

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.

