**Ref: IPC13**

# POLICY FOR THE PREVENTION AND CONTROL OF TRANSMISSIBLE SPONGIFORM ENCEPHALOPATHIES (CREUTZFELDT-JAKOB DISEASE) MINIMISING THE RISK OF TRANSMISSION

| | |
|---|---|
| **Executive Sponsor & Function** | Executive Director of Nursing, AHPs & Medical Science |
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| **Approved by:** | Quality, Safety and Performance Committee |
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## Contents

## ABBREVATIONS

| | |
|---|---|
| ACDP | Advisory Committee on Dangerous Pathogens |
| BSE | Bovine Spongiform Encephalopathy |
| CFS | Cerebral spinal fluid |
| CNS | Central nervous system |
| CJD | Creutzfeldt-Jacob Disease |
| COSHH | Control of substance hazardous to health |
| CSSU | Central Sterile Services Unit |
| DOH | Department of Health |
| FRSM | Fluid Resistant Surgical Mask |
| HCW | Health Care Worker |
| JPAC | Joint United Kingdom (UK) Blood Transfusion and Tissue Transplantation Services Professional Advisory Committee |
| IPCT | Infection Prevention & Control Team |
| LP | Lumbar Puncture |
| NPC | National Prion Clinic |
| OCCH | Occupational Health |
| PPE | Personal Protection Equipment |
| SCIPS | Standard Infection Control Precautions |
| TSE | Transmissible Spongiform Encephalopathies |
| vCJD | Variant CJD |

## 1. POLICY STATEMENT

This policy aims to prevent the transmission of prion diseases, including Creutzfeldt-Jakob Disease (CJD) and variant CJD (vCJD), within Velindre University NHS Trust through the implementation of proportionate, risk-based controls in accordance with national guidance.

While the Trust does not currently undertake surgical or endoscopic procedures involving medium or high-risk tissues, should such services be introduced, appropriate decontamination protocols, instrument tracking, and traceability systems must be established prior to commencement.

## 2. SCOPE OF POLICY

This policy applies to all healthcare workers (HCWs) and contractors within Velindre University NHS Trust who may provide care to, or handle specimens from, individuals with suspected or confirmed CJD/vCJD, or those identified as being at increased risk.

Welsh Blood Service colleagues should refer to the latest guidance from the Joint United Kingdom (UK) Blood Transfusion and Tissue Transplantation Services Professional Advisory Committee (JPAC) and the Department of Health and Social Care (DHSC), including the September 2024. JPAC Position Statement and updated laboratory containment measures (Nov 2021).

## 3. AIMS AND OBJECTIVES

To ensure all staff are informed of the risks associated with transmissible spongiform encephalopathies (TSEs) and are equipped to prevent iatrogenic transmission, particularly during invasive procedures and the handling of instruments, tissues, and clinical waste..

## 4. RESPONSIBILITIES

**4.1** **The Chief Executive**: Holds overarching accountability for Infection Prevention and Control (IPC), including ensuring adequate resources and organisational compliance.

**4.2** **Executive Director of Nursing, Allied Health Professionals & Health Science**: Acts as the executive lead for IPC, responsible for providing expert advice, overseeing training and monitoring compliance.

**4.3** **Departmental Managers/ Clinical Directors**: Ensure staff access and adhere to the policy; notify IPCT of relevant cases; maintain traceability; provide PPE and training; support incident management.

**4.4** **Clinical staff**: Apply SICPs, assess patient risk, notify IPCT of suspected or confirmed cases, use single-use devices where appropriate, report exposures, and liaise with Occupational Health.

**4.5** **Theatre Staff**: Review infection alerts, verify instrument integrity and tracking, use single-use instruments for medium/high-risk tissues, and ensure documentation systems are in place.

**4.6** **Infection Prevention and Control (IPCT**): Provide expert guidance, conduct surveillance, review policy, and coordinate incident responses with senior leadership and external agencies.

## 5. KEY DEFINITIONS

**Prion diseases**, or transmissible spongiform encephalopathies (TSEs), are fatal neurodegenerative disorders caused by the accumulation of misfolded prion proteins. These may be sporadic, familial, or acquired (including iatrogenic and variant forms). They have prolonged incubation periods and no known effective treatment.

