



INFORMATION LEAFLET FOR PATIENTS WITH MOTOR NEURONE DISEASE WHO WISH TO AUTHORISE THEIR OWN POST MORTEM EXAMINATION

If you wish to make arrangements for a post mortem examination to take place, this is now possible under the Human Tissue (Scotland) Act 2006 which allows you to say exactly what should happen to your body after death.

This leaflet aims to provide information for people who have been diagnosed with motor neurone disease and who may wish to make arrangements before they die for what happens to their body after death. In particular, information is provided for people who wish to indicate their willingness for a post mortem examination to be carried out following their death, the purpose of which may be to provide a full diagnosis for their families and/or to donate tissue samples and/or organs for research purposes.

Although the results of a post mortem examination cannot benefit you directly, it may contribute to the advancement of medical knowledge and education in relation to motor neurone disease.

It is vital that you feel you have sufficient information to make the important decision of whether you wish to authorise a post mortem examination to happen after your death. We have prepared some information for you in the format of answers to questions that are often asked. Please take some time to read the following information carefully and discuss it with your family, friends or general practitioner if you wish.

If you do decide that you wish to make these pre-arrangements, the paperwork attached to this leaflet should be completed in conjunction with your next of kin. You should in any case make your decision known to your family and to your family doctor.

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What is a post mortem examination?

After death your body would be taken to the hospital mortuary at the Royal Infirmary of Edinburgh where a pathologist, assisted by skilled mortuary staff, would make an external and internal examination of the body cavities. The post mortem examination undertaken can be limited if you wish to only make available tissues from the central nervous system (brain and spinal cord), or may be more extensive in which case the organs of the chest and abdomen are also examined. During this examination the major organs, including the brain, would be lifted out and examined. Before the organs are returned to the body small samples of each would be retained for later examination under a microscope to confirm the diagnosis, and specific tissue samples would be stored for research purposes. There will be no costs passed onto your family with regard to the transport of the body to the Royal Infirmary of Edinburgh for those from the Lothian or Fife Health Board areas.

After the post mortem examination, the body is carefully reconstituted by the mortuary staff. There is no disfigurement of the body and the face and hands are not touched. The body is then released to the family for funeral arrangements with all organs replaced. The pathologist will prepare a report of the diagnostic findings and the cause of death, information which may be helpful to your family.

If your death occurs suddenly, or away from home, it might be that your doctor is unable to sign a death certificate because they are unsure of the cause of death. In such cases your death might be further investigated by the medicolegal authorities (Procurator Fiscal in Scotland or Coroner in England and Wales) who are likely to state that a forensic post mortem examination will take place to establish the cause of death. Even in these circumstances, it is helpful for the legal authorities and for your family if you have stated your wishes about what you want to happen to your body.

The post mortem examination also forms an essential contribution to the training both of young doctors who wish to specialise in pathology and of other health care workers who require to have an in depth knowledge of the working of the human body.

What do we mean by tissue?

Tissue is the word used for a collection of specialised cells within the human body that perform a specific job. All organs, including the brain and heart, are made up of tissue.

What do we mean by organ?

An organ, such as the lung, heart or brain is a collection of tissue or tissues which together undertake a specific function within the body. Some organs perform very complex tasks and when they are altered by disease, require careful and comprehensive examination. It is only by examination of the effects of disease or of the effects of treatment that medical knowledge can advance.

I know that I suffer from motor neurone disease. Is it still useful for a post mortem examination to be undertaken?

There is active research aimed at finding cures for future sufferers of this condition. It is essential for the long term success of these research programmes that human tissue derived from autopsy examinations is available, and your decision to make tissue available for

research after your death will benefit research scientists and hopefully, in time, other patients.

Is post mortem examination still possible if I have not arranged it beforehand?

Yes. Your next of kin can authorise a post mortem examination through the usual hospital channels. At the time of death a member of the medical staff will talk with your relatives and at this point your next of kin can discuss the possibility of a post mortem examination with them.

NHS Lothian has a contract with an approved funeral director and this avoids any additional costs for relatives. Funeral arrangements can be made with any funeral director but transport of the deceased to a from the Royal Infirmary Edinburgh will be undertaken by Barclays Funeral Directors and there will be no cost to relatives.

