The Royal Wolverhampton NHS Trust

Post Mortem Examination of a Baby: Information for Parents

Maternity

We are very sorry that your baby has died. Please accept our sincere condolences to you and your family. We understand that this is a very sad time for you and that it may be extremely difficult for you to think about any further examination of your baby. We hope that this booklet from New Cross Hospital will help you to understand the reasons for undertaking a post mortem examination, what is involved and its potential value. There is no right or wrong choice and your final decision may depend on a number of things including your own values and beliefs. It will hopefully help you to decide whether it is the right option for you.

Talking it over

You will probably have lots of questions - initially you can talk to the Doctor, Midwife or Nurse who was caring for your baby - if they do not know the answer to a question, they will know who else to ask. At New Cross Hospital we have Specialist Bereavement Midwives and Nurses who you can talk to and who will support you.

It can sometimes help to talk to other people about the decisions you have to make. Please remember the decision is ultimately yours. If possible, try to talk to your partner, family and friends. It may also be helpful to contact one of the organisations listed below. We want you to have as much information as you need to make your decision.

If you need any support with communication, for example you are hard of hearing please inform the person giving you this leaflet so that they can arrange this for you.

When you are ready a senior member of our team will ask you if you wish to think about having a post mortem examination. They will be able to talk you through your options too and answer any questions you may have. It is also helpful to read the SANDS Bereavement Support Book - there is a section called understanding why your baby died.

This section provides information regarding post mortem - it will help you to make an informed choice. If you have not been given the booklet and would like a copy please advise the midwife, nurse or doctor caring for you or you may wish to access this information using the following link: https://www.sands.org.uk/sands-bereavement-support-book

There are also details of support organisations at the back of this leaflet if you want to talk to them before you decide

The prevention of infection is a major priority in all healthcare and everyone has a part to play.

- **Please decontaminate your hands frequently for 20 seconds using soap and water or alcohol gel if available**
- **If you have symptoms of diarrhoea and/or vomiting, cough or other respiratory symptoms, a temperature or any loss of taste or smell please do not visit the hospital or any other care facility and seek advice from 111**
- **Keep the environment clean and tidy**
- **Let's work together to keep infections out of our hospitals and care homes.**

What is a post mortem?

A post mortem is a medical examination of a body which is carried out after someone has died. It is the final investigation to try and find out why your baby passed away. You will need to give your consent to have a hospital post mortem. An examination cannot be carried out without your agreement unless it is ordered by the Coroner (please see Coroner's Post Mortem information).

What information can a post mortem give?

A post mortem examination may help to give more information about why your baby died. It may not give a definite cause of death but it can rule out possible causes. Post mortems can also:

1. Confirm or change existing diagnosis
2. Identify conditions not previously diagnosed
3. Exclude common causes that could have caused your baby's death such as infection, medical conditions affecting your baby and growth restrictions
4. Provide information about genetic disorders
5. Help assess the chances of problems happening in any future pregnancies
6. Provide information to help mothers and babies in the future through research.

However, having a post mortem examination:

1. May not always give a specific cause of death
2. May delay funeral arrangements (delays can sometime be shortened by contacting the team at Birmingham Women's Hospital).

Who decides whether a post mortem examination should take place?

There are two types of post-mortem examination:

1. **Consented Hospital Post Mortem**
   If it is not necessary to refer your baby's/child's death to HM Coroner, the medical team may offer you the opportunity for a consented post-mortem examination.

   This can only be done with written consent. For stillborn babies regardless of gestational age, the mother must give this consent (although both parents should be involved, if possible). For a child, a person with parental responsibility can give consent or a child with the capacity to make the decision can give their consent before death.

2. **Coronor's Post Mortem**
   Sometimes after a baby's death doctors cannot immediately issue a death certificate and they are obliged to inform the coroner.

   Usually this occurs when the doctor is uncertain of the cause of death, the death has occurred suddenly, or soon after an operation. The coroner (a lawyer who investigates unknown or unexpected deaths) then decides whether it will be necessary to have a post mortem examination. If the coroner orders a post mortem this is required by law and you cannot legally refuse a Coroner's post mortem. If you have any objections these will be noted. The Coroner's officer will contact you to make sure you understand why this has been ordered and to discuss the process

Who will carry out the post mortem?

