

## CREUTZFELDT- JAKOB DISEASE (CJD) AND VARIANT CREUTZFELDT- JAKOB DISEASE (VCJD) POLICY

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## DOCUMENT CONTROL

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<b>Intended recipients:</b> All clinical staff whatever their grade, role or status., permanent, temporary, full-time, part-time staff including locums, bank staff, volunteers, trainees and students.			
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## CONTENTS

<b>Section</b>	<b>Summary of Section</b>	<b>Page</b>
Doc	Document Control	2
Cont	Contents	<b>3</b>
1	Introduction	4
2	Purpose & Scope	5
3	Duties and Responsibilities	5
4	Explanation of Terms used	6
5	Identification of CJD Patients at Risk of Developing CJD	7
6	Transmission	8
7	General Hospital Care	9
8	Surgical Instruments	10
9	Decontamination of Surgical Instruments	10
10	Dentistry	11
11	Inoculation Injuries	11
12	Actions to be Taken Upon Notification of Previous Treatment of a Patient with Suspected CJD or vCJD	12
13	Training Requirements	12
14	Equality Impact Assessment	12
15	Monitoring Compliance and Effectiveness	13
16	Counter Fraud	13
17	Relevant Care Quality Commission (CQC) Registration Standards	13
18	References, Acknowledgements and Associated documents	14
19	Appendices	15
Appendix A	Pre-Operative Screening for Endoscopy and Low Risk Procedures – Guidance for Clinicians	16
Appendix B	Classification of Risk Groups	17
Appendix C	Care of the Deceased	19

## 1. INTRODUCTION

- 1.1 Transmissible spongiform encephalopathies (TSEs) are a group of diseases which affect both humans and animals. They are caused by agents currently thought to be infectious proteins known as prions, which do not share the normal properties of viruses and bacteria and are resistant to conventional chemical and physical decontamination methods.
- 1.2 Human forms of TSE fall into 3 groups as shown in **Table 1**. These cause a variety of neurological symptoms including dementia and personality changes as well as neuromuscular symptoms such as unsteadiness and involuntary muscular jerking. All human TSEs are extremely rare. There is currently no effective treatment available and the outcome is invariably fatal.
- 1.3 Variant CJD (vCJD) is a form of CJD first identified in 1996, thought to be linked to Bovine Spongiform Encephalopathy in cattle.
- 1.4 **Table 1: Classification of TSEs**

Idiopathic diseases	Sporadic Creutzfeldt-Jakob (CJD) Sporadic fatal insomnia Variably Protease-Sensitive Prionopathy (VPSPr)
Familial disease	Familial CJD Gerstmann-Straussler-Scheinker disease (GSS) Fatal familial insomnia
Acquired diseases	Iatrogenic CJD Kuru Variant CJD (vCJD)

- 1.5 There is no evidence that TSEs can be spread from person to person by close or normal social contact. However, there have been documented cases of spread via the administration of hormones prepared from human pituitary glands, dura mater grafts and following neurosurgical procedures with inadequately decontaminated instruments. In addition, vCJD has been reported in recipients of blood transfusion from donation taken from individuals who later developed vCJD. Although not proved, this route of transmission is considered highly likely. To date there have been no documented cases of occupational transmission.
- 1.6 In most routine clinical contact, no additional precautions are needed for the care of patients with or at risk of developing TSE. However, when certain invasive interventions involving high or medium infectivity risk tissues are performed there is the potential for exposure to the agents of TSEs. In these situations it is essential that appropriate control measures are in place to prevent the iatrogenic transmission of TSEs.
- 1.7 As CJD accounts for 95% of all reported TSEs the term CJD has been used throughout this policy for all human TSEs.

## **2. PURPOSE & SCOPE**

- 2.1 To provide all staff with clear instructions for the efficient management of Creutzfeldt-Jakob disease (CJD) and variant Creutzfeldt-Jakob disease (vCJD) to reduce potential risk.
- 2.2 The procedural document applies to all clinical staff (including Temporary, Locum, Bank, Agency and Contracted staff).

