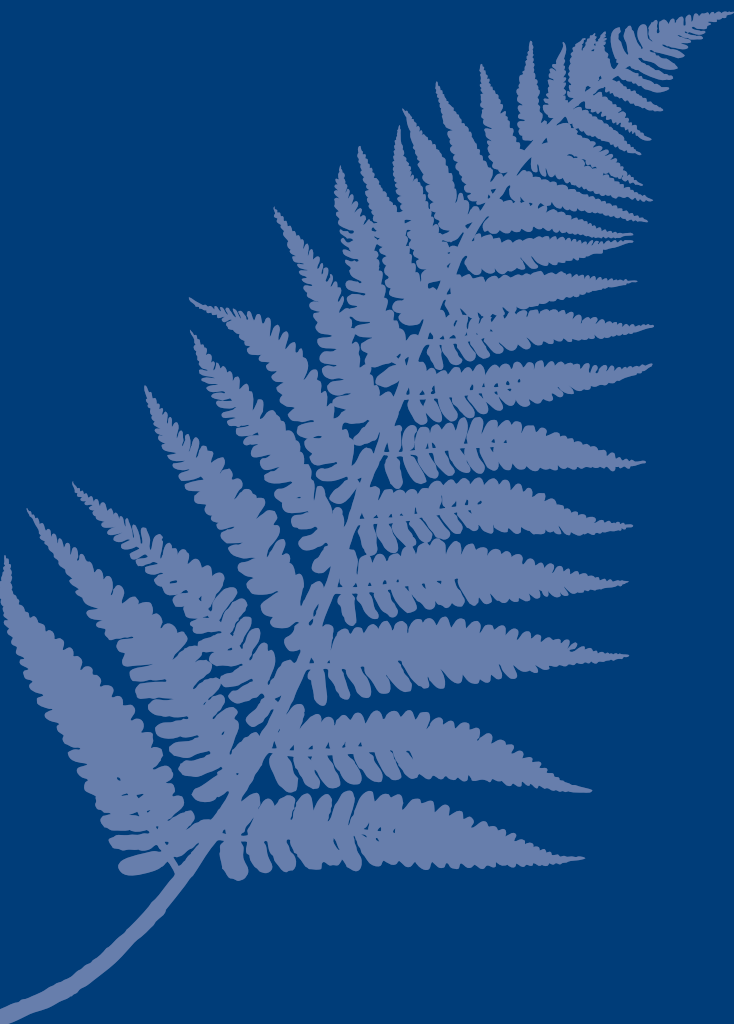


# Deciding about a post mortem examination

## Information for parents



Second edition © Sands 2016

No part of this booklet may be reproduced in whole or part, in any form or by any electronic or mechanical means without the prior written permission from Sands. All rights reserved.

Whilst every care is taken providing information, please note that it is of general nature and that readers should seek professional or expert advice as appropriate to their specific circumstance. Sands does not accept any liability, including liability for any error or omission.

All information is correct at the time of going to print: May 2016.

**Sands**

Victoria Charity Centre  
11 Belgrave Road  
London, SW1V 1RB

**t:** 020 7436 7940

**e:** [info@uk-sands.org](mailto:info@uk-sands.org)

**w:** [www.uk-sands.org](http://www.uk-sands.org)

**Helpline** 020 7436 5881 [helpline@uk-sands.org](mailto:helpline@uk-sands.org)

**Sands message boards** [www.sandsforum.org](http://www.sandsforum.org)

**Sands publications** 0845 6520 445 or order online at [www.uk-sands.org/shop](http://www.uk-sands.org/shop)

Registered as a charity in England and Wales (299679) and in Scotland (SC042789)

Text written by Judith Schott and Alix Henley

We are grateful to the many parents and health professionals across the United Kingdom who have helped with the development of this booklet.

---

**“Every parent should have the option of a post mortem when their baby dies.”**



# Contents

<b>Introduction</b>	<b>06</b>
<b>Deciding about a post mortem</b>	<b>07</b>
What is a post mortem?	07
Making a decision	07
Coroner and procurator fiscal post mortems	08
What might a post mortem tell you?	09
Are there different kinds of post mortem?	10
Would a post mortem include genetic testing?	13
Where and when would a post mortem be done and how long would it take?	14
Who else would be present at a post mortem?	14
What if a pathologist recommends special examination of an organ?	15
When do I have to decide?	16
If I decide to have a post mortem, what happens next?	16

<b>Before and after a post mortem</b>	<b>17</b>
Would I be able to see my baby before a post mortem?	17
Could I take my baby out of the hospital before a post mortem?	17
Could I see my baby after a post mortem?	18
When would I get the post mortem results?	19
What usually happens to tissue samples after a post mortem?	20
How long are medical records kept?	23
<b>Professional training and research</b>	<b>24</b>
Training professionals	24
Research to try to prevent future deaths	25
<b>Some specialist words</b>	<b>26</b>
<b>More detail about a complete post mortem</b>	<b>29</b>
<b>More information and support</b>	<b>33</b>
How Sands can help	34
Sands support resources	35
<b>Useful addresses</b>	<b>36</b>
<b>Notes</b>	<b>38</b>

# Introduction

We are very sorry that your baby has died. We know that this is a very distressing and difficult time, and that it is not easy to decide about a post mortem examination.