**High-risk tissues** include the brain, spinal cord, cranial nerves, cranial ganglia, and posterior eye structures. In cases of vCJD, additional tissues such as tonsils, appendix, spleen, thymus, adrenal glands, lymph nodes, and gut-associated lymphoid tissue are also considered high-risk. Other tissues and fluids are generally low risk.

**Classification of TSEs:**

- ***Idiopathic***: Sporadic CJD, Sporadic Fatal Insomnia, VPSPr
- ***Familial*****:** Familial CJD, GSS, Fatal Familial Insomnia
- ***Acquired*****:** Iatrogenic CJD, Kuru, Variant CJD

### 5.1 Transmission

CJD is not transmitted through casual contact. Standard Infection Control Precautions (SICPs) are sufficient for routine care. Additional precautions are required for procedures involving high/medium-risk tissues or potential contamination with CSF, neural, or lymphoid tissue.

**Patient Groups**:

- *Symptomatic*: Definite, probable, or possible CJD/vCJD – refer to neurology.
- *Asymptomatic but at increased risk*: Includes familial mutations, historical iatrogenic exposures, and notified blood component recipients – notify IPCT.

**Decontamination and Waste Management**

- Spills must be promptly contained and disinfected using 10,000 ppm chlorine.
- Skin/mucosal exposure requires immediate washing and reporting to OCCH.
- Waste from high/medium-risk tissues must be incinerated; low-risk waste is managed as standard clinical waste.

| Diagnosis | High/Medium-Risk Tissues | Low-Risk Tissues/Fluids |
|---|---|---|
| Definite CJD/vCJD | Incinerate | Standard clinical waste |
| Probable CJD/vCJD | Incinerate | Standard clinical waste |
| At increased risk | Incinerate | Standard clinical waste |

### 5.2 Inoculation/Exposure Incidents

Provide first aid, report the incident, complete documentation, and contact OCCH. Manage in line with the Trust's sharps policy. No occupational transmission has been confirmed to date.

### 5.3 Incident Management (retrospective exposure)

If a patient with suspected/confirmed CJD/vCJD has previously undergone surgery or endoscopy, notify IPCT immediately. An incident review must be convened and relevant external agencies informed.

### 5.4 Care of the Deceased

Standard precautions apply. Use body bags as appropriate and complete the Infection Hazard Notification Sheet. Post-mortems require consultation with a Consultant Histopathologist and can be conducted in any suitably equipped mortuary.

### 5.5 Diagnosis of Definite, Probable and Possible CJD

Refer to ACDP guidance for internationally accepted criteria for definite, probable, and possible CJD/vCJD. Suspected cases must be referred to a neurologist or appropriate specialist.
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/209761/Annex_B_-_Diagnostic_criteria.pdf.

### 5.6 Asymptomatic Patients at familial risk

Includes individuals with two or more affected blood relatives or those with confirmed genetic mutations linked to familial CJD.

### 5.7 Asymptomatic Patients at Iactogenic Risk

Includes recipients of human-derived pituitary hormones, dura mater grafts, and those exposed to instruments or biological materials from individuals who later developed CJD/vCJD.

Some recipients of UK-sourced blood products (1980–2001) may fall into the ‘at risk’ category for vCJD.

## 6. IMPLEMENTATION/POLICY COMPLIANCE

### 6.1 General Hospital Care

Patients with CJD do not require isolation and may be cared for in open wards using Standard Infection Control Precautions (SICPs). Routine contact poses no known risk; however, procedures involving cerebrospinal fluid (CSF), biopsies, or blood samples require enhanced PPE, including gloves, apron, fluid-resistant surgical mask (FRSM), and eye protection.
Although CJD/vCJD cases have been reported in healthcare workers, no occupational transmission has been confirmed. The greatest risk arises from exposure to high-infectivity tissues via sharps injuries or mucosal contact. Staff must be informed of relevant risks and appropriate safety measures.
Most body fluids and secretions are considered low risk. Small-volume blood exposures are also low risk, though transmission via large-volume transfusion has been documented.

#### 6.1.1 Used or Foul Linen

- Contaminated linen should be placed in a red water-soluble alginate bag within a white linen bag and processed according to IPC 05 guidelines. No additional treatment is required.