The postmortem is carried out by a doctor called a Perinatal Pathologist. This is a type of specialist doctor who studies disorders that affect babies and placentas to try and find out why a baby has died.

Where is the post mortem carried out?

Babies from New Cross Hospital will have their post mortem carried out off site. Firstly, they are transferred to Birmingham Women's Hospital, our nearest specialist unit. They will then decide where the examination will be carried out. Your baby may have to be transferred to Liverpool, Manchester, Sheffield or Cambridge. Your bereavement midwife / nurse will let you know the exact location when this has been decided.

When do I have to decide about a post mortem?

It is important that you are given time to make your decision and that you spend all the time you need with your baby. It may be helpful to talk it over with family members. Ideally this should be made before you leave the hospital. Once you have made your decision it would be helpful to inform the member of staff looking after you. Sometimes parents do change their minds and for that reason members of staff may ask you a second time. The hospital staff and your bereavement midwife will support you during this time.

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

If you decide to go ahead with a post mortem, you will be asked to sign a consent form. This will be done by one of our senior doctors or one of our bereavement midwives / senior midwives / bereavement nurses. You will be given a copy of the consent.

After signing it, you will be given a period of 48 hours in which you can change your mind. You will be given the number of the Pathology Office at Birmingham Women's Hospital and at the Swan Suite at New Cross to contact if this should be the case. You should also have a number for your bereavement midwife / nurse.

How soon will the post mortem be carried out?

When you are ready to say goodbye to your baby, he/she will be transferred to the Swan Suite at New Cross Hospital. It is usual practice for your baby to be transferred by our Funeral Directors to Birmingham Women's Hospital as soon as possible after 48 hours.

A member of staff from the Swan Suite will inform you when your baby has been returned to them if you have requested this. Throughout this process your baby will be cared for with respect and dignity by the Swan Suite staff and the perinatal pathology team at the hospital carrying out the examination.

Will the post mortem examination delay the funeral?

Arrangements for a funeral service can be made as soon as the post mortem is complete and your baby is returned to New Cross Hospital or in the case of a coroners post mortem to the families chosen funeral director.

If, because of your religion, it is necessary to have the funeral within a certain time, please inform the doctor or other health professional discussing the post mortem examination with you and the pathologist will try to accommodate this, if possible.

What are the different types of post mortem examination?

The amount of information that can come from a post mortem depends upon the type of post mortem chosen.

A Complete post mortem

This type of examination will give you the most information about why your baby may have died.

The baby will first be examined externally for any signs of abnormality. X-rays and medical photographs will be taken. Skin samples may be taken for genetic testing (changes in the chromosomes or DNA) and for an infection screen.

The Pathologist will then carry out an internal examination which involves removal and inspection of all the main organs of the body. This is done by careful incision on the front of the body and at the back of the head.

Small tissue samples are taken from each of the organs for examination.

These samples are placed on small blocks of paraffin to preserve them and from there very thin sections of tissue are cut and placed on glass slides for examination under a microscope.

Following examination, the baby's body is carefully and delicately restored. The organs are replaced into the baby's body and the skin repaired.

The placenta will also be examined.

All X-rays, photographs and tissue samples will be stored securely with your consent.

A Limited Post Mortem
This is done in the same way as a complete post mortem. The only difference is that you can decide which organs will and will not be examined.

For example, an ultra sound may have revealed an abnormality in a particular organ so you might want to have only that organ examined.

This type of examination will not give you as much information as a complete post mortem.

The placenta will be examined.

Great care and respect are taken during both complete and limited post mortems. The face, arms, legs hands and feet are not usually affected. Following the examination the marks made at post mortem are not normally visible and may be covered with clothes, blankets and a hat.

An External Post Mortem
Only the outside of the baby's body is examined carefully for any signs of abnormality. No internal organs are examined or removed.

X-rays and medical photographs are taken. If you agree small skin samples may be taken for genetic testing. The placenta is also examined.

This type of post mortem examination can only give us limited information.

The level of information obtained by a post mortem depends on how complete the examination is, with most information coming from the full post mortem.

Other information given as part of the post mortem consent process

What is genetic testing?

Genetic testing is not automatically carried out. It will be recommended if the pathologist thinks it is likely to provide useful information. An example may be if your baby is born with an abnormality, or a genetic disorder is suspected. It can also be useful if you think you might consider another pregnancy in the future as the testing can assess the risks of the same condition happening again. Genetic testing may also confirm the sex of your baby if your baby died early on in pregnancy.

