

## **Information for patients undergoing surgery or neuro-endoscopy on high risk tissues**

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:

**Have you ever been notified that you are at risk of CJD or vCJD for public health purposes?**

**Have you any history of CJD or other prion disease in your family?**

**Have you ever received growth hormone or gonadotrophin treatment?**

**Have you had surgery on your brain or spinal cord at any time in the past?**

**Since 1980, have you had any transfusions of blood or blood components (red cells, plasma or platelets)?**

### **What is CJD?**

Creutzfeldt-Jakob disease (CJD) is a rare brain disorder that affects about 1 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 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 been treated with growth hormone or gonadotrophin infertility treatment because these used to be prepared from pituitary glands. Some of these hormone treatments have been linked to CJD infection - these hormones 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 is the type of CJD which is caused by eating meat from cows infected with BSE. vCJD can be spread through blood transfusions.

We don't 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 now examine your medical records in more detail to determine whether or not you may have an increased risk of CJD.

### **What will happen then?**

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 informed and 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 don't 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?**

Unfortunately 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.

- Health Protection Agency website: [www.hpa.org.uk/cjd](http://www.hpa.org.uk/cjd)
- CJD Support Network website: [www.cjdsupport.net](http://www.cjdsupport.net)
- National CJD Surveillance Unit website: [www.cjd.ed.ac.uk](http://www.cjd.ed.ac.uk)
- National Prion Clinic website: [www.nationalprionclinic.org/](http://www.nationalprionclinic.org/)