We hope you will find this booklet helpful. It explains what a post mortem is and the possible benefits of having one. It also describes the choices you can make so that you can decide what is right for you. It is based on what a number of bereaved parents have told us that they wanted to know.

The information is organised as questions, so that you can look up the things you want to know and don't have to read the whole booklet. You can pick just the questions that you want answers to.

Some of the practical details about timing and other arrangements described in this booklet vary a good deal across the United Kingdom. You may get written information with details of local arrangements from your own hospital. If you have any more questions, please ask the person who discusses the post mortem with you.

Specialist words that may be unfamiliar are in **bold type** the first time they appear, and are explained on page 24 at the end of this booklet.

# Deciding about a post mortem

## What is a post mortem?

A post mortem (also called an autopsy) is the medical examination of a body after death. Babies are examined by a **perinatal** or a paediatric **pathologist**, a doctor who specialises in identifying conditions that affect babies, and who examines babies to find out why they died.

A senior doctor, midwife, nurse or other health professional will ask if you want to consider a post mortem. Unless it has been ordered by a **coroner** or a **procurator fiscal** (see page 8), a post mortem cannot be done without your **consent** or **authorisation**. (“Consent” is the legal term used in England, Wales and Northern Ireland. “Authorisation” is the legal term used in Scotland. For simplicity, we use “consent” in most of this booklet.)

If you decide to have a post mortem, you can be confident that the staff will take great care of your baby at all times.

## Making a decision

Some parents are sure from the beginning that they want a post mortem, but others may not be sure. It is your decision (except in a coroner’s or procurator fiscal’s case, see page 8).

If you think you might want a post mortem but have questions or worries, the person who discusses the post mortem with you should be able to answer them for you. Please say if you have any special wishes or concerns.

Before you decide about a post mortem, you may want to take some time to think it over, to talk to a family member or friend, to someone of your own religion, or to another doctor, midwife or nurse. You may want to talk to the pathologist or to one of his or her staff. You might also find it helpful to ring the Sands Helpline to talk through your decision – please see the back of this booklet for contact details.

If you are sure that you don't want a post mortem, please say so. However, sometimes parents say "no" when first asked, and change their minds when they have had more time to think. So you may find that staff ask you a second time just to be sure.

---

### **Coroner and procurator fiscal post mortems**

Occasionally a coroner, or in Scotland a procurator fiscal, will order a complete post mortem to find out why a baby has died. In this situation the post mortem is required by law and you will not be asked for your consent or authorisation. The coroner's or procurator fiscal's officer will contact you to explain the procedure, and to make sure you understand why the post mortem was ordered. You will be told the results of the post mortem. The way the post mortem is done is the same, so much of the information in this booklet will still be relevant.

---



## What might a post mortem tell you?

- ▶ **If your baby died before birth** A post mortem is likely to give important information. In stillbirths where there is a diagnosis, between 50% and 60% of post mortems confirm the diagnosis; between 10% and 30% provide new information which changes the diagnosis; and about 20% provide other important new information. Although a post mortem does not always find a definite cause for a stillbirth, it may tell you what did not cause it.
- ▶ **If your baby was born alive and then died** You may already know the immediate cause of your baby's death. However, a post mortem can still be useful. It may confirm the diagnosis that was made while your baby was alive, may discover additional problems, and may help to assess the usefulness of any treatment that your baby was given. One study of post mortems on babies born before 28 weeks found that 80% gave new information, and 28% changed the diagnosis.

Even if a post mortem does not give you any new information, it may confirm that, apart from the direct cause of death, there was nothing else wrong with your baby.

- ▶ **If you had a termination because of problems found during the pregnancy** A post mortem can be helpful if you have had to make the difficult and distressing decision to terminate a pregnancy because there was something seriously wrong with your baby.

Even though detailed scans and diagnostic tests are always done during pregnancy, at least 30% of post mortems following a termination find important new information. Whether a post mortem confirms an earlier diagnosis or finds new information, it can help the doctors understand your baby's condition and assess the chances of the same problems happening in a future pregnancy.

- ▶ **An examination of the placenta (afterbirth)** often gives very useful information, especially after a stillbirth. During this examination, samples are taken for study under the microscope; this can be valuable even if you have an external only examination (see page 12).

