

Understanding why your baby died

Reasons for a baby's death

When your baby dies, it can feel very important to understand why. Sometimes the cause of death is clearly related to a medical condition in the mother or baby. For many babies the cause is not clear straight away and investigations can help to understand what happened. Sadly, in many cases, even after full investigations the cause of death may remain unclear. This is because there is still a lot that we don't understand about why many babies die.

Finding out why a baby died

Parents of babies who have died may not have answers from medical staff before or immediately after their baby is born. This is because most baby deaths are unexpected and there needs to be an investigation into what was happening in the baby or the mother's body that caused the baby to die.

Some parents are keen to know why their baby has died. Others may feel unsure or worried about this in case it exposes medical problems that could affect other pregnancies. Not all baby deaths are understood and more research is needed to understand why babies die. There are, however, two possible investigations that might provide some answers. The first is a post-mortem; the second is a review of care.

It can sometimes be clear that a baby died because of direct harm to the baby or its mother, or because of something that happened during pregnancy. Women who are victims of abuse and have become pregnant in this context are more likely to experience injuries that can cause a baby to die. If you are a victim of abuse and need support, please contact www.womensaid.org.uk.

While doctors may not find all the answers about why your baby died, you should be able to discuss what happened and ask any questions you may have once the results of any investigations are shared with you.

1. Post-mortem examinations

It can be very hard to think about a post-mortem examination for your baby. Staff at the hospital will talk with you about what is involved and try to answer any questions you have. If you are unsure what to do, you can discuss how you feel with them. You might also like to discuss this with your family and friends, your doctor, or a midwife or nurse. The staff on the Sands Helpline are also available to provide you with support.

What is a post-mortem?

A post-mortem is a medical examination of your baby's body. The examination is carried out a specialist doctor called a perinatal pathologist who will try to find out the reason for your baby's death.

Usually, a senior health professional will talk with you about having a post-mortem examination. A post-mortem examination cannot be done without your consent ¹. You can choose to have a full or a limited post-mortem (see below). An examination of your placenta (the part of a woman's womb that nurtures the baby during pregnancy) can also provide important information about the cause of death.

The choice about having a post-mortem is very personal. Only you can decide what to do.

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

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

Bereaved mother

In some limited circumstances, a post-mortem can be ordered without parental consent, by a coroner (England, Wales and Northern Ireland) or procurator fiscal (Scotland).

If you consent to a post-mortem, you will still be able to see your baby in hospital until the time of the post-mortem. You will sometimes be able to take your baby home following the birth before the post mortem, but it is important to check if this is possible with the team looking after you.

When the time comes for the post-mortem examination, hospital staff will take your baby to a mortuary. Keepsakes such as soft toys and blankets can stay with your baby, and your baby will be well looked after and treated with respect. You will be able to see your baby again, if you wish, after the examination has been completed. Some parents choose to say goodbye to their baby before the post mortem. Ask staff any questions you have and they will be able to help.

When should a post-mortem take place?

A post-mortem will usually provide the most information if it is carried out within a few days of a baby's death. If you need to hold the funeral within 24 or 48 hours, tell the staff at the hospital as they may be able to arrange a post-mortem within this time. Sometimes, babies need to be transported to specialist centres in other hospitals where post-mortems can take place.

Once you have consented to have a post-mortem examination, you can change your mind and withdraw consent. It is best to ask the hospital how much time you have to do this.

What might a post-mortem examination tell you?

A post-mortem examination of your baby and of the placenta may help to find out why your baby has died. Although it does not always find a definite cause of death, it may still answer some question. Here are a few examples of why a post-mortem might be useful:

- It can confirm or change a diagnosis.
- It may find conditions that have not been diagnosed before.
- It can exclude some common causes of death, such as medical problems with your baby, infections or growth restrictions.
- It can help assess the chances of problems happening again in a future pregnancy.
- It can help provide information about a genetic condition.
- It may tell you the gender of your baby.

Even if your medical team already suspect the cause of your baby's death, a post-mortem might confirm this.

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

Sophie



Ending a pregnancy for medical reasons

A post-mortem examination may be helpful if you have had to end a pregnancy for medical reasons, even if there were detailed scans and tests done during pregnancy. Whether or not a post-mortem is possible will depend on the stage of pregnancy and the method used to end the pregnancy. It is best to discuss this with the hospital staff as they can advise you on your options.

Future pregnancies

A post-mortem examination may discover if there was a problem that could affect any future pregnancies. Whether a post-mortem examination confirms an earlier diagnosis or finds new information, it can help the doctors understand your baby's condition or cause of death and can assess the chances of the same problems happening in a future pregnancy.

Limited and Complete examinations

You can choose to have a complete or a limited post-mortem examination on your baby. Your placenta can be part of the post-mortem. Each option will give different amounts and kinds of information.

A complete post-mortem measures, weighs and examines all the internal organs in detail to find out why the baby died. The baby's face, arms, legs, hands and feet are not usually affected. After the examination, your baby's body is carefully restored, as following an operation.

