The ROYAL MARSDEN
NHS Foundation Trust

Further details about your child's postmortem examination and/or postmortem biopsies

Children's Unit

Patient Information

NHS

Introduction

The aim of any postmortem examination is to work out what happened and to uncover further information which may be relevant to understand the reasons for death. It is a detailed physical examination of your child after they have died. Sometimes, some form of imaging scans are completed followed by examination of your child and taking some tissue samples.

The consent form states the nature and extent of the postmortem examination, and your explicit permission is required for retention of any organ or tissue for any purpose.

There are many options open to you and nothing will begin until the agreed cooling off period is complete. This cooling off period is usually a minimum of 24-hours after your child has died.

What is a postmortem examination?

There are different methods of postmortem examination. You will have several choices. Recent advances in medicine including MRI and CT scanning, and advances in endoscopic surgery, often called 'keyhole surgery', mean that an alternative approach to the postmortem examination may now be possible in some cases. It is entirely your decision to give permission for a hospital postmortem examination or postmortem biopsy.

A complete postmortem examination

This involves a detailed examination of your child's organs and tissues. This will include some imaging and uses traditional methods to examine your child. The postmortem 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 your child's body. Afterwards all incisions will be repaired and covered.

If a detailed neuropathological (brain) examination is also agreed, then this is a longer process taking at least two weeks.

You will be asked if you wish to delay funeral arrangements until the brain can be returned, or to donate the whole brain for research or have the brain 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.

A limited postmortem examination

You can specify which areas of the body which will be examined. There will still be an external examination and sometimes some imaging scans. Any incisions needed will be made to the specified areas only and then closed. 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.

Minimally invasive postmortem

This will include an external examination and sometimes some imaging. There are various options including MRI or CT scans, x-rays, ultrasound scans or a microfocus CT scans. What is carried out will depend on your child’s medical history and the resources of the pathology team conducting the postmortem.

This will be followed by a targeted ‘keyhole surgery’ examination of the internal organs via a small incision (approximately less than 2 cm or 1 inch) in the relevant area on the body (usually the abdomen). A telescope is passed 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. Sometimes it may be possible to use ultrasound instead to guide the instruments to ensure the samples we take are suitable. Afterwards, only the telescope and/or biopsy needle puncture marks will be visible, which will then be closed. There will be no other incisions made, no organs will be retained, and your child’s head will not have any incisions made.

If neuropathological examination is required, this will be carried out in the same way as a complete postmortem examination as described above.

Postmortem 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.

External and imaging biopsy

Your child will have an external examination, and we may carry out some imaging depending on your child's medical history. There are various options including MRI or CT scans, x-rays, ultrasound scans or microfocus CT scans.

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. Options include MRI, CT scans, x-rays, ultrasound scans or microfocus CT scans.

Who carries out the postmortem?

A pathologist carries out the postmortem examination in the mortuary assisted by an anatomical pathology technologist (APT). A pathologist is a fully qualified medical doctor who has specialist training in pathology. Pathology is the study of disease processes. 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 postmortem examination.

What is a research postmortem?

Research studies:

You may also be asked if you want to help with a research study, perhaps by agreeing to additional imaging or samples. Your oncologist should explain the research study to you fully and answer any questions before you decide. They may write this on the consent form for the postmortem examination or ask you to sign a separate form.

At the Royal Marsden we have been able to offer further options for parents to consider when discussing postmortem examinations. The postmortem examination options that you can now choose from have been developed due to parents participating in research projects involving their child. 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 postmortem discussion. This is your choice, and we will only go ahead if you consent to any of the research options presented to you.

Additional imaging

To be sure that each type of imaging technique used is accurate and provides the same quality of information and diagnosis as an invasive postmortem 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. Whichever type of postmortem examination you choose you will be asked if it is acceptable for us to take additional imaging. This means while your child is with the pathologist, they may take multiple images using the different methods. These images will be specifically taken for research purposes and will not be used to give clinical information, nor will they delay the postmortem examination in any way. This research will give more information to help parents in the future and help other professionals in postmortem examination techniques.

Additional tissue samples

Tissue samples are taken routinely at postmortem examination. These samples are used for diagnostic purposes and may also be used for additional purposes such as quality assurance and audit, training and ethically approved research. Whichever type of postmortem examination you decide to consent to you may be asked if it is acceptable for us to take additional tissue samples. The samples taken at postmortem 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

It is difficult to get enough information from a visual (macroscopic) examination of whole organs. Sometimes, 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 postmortem, 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 standard 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.

You can choose as many or as few of these 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.

What will my child look like after a postmortem 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 postmortem examination will have been done in a sensitive way and where possible most of the incisions will be 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 postmortem 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 with your funeral director or one of the paediatric palliative care team.

Who can I talk to about my child's postmortem results?

Following the postmortem examination, the results of all investigations will be issued in a standard postmortem examination report. This will be sent to your child's oncologist.

If you would like to receive the report, and to have a detailed discussion about the results of the postmortem examination or biopsy, you can ask to have an appointment with your child's oncologist. They will go through the report with you, if you wish, explaining medical terms or details.

Where can I seek further information and support?

Talk to your child's oncologist or a member of the palliative care team in the first instance as they will probably have been your point of contact up to now.

Children and Young People's Palliative Care Team

Tel 020 8661 3625

Monday to Friday, 9am – 5pm

If you would like to talk to other parents who have experienced the death of a child, please contact:

Child Death Helpline:

Freephone 0800 282 986 or free from a mobile 0808 800 6019

Notes and questions

References

This booklet is evidence based wherever the appropriate evidence is available, and represents an accumulation of expert opinion and professional interpretation.

Details of the references used in writing this booklet are available on request from:

The Royal Marsden Help Centre
Telephone: Chelsea 020 7811 8438 / 020 7808 2083
Sutton 020 8661 3759 / 3951
Email: patientcentre@rmh.nhs.uk

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Should you require information in an alternative format, please contact The Royal Marsden Help Centre.

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