and to focus on "getting on with life". For more information see our booklet *Mainly for fathers*.

"I think, if the truth be told, we've probably moved a bit further apart. I don't think we communicated how we were feeling particularly well. Maybe it's our inability to share how we feel, or maybe just thinking that I've shut this chapter door. I want to get on with my life." Dad

Same-sex partners may also find that other people expect them to be strong and to focus on supporting the mother. Friends and acquaintances, as well as health professionals, may show far more concern for the mother than for her partner, who may feel left out and ignored.

Differences in the way that people grieve and conflicting expectations can easily lead to misunderstandings, hurt feelings, anger and arguments. These are even more distressing at a time when many couples feel that they should be especially close and supporting each other.

Such difficulties can affect all aspects of a couple's relationship, including their sex life. While sex may be a source of comfort and intimacy for one partner, the other partner may not even be able to consider the idea, especially soon after the baby's death. For more information see our booklet *Sexual relationships after the death of your baby*.

It's important to try to be patient and gentle with each other. Try to tell each other how you feel, and to really listen to each other – even if this is very difficult. Bear in mind that men and women often grieve in very different ways. Try to accept what your partner is saying and doing; everyone copes and reacts differently.

It can be very helpful for each of you to get some support from other people so that you don't have to rely totally on each other. You may also want to call our Helpline, join our online forum, or attend a local Sands support group. Some couples go to a group together, partly to hear how others are coping.

Children

Children can be deeply affected when a baby dies. Toddlers and young children may be quick to sense changes in the people who are close to them, even if they are too young to understand what has happened. This can make some children feel anxious and insecure. They may behave badly, which can be extremely hard for distressed parents to deal with.

Parents of older children may be unsure how to talk to them about the baby's death, how much to involve them, and whether they should or should not attend the funeral.

Parents who have other children may find it helpful to read our booklet *Supporting children when a baby has died*. We also stock a number of books that parents can read with their children to help them discuss what has happened and how they feel. You can order these from our shop.

Grandparents

Grandparents grieve when an expected granddaughter or grandson dies. It's also very painful for them to see their own child and his or her partner so unhappy, and to feel powerless to make it better. They may find it helpful to read our booklet *Information and support for grandparents*.

Some grandparents may also be reminded of their own childbearing losses. They may never have spoken about them and are unlikely to have been well cared for or supported.

Other people

Family members and friends are likely to be shocked by your baby's death and may not know what to say or do. You may also find it difficult to express just how overwhelmed and devastated you feel. Sometimes parents are lucky enough to have one or more friends or family members who really listen and who don't get uncomfortable or upset when they cry.

"My closest male friend John...gave me what I can only describe as a kind of hug only fathers give their sons. I will be forever indebted to him. For that moment he could not change the pain but he carried some of it for just long enough when I could not." Dad

However, most people simply don't understand the impact of the death of a baby. Some may worry that mentioning your baby will upset you. They may try to talk about other things, or may avoid you altogether. A few friends and acquaintances may even cross the road to avoid having to say anything at all.

Some people may say things that are hurtful in an attempt to provide comfort, such as, "It was probably for the best" or, "At least you can have other children". As a result, you may feel cut off even from the people who used to be closest to you and from whom you expected the most support. This can be extraordinarily difficult to deal with.

Many parents in this situation find that they have to tell their friends and families what they want from them. For example, you may need to say when you want to talk and when you don't, when you want someone to come round and when you don't, when you would like them to cook a meal and bring it round and leave, or when you need some shopping done.

Perhaps most importantly, you may have to tell friends and family when you need them simply to listen to you without offering you any advice or answers. Most people will be relieved to know what they can do to help.

Having a close friend, family member or acquaintance who is pregnant or has a baby can be particularly hard. You may know several couples whose babies were due about the same time as yours, especially if you attended antenatal classes. Try not to feel guilty if you don't want to see them or feel unable to return their calls or texts.

Some family members and friends may not contact you at all. It is natural to feel hurt or angry at this, but they almost certainly don't know what to say. Perhaps, before your baby died, you too might have found it difficult to know what to say and do. Family members and friends may find it helpful to read our booklet *For family and friends: how you can help*.

Many parents find it easier to talk to others who have had similar experiences. Some contact our Helpline or a local Sands support group very soon after their baby's death, others wait weeks or months. Many connect with other parents via the online forum on our website. Most parents say that the comfort of being able to say exactly how they feel, and of being completely accepted and understood, is invaluable. It helps them not to feel so alone.

