6.12.05

Health Protection Agency

Health Protection Scotland

VARIANT CREUTZFELDT-JAKOB DISEASE (vCJD) and BLOOD TRANSFUSIONS

INFORMATION FOR PATIENTS

This information has been developed for people who have been informed by their doctor that they are considered 'at-risk' of vCJD due to having received a blood transfusion from a donor who also donated blood to a patient who later developed vCJD. We hope it will go some way to answering your first questions.

1. Why are some patients – including me - being contacted now about past blood transfusions?

Medical records show that you have received a blood transfusion from a donor who also donated blood to a patient who later developed variant Creutzfeldt-Jakob disease (vCJD). There is a possibility that this donor was the source of vCJD infection for the patient who developed vCJD, and there is therefore a possibility that vCJD could have also been passed on to you by blood transfusion from this donor.

With the information available to us at present, there is reason to suspect that recipients of this donor's blood, such as yourself, may be at an additional risk of vCJD due to transfusion. This risk is 'additional' since it is on top of the general risk for many people in the UK from eating beef in the past (when BSE was common in cattle).

If so, it might be possible for you to pass vCJD on to others in certain circumstances. This means that you and the people providing your healthcare need to take some special precautions to reduce the risk to other people. This is why it is important that you know, even if this causes you anxiety.

2. What is variant Creutzfeldt-Jakob disease?

Creutzfeldt-Jakob Disease, or CJD, is one of a group of diseases called TSEs (transmissible spongiform encephalopathies). These are rare and fatal diseases in humans and animals that affect the structure of the brain. In

animals the best-known TSE is BSE (bovine spongiform encephalopathy), sometimes referred to in the news as 'mad-cow disease'.

There are four main types of CJD:

- sporadic CJD (arising spontaneously) is the most common and accounts for 85% of cases
- familial (with genetic causes)
- iatrogenic (through medical treatment), and
- variant CJD (vCJD). Variant CJD is believed to be the human form of BSE.

People who have lived in the UK (and are over 9 years old), have probably been exposed to BSE through their diet (particularly beef and beef products) and so are at a possible risk of developing vCJD.

3. How does this information affect me?

If you have been informed that you are 'at-risk of vCJD for public health purposes', you are being asked to take the following actions in order to reduce the chance of passing on vCJD to other people:

- **Do not donate blood.**
- **Do not donate organs or tissues.**
- **Tell whoever is treating you before you undergo medical, surgical or dental treatment, so they can arrange any special procedures for the instruments used in your care. This should include treatment at private clinics.**
- **It would be best if you tell your family about this in case, for any reason, you need medical care in the future and your family can help by telling the doctors.**

4. Why am I asked to take these actions?

It is probable that vCJD can be spread by blood transfusion and by tissue/organ transplants. There is currently no way to detect vCJD infection in blood, or to remove it. The blood transfusion and transplant services therefore ask anyone who is at an increased risk of having vCJD infection not to donate, so that the risk of passing infection on to blood and transplant recipients is reduced.

It is possible that vCJD could spread between people having surgical operations. This is because the abnormal 'prion' proteins, which are thought to cause vCJD, are very hard to destroy. Surgical instruments could still have infectious prion proteins on them, even after they have been thoroughly washed and disinfected. If this happens, then the prion proteins could infect someone else with vCJD, when the instruments are used in

another operation. This is why we ask you to tell your doctors, and ask your GP to record this information in your notes.

5. Does this mean I'm going to suffer from vCJD?

The risk of this happening is unknown. You have been identified as being **at-risk of vCJD for public health purposes.** This does **not** mean you will actually develop vCJD. However, special precautions can be taken to prevent you passing on the infection to other people.

It is impossible to put an exact figure on the chances of getting vCJD infection, either from BSE-infected beef and beef products, or the possible additional risk from receiving a blood transfusion from a donor who is at increased risk of vCJD.

We also do not know whether – if you do have vCJD infection – your infection will stay 'asymptomatic' and 'sub-clinical' and never affect your health, or whether it will ever develop and make you ill.

Although there are many unknowns, the reason we are telling you this now is because you can help with precautions to protect others. This cautious approach is being taken in the UK to provide the best protection for the population in general.

It is unlikely that any symptoms you may have will be the start of vCJD. If you are concerned, please arrange to see your GP. Your GP will be able to arrange for you to see an expert if appropriate.

6. What about tests and treatments?

Can I be tested to see if I am infected?

Not at present. Scientists are working very hard to develop tests, but as yet there is no blood test available that can be used to identify someone who has been infected.

Tests for vCJD can sometimes be done on samples of certain tissues removed from a person's body; this is called a 'biopsy'.

Biopsies can be useful in helping confirm a diagnosis of vCJD in someone who is actually suffering symptoms suggestive of the disease. However, their use in people who are well is nowhere near as helpful and their use is not generally recommended.

Is there any treatment available?

There is no treatment or cure for vCJD at present although research is underway into potential treatments for the disease. One trial of a

treatment for patients who are diagnosed with vCJD disease is in progress at the NHS National Prion Clinic and the Medical Research Council's Prion and Clinical Trials Unit.

Will I be contacted when a test or treatment becomes available?

If tests or treatments that might help you become available, this information will be sent to you via your GP (or directly to you if you do not have a GP).

7. I'm 'at-risk for public health purposes' - what happens now?

You need do nothing other than follow the advice given above (see Section 3).

Normal social contact and household activities do not spread the infection. Your family and friends are not at risk from you and you do not need to take any special precautions in your normal life.

Variant CJD is not infectious in the usual ways. There is no evidence that it can be passed on between people by sneezing or coughing (like colds and flu), sharing utensils, by skin contact, or through kissing or sexual intercourse.

There is currently no evidence of any transmission of vCJD (or any other prion diseases in man or animals) by occupational exposure. There is no need to inform your employer (unless of course you are asked about this at any time e.g. by your occupational health department). If you are a doctor or nurse or other healthcare worker, there is no evidence of a transmission risk from you to your patients, or from patients to you.

There is also no evidence that vCJD can be sexually transmitted or passed from parent to child. However, as a precautionary measure, men who are 'at-risk' for public health purposes should not donate sperm, and women who are 'at-risk' for public health purposes should not donate breast milk.

8. Will this affect my medical or dental care?

Your care should not be compromised in any way – it will be just the instruments that may be treated differently. A note of this information will be made in your hospital medical records and your GP's notes.

Routine dental care should not be affected. As for all dental patients, satisfactory standards of cleaning instruments are required. In the unusual event that routine dental care leads to more complicated surgery of the head and neck, special precautionary measures (again, only concerning the instruments used) may need to be taken to reduce any possible

transmission of vCJD. This is why we ask you to tell your dentist about your 'at-risk' status. Your dentist should include this information in their letter if he/she refers you for surgery. (Your dentist can find further information from the web-link at the end of this document.)

You will not need extra medical follow-up because you are 'at-risk' of vCJD for public health purposes. However, your GP will always be willing to see you if you have any worries about your health.

Should any medical follow-up, or other actions, become advised in the future, you will be informed (via your GP, or directly if you do not have a GP).

9. Will this mean I won't be able to get life insurance?

The Association of British Insurers have informed the Panel that their members do not refuse insurance just because someone is categorised as 'at-risk for public health purposes'. Nor will being 'at-risk' affect existing insurance policies. In taking out a new policy, all questions should be answered truthfully, since concealing relevant information might render any policy invalid. If no relevant question is asked, the information need not be volunteered.

10. Who decided that I should be contacted?

In 2000 an expert advisory committee called the CJD Incidents Panel (the Panel) was set up to advise on the handling of 'incidents' of possible transmission of CJD, including vCJD, in a healthcare setting. This committee includes medical and other experts as well as non-medical members who represent the views of patients and members of the public. The Panel assesses the risk to other patients, and advises whether patients should be contacted and informed about their possible exposure.

The Panel has agreed that, in general, where patients may have been exposed to an identified additional risk of developing CJD, on top of the general risk in the population, they should be contacted. These patients are considered to be **'at-risk for public health purposes'** and are given advice about what they should do to avoid putting other people at risk.

When a patient is diagnosed with vCJD, checks are made to find out whether the patient ever donated blood or ever received blood. This can result in the identification of blood donors or blood recipients that may be at increased risk of being infected with vCJD. The Panel then decides what should be done about the patients identified as at increased risk of vCJD due to blood transfusion.

In May 2005, the Panel recommended that 'donors to vCJD cases' should be considered to be 'at-risk for public health purposes'. In September 2005, the Panel further advised that certain recipients of other donations from these donors should also be informed of their possible exposure by transfusion and considered to be 'at-risk' of vCJD.

There are uncertainties in estimating the risk of infection with vCJD due to blood transfusion and a cautious approach has been taken. Where the increased risk is estimated to be approximately 1 in 100 or greater, it was decided that transfused recipients should be informed of their increased risk of vCJD, and considered to be 'at-risk' of vCJD for public health purposes. This is considered the best balance between protecting the public from further spread of vCJD and causing excessive anxiety to people at increased risk of vCJD.

11. Who else is affected by this?

Other groups of patients considered as 'at-risk of vCJD for public health purposes' include:

- patients who have received a blood donation from a donor who later developed vCJD;
- patients who have been treated with certain plasma products that may have been contaminated with vCJD infection from the donors of the plasma;
- donors of blood to patients who later developed vCJD, and
- certain patients who have been operated on with surgical instruments previously used on a patient with vCJD.

12. What measures are being taken to reduce the risk of vCJD?

From food: A number of measures have minimised the risk of getting vCJD from eating BSE-infected meat and meat products. These include banning the feeding of animal protein to other animals, and removing certain parts (e.g. the brain and nerves in the spine) of animals from the food we eat.

From surgical instruments: In the healthcare setting, the abnormal 'prion' protein, the infective agent that causes vCJD, is very hard to destroy. Using surgical instruments only once, or destroying those that have been used on patients diagnosed with vCJD, is one way to guard against passing on vCJD. In recent years much effort has also gone into ensuring that the decontamination of all surgical instruments is to the highest standards. The aim is to remove as much potentially infected material from the instruments as possible.

From blood: The UK Blood Services have taken a number of precautionary measures:

- Withdrawal and recall of any blood components, plasma products or tissues obtained from any individual who later developed vCJD (December 1997).
- Importing plasma from the US to manufacture plasma products (1998).
- Removal of white blood cells (leucodepletion) from all blood components (Autumn 1999).
- Importing fresh frozen plasma from the US for patients born on or after 1st January 1996 (March 2004), extended to all children under 16 years of age (Summer 2005).
- Not accepting donations from people who have received a blood transfusion since 1980 (April 2004). This was later extended to include two new groups: apheresis donors and donors who are unsure if they have previously had a blood transfusion (August 2004).
- Promoting appropriate use of blood and tissues and alternatives throughout the NHS.

Asking you, and all other people identified as 'at-risk of vCJD for public health purposes', not to give blood, organs and tissues and to tell their healthcare providers is one further measure to reduce the risk of vCJD transmission by blood transfusion, organ and tissue transplantation and by surgical instruments.

13. General information about vCJD

What is the cause of vCJD?

Infections like flu and chest infections (e.g. pneumonia) and stomach infections are caused by viruses, bacteria or parasites. Variant CJD, and the other TSEs, are different from these common infections. The cause is an abnormal protein known as a 'prion'.

How do you catch vCJD?

From food: Variant CJD is believed to be caused in the first instance by exposure to the abnormal prion protein that causes BSE. Many of the UK population have been exposed through eating BSE-infected beef and beef products in the 1980s and early 1990s.

From blood: Two patients have been found to have vCJD infection after having received transfusions from donors who later developed vCJD. One of these two patients did not develop symptoms of vCJD and died of

unrelated causes. There have not yet been any cases amongst recipients of plasma products sourced from individuals who later developed vCJD.

From surgical instruments: So far there are no recorded instances of vCJD being spread through surgery. There are however good reasons to believe that variant CJD may be transmitted between patients in the healthcare setting by contaminated instruments. (There are recorded cases of sporadic CJD being spread through surgery in the past.)

How many cases of vCJD are there?

So far, around 150 cases of vCJD have occurred in the UK and a handful in other, mainly European, countries.

Since 2000, the numbers of cases of vCJD in the UK have been declining. In 2004 there were only 9 cases. However no one knows how many people will contract this disease in the future, or how many people have 'asymptomatic' or 'sub-clinical' infections.

14. Sources for additional information

The process of informing individuals that they are identified as 'at-risk' for public health purposes, and the special precautions they should take is coordinated by the Health Protection Agency (HPA) in England, Wales and Northern Ireland, and in Scotland by Health Protection Scotland (HPS – formerly the Scottish Centre for Infection and Environmental Health).

More information about CJD with useful links is available from their websites HPA: http://www.hpa.org.uk/infections/topics_az/cjd/menu.htm
Health Protection Scotland: http://www.hps.scot.nhs.uk

Further information about CJD is also available from:

CJD Support Network http://www.cjdsupport.net Helpline: tel 01630 673973

Human BSE Foundation http://www.hbsef.org

Department of Health
http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/CJD/CJDGeneralInformation/fs/en
including information for dentists at:
http://www.dh.gov.uk/PublicationsAndStatistics/LettersAndCirculars/DearColleagueLetters/DearColleagueLettersArticle/fs/en?CONTENT_ID=4102752&chk=7HspvA
also accessible via link from
http://www.hpa.org.uk/infections/topics_az/cjd/incidents_panel.htm

National CJD Surveillance Unit http://www.cjd.ed.ac.uk

National Prion Clinic http://www.nationalprionclinic.org/

National Public Health Service for Wales
http://www.wales.nhs.uk/sites/home.cfm?OrgID=368

Department of Health, Social Services and Public Safety, Northern Ireland
http://www.dhsspsni.gov.uk/phealth/index.asp

NHS Direct Online http://www.nhsdirect.nhs.uk

This information sheet was prepared in November 2005.
To check for any update to the information in this leaflet, please see the current version of this information sheet, 'vCJD and Blood Transfusion – Information for Patients' that can be found at
http://www.hpa.org.uk/infections/topics_az/cjd/information_documents.htm