

Post-mortem examination – your choices about organs and tissue

When someone dies it can be a distressing and confusing time for family members. In some circumstances a post-mortem examination may be required or requested. This is an examination of a body after death and during this examination; organs and tissue samples may need to be removed for investigation. After the post mortem-examination decisions will need to be made about what should happen to the removed organs and tissue samples.

This information has been provided to support those who are bereaved and are affected by a post-mortem examination. It may also be useful for professionals who work with the bereaved or seek consent for post-mortem examinations.

If a post-mortem examination is required or requested then a discussion should take place between you and a professional from the hospital or the coroner's service. This discussion should cover what you can expect; what will happen; and what your rights are. It should also provide you with information to help you make decisions about what happens to organs and tissue samples that may need to be removed for investigation.

During a difficult time you may wish to take this information away with you to read in your own time and to refer back to during or after your discussions.

*This information takes the form of questions and answers and can be used in full or in part, as required. It applies in England and Wales. It does not apply in Northern Ireland or in Scotland. See **Further information and support** section for more details.*

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If a post-mortem examination is required or requested what should you expect?

- That in some cases you will be asked to make some decisions. These may be to discuss any need for consent, or to decide what happens to organs and tissue samples that may need to be removed for investigation. Your wishes will be respected.
- That you will have the opportunity to have a discussion with a professional trained in seeking consent. This should include a full explanation of what the organs and tissue samples may be used for, and any benefits to the family of keeping tissue. This is so that you have all the information you need to help you reach a decision.
 - That any particular needs that you have, which could be cultural, religious or practical, will be taken into account as far as possible.
 - That where consent is not given for storage of organs or tissue samples they are disposed of in a timely and respectful manner.

What is a post-mortem examination?

A post-mortem examination is the examination of a body after death and can also be called an autopsy. Post-mortem examinations are carried out for two main reasons:

1. At the request of a Coroner, because the cause of a death is unknown, or when a death happens unexpectedly or suddenly.
2. At the request of a hospital, to provide information about an illness or cause of death, or to advance medical research.

These medical examinations of the body can be extremely useful in determining how, why and when someone has died, or providing information about the effect of treatment given, or the events leading up to death. They can also be useful to better understand how a disease has spread; or whether the person who died had a genetically inherited disease. Finding out more about illnesses may help doctors treat patients in the future.

Post-mortem examinations are carried out by Pathologists, trained doctors who work to standards set by the Royal College of Pathologists and the Human Tissue Authority (HTA).

A Coroner's post-mortem examination is carried out under the authority of a Coroner to find out how someone died, and whether an inquest is necessary. You will not be asked to give consent for a Coroner's post-mortem examination. This is because the Coroner is required by law to investigate deaths which are violent, unnatural or sudden with unknown cause, or those which occurred in prison.

In some circumstances a Coroner may open an inquest into the death of an individual after a post-mortem examination. If the Pathologist certifies that they have a bearing on the cause of death, the Coroner may require that any retained organs and tissue blocks and slides are kept until the Coroner's function is complete. Similarly if there is a possibility of criminal involvement in the death, tissue may be needed by the police as evidence, separate to the Coroner's requirements.

In both cases, the tissue samples, blocks and slides or organs may need to be kept for several months, in some cases, years. As a result this may affect what you want to happen to them.

If there is a need for an inquest, this and the implications will be discussed with you by the Coroner's office.

A hospital post-mortem examination is sometimes requested by a hospital, to provide information about an illness or cause of death, or to advance medical research. A hospital post-mortem examination can only take place with consent. Sometimes the person may have given consent before they died. Where this is not the case a person close to them can give [consent](#). In these circumstances, the Medical Certificate of the Cause of Death will usually have been issued before the post-mortem examination, but the doctors who looked after the person before they died may request the examination to obtain more information.

Hospital post-mortem examinations can be limited to certain areas of the body, such as the head, chest or abdomen, and this will be discussed with you when your consent is sought. Only those organs or tissue you agree to can be removed and will be examined.