Our contact details are on page 55 of this booklet. There is a list of other charities that can offer support on page 58 and 59.

Rights and financial benefits

The following information is correct as of August 2013, but rights and benefits may change. You can check the websites and contact the advice lines on page 57 to find out more.

What are you entitled to?

Whether you have a right to financial benefits or time off work depends on many things, including whether you are or were employed, your income or your earnings before the birth, and whether your baby was stillborn or lived for a short time after the birth.

Financial benefits

It may seem strange and perhaps upsetting to think about claiming benefits when your baby has died. However, many bereaved families find themselves facing unexpected financial strain. So it is important to find out about all the benefits to which you may be entitled.

Maternity and paternity benefits are complicated. They are administered by several government agencies and, in some cases, by employers. You will find clear helpful information in the Money Advice Service's leaflet *Late miscarriage, stillbirth, neonatal death – A guide to the financial help available*. You should have received this at the hospital or from your community midwife or health visitor. You can also get a copy from the Sands shop or our Helpline (see page 55).

If your baby was born dead before 24 completed weeks of pregnancy

After a late miscarriage, parents are not entitled to maternity or paternity rights or benefits. But you do still have some entitlements if you are in paid employment.

Mothers are entitled to:

Sick Leave Sick leave taken immediately after a miscarriage is likely to be “protected” in the same way as sick leave for a pregnancy-related illness. As with other sick leave, you need a Fit note (previously called a Sick note) from your GP.

You should not be treated unfavourably for being off sick following a miscarriage, and it is good practice for your employer to record the leave separately from other sick leave, so that it does not count towards your sickness record. However, if you are off sick for some time, it may be arguable that this is no longer pregnancy related and you should seek advice from Working Families (see page xx) or the Citizen's Advice Bureau if you are worried.

Sick Pay If you have had a late miscarriage, you are entitled to the same benefits as any other employee who is off sick. You will at least get Statutory Sick Pay – this is paid for up to 28 weeks, or more if your contract of employment allows it – or income-related benefits from the state.

Compassionate Leave or Time Off For Dependants If you are not sick, your employer may give you Compassionate Leave or Time Off For Dependants (TOFD). You are legally entitled to Time Off For Dependants in certain circumstances, but your entitlement to Compassionate Leave depends on your contract of employment and your employer's policy.

Fathers or partners – including same-sex partners – may be entitled to:

Sick Leave and Sick Pay, Compassionate Leave or Time Off For Dependants from your employer.

Follow-up appointments

If your baby was stillborn after 24 completed weeks of pregnancy OR if your baby was born alive at any stage of pregnancy and then died

Mothers in paid employment are entitled to:

52 weeks' Maternity Leave You should normally have told your employer that you were pregnant before the 24th completed week of your pregnancy. If you gave birth before your Maternity Leave started, your leave starts the day after you gave birth.

You may also be entitled to **Maternity Pay** from your employer and **Maternity Allowance**.

Fathers or partners – including same-sex partners – in paid employment may be entitled to:

One or two consecutive weeks' Ordinary **Paternity Leave** from your employer. You should normally have informed your employer before the 24th completed week of pregnancy that you plan to take Paternity Leave.

You may also be entitled to **Sick Leave** and **Sick Pay, Compassionate Leave** or **Time Off For Dependants** from your employer.

Mothers who are self-employed or not in paid employment may be entitled to:

Maternity Allowance, or income-related benefits from the State.

Postnatal check-up appointment

It's important that all mothers have a six-week postnatal check-up. This can be at the GP's surgery or at the hospital. Some women may prefer to see their GP instead of returning to the hospital where their baby died. When you make the appointment, you may want to check that you will not be expected to wait with mothers who have had a healthy baby.

The main purpose of this appointment is to check the mother's physical recovery after the birth. Couples may want to go together as this is also an opportunity to talk about your baby and about how you and your family are coping.

If another pregnancy is an option for you, you may want to discuss contraception so that you have time before thinking about another pregnancy. You may also want to discuss the best time to start trying for another baby.

Some parents find it helpful to write down their questions before going to this appointment.

Post mortem results appointment

Your appointment to discuss the post mortem results will usually be at the hospital. Some parents find it very hard to go back to the place where their baby died. But it's important to have this opportunity to discuss the results with the consultant who cared for you or your baby.

