



Understanding why your baby died



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About this booklet

We are very sorry your baby has died.



You might have some questions about why this has happened.



This booklet tells you what doctors at the hospital will do to understand why your baby died.



Your worries and questions about why your baby died are really important.
The hospital must listen to you.



This booklet is to help you understand what to expect and how to be involved.



Understanding why your baby died

Some parents want to know why their baby died and some parents don't.

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2

There are 2 things hospitals can do to try to find out why it happened:



1. A review of your care

This is when doctors and midwives look at how staff cared for you and your baby.

They check to see if the care you got was the right care for you.



A review happens for every baby who dies after 22 weeks of pregnancy.

It also happens for babies who die soon after they are born.



2. A post-mortem

This is when doctors look more closely at your baby's body.



A post-mortem usually only happens if you agree.

We tell you more about a post-mortem on **page 13 to 19**.

1. A review of your care



A **review** means looking at the care you and your baby got from doctors, nurses and midwives:



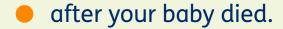
when you were pregnant



 when you were having your baby.
 Even if that was at home or somewhere else

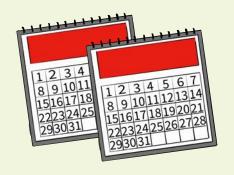


 after your baby was born, if they lived for a short time





Staff should tell you about this review before you leave hospital.



About the review

The review happens in the weeks and months after your baby died.



It is done by a review team. The team has doctors, midwives and nurses in it. Some of the team might have been involved in your baby's care.



The team will:

 try to understand what happened and why your baby died



try to answer any questions you have



 look at any test results from you and your baby



talk to any staff who looked after you



check the hospital gave you the right care.

What a review means for you



Your thoughts and feelings about your care are very important.

The review team must listen to you.



You might know things that the hospital doesn't know.

This could be things about your pregnancy or your baby before they died.



Some parents have lots of questions about what happened to their baby.

Some parents only have a few questions.



You might have thoughts or questions about:

things you were not happy about



 things you do not understand about your care



You have the right to ask any questions and have them answered.

Your key contact



Before you leave the hospital, staff will give you the name of a **key contact**. This is someone for you to talk to about the review.

Ask who this person is if you are not sure.



Your key contact will:

 let you know what is happening with the review



 ask if you have any questions you would like the review team to answer



 ask if you have any thoughts or feelings you want to share with the review team.



It can take weeks or months to get all the information for the review.



Your key contact should keep in touch with you and let you know what is happening.

You can contact them too if you have any questions or want to talk to them.

Sharing the review with you



When the review is finished, a doctor will write a letter or a report.

It will try to explain what happened and why your baby died.



The review team must be open and honest about what they found out.

The letter or report should answer any questions you have asked.



The doctor will send you a copy of the letter or report by post or email.

You can decide if you want a letter or a report.



You can have a meeting with the hospital to talk about what the letter or report says.

You can have a family member, friend or someone you trust at this meeting.



If you don't agree with what the letter or report says, you should tell your key contact.

They should tell the doctor that you do not agree with what it says.



If you are still not happy with what staff say, we can give you information about what else you can do.

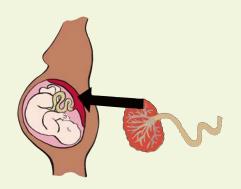
We tell you how to contact us on page 26.

2. A post-mortem



A **post-mortem** is when a doctor looks at your baby's body to find out why your baby died.

Sometimes a post-mortem is helpful.



They should also test your **placenta**. The **placenta** helps your baby to grow.

While your baby is in your tummy, they are attached to a placenta.



Looking at your placenta can help doctors work out why your baby died.



You might find it upsetting to think about having a post-mortem for your baby.



You can watch a short video online about post-mortems. The video tells you what happens in a way that is easy to understand:

www.sands.org.uk/professionals/ professional-resources/held-in-ourhearts-parent-parent-post-mortemauthorisation



Agreeing to a post-mortem

A doctor or midwife will ask if you would like a post-mortem to happen.



They will explain what this means.
They will only do a post-mortem if you want one.



If you do want a post-mortem, they will ask you to sign a form saying you agree.



If you are unsure about having a post-mortem, you can talk to:

 doctors and midwives at the hospital



your friends and family



 your religious or cultural leaders, if these are important to you



the Sands Helpline. You can phone us at:

0808 164 3332



If you agree to a post-mortem, it is ok to change your mind.



But you only have a short time to change your mind. You must let the hospital know within 2 days.



When a post-mortem happens

Post-mortems need to be done a few days after your baby has died.



Staff at the hospital will tell you how long it will take to do the post-mortem.



If you need to have a funeral for your baby quickly, please tell the hospital staff.



After a post-mortem

The hospital staff will ask where you want your baby's body to go after the post-mortem.



You might ask a **funeral director** to take your baby to a funeral home.

A **funeral director** is someone who can help you to arrange a funeral.



Or you might want to take your baby home for a short time before the funeral.

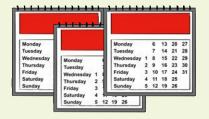


You can talk to hospital staff about what you want to do.

Post-mortem report



You will get a report of the post-mortem. It will tell you what the doctors found out.



It can take a long time to get the post-mortem report. It can take at least 3 months.



Staff will tell you how long it might take.

About the coroner or procurator fiscal



When a baby dies after being born and doctors don't know why or are worried about why the baby died, the law says the hospital must:



 tell the coroner if the hospital is in England, Wales or Northern Ireland.

or



 tell the procurator fiscal if the hospital is Scotland.



The **coroner** and **procurator fiscal** are a type of special judge. They look into why people have died.



In Northern Ireland the law is a little bit different. It says hospitals must tell the coroner if a baby dies before they are born, if doctors don't know why it has happened



The coroner or procurator fiscal decide if an investigation needs to happen and what type of **investigation** it should be.

An **investigation** is a bit more serious than a review. It is when doctors look closely at what went wrong and why it went wrong.



Sometimes, the coroner or procurator fiscal might say there has to be a post-mortem on your baby.



This is because they are worried about why your baby has died and want more information. This does not happen very often.



If there has to be a post-mortem, the coroner or procurator fiscal will speak to you about it.



They can say there has to be a post-mortem, even if you do not agree.



The coroner or procurator fiscal will write a report about what they find out. They will share this report with you.



It might take a long time to get this report. The coroner should let you know what's happening and how long it will take.



If you find it hard to understand the report, you can ask them to write it so that it is easier to understand.

Patient Safety Investigation



If the hospital did not give you the right care they will do an investigation.



In England and Wales the investigation is called a **Patient Safety Incident Investigation**.



In Northern Ireland the investigation is called a **Serious Adverse Incident Investigation**.



In Scotland it is called a **Serious Adverse Event Review**.



You have a right to be involved in the investigation. You can tell the hospital your thoughts and feelings about your care.



If the investigation finds the hospital did not give you the right care, they must be honest and open with you about it.

Sharing what went wrong means staff can change how they give care to other families in the future.



This might stop the same thing from happening to other families and babies.

Other investigations that only happen in England



If your baby died during or after labour and you were more than 37 weeks pregnant, there might be an **independent** investigation.



Independent means people who do not work for the hospital will look at what happened.



This type of investigation will only happen if you want it to. Your key contact will ask you what you want to happen.



Independent investigations and hospital reviews can sometimes happen at the same time.



Contact us

If you need help and support you can contact us.



Phone:

0808 164 3332



Email:

helpline@sands.org.uk



Online:

www.sands.community