

## **Understanding NICE guidance**

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Information for people who use NHS services

# **Creutzfeldt–Jakob disease: reducing the risk of transmission by surgical instruments**

*The Chief Medical Officers of the UK asked NICE to advise the NHS on how best to manage the risk of transmission of CJD and vCJD during interventional procedures*

This leaflet describes the steps doctors and other healthcare professionals should take to reduce the risk of transmitting (passing) Creutzfeldt–Jakob disease (CJD) between patients having certain types of interventional procedures. It explains guidance (advice) that NICE (the National Institute for Health and Clinical Excellence) has given to the NHS in England, Wales, Scotland and Northern Ireland. It does not describe CJD or any procedures in detail – if you are being offered a procedure or treatment a member of your healthcare team should give you full information and advice. Some sources of further information and support are on the back page.

See page 6 for an explanation of terms.



## Who is affected by the guidance?

The guidance covers the management of all patients who are having procedures involving surgical instruments or endoscopes (see page 6 for an explanation of terms) that might pose a risk of transmission of CJD.

However, it does not cover:

- patients who have been diagnosed as having definite, probable or possible CJD
- patients with brain symptoms of unknown cause for whom doctors are considering the diagnosis of CJD
- patients without symptoms but who are at risk of having familial (inherited) forms of CJD or who have already had a procedure that may have exposed them to CJD.

## What does the guidance cover?

The guidance covers:

- the use of reusable and single-use instruments in surgical procedures, including the use of endoscopes, laryngoscopes and related accessories
- arrangements for cleaning, sterilising and tracking the use of reusable instruments.

It does not specifically look at:

- blood transfusions, or exposure to blood or body fluids in the workplace
- life support machinery
- the risk of CJD from medicines or other products of human or cow origin
- risks from transplantation
- cleaning and reuse of single-use instruments
- procedures carried out by 'high street' dentists (although hospital surgery on the jaw and face is covered).

## What is Creutzfeldt–Jakob disease?

Creutzfeldt–Jakob disease (CJD for short) is an incurable brain disease that leads to dementia and death.

There are different types of CJD. Most cases of CJD are sporadic CJD. Sporadic CJD affects about 1 in a million people, and its cause is not known.

Another form of CJD is called 'familial CJD', which means it is inherited and runs in families. Familial CJD affects about 1 in 9 million people.

A new form of CJD was found in the UK in 1996 and is called variant CJD (vCJD). vCJD affects younger people, and is probably caught by eating food from cattle infected with BSE ('mad-cow disease'). At the beginning of September 2006, 156 people in the UK had died from definite or probable vCJD.

All types of CJD are thought to be caused by prions, abnormal infectious forms of a protein found in almost all body tissues, but at highest levels in brain and nerve cells. There is no treatment against prions, and unlike bacteria or viruses, prions cannot be killed or inactivated by normal hospital cleaning or sterilisation methods.

*If you have any concerns about CJD you can talk to your doctor or another healthcare professional*

*In the UK, there have been only four cases of transmission of sporadic CJD through surgical instruments, and all of these happened more than 30 years ago*

*There have been no cases of transmission of vCJD by contaminated instruments reported so far*

## **Risk of transmission during surgery and endoscopy**

If people who already have CJD have surgery or another procedure there is a small possibility that the instruments used could become contaminated with prions, and CJD could be passed to another patient. CJD that is caused by transmission during surgery or other medical procedures is called 'iatrogenic CJD'.

The risk of transmission of CJD during surgical or other procedures is bigger for procedures on 'high-risk tissues', which are tissues that have higher levels of prions. NICE defined **high-risk tissues** as those inside the very outer layer of the brain and also the retina of the eye and the optic nerve.

NICE defined **high-risk surgical procedures** as certain operations inside the brain (but not operations on the spine or nerves) and operations on the retina or optic nerve at the back of the eye. Neuroendoscopy (where a tube is inserted in the brain) is also a high-risk procedure. There is a list of high-risk procedures in the guidance on the NICE website.

The risk of transmitting sporadic or familial CJD through contaminated instruments is very small. In the UK, there have been only four cases of transmission of sporadic CJD through surgical instruments, and all of these happened more than 30 years ago.

There have been no cases of transmission of vCJD by contaminated instruments reported so far. But there is a risk it could happen in the future. And because symptoms of vCJD can take a long time to appear, there may already be people who have been infected through interventional procedures but who have not yet become ill.

## What has NICE said?

NICE says that special precautions should be used for **high-risk procedures**:

- urgent steps should be taken to stop instruments that are used on high-risk tissues being moved from one set of instruments to another
- systems to track instruments should be set up
- extra instruments needed during a procedure should either only be used once, or be kept with the set with which they were used
- hospitals should make sure they have enough instruments available for all circumstances.

For neuroendoscopy (a procedure using a tube inserted into the brain):

- whenever possible, surgeons should use rigid endoscopes that can be autoclaved (steam cleaned at a high temperature and pressure), and they should be thoroughly cleaned and autoclaved every time they are used
- accessories used through endoscopes (for example, instruments for biopsies) should be used once only.

There should be a separate pool of new neuroendoscopes and reusable surgical instruments for high-risk procedures carried out on children born after 1 January 1997 who have not had such a procedure before. These instruments should not be used for patients born before this date or who have had high-risk procedures before this guidance was issued.

NICE is not recommending single-use instruments for the procedures covered by this guidance, except for the neuroendoscopy accessories mentioned above. This is because the estimated risk of transmission of CJD is too low to justify the high cost of single-use instruments. As well as the high-risk procedures, this advice on single-use instruments also includes other kinds of neurosurgery and endoscopy, eye surgery, removal of tonsils and laryngoscopy.

When single-use instruments are used they should meet the same high standards required for reusable instruments. Single-use instruments of poorer quality than the reusable ones they are replacing can harm patients and should not be bought or used.

This advice assumes that new and more effective ways of decontaminating instruments are going to become available for use in the NHS within the next 5 years. NICE recommends that the safety of these methods and how effective they are at removing prions should be thoroughly tested as a matter of urgency. Until new methods are available, doctors should follow current guidelines on decontamination.

*High-risk surgical procedures are certain operations inside the brain and operations on the retina or optic nerve at the back of the eye. Neuroendoscopy is also a high-risk procedure*

*A high-risk tissue is any tissue inside the outer layer of the brain, and the retina in the eye, and the optic nerve*

*The full guidance has a list of high-risk procedures*

## Explanation of terms

**Accessories for endoscopes** Instruments attached to or passed through the tube of an endoscope and used to carry out surgical or medical procedures inside the body.

**Autoclave** A device that uses high pressure steam heat to sterilise surgical instruments.

**Decontamination** A combination of processes carried out on surgical and other instruments that have been used on a patient in order to make them safe for use on another patient and for handling by healthcare professionals.

**Endoscope** A thin telescope-like instrument that is inserted into the body. Surgical and medical procedures can be carried out using instruments ('accessories') attached to or put through the tube of the endoscope. Endoscopes can be flexible or rigid.

**Endoscopy** A procedure that uses an endoscope.

**Familial CJD** An inherited form of CJD. Familial CJD runs in families.

**High-risk procedures** For this guidance NICE defined high-risk procedures as certain operations inside the brain (but not operations on the spine or nerves), operations on the retina or optic nerve, and neuroendoscopy. There is a list of high-risk procedures in the guidance on the NICE website.

**High-risk tissues** For this guidance NICE defined high-risk tissues as those inside the very outer layer of the brain and also the retina of the eye and the optic nerve.

**Iatrogenic CJD** CJD that is caused by transmission during surgery or other medical treatment.

**Interventional procedure** For the NICE guidance on the transmission of CJD, an interventional procedure is defined as surgery, endoscopy or laryngoscopy. Endoscopy and laryngoscopy are explained elsewhere in this box.

**Laryngoscope** An instrument that is used to examine the larynx or 'voice box'. The larynx is a tube-shaped structure at the entrance to the windpipe (trachea). A laryngoscope can also be used by an anaesthetist to insert a tube to help a patient breathe during an operation.

**Laryngoscopy** A procedure that uses a laryngoscope.

**Neuroendoscope** An endoscope that is inserted into the brain.

**Neuroendoscopy** A procedure using a neuroendoscope.

**Optic nerve** The nerve linking the eye to the brain.

**Prion** An abnormal infectious form of the prion protein. The prion protein is a normal protein found in almost all body tissues, but is at highest levels in brain and nerve cells.

**Retina** The light-sensitive nerve tissue lining the inside of the eye.

**Reusable instrument** An instrument that is used more than once.

**Single-use instrument** An instrument that is used once on an individual patient and then thrown away.

**Sporadic CJD** The most common form of CJD. It affects about 1 in a million people and its cause is unknown.

**Sterilisation** Used to remove all microorganisms from an object, including viruses and bacterial spores. Routine sterilisation methods do not destroy prions.

**vCJD** A new form of CJD found in the UK in 1996. It affects younger people, and is probably caught by eating food from cattle infected with BSE ('mad-cow disease').

## More information on CJD

The full guidance has more information about CJD and the procedures covered (details below). If you are going to have one of the high-risk procedures mentioned in this leaflet and have any concerns about CJD or vCJD you should talk to your doctor or other healthcare professional. NHS Direct online ([www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)) may also be a good starting point for finding out more.

### About NICE

NICE produces guidance (advice) for the NHS about preventing, diagnosing and treating different medical conditions. This guidance was developed by a specially formed CJD Advisory Subcommittee – a group of independent experts that included healthcare professionals and people representing patients and carers. They considered the research on the transmission of CJD during interventional procedures and its prevention, and considered the costs involved. Staff working in the NHS are expected to follow this guidance.

*This leaflet and the full guidance aimed at healthcare professionals are available at [www.nice.org.uk/IIPG196](http://www.nice.org.uk/IIPG196)*

*You can order printed copies of this leaflet from the NHS Response Line (phone 0870 1555 455 and quote reference N1149).*

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