If your baby was stillborn or died in the maternity unit, you will probably see your obstetric consultant or another senior obstetrician.

If your baby died in the neonatal unit, you will probably see the consultant neonatologist who looked after your baby, or another senior neonatologist. They will not have the mother's hospital notes. If you, the mother, want to discuss your antenatal care and what happened during the labour, you should ask for the consultant obstetrician to be at the same appointment or make another appointment to see him or her.

It's a good idea to ring the consultant's secretary before the appointment, to make sure that you won't be asked to wait in the same area as pregnant women or women with their babies.

Discussing the post mortem results

Many parents have high expectations of the post mortem examination and hope that the results will provide some information about why their baby died. However, sadly, sometimes doctors can find no clear reason why a baby died.

The consultant will explain the post mortem results and discuss them with you. You will normally be given a summary of the results; the full report will be sent to the mother's GP. If you want your own copy of the full report, the mother can write to the hospital to ask for one.

If a genetic abnormality has been found, you may be offered an appointment with a genetic counsellor.

Before any appointment, it's a good idea to write a list of questions you want to ask. If another pregnancy is an option for you, you may want to ask if there are any implications for a future pregnancy, and what could be done in the future to reduce any risks. You may also want to discuss the best time to start trying for another baby.

The weeks and months ahead

After the funeral and the post mortem results, you may feel very sad and empty. Many parents find it hard to believe that they will ever feel all right again. Parents often feel under pressure from other people to "get over" the death of their baby in a few weeks. Parents may also feel they have to hide their grief and put on a happy face.

"Nothing is ever the same after losing a baby. But people want you to get back to how you were. They expect you to do it fairly quickly." Mum

Other people may expect parents who have lost one or more from a multiple birth but have a living baby, to be happy. But having a living child is unlikely to reduce grief for the baby or babies who have died.

The emotional roller-coaster that many grieving parents go through in the weeks and months after their baby has died is a natural response to loss. Most parents recover and can function normally with time, but some may need professional help along the way.

Some mothers also suffer from postnatal depression. This is different from the sadness that is a normal part of grieving. Some parents have persistent flashbacks of the events surrounding their baby's death and may put these down to grief, when in fact they may be suffering from post-traumatic stress disorder. If, after about six months, you are still finding it very hard to manage everyday life or work, it's a good idea to ask for professional help. Make an appointment with your GP and explain how you are feeling. If necessary he or she can refer you for specialist help and support.

Remembering your baby

The longer term

It's very common for parents to experience renewed waves of grief even long after their baby's death. These may come out of the blue, or may be triggered by events and dates; for example, the date your baby was due, anniversaries of his or her death, Mother's Day, Father's Day, family celebrations, and festivals.

It may be helpful to anticipate times, such as the anniversaries of your baby's death, when you may feel new waves of grief. Think about keeping the week around the anniversary reasonably free and taking the actual day off from work or from your usual routine. You could do something special and different that gives you time and space to remember, perhaps with your partner or a friend.

Many parents also feel waves of sadness when other children who were born around the same time are starting nursery or primary school or beginning to be independent. For parents of twins or more babies of whom one died, such milestones are particularly poignant. A living child's progress is inevitably a reminder of what might have been.

"The pain is still deep inside, surfacing occasionally, but you get through somehow. You have to. I still cry, with some days being better than others. Seeing all the other mothers passing with toddlers her age and imagining what she would look like, it always brings a tear or two so I have to turn away." Mum

Many parents say that life is never the same after the death of their baby. He or she will always remain an important part of their lives, but they can also function normally, once the acute pain and grief of the early days have gone.

Over time, you may want to create additional ways of remembering your baby. For example, you may want to have your baby's name, handprint or footprint engraved on a piece of jewellery, or to wear your baby's birthstone. You could also inscribe a bench or a piece of sculpture with your baby's name.

If you have a garden, you could plant a tree, or a rose or other shrub, perhaps one that flowers or produces berries in the month in which your baby died. Or you could plant a small tree or shrub in a pot, so that you can take it with you if you move. There may also be special places or gardens locally where you can plant a tree in your baby's memory or donate a bench.