#### 6.1.2 Ward-Based Invasive Procedures

- Such procedures must be performed only by trained personnel. Single-use items must be used and disposed of via high-temperature incineration.

### 6.1.3 Laboratory Specimens

- Routine specimens may be processed normally. High-risk samples (e.g. brain, spinal cord, eye, lymphoid tissue) require prior consultation with the receiving laboratory and must be clearly labelled as biohazard. CJD is classified as a Hazard Group 3 agent under COSHH.

**Hazard Group Definitions:**

- Group 1: Unlikely to cause human disease
- Group 2: May cause disease; low community risk; treatment available
- Group 3: Severe disease; serious occupational hazard; may spread; treatment available
- Group 4: Severe disease; high community risk; no effective treatment

### 6.1.4 Drug Administration

Only staff aware of the associated risks should administer injections or collect samples. Procedures must follow SICPs, using appropriate PPE, avoiding sharps injuries, and ensuring safe disposal of waste and equipment.

## 6.2 CARE OF PATIENTS KNOWN, SUSPECTED OR 'AT RISK' FOR TSE/CJD

### 6.2.1 Patient Groups Requiring Specific Precautions

**Precautions apply to the following groups:**

- Symptomatic patients (definite/probable/possible CJD/vCJD)
- Asymptomatic patients identified as 'at risk'
- Patients with familial or iatrogenic risk factors

The Infection Prevention and Control Team (IPCT) must be notified of all such cases. Fouled linen requires no additional precautions. Waste must be treated as clinical waste and incinerated.

### 6.2.2 Invasive Medical Procedures

Procedures such as lumbar puncture must follow strict guidelines due to prion resistance to standard decontamination methods.

### 6.2.3 Precautions to be taken

- Invasive procedures must be performed with care to avoid inoculation injuries.
- PPE must include gloves, apron, gown, FRSM, and eye protection.
- Use impervious bedding protection during procedures.
- Single-use instruments must be used and incinerated if contaminated.
- Blood collection must follow standard precautions to prevent parenteral exposure.

## 6.3 PROCEDURES FOR DISINFECTION OF SURFACES, SPILLAGES, SKIN

### 6.3.1 Surfaces and Spillages

- Prompt removal and cleaning of spills is essential.
- Use 10,000 ppm chlorine disinfectant after cleaning.
- Dispose of contaminated materials, including cleaning tools, as clinical waste.
- Ensure adequate ventilation during disinfection.

### 6.3.2 Skin and mucous membranes

- Wash contaminated skin with soap and water.
- Irrigate exposed mucous membranes with clean water.
- Report all exposures immediately and follow sharps policy guidance.

### 6.3.3 CSF and Non-Neural Biopsy Tissue

Only trained staff should collect CSF or biopsy specimens. PPE must be worn. All contaminated equipment, including non-disposable items, must be incinerated.

## 6.4 CLINICAL WASTE

Clinical waste from patients with definite, probable, or increased risk of CJD/vCJD must be managed according to the level of tissue infectivity. High or medium-risk tissues require disposal via high-temperature incineration in authorised facilities, as outlined in Welsh Health Technical Memorandum 07-01.

| Diagnosis | High/Medium risk tissue | Low risk tissue/fluids |
|---|---|---|
| Definite CJD/vCJD | Incinerate | Standard clinical waste disposal |
| Probable CJD/vCJD | Incinerate | Standard clinical waste disposal |
| At increased risk | Incinerate | Standard clinical waste disposal |

Low-risk materials include urine, saliva, sputum, blood, and faeces. Blood from vCJD patients is considered low risk unless transfused in large volumes.

## 6.5 INNOCULATION INJURIES

In the event of sharps injuries or contamination:

- Encourage bleeding, wash with warm soapy water, and apply a waterproof dressing.
- Irrigate eyes or mouth thoroughly if exposed.
- Report incidents to the Ward Manager and submit an adverse event report.
- Notify Occupational Health (OCCH), which will maintain records of all exposures.
- No occupational transmission has been confirmed to date.

