



Post mortem examinations: information for families

This booklet from Great Ormond Street Hospital (GOSH) explains about examination after death (post mortem examinations), what will happen and which decisions you will need to make.

We know this is a very difficult time for you and your family and it is hard to be asked to make decisions about further examinations of your child. Unfortunately, these decisions often need to be made quickly and we want you to be able to make an informed decision about what can happen next.

When you look back, we want you to feel you had access to enough information to make the best possible decision. We hope this information will supplement your discussions with hospital staff and be useful to refer to in the future.

Talking it over

You will probably have lots of questions – in the first instance, talk to the doctor or nurse who was caring for your child – if they cannot answer, they will know who else to ask. It can sometimes help to talk to other people about the decisions you have to make, but remember the decision is ultimately yours. If possible talk to your partner, family and friends or those supporting you, you may even like to contact one of the organisations at the back of this leaflet.



If you would prefer not to have a detailed explanation at present, please tell the doctor this when you are discussing the post mortem examination options.

Summary

An examination after death or post mortem examination is the final stage in investigating your child's illness. It is a detailed physical examination of your child after he or she has died. A biopsy is a small sample of tissue from your child, for example, heart, brain or skin. There are five types of post mortem examination:

- a coroner's or forensic post mortem examination
- a complete hospital post mortem examination
- a limited hospital post mortem examination
- a minimally invasive autopsy
- a post mortem biopsy

A coroner's or forensic post mortem examination can be carried out without your permission. You should, however, be given an explanation of the process and the reasons for it. You will also be given the options of what to do with any samples after the coroner's investigation is completed.

No type of hospital post mortem examination (complete, limited, minimally invasive autopsy or biopsy) is a legal requirement, so it will only go ahead with your permission. The consent form, which you will be asked to sign, asks you which type of post mortem examination you agree to but also what you agree to in



relation to samples of tissue or whole organs which may need to be kept for detailed examination. You may be asked permission for a hospital post mortem examination to help increase understanding of your child's illness or to contribute to teaching and medical knowledge to help children and families with similar conditions. You may also choose to request a hospital post mortem examination if it is not offered. No samples of tissue or organs will be kept permanently without your explicit, signed consent.

You will be able to see and hold your child after the post mortem examination if you wish. A nurse will take you to the bedroom (formerly known as the viewing room) in the mortuary. All signs of the post mortem examination will be hidden by your child's clothes and hair, but your child's skin tone, colour and temperature may have changed, which is normal after death.

You will be able to arrange the details (but possibly not the date) of your child's funeral, before the post mortem examination has taken place. Either the hospital doctor or the coroner's office should be able to give you an approximate idea of when you will be able to hold your child's funeral.

If you would like a more detailed discussion about the post mortem examination report when it is available, you can ask for an appointment with the hospital doctor to discuss it.

If you would like to talk to other parents who have experienced the death of a child, you may like to contact the Child Death



Helpline on Freephone 0800 282 986 from a landline or on 0808 800 6019 from mobile phone to talk things over.

If you do not want to know any further, more detailed information about your child's post mortem examination, please stop here. If you want to read further details, please continue on the next page.





Further information about your child's post mortem examination or post mortem biopsies

The aim of any post mortem examination is to work out what happened and to uncover further information which may be relevant to understand the reasons for death. It may also provide a specific diagnosis if this was not reached beforehand.

This examination is another stage in investigating your child's illness. It is a detailed physical examination of your child after he or she has died. Some post mortem examinations are legally required, others are not. Usually some form of imaging scans are completed followed by sampling and examination of your child.

If it is important to you to have the funeral within 24 hours, everyone involved will do their best to enable this to happen, however this may not be guaranteed.

Coroner's or forensic post mortem examinations

In some circumstances, doctors cannot immediately issue a death certificate and they are obliged to inform the coroner. Coroners are usually medically or legally trained and appointed by the Government to their post. They are bound by a legal framework as well as their own code of conduct. They will be the main contact for you throughout their investigation.