## **3. DUTIES AND RESPONSIBILITIES**

### **3.1 The Trust Board, via the Chief Executive, will:**

- ensure there are effective and adequately resourced arrangements for the management of CJD and vCJD within the trust;
- identify a board level lead for infection prevention and control;
- ensuring that the role and functions of the director of infection prevention and control are satisfactorily fulfilled by appropriate and competent persons as defined by DH, (2008, revised 2015).

### **3.2 Director of Infection Prevention and Control (DIPC) will:**

- oversee the local control of and the implementation of the Creutzfeldt-Jakob disease (CJD) and variant Creutzfeldt-Jakob disease (vCJD) policy;
- convene incident review meeting if a patient has had surgery or endoscopy performed and is subsequently found to have had symptoms of CJD or is identified as at risk of developing CJD;

### **3.3 The Infection Prevention and Control Assurance Group will:**

- ensure that the procedures for the management of CJD and v CJD are continually reviewed and improved within the Trust;
- ensure that lessons learned from any CJD incident are actioned and learning is disseminated throughout the Trust.

### **3.4 The Infection Prevention and Control (IPC) Team will:**

- advise on additional precautions required for symptomatic patients or those identified as being at risk of developing CJD who are undergoing surgery involving contact with high risk tissues (brain, spinal cord, posterior eye);
- advice on precautions required for other symptomatic patients or those identified as being at risk of developing CJD, as required;
- education and training regarding this policy.

3.5 **Ward and Team Managers/Hospital Matrons** will:

- ensure all their staff are aware of and follow the actions of this policy;
- ensure that all needlestick and similar incidents are reported as per RIDDOR guidelines;
- ensure that staff are released to attend relevant Training and for recording attendance at training in local training records. All non-attendance at training will be followed up by managers.

3.6 **All healthcare staff** will:

- ensure the infection prevention and control precautions detailed in this policy are followed for any patient with suspected or confirmed CJD or vCJD;
- inform the IP&C Team if a patient is confirmed or suspected as having CJD or vCJD;
- inform Staff Occupational Health provider if they receive a needlestick or other contamination injury from a patient with confirmed or suspected CJD or vCJD;
- follow the actions of this policy;
- book themselves onto and attend initial and update mandatory training.

3.7 **Staff Occupational Health Provider** will:

- advise staff involved in needlestick or inoculation incidents involving patients confirmed or suspected as having CJD or v CJD;
- staff Occupational Health Department will keep a record of all accidents and occurrences with an infectious or potentially infectious material involving the exposure of staff;
- the record will be kept for 40 years.

3.8 **The Learning and Development Department** will:

- enter all data relating to mandatory and non-mandatory training attendance onto the Electronic Staff Record (ESR) system and report non-attendance to Ward and Team Managers.

#### 4. **EXPLANATIONS OF TERMS USED**

4.1 **Creutzfeldt Jakob Disease (CJD)** - A human form of transmissible spongiform encephalopathy, which causes a variety of neurological symptoms including dementia and personality changes. The outcome is invariably fatal.

4.2 **Latrogenic CJD** - A form of CJD which occurs when CJD is accidentally transmitted during medical or surgical procedures.

4.3 **Prions** - Infectious proteins which do not share the normal properties of viruses and bacteria and are resistant to conventional chemical and physical decontamination methods.

- 4.4 **Transmissible Spongiform Encephalopathies (TSE)** - A group of neurological diseases affecting both humans and animals thought to be caused by a build up of prions in the brain.
- 4.5 **Variant Creutzfeldt Jakob Disease (vCJD)** - A form of CJD first identified in 1996, thought to be linked to ingesting meat from cattle infected with Bovine Spongiform Encephalopathy.
- 4.6 **High Risk Procedure** – Procedures that involve handling of tissue with high risk of CJD transmission. High risk tissues include brain, spinal cord, cranial nerves, specifically the entire optic nerve and the intracranial components of the other cranial nerves, cranial ganglia, posterior eye, specifically the posterior hyaloid face, retina, retinal pigment epithelium, choroid, subretinal fluid and optic nerve, pituitary gland.
- 4.7 **Medium Risk Procedure** – Procedures that involve handling of tissue with medium risk of CJD transmission. Medium risk tissues are spinal ganglia and olfactory epithelium. In patients with suspected or confirmed vCJD the following tissues are also medium risk; tonsil, appendix, spleen, thymus, adrenal gland, lymph nodes and gut-associated lymphoid tissues.
- 4.8 **Low Risk Procedure** - All procedures other than the high and medium risk procedures. Operations on the anterior eye have recently been downgraded to low risk procedures.
- 4.9 **Lymphoid Tissue** – Lymph nodes, appendix, spleen, thymus, tonsil, adenoids and gastro intestinal tract sub- mucosa.