## 6.6 ACTIONS FOLLOWING NOTIFICATION OF SUSPECTED CJD OR vCJD IN A PATIENT WITH PRIOR SURGERY OR ENDOSCOPY

Any suspected case of CJD/vCJD must be reported to the IPCT, regardless of inpatient status. An incident review committee will be convened, comprising:

- Executive Director of Nursing, AHPs & Health Sciences
- Head of Infection Prevention & Control (or deputy)
- IPC Doctor/Microbiologist
- Health and Safety Manager (or deputy)
- Head of Nursing VCC (or deputy)
- Decontamination Lead
- Medical Director (or deputy)

Public Health Wales and the National CJD Research and Surveillance Unit (NCJDRSU) must be informed as appropriate.

## 7. RELEVANT NATIONAL REQUIREMENTS

The policy aligns with the Health and Social Care Act 2008 and its associated Code of Practice on infection prevention and control (updated 2015).

Comprehensive guidance on the prevention and management of CJD and vCJD is available via the Department of Health and Social Care and the Advisory Committee on Dangerous Pathogens (ACDP) TSE Subgroup:

https://www.gov.uk/government/publications/guidance-from-the-acdp-tse-risk-management-subgroup-formerly-tse-working-group

Key documents include:

- Health and Safety Management of Transmissible Spongiform Encephalopathy (TSE).
- Laboratory containment and control measures (updated November 2021)
- Infection Control in healthcare and community settings
- Annexes covering tissue infectivity, diagnostic criteria, decontamination, transport, endoscopy, post-mortem care, surgical instrument management, and risk assessments across specialities (e.g. ophthalmology, urology, liver transplantation).

Additional resources:

- Joint United Kingdom (UK) Blood Transfusion and Tissue Transplantation Services Professional Advisory Committee. Donor Selection Guidelines. https://www.transfusionguidelines.org/dsg
- Welsh Health Technical Memorandum 01-01: Decontamination of surgical instruments (medical devices) used in acute care. Part A: Management and Provision. https://nwssp.nhs.wales/ourservices/specialist-estates-services/specialist-estates-services-documents/whtms-library/whtm-01-01-decontamination-of-surgical-instruments-medical-devices-used-in-acute-care-part-a-management-and-provision-pdf/

## 8. REFERENCES, BIBLIOGRAPHY, ACKNOWLEDGEMENTS AND ASSOCIATED DOCUMENTS

Advisory Committee on Dangerous Pathogens (ACDP)
https://www.gov.uk/government/groups/advisory-committee-on-dangerous-pathogens

Advisory Committee on the Safety of Blood, Tissues and Organs (SaBTO)
https://www.gov.uk/government/groups/advisory-committee-on-the-safety-of-blood-tissues-and-organs

Association of British Neurologists
http://www.theabn.org/

CJD International Surveillance Network
http://www.eurocjd.ed.ac.uk/

CJD Letter to Neurologists from UK CMOs 2025
https://bso.hscni.net/wp-content/uploads/2025/09/25-08-29-CJD-letter-to-neurologists-from-UK-CMOs_final.pdf

CJD Support Network
http://www.cjdsupport.net/

Department of Health and Social Care (2021). Minimise transmission risk of CJD and vCJD in healthcare settings. Prevention of CJD and vCJD by the Advisory Committee on Dangerous Pathogens' Transmissible Spongiform Encephalopathy (ACDP TSE) subgroup. https://www.gov.uk/government/publications/guidance-from-the-acdp-tse-risk-management-subgroup-formerly-tse-working-group

DA (81)22 Report of the Advisory Group on the Management of Patients with Spongiform Encephalopathy (Creutzfeldt-Jakob Disease) (CJD).

DA (84)16 Management of Patients with Spongiform Encephalopathy (Creutzfeldt-Jakob disease) (CJD).