The HTA recommends that you should be given 24 hours to consider your decision about the post-mortem examination, and that you will be given details of someone to contact if you change your mind.

What happens during a post-mortem examination?

The post-mortem examination will be carried out as soon as possible and usually within two to three working days after the death. It may be possible to arrange it within 24 hours if necessary. The examination will be carried out in a post-mortem examination room, rather like an operating theatre, which is licensed and inspected by the HTA.

During a standard post-mortem examination the body is opened and organs are removed for examination. Most of the time, a diagnosis can be made by looking at the organs, and they will then be returned to the body.

What are organs and tissue?

Organs and tissue are made up of cells. **Tissue** is a collection of cells with a specific role. Tissues include blood, blood vessels and muscle. Small samples or biopsies taken from organs are often classed as tissue. **Organs** are made up of more than one type of tissue and have a specific role in the body. They also have their own structure and blood supply. The body has many organs including the brain, heart, lungs, kidneys and liver.

Why do organs and tissue need to be retained?

In around 20% of adult post-mortem examinations and in most paediatric post-mortem examinations, the cause of death is not immediately obvious. A diagnosis can only be made by retaining small tissue samples of relevant organs for more detailed examination. The Pathologist may need to retain a whole organ for a full assessment to allow an accurate diagnosis of the cause of death to be made. For example, this may be the brain in cases where there has been a head injury or the possibility of a complex disease like Alzheimer's disease or multiple sclerosis, or the heart to confirm disorders like congenital heart conditions. When this happens the organ or tissue is normally sent to a specialist unit.

These full assessments often take weeks or even a few months to complete, depending on the extent of the investigations required. Once they are complete, the Pathologist will produce a report for the Coroner or the medical staff responsible for the care of the person before they died.

Tissue samples

Small tissue samples which are needed for further examination are usually set into blocks made from paraffin wax. The wax blocks are sliced into very thin layers, which are about ten times thinner than a hair. These slices are placed onto glass slides and stained with a special dye to allow cells to be studied under a microscope.

Organs

If whole organs, part of an organ, or tissue are needed for more detailed examination, they will normally be treated with a chemical that preserves them. Samples of the organ or tissue may then be processed into blocks and slides as described above.

What happens when the post-mortem examination is complete?

When the post-mortem examination is complete, you will be told whether tissue samples and organs have been retained.

If tissue samples and organs have been retained then you should expect to be given a choice about what happens to them when they are no longer needed by the Coroner or the hospital. Your consent will be needed for any tissue samples or organs to be kept for future use such as research or education and training of medical staff. [An example of a consent form.](#)

Blocks and slides

With your consent, the tissue blocks and slides may be stored as part of the record of the post-mortem examination, sometimes called the pathology or medical record, in case they are useful to your family in the future. If the post-mortem examination takes place in a Local Authority Public Mortuary, rather than an NHS Mortuary, then your consent will be taken to mean that you agree to the transfer and storage of the blocks and slides within the healthcare sector.

The samples may also be useful for one or more of the following: teaching, [research](#), clinical audit or quality assurance (this list is not exhaustive). These samples can be a very valuable resource that helps answer important medical questions and improve patient care for others. However, for them to be kept and used for these purposes, your consent must have been given.

Alternatively, where consent is not given for storage of organs or tissue samples they are disposed of in a timely and respectful manner. In summary, your options are:

- The organisation storing the blocks and slides may dispose of them.
- If a funeral has already taken place, then the blocks and slides can be returned to you, usually via your funeral director. It is advisable to discuss this with your funeral director when the funeral is arranged as there may be a charge for this. There may also be health and safety issues that may prevent this option.

- The blocks and slides may be returned with the body before the funeral. It is important to realise that choosing this option could significantly delay the funeral. Some crematoria do not allow blocks and slides to be cremated with the body.

Whole organs and tissue samples

Organs and tissue samples cannot be stored as part of the medical record in the same way that blocks and slides are. They can be re-united with the body, or buried

or cremated separately. Alternatively they can be retained for future use in teaching, ethically approved research, audit and other clinical purposes, but only with your consent. Organs and tissue can be a very valuable resource which assists in improving patient care for others. For example, there is a considerable amount of research carried out on retained organs, particularly brains, which are usually stored in collections known as brain banks.

