



# Post-Mortem Examination of a Child

## Further Information Leaflet

This leaflet is intended to be read along with the basic information leaflet and contains more information about the post-mortem examination itself, retention of organs and tissue blocks and slides and the uses of the medical record.

## Index

- 1 - Post-mortem examination
- 2 - Tissue samples, blocks and slides
- 3 - Uses of the medical record
- 4 - Genetic testing
- 5 - Organ retention
- 6 - Conditions and requests
- 7 - Standards
- 8 - Disagreement about post-mortem examination
- 9 - Further information

## 1 What happens in a post-mortem examination?

A post-mortem examination, sometimes called an autopsy, is not just an internal examination. It includes the clinical history, photography, X-rays and external examination as well as many possible tests including virology (the study of viruses), bacteriology (the study of bacteria) and, provided there is permission to do so, genetic investigations (see Section 4 below).

The body will have a careful external examination. In a standard, full autopsy examination two incisions are made. One to examine the internal organs of the chest and abdomen and the second to examine the contents of the skull. This second incision is made towards the back of the head, behind the hairline. Occasionally, other small incisions may have to be made but these will be done carefully and in such a way as they are not visible after the examination. Small tissue samples will be taken from each organ and examined under the microscope (see below). Swabs, fluids or very small tissue samples may be taken for other tests such as virology, microbiology, biochemistry and genetics if indicated. (See next section, *What are tissue samples, blocks and slides?*)

In some rare cases, small samples could be stored frozen, for later studies using biochemical or genetic tests. Usually these tests would be undertaken to make a specific diagnosis in your child, but occasionally they may have implications for the whole family. If this is the case, you will be consulted and the implications discussed with you.

Once the post-mortem examination is completed, the organs are all returned to the body unless you have given authorisation for their retention beyond that point. The body is then carefully restored, usually by a mortuary technician in such a way that when fully clothed you cannot see the incisions. You should be able to see and hold your child after the examination if you wish.

## 2 What are tissue samples, blocks and slides?

Tissue samples are usually just a small part of an organ, but where a child is very small and the organs are tiny, the pathologist may need to take up to half of the organ. The pathologist will take great care not to take the whole organ. These *tissue samples* are placed in formalin (a process called fixation) and are often placed directly into small plastic cases, labelled with a unique number. The tissue is then chemically treated to remove water, which is replaced by wax. This produces a hard *tissue block* from which a very thin section can be cut. This thin section (ten times thinner than a human hair) is mounted on a *glass slide* before being stained. Staining is a process which allows the section to be seen easily when examined under a microscope. Tissue blocks and glass slides are stored in special cabinets and are kept securely in laboratories that keep very good records. Access to the laboratory is carefully controlled.

#### *What is residual tissue?*

After tissue blocks have been prepared, some slivers or small samples of tissue may be left. These will be disposed of by the hospital.

### 3 Uses of the medical record

#### *What can be done with the medical record?*

If you give authorisation for a post-mortem examination, then the tissue blocks and slides from it become part of your child's medical record. The medical record also consists of the case notes, photographs and X-rays. It is an important part of ensuring the quality of care that the work of doctors is routinely audited. Audit means checking that the procedures used to diagnose, treat and care for patients are up to date and meet the highest standards. It means checking what effect care has on patients and how resources are used. Audits can also help doctors to learn from other cases. The General Medical Council advises doctors in their guide, 'Good Medical Practice', that they must take part in regular audits. The photographs and X-rays taken of your child may produce useful lessons or show rare conditions that could educate other doctors. If these were to be used in this way, they would be used anonymously and any identifying feature removed. In the same way, slides can be used to teach other doctors or can be used as part of a test in a scheme such as the National Paediatric Pathology External Quality Assurance scheme, which regularly tests paediatric and perinatal pathologists' knowledge.

Examining tissue is one of the most important ways in which doctors learn about illness and how to treat it. Students training to be pathologists need to watch and learn about post-mortem examinations, and discuss the findings with an experienced doctor. Sharing information between doctors and hospitals is also very important for public health surveillance, which means making sure that infectious diseases do not spread throughout the local or national population. Ways of examining tissues get better all the time. In cases of genetic disorders, looking back to the tissue of deceased family members may help to make a diagnosis in other living members of the family so that they then receive the correct treatment. This is why we recommend that the tissue blocks and slides remain with the hospital record.

#### *What about research?*

Research is a valuable part of medicine and is how new understanding of disease processes can help in the search for new treatments. Research can vary from a simple study reviewing diagnoses already made to see if there is a new pattern to more complex tests involving gene probes that have only recently been discovered. All research is governed by Research Ethics Committees (RECs) which might be in the local area, or that cover a number of areas (multicentre research ethics committees - MRECs). Both RECs and MRECs have members of the public on the committee.

