

Understanding
why your
baby died

Some parents are keen to know why their baby has died. Others may feel unsure. 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.

Post-mortem examinations

It can be very hard to think about a post-mortem examination for your baby. If you think you might want a post-mortem examination and are feeling unsure about it, you can discuss this with the staff at the hospital. 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 clinical investigation to help understand any factors that might have contributed to your baby's death. You will usually have the opportunity to spend time with your baby in hospital or to take them home. The hospital staff will give you advice on how to keep your baby cool so that their condition does not deteriorate. You may be able to borrow a cold cot or unit from the hospital, or a nearby children's hospice, to take home.

Usually, a senior health professional will talk with you about the option of having a post-mortem examination. Unless it has been ordered by a coroner (England, Wales and Northern Ireland) or a procurator fiscal (Scotland), a post-mortem examination cannot be done without your consent or authorisation¹.

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".

Your baby will be examined by a specialist doctor who will try to find out the reason for your baby's death. Keepsakes such as soft toys and blankets can be included with your baby, and your baby will be well looked after and treated with respect. You will be able to see your baby until the time of the post-mortem and, if you wish, after it has been completed. Some parents choose to say goodbye to their baby in advance of the post-mortem.

Ask the staff if you have any questions about the post-mortem.

You may also like to look at this animation for parents:

www.sands-lothians.org.uk/post-mortem-animation.

When should a post-mortem take place?

A post-mortem will usually provide the most information if carried out within a few days of the 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 be carried out.

What might a post-mortem examination tell you?

A post-mortem examination of your baby and of the placenta (afterbirth) 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 questions and rule out some possible causes of death. Here are a few examples of why a post-mortem might be useful:

- It can confirm or change an existing diagnosis.
- It may identify conditions that have not been diagnosed previously.
- 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 recurring in a future pregnancy.
- It can help provide information about a genetic condition.
- It may tell you the gender of the baby.

If you already know the immediate cause of your baby's death, a post-mortem might confirm this or highlight additional problems that might be useful for you to know for a possible future pregnancy.

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.

“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

When is a post-mortem compulsory?

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). In Northern Ireland, the coroner may order a post-mortem even when a baby has died before birth and the cause of death is uncertain. In these cases, the coroner usually agrees that the doctor can issue a stillbirth certificate.

Once the coroner or procurator fiscal decides that no further examinations are required, they will inform the registrar. You will

then be able to obtain the certificates that you need to organise your baby's funeral. You will be told the results of the post-mortem examination but these may not be ready for up to 12 weeks.

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 though detailed scans and diagnostic tests may have been done during pregnancy, a post-mortem examination, following the ending of a pregnancy for medical reasons, might find additional information. 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.

Limited examinations

If you do not want a full post-mortem, you could choose to have a limited examination of certain organs, skin samples, or an external examination of your baby. You might also decide to 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.

Future pregnancies

A post-mortem examination may also discover whether 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.

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 for 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 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 an anomaly or if the doctors think that your baby may have an underlying genetic disorder. If your baby is smaller than expected and there is no other explanation for their death, a genetic test can sometimes explain what happened. 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.

Many parents find post-mortems helpful. The information they gain may help them come to terms with the death of their baby.

Reviews

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, and when the baby died after birth. This is a part of standard NHS care and all baby deaths should be reviewed.

There are different types of review:

- Hospital review: The Perinatal Mortality Review Tool (PMRT) in England, Wales and Scotland is a review of your care that should be carried out for all babies who die after 22 weeks gestation.
- NHS Serious Incident Investigation (SII) when it is thought something may have gone wrong with the quality of NHS care.
- Health Safety Investigation Branch (HSIB) investigation (England only) for babies born at 37 weeks or later.
- Coroner's (procurator fiscal in Scotland) inquest, when there is concern about the circumstances of the death.

Hospital reviews

The death of a baby before or shortly after birth should always be reviewed by the hospital to understand what happened. This review is designed 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 of 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 or concerns you may have.
- Look at medical records and test results, including a post-mortem, if you have consented to one.
- Talk to staff involved.
- Look at guidance and policies.

The review may also provide the hospital with information that it needs to change the way that staff work. It could also reveal that the care provided was not at fault, but there were other contributory factors. Your thoughts, feelings and questions are important. Before you leave hospital, staff should inform you about the review process and ask you if you would like to share your experience or ask any questions about your care. To support you in doing this, the hospital should provide you with a key review contact.



Your key review contact will:

- Call you within 10 days of your 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

It can take many weeks to gather all the information required for a review process. We understand that this is a long time to wait and if you would like to meet with a consultant before the review takes place, you can arrange this through your review contact. The hospital may, however, not have any further information at that time about why your baby died. Once the review report has been completed, a consultant can discuss its findings with you. 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.

Other investigations

If something has gone wrong 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. Deaths in maternity and neonatal care that trigger an SII will usually include a death where the mother arrived in labour close to her due date but the baby subsequently and unexpectedly died either during labour, at birth, or shortly after.

In England, if your baby died at term (37 weeks or more) due to an unexpected event, it may be investigated by the Healthcare Safety Investigation Branch (HSIB). Like an NHS SII, it will carry out an investigation if your baby died during or after delivery because something went wrong in labour. The difference is that HSIB investigations are wholly independent and not run by staff from the Trust where the baby was born or died. An NHS hospital review will still be carried out even if an HSIB investigation is also being done, but any hospital review will not conclude its findings until the HSIB has finalised its report. For more information go to: www.hsib.org.uk/maternity.

When a baby dies as a newborn the hospital must, by law, inform the coroner (or procurator fiscal in Scotland). It is their job to ascertain where and when the baby died. They can establish the cause of death and determine whether it is thought to be “unnatural”. 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. The coroner may then write a report about any specific concerns.

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 require a post-mortem. In this instance, parents are not asked for their consent, but the coroner’s office will keep them informed about any decisions that are made.

As parents, you will be given the details of when and where the inquest will take place. You may be called in as a witness, in which case you must attend the inquest. You can ask any questions you have at the inquest. There may be other professionals who are asked to be witnesses.

In Northern Ireland all stillbirths as well as neonatal deaths must be reported to the coroner.