Who can give consent?

The most important wishes to consider are those of the person who has died. If it is known that the person who has died gave consent or specifically did not want to give consent to the retention of tissue samples or organs, then those wishes must be respected.

If their wishes are not known, then a person nominated by them when they were alive, or someone in a relationship with them or closely related, must give consent. The Human Tissue Act defines a list of [‘qualifying’ relationships, which are ranked](#). That means that the person nearest the top of the list should be approached and a decision of that person cannot be overturned by someone below them in the list. The spouse or partner is highest on the list, and a long term friend is at the bottom. If there is more than one person at the same level, for instance there may be two or more siblings, consent is only required from one of them.

As defined in the Coroners Rules, any ‘properly interested person’ may give a decision to the Coroner about how the samples must be treated when their investigation has ended. Whilst the relationships between the person who has died and the properly interested person are similar to ‘qualifying relationships’, they are not ranked in the same way. If a decision to retain tissue samples or organs is made by a properly interested person, a Pathologist or another healthcare professional may need to contact the family to make sure the requirements of the Human Tissue Act are met for storage and / or use of the material for medical research or other purposes.

What is the role of the Human Tissue Authority (HTA)?

With the interests of the public and those we regulate at the centre of our work, we aim to maintain confidence by ensuring that human tissue is used safely and ethically, and with proper consent. In England, Wales and Northern Ireland, all hospital and local authority mortuaries where post-mortem examinations take place are licensed and inspected by the HTA and must show they meet our standards. Valid consent is at the centre of the Human Tissue Act – the law that established the HTA.

If our standards are not met, we take action which ranges from providing advice and guidance, restricting activity in a mortuary or, in extreme cases, asking an

establishment to stop working until our standards are met. The HTA does not regulate Coroners and is not responsible for the professional practice of Pathologists.

More information about our work, including a code of practice on Post-mortem examination, is available at: www.hta.gov.uk. If you have any questions please [contact us](#) email enquiries@hta.gov.uk or phone 020 7269 1900.

How do I make a complaint?

Complaints or allegations about your experience at an establishment licensed by the Human Tissue Authority (HTA)

A list of establishments licensed by the HTA is available at

www.hta.gov.uk/licensingandinspections/listoflicensedestablishments.cfm

If you have a complaint or concern about an organisation licensed by us you should first raise the issue directly with them, so they have the opportunity to deal with your concern themselves. If you are not satisfied by the response you can contact the independent complaints handling channels such as the Parliamentary and Health Service Ombudsman at www.ombudsman.org.uk/ or by calling 0345 015 4033. If it is a public mortuary please contact your local authority.

The HTA will assess any allegations (including whistle blowing) made to us according to the risk of not meeting the requirements of the Human Tissue Act 2004 (the Act) or our licensing standards. If you have an allegation about a licensed establishment please email enquiries@hta.gov.uk or telephone 020 7269 1900.

Complaints about a Pathologist who conducts the post-mortem examination

Most complaints about Pathologists can be dealt with through the doctor's employers, who will have their own procedures for dealing with complaints. The General Medical Council, which is responsible for ensuring that doctors in the UK have the right knowledge and skills to practise medicine safely, deals with the most serious complaints about a doctor's practice. The General Medical Council can take action to stop or restrict a doctor's practice. You can submit a complaint online at www.gmc-uk.org/patient_online_complaints. For further information, or if you wish to speak to an adviser, please telephone 0161 923 6602.