Sometimes a post mortem does not find a definite reason why the baby died. This can be extremely disappointing. But even if no definite cause is found, a post mortem may still answer some questions and rule out some possible causes. Finding out what did *not* cause the death of your baby is especially helpful if you think you may have another baby in the future; it could provide useful information to the doctors who would organise your care.

The results of a post mortem can also contribute to valuable research which may prevent more deaths in the future.

## Are there different kinds of post mortem?

*This section describes the main points of a post mortem. If you would like a more detailed description, please see page 30.*

There are three different kinds or levels: a complete post mortem, a limited post mortem or an external post mortem.

- ▶ **A complete post mortem** is the most thorough investigation and will give you the most information. If you think you may have another baby in the future and are worried that the problem might occur again, a complete post mortem is also the best way to try to find out; the results could help the doctors organise the right care for you.

The pathologist examines the outside of the body very carefully for any signs of abnormality, and then measures, weighs and examines all the internal **organs** in detail to try to find out why the baby died.

The placenta (afterbirth) is also examined if it is available. The pathologist takes small samples of **tissue** from the organs for examination under a microscope, before returning all the organs to the body. If the baby's organs are very small it may not be possible to take samples and the whole organ will be processed and examined under a microscope.

If you agree, genetic tests will usually be carried out on some tissue samples. Genetic testing is especially useful if your baby had an abnormality, even a very minor one, or if the doctors think that your baby may have an underlying genetic disorder (see page 13).

If you agree, the tissue samples, including those used for genetic testing, will be kept as part of the medical record: this means that they can be re-examined for more information if new tests or further information become available, or if you have more questions.

Note: Under Scottish law, tissue samples are automatically kept as part of the medical record (See also page 20).

The pathologist may examine the tissue samples and samples of body fluids, such as blood or urine, for infection and other possible problems. He or she usually takes x-rays and medical photographs. These photographs are specifically for medical diagnosis and are different from any photos of your baby that you or the ward staff might take. They will be kept as part of the medical record.

After the examination, the baby's body is carefully repaired in the same way as after an operation.

- ▶ **A limited post mortem** may give you some useful information, especially if it is known that your baby had a specific abnormality. It is unlikely to give you additional information about other problems or a possible underlying condition.

A limited post mortem is done in exactly the same way as a complete post mortem. The only difference is that you decide which internal organs or areas of the body will and will not be examined. If an ultrasound scan has shown abnormalities in a specific organ, you might want only that part of the body to be examined. There may also be parts of your baby's body you do not want examined.

If you are considering a limited post mortem, the person discussing it with you will tell you how useful it is likely to be in your baby's case. He or she may need to speak to the pathologist first to be sure.

- ▶ Both a **complete** and a **limited post mortem** are always done carefully and respectfully, in the same way as an operation. The baby's face, arms, legs, hands and feet are not usually affected. The marks of a post mortem are not usually visible when a baby is carefully wrapped in a blanket or fully clothed.
- ▶ **An external post mortem** may not give you any new information. If you are considering this option, the person discussing the post mortem with you will tell you if it is likely to be useful in your baby's case.

The pathologist examines the outside of the baby's body very carefully for any signs of abnormality, but does not examine any internal organs or take any tissue from them. The placenta (afterbirth) is also examined if it is available.

The pathologist also takes x-rays and medical photographs. These photographs are specifically for medical diagnosis and are different from any photos of your baby that you or the ward staff might take. They will be kept as part of the medical record.

If you consent, tissue from the placenta (afterbirth) and a small skin sample will be taken for genetic testing.

- ▶ If you choose an **external** or a **limited post mortem**, and the pathologist thinks that a more detailed examination would provide important information about why your baby died, you may be contacted to ask whether you would consider this.

## Would a post mortem include genetic testing?

Genetic testing is always recommended if the doctors think it will give useful information, but it can only be done if you give consent.

Genetic testing involves examining a baby's chromosomes (DNA). These can be extracted or grown from small samples of skin, tissue from an organ, and/or samples from the placenta (afterbirth). If you agree, these samples, or the DNA extracted from them, will be kept as part of the medical record so that further tests can be done if recommended by a specialist geneticist.

Genetic testing is especially useful if your baby had an abnormality, even a very minor one, 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 his or her death, a genetic test can sometimes explain what went wrong. If you think you may have another baby in the future, genetic testing can be particularly useful in assessing the risk of the same thing happening again. If your baby died early in the pregnancy, genetic testing may be able to confirm his or her sex.

If a genetic disorder is found, you will be able to discuss it and whether it might affect future pregnancies with the doctor who gives you the post mortem results. You may also be offered an appointment with a genetic counsellor. If the disorder or condition is inherited, you will need to consider whether to tell other family members.

## Where and when would a post mortem be done and how long would it take?

A post mortem is usually done the next working day after the baby is received in the mortuary. The baby is kept safely in the mortuary until the post mortem is completed.

Depending on the type of post mortem, and on where it is done, the examination of the body and the taking of samples is usually completed within a week. The baby can then be returned for the funeral.

