



Who has an increased risk of CJD?

This leaflet explains why different groups of people have an increased risk of CJD. Please read this together with the leaflet '**Information for people with an increased risk of CJD**'.

Several groups of people have an increased risk of CJD. Everyone in these groups should follow [advice](#) to reduce the risk of spreading the infection to other people through their medical care. CJD stands for Creutzfeldt-Jakob Disease. There are several types of CJD. In this leaflet the term CJD includes all types, unless a particular type of CJD is specified.

The following groups of people have an increased risk of CJD

Related to blood transfusions

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

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

Related to other medical care

People who have been treated with certain plasma products produced in the UK between 1980 and 2001

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.

If you have been infected with CJD, then you could spread CJD to other patients if you donate blood, organs and tissue or have an operation.

If you are going to have an operation, special precautions should be taken with the surgical instruments that are used on you if you need certain types of surgery or investigation. This should reduce the risk of CJD (including variant CJD) being passed to others in operations. Please follow our [advice](#) to help reduce the risk of spreading the infection to other people.

Advice on how to stop CJD spreading 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, tell whoever is treating you beforehand so 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 any medical or surgical procedures in the future and are unable to tell them yourself.

Related to blood transfusions

People who have received blood from a donor who went on to develop variant CJD

Your medical records show that you have received blood from a donor who later developed variant CJD.

We know that variant CJD can be spread by blood transfusions. Four people in the United Kingdom have been infected in this way. This was first reported in 2003. The HPA has contacted you and everyone else who received blood from donors who went on to develop variant CJD and has informed you that you may have been exposed to variant CJD.

It is impossible to put an exact figure on your increased risk of variant CJD because you were given blood from a donor who later developed variant CJD. There are no tests at present that can identify a person who is infected with variant CJD before they become ill, or that can detect blood that is infected with variant CJD.

Everyone in the United Kingdom who has received a blood transfusion since 1980 is asked not to give blood themselves, to reduce the chance of passing on variant CJD. You are already in this group.

If you have been infected with CJD, then you could spread CJD to other patients if you donate organs and tissue or have an operation. Please follow our [advice](#) to help reduce the risk of spreading the infection to other people.

People who have given blood to someone who went on to develop variant CJD

Your medical records show that your blood was given to a patient who later developed variant CJD.

We cannot tell how this patient became infected with variant CJD. Most people who have variant CJD acquired it through eating beef and beef products from cattle that were infected with bovine spongiform encephalitis (BSE). Four people in the United Kingdom have been infected with variant CJD from blood transfusions. It is possible that this patient's variant CJD infection came from your blood and that you could be infected with variant CJD, even though you feel healthy. People who are infected with CJD may remain well for many years, and it is possible that some may never become ill.

It is impossible to put an exact figure on your increased risk of variant CJD. The chance that you are infected with variant CJD is very small, but there are no tests at present that can identify a person who is infected with variant CJD before they become ill, or that can detect blood that is infected with variant CJD.

If you have been infected with CJD, then you could spread CJD to other patients if you donate blood, organs and tissue or have an operation. Please follow our [advice](#) to help reduce the risk of spreading the infection to other people.

People who have received blood from a donor who has also given blood to someone who went on to develop variant CJD

Your medical records show that you have received blood from a donor who has also given blood to someone who later developed variant CJD.

We do not know how that person became infected with variant CJD. Most people who have variant CJD have acquired it through eating beef or beef products from cattle that were infected with BSE. Four people in the United Kingdom have been infected with variant CJD from blood from a donor who later developed variant CJD. It is possible that the blood donor was the source of that patient's variant CJD infection. It is also possible that you too may be infected with variant CJD from the same blood donor.

The blood donor has no signs of CJD, and no longer donates blood. There are no tests at present that can identify a person who is infected with variant CJD before they become ill, or that can detect blood that is infected with variant CJD. People who are infected with CJD may remain well for many years, and it is possible that some may never become ill.

The chance that you are infected with variant CJD is very small but it is impossible to put an exact figure on your increased risk.

Everyone in the UK who has received a blood transfusion since 1980 is asked not to give blood themselves because they may have become infected with variant CJD. This reduces the chances of passing on variant CJD. You are already in this group.

If you have been infected with CJD, then you could spread CJD to other patients if you donate organs and tissue or have an operation. Please follow our [advice](#) to help reduce the risk of spreading the infection to other people

Related to surgery

People who have had an operation using instruments that had been used on someone who went on to develop CJD

Your medical records show that you have had an operation using surgical instruments that had been used previously on a patient who went on to develop CJD.