You can ask if you might see the results of any research that your child's organs or tissue were involved in, but it may not be possible to identify their contribution to a research study. The research institution will have records of its publications, and may have a website giving details of the sort of research it carries out. You should be able to obtain details of the sort of research carried out by the lead researcher and the institution.

## 4 Genetic testing

Genetic tests vary from the examination of chromosomes (often from a blood or skin sample) to tests of specific genes causing specific diseases. If such a test is positive, it may have implications for the rest of the family. Under the Human Tissue Act 2004, someone may commit an offence if he has bodily material and intends that human DNA in material will be analysed without consent, as set out in that Act. There are certain specific exceptions to this such as tests to make a clinical diagnosis.

## 5 Organ retention

The main organs of the body are the brain, heart, lungs, kidney and liver. Each organ carries out many different functions and is composed of different tissues and could reveal more information when studied for longer. If you have authorised retention of an organ, the pathologist can study it in order to expand the information available. For example, the brain has many different specialised areas and is extremely soft. In order to examine the brain thoroughly, it has to be hardened in fixative for a minimum of one week (ideally 3-4 weeks) and it may take some time to get the results of a neuropathological examination. Doctors who specialise in the study of disorders of the brain and spinal cord are called neuropathologists.

### *What happens after the retention and examination of an organ?*

If you authorise the retention of organs for further examination or gift them for research, your wishes will be followed, as will any instructions concerning disposal.

If you authorise the retention of an organ for further examination, you need to consider how it might be dealt with after the examination is complete. If the examination or a preliminary examination can be completed before the funeral, the organ can be returned to your child's body, and you might wish to consider delaying the funeral to allow this to happen. You should discuss with the hospital how much of a delay would be involved.

If you do not feel you need to have the organs returned to your child's body before the funeral, you can ask the funeral director who is making the funeral arrangements to arrange for the later disposal of organs. Alternatively, the hospital can arrange this for you and you may wish to ask for more details

about what the hospital's arrangements for disposal are. You may feel that you would like more use to be made of any organ that you authorise to be retained for diagnosis. There are many research studies in different areas of medicine that could benefit from a donation, and a gift such as this would be greatly appreciated and could help in research or education of future doctors. Please discuss this with the person who is explaining the post-mortem examination, and they should know who to ask about what can be done.

If you authorise the retention of an organ for education, audit or research it will usually not be returned and will be respectfully disposed of by the hospital or researcher once the purpose for which it has been retained has been completed.

## 6 What sort of conditions can I make?

You may have specific religious requirements about the timing of the funeral or washing of your child's body. If you do, please tell the hospital staff and ask them to note these on the form.

If there is specific research that you would like your child's organs and tissue to be donated to, or if there are specific types of research that you would object to, then the authorisation form provides a place to record those wishes. You may want the organs to be held for only a limited period of time. Again, if so, please say so on the authorisation form.

## 7 Standards

**How do I know that only what I have authorised will be carried out?**  
The Human Tissue (Scotland) Act 2006, which came into operation on 1 September 2006, makes it an offence to carry out a post-mortem examination or retain organs without proper authorisation. These offences carry severe penalties, including fines and imprisonment.

NHS Quality Improvement Scotland has produced standards for post-mortem examinations that must be followed by NHS personnel in Scotland. These are available on their website [www.nhshealthquality.org](http://www.nhshealthquality.org) and you can ask for a copy to read. One of the standards is that there is a check on what has been authorised and what is then carried out by the pathology department. The Royal College of Pathologists has also published guidelines about post-mortem practices and has published patient leaflets and guidance about the retention of tissue and organs at post-mortem examinations.

## 8 Disagreement about post-mortem examination

What if there is family disagreement about a post-mortem examination?

The post-mortem examination can go ahead if a person who has parental rights and responsibilities in relation to the child authorises it, or, in the case of a child who died aged 12 or over, the child him or herself, or his or her nominated representative authorises it. There may be unusual circumstances in which another person with parental rights and responsibilities disagrees over whether a post-mortem examination should be carried out. Where the disagreement cannot be resolved through discussion, the hospital will need to decide if the post-mortem examination can go ahead.

## 9 Further information

What else can I read about post-mortem examination?

*Standards for the management of post-mortem examinations:* NHS Quality Improvement Scotland April 2003

Royal College of Pathologists: *Guidelines on Autopsy Practice*, September 2002

Medical Research Council (MRC). *Human Tissue and Biological Samples for Use in Research: Operational and Ethical Guidelines* MRC 2001.

The hospital will have a list of local and national organisations who can offer support and further information.

