

Information for Parents Considering Giving Consent for a Post-mortem



What is a Post-Mortem?

The post-mortem will be carried out at Birmingham Women's Hospital.

A post-mortem (also known as an autopsy or necropsy) is a detailed examination made after death to try to find out why your baby died or, if abnormalities were detected by ultrasound, to confirm those findings and to identify any others that were not detected before delivery. The information it provides may help you understand what was wrong with your baby and is important for your doctors in counselling you about the likelihood of the same things happening again in a future pregnancy and what treatment or tests they can offer. The results of the post mortem will be discussed with you when you see your doctor (either obstetrician or paediatrician) in around 3-4 months.

Most information will be provided by a full post-mortem examination. This includes a careful external and internal examination, an x-ray of the body and photographs of any abnormalities. The internal examination is made through an incision on the front of the body and one on the back of the head. In addition, small pieces of tissue, a couple of millimeters in thickness, and up to postage stamp size, are taken for examination under the microscope. This is necessary because not all changes can be identified with the naked eye. The photographs and x-rays, the pieces of tissue taken for microscopic examination and the slides made from them will be kept indefinitely, in case it is necessary in the future to reconsider the diagnosis. Samples may also be taken to check the baby's chromosomes, look for infection and for storage in case a DNA test is required.

It is sometimes necessary to retain a whole organ for a more detailed examination. This is most often the brain, which cannot be fully examined unless it has been preserved first. Very occasionally, other organs, such as the heart need to be retained.

Preservation takes up to one week, but once the examination is complete the organ can be reunited with the body. This may mean a small delay in arranging the funeral, but allows the pathologist to get the maximum amount of information about your baby. A full examination of the brain is particularly important in cases where a brain abnormality has been identified on scan or when the cause of the baby's problems may lie in the brain. The need for organ retention can be discussed with the person explaining the post mortem to you or with the doctors in the pathology department at Birmingham Women's Hospital.

After the post mortem, the organs apart from the small samples taken for microscopic examination (referred to as tissue blocks and slides) are returned to the body and the skin is repaired by our expert technicians.

The Human Tissue Act (2004) is the law governing the performance of post mortem examinations and the storage of tissue from humans as well as the Human Tissue Regulations (2007). Birmingham Women's Hospital is Licensed by the Human Tissue Authority to perform post mortems and to store tissue. Our procedures, consent form and consent process is compliant with the requirements of the Human Tissue Act.

Post-Mortem Consent Form

1. Agreement to a post-mortem examination

If you wish a post-mortem to be carried out complete this section with the name of your baby.

2. Limiting the post mortem examination

You may decide to limit the extent of the examination. The pathology department recommends that a full examination be performed in order to provide you with as much information about your baby as possible.

The Post-Mortem Consent Form

However, if you decide to limit the examination to certain areas or to one of the other options, the pathologist will endeavor to obtain the maximum information that the extent of the examination allows. Please indicate which parts of the examination you **DO NOT** want to take place.

3. Agreement to use of blocks and slides for Medical Research and Education

Tissue blocks and slides are a valuable resource for teaching tomorrow's doctors and for medical research. If you agree to allow your baby's blocks and slides to be used for teaching and research, they will be treated with respect. They will still be available for diagnostic purposes for your family. These tissue samples will only be used for research projects that have been approved by an Independent Ethics Committee and the Research and Development Department at Birmingham Women's Hospital NHS Trust. Research will normally be into problems of pregnancy, prematurity or infancy.

You may agree to tissue blocks and slides being used for research and teaching, or you may prohibit any tissues or tissue from specific organs from being used for these reasons

4. If a research project requires additional tissue samples or whole organs, you will be asked to consent to this separately by a member of the research team.

Please note: not all babies in whom consent for these purposes is given will be suitable, but we will match them with relevant research or teaching programmes whenever possible.

4. Diagnostic Genetic Testing

In a proportion of post mortems it is necessary to take samples to check the baby's chromosomes or to test his/her DNA for a specific genetic condition. The results of these tests will help to provide an explanation for a baby's problems and will assist the doctors in providing you with a risk of the same problem affecting a future child. It may also allow an early genetic test in a future pregnancy.

5. Organ Retention

If it is decided by a Pathologist that they require specialist opinion regarding an organ, they will discuss this with you about retaining the organ until further results can be obtained and how you like the organ managed thereafter.

7. Other requests or concerns

If you have any requests or concerns that have not been covered elsewhere please put them here.

8. Signature

When you have completed the form, and are clear that you understand why the examination is being performed and what you have consented to, you should sign in the box. You can only consent to post mortem if you are the mother or father (or legal guardian) of the baby. If you are not clear about any aspect of the consent form or post mortem, please ask the person who is discussing the post mortem with you to explain further. He/she should also be able to provide you with further written information or can contact or put you in contact with the pathologist. Your signature should be witnessed by the member of staff taking consent or a friend.

9. Signature of a member of staff seeking consent

This should be completed by the member of staff taking your consent. Whom you can ask any questions about the Post Mortem examination.

If your symptoms or condition worsens, or if you are concerned about anything, please call your GP, 111, or 999.

Patient Experience

We know that being admitted to hospital can be a difficult and unsettling time for you and your loved ones. If you have any questions or concerns, please do speak with a member of staff on the ward or in the relevant department who will do their best to answer your questions and reassure you.

Feedback

Feedback is really important and useful to us – it can tell us where we are working well and where improvements can be made. There are lots of ways you can share your experience with us including completing our Friends and Family Test – cards are available and can be posted on all wards, departments and clinics at our hospitals. We value your comments and feedback and thank you for taking the time to share this with us.

Patient Advice and Liaison Service (PALS)

If you have any concerns or questions about your care, we advise you to talk with the nurse in charge or the department manager in the first instance as they are best placed to answer any questions or resolve concerns quickly. If the relevant member of staff is unable to help resolve your concern, you can contact the PALS Team. We offer informal help, advice or support about any aspect of hospital services & experiences.

Our PALS team will liaise with the various departments in our hospitals on your behalf, if you feel unable to do so, to resolve your problems and where appropriate refer to outside help.

If you are still unhappy you can contact the Complaints Department, who can investigate your concerns. You can make a complaint orally, electronically or in writing and we can advise and guide you through the complaints procedure.

How to contact PALS:

Telephone Patient Services: 0300 123 1732 or via email at: wah-tr.PET@nhs.net

Opening times:

The PALS telephone lines are open Monday to Thursday from 8.30am to 4.30pm and Friday: 8.30am to 4.00pm. Please be aware that a voicemail service is in use at busy times, but messages will be returned as quickly as possible.

If you are unable to understand this leaflet, please communicate with a member of staff.