## 5. IDENTIFICATION OF CJD PATIENTS OR PATIENTS AT RISK OF DEVELOPING CJD

In order to ensure that appropriate infection prevention and control measures are put in place, symptomatic patients (i.e. those who fulfil the diagnostic criteria for definite, probable or possible CJD or vCJD) and asymptomatic patients considered at risk of developing CJD (i.e. those with no clinical symptoms but who are potentially at risk of developing the familial disease or at risk due to iatrogenic exposures) must be appropriately identified. This is especially important if they are to undertake any surgical or endoscopic procedure.

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

For symptomatic cases there are internationally accepted diagnostic criteria for definite, probable and possible CJD or vCJD. These can be found at:

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/209761/Annex\\_B\\_-\\_Diagnostic\\_criteria.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/209761/Annex_B_-_Diagnostic_criteria.pdf)

Patients suspected of having CJD or vCJD must be referred to a neurologist or consultant with appropriate expertise for investigation.

**5.2 Asymptomatic Patients** at risk from familial forms of CJD linked to genetic mutations:

- individuals who have or have had two or more blood relatives affected by CJD or other prion disease, or a relative known to have a genetic mutation indicative of familial CJD;
- individuals who have been shown by specific genetic testing to be a significant risk of developing CJD or other prion disease.

**5.3 Asymptomatic Patients** potentially at risk from iatrogenic exposure:

- recipients of hormone derived from human pituitary glands, e.g. growth hormone, gonadotrophin;
- individuals who have received a graft of dura mater. (People who underwent neurosurgical procedures or operations for a tumour or cyst of the spine before August 1992 may have received a graft of dura mater, and should be treated as at risk, unless evidence can be provided that dura mater was not used);
- patients who have been contacted as potentially at risk because of exposure to instruments used on, or receipt of blood, plasma derivatives, organs or tissues donated by, a patient who went on to develop CJD or vCJD.

**5.4** The National CJD surveillance Unit (NCJDSU) must also be informed of all suspect cases.

Contact details for the unit are:

National CJD Surveillance Unit  
Western General Hospital  
Crew Road  
Edinburgh  
EH4 2XU  
Telephone 01313 5371980

## **6. TRANSMISSION**

- 6.1** Brain, CSF (cerebral spinal fluid), eye and nerve tissues are infectious and there have been rare cases of transmission due to inadequate decontamination of surgical instruments. Cross infection has occurred in neurosurgery and via certain tissue grafts, e.g. corneas.
- 6.2** Normal social or routine clinical contact with CJD/vCJD patients does not present a risk to health care workers and the community.



## 7. GENERAL HOSPITAL CARE

7.1 **General Ward Procedures** - In most routine clinical contact, no additional precautions are required when caring for patients with symptoms of CJD/vCJD or those identified as being at risk of developing CJD/vCJD. Standard infection control precautions are sufficient and isolation of patients is **not** necessary.

7.2 All healthcare workers who care for patients with confirmed or suspected CJD or vCJD should be knowledgeable in the nature of the risk to themselves or others, including which body tissues pose greatest risk of contamination, which procedures would lead to possible exposure to high risk body tissues and the relevant safety procedures if there is potential exposure to these body tissues.

7.3 **Used or Foul Linen (contaminated with body fluids or excreta)** - Place in a water soluble alginate bag and white linen bag. The linen can be washed in accordance with the Laundry Policy, and no further processing requirements are necessary.

### 7.4 Precautions during Ward Based Invasive Procedures

- ward based invasive procedures must only be taken by trained and competent personnel;
- single use / disposable items must be used and disposed of as clinical waste for incineration.

### 7.5 Laboratory Specimens

- blood and other specimens can be collected and processed in the same way for other patients;
- samples from known or suspected patients should be clearly marked with a High Risk Sticker. CJD is classified as Hazard Group 3.