However, many babies are transferred to a regional centre where post mortems are done by a specialist perinatal pathologist. This means that there may be a short delay until the baby is transferred back to the hospital where he or she was born, depending on how soon transport is arranged. The baby is taken there and back carefully and respectfully by a funeral director or by special transport organised by the hospital.

The person who discusses the post mortem with you will tell you where your baby's post mortem would be done, and when your baby is likely to be returned for the funeral.

## Who else would be present at a post mortem?

The pathologist is usually assisted by one or more **anatomical pathology technologists**. Post mortems may also be watched by trainee pathologists or other professionals who need to understand what happens at a post mortem, as part of their training. If you don't want anyone else to be present at the post mortem, tell the person who discusses the post mortem with you. Your wishes will be noted on the consent form.

## **What if a pathologist recommends special examination of an organ?**

Very rarely, a pathologist may recommend keeping an organ, usually the brain or the heart, for longer to enable much more detailed examination that will provide important new information, or to discuss the diagnosis with another specialist. In this case, it is sometimes necessary to keep the organ for a few weeks. This can only be done if the parents consent.

In most hospitals this is very rare so you will not be asked to consider it.

In a few hospitals, parents are routinely asked if they will consent to keeping an organ for longer. This is more likely if the post mortem would be done in a hospital that specialises in investigating a particular condition. It is also more likely when parents want to hold the funeral within a very short time, or if they request an urgent funeral for religious reasons, as there may not be time for a full examination of the organs before the funeral.

If you are not asked about keeping an organ for more detailed examination when you complete the post mortem consent form, it is very unlikely that it will be recommended later. However, if it is, someone from the hospital will contact you to discuss it. He or she will explain the reasons for the recommendation, tell you how long it is likely to take, and answer any questions. It will not be done without your consent. If you want the organ returned to your baby's body before the funeral, this would affect the timing of the funeral.

## **When do I have to decide?**

To get the most useful results, a post mortem should ideally be done within a few days of your baby's death. But it is also very important that you take the time you need to decide.

If, for religious reasons, you need to hold the funeral within 24 or 48 hours, please tell the person who discusses the post mortem with you straight away. They will speak to the pathologist to see if it could be completed in time. An urgent post mortem is not usually possible at weekends or bank holidays. It may also not be possible if there is no specialist perinatal pathologist locally and your baby would need to be transferred to another hospital for the post mortem (see page 14).

## **If I decide to have a post mortem, what happens next?**

If you decide to have a post mortem, you will be asked to sign a consent form or, in Scotland, an authorisation form. You will be offered a copy of the form to keep.

After you sign the form there is a short period – in most places 24 hours – during which you can change your mind about anything you have agreed to. You will be given details of the time limit and the person to contact if you change your mind. You can also phone this person if you have any further questions before the post mortem is due to begin. (The system in Scotland is slightly different and will be explained to you.)

If you have an urgent post mortem there will not usually be time to change your mind after you sign the consent or authorisation form.



# Before and after a post mortem

## **Would I be able to see my baby before a post mortem?**

If you decide to have a post mortem, you can see your baby at any time before it begins. If your baby needs to be taken to another hospital for the post mortem, you can see your baby until he or she is transferred.

Before a post mortem, some parents dress their baby or wrap him or her in a special blanket. They may add something special to be kept with their baby – for example, a small cuddly toy, a photograph of themselves or a religious item.

After a post mortem, the baby is dressed or wrapped in a blanket as he or she was before. The staff ensure that all special items stay with the baby.

## **Could I take my baby out of the hospital before a post mortem?**

If you decide to have a post mortem, you can still usually take your baby home or to a place outside the hospital that is important to you if you want. You cannot take your baby out of the hospital if a coroner or a procurator fiscal has ordered a post mortem (see page 8).

If your baby has been in the neonatal unit and has had catheters or a chest drain inserted, taking your baby out might move these tubes and could affect some of the findings of a post mortem. The person who discusses the post mortem with you will explain this so that you can decide what to do.

If you want to take your baby out of the hospital before the post mortem, you need to tell the staff. Many hospitals give parents a form to take with them that confirms their right to take their baby out. The staff should also give you information about keeping your baby cool. They will tell you when to bring your baby back and where to take him or her. It is important to bring your baby back to the hospital fairly quickly; a post mortem gives more information if it is done within a few days of the death and the body has been kept as cool as possible.

## **Could I see my baby after a post mortem?**

If you decide to have a post mortem, you can usually see your baby afterwards if you want to. This would usually be in a special quiet room in or near the hospital mortuary, or at the funeral director's.

Your baby's appearance will naturally have changed in the time that has passed since the death. The marks of a post mortem are not usually visible when a baby is carefully wrapped in a blanket or fully clothed. The person who discusses the post mortem with you can tell you more about what to expect.

