

Information for people completing a screening questionnaire on CJD prior to admission to hospital

When filling in a screening questionnaire relating to Creutzfeldt-Jakob Disease (CJD) or other prion diseases prior to admission to hospital for a surgical procedure we can assist with any questions you may have.

If you are not sure if you fall into a risk category or are uncertain what to answer on the screening questionnaire please contact the CJD Support Group Network (CJDSGN) so that we can assist you and/or refer you to where you can obtain necessary information.

If your answer is yes to any of the questions relating to CJD and other prion diseases on the admission form then it is important that the hospital receives this information prior to the day of your admission and that admission staff understands that this information needs to be referred to the infection control department.

Questions do vary on admission forms – examples of possible questions are;

- Have you received human pituitary hormones prior to 1985,
- Do you have a family history of 2 or more relatives with CJD or other unspecified progressive neurological disorder?
- Have you had a first degree relative with CJD or other prion disease?
- Have you had neurosurgery or spinal surgery that included a dura mater draft prior 1990?

The CJDSGN can assist you by making sure the hospital is aware of your risk well in advance so that appropriate advice can be obtained thus, hopefully, avoiding delays. We have developed a large network of health care professionals who are happy to share their knowledge and assist.

It is not uncommon for patients to be sent home if the risk is only identified by theatre staff on the day of the procedure or surgery. This can be avoided with good advance planning that we can facilitate on your behalf.

It is important that hospital staff become aware that no special precautions need to be taken when a procedure involves low infectivity tissue even if you are considered to be an 'at risk of CJD' patient.

If you are an 'at risk of CJD' patient needing a procedure that does involve high infectivity tissue (refer the infection control guidelines) then it may be necessary for the hospital to implement special precautions and advance knowledge will assist them to provide your care with as little delay as possible.

Don't forget that being at increased risk of developing CJD does not mean that you have CJD!!!

If you do experience any adverse situations we are here to assist and advocate on your behalf. The more problems that are brought to our attention the more we can work towards some positive changes and more knowledge.

National Toll Free number 1800 052466