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| Suspected Creutzfeldt-Jakob Disease Post-Mortems |
| **Information Sheet** |

What is Creutzfeldt-Jakob disease?

Creutzfeldt-Jakob disease (CJD) is one of the family of prion diseases. Prion diseases are characterised by the accumulation of an abnormal form of cellular protein in the brain. This protein may be transmitted in certain, very specific, situations from one person to another. The disease-causing protein is also very resistant to normal methods of eliminating infection.

For these reasons, post-mortems involving suspected cases of CJD follow specific procedures designed to maximise diagnostic information and minimise the risk to hospital staff from the tissue. However, a post-mortem is the only way to absolutely confirm CJD, which is why it is preferable to do one.

How long does the post-mortem procedure take?

The post-mortem is limited to the brain, so it can generally be removed the same day as the patient arrives. The body can usually be returned to family that day.

Can the brain be returned to the family after the post-mortem?

No. The brain and its coverings are a potential infection hazard. Even if the post-mortem does not confirm a diagnosis of CJD, the brain is unable to be returned because it is examined in an area and using instruments that have been used for other CJD cases. **If you, or your family, do not wish the brain to be retained and disposed of by the hospital you should decline permission for a post-mortem.**

Will we be able to view our loved one after the post-mortem?

Yes, you can view the body of your loved one after the post-mortem. However, contact such as touching or kissing is not advised. Embalming is not recommended either because of the risk of infection for the undertaker. This may mean that in some situations the undertaker will suggest you should not view the body.

What happens to the brain after the post-mortem?

Around 20 postage stamp-sized samples are taken from the brain for examination. This involves processing this tissue into small wax blocks. A small piece of frozen brain (around 2 – 3 cubic cm) is also kept for specialist testing overseas. The remaining brain is retained by the hospital until the examination is complete and no further testing is needed. After this the brain is respectfully cremated by an undertaker in Christchurch.

How long does it take to get a result from the post-mortem?

A provisional result is generally available around 8-12 weeks after the post-mortem. However, a final result may take a further six months as tissue has to be sent overseas to confirm the results.

What happens to the tissue sent overseas?

Specific tests are performed in either the United Kingdom or Australia to confirm the presence of the abnormal prion protein. Testing the small piece of frozen brain tissue is used to type which “strain” of prion protein is present.

Will the tissue sent overseas be returned?

The wax blocks and tissue slides are returned to New Zealand and stored by the pathology department at Christchurch Hospital. The overseas laboratory will usually keep a separate copy of tissue slides as part of the medical record and in case of future questions. If frozen tissue has been sent it is impractical to return it to New Zealand. Therefore, it will be respectfully disposed of overseas.

Is genetic testing performed on the tissue?

DNA may be stored from the brain tissue so that further testing can be performed subsequently if required. However, no genetic testing for prion protein *(PRNP)* mutations is carried out without specific written consent – usually in conjunction with genetic counselling. This consent is separate to the consent given for the post-mortem examination. If you have any concerns regarding a possible genetic component to the disease, please discuss this with the neurologist or physician involved.

Is research performed on the tissue?

No. Research is not performed on the brain tissue without specific written consent.

*If you have any further questions around the autopsy procedure, please discuss these with the clinical team.*

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