



A GUIDE TO THE POST MORTEM EXAMINATION OF A BABY

Notes for Parents and Families

Who Have Lost a Baby

This document was produced by the Department of Cellular Pathology, Royal Victoria Infirmary, Newcastle upon Tyne, and is based on guidance from the Department of Health.

We understand that this is a difficult time for you to consider such an issue as a post mortem examination and you may find it hard to ask questions. Parents may find it helpful to know as much as possible about why their baby died and it is your right to have the information which a full post mortem examination can give. A post mortem can only be done with your permission (unless ordered by the coroner). So it is important for you to know as much as possible about what happens at a post mortem, the results you can expect and the choices you have. This booklet has been written with the help of other parents to give you clear information about the post mortem and its potential value. Please take the time to read it, and discuss it with your family if you wish, before you complete the consent form, and ask us if any thing is unclear or you have any questions.

You may also find it helpful to access the SANDS leaflet available at:

<https://www.sands.org.uk/support/bereavement-support/deciding-about-post-mortem-information-parents>

What is a post mortem examination?

A post mortem is an examination of a body after death. It is also called an autopsy. Post mortems are carried out by pathologists - doctors who specialise in the diagnosis of disease and the identification of the cause of death.

Why do a post mortem examination?

A post mortem examination can provide information about your baby's illness that would not be discovered any other way, although it is worth pointing out that even a post mortem examination cannot always provide a full explanation of what happened.

The information from the post mortem examination is used to:

- Identify a cause of death or miscarriage.
- Confirm the nature and extent of any illness.
- Identify conditions that may not have been previously diagnosed.
- Help to plan future pregnancies and care in pregnancy.
- Assess the effects of treatment and drugs and identify any complications or side effects.
- Diagnose and treat conditions in other children in the family.

It is also possible that the information gained may benefit other families who suffer from similar problems.

Who decides whether a post mortem should taken place?

A hospital can request that a post mortem examination is carried out, but this can only be done with your consent. Alternatively you can ask for a post mortem to be done. If the hospital requests a post mortem and you do not want to agree to a full post mortem examination you are under no obligation to agree to one.

What if I get confused about what I am agreeing to?

The hospital staff should make sure you know enough about the post mortem examination to allow you to decide if you wish to give your consent. They will discuss the alternatives with you. Although they may recommend a particular option it is important that you come to your

own decision. They will ask you to say whether you have understood the information you have been given. If you are not sure don't hesitate to say so.

Will I be able to ask questions?

You can ask as many questions as you like. You may also want to discuss the decision about a post mortem examination with other family members.

People vary as to how much information they want about what will happen during a post mortem examination. If you would rather not know about certain aspects, please say so. If on the other hand you would like more detail or would like to discuss the matter further with a health professional, please ask.

When and where is the post mortem done?

Post mortems are usually carried out within 2-3 working days, because the earlier the examination is held the more likely it is to give useful information. If because of your religion you must have a funeral within 24 hours, please let the hospital know and a pathologist will try to perform the post mortem within this time limit.

Post mortems take place in a mortuary. In our region, post mortem examinations of babies are undertaken in Newcastle by specialist Paediatric Pathologists. If you are in a hospital outside Newcastle, staff should tell you if your child is to be transferred.

The pathologist is helped by other staff, usually at least one mortuary technician. Sometimes medical students, doctors and other health care professionals may attend the post mortem examination for training purposes or to act as a quality check on standards of care. If you do not wish any other than the pathologist and mortuary technician to attend the post mortem, please indicate this on the consent form.

What happens in a post mortem examination?

The examination is undertaken to standards set by the Royal College of Pathologists. The pathologist will usually make two openings, one down the front of the body and another across the back of the head. This allows the pathologist to remove and examine all the major internal organs (or those agreed beforehand with you), and to take samples of tissue and fluid (such as blood) for later examination in detail. The organs are then returned to the body, although they cannot be returned to their original position within the body, except for the brain.

Can I see my baby's body after the post mortem?

Yes. After the post mortem the mortuary staff will prepare your baby's body for you to see and hold again if you wish, but you should be prepared for there to be changes to your baby's body after death and you might want to discuss beforehand with the mortuary staff, bereavement officer or funeral director what to expect.

Can I find out the results of the post mortem?

The post mortem report will usually be sent to the Consultant Obstetrician and/or Consultant Paediatrician involved in your care. You should be offered an appointment to review the findings. The turnaround time for a Post mortem report varies between 10 weeks to 6 months after the postmortem examination took place, and you can ask for a copy of the report. You may wish to ask for such an appointment if it is not offered.

EXPLANATION OF THE CONSENT FORM YOU WILL ASKED TO SIGN

Is the consent form binding?

