



Information for people who have an increased risk of CJD

CJD stands for Creutzfeldt-Jakob Disease. There are several types of CJD. In this leaflet the term CJD covers all types unless a particular type of CJD is specified.

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Who has an increased risk of CJD?

You are one of over 5,000 people in the United Kingdom who have an increased risk of CJD because of an operation, blood transfusion or other medical treatment in the past. The leaflet 'Who has an increased risk of CJD?' explains these risks in detail.

Am I going to get CJD?

We do not have enough information at present to answer this question. Everyone in the UK has a small risk of developing CJD. We believe that the chance that you could develop CJD is very small, but it is greater than for other people. You may never develop CJD even if you are infected. But you and those looking after you can take some safety measures to reduce the chance that you could pass it to others.

What is CJD?

CJD is a very rare disease in humans. It affects the structure of the brain and leads to death. CJD is one of a group of diseases called transmissible spongiform encephalopathies (TSEs) that affect animals as well as humans. BSE (bovine spongiform encephalopathy), sometimes referred to as 'mad cow disease' is a type of TSE that affects cattle. These diseases are caused by an abnormal form of a prion protein which accumulates in the brain. There are four types of CJD.

Types of CJD

Sporadic CJD occurs spontaneously. No one knows what causes it and it is found throughout the world. It is the most common type of CJD. In the United Kingdom, 87 people died of sporadic CJD in 2008.

Variant CJD is the human form of BSE. Many people in the United Kingdom were exposed to BSE because they ate beef and beef products from cattle that were infected with BSE. There have been under 170 cases of variant CJD in the United Kingdom since 1995 and a few cases in other countries. One person died of variant CJD in the United Kingdom in 2008.

Genetic or inherited CJD is caused by a faulty gene which parents may pass on to their children. In the United Kingdom, five people died from genetic forms of human prion disease in 2008.

Iatrogenic CJD is CJD (sporadic, variant or genetic) that is spread through medical treatment such as blood transfusion, surgery or treatment with contaminated human hormones. Five people died from iatrogenic CJD in the United Kingdom in 2008. Sporadic CJD has occasionally been spread through brain surgery and eye surgery. It has also been transmitted by treatment with growth hormone and gonadotrophin prepared from infected humans. Variant CJD is not known to have spread through surgery.

Four people in the United Kingdom have been infected with variant CJD following blood transfusions. Three of these patients developed symptoms of vCJD, and the fourth died of an unrelated cause. This patient's vCJD infection was detected at post mortem. One haemophilia patient has also been found to be infected with vCJD when tested at post mortem. This patient never developed symptoms of vCJD and died of an unrelated cause. No other types of CJD are known to have spread through blood.

What should I do if I think I may have CJD?

It is very unlikely that any new symptoms that you notice will be the start of CJD. CJD can cause many different symptoms, including psychiatric, neurological and physical symptoms. If you develop an illness which could be CJD, your GP can arrange for a specialist doctor to carry out a full neurological examination.

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

There is no blood test available yet which could show if you have CJD. Scientists are working very hard to develop tests, and if a suitable test does become available, we will send you information about it through your GP.

How can you treat CJD?

Unfortunately, there is no treatment or cure for CJD at present. Scientists are researching the causes and possible tests and treatments for the disease. If suitable treatment becomes available, information will be sent to you through your GP.

What about my medical and dental care?

You do not need extra medical checks because you have an increased risk of CJD. Your doctor will, however, always be willing to see you if you have any worries about your health.

The only difference in your treatment is that special safety measures may be needed for the instruments that are used if you need certain types of surgery or investigations. Your doctors will include this information in your hospital medical records and your GP records.

You should tell your dentist that you have been informed that you have an increased risk of CJD. Your routine dental care, including root canal treatment, should not be affected. If you need more complicated surgery on your head or neck, special safety measures may be needed for the surgical instruments that are used on you. Your dentist should include this information in their letter if they refer you for surgery.

What about life insurance?

Members of the Association of British Insurers do not refuse to offer life insurance just because the person has an increased risk of CJD. Nor will having an increased risk of CJD affect your current life insurance policy (if you have one). If you take out insurance, you must answer all questions fully and truthfully, or your policy will not be valid.

What if I travel abroad?

You are able to obtain travel insurance in the usual way. If you take out a new policy, you must answer all questions truthfully, or your policy may not be valid.

