



BEAUMONT HOSPITAL

**Information Leaflet on the
Post Mortem examination
of Patients with a
Differential Diagnosis of
Creutzfeldt-Jakob Disease (CJD)**



INCJDSU

Irish National Creutzfeldt-Jacob
Disease Surveillance Unit

The Post Mortem (autopsy) Examination

Introduction

The death of a loved one can be a difficult and traumatic time for family and friends. Staff at Beaumont Hospital sympathise with you and will try in whatever way possible to be helpful and supportive at this difficult time. It may seem a major intrusion to introduce the question of a post mortem examination (also called an autopsy). There are however, very good reasons why this is necessary, which will be outlined in this Information Booklet.

The booklet explains why a post mortem is required and gives details of what is involved. It supplements the information you will have received from hospital staff at the time of your family member's death. You should be cautioned that this document gives explicit details of the post mortem examination that some may find distressing. You may prefer to have a relative or friend read the leaflet on your behalf or you may prefer to wait until you have been contacted by a staff member following the post mortem before reading the leaflet.

Why is a post mortem necessary?

The post mortem examination is one of the most informative examinations in medicine. It provides objective details on a patient's illness, on the response to treatment and on the cause of death. Modern diagnostic tests may provide a lot of information but they do not provide all the answers. The post mortem is the ultimate means of establishing a medical diagnosis and cause of death.

Why is a post mortem necessary for patients who may have CJD?

CJD is a notifiable disease in Ireland. The 1947 Health Act entitles the Minister for Health to specify by regulation the diseases that are infectious diseases and covered by legislation (i.e. so-called notifiable diseases). A definitive diagnosis of CJD is usually only made after death and as a result, all patients with a potential diagnosis of CJD must be notified to the coroner. The coroner will then instruct the Neuropathologist in Beaumont Hospital to perform the post mortem on his/her behalf.

What is a post mortem?

(Please note that this section of the booklet contains specific information about the post mortem examination)

A post mortem is an examination of the body of a person who has died. The procedure is performed to verify the cause of death and/or examine the effects of treatment. Post mortems are performed by a pathologist who is a medical doctor specifically trained to identify disease in organs and tissues.

The pathologist firstly ensures that there is valid instruction from the coroner or the family to proceed with the post mortem, confirms the identity of the deceased and reviews the clinical record and the accounts of the circumstances of death.

External Examination

The skin and surface of the body is examined and any abnormalities or lesions are noted. Diagnostic images (such as x rays or scans) or photographs of lesions or scars may very rarely be taken.

Internal Examination

This part of the examination is like an operation. In most query CJD cases the post mortem is limited to examination of the brain only. This requires that an incision is made at the back of the scalp so that the top of the skull can be opened and the brain removed and examined. In certain cases a more detailed examination of the body is required. This means that a large midline incision is made from the neck to the pubic area. The major organ systems are carefully removed and examined.

Any diseased areas in the organs or tissues are noted and may on rare occasions be photographed. Small portions of tissue from each organ are taken for laboratory testing.

It is not normally obvious that a post mortem examination has taken place and the body can be viewed afterwards as if no such examination had been performed. Great care is taken with the appearance of the deceased and most of the incisions will be hidden by clothes or hair. However, be aware that the cause of death and the normal changes which occur after death may impact on the appearance of the body.

It is recommended that the deceased be embalmed. This should be carried out in an appropriate facility (CJD Surveillance Centre at Beaumont Hospital, by a qualified competent embalmer appointed by your funeral director who fulfils the requirements of Beaumont Hospital).

An account of the post mortem findings is written up by the pathologist and later results of any special examinations or tests may be added. The report is forwarded to the coroner who following review may sign the death certificate which will state the cause of death. Sometimes the coroner may request additional information from other doctors who treated the patient. In certain circumstances the coroner may order an inquest to take place. An inquest is a hearing of all evidence pertaining to a patient's death concluding with a death certificate being issued. Further information about the inquest process is available on request from your liaison social worker.