It will not be done without your consent.

Genetic testing involves the examination of a baby's chromosomes (DNA) taken from a skin sample, tissue from an organ or from placental tissue.

If genetic testing is carried out on your baby, you will receive the results when you attend the follow up appointment with your Consultant. You may be referred to a genetic counsellor if appropriate.

What happens if the pathologist recommends special examination of an organ?

This practice is very unusual. Rarely a pathologist may recommend keeping an organ, usually the brain or heart, for detailed examination that may provide new information. This can take a few weeks and will not be done without your consent.

In this case you will be contacted by someone from the hospital who will explain the reasons for this and who will be able to answer any of your questions. If you wish to have the organ returned to the body before the funeral, this can delay the timing of the service.

What happens to the tissue samples?

Once the tissues have been examined, they are usually kept with your consent in the hospital pathology department at Birmingham as part of your baby's medical record. Keeping the samples for possible re-examination is recommended as new tests may become available which could provide more information as to why your baby died. If you consider having another baby in the future re- examination of the tissue may help to assess the risks of this baby being affected by the same condition.

If you do not want the samples to be kept you can either ask the hospital to dispose of them or have the samples returned to you. In the latter case this may take up to 3 months. If you do wish the samples to be returned to you for disposal, they can be buried with your baby as long as you are happy to have the funeral delayed for this purpose. The tissue samples cannot however be cremated. It is possible to change your mind and return the samples to the hospital for sensitive disposal.

Professional training & research

As part of the consent process, you will be asked if you are agree to the tissue samples being used for training purposes. Training future doctors and other health professionals to identify different conditions that can affect babies is very important. Whenever material such as tissue samples, medical photographs and X-rays as well as information from post mortems are used for training purposes, any identification is removed to protect confidentiality.

You will also be asked if you are happy to consent to the tissue samples being used for specialist research that may help to prevent deaths and develop new treatments. All research must be approved by a Research Ethics Committee.

All identification is removed to protect confidentiality. Please note if you do agree this does not mean that your information will be used.

Is the placenta examined?

Examination of the placenta is carried out as part of the post mortem procedure. Tissue samples are taken by the Pathologist and examined under a microscope. The examination can provide very useful information especially in the case of a stillbirth. The results will form part of the final post mortem report.

If you decide not to proceed with a post mortem for your baby, it is possible just to have the placenta examined.

Can I see my baby after the post mortem?

Yes, once the examination has been completed your baby will be transferred back from Birmingham Women's Hospital to the Swan Suite at New Cross Hospital. Appointments can be made at our Swan Suite by contacting them direct. You may also be able to visit your baby at your chosen Funeral Director when they are transferred if you prefer. In this case you should contact them directly to arrange this. Your bereavement midwife/nurse will support you with this.

What will my baby look like after the examination?

It is important to be aware that your baby's appearance may naturally have changed in the time that has passed since death. Some of these changes are not connected to the post mortem examination. There is small chance your child's skin may look different and that their lips and nails may look darker than before. You may also notice marks on your child's skin that look like bruises; they are not. These occur naturally where the blood settles when a heart stops beating. The post mortem will have been done in a very sensitive way and the marks from the examination are normally hidden by your child's clothes or hair, so you should not notice these while they are dressed. If your baby is very small and fragile or died some time before birth, you may be advised to say goodbye before the post mortem. Please discuss any concerns you may have with hospital staff and the bereavement midwives.

When will the results of the post mortem be available?

The perinatal pathologist will write a post mortem report and send it to your consultant. You will then be sent an appointment to discuss this with them. This is usually around 4 months of the examination being carried out. If the Coroner has requested the post mortem the results can take much longer. You can ask for more information on this from your local Coroner's Officer who will be able to give you more information regarding this.

It is an opportunity for you to ask any questions and it may be helpful to write them down before the meeting. If you require an interpreter at this meeting one will be booked for you by our secretarial team. It is also helpful to take someone with you to the appointment. The consultant will offer you a copy of the post mortem results at that time.

We hope this booklet has helped you to make a decision about a post mortem for your baby and has answered any questions you may have had. If there is anything you would like to talk about please ask the person who discusses the post mortem with you, your consultant or one of our bereavement midwives.