Health and Care Quality Standards 2023. https://www.gov.wales/sites/default/files/publications/2023-05/health-and-care-quality-standards-2023.pdf

HSE (2023). The Approved List of biological agents. Advisory Committee on Dangerous Pathogens. Health and Safety Executive. http://www.hse.gov.uk/pubns/misc208.pdf

HSE (2019). Managing infection risks when handling the deceased. Guidance for the mortuary, post-mortem room and funeral premises, and during exhumation.HSG283. http://www.hse.gov.uk/pUbns/priced/hsg283.pdf

Infection prevention and control of CJD and variant CJD in healthcare and community settings Department of health (2015) https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/427854/Infection_controlv3.0.pdf

Joint United Kingdom (UK) Blood Transfusion and Tissue Transplantation Services Professional Advisory Committee (2024). Position Statement. Variant Creutzfeldt-Jakob disease. https://www.transfusionguidelines.org/document-library/position-statements

Joint United Kingdom (UK) Blood Transfusion and Tissue Transplantation Services Professional Advisory Committee (JPAC). https://www.transfusionguidelines.org/red-book

National CJD Research Surveillance Unit (NCJDRSU) http://www.cjd.ed.ac.uk/

National Prion Clinic (London) http://www.prion.ucl.ac.uk/clinic-services/

NEUROPRION Network of Excellence https://www.neuroprion.org/

NHS Blood and Transplant http://www.nhsbt.nhs.uk/

NICE interventional procedures guidance https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-interventional-procedures-guidance

NICE (2020): Reducing the risk of transmission of Creutzfeldt-Jakob disease from surgical instruments used for interventional procedures on high-risk tissues https://www.nice.org.uk/guidance/ipg666/resources/reducing-the-risk-of-transmission-of-

creutzfeldtjakob-disease-cjd-from-surgical-instruments-usedfor-interventional-procedures-on-highrisk-tissues-pdf-1899874227866821

Public Health England
https://www.gov.uk/government/collections/creutzfeldt-jakob-disease-cjd-guidance-data-and-analysis

Public Health Wales
http://www.wales.nhs.uk/sitesplus/888/page/43948

University of Edinburgh's Centre for Clinical Brain Sciences
http://www.ed.ac.uk/clinical-brain-sciences
Welsh Blood Service
https://www.welsh-blood.org.uk/

Welsh Health Technical Memorandum 07-01: Safe Management of Healthcare Waste'.
https://nwssp.nhs.wales/ourservices/specialist-estates-services/specialist-estates-services-documents/whtms-library/whtm-07-01-safe-management-of-healthcare-waste-pdf/

## 9. GETTING HELP

### 9.1 Internal Support

For advice and support regarding CJD-related infection prevention and control, contact the Velindre Infection Prevention and Control Team (IPCT): 02920 196129

### 9.2 National Organisations

Healthcare professionals can seek expert guidance from the following:

- **National CJD Surveillance Unit (NCJDRSU)** – Clinical and neuropathological advice: https://cjd.ed.ac.uk/
- **National Prion Clinic (UCLH)** – Specialist services and consultation: https://www.uclh.nhs.uk/our-services/find-service/neurology-and-neurosurgery/national-prion-clinic
- **CJD Support Network** – Support for patients and families, coordination of care: http://www.cjdsupport.net/

## 10. RELATED POLICIES

This policy should be read in conjunction with the following Trust document:-

- IPC 04 - Decontamination of Equipment Policy
- IPC 05 - National Infection Prevention and Control Manual (NIPCM)
- IPC 11 - Transport of Specimens
- Verification of Expected/ Anticipated Death by a Registered Nurse Policy (Nursing Policy)
- QS 24 - Medical Devices and Equipment Management Policy
- QS 35 - Safe Use of Sharps Policy
- PP 08 - Trust Waste Management Policy
- SOP 22 - Clinical Trial Human Biological Sample Spillage/Breakage

## 11. INFORMATION, INSTRUCTION AND TRAINING

### 11.1 Training Requirements

All relevant staff must complete mandatory annual IPC training, with role-specific updates identified through training needs analysis.

## 12. MAIN RELEVANT LEGISLATION

Compliance with the following legislation is essential to ensure the safe handling of devices and substances, and to prevent cross-contamination affecting patients and healthcare workers:

Health and Safety at Work etc. Act 1974
www.legislation.gov.uk/ukpga/1974/37

Management of Health and Safety at Work Regulations 1999
The Stationery Office www.legislation.gov.uk/uksi/1999/3242/contents/made

Control of Substances Hazardous to Health Regulations 2002 (revised 2020)
The Stationery Office www.legislation.gov.uk/uksi/2002/2677/contents/made