Doctors need your consent before they can carry out the post mortem examination. The consent form acts as a written record of your decision, making it clear to everyone what you have and have not agreed to. If you change your mind before the post mortem has taken place you can modify or withdraw your consent – even after signing.

COMPLETE AND LIMITED POST-MORTEM EXAMINATIONS

A **complete** post-mortem examination gives you the most information. It consists of an external examination, examining the internal organs, taking and examining samples of tissue under a microscope, and taking X-rays and medical photographs. It may also include tests for infection and other possible problems. If you think you may have another baby in the future and are worried that the problem might occur again, a complete examination is the best way to try to find out

A **limited** examination consists of an external examination, examining the internal organs only in the area(s) that you agree to, taking and examining samples of tissue under a microscope, and taking X-rays and medical photographs. It may also include tests for infection and other possible problems. The internal examination can be limited parts of your baby's body, such as the brain, or chest, or abdomen and pelvis: the doctor or other health professional who discusses the post mortem with you will be able to explain what the options are. However, as the term suggests, this is likely to provide only limited information about the cause of your baby's death or illness, and make it less likely that an explanation will be found. Because of this, the doctor may advise you that a limited examination would not be of enough benefit to be worth doing.

A limited form of post mortem examination can sometimes be performed using cross-sectional imaging, such as CT or MRI scanning. This is not currently offered at Newcastle Upon Tyne Hospitals NHS Trust.

KEEPING TISSUE SAMPLES

Tissue samples will only be kept with your consent. Some of the tissue and fluid samples may be used to test for infections. Others are examined under the microscope: although some information can be obtained from looking directly at organs in the post mortem examination, often the only way to understand properly what has happened is to look at part of an organ with a microscope. Small pieces of organ tissue are removed and placed in small plastic cassettes. These samples vary in size, but for larger babies are usually up to about 1cm square in size (about the size of a 1p piece) and up to 5mm thick.

This is the actual size of a typical tissue block →



Samples from the brain may be larger (up to about 2 x 2 x 2cm). For smaller babies, the samples are generally much smaller. The tissue is chemically treated to remove water, which is replaced with wax. These tissue blocks become hard so that very thin sections - 10 times thinner than a human hair - can be cut off. Sections are placed on glass slides so that they can be examined under a microscope, using the same techniques as those used to examine tissue from living patients. Tissue samples may also be used for genetic tests. If it is felt that this may be useful, you will be asked to complete a separate consent form.

If you give your consent, these blocks and slides may be kept for review in the future. This can be very useful because ways of examining tissues improve year on year, and in the future it may be possible for further tests relating to your baby's cause of death or illness to be carried out on your behalf. Also, in cases of genetic disorders, looking back to the tissue of deceased family members may help make a diagnosis in living members of the family, so that they receive the correct treatment. Blocks and slides are kept in special secure cabinets. With your consent, tissue blocks and slides may be used in training doctors and other health professionals. They are also helpful for quality assurance and audit purposes, to ensure that special tests are working well for other patients.

Will tissue samples be used for general medical research?

Samples are only for research if you give your permission. If you consent, tissue blocks and slides can be used in ethically-approved research which may benefit other people in the future. When a new disease or health problem emerges, examination of tissue on a wide scale may provide clues about how and why the disease emerged – and how to respond. This happened with variant CJD following BSE. The majority of research adds just a little understanding to the building of knowledge – occasionally it is ground breaking. But all research is important, even if it does not merit a newspaper headline. We ask for your help to continue improving our knowledge and our ability to help other patients.

Can I choose to donate tissue just to certain areas of research?

Yes. If there is any particular type of research you are worried about you should discuss this with a member of hospital staff. You do not have to give overall consent but can exclude certain types of medical research.

KEEPING WHOLE ORGANS

In very specific circumstances, and with your consent, it may be desirable to keep a whole organ to allow it to be examined by a specialist in another hospital. This will usually take several weeks, and would normally delay the funeral. Should this happen, we need to know what to do with any organs when they are returned. However, no organs will be retained unless specific consent is given.

WHAT OTHER INVESTIGATIONS WILL BE PERFORMED?

We will routinely take X-ray images of your baby, as this can help detect skeletal (bone) disease. Sometimes, other imaging techniques may be used, such as MRI scanning, for example to visual brain abnormalities. If there is a suspicion of infection, tissue and body fluids (such as blood or cerebrospinal fluid) may be taken for microbiological or virological analysis. Body fluids may also be submitted for biochemical analysis in some cases. Genetic analysis is routinely undertaken to look for inherited diseases, and you will be asked for specific consent for this.

In rare circumstances, toxicological analysis may be performed if it is possible that drugs, chemicals or poisons contributed to the cause of death. In these circumstances, the post mortem report will usually be delayed by about 6 weeks.