For further information please contact

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Useful contacts / support numbers:

SANDS (Stillbirth and Neonatal Death Charity)
Tel: 08081643332

Website: www.uk-sands.org Email: helpline@sands.org

You may wish to download the Sands Bereavement Support App: www.sands.org.uk/app

Sands Wolverhampton Support email: support.wolverhampton@sands.org.uk

Lily Mae foundation
Tel:01976535716

Website: www.lilymeafoundation.org

ARC Antenatal Results and Choices
National helpline is answered by trained staff Monday to Friday, 10.00am-5.30pm. Call 0207 713 7486.

Website: www.arc-uk.org

Bliss The Special Care Baby Charity
Email helpline: hello@bliss.org.uk

Website: www.bliss.org.uk

Child Bereavement UK
Helpline: 0800 028 8840

Email Support: support@childbereavementuk.org

Website: www.childbereavementuk.org

Miscarriage Association
Helpline 01924 200799 (Mon to Fri 09:00 to 16:00)

Website: www.miscarriageassociation.org.uk

Termination for medical reasons Mammas
Website: www.tfmrmammas.com

4louis
Website: www.4louis.co.uk

Mariposa Trust
Website: www.sayinggoodbye.org

Email: office@sayinggoodbye.org

Twins Trust Charity
Telephone: 01252 332 344

Website: www.twinstrust.org

West Midlands Perinatal Pathology Department
Birmingham Women's Hospital Tel: 0121 3358210

Specialist Midwives for Bereavement Services

carole.sadler@nhs.net
07814 249255 (mobile)

01902 695149 (direct line)

kirsty.malcolm3@nhs.net
07341 123002 (mobile)

01902 6951698 (direct line)

Specialist Neonatal Nurse for Bereavement Services
rwh-tr.nnufamilysupport@nhs.net

New Cross Hospital

07974 254129

01902 707239 (direct line)

Early Pregnancy Bereavement Nurse
Early Pregnancy Assessment Unit (D18) New Cross Hospital

Ext: 84606 Mob: 07917 398313

Email: emily.cooper46@nhs.net

Swan Suite (mortuary / chapel of rest)
New Cross Hospital: 01902 695516 (direct line)

New Cross Bereavement Office:

Telephone 01902 695091 (direct line)

New Cross Chaplaincy Department:

01902 695098 (direct line)

English

If you need information in another way like easy read or a different language please let us know.

If you need an interpreter or assistance please let us know.

Lithuanian

Jeigu norėtumėte, kad informacija jums būtų pateikta kitu būdu, pavyzdžiui, supaprastinta forma ar kita kalba, prašome mums apie tai pranešti.

Jeigu jums reikia vertėjo ar kitos pagalbos, prašome mums apie tai pranešti.

Polish

Jeżeli chcieliby Państwo otrzymać te informacje w innej postaci, na przykład w wersji łatwej do czytania lub w innym języku, prosimy powiedzieć nam o tym.

Prosimy poinformować nas również, jeżeli potrzebowaliby Państwo usługi tłumaczenia ustnego lub innej pomocy.

Punjabi

ਜੇ ਤੁਹਾਨੂੰ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਰੂਪ ਵਿਚ, ਜਿਵੇਂ ਪੜ੍ਹਨ ਵਿਚ ਆਸਾਨ ਰੂਪ ਜਾਂ ਕਿਸੇ ਦੂਜੀ ਭਾਸ਼ਾ ਵਿਚ, ਚਾਹੀਦੀ ਹੈ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਸਾਨੂੰ ਦੱਸੋ।

ਜੇ ਤੁਹਾਨੂੰ ਦੁਭਾਸ਼ੀਏ ਦੀ ਜਾਂ ਸਹਾਇਤਾ ਦੀ ਲੋੜ ਹੈ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਸਾਨੂੰ ਦੱਸੋ।

Romanian

Dacă aveți nevoie de informații în alt format, ca de exemplu caractere ușor de citit sau altă limbă, vă rugăm să ne informați.

Dacă aveți nevoie de un interpret sau de asistență, vă rugăm să ne informați.

Traditional Chinese

如果您需要以其他方式了解信息，如易读或其他语种，请告诉我们。

如果您需要口译人员或帮助，请告诉我们。

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