Infection Prevention and Control Team

Creutzfeldt-Jakob Disease (CJD)

Information for patients, relatives and carers
This information sheet has been provided to help answer some of the questions you may have about CJD.

**What is CJD?**

CJD stands for Creutzfeldt-Jakob Disease. CJD is a very rare disease in humans affecting the structure of the brain and leading 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:

1. **Sporadic 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.

2. **Variant CJD**  
   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 less than 170 cases of variant CJD in the United Kingdom since 1995 and a few cases in other countries.

3. **Familial CJD**  
   Familial CJD is caused by a faulty gene which parents may pass on to their children.

4. **Iatrogenic CJD**  
   Iatrogenic CJD is CJD (either sporadic, variant or familial) that is spread through medical treatment such as blood transfusion, surgery or treatment with contaminated human hormones. 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.

**Who has an increased risk of CJD?**  
Several groups of people have been identified and informed that they are at an increased risk of CJD either because of an operation, blood transfusion or other medical treatment in the past. These groups of people should follow advice to reduce the risk of potentially spreading the infection to others through medical care. Those identified as at increased risk are listed below.

**Risks related to blood and plasma:**

- People who have received blood from 300 or more donors
- People who have received blood from a donor who went on to develop variant CJD
- People who have given blood to someone who went on to develop variant CJD
- People who have received blood from a donor who has given blood to another person who went on to develop variant CJD
- People who have been treated with certain plasma products produced in the UK between 1990 and 2001
Risks related to surgery
- People who have had surgery using instruments that had been used on someone who went on to develop CJD
- People who have had a neurosurgical procedure or an operation for a tumour or cyst of the spine before August 1992
- People who have received an organ or tissue from a donor infected with CJD or at increased risk of CJD

Risks related to other medical care
- People who have been treated with growth hormone sourced from humans before 1985
- People who have been treated with gonadotrophin sourced from humans before 1973
- People who have been told by a specialist that they have a risk of developing an inherited (genetic) form of CJD that runs in families.

However you must reduce the risk of potentially spreading CJD to other people by following this advice:
- Do not 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
- Do not donate organs or tissues, including bone marrow, sperm, eggs or breast milk
- If you are going to have any medical or surgical procedures, tell whoever is treating you beforehand so they can make special arrangements for the instruments used to treat you
- We advise that you tell your family about your increased risk. Your family can then tell the people who are treating you about your risk of CJD if you need any medical or surgical procedures in the future and are unable to tell them yourself.

What should I do if I have been identified as being at increased risk of CJD?
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.

Can I have a blood test to see if I am infected with CJD?
There is no blood test yet available which could show if you have CJD.

How is CJD treated?
Unfortunately, there is no treatment or cure for CJD at present.
Further information

CJD Support Network
www.cjdsupport.net
Helpline: 01630 673973

Public Health England
www.gov.uk/phe

National CJD Surveillance Unit
www.cjd.ed.ac.uk

National Prion Clinic
www.nationalprionclinic.org

Department of Health
www.dh.gov.uk

If you have any queries or concerns about your condition, please do not hesitate to speak to the nurses and doctors looking after you.

Infection Prevention and Control Team

- Andover War Memorial Hospital
  Telephone: 01962 825156

- Basingstoke and North Hampshire Hospital
  Telephone: 01256 486774

- Royal Hampshire County Hospital
  Telephone: 01962 825156

www.hampshirehospitals.nhs.uk