

# **Understanding why your baby died**

## Finding out why your baby died

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

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

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

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

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

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

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

This booklet explains the investigations and reviews in more detail.

## Post-mortem investigation

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

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

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

## Placental examination

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

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



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<sup>1</sup> "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".

## What might a post-mortem investigation tell you?

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

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

## Different levels of post-mortem

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

There are various levels of post-mortem

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

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

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

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

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

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

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

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

Bereaved mother

## When should a post-mortem take place?

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

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

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

Sophie

## **Does a post-mortem investigation include taking tissue samples?**

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

## **Does a post-mortem investigation include genetic testing?**

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

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

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

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



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

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

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

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

## Reviews and investigations of care: A hospital review

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

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

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

Once you have returned home, your key contact will:

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

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

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

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

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



## Keeping you informed during a review

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

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

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

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

## Hospital and independent investigations of your care

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

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

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

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

## Independent investigations

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

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

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

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

## Feelings around reviews and investigations

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

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

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

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