7.6 **Drug Administration** – Only personnel aware of the hazard involved should carry out injections.

### 7.7 Spillage of Potentially CJD Infectious Materials –

- remove using absorbent material;
- a chlorine based solution at a concentration of 20,000ppm must be used;
- waste must be disposed of as clinical waste;
- disposable gloves and apron should be worn when removing spillages and disposed as clinical waste.

7.8 **Last Offices** - (refer to appendix C). Relatives may wish to have contact with the body, this should not be discouraged. No extra precautions are required. The patient should be placed in a body bag prior to transportation to the mortuary.

The Funeral Directors/ Mortuary staff should be informed of the patient's CJD status prior to them handling the body. A post mortem is generally indicated.

## **8. SURGICAL INSTRUMENTS (including Endoscopy)**

8.1 Whilst the risk of transmitting CJD through invasive medical procedures is uncertain precautionary action should be taken to prevent the possible transmission of infection.

8.2 There are 4 main factors that determine whether the use of a surgical instrument is likely to transmit CJD between patients.

- the type of procedure and tissues/fluids that come into contact with the instrument;
- the infectivity of the tissues in the patient with CJD that come into contact with instruments;
- the amount of infectivity remaining on the instruments following decontamination;
- the susceptibility of subsequently exposed patients.

High Risk Procedures are considered those that involve brain tissue, procedures that pierce the dura mata, contact with cranial ganglia or the pineal or pituitary glands.

Medium Risk Procedures are other invasive procedures on the eye, anaesthetic procedures involving the lymphoreticular system during tonsil surgery. For vCJD patients any contact with lymphoreticular system applies as medium risk and prior to the procedure advice from the Infection Prevention and Control Team must be sought.

Low Risk Procedures all procedures performed in Somerset Partnership NHS Foundation Trust are classified as low risk.

8.3 It is essential that all new instruments if reusable can be thoroughly cleaned before reprocessing.

## **9. DECONTAMINATION OF SURGICAL INSTRUMENTS (including Endoscopy)**

9.1 Single use instruments will be used for most procedures carried out on CJD suspected or known cases.

9.2 In the event that a patient known or highly suspected of CJD is admitted for endoscopy the National CJD Surveillance Unit in Edinburgh must be contacted prior to the procedure. A dedicated endoscope with decontamination instructions will then be especially sent.

9.3 If single use disposable instruments are not available, under no circumstances must the instruments be re-used., The Somerset Partnership NHS Foundation Trust Infection Prevention and Control Team must be contacted.

9.4 If non-disposable instruments are used, they must be withdrawn and quarantined, and expert advice for disposal sought.

## **10. DENTISTRY**

10.1 The transmission risk from dental instruments is thought to be very low so long as standard Infection and Control standards are adhered to.

10.2 There is no reason a patient with known or potential CJD should not receive routine dental care, and patients should receive the same care provided to those not known to be at risk.

10.3 Instruments should be reprocessed following normal protocols and procedures and may return to general use following this process.

10.4 The exceptions to this are endodontic instruments, Files Reamers and 3 in 1 tips, which are single-use disposable instruments.

## **11. INNOCULATION INJURIES**

11.1 For any incident involving 'sharps', or contamination of abrasions with blood or body fluid(s), wounds should be gently encouraged to bleed, gently washed (avoid scrubbing) with warm soapy water, rinsed, dried and covered with a waterproof dressing, or further treatment given appropriate to the type of injury.

11.2 Splashes in the eyes or mouth should be dealt with by thorough irrigation.

11.3 The accident should be reported to the Ward Manager/Ward Sister and a DATIX untoward event reporting form completed. The ward manager/sister should report as per RIDDOR guidelines (described within the Untoward Event Reporting Policy) as applicable.

11.4 Staff **must** telephone Staff Occupational Health provider and report injury. (Refer to Needle stick and Contamination Injury policy).

11.5 Staff Occupational Health provider will keep a record of all accidents and occurrences with an infectious or potentially infectious material involving the exposure of staff.