Complaints about a Coroner's personal conduct

A complaint about a Coroner's personal conduct, such as inappropriate behaviour or comments, should be made to the Office for Judicial Complaints (OJC). This incurs no cost and can be done online on the Office for Judicial Complaints website at: www.judicialcomplaints.judiciary.gov.uk/. Alternatively, the complaints form can

be downloaded and sent by fax, post or email. The complaint may either be made using the suggested form or by letter or email. The OJC's contact details are: Office for Judicial Complaints Steel House 11 Tothill Street 3rd Floor, 3.01-3.03 London, SW1H 9LJ, Tel: 020 3334 0145; email: inbox@ojc.gsi.gov.uk; fax: 020 3334 0031; Minicom VII 020 334 0146 (Helpline for the deaf and hard of hearing).

All complaints about the conduct of deputy coroners and assistant deputy coroners should be sent to the Coroner in writing. If it is considered that the Coroner's handling of a complaint about a deputy or assistant deputy amounts to personal misconduct of the Coroner then that allegation might be referred to the Office for Judicial Complaints. However, the Office of Judicial Complaints could not deal with or determine the actual complaint against the deputy or assistant deputy coroner.

Complaints about the coroner's service

All complaints about the administration of the coroner service or the conduct of coroners' officers should be raised first with the relevant Coroner, in writing. The letter should also be copied to the local authority which funds the service.

A complaint may also be made direct to the relevant local authority. If you are dissatisfied with the council's response, the next step is to complain to the Local Government Ombudsman at www.lgo.org.uk/making-a-complaint, or by calling 0300 061 0614 or 0845 602 1983. Alternatively, a complaint may be made in writing to: The Local Government Ombudsman, PO Box 4771, Coventry CV4 0EH.

There is no charge to complain about the standard of service from a coroner's office.

Complaints about the Human Tissue Authority (HTA)

A complaint about the HTA, its staff or Members can be made face to face, by letter, email or telephone. Correspondence should be sent by post or email to Complaints Officer, Human Tissue Authority, 151 Buckingham Palace Road, London, SW1W 9SZ; email enquiries@hta.gov.uk. You can also call 020 7269 1900. More information about the HTA's complaints policy can be found at:

www.hta.gov.uk/aboutus/complaintsprocedure.cfm

Further information and support

Cruse Bereavement Care: For help and support you can telephone the Cruse Bereavement Care national helpline on 0844 477 9400 or email helpline@cruse.org.uk. Their website is at: www.crusebereavementcare.org.uk/

Foundation for the Study of Infant Deaths (FSID) have a Freephone helpline, 0808 802 6868 and they provide bereavement support through their befriender network and bereaved parents discussion forum at:

<http://fsid.org.uk/page.aspx?pid=309>

INQUEST provides a specialist, comprehensive advice service to bereaved people in England and Wales on contentious deaths and their investigation.

www.inquest.org.uk/

The Ministry of Justice has published a leaflet A Guide to Coroners and Inquests, which can be downloaded from the DirectGov website:

www.direct.gov.uk/en/Governmentcitizensandrights/Death/WhatToDoAfterADeath/DG_066713

Patient Concern is an organisation committed to promoting choice and empowerment for all health service users. They have published a *leaflet All you need to know about post mortems*, which can be obtained by emailing the organisation on patientconcern@hotmail.com or writing to Patient Concern, PO Box 23732, London, SW5 9FY.

Stillbirth and Neonatal Death charity (Sands) supports anyone affected by the death of a baby and promotes research to reduce the loss of babies' lives. They have published a range of support and information leaflets at: www.uk-sands.org/Publications/Support-and-information-leaflets.html

Their helpline number is 020 7436 5881.

Northern Ireland

The HTA regulates post-mortem examination in Northern Ireland although this guidance does not apply there. Updated information for Northern Ireland will be available on the Department of Health, Social Services and Public Safety (DHSSPS) website in due course.

Scotland

The HTA does not regulate post-mortem examination in Scotland and this guidance does not apply there. The Scottish Government's website provides some general information at www.scotland.gov.uk/Publications/2004/02/18927/33310. You can also call the Central Enquiry Unit on 08457 741 741, or 0131 556 8400; or fax 01397 7950. Alternatively you can email ceu@scotland.gsi.gov.uk or write to General Enquiries, St. Andrew's House, Regent Road, Edinburgh, EH1 3DG.

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