The Sands Garden

You may like to visit the Sands Garden at The National Memorial Arboretum in Alrewas, Staffordshire (www.thenma.org.uk), which is open every day except Christmas Day. The Garden is dedicated to the memory of all babies who have died. It is a tranquil place where families can remember their own baby in peace.

The paths within the garden are lined with stones or pebbles on which families have written their baby's name or a short message. If you would like to visit and add your own stone, use one that is no bigger than 7 cm in diameter and write on or decorate it with indelible markers. Stones and indelible markers are sold in the National Trust shop at the Arboretum.

You might also want to attend the Sands Open Day and Memorial Service which is held towards the end of June at the Arboretum each year. Information about the service is posted on our website each year in March (see back page for web address). There are also local Sands gardens in several places in the UK. Contact the Helpline to find out if there is one near you.

Lights of Love Services

These are held every year in December in several towns in the UK. During the service, parents and families can light a tea light in memory of their baby and write a message to hang on a Christmas tree. The date and venues for each year's Lights of Love services are announced on the website each autumn. There will also be information about how to have a message card placed on the tree if you can't come.

Fundraising

Many hundreds of parents, family members and friends also raise funds for Sands in memory of their baby. To find out about the many ways you can give, please visit the Get involved section of our website, call our helpline or email fundraising@uk-sands.org.

These are some of the ways parents have chosen to remember their baby:

- ▶ drying and pressing flowers from the funeral
- ▶ choosing a special candle holder and lighting a candle for their baby at family occasions and other special times
- ▶ buying or making a special ornament or picture
- ▶ having their baby's photo re-created as a painting or a sketch
- ▶ naming a star
- ▶ making a piece of cross-stitch or needlework
- ▶ creating a scrapbook
- ▶ having a piece of jewellery made
- ▶ getting a tattoo

One day at a time

- ▶ Be gentle with yourself and give yourself time to grieve and time to heal
- ▶ Try not to expect too much of yourself
- ▶ Be patient with your partner, especially when he or she reacts differently from you
- ▶ Accept practical and emotional support from other people
- ▶ Try not to waste energy being angry with people who say or do the wrong thing
- ▶ If possible, give yourself at least a year before making any big decisions such as moving, changing your job, or changing your lifestyle
- ▶ If another pregnancy is an option for you, give yourself time to recover first, both physically and emotionally
- ▶ Accept and welcome the times when you feel less sad and begin to enjoy life again. They don't mean that you no longer care, or that you have forgotten your baby

Although it's a cliché, time does bring healing. Parents do reach what one mother calls a "new normal", and most of them keep forever a special place in their hearts for their baby son or daughter.

How Sands can help

Sands is a national charity offering information and emotional support when a baby dies before, during, or shortly after birth.

17 babies are stillborn or die shortly after birth every day in the UK, and each year we support thousands of families whose babies have died.

At Sands there are people who understand what it's like, because many of us have been through this devastating experience ourselves.

You may not want anything from us right away. We are here to help whenever you feel you need it. That may be now or in a few weeks, months or even years.

As well as supporting mothers, fathers and same sex partners, we are also here to help other members of the family and the many other people who may be touched by a baby's death, including friends, colleagues and health care staff. All are welcome to contact us for support and information.

Do you want to speak to someone on our helpline?	020 7436 5881
Do you want to email the Helpline for support?	helpline@uk-sands.org
Do you want to connect with others whose baby has died?	www.sandsforum.org
Do you want to find out about a Sands group near you?	helpline@uk-sands.org
Do you want to know about our other support booklets?	Please see page 56
Do you want to see what's on offer at our shop?	www.shop-sands.org/ shop/
Do you want to know more about what we do?	www.uk-sands.org
Do you want to make a donation or fundraise?	fundraising@uk-sands.org
Do you want to write to us?	Sands, 3rd Floor, 28 Portland Place, London, W1B 1LY

Sands support resources

If you would like more information on any of the subjects we have mentioned, please see our current list of Sands booklets below. You can read or download copies of our booklets on the Support section of our website www.uk-sands.org or you can order copies from our online shop www.uk-sands.org/shop or by calling 0845 6520 448.

Sands booklets

When a baby dies before labour begins

Saying goodbye to your baby

Deciding about a post mortem - Information for parents

Mainly for fathers

Supporting children when a baby has died

Sexual relationships after the death of your baby

Information and support for grandparents

For family and friends: how you can help

Returning to work after the death of your baby

Information for employers: Helping a bereaved parent return to work

Another pregnancy – for parents whose baby has died

Where to get more information about rights and benefits

Money Advice Service

For an up-to-date summary of financial benefits, go to:

www.moneyadvice.service.org.uk.

