



Information for family members who have lost a loved one to Creutzfeldt-Jakob disease (CJD) or for people advised that they are at increased risk of developing Classical CJD (cCJD)

Family members who have lost a first or second degree relative to confirmed or suspected CJD, or have a relative suffering from suspected CJD, or individuals who have been informed that they are considered to be at increased risk of developing CJD, will be deferred from donating blood and may face screening questionnaires when completing a hospital admission form.

Family Members of a CJD patient

If you are a family member of a CJD patient and a DNA test has ruled out a genetic cause thus confirming that your loved one suffered from sporadic CJD then according to the infection control guidelines you should **not** be treated as an 'at risk of CJD' patient.

If you are a member of a family affected by genetic CJD but have yourself undergone predictive testing with a negative result for a genetic mutation to CJD or other prion diseases then you are considered to be at background risk as is the general population. Standard precautions only will be required for any procedures you may require.

'At risk of CJD' patients

If you are unsure if you fall into an 'at risk of CJD' category please contact the CJD SGN on toll free 1800 052466 and we can assist you.

Information for patient at 'increased risk of developing CJD'

- Disclosure of risk is a moral obligation not a legal obligation.
- If you are unsure of what box to tick on an admission form please contact us for advice.
- It is important that the hospital is aware of your risk status prior to admission so that staff have time to consult with the infection control department
- If your surgery or procedure does not involve high infectivity tissue ie brain, dura mater, Pituitary gland, spinal cord, Posterior eye (including retina, vitreous humour and optic nerve standard precautions will apply for the sterilisation of instruments involved in your procedure. It is however, important that time is allowed for the hospital staff to confirm this if necessary with infection control experts.

- If you are in an 'at risk of CJD' category and your procedure does involve high infectivity tissue then it may take some extra time to organise the availability of instruments that once used during your surgery can be quarantined for your use only. The earlier discussion begin with the hospital infection control staff the less delays should be experienced. Remember that our role is to assist you through each stage of this procedure and to liaise with the hospital on your behalf when needed.
- If you are having a endoscope standard precautions apply unless the procedure you are having involves a ventriculoscope. When used on a high or low risk patient a ventriculoscope must be destroyed or kept for your exclusive use o the patient. All other endoscopes may be processed using routine reprocessing.
- For all routine dental procedures instruments used can be routinely reprocessed. Routine dental treatment includes filling or cleaning of teeth, , root canal treatment and tooth extractions. If however, you require major dental surgery your dentist should refer to the Infection control guidelines <http://www.cjdsupport.org.au/docs/chapter31.pdf>