If your baby is very fragile or very small, or died some time before the birth, you may be advised to say goodbye before the post mortem. If you have decided to delay the funeral because further examination of an organ or a specialist referral is recommended, you may also be advised to say goodbye before the post mortem.

## When would I get the post mortem results?

The time until the results are available varies a good deal between hospitals and also depends on the tests that are done. Some tests on tissue samples can take several weeks; a few special tests may take even longer. You should be given a hospital appointment to discuss the results within 6 to 12 weeks. The person who discusses the post mortem with you will be able to give you more definite information.

If your baby was stillborn or died in the maternity unit, the appointment to discuss the results will probably be with your **obstetric consultant** or another senior **obstetrician**. If your baby died in a **neonatal** or **paediatric** unit, the appointment will probably be with the consultant who looked after your baby or another senior **neonatologist** or **paediatrician**, as well as an obstetrician. It is a good idea to ring the consultant's secretary before the appointment, to make sure that you will not be asked to wait in the same area as pregnant women or women with their babies.

You may want to write down any questions you think of before the meeting. You may also want to take someone else with you. He or she may be able to remember more than you can about the discussion, and may be able to remind you later of things you may not have taken in.

The hospital doctor will give you either a copy of the full post mortem report or a summary. If you are given a summary but want a copy of the full report, please ask for one. The full report is usually also sent to the mother's GP.

It can be hard to take in all the information at the meeting at the hospital, and you may want to make an appointment with the GP to go through the results again and discuss what they mean.

## **What usually happens to tissue samples after a post mortem?**

As part of the post mortem examination, the tissue samples are placed in small blocks of paraffin wax (about the size of a small matchbox). This preserves them and enables very thin sections of tissue (ten times thinner than a human hair) to be cut. The sections are placed on glass slides and examined under a microscope.

Once the samples have been examined, they are usually kept – provided you agree to this – in the hospital's pathology department as part of the mother's or the baby's medical record. If genetic testing is done, samples of the baby's DNA will also be kept, with your consent, as part of the record. Sometimes tissue samples for genetic analysis, and also blood samples, will be frozen for analysis in the future rather than processed into wax blocks. Using frozen samples can give better results than using only samples that have been processed into blocks and slides.

If you don't want any tissue blocks and slides or frozen samples to be kept, they can either be disposed of by the hospital or returned to you.

Tissue that is not needed for examination is returned to the baby's body before the body is repaired, unless you have given consent for it to be used for research and education, or for quality control and audit.

*Under Scottish law, samples are automatically kept as part of the medical record. The options that follow are therefore not relevant in Scotland.*

▶ **If you consent to samples being kept as part of the medical record.**

Keeping samples for possible re-examination in the future is highly recommended.

If new information becomes available, or more sophisticated tests are developed, it may be possible to re-examine the samples to find out more about why your baby died. You might also want another pathologist to give a second opinion on the post mortem findings.

If you might consider having another baby in the future, keeping the samples also means that they can be re-examined if it might help to assess the risks of another baby being affected.

▶ **If you don't consent to samples being kept as part of the medical record.** In this case it will not be possible to review the diagnosis later.

You can ask the hospital either to dispose of the samples or to return them to you. This would usually be when all the tests have been completed, generally after three months or longer, though in some places they can be released earlier. Any frozen tissue samples are processed into blocks before release, so that they can be transported safely.

Some hospitals keep tissue blocks and slides and frozen samples for a year in case parents change their minds and decide that they can be kept for possible future examination. You can ask for this if you want.

### **Disposal by the hospital**

Most hospitals send blocks and slides to a specialist contractor for disposal, because most crematoriums will not accept blocks or slides for cremation.

## Returned to you

If you are considering having the samples returned to you, you need to think about what you would do with them.

- ▶ You could decide to delay the funeral until the samples are released and bury them with your baby.
- ▶ If you don't want to delay the funeral, it will not normally be possible to bury anything with your baby later. If the hospital has organised the funeral and your baby is buried in a shared grave, it will not be possible to re-open the grave. If your baby is buried in a single grave, you will need to get permission from the cemetery owner to re-open the grave and this may be expensive.
- ▶ As mentioned above, in most places blocks and slides cannot be cremated.

Sometimes parents who have the blocks and slides returned to them, later change their minds. You can return the blocks and slides to the hospital at any time. You can ask the hospital either to store them as part of the medical record, or to dispose of them.

**Note:** If the blocks and slides are kept as part of the medical record, you will be asked if they can also be examined to check the quality of hospital pathology services to ensure that high standards are being maintained.

## **How long are medical records kept?**

Medical records – including blocks and slides and any frozen tissue samples, if the parents have given consent for them to be kept as part of the medical record – must be kept for at least 25 years after the date of the baby's death.

