

Post Mortem Information Sheet

You have been given this information sheet because you have given consent for your next of kin or relative to have a post mortem performed by staff at University College London Hospital on behalf of the National Prion Clinic. This post mortem may be being performed to help clarify the diagnosis, for research purposes, or a combination of both.

Once your next of kin or relative has died, all you need to do is contact staff at the clinic to let them know the contact details of the funeral directors you have chosen. Someone from the funeral directors or another appointed person can do this if it is more appropriate. Post mortems for people affected by Prion Disease are made a priority and are usually performed between one and four days of the person passing away (although not at weekends). Having a post mortem should not delay the funeral service although we do ask that families do not finalise a date until the post mortem has been organised. It may be possible to have an open casket at the funeral, please contact the clinic if this was not discussed when you gave consent.

Once we have the funeral directors details we forward this along with a copy of your consent form to the post mortem staff. They will liaise with the funeral directors to arrange the transport of your relative. The funeral directors bring your relative to London, wait at the hospital whilst the post mortem is performed, and then bring your relative back to the funeral home with them. The National Prion Clinic will cover the cost of the transport and we will arrange for the funeral directors to invoice us. You do not have to be involved in the post mortem arrangements.

We will contact you as soon as the results of the post mortem are available. Due to the type of tests that need to be performed to diagnose prion disease this can take several months. If you have not heard from us please contact the clinic for an update. If you wish you can come to one of our outpatient clinics on Tuesday mornings at the National Hospital for Neurology to discuss the results. Or if you prefer we can call or write to you, or inform your G.P. who can discuss the results with you locally.

We appreciate that your relative's illness and passing are both difficult and upsetting for all who cared for them, and we wish to make having a post mortem in London as anxiety free as possible. In order to monitor this service we will send you a short evaluation form and stamped address envelope so you can share your experiences with us.

You should have received a copy of the post mortem consent form and an information booklet when you gave consent, or be expecting them in the post. You will have discussed the exact details of what you have given consent for and this will be documented on the consent form. If you do not have copies of these, or you have if you have any questions regarding the post mortem or anything about prion disease, please do not hesitate to contact us

Doctor _____ Nurse: _____

Tel: _____ Tel: _____

Email: _____ Email: _____