11.6 There is no evidence to date that transmission through occupational exposure has occurred.

## **12. ACTIONS TO BE TAKEN UPON NOTIFICATION OF SUSPECTED CJD OR vCJD IN A PATIENT WHO HAS PREVIOUSLY UNDERGONE SURGERY OR ENDOSCOPY WITHIN SOMERSET PARTNERSHIP**

- 12.1 The Infection Prevention and Control Team **must** be informed of any suspected case of CJD or vCJD regardless if they are currently an in-patient of the Trust or not, to allow for appropriate actions to be taken.
- 12.2 An incident review committee will be convened by the Trust Director of Infection Prevention & Control to manage the incident and decide the actions that are required:
- the DIPC or deputy;
  - the Lead Infection Prevention and Control Nurse or deputy;
  - the Trust Infection Prevention and Control Doctor;
  - the Risk Manager or deputy;
  - Service Manager;
  - relevant Matron;
  - Decontamination Lead;
  - the Medical Director or deputy.
- 12.3 In the event of an incident the Public Health England (Health Protection Team) will be informed and the Department of Health's CJD Incident Panel.

## **13. TRAINING REQUIREMENTS**

- 13.1 The Trust will work towards all staff being appropriately trained in line with the organisation's Staff Mandatory Training Matrix (training needs analysis). All training documents referred to in this policy are accessible to staff within the Learning and Development Section of the Trust Intranet.
- Trust Induction training;
  - Hand Hygiene training;
  - Infection Prevention and Control training;
  - Untoward Event Reporting training.

## **14. EQUALITY IMPACT ASSESSMENT**

- 14.1 All relevant persons are required to comply with this document and must demonstrate sensitivity and competence in relation to the nine protected characteristics as defined by the Equality Act 2010. In addition, the Trust has identified Learning Disabilities as an additional tenth protected characteristic. If you, or any other groups, believe you are disadvantaged by anything contained in this document please contact the Equality and Diversity Lead who will then actively respond to the enquiry.

## **15. MONITORING COMPLIANCE AND EFFECTIVENESS**

### **15.1 Monitoring arrangements for compliance and effectiveness**

- Overall monitoring will be by the Infection Control Assurance Group.

### **15.2 Responsibilities for conducting the monitoring**

- the Infection Prevention and Control Assurance Group will monitor procedural document compliance and effectiveness where they relate to clinical areas.

### **15.3 Methodology to be used for monitoring**

- incident reporting and monitoring;
- the IPC Team will monitor known or suspected cases of CJD/vCJD and adherence to the procedures outlined within this policy. Any actions identified will be implemented and monitored via the Infection Prevention and Control Assurance Group;
- an incident review committee will be convened by the Trust Director of Infection Prevention & Control following notification of any suspected CJD/vCJD case to review previous treatment and decide on any further actions.

### **15.4 Frequency of monitoring**

- the Infection Prevention and Control Assurance Group reports to the Clinical Governance Group every quarter and will escalate and areas of concern and risk issues.

## **16. COUNTER FRAUD**

16.1 The Trust is committed to the NHS Protect Counter Fraud Policy – to reduce fraud in the NHS to a minimum, keep it at that level and put funds stolen by fraud back into patient care. Therefore, consideration has been given to the inclusion of guidance with regard to the potential for fraud and corruption to occur and what action should be taken in such circumstances during the development of this procedural document.

## **17. RELEVANT CARE QUALITY COMMISSION (CQC) REGISTRATION STANDARDS**

17.1 Under the **Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 (Part 3)**, the **fundamental standards** which inform this procedural document, are set out in the following regulations:

Regulation 9:	Person-centred care
Regulation 10:	Dignity and respect
Regulation 11:	Need for consent
Regulation 12:	Safe care and treatment
Regulation 17:	Good governance
Regulation 20:	Duty of candour

17.2 Under the **CQC (Registration) Regulations 2009 (Part 4)** the requirements which inform this procedural document are set out in the following regulations:

Regulation 11:	General
Regulation 12:	Statement of purpose
Regulation 16:	Notification of death of service user
Regulation 18:	Notification of other incidents

17.3 Detailed guidance on meeting the requirements can be found at <http://www.cqc.org.uk/sites/default/files/20150311%20Guidance%20for%20providers%20on%20meeting%20the%20regulations%20FINAL%20FOR%20PUBLISHING.pdf>

### **Relevant National Requirements**

Nice Interventional Procedure Guidance 196(2006) Patient Safety and reduction of Creutzfeldt-Jacob disease via interventional procedures

Decontamination Health Technical Memorandum 01-05: Decontamination in Primary Care Dental Practices (2013)

Department of Health Guidance: Minimise transmission risk of CJD and vCJD in healthcare settings (2012, revised 2015)

Department of Health (2008) The Health and Social Care Act 2008, Code of Practice for health and social care on the prevention and control of infections and related guidance (updated 2015).

