

Post-Mortem Examination of a Child

Information Leaflet

Summary

The post-mortem examination is an important medical investigation to try to find the cause of your child's death. Ideally the post-mortem examination should take place within two or three days of death.

Your child's face, hands and feet are not normally affected by the post-mortem examination.

You should be able to see and hold your child again after the post-mortem examination.

You, hospital staff or funeral directors can take pictures of your child before the post-mortem examination if you wish.

The final results of the examination should be available in 30 days and a copy of the pathologist's report is sent to your general practitioner. You can request a copy of it.

Whole organs will only be kept if there is proper authorisation to do so.

If you do not wish a full post-mortem examination, talk to hospital staff about other tests that may be done.

Ask as many questions as you wish.

Information about a child's post-mortem examination

We would like to offer our sympathy on the death of your child. Your child will be treated with all dignity and respect while he or she remains in our care.

We understand that this is a very difficult time for you and it may be hard to think about a post-mortem examination. This leaflet has been written (with the help of other bereaved parents) to give you clear information about the reasons for carrying out a post-mortem examination, and what you would need to decide.

About the authorisation form

The authorisation form is based on the requirements of the Human Tissue (Scotland) Act 2006. Unless the post-mortem examination has been ordered by the Procurator Fiscal, authorisation is needed for a post-mortem examination to be carried out. If your child was less than 12 years old, only someone with parental rights and responsibilities can give that authorisation.

You don't need to read this paragraph unless your child was aged 12 or over.

Your child may have left clear instructions authorising a post-mortem examination, saying what can be done with his or her body, and these instructions must be respected. Your child may instead have

chosen what the 2006 Act calls a nominated representative to make such decisions. If the hospital knows who this person is, he or she will be asked whether or not a post-mortem examination should go ahead. The nominated representative has the right under the law to authorise a post-mortem examination whatever views others may have. If your child left no instructions and did not nominate someone else to make these kinds of decision, someone with parental rights and responsibilities for the child can authorise a post-mortem examination. If you are not sure whether you are the nominated representative, please check with hospital staff.

The authorisation form means there is a written record of your decisions and makes it clear to everyone what you have or have not agreed to. If you change your mind before the post-mortem examination has taken place, you can withdraw your authorisation, even after signing. Ask the hospital staff to tell you how much time you have in which to do this, and whom you should contact.

What do I need to know?

People have different views on how much information they want about a post-mortem examination. You may not want to know anything about the post-mortem examination. This leaflet provides basic information. But if you would like more detail, you can ask to talk things over with another health professional, such as a pathologist. Or there is a second leaflet

with more detailed information about what is involved in post-mortem examinations. Let us know if you want to see this.

Why carry out a post-mortem examination?

A post-mortem examination can help families understand why their child died. Sometimes families ask questions that can only be answered with information from a post-mortem examination. It is also possible that the information from it may benefit other families who suffer from similar problems in the future. A post-mortem examination cannot always provide a reason for the death, but it may answer questions that you, or the doctors caring for your child, may have. The main reasons for a post-mortem examination are to:

- Identify the cause of death
- Discover the nature of the illness (if this is not already known)
- Identify conditions that may not have been diagnosed
- Identify complications or side-effects of treatments and drugs
- Help plan future pregnancies and care in pregnancies
- Diagnose conditions that might affect other members of the family.

When is a post-mortem carried out?

Post-mortem examinations are usually carried out within 2-3 working days of death occurring. They take place in the mortuary. If, because of your religion a funeral must take place within 24 hours, please let us know and we will try to undertake the post-mortem within this time.

The notes below follow the order of the sections in the authorisation form.

Section 1

Authorisation of a post-mortem examination

What is a post-mortem examination?

A post-mortem is an examination of a body after death. It is also called an autopsy. Post-mortem examinations are carried out by pathologists – doctors who specialise in the diagnosis of disease and the identification of the cause of disease. Paediatric or perinatal pathologists have further training in disorders that affect children.

What happens in a full post-mortem examination? (Section 1A)

A full post-mortem examination includes an external and an internal examination. It is done with the same care that would be used if your child were having an

operation. If you wish to have a more detailed explanation of a full post-mortem examination, please see the other leaflet. Small tissue blocks and slides, photographs and X-rays may be made and will be kept as part of the medical record. Your child's face, hands and feet will not be affected by the examination and you should be able to see and hold your child afterwards if you wish.

Are there different options available? (Section 1B)

If you do not want to agree to a full post-mortem examination, you might consider a limited examination. The doctor or other health professional who discusses the post-mortem examination with you will be able to explain what the options are. Usually, it means that only certain parts of your child's body are examined, and the form sets out the choices. Tissue block samples and slides, photographs and X-rays may be made in the same way as for a full post-mortem examination.

The external examination (Section 1C of Child Under 12 Years of Age form): an even more limited post-mortem examination is an external examination, where only images and possibly small skin samples are taken with your authorisation. This is intended only as a check of your child to look for any abnormality which can be seen from the outside.

However, limited or external examinations provide only limited information about

your child's cause of death or illness, whereas a full post-mortem examination will always provide more information.

What can be done with the medical record?

Tissue blocks and slides, photographs, X-rays and other images taken during the post-mortem examination will form part of your child's medical record. They may be useful for the family in future, perhaps to diagnose conditions in other family members or if more information becomes available about the condition your child had.

The medical record can also be used for audit, education, training or research. Education includes teaching and training all types of doctors, nurses and health professionals so they can provide the best care for patients in the future. Audit means checking the quality of care, procedures and tests to make sure they continue to meet the highest standards.

Research may benefit other patients. For example, when a new disease or health problem emerges, examining tissue on a wide scale may provide clues about how and why the disease emerged, and how to respond.

If any photographs could identify your child, you will be asked specifically to allow them to be used. If extra tissue or images are requested specifically for education, audit or research you would be asked to give separate permission for this.

What are tissue samples, blocks and slides?

Although some information can be obtained from looking directly at organs and tissues in a post-mortem examination, often the only way to understand properly what has happened is to look at small tissue samples under the microscope. These samples are very small: slightly thicker, but usually no larger, than a postage stamp.

Section 2

Retention and examination of whole organs

Will any organs be kept?

There may be benefits in keeping a whole organ or parts of an organ to carry out a more detailed examination. This will usually be the case if there is an abnormality of the brain, but sometimes the pathologist may need to examine a heart or other organs with an inborn abnormality. Organs will not be retained without your authorisation, or unless your child was aged 12 or over and has authorised this.

If this is discussed with you, there are a number of other points to consider. The form sets out the types of organ that could be kept, and the ways in which they could be used. If your child was over 12 and left instructions about these matters, the hospital will follow these instructions.

Where organs are not being kept indefinitely, the person discussing the form with you will explain the position. If your child was over 12, any wishes your child left should be followed. In other cases, you will be asked what should happen.

Section 3

Other requests or conditions

Can I make any conditions?

If you wish to make any special request or condition, you can say so in section 3 of the authorisation form. For example, there may be religious obligations that you need to have followed, or you may wish to allow organs to be used for some sorts of research but not others.

General questions

What happens after the examination has been completed?

Care is taken during and after the examination so that your child can be dressed in his/her own clothes, and you may see your child after the examination. Your child's skin and colouring will change naturally after death, whether or not a post-mortem examination has been carried out.

Can I find out the results of the post-mortem?

Yes. The pathologist will write a preliminary report within 2 days and will aim to send a final report to the doctor caring for your child within 30 days. A copy will also be sent to your general practitioner (GP). You will be offered an appointment to discuss the results either at the hospital or with your own GP. You can ask for a report written in language you understand.

What should I know before deciding?

The hospital staff should make sure you have enough information to decide if you wish to give your authorisation. They will discuss the choices with you. It is important you understand what is involved and come to your own decision. They will ask you whether you have understood the information you have been given and feel able to make a decision. If you are not sure, please say so.

What if I change my mind?

If you change your mind before the post-mortem has taken place you can withdraw your authorisation, even after signing the form. Ask the hospital staff to tell you how much time you have in which to do this, and who you should contact.

If you authorise the use of the medical record or organs, you can change your mind at any time, unless the medical records or organs have already been used for authorised purposes.

How long do I have to decide?

You should take as much time as you need to make a decision, although there is a time limit because of changes that take place after death naturally. You may wish to discuss things with your spiritual adviser. There are also some tests that are better done sooner rather than later.

We hope this information is helpful but please ask if there is more information you need.