

### **PATIENT INFORMATION**

# Post Mortem Examination Procedure – A Guide to the

You have been asked to read this booklet because someone close to you has died. On behalf of our staff, we would like to express our sympathy to you and your family following your loss.

We understand that this is a difficult time for you to consider such an issue as a post mortem examination, but we hope this booklet will help you understand the reasons for undertaking a post mortem examination, what it involves, 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 anything is unclear or you have any questions.

The hospital's Bereavement Officer can be contacted on 01803 654818 between
9.30am and 4.00pm – Monday to Thursday
9.30am and 1.00pm on Friday

You may prefer to speak to another member of staff, possibly someone you got to know while they were looking after your partner or relative. The main thing to remember is that you can ask as many questions as you like and if you would rather not hear details that you find upsetting, just say so.

Coroner's officers and hospital staff are aware that this is not an easy subject for people to deal with. They will want to help you make the decision that is right for you and your family.

#### 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. It is the final step in the investigation of a person's illness, or their cause of death.

#### Why do a post mortem examination?

A post mortem examination can provide information about the illness or other cause of death. Without a post mortem, the cause of death can be wrong in up to 30% of cases, although it's worth pointing out that even a post mortem examination cannot always provide a reason for the death.

Post mortem examinations help the medical profession by providing information about illness and health that would not be discovered any other way. Much of what we know about illness today came from such examinations. They help to:

- Identify the cause of death.
- Confirm the nature of the illness and/or the extent of the disease
- Identify other conditions that may not have been diagnosed.
- Assess the effects of treatments and drugs, and identify any complications or side-effects.

A post mortem examination can help people understand why a loved one died. Sometimes families or partners ask questions that can only be answered with information from a post mortem examination. It is also possible that the information gained may benefit future children in the family, or other patients who suffer similar problems.

Donating organs for transplant is handled separately from the post mortem procedure. Please ask if you want to know more.

#### Who decides whether a post mortem should take place?

By law a coroner can order a post mortem examination to be done. There are three main reasons why a death is referred to the coroner:

- A death has been sudden and unexpected.
- A person has been ill but the doctor confirming the death is not certain
- · Why it happened at that particular time.
- A death has been the result of an accident or unusual circumstances (including deaths following a medical procedure such as surgery).

A hospital can request that a post mortem examination is carried out, but this can only be done with the consent of the next-of-kin, or if the deceased explicitly gave their permission to a post mortem before they died. Or you, as the next-of-kin, may ask for a post mortem to be done.

#### What if I don't want a post mortem to be carried out?

In most cases it is not up to the next-of-kin. The majority of post mortems are ordered by the coroner, who does not need your consent to carry out the examination. 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. You might however consider a limited examination. The doctor or other health professional who discusses the post mortem with you will be able to explain what the options are. Usually it means that only certain parts of the body are examined. Sometimes such examination can be very useful. However, as the term suggests, this is likely to provide only limited information about the cause of death or illness. Because of this the doctor may advise you that a limited examination would not be of enough benefit to be worth doing.

#### When is a post mortem examination done?

Post mortems are usually carried out within 2-3 working days of death because the earlier the examination is held, the more likely it is to yield useful information. They take place in a mortuary. If, because of your religion, you must have a funeral within 24 hours, please let the hospital or coroner's officer know and the pathologists will try to do the post mortem within this time limit. The coroner's officer will normally be able to let you know the date, time and place of a post mortem ordered by the coroner.

#### Is anyone but the pathologist present during the post mortem?

The pathologist is helped by other staff, usually at least one mortuary technician. Sometimes medical students, doctors and other health care professionals may attend a post mortem examination for educational purposes or to act as a quality check on standards of care. If the coroner has ordered the post mortem, as next-of-kin you have the right to be represented at the examination by a medical practitioner, if you wish.

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

The pathologist, working to standards set by the Royal College of Pathologists, will remove and examine all the major internal organs (or those agreed beforehand with you) and will take samples of tissue and fluid (such as blood) for later inspection in detail. The organs are then returned to the body (although they cannot be returned to their original positions within the body).

The samples of tissue taken for testing are usually kept as part of the person's medical records in case they are needed to answer further questions about the cause of death, or to help answer questions regarding illnesses of other family members in the future.

### What happens to tissue samples removed for more detailed examination?

Although some information can be obtained from looking directly at organs in a post mortem, often the only way to understand properly what happened is to look at part of an organ with a microscope. Small pieces of tissue are removed and placed in small, usually plastic, cassettes. These samples are usually less than 1 cm² in size (smaller than a standard postage stamp) and up to 5 mm thick. Often samples are much smaller, although samples from the brain or lungs may be larger: about 2 cm². The tissue is chemically treated to remove water, which is replaced with wax. These tissue blocks become hard, so that very thin sections - ten times thinner than a human hair - can be cut from them. They are placed on glass slides so that they can be examined with a microscope. More blocks and slides are kept in special cabinets designed for this purpose, which are kept securely. These techniques are the same as those used to examine tissue from living patients.