Reporting of Injuries, Diseases and Dangerous Occurrences Regulations (1995) (RIDDOR).

## **18 REFERENCES, ACKNOWLEDGEMENTS AND ASSOCIATED DOCUMENTS**

### **18.1 References**

Transmissible Spongiform Encephalopathy Agents: Safe Working and Prevention of Infection. Infection Control of CJD and related disorders in the healthcare setting. Advisory Committee on Dangerous Pathogens, Spongiform Encephalopathy Advisory Committee. June 2003: Updated March 2007.

Minimise transmission risk of CJD and vCJD in healthcare settings. 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>

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/270735/Annex J Assessment to be carried out before surgery and or endoscopy to identify patients with or at risk of CJD or vCJD.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/270735/Annex_J_Assessment_to_be_carried_out_before_surgery_and_or_endoscopy_to_identify_patients_with_or_at_risk_of_CJD_or_vCJD.pdf)

Department of Health (2008) The Health and Social Care Act 2008, Code of Practice for health and social care on the prevention and control of infections and related guidance. (revised 2011)

## 18.2 Cross reference to other procedural documents

Cleaning of Equipment and Decontamination Policy  
End of Life Care Policy (Incorporating Infection Prevention and Control of Deceased patients and Care of Patients in the Last Days of their Life)  
Hand Hygiene Policy  
Health and Safety Policy.  
Healthcare (Clinical) Waste Policy  
Infection Prevention and Control Standard Precautions Policy  
Laundry Policy  
Medical Devices Policy  
Needlestick and Contamination Injury Policy  
Outbreak of Infection – Policy for management and Control  
Risk Management Policy and Procedure  
Risk Management Strategy  
Untoward Event Reporting Policy and Procedure

All current policies and procedures are accessible in the policy section of the public website (on the home page, click on 'Policies and Procedures'). Trust Guidance is accessible to staff on the Trust Intranet.

## 19. APPENDICES

19.1 For the avoidance of any doubt the appendices in this policy are to constitute part of the body of this policy and shall be treated as such.

Appendix A Pre-Operative screening for Endoscopy and Low Risk Procedures – Guidance for Clinicians  
Appendix B Classification of Risk Groups  
Appendix C Care of the Deceased

### Pre-Operative Screening for Endoscopy and Low Risk Procedures Guidance for Clinicians

At a local level arrangements should be put in place to ensure that patients who have been notified they are at increased risk of CJD/vCJD are identified before surgery or endoscopy, to allow appropriate infection prevention and control procedures to be followed.

**All** patients about to undergo **any** elective or emergency surgical or endoscopic procedure should be asked the question:

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

The actions to take based on the response to the above question are:

Patient's response	Action
No	Surgery or endoscopy should proceed using normal infection prevention and control procedures unless the procedure is likely to lead to contact with high risk tissue.
Yes	<p>Please ask the patient to explain further the reason they were notified.</p> <p>Special infection prevention and control precautions should be taken for all surgery or endoscopy involving contact with medium or high infectivity tissues and the local infection prevention and control team should be consulted for advice.</p> <p>Detailed guidance on the precautions to be taken during the treatment of patients with or at increased risk of CJD or vCJD, can be found at:</p> <p><a href="https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/270735/Annex_J_Assessment_to_be_carried_out_before_surgery_and_or_endoscopy_to_identify_patients_with_or_at_risk_of_CJD_or_vCJD.pdf">https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/270735/Annex_J_Assessment_to_be_carried_out_before_surgery_and_or_endoscopy_to_identify_patients_with_or_at_risk_of_CJD_or_vCJD.pdf</a></p> <p>The patient's response should be recorded in their medical notes for future reference.</p>
Unable to respond	Surgery or endoscopy should proceed using normal infection prevention and control procedures <b>unless</b> the procedure is likely to lead to contact with high risk tissue. