

Patient information

Creutzfeld-Jacob Disease (CJD) Screening and Surgery (Transmissible Spongiform Encephalopathies - TSEs)

Infection Prevention and Control - Aintree Hospital

What are Transmissible Spongiform Encephalopathies (TSEs)?

Transmissible Spongiform Encephalopathies (TSEs) are a group of rare degenerative brain disorders characterised by tiny holes that give the brain a 'spongy' appearance.

This leaflet has been written to give you information on these disorders and explain why we screen for TSEs at Aintree Hospital.

We follow Department of Health recommendations and would like to reassure you that our procedures are safe.

You may have heard of these diseases being called:

- Creutzfeld-Jacob Disease (CJD).
- vCJD (variant CJD).
- Mad Cow Disease.

There are even rarer conditions related to these called:

- Gerstmann-Straussler-Scheinker Syndrome (GSS).
- Fatal Familial Insomnia (FFI).
- Kuru.

In this leaflet we use the term TSE to include all these conditions.

What causes TSEs?

TSEs are caused by a tiny protein fragment called **prions** which can be passed on in various ways to humans.

Sometimes these conditions are inherited but rarely can they be caused by organ - transplantation, the use of drugs or grafts derived from human tissues or from surgical instruments previously used on a patient with a TSE.

Prions are not a living organism in the same way that bacteria and viruses are. Because of this it is not easy to kill prions by sterilisation with heat etc.

All our surgical instruments are cleaned and decontaminated carefully and then sterilised in high temperature and high-pressure sterilising machines.

This is performed to a very high standard and as a result of this there is absolutely no risk of conventional infection from our equipment and instruments.

What will happen at my pre-surgery screening?

As part of the screening process which all patients undergo before surgery we now need to ask patients about these conditions before your surgery is performed.

This screening process is designed to identify patients who may be infectious for TSEs.

As sterilisation and decontamination processes do not work as well for prions we need to identify patients who might have a TSE so that we can take extra precautions to ensure that any infection is not passed on to others.

Anyone who has been exposed to the risk of developing a TSE should have been contacted through public health screening procedures and notified about the risk.

What are high risk operations?

Some parts of the body (primarily brain, spinal cord and the back of the eye) are classed as “high risk” tissues and surgery or endoscopy on these tissues needs more detailed risk assessment.

What will you ask me?

We now must ask every patient who comes to the hospital the following main screening question.

This applies to all hospitals and clinics undertaking surgery and endoscopy.

“Have you ever been notified that you are at risk of CJD or vCJD for public health purposes?”

How you answer this question will then determine what we do next. This question has been designed to identify anyone who has been told that they **might** be infectious.

If you have not been contacted and told you are at risk you should answer the question with a “no”.

Answering this question with a “yes” does not mean that you have a TSE. It means that you **might** have been exposed to prions.

Even if you were definitely exposed to prions it does not mean you have become infected.

It is the aim of this screening process to err on the side of safety and ensure that surgical instruments are not re-used on patients after they have been used on a patient who **might** be infectious.

What impact will my answer have on my care?

There will be **no** change in your treatment, no matter how you answer the main screening question.

If you cannot answer the question with a “no”, the only thing that might happen is we may need to delay your treatment until we have more information.

- If you answer “**no**” to the main screening question then your treatment including surgery or endoscopy will continue as planned.
- If you answer “**yes**” to the main screening question we will then need to ask you some more detailed questions. This is to try and obtain enough information to allow us to work out if there is a real risk. We may need to trace more details of your previous medical history or care.

If this further information allows us to rule out any risk then your treatment would go ahead as planned.

- If you answer “**yes**” to the main screening question and we cannot find out more details of medical history (or what we find does not rule TSE out) we will go ahead with your planned treatment exactly as originally planned. The only difference will be that surgical instruments will be destroyed or quarantined after your surgery rather than re-used to reduce any infection risk.
- If you are unable to answer the main screening question and your surgery is on a “low risk” part of the body (see top of the page for high risk tissues – the rest of the body is low risk) we can continue as normal.

What will happen if I am having a high risk operation?

If you are having a high risk operation (see top of page) you will be asked 4 more questions about previous surgery, certain drugs, blood transfusion and any history of TSE in you or your family.

How we then proceed will depend upon your answers. If all your answers are “no” we can carry on as normal.

If you answer “yes” to any question we will need to follow this up to discover more details.

If you cannot be sure of how to answer these questions we will need to look into this more closely and will discuss how we will proceed with you.

Feedback

Your feedback is important to us and helps us influence care in the future.

Following your discharge from hospital or attendance at your outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

Further information:

If you have any questions or queries please
Tel: 0151 525 5980

Creutzfeldt - Jakob disease

<http://www.patient.co.uk/doctor/Creutzfeldt-Jakob-Disease.htm>

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