Sometimes organs need to be 'fixed' (preserved with chemicals) before samples can be taken. In this case, it may be some weeks before the organs can be returned to the body.

### Does the hospital keep tissue samples removed during the post mortem?

Yes, in particular if they have been made into blocks and slides (see above) for examination under a microscope. They can be very useful because ways of examining tissues improve year on year, and 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. Tissue blocks and slides may be used in training doctors and other health professionals. They are also helpful for quality assurance and audit purposes. For example, tissue samples may be needed to check on standards in a hospital pathology service.

#### Will tissue samples be used for general medical research?

Only if you give your permission. With your consent tissue blocks and slides can be used in research which may benefit other people in 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. Special committees must approve any research, to make sure it is ethical, and that sufficient consent has been given. Tissue must not be used for research without your agreement.

# What happens to any tissue removed during the post mortem but not prepared for further examination?

When a tissue sample is taken it is often larger than the piece needed for making into a block. This is necessary because to trim unfixed or fresh tissue to the exact smaller size needed for processing may damage it. Any tissue left over is usually disposed of immediately or may be returned to the fixing solution for further storage. After tissue slides have been prepared the unused (or residual) tissue in the block is usually stored indefinitely in case additional slides need to be made in future or new techniques are developed which mean the case can be reviewed. Only if you give your consent can this residual tissue be used in medical education or research.

#### Are photographs taken during the post mortem?

Often the pathologist will take x-rays or other images (including photographs and CT scans) of part of the body or of an organ during the examination, to be studied again later. These images are usually kept indefinitely as part of the person's medical records. They may also be used for medical education, audit, or research, in which case any information which would allow your partner or relative to be identified will be removed. If you object to images being used in this way, you must say so.

#### What happens after the examination has been completed?

Some tests may take several days or weeks. Also the making of blocks and slides from certain organs (e.g. the heart or the brain) requires the removal of and 'fixing' of those organs - if this is the case, those organs will not be able to be returned to the body for some weeks. Hospital staff, or the coroner's officer, can advise if this is likely and how long tests may take. You may wish to have the funeral during this time.

### Who decides what happens to tissue or organs kept for further examination?

Once the coroner's duties have been completed, you do, as next-of-kin, other than the tissue samples prepared for examination under microscope (see above). You have four options:

- You can ask for any organs and tissue that have been retained to be returned to the funeral director (or direct to you) once the tests are complete. You will then need to arrange for a separate cremation or burial service for these.
- You can delay the funeral so that organs and tissue may be returned to the body for burial or cremation.
- You can donate tissue samples or organs for use in medical education or research.
- You can ask the hospital to dispose of the organs and tissue in a lawful way. This is usually by incineration.

#### Can I see the body after the post mortem?

Yes. After the post mortem the mortuary staff will prepare the body for you to see again, if you wish, and for the undertaker to prepare it for the funeral.

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

A copy of the post mortem report will usually be sent to your partner or relative's GP either by the hospital or coroner's office. You can also arrange to discuss the findings of the post mortem with the doctor in charge of your relative or partner's care at the hospital. This may be some weeks later, after all the tests are complete. In the case of a post mortem ordered by the coroner, because its purpose is to identify the medical causes leading to death, the results may be limited in scope. You should still be able to obtain a copy of the report from the coroner's office, although there is generally a fee for this, unless an inquest has been ordered following the post mortem. You should be informed as soon as the coroner's report is available.

# Why do hospitals need people to donate tissue and organs for medical research, education, audit or quality assurance?

Examining tissue is one of the most important ways in which doctors learn about illness and how to treat it. Tissue blocks and slides are used to train medical students and new doctors, to help experienced doctors continue to learn about new conditions or treatments, or to teach specialist knowledge.

Sharing information between doctors is important in maintaining high standards of care. Doctors 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 - making sure that infectious diseases (such as hepatitis, measles or tuberculosis) do not spread throughout the local or national population.

Medical education, audit and quality assurance are an integral part of health care and blocks and slides taken for diagnosis may be used in this way.

However, we will ask for your consent to retain major whole organs for any of these purposes.

Research is vital for the progress of medicine. Thanks to it, we can understand and, in many cases, cure diseases that were incurable in the past. 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 doesn't 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 or organs 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.

### What happens to organs or tissue donated for medical research, education or audit?

They cannot usually be returned to you. After they have been used, they will normally be disposed of by incineration. In some cases they may be used for many years before disposal.

#### Is the consent form binding?

Unless it has been ordered by the coroner, the hospital needs your consent before it 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. The hospital or coroner's office will tell you how much time you have in which to do this.

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

The hospital staff or coroner's officer should make sure you know enough about the post mortem examination 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 (such as a pathologist) please ask.

For further assistance or to receive this information in a different format, please contact the department which created this leaflet.