Usually this occurs when the doctor is uncertain of the cause of death, the death has occurred suddenly, or soon after an operation. There are a number of other less common reasons. The coroner then decides whether it will be necessary to have a post mortem examination. As the law states that a coroner's post mortem is needed under the above circumstances, you will not be required to give your permission.

A Coroner's officer will contact you to discuss the process but you may wish to get further information and support from the Bereavement Service at GOSH.

Hospital post mortem examination and biopsies

The hospital doctor may ask your permission to perform a post mortem examination, perhaps not to establish the cause of death, but to help you and clinical staff to understand your child's illness in greater detail or to help increase medical knowledge. If this is the case, the doctor will discuss it with you, explain what is involved and ask you to sign a consent form.

The consent form states the nature and extent of the post mortem examination, and your explicit permission is required for retention of any organ or tissue for any purpose. You may also be asked if you want to help with a research project, perhaps by agreeing to additional imaging or samples. Clinical staff should explain the research project to you fully and answer any questions before you decide. They may write this on the



consent form for the post mortem examination or ask you to sign a separate form.

There are many options open to you and nothing will begin until the agreed cooling off period is complete.

Description of post mortem examinations

Previously a complete post mortem examination was the only option available for parents to consider. Although many parents would like to know more about why their child died they could not, for whatever reason, agree to a complete post mortem examination. The advances in post mortem examination techniques mean we can now offer a number of alternatives.

There are four methods of post mortem examination and one method of biopsy. You will have a number of choices. Recent advances in medicine including MRI and CT scanning, which are special types of scan to get images of the body, and advances in endoscopic surgery, often called 'keyhole surgery', mean that an alternative approach to the post mortem examination may now be possible for some conditions. It is entirely your decision to give permission for a hospital post mortem examination or biopsy.

A complete post mortem examination

This involves a detailed examination of all your child's organs and tissues. This will include some imaging and uses traditional methods to examine your child. The post mortem examination is carried out via incisions similar to those made in a surgical



operation, with the incisions made to the chest and abdomen and behind the head if the brain is also examined. The internal organs are examined, small samples of each organ are taken and then the tissue not taken for sampling is returned to the body. Afterwards all incisions will be repaired and covered.

If a detailed neuropathological (brain) examination is necessary due to a known or suspected neurological disorder, this is a longer process taking at least two weeks. This means you will be asked for your instructions regarding the left over tissue following the extended process. As this cannot be returned to your child immediately, you will be asked if you wish to delay funeral arrangements until the brain can be returned, to donate the brain for research or have this returned to your funeral directors for separate burial or cremation at a later time. This will be your choice and you will be given ample time to think about this. More detail can be found in the *scheduled purposes* section later in this leaflet.

A Minimally Invasive Autopsy

This will include an external examination and we will carry out some imaging. There are various options including MRI or CT scans, x-rays, ultrasound scans or microfocus CT scans – which is carried out will depend on your child's individual needs. This will be followed by a targeted 'keyhole surgery' examination of the internal organs via a small incision (approximately <2cm/1 inch) in the relevant area on the body (usually the abdomen). We pass a telescope through the incision which allows us to biopsy or remove and inspect the



organs as appropriate. We may take samples for infections, metabolic disease and examination of tissue under the microscope. These are the same as would be taken in a complete post mortem examination. Sometimes it may be possible to use ultrasound instead to guide the instruments to ensure the samples we take are suitable for diagnosis.

Afterwards, only the telescope and/or biopsy needle puncture marks will be present, which will then be closed. There will be no other incisions made, no organs will be retained and the head will not have any incisions made. If neuropathological examination is required, this will be carried out in the same way as a complete post mortem examination as described above.

A limited post mortem examination

You can specify which areas of the body which will be examined. There will still be an external examination and some imaging scans. Any incisions needed will be made to the specified areas only and will be closed in the usual way. This is very useful for neuropathological conditions if you only agree to the head being examined. If the spinal cord is to be examined as part of the neuropathological process, we will discuss the method for this with you.