Surgical instruments used on patients who are infected with CJD could spread infection to other patients having surgery. This is because the abnormal prion proteins that cause CJD are very hard to destroy. Surgical instruments that have been properly washed and disinfected may still have infected prion proteins on them and could then spread CJD to other patients.

We do not know what the chance is of getting CJD after having surgery, but it seems to be very small. We do not know of any people infected with variant CJD as a result of surgery. There have been only four reports worldwide of people infected with sporadic CJD from instruments used during neurosurgery (operations on the brain and spinal cord), and these cases happened many years ago.

If you have been infected with CJD, then you could spread CJD to other patients if you donate blood, organs and tissue or have an operation. Please follow our [advice](#) to help reduce the risk of spreading the infection to other people.

People who have had a neurosurgical procedure, or an operation for a tumour or cyst of the spine before August 1992, and who may have received a graft of dura mater tissue in this procedure

Your medical records show that you had a neurosurgical procedure before 1992 in which you may have received a graft of dura mater tissue from humans. Dura mater is a tough lining round the brain and spinal cord. Dura mater grafts obtained from humans were used in many neurosurgical procedures and operations on tumours or cysts of the spine. These grafts were banned in the United Kingdom in 1992.

Everyone who received a dura mater graft obtained from humans has an increased risk of CJD. Many thousands of people have been treated with

these grafts throughout the world. Over 190 of these patients worldwide have developed CJD and the grafts that they received must have been made from people who had been infected with CJD, even if they did not show any signs of the disease. There is no test that can detect a graft which is infected with CJD.

If you have been infected with CJD, then you could spread CJD to other patients if you donate blood, organs and tissue or have an operation.

If your operation took place some years ago, the hospital may no longer have a record of whether you received a graft of dura mater tissue from humans, and you should follow the same advice as someone who knows that they were given a graft of human tissue. Please follow our [advice](#) to help reduce the risk of spreading the infection to other people.

People who have received an organ or tissue from a donor infected with CJD or at increased risk of CJD

Your medical records show that you have received an organ or tissue donated by someone who is at increased risk of CJD.

We do not know what your chance is of getting CJD after receiving an organ or tissue transplant. But it is very likely that the benefits of your transplant are much greater than the risk of being infected with CJD. You may wish to discuss this with your surgeon.

We do not know of anyone who has been infected with variant CJD from an organ or tissue donation. Two people might have been infected with CJD by corneal grafts donated by people who had sporadic CJD. These donations took place in the 1960s and 1970s.

Four people in the United Kingdom have been infected with variant CJD through blood transfusions.

If you have been infected with CJD, then you could spread CJD to other patients if you donate blood, organs and tissue or have an operation. Please follow our [advice](#) to help reduce the risk of spreading the infection to other people.

Related to other medical care

People who have been treated with certain plasma products produced in the United Kingdom between 1980 and 2001

Clotting factors (used for patients with bleeding disorders) and antithrombin

Your medical records show that you have a bleeding disorder or congenital antithrombin III deficiency¹ and you been given clotting factors or

¹ Congenital and acquired haemophilia (Haemophilia A and Haemophilia B), Von Willebrand Disease, other congenital bleeding disorders and congenital antithrombin III deficiency.

antithrombin prepared from plasma (part of blood) sourced and produced in the United Kingdom² between 1980 and 2001.

You have an increased risk of variant CJD because you are one of many patients who have been treated with clotting factors prepared from the plasma of many donors. The larger the number of people that have donated plasma that was used to prepare these clotting factors, the greater the chance that one of them was infected with variant CJD, even though they appeared to be healthy. The chance that you are infected with variant CJD is thought to be very small.

We do not know your increased risk of variant CJD from treatment with clotting factors or antithrombin. Four people in the United Kingdom have been infected with variant CJD following blood transfusions from blood donors who later developed variant CJD. One haemophilia patient has been found to have evidence of infection with the variant CJD abnormal prion protein, only in the spleen, when tested at post mortem. This patient did not have any symptoms of variant CJD, and died of an unrelated cause. A final view as to how this haemophilia patient became infected with the vCJD abnormal prion protein has yet to be reached and investigations are therefore continuing to establish this. Most people who have variant CJD have acquired it through eating beef or beef products from cattle that were infected with bovine spongiform encephalitis (BSE), but we do not know what the chance is that you could have been infected with variant CJD in this way either.

If you are infected with variant CJD, then you could spread variant CJD to other patients if you donate organs and tissue or have an operation.

Please follow our [advice](#) to help reduce the risk of spreading variant CJD to other people.