What happens to my body after the post mortem examination?

Following the post mortem examination and removal of tissue samples and/or organs your body will be returned to the undertaker who will be responsible for the funeral arrangements.

Will my family be able to view my body?

Yes. Your family would be able to view your body either before or after the examination if they so wish. The procedure of post mortem examination and tissue retrieval does not disfigure the body and should not cause your family any added distress.

If I agree to donate organs and tissue samples for research, how long will my tissue be stored?

The preservation techniques ensure that tissue will be usable in research studies for many years. Generally, tissue will be used for as long as it is feasible to do so.

If I agree to donate for research, how will my organs and/or tissue samples be used?

These will be used for ethically approved medical research in the field of motor neurone disease. This may include research into the causes of disease and the development of effective treatments, sometimes by drug companies. Donated human tissues are used in research on a not-for-profit basis. Your family would not benefit financially if any research leads to the development of a new test or treatment.

Tissue may be used for protein, RNA or DNA analysis in future studies, and may be used for genetic studies.

Will my decision affect the funeral arrangements?

No, the funeral arrangements can proceed and will not be delayed or otherwise affected by your agreement to make a donation.

What other information will be required?

The pathologist undertaking the post mortem examination will need to have access to your medical history, therefore permission will be requested to access your medical records.

What about confidentiality?

You can be sure that your identity and that of your family is totally confidential and that no identifying details will ever be made public.

All information obtained in this study will be stored securely in the Academic Department of Pathology, University of Edinburgh and retained indefinitely. The information may be shared in an anonymised form with other researchers, including commercial organisations, who are carrying out ethically approved research into motor neurone disease.

We request permission to contact your GP to let them know that you have agreed to take part in this study.

Researchers from other centres can request tissue to support their research programmes. Tissue will only be released to research groups with peer reviewed funding and full ethical approval for the studies being proposed. All tissue released will be completely anonymised to the research group with patient identifying data being known only to senior core staff within the Edinburgh brain bank.

What if I do not wish to proceed or I change my mind after prearranging this post mortem examination?

You may wish to change your mind after prearranging what happens to your body after death. If, after reading this leaflet you do not wish to go ahead with these arrangements, you need do nothing further. **If, after signing the attached authorisation forms you decide to change your mind, the forms can be retrieved and authorisation withdrawn (in the presence of one witness).** In this case no post mortem examination will take place. The signed forms indicating that you do not wish a post mortem examination should be placed in the care of whoever will look after arrangements after your death and your family doctor should be notified.

If you believe that you have been harmed in any way by taking part in this study, you have the right to pursue a complaint and seek any resulting compensation through NHS Lothian who are acting as the research sponsor. Details about this are available from the research team. Also as a patient of the NHS, you have the right to pursue a complaint to the Patient Liaison Manager, NHS Lothian Complaints Team, Waverley Gate 2nd Floor, 2 - 4 Waterloo Place, Edinburgh, EH1 3EG (0131 536 3370). Note that the NHS has no legal liability for non-negligent harm. However, if you are harmed and this is due to someone's negligence, you may have grounds for a legal action against NHS Lothian but you may have to pay your legal costs.

Who has reviewed the study?

The East of Scotland Research Ethics Service REC 1, which has responsibility for scrutinising all proposals for research on humans, has examined the proposal and has raised no objections from the point of view of research ethics. It is a requirement that your records in this research, together with any relevant medical records, be made available for scrutiny by

monitors from NHS Lothian, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

If there is a belief that any harm has been suffered by taking part in this study, there is a right to pursue a complaint and to seek any resulting compensation through NHS Lothian who is acting as the research sponsor. Details about this are available from the research team. Also as a patient of the NHS, you have the right to pursue a complaint to the Patient Liaison Manager, NHS Lothian Complaints Team, Waverley Gate 2nd Floor, 2 - 4 Waterloo Place, Edinburgh, EH1 3EG (0131 536 3370). Note that the NHS has no legal liability for non-negligent harm. However, if you are harmed and this is due to someone's negligence, you may have grounds for a legal action against NHS Lothian but you may have to pay your legal costs.

Thank you for taking the time to read this Information Sheet and for considering taking part in this study.