Usually, a baby who died after birth has his or her own medical record; information about a baby who died before birth is kept as part of the mother's medical record. The baby's mother can write to the hospital at any time and ask to see the medical record. There will be a charge for copies of the documents.

# Professional training and research

*You may be asked if you will consent to material taken during the post mortem being used to train professionals or, occasionally, for research to try to prevent future deaths. This is entirely your decision. Nothing will be used unless you give your consent.*

## Training professionals

Training future doctors and other professionals, including specialist pathologists, to identify the different conditions that can affect babies is very important. Samples of tissue, x-rays and medical photographs, and information from post mortem reports are essential for this kind of training.

If you decide to have a post mortem, you may also be asked if you consent to material that was taken as part of the post mortem being used to train health professionals. When any material is used for training, names and all other identifying details are always removed first to protect confidentiality.

If you have agreed to an organ being kept for further detailed examination (see page 15), you may also be asked if you would consent to it being used for training. When the organ is no longer needed, it would be disposed of respectfully as required by the **Human Tissue Authority**.



## Research to try to prevent future deaths

Some hospitals do specialist research that may help to prevent more deaths in the future, or may help in the development of new treatments.

Depending on the hospital, you may be asked if you will consent to tissue samples and other items that were taken as part of the post mortem being kept and used for research. If you have agreed to an organ being kept for specialist examination (see page 15), you may be asked if you would consent to it being used for research when the pathologist has completed the post mortem.

All research must be approved by the relevant NHS local or multi-centre Research Ethics Committee. No research can be done without the parents' consent. Names and other identifying details are removed when material is used for research. When it is no longer needed, the material is disposed of respectfully as required by the law.

If you agree to some or all of the items that were taken as part of the post mortem being used for research, you can change your mind at any time in the future. If you do change your mind, please contact the hospital where your baby died and ask for the histopathology department.

**We hope that this booklet has helped you to make a decision about a post mortem for your baby. If you have any more questions, please ask the person who discusses the post mortem with you. You may also want to ring the Sands Helpline to talk to someone about your decision.**

# Some specialist words

**Anatomical pathology technologist (APT)** Professional staff who assist and support pathologists in conducting post mortem examinations, and who ensure dignity and respectful care in the mortuary.

**Authorisation** Agreement that something can be done. "Authorisation" is the legal term used in the Human Tissue (Scotland) Act 2006 which applies in Scotland. The equivalent term in England, Wales and Northern Ireland is "consent".

**Bereavement midwife** A midwife who specialises in the care and support of parents whose baby has died.

**Consent** Agreement that something can be done. "Consent" is the legal term used in the Human Tissue Act 2004 which applies in England, Wales and Northern Ireland. The equivalent term in Scotland is "authorisation".

**Consultant** A senior doctor who has completed all of his or her specialist training, and is ultimately responsible for the care of all the patients cared for by his or her team.

**Coroner** An independent legal official, either a doctor or lawyer, who is responsible for investigating deaths in particular situations.

**Human Tissue Authority (HTA)** A regulatory body set up by the government to ensure that the Human Tissue Act (passed in 2004) is put into practice. The HTA produces Codes of Practice with practical guidance on consent, post mortem examinations and the disposal of tissue and organs. It also inspects and licences all departments in England, Wales and Northern Ireland that do post mortems. Scotland has its own Human Tissue Act passed in 2006. The HTA's remit does not cover post mortems in Scotland.

**Incision** A cut in the skin to allow the internal organs to be examined. An incision is done in the same way as for an operation. When the post mortem is finished, the skin surfaces are carefully sewn together or joined with a special adhesive.

**Neonatal** The care of newborn babies.

**Neonatologist** A doctor who specialises in the care of newborn babies.

**Obstetric** The care of women during pregnancy and around childbirth.

**Obstetrician** A doctor who specialises in the care of women and their babies during pregnancy and birth.

**Organ** A part of the body composed of more than one tissue that forms a structural unit responsible for a particular function; for example, the heart, lungs, brain etc.

**Paediatric** The care of infants and children.

**Paediatrician** A doctor who specialises in the care of infants and children.

**Pathologist** A doctor who specialises in finding the cause of death. Perinatal and paediatric pathologists are doctors who specialise in identifying conditions that affect babies and who examine babies to find out why they died.

**Perinatal** The time around birth.

**Procurator fiscal** (Scottish) A legal officer who is responsible for investigating deaths in particular situations.

**Tissue** A collection of cells that have a particular function.



# More detail about a complete post mortem

*You may feel you already have enough information about a post mortem to make your decision. The following is for those parents who would like a bit more information about the examination process.*

A **complete post mortem** is the most thorough examination and gives the most information. If you think you may have another baby in the future and are worried that the problem might occur again, a complete post mortem is the best way to try to find out; the results could help the doctors organise the care you need.