Coroner's Post Mortems

The Coroner is an independent official with responsibility under the law for the medico legal investigation of certain deaths. He/she is legally obliged to enquire into the circumstances of sudden, unexplained, violent or unnatural deaths.

REFERRAL OF A DEATH TO THE CORONER IS INDEPENDENT OF THE FAMILY'S WISHES AND FAMILY PERMISSION IS NOT REQUIRED AND THEREFORE IS NOT SOUGHT. IT IS AT THE CORONER'S DISCRETION TO DETERMINE IF A POST MORTEM IS REQUIRED.

When performing a Coroner's post mortem, the hospital pathologist is acting independently of the hospital as an officer of the Coroner. When the deceased has been referred to the Coroner for his deliberation, a member of

your family will have been asked to do a visual identification to a member of An Garda Síochána (This is normal practice as the Garda acts on behalf of the Coroner). Your family member will have been asked to sign a form indicating that they have been advised that the brain of the deceased will be retained for examination. Following the post mortem, you/your family member will be contacted with further information as outlined in this booklet. You have the option of requesting 'no further contact' in relation to the post mortem and organ retention process. If this is the case the retained organ will be cremated in Glasnevin Crematorium. (You will however be asked to sign Glasnevin Cremation Forms to indicate this decision)

What will happen to any organs retained during post mortem?

Following the post mortem, the pathologist will provide written notification to the liaison social worker indicating what organs have been retained. In most cases it will be at least four months before organs are released from the Pathology Department. You will be contacted by the liaison social worker if you indicated this who will advise you of the options that are available in relation to the sensitive disposition of any retained organs. The social worker will be happy to meet with you to discuss organ retention, organ burial or cremation and any other information or support you might require at this difficult time.

The following are the options that will be discussed with you in relation to the final disposition of the organ(s)

Return to family for private burial:

The retained organ is placed in a small casket engraved with the name of the deceased. Following liaison between the social worker, the family and the undertaker the casket can be collected from the mortuary. If the family do not wish to be present the funeral director can collect and arrange the burial on your behalf.

Cremation

The retained organ can be cremated in Glasnevin Crematorium. No ashes are returned to the family following the cremation. The next of kin of the

deceased will be required to complete some forms from the Crematorium before cremation can proceed. The liaison social worker will assist you with the process. The hospital will cover the cost incurred for the burial/cremation of the retained organ.

Will a post mortem examination delay the funeral?

Every effort is made to perform the post mortem in a timely fashion so funeral arrangements should not be delayed. The body is usually released to the undertaker on the day of the post mortem examination. We would ask however that you check with our Mortuary Services Co Ordinator before making any final funeral arrangements. Telephone number: 8528180.

Who issues the Death Certificate?

The death will be registered when the coroner's process is completed. The coroner may also request additional reports from the medical team that attended the patient. This process can, in most cases, take anything from 16 weeks to complete. The liaison social worker who will contact you following the post mortem will arrange for interim death certificates along with an information sheet on accessing the death certificate to be sent to you. This certificate can be used in some circumstances while waiting the issuing of the final certificate.

Can I get a copy of the post mortem report?

The post mortem report takes a number of months to complete. On completion of a coroner's investigation the coroner may release the report, on request, to the family or other interested parties. Families who wish to get a copy of the post mortem report can do so by contacting the coroner's office in the region where the death took place, details are available at www.coroners.ie

What is an Inquest?

An inquest is an enquiry in public by a coroner into the circumstances surrounding a death. The purpose of the inquest is to establish the facts surrounding the death and to place these facts on public record. An inquest must be held when the death is due to unnatural causes, the decision to hold an inquest is otherwise at the discretion of the Coroner. The inquest will establish the identity of the deceased, how, when and where the death occurred and the particulars which are required for the death to be registered by the Registrar to allow a death certificate to be issued.

This is a difficult time for you and your family. Please be assured of whatever information and support we can provide. Please contact the Liaison Social Worker at 8093953 if we can be of assistance to you.

The Liaison Social Worker will also be happy to advise you of bereavement support services available in the hospital or close to where you live.