In the “Search this site” box enter one of the following phrases:

“Late miscarriage / Stillborn / Died shortly after birth”

Money Advice Line: 0300 500 5000 (English) or **0300 500 5555** (Welsh)

Government websites

These UK government websites contain more detailed information about the different benefits to which you may be entitled and how to claim them, as well as links to downloadable claim forms, email addresses, telephone numbers etc.

England, Wales, Scotland: www.gov.uk Select **Benefits**

Northern Ireland: www.nidirect.gov.uk Select **Money, tax and benefits**

Enter what you are looking for into the search box at the top of the page and click on **Go**.

For most benefits you can also phone or visit your local Job Centre or JobCentre Plus (in Northern Ireland: Jobs and Benefits Office, or Social Security Office).

For more help and advice on employment or financial issues:

Working Families www.workingfamilies.org.uk

A campaigning charity which supports and gives a voice to working parents. Gives financial and other advice over the phone or by email.

Freephone helpline: 0800 013 0313

Email: advice@workingfamilies.org.uk

Useful addresses

Other charities that can offer support

Bliss - the special care baby charity

www.bliss.org.uk

Support, advice and information for families of babies in intensive care and special care, including bereaved families.

Helpline: 0500 618 140 **Email: hello@bliss.org.uk**

Child Bereavement UK

www.childbereavement.org.uk

Supporting families when a child dies and when a child is bereaved.

Support and information: 01494 568 900

Email: support@childbereavementuk.org

Miscarriage Association

www.miscarriageassociation.org.uk

Support and information for those affected by pregnancy loss.

Network of support groups and telephone contacts throughout the UK.

Helpline: 01924 200 799 **Email: info@miscarriageassociation.org.uk**

TAMBA Bereavement Support Group

www.tamba-bsg.org.uk

Support for families who have lost one or more children from a multiple birth. (Part of the Twins and Multiple Births Association – TAMBA)

Helpline: 0800 138 0509 **Email: [Use the form on their website](#)**

Winston's Wish

www.winstonswish.org.uk

Help and support for bereaved children and young people up to the age of 18.

Helpline: 0845 203 0405 **Email: info@winstonswish.org.uk**

To prevent baby-related mailings

Baby Mailing Preference Service (MPS)

www.mpsonline.org.uk/bmps

Free site where parents can register online to stop or reduce baby-related mailings of samples, advertisements etc.

Address: DMA House, 70 Margaret Street, London, W1W 8SS

Email: bmps@dma.org.uk

About Sands

Sands, the stillbirth and neonatal death charity, was founded in 1978 by a small group of bereaved parents who were devastated by the death of their babies, and by the total lack of acknowledgement and understanding of the significance and impact of their loss.

Since that time, we have supported many thousands of families whose babies have died, offering emotional support, comfort and information. Today Sands operates throughout the UK and focuses on three main areas of work:

We support anyone affected by the death of a baby

Bereavement support is at the core of everything we do. Some of the services that we offer include:

- ▶ Helpline for parents, families, carers and health professionals
- ▶ UK-wide network of support groups run by trained befrienders
- ▶ Online forum and message boards enabling bereaved families to connect with others
- ▶ Website and a wide range of booklets, books and other resources.

We work in partnership with health professionals to try to ensure that bereaved parents and families receive the best possible care

We offer resources and a comprehensive programme of training, workshops and talks for health professionals that give practical guidance on how to meet parents' needs and provide good bereavement care.

We promote and fund research that could help to reduce the loss of babies' lives

The UK has one of the highest rates of perinatal death in the developed world. The shocking reality is that, in spite of medical advances, 17 babies are stillborn or die under one month old every day.

We raise vital funds for research and campaign for the government to address this situation as a matter of priority.

We depend on the extraordinary energies of our supporters to raise the vital funds that we need to deliver the wide range of services that we offer.

If you would like any further information or support please contact us or visit our website.

Support:

t: 020 7436 5881

e: helpline@uk-sands.org

Enquiries:

t: 020 7436 7940

e: info@uk-sands.org

Write to us:

3rd Floor, 28 Portland Place,
London, W1B 1LY

Website:

www.uk-sands.org