The Health and Safety (Sharp Instruments in Healthcare) Regulations 2013
www.legislation.gov.uk/uksi/2013/645/pdfs/uksi_20130645_en.pdf
www.hse.gov.uk/pubns/hsis7.pdf

Reporting of Injuries, Diseases and Dangerous Occurrences Regulations 2013 (RIDDOR)
www.legislation.gov.uk/uksi/2013/1471/made

**Appendix1: Infection Hazard notification sheet (HSE Document)**

| | | | | |
|---|---|---|---|---|
| 1 | Name of deceased | | | |
| 2 | Date and time of death | | | |
| 3 | Source (hospital, ward or other) | | | |
| 4 | Infection risk from the deceased [1] | | | |
| 4a | Does the deceased present an infection risk? (ring as appropriate) | | | |
| | Yes | Suspected | None suspected | |
| 4b | If yes, what are the likely routes of transmission? (ring all that apply) [2] | | | |
| | Airborne | Droplet | Contact | |
| 4c | Infection (if permitted to disclose) [3] | | | |
| | | | | |
| 4d | Provide any relevant information to enable the deceased to be handled safely [4] | | | |
| | | | | |
| 5 | Condition of the deceased [5] | | | |
| 5a | Is the deceased leaking body fluids? Please provide details | | | |
| | | | | |
| 5b | Have accessories that present a risk of sharps injury been removed? | | | |
| | | | | |
| 5c | If yes, have the puncture points been covered or sealed? | | | |
| | | | | |
| 5d | If no, please provide details and location | | | |
| | | | | |
| 5e | Does the deceased have an implantable device? (ring as appropriate) | | | |
| | No | Yes and switched off | Yes but not switched off | |
| 5f | If yes please provide details and location | | | |
| | | | | |
| 5g | Was the deceased receiving radiotherapy? (If yes, please provide details) | | | |
| | | | | |
| 6 | Signed [6] | | | |

| | | |
|---|---|---|
| | Print name | |
| | Hospital | |

Infection Hazard Notification Sheet v1 June 2019

*This information needs to be handled sensitively and securely to ensure confidentiality of the deceased's personal information. It should be shared only with those who need it to handle the deceased safely (as required by the Health and Safety at Work etc. Act 1974). This form provides one means of sharing the pertinent information.*

Notes

1. Providing sufficient information on infection risks from handling the deceased will enable the appropriate precautions to be taken. Where infection is the primary cause of death, please ring 'Yes' for Q4a. Infection may not be the primary cause of death but if the deceased was suffering from an infection, please ring 'Yes' or 'Suspected' for Q4a. Where there are no indications that the deceased was suffering from an infection, or where the deceased was on a course of antimicrobial medication that would minimise the infection risk, please ring 'None suspected*'* for Q4a and proceed to section 5, 'Condition of the deceased'.

2. When handling the deceased, standard infection control precautions (SICPs) are considered the minimum protective measures to be used. In Q4b provide information on how exposure to infection may occur. This will help those handling the deceased to consider adopting additional control measures (transmission-based precautions or TBPs) appropriate to the route by which they can be exposed and transmission can occur.

3. If the infection is known it is helpful, though not essential, to provide specific details in Q4c of the infectious agent, to inform the risk assessment and assist with possible treatment should exposure occur. This information may only be disclosed with prior permission of the deceased or their family.

4. In Q4d provide any information relevant to infection risk that may assist in deciding whether and how the deceased should be handled during viewing, preparing (hygienic preparation), embalming, post-mortem examination or exhumation. For example, indicate why a body bag has been used, whether a body bag is necessary, and details of any counter-indications that may prevent specific activities (e.g. embalming) being performed. It may be appropriate to consult Appendix 1 of this publication (*Managing infection risks when handling the deceased*) for further information.

5. In section 5 provide information on the condition of the deceased that would be helpful in deciding whether and how they should be handled. It highlights important issues, e.g. sharp medical devices or implantable devices (e.g. pacemakers), their location and whether they need to be removed.

6. In hospital cases, the doctor and/or nursing staff with knowledge of the deceased's condition is asked to sign section 6 of this form. Where a post-mortem examination has been undertaken, the pathologist (or qualified anatomical pathology technologist) is asked to sign. In non-hospital situations (e.g. community setting), the doctor with knowledge of the deceased's condition is asked to sign.