If you need an operation or endoscopy while abroad, you should tell the medical staff beforehand that

- Doctors in the United Kingdom must take special infection control measures during some surgical procedures and investigations to reduce the risk of passing on CJD
- They should contact their own national organisation for advice on controlling infections. They can then call the Health Protection Agency duty doctor on 0044 208 200 6868 to obtain advice about the recommended safety measures.

If you cannot tell medical staff beforehand, tell them as soon as possible afterwards

Will this affect my family and friends or my work?

- You can carry on living your life as usual. There is no evidence that CJD can be passed from one person to another by sneezing or coughing, sharing cups, knives, forks and so on, by touching, kissing or having sex. There is no evidence that CJD can be passed from a woman to her unborn baby, or by breastfeeding.
- You can continue to treat cuts and minor injuries as usual, and you do not have to take any special precautions.
- If you are a man you should not donate sperm, and if you are a woman you should not donate eggs or breast milk. This is an extra precaution even though there is no evidence that these can spread CJD.
- There is no evidence that CJD has spread between people through work and there is no need to tell your employer. If you are a doctor, nurse or other healthcare worker, there is no evidence that you could infect your patients or that your patients could infect you.

Advice on how to reduce the risk of spreading CJD to other people

You have been identified as being at increased risk of CJD. You can reduce the risk of spreading CJD to other people by following this advice.

- Don't donate blood. No-one who is at increased risk of CJD or who has received blood donated in the United Kingdom since 1980 should donate blood
- Don't donate organs or tissues, including bone marrow, sperm, eggs or breast milk
- If you are going to have any medical or surgical procedures, you should tell whoever is treating you beforehand so that they can make special arrangements for the instruments used to treat you
- You are advised to tell your family about your increased risk. Your family can tell the people who are treating you about your risk of CJD if you need medical or surgical procedures in the future and are unable to tell them yourself.

How could surgery spread CJD?

The surgical instruments used to treat you could spread CJD to other patients who have surgery after you. This is because the abnormal prion proteins that cause CJD are very hard to remove or destroy. Surgical instruments that have been properly washed and disinfected may still have prion protein on them and could spread CJD to other patients.

How could blood, tissue or organ donations spread CJD?

If a blood donor or organ donor is infected with CJD but has no signs of the disease, their blood, tissues and organs may still spread CJD to other people. This is because the abnormal prion proteins are present in different parts of the body in CJD before symptoms develop. Blood transfusions have spread variant CJD, but they have not spread sporadic or genetic types of CJD.

There is no test at present that can detect blood that is infected with CJD, and no method that can completely remove abnormal prion protein from blood. The blood transfusion and transplant services ask anyone with an increased risk of any type of

CJD not to donate blood, tissues or organs. This is to reduce the risk of passing CJD to others.

Who decided that I am at risk of CJD?

In 2000, the Department of Health set up a committee of experts (the CJD Incidents Panel) to give advice on the risk that CJD could pass from patient to patient. The Panel assesses the risk to patients, and gives advice to doctors about contacting people and informing them about their increased risk of CJD.

What happens now?

Ask your GP or specialist doctor for support if you have any worries about CJD. They will answer your questions and help provide any further support you may need. The Health Protection Agency will contact you through your GP or specialist doctor if there is any new information for people with an increased risk of CJD, or any research studies that you may be able to take part in to help scientists learn more about CJD.

If you do not have a GP, and are not under the care of a specialist, the Health Protection Agency or Health Protection Scotland will contact you directly.

More information about CJD is available from the following websites:

CJD Support Network:

www.cjdsupport.net Helpline: 01630 673973

Health Protection Agency:

www.hpa.org.uk/cjd

National CJD Surveillance Unit:

www.cjd.ed.ac.uk

National Prion Clinic:

www.nationalprionclinic.org/

Department of Health:

<http://www.dh.gov.uk/en/Publichealth/Communicablediseases/CJD/CJDgeneralinformation/index.htm>

Information for dentists at:

http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleagueletters/DH_074001 and

http://www.hpa.org.uk/infections/topics_az/cjd/guidance.htm

We last updated this leaflet in August 2009. To check for any new information, please see the latest version at www.hpa.org.uk/cjd

We welcome feedback on this leaflet – please send your comments to: cjd@hpa.org.uk