

Minimally



Invasive Autopsy and Imaging

Information for families

Great Ormond Street Hospital
for Children NHS Foundation Trust

This leaflet has been designed to ensure we provide as much information as necessary to help you to make the decisions that are right for your family. We know that this is a difficult time for you and appreciate the time you are taking to read this information.

Whether you decide to continue with one of the options for post mortem examination or not, please be assured we will care for your baby and treat them with respect at all times. The post mortem examination consent form enables you to make the choices which are suitable for you and your baby.

The team are all experienced and specialise in working with children and babies who have died.

Why a Post Mortem Examination is useful

The aim of any post mortem examination is to work out what happened and to uncover further information which may help to understand the reasons and to provide a specific diagnosis. Traditionally, before the post mortem examination, some form of imaging takes place, including x-rays and/or photographs. The post mortem examination which then follows is carried out via incisions similar to those made in a surgical operation. The organs are examined, small samples taken and the organs are then returned to the body. While this is the current standard method of post mortem examination, many recent advances in medicine including MRI and CT scanning, which produce very detailed images of the body, and advances in endoscopic surgery, often called 'keyhole surgery', mean that an alternative approach to the post-mortem may now be possible in some cases.

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

The next section describes each option and what to complete on the consent form.

■ A Complete Post Mortem Examination – PME

This will include some imaging and uses the traditional methods to examine your baby, as mentioned earlier in this leaflet. The person discussing consent with you will be able to go into more detail upon request.

■ Minimally Invasive Autopsy – MIA

Your baby 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 baby's individual needs.

This will be followed by a targeted 'keyhole surgery' examination of the internal organs via a small (approximately <2cm/1 inch) incision in the abdomen, through which we pass a telescope 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. The samples are the same as would be taken in a traditional 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 small telescope incision and/or biopsy needle puncture

marks will be present, which will then be closed as would happen following 'keyhole surgery' in life. There will be no other incisions made and no organs will be retained. If there is a specific need to examine the brain, this will be removed using a standard (traditional) approach and samples taken.

■ **A Limited Post Mortem Examination**

Only those areas which you list will be examined. There will still be an external examination and some imaging. The incisions will be made to specific areas and will be repaired as with all post mortem examination approaches.

■ **External and Imaging Autopsy (EIA)**

Your baby 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 baby's individual needs. We will not make any incisions nor take any samples from your baby. If you have given permission for storage of genetic tissue and your baby's placenta is not suitable we may have to take a small piece of umbilical cord from baby.

Types of imaging

The team will work out which type of imaging will give them the most information about your baby. This will differ according to your baby's age, weight and specific medical information. The most frequently used imaging are x-rays, CT scans to look at bones and MRI or ultrasound to look inside at your baby's tissues. If your baby is particularly small (under 20weeks' gestation), a different technique called microfocus CT might be the most useful – the team will discuss this with you. Currently microfocus CT 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.

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 taking part in research projects involving their baby. Many of those parents who took part in research projects felt this was important for them during their bereavement.

We will ask you about the possibility of using images and samples for research during our discussion about the post mortem. This is your choice and we will only go ahead if you agree to any of the research options presented to you.

Additional imaging

In order to be sure that each type of imaging techniques used is accurate and provides 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, we will ask you if it is acceptable for us to take additional imaging. This means that while your baby is with us, we may take multiple images using the different methods as listed above before the agreed type of post mortem examination 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 agree, 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 to understand what happened to your baby.

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 to advance knowledge and techniques for the future.

Scheduled purposes

- Quality assurance and control – For example, having the ability to use images and/or samples to check that our processes and equipment give reliable results
- Audit – Analysis and examination to show the accuracy of our reports.
- Teaching and education – Demonstration and training for professional staff in anatomy, physiology, radiology, and professionals in related areas.
- Ethically-approved research – All research projects need ethical approval before they can go ahead. Examples of recent research at GOSH include using keyhole surgery, looking for disease in specific age groups, identifying natural changes in organs and tissue.

Please be assured, your baby will be treated with care and respect at all times while undergoing any procedure.

Placenta examination

Regardless of the agreed type of post-mortem examination, the placenta will usually be transferred to us with your baby. The placenta will be examined and sampled so even if you have only agreed to an external and imaging autopsy, you will still be asked about tissue blocks and slides taken from the placenta.

Report

Following the post mortem examination, the results of all investigations will be issued in a standard post mortem report. You will usually be offered a follow up appointment and will have full access to the report via your doctor.

Do I have to agree to a post mortem examination?

It is entirely up to you to decide. You will be given as much information as you need to ensure you make an informed decision. You will have already been given a booklet explaining traditional post mortem examinations. This leaflet has been designed to give you more information about the alternative specialist options available at GOSH.

Do I have to agree to take part in additional imaging or additional tissue research?

It is completely your decision. If you decide to take part, please ensure this is indicated on the consent form. You may be asked to sign a separate consent form for a specific project. If you do not wish to take part in research, please ensure this is indicated on the consent form.

Who do I speak to if I have further questions or concerns?

If you would like to speak to someone who is not directly involved in the study, please contact The Mortuary Team, (Great Ormond Street Hospital).

**Tel: 020 7829 7906 or 020 7405 9200
Ext 7906. You can also send an email to gosh.mortuary@nhs.net**

If you have any complaints about the way in which the project is being or has been conducted, please discuss them with the mortuary team at Great Ormond Street Hospital in the first instance.

If the problems are not resolved, or you wish to comment in any other way please contact the hospital **PALS service on 020 7829 7862 (direct line) or email pals@gosh.nhs.uk**

There are also a number of charities and patient support groups that support parents whose baby or child has died. You may wish to contact them for support at this difficult time. They include:

- **Sands**, the stillbirth and neonatal death charity
Helpline 020 7436 5881 Website www.uk-sands.org
- **The Lullaby Trust**, for anyone affected by a sudden infant death
Helpline 0808 802 6868
Website www.lullabytrust.org.uk
- **The Child Death Helpline**, for anyone affected by the death of a baby or child of any age
Helpline 0800 282 986 or 0800 800 6019

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Great Ormond Street Hospital for Children NHS Foundation Trust
Great Ormond Street
London WC1N 3JH

www.gosh.nhs.uk