External and Imaging Autopsy (EIA)

Your child will have an external examination and we will carry out some imaging. There are various options including MRI or CT scans, x-rays, ultrasound scans or microfocus CT scans – which is carried out will depend on your child's individual needs.



Post mortem biopsy

This means a small sample of tissue is taken from a specific area of your child's body, possibly using ultrasound as a guide.

Types of imaging

The type of imaging used to get the best information about your child will be decided by the team. This will differ according to your child's age, weight and specific medical information. There are various options including MRI or CT scans, x-rays, ultrasound scans or microfocus CT scans – which is carried out will depend on your child's individual needs. Microfocus CT scanning is often the best option if your baby is particularly small (under 20/40 weeks gestation). Currently microfocus CT scanning involves using a fixative solution which provides the best imaging for diagnostic purposes, but can leave your baby's skin slightly different in texture and colour.

Who carries out the post mortem examination

Whether the post mortem examination has been ordered by the coroner or requested by your hospital doctor, the way it is carried out is the same. A pathologist carries out the post mortem examination in the mortuary assisted by an anatomical pathology technologist (APT).

A pathologist is a fully qualified doctor who has then had extra training in pathology – the study of disease processes. The pathologists who work at GOSH are fully trained doctors, who have specialised in pathology and then had specialist paediatric



training. Pathologists, like all doctors, are bound by a strict code of conduct and will treat your child with respect at all times.

The APT is a member of the team specially trained in anatomy and physiology and is responsible for the continued care of your child before, during and after the post mortem examination.

Research

Recently, at GOSH we have been able to offer alternative options for parents to consider when discussing post mortem examinations. The post mortem examination options that you can now choose from have been developed due to parents participating in research projects involving their baby. Many of those parents who participated in research projects felt this was important for them during their bereavement. You will be asked about the possibility of using images and samples for research during the post mortem discussion. This is your choice and we will only go ahead if you agree to any of the research options presented to you.

Additional imaging

As part of the examination we will carry out some imaging. There are various options including MRI or CT scans, x-rays, ultrasound scans or microfocus CT scans – which is carried out will depend on your child's individual needs. This imaging forms part of the diagnostic process used to gain information to enable us to issue the final post mortem examination report.



In order to be sure that each type of imaging techniques used are accurate and provide the same quality of information and diagnosis as an invasive post mortem examination, we need to find out how the images produced are affected by the normal changes that happen to tissues and bones after death. To do this we need to compare different types of scans and other imaging techniques and to repeat them over time.

Whichever type of post mortem examination you choose you will be asked if it is acceptable for us to take additional imaging. This means while your child is with us we may take multiple images using the different methods as listed above before the type of post mortem examination you have agreed to takes place. These images will be specifically taken for research purposes and will not be used to give clinical information, nor will they delay the post mortem examination in any way. This research will give more information to help parents in the future and help other professionals in post mortem examination techniques.

Additional tissue samples

Tissue samples are taken routinely at post mortem examination. These samples are used for diagnostic purposes and may also be used for additional scheduled purposes such as quality assurance and audit, training and ethically approved research.

Whichever type of post mortem examination you decide to consent to you may be asked if it is acceptable for us to take



additional tissue samples. These samples will be specifically taken for the scheduled purposes listed below and will not be used diagnostically.

The samples taken at post mortem examination are very small. If you agree to this we will be able to take extra tissue which can then be used in a variety of ways to further educate and demonstrate current processes, also advance knowledge and techniques for the future.

Retaining samples, tissues and organs – further scheduled purposes

It is difficult to get enough information from the initial visual (macroscopic) examination of whole organs. In this case, the pathologist will remove small samples of tissue to examine under a microscope (microscopic examination). These samples will usually be treated with chemicals and have wax added so that they can be made into a block. This can then be sliced very thinly so that sections containing tissue can be examined more easily. These samples – tissue blocks and slides – form part of your child's medical record and so will be retained indefinitely, unless you specify otherwise.