People treated with albumin

Assessment of your medical records shows that you have been treated with albumin made from plasma (part of blood) that was donated by someone who went on to develop variant CJD.

We do not know what the chance is that you have been infected with variant CJD from treatment with albumin but it is likely to be very small. Four people in the United Kingdom have been infected with variant CJD following blood transfusions from blood donors who later developed variant CJD. Most people who have variant CJD have acquired it through eating beef or beef products from cattle that were infected with bovine spongiform encephalitis (BSE), but we do not know what the chance is that you could have been infected with variant CJD in this way either.

If you have been infected with variant CJD then you could spread variant CJD to other patients if you donate blood, organs and tissue or have an operation.

² Factor VIII, factor IX, factor VII, factor XI, factor XIII and prothrombin complexes, as well as antithrombin.

Please follow our [advice](#) to help reduce the risk of spreading variant CJD to other people.

People treated with Factor IX (used for patients without a bleeding disorder for the reversal of anticoagulant therapy)

Assessment of your medical records shows that you have been treated with Factor IX made from plasma (part of blood) that was donated by someone who went on to develop variant CJD.

We do not know what the chance is that you have been infected with variant CJD from treatment with Factor IX but it is likely to be very small. Four people in the United Kingdom have been infected with variant CJD following blood transfusions from blood donors who later developed variant CJD. Most people who have variant CJD have acquired it through eating beef or beef products from cattle that were infected with bovine spongiform encephalitis (BSE), but we do not know what the chance is that you could have been infected with variant CJD in this way either.

If you have been infected with variant CJD then you could spread variant CJD to other patients if you donate blood, organs and tissue or have an operation.

Please follow our [advice](#) to help reduce the risk of spreading variant CJD to other people.

People who have been treated with growth hormone from humans before 1985

Your medical records show that you were treated with growth hormone prepared from human pituitary glands between 1958 and 1985. Many thousands of children were given this treatment, and over 190 are known to have developed CJD worldwide.

This is because the hormone was prepared from pituitary glands from people some of whom must have been infected with CJD, even if they had shown no signs of the disease while they were alive. The use of growth hormone prepared from humans was banned in the United Kingdom in 1985.

If you are infected then you could spread CJD to other patients if you donate blood, organs and tissue or have an operation. Please follow our [advice](#) to help reduce the risk of spreading the infection to other people.

The Institute of Child Health supports people who have received human derived pituitary growth hormone. Contact: L.Davidson@ich.ucl.ac.uk Tel: 020 7404 0536.

People who have been treated with gonadotrophin hormones sourced from humans before 1973

Your medical records show that you were treated with gonadotrophin prepared from human pituitary glands before 1973. Many women were given this treatment, and four are known to have developed CJD worldwide.

This is because the gonadotrophin was prepared from pituitary glands from people some of whom must have been infected with CJD, even if they had shown no signs of the disease while they were alive. The use of gonadotrophin prepared from humans was banned in the United Kingdom in 1973.

If you are infected then you could spread CJD to other patients if you donate blood, organs and tissue or have an operation. Please follow our [advice](#) to help reduce the risk of spreading the infection to other people.

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

Someone in your family has an inherited (genetic) form of CJD that runs in families. Inherited CJD is rare, and accounts for 15 out of every 100 cases of CJD in the United Kingdom. Eight people died of inherited forms of CJD and other prion diseases in the United Kingdom in 2007.

A faulty gene causes inherited CJD disease, and this faulty gene can be inherited (passed) from parent to child. You should discuss your risk with a genetic specialist.

If you are carrying the faulty gene, then you could spread CJD to other patients if you donate blood, organs and tissue or have an operation. No cases have been reported of inherited CJD being spread to others in this way but it is possible that this form of CJD could infect other people.

Please follow our [advice](#) to help reduce the risk of spreading the infection to other people.

The National Prion Clinic offers help and support to people at risk of genetic CJD: www.nationalprionclinic.org/.

Where can I find out more?

More information on CJD and what to do is contained in the leaflet 'Information for people who have an increased risk of CJD'.

The following organisations offer further information and support.

- CJD Support Network website: www.cjdsupport.net Helpline: 01630 673973
- Health Protection Agency website: www.hpa.org.uk/cjd
- National CJD Surveillance Unit website: www.cjd.ed.ac.uk
- National Prion Clinic website: www.nationalprionclinic.org/
Institute of Child Health: 30 Guilford Street, London WC1N 1EH
Leah Davidson coordinates care for people affected by growth hormone related iatrogenic CJD
Tel: 020 7404 0536 Email: L.Davidson@ich.ucl.ac.uk

We last updated this leaflet in February 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