

Posterior segment eye surgery (back of the eye) in relation to Creutzfeldt-Jakob disease (CJD)

Information for patients from the Infection Prevention and Control Team

Part of your routine assessment before surgery includes some questions to find out whether you could have an increased risk of Creutzfeldt-Jakob disease (CJD). We will ask you:

- **If you have ever been told that you are at risk of CJD or vCJD for public health purposes?**
- **If have you any history of CJD or other prion disease in your family?**
- **If you have ever had growth hormone or gonadotrophin treatment?**
- **If you have had surgery on your brain or spinal cord at any time in the past?**
- **If since 1980, you have had any transfusions of blood or blood components (red cells, plasma, or platelets)?**

What is CJD?

CJD is a rare brain disorder that affects about one in a million people each year. CJD is thought to be caused by the build up in the brain of an abnormal form of a protein called a 'prion'.

Unfortunately CJD is fatal, and as yet there is no known cure. There are different types of CJD, including variant CJD (vCJD). vCJD is caused by eating meat from cows infected with BSE.

How can CJD spread from person to person?

A person who is infected with CJD may have abnormal prion protein in their body for years before becoming ill. If that person has an operation, or donates blood, tissues, or organs, during that time, the abnormal prion protein that causes CJD could spread to other patients.



Why are we asking you about CJD before your operation?

The abnormal prion protein that causes CJD is very hard to remove or destroy. If surgical instruments are used on a patient who is infected with CJD they may still have prion protein on them, even after they have been properly washed and disinfected. They could then spread CJD to other patients. This is particularly important for operations on the brain, spinal cord, and the back of the eye, as these parts of the body could contain the largest amount of abnormal prion protein.

What have these questions got to do with CJD?

CJD has been spread in several ways, and different groups of people may have an increased risk of CJD.

- We ask whether there is anyone in your family who has had CJD because some types of CJD can be inherited. These types of CJD are caused by faulty genes and may be passed from parent to child.
- We ask whether you have had surgery on the brain or spinal cord because some of these operations used to use grafts of 'dura mater' (the tough lining round the brain and spinal cord). Some of these grafts have been linked to CJD infection; these grafts are no longer used.
- We ask whether you have had a large number of blood transfusions as this could be related to an increased risk of variant CJD (vCJD). vCJD can be spread through blood transfusions.

We do not know how many blood donors are infected with vCJD, even though they appear to be healthy, or how easily vCJD might spread through blood transfusions. This means that the risk of vCJD to someone who has received blood is very uncertain. It is only worth considering if patients have received extremely large amounts of blood. Even then the risk is still very uncertain.

What happens if I answer 'yes' to any of these questions?

If you answer 'yes' to any of these questions, medical staff will look at your medical records in more detail to determine whether or not you may have an increased risk of CJD.

What will happen if I have an increased risk of CJD?

If you do have an increased risk of CJD special precautions will be taken with the surgical instruments used in your operation. Your GP will be told and they will ask you to come and discuss what this means in more detail.

Please remember that the overall risk of CJD spreading by these routes is generally very low. These questions are an extra measure to prevent CJD spreading through surgery. This should not affect the medical care you receive now or in the future.

What if I do not have a GP?

The Health Protection Unit for your area will make sure that another doctor discusses this with you.

Can I have a blood test to see if I am infected with CJD?

No, there is no blood test available yet which could show if you have CJD.

Where can I find out more?

The following organisations offer further information and support.

- **Public Health England**
Web: www.gov.uk/government/collections/creutzfeldt-jakob-disease-cjd-guidance-data-and-analysis#diagnosis-and-management
- **CJD Support Network**
Web: www.cjdsupport.net
- **National CJD Research and Surveillance Unit**
Web: www.cjd.ed.ac.uk
- **National Prion Clinic**
Web: www.nationalprionclinic.org/

This leaflet has been produced with and for patients

If you would like this information in **another language, audio, Braille, Easy Read, or large print** please ask a member of staff. You can ask someone to contact us on your behalf.

Any complaints, comments, concerns, or compliments please speak to your doctor or nurse, or contact the Patient Advice and Liaison Service (PALS) on 01227 78 31 45, or email ekh-tr.pals@nhs.net

Patients should not bring in large sums of money or valuables into hospital. Please note that East Kent Hospitals accepts no responsibility for the loss or damage to personal property, unless the property had been handed in to Trust staff for safe-keeping.

Further patient leaflets are available via the East Kent Hospitals web site www.ekhuft.nhs.uk/patientinformation