If you do not want a complete post-mortem, you can choose to have a limited examination of certain organs, skin samples, or an external examination of your baby.

You can have an examination of your placenta. This can provide extremely valuable information. During this examination, samples are taken for study under a microscope. Hospitals do not have to ask for consent to examine your placenta but should inform you if they intend to do this.

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

Does a post-mortem examination include genetic testing?

With your consent, as part of a post-mortem examination, a piece of tissue about the size of a postage stamp or a blood sample can be taken which can then be stored and/or sent to test for conditions in your baby's DNA, also known as genetic testing. Any samples stored can be sent for testing in the future and can help provide information for future pregnancies.

In England, Wales and Northern Ireland human tissue samples can be stored with your consent only. In Scotland, samples automatically form part of the medical record.



Genetic testing may be especially useful if your baby had a condition relating to how cells in his or her body were formed or if the doctors think that you or your partner carry a genetic disorder.

If you think you may have another baby in the future, genetic testing may be particularly useful for assessing the risk of the same thing happening again. Depending on when your baby died, genetic testing may also be able to confirm their gender.

When is a post-mortem obligatory?

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). The coroner can order a post-mortem without parental consent, though this does not happen in all cases. In Northern Ireland, the coroner may also order a post-mortem when a baby has died before birth and the cause of death is uncertain. There is more information below.

Coroner investigations

When a newborn dies the hospital must, by law, inform the coroner. In Northern Ireland stillbirths and neonatal deaths must be reported to the coroner.

It is not common for a coroner to open an inquest into the death of a newborn in hospital but if they do, they may ask for a post-mortem.

If the coroner is concerned about the circumstances of the baby's death being suspicious, they will open an investigation and then possibly an inquest, which is a fact-finding inquiry around a death. The results may not be ready for up to 12 weeks, and sometimes may take even longer than this.

If there is an inquest, a baby's parents will be given the details of when and where it will take place. You may be called in as a witness, in which case you must attend. There may be healthcare professionals called in as witnesses too. You can ask any questions you have at the inquest.

Once all investigations are over, the coroner will inform the Registrar of Births and Deaths. You will then be able to have the certificates that you need to organise your baby's funeral.

2. Reviews of care

Another process for trying to understand why your baby died is a review of the care that mother and baby received. This includes care during pregnancy, during labour or after birth. This is a part of standard NHS care and all baby deaths should be reviewed.

There are different types of review

- There should be a hospital review of care for all babies who die after 22 weeks of pregnancy, regardless of what may be the cause of death. In England, Wales and Scotland this should follow a review process called the Perinatal Mortality Review Tool (PMRT)
- If it is thought something may have gone wrong with the quality of NHS care, the hospital should carry out a Serious Incident Investigation (SII)
- In England, an external body called the Healthcare Safety Investigation Branch (HSIB) will carry out an investigation for babies born at 37 weeks or later.

Hospital reviews

The death of a baby before or shortly after birth should always be reviewed by the hospital to understand what happened. A review should offer to support you and other members of your family to understand why your baby died. It could also help to prevent other babies from dying from the same cause. In the weeks after your baby died, the hospital will hold a review meeting.

The review meeting will:

- Try to understand what happened and why your baby died.
- Answer any questions you may have.
- Look at medical records and test results, including a post- mortem if you have one.
- Talk to staff involved.
- Look at the guidance staff follow in similar cases.

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



Your thoughts, feelings and questions are important. Before you leave hospital, staff should inform you about next steps and offer the chance to ask any questions about your care then or in future. To support you in doing this, the hospital should provide you with a contact person called a 'key review contact'. Your key review contact will:

- Call you within 10 days of you going home to inform you again about the review process.
- Ask if you would like to ask any questions or share your concerns with the review team.
- Give you choices about how you might contribute to the review, either in person, online or via telephone or email.

Keeping you informed during a review

It can take many weeks to gather all the information required for a hospital review process. This may feel like a long time to wait and if you would like to meet with a senior doctor before the review takes place, you can arrange this through your review contact.

Once the review is completed, a report is written and you will be invited to discuss the results. The hospital can also send you the review report by post or email if you prefer. For more information about the PMRT hospital review process go to:

[www.npeu.ox.ac.uk/pmrt/information-for-bereaved-parents.](http://www.npeu.ox.ac.uk/pmrt/information-for-bereaved-parents)

Other investigations

If something has gone wrong with care that may have caused your baby's death, an urgent investigation called an NHS Serious Incident Investigation (SII) is begun. This is so that the NHS can be open and honest with families about any mistakes and learn from poor care. This learning could prevent future harm or deaths. The NHS should take the views of families into account when deciding whether or not an SII is needed.

For more information go to:

www.hsib.org.uk/maternity/information-families/

Feelings around reviews

It can be difficult to go through a review and discuss details of why your baby died. You may find that some days you are keen to know what happened, but feel anxious as you approach the time when the results are going to be shared with you. You may worry about hearing details or medical facts that are hard to understand or feel angry with the people who cared for you. It is important that you look after yourself during this time.

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