When we ask your permission for a hospital post mortem, we will also ask to keep blocks and slides, or sometimes, whole organs like the heart or brain. We will ask what you want us to do with the samples or organs once the examinations are finished. You may wish to agree for the tissue blocks and slides and/or whole organs to be used for other purposes such as



teaching, research, quality control and audit. These are called scheduled purposes and are explained below.

- **Quality assurance or control** – for example, using images and/or sample to check that the processes followed gives accurate results or testing new equipment to make sure it is suitable for our needs.
- **Audit** – for example, assessing processes against agreed standards to show that they are accurate.
- **Teaching and education** – such as training professional staff in anatomy, physiology and radiology.
- **Ethically approved research** – all research projects need ethical approval, that is review by a group of independent people to make sure that the project is safe and worthwhile. Examples of research carried out at GOSH include using keyhole surgery, looking for disease in specific age groups and identifying natural changes in organs and tissue.

You can choose as many or as few of the scheduled purposes as you wish. You may want a separate service to reunite the blocks and slides with your child, or you can request sensitive disposal of them in a respectful way by GOSH.

Seeing your child after the post mortem examination

It is quite usual to want to see your child again but you may have questions about how they will look. Each child is different, but you should expect the following:



- The post mortem examination will have been done in a sensitive way and most of the incisions are hidden by your child's clothes or hair, so you should not notice these while they are dressed.
- You may also notice the normal changes that happen after death, which are unconnected with the post mortem examination. There is small chance your child's skin may appear different, perhaps a little dry and their lips and nails may look redder than before.
- You may also notice marks on your child's skin that look like bruises. These are not bruises, but marks from where the blood settles when the heart stops beating.
- Your child may also feel very cold, this is necessary to ensure that your child is cared for in the most appropriate way.

If you have any questions about your child's appearance when you see them, please talk them over straight away with the APTs or nurses who will be with you.

Registering your baby or child's death

After a coroner's or forensic post mortem examination has been completed, the Coroner's Office will contact you to explain how to register your child's death. Details about our local Register Office are contained in the *When a child dies* booklet, which your nurse will have given you.

If you have chosen to have a complete or limited hospital post mortem examination, we will give you a death certificate straight



away so you can register your child's death. There is a box on the form to let the Register Office know that a hospital post mortem examination is going ahead.

If the coroner opens an inquest – this is a legal process to establish the circumstances leading up to, and the cause of, your child's death – a death certificate will not be issued, but a certificate for burial or cremation will be issued instead. The coroner will also have to give permission if you wish your child to be cremated. In this case, a death certificate may not be issued until after the inquest.

Talking to the doctor or coroner

Following the post mortem examination, the results of all investigations will be issued in a standard post mortem examination report. If you would like a detailed discussion about the results of the post mortem examination or biopsy, you can ask to have an appointment with your child's doctor or the coroner's officer, depending on the type of post mortem your child had.

They will go through the report with you, if you wish, explaining medical terms or details which may be difficult to understand at first. The medical or legal terms in which the report is written may sound rather formal and medically detailed in relation to your child, and you may like to have a partner, relative or friend with you for support.



What next?

If the post mortem examination or biopsy has shown that a genetic abnormality played a part in your child's death, it can be arranged for you to see a genetic counsellor who can advise you about plans for any future pregnancies.

Further information and support

Talk to your child's clinician in the first instance as they will probably have been your point of contact up to now.

Our Bereavement Service can also offer information and support – call them on 020 7813 8551

If you want to know more about research, talk to the clinician or researcher, or contact the Mortuary at GOSH on 020 7829 7906 or email gosh.mortuary@nhs.net

If you would like to discuss anything with our Patient Advice and Liaison Service (Pals) team, call in at the Pals Office in the main reception area, call them on 020 7829 7862 or email pals@gosh.nhs.uk

If you would like to talk to other parents who have experienced the death of a child, please contact the Child Death Helpline on Freephone 0800 282 986 or free from a mobile 0808 800 6019.