A complete post mortem begins with a very careful external examination of the body for any signs of abnormality. The placenta (afterbirth) is also examined if it is available. The pathologist then makes an **incision** down the front of the baby's body so that the internal organs can be removed, measured, weighed and examined in detail to see if there are any abnormalities or signs of what was wrong. Another incision is made around the head so that the brain can be examined.

Some information can be obtained just by looking carefully at organs and tissues. However, often the only way to understand fully what happened is to examine them under a microscope.

For this, the pathologist takes small samples of tissue – usually a bit thicker but no larger than a postage stamp – from the organs. These are placed in small blocks of paraffin wax, about the size of a very small matchbox. The wax blocks preserve the tissue and make it possible to cut extremely thin slices or sections of tissue from them. Each section is ten times thinner than a human hair. The tissue sections are placed on glass slides and stained with special dyes, so that they can be examined under a microscope for abnormalities or signs of what went wrong.

If you agree, the blocks and slides will be kept as part of the medical record. This is so that they can be re-examined to try to find out more if new tests or new information become available, or if you have further questions.

If genetic testing is done, samples of the baby's DNA will also be kept, with your consent, as part of the record. Sometimes tissue samples for genetic analysis, and also blood samples, are frozen for analysis in the future rather than processed into wax blocks. Using frozen samples can give better results than using only samples that have been processed into blocks. Note: Under Scottish law, samples are automatically kept as part of the medical record and you will not be asked for your consent.

Certain organs, such as the brain and heart, may have to be specially prepared by immersing them in formalin before samples can be taken for examination under a microscope. This preparation usually takes 24 or 48 hours in the case of the heart; occasionally a little longer in the case of the brain.

The pathologist may also examine the tissue samples and samples of body fluids, such as blood or urine, for infection and other possible problems. He or she usually takes x-rays and medical photographs. These photographs are for medical diagnosis and are different from any photos of your baby that you or the ward staff might take. The photographs and x-rays are often discussed with other specialist doctors who may be able to explain what happened; for example, specialist paediatric radiologists who are more skilled at interpreting x-rays, or specialist geneticists who are more skilled at recognising some genetic abnormalities. The x-rays and medical photographs will be kept as part of the medical record and can be very useful if new information or new tests become available later and you want the diagnosis reviewed.

After the examination, the organs and the tissue that is not used for blocks or slides are put back into the baby's body, and the body is carefully repaired in the same way as after an operation.

Very rarely, doctors may recommend much more detailed examination of an organ in order to get a complete diagnosis, or may recommend asking another doctor for a specialist opinion. This could affect the timing of your baby's funeral. It cannot be done without your consent. For more about this see page 15.



# More information and support

Our booklet *Saying goodbye to your baby* covers the things that you may find helpful in the time immediately before and after your baby is born. It covers other things you may need to think about in the next few days and weeks, for example; going home from the hospital, a funeral, registering your baby's birth or stillbirth, employment rights and financial benefits, and the postnatal check-up. It also discusses how you may feel over the next few weeks and months, and suggests things that other parents have found helpful.

If the midwife or nurse looking after you doesn't have a copy of *Saying goodbye to your baby* to give you, you can order one from our website or by phone (see the back of this booklet for contact details).

# How Sands can help

Sands is a national charity offering information and emotional support when a baby dies before, during, or shortly after birth. We support anyone affected by the death of a baby for as long as it's needed.

At Sands there are people who understand what it's like, because many of us have been through this devastating experience ourselves.

You may not want anything from us right away. We are here to help whenever you feel you need it. That may be now or in a few weeks, months or even years.

As well as supporting mothers, fathers and same sex partners, we are also here to help other members of the family and the many other people who may be touched by a baby's death, including friends, colleagues and health care staff. All are welcome to contact us for support and information.

<b>Do you want to speak to someone on our helpline?</b>	<b>020 7436 5881</b>
<b>Do you want to email the Helpline for support?</b>	<b>helpline@uk-sands.org</b>
<b>Do you want to connect with others whose baby has died?</b>	<b>www.sandsforum.org</b>
<b>Do you want to find out about a Sands group near you?</b>	<b>helpline@uk-sands.org</b>
<b>Do you want to know about our other support booklets?</b>	<b>Please see page 35</b>
<b>Do you want to see what's on offer at our shop?</b>	<b>www.uk-sands.org/shop</b>
<b>Do you want to know more about what we do?</b>	<b>www.uk-sands.org</b>
<b>Do you want to make a donation or fundraise?</b>	<b>fundraising@uk-sands.org</b>
<b>Do you want to write to us?</b>	<b>Sands Victoria Charity Centre 11 Belgrave Road London, SW1V 1RB</b>

## **Sands support resources**

If you would like more information on any of the subjects we have mentioned, please see our current list of Sands booklets below. You can read or download copies of our booklets on the Support section of our website [www.uk-sands.org](http://www.uk-sands.org) or you can order copies from our online shop [www.uk-sands.org/shop](http://www.uk-sands.org/shop) or by calling 0845 6520 445.

### **Sands booklets**

*When a baby dies before labour begins*

*Saying goodbye to your baby*

*Deciding about a post mortem: information for parents*

*Deciding about a funeral for your baby*

*Mainly for fathers*

*Supporting children when a baby has died*

*Sexual relationships after the death of your baby*

*Information and support for grandparents*

*For family and friends: how you can help*

*Returning to work after the death of your baby*

*Information for employers: helping a bereaved parent return to work*

*Another pregnancy? After a late miscarriage, stillbirth or neonatal death*

*Long ago bereaved*

# Useful addresses

## Other charities that can offer support

### **ARC – Antenatal Results and Choices**

**[www.arc-uk.org](http://www.arc-uk.org)**

Provides non-directive support and information to parents before, during and after prenatal testing and following a termination for fetal anomaly.

**Helpline: 0845 077 2290 or 0207 713 7486** (for mobile phone users)

**Email: [info@arc-uk.org](mailto:info@arc-uk.org)**

### **Bliss - the special care baby charity**

**[www.bliss.org.uk](http://www.bliss.org.uk)**

Support, advice and information for families of babies in intensive care and special care, including bereaved families.

**Helpline: 0500 618 140 Email: [hello@bliss.org.uk](mailto:hello@bliss.org.uk)**

### **Child Bereavement UK**

**[www.childbereavement.org.uk](http://www.childbereavement.org.uk)**

Supporting families when a child dies and when a child is bereaved.

**Support and information: Freephone 0800 02 888 40 or 01494 568900**

**Email: [support@childbereavementuk.org](mailto:support@childbereavementuk.org)**

### **Miscarriage Association**

**[www.miscarriageassociation.org.uk](http://www.miscarriageassociation.org.uk)**

Support and information for those affected by pregnancy loss.

Network of support groups and telephone contacts throughout the UK.

**Helpline: 01924 200 799 Email: [info@miscarriageassociation.org.uk](mailto:info@miscarriageassociation.org.uk)**

### **TAMBA Bereavement Support Group**

**[www.tamba.org.uk/bsg](http://www.tamba.org.uk/bsg)**

Support for families who have lost one or more children from a multiple birth. (Part of the Twins and Multiple Births Association – TAMBA)

**Helpline: 0800 138 0509    Email: use the form on the website**

### **Winston's Wish**

**[www.winstonswish.org.uk](http://www.winstonswish.org.uk)**

Help and support for bereaved children and young people up to the age of 18.

**Helpline: 0845 203 0405    Email: [info@winstonswish.org.uk](mailto:info@winstonswish.org.uk)**

## **Regulators**

### **HTA - (Human Tissue Authority)**

**[www.hta.gov.uk](http://www.hta.gov.uk)**

Regulates and monitors organisations carrying out post mortems in England, Wales and Northern Ireland.

**Telephone: 020 7269 1900    Email: [enquiries@hta.gov.uk](mailto:enquiries@hta.gov.uk)**

# Notes



# About Sands

Sands, the stillbirth and neonatal death charity, was founded in 1978 by a small group of bereaved parents who were devastated by the death of their babies, and by the total lack of acknowledgement and understanding of the significance and impact of their loss.

Since that time, we have supported many thousands of families whose babies have died, offering emotional support, comfort and information. Today Sands operates throughout the UK and focuses on three main areas of work:

## **We support anyone affected by the death of a baby**

Bereavement support is at the core of everything we do. Some of the services that we offer include:

- ▶ Helpline for parents, families, carers and health professionals
- ▶ UK-wide network of support groups run by trained befrienders
- ▶ Online forum and message boards enabling bereaved families to connect with others
- ▶ Website and a wide range of booklets, books and other resources.

We depend on the extraordinary energies of our supporters to raise the vital funds that we need to deliver the wide range of services that we offer.

## **We work in partnership with health professionals to try to ensure that bereaved parents and families receive the best possible care**

We offer resources and a comprehensive programme of training, workshops and talks for health professionals that give practical guidance on how to meet parents' needs and provide good bereavement care.

## **We promote and fund research that could help to reduce the loss of babies' lives**

We believe many babies' deaths could be prevented with better care and information. We raise vital funds for research to understand why babies die and how to save lives. We also campaign to make addressing the tragedy of too many baby deaths a government priority nationally.

**If you would like any further information or support please contact us or visit our website.**

### **Support:**

t: 020 7436 5881

e: [helpline@uk-sands.org](mailto:helpline@uk-sands.org)

### **Enquiries:**

t: 020 7436 7940

e: [info@uk-sands.org](mailto:info@uk-sands.org)

### **Write to us:**

Victoria Charity Centre

11 Belgrave Road

London, SW1V 1RB

### **Website:**

[www.uk-sands.org](http://www.uk-sands.org)