



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

Information for patients from Infection Prevention and Control

You have been referred for posterior segment eye surgery. 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 you have a history of CJD or other prion disease in your family?**
- **If you have had growth hormone or gonadotrophin treatment?**
- **If you have had surgery on your brain or spinal cord?**
- **If since 1980, you have had any transfusions of blood or blood components (red cells, plasma, or platelets)?**

We hope the leaflet will help to answer some of the questions you may have. If you have any further questions or concerns, please speak to a member of your healthcare team.

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 (bovine spongiform encephalopathy).

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. The abnormal prion protein could spread to other patients, if during that time the person:

- has an operation; or
- donates blood, tissues, or organs.

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. 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 your brain or spinal cord because in the past some of these operations used grafts of 'dura mater'. Dura mater is 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 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 you may have an increased risk of CJD.

What will happen if I do 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.

Further information

- Creutzfeldt-Jakob disease (CJD): guidance, data and analysis: UK Health Security Agency (UKHSA) (<https://www.gov.uk/government/collections/creutzfeldt-jakob-disease-cjd-guidance-data-and-analysis>)
- CJD Support Network (<https://cjdsupport.co.uk/>)
- National CJD Research and Surveillance Unit (University of Edinburgh) (<https://www.cjd.ed.ac.uk/>)
- National Prion Clinic (University College London Hospitals NHS Foundation Trust (UCLH)) (<https://www.ucl.ac.uk/national-prion-clinic/>)
- NHS: Creutzfeldt-Jakob disease (<https://www.nhs.uk/conditions/creutzfeldt-jakob-disease-cjd/>)

This leaflet has been produced with and for patients.

Please let us know:

- If you have any accessibility needs; this includes needing a hearing loop or wanting someone to come with you to your appointment.
- If you need an interpreter.
- If you need this information in another format (such as Braille, audio, large print or Easy Read).

You can let us know this by:

- Visiting the Trust web site (<https://www.ekhuft.nhs.uk/ais>).
- Calling the number at the top of your appointment letter.
- Adding this information to the Patient Portal (<https://pp.ekhuft.nhs.uk/login>).
- Telling a member of staff at your next appointment.

Any complaints, comments, concerns or compliments, please speak to a member of your healthcare team. Or contact the Patient Advice and Liaison Service on 01227 783145 or email (ekh-tr.pals@nhs.net).

Patients should not bring 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 has been handed into Trust staff for safe-keeping.

Further patient information leaflets are available via the East Kent Hospitals' web site (<https://www.ekhuft.nhs.uk/patient-information>).

Reference number: Web 143

First published:
December 2010

Last reviewed:
January 2025

Next review date:
May 2028

Copyright © East Kent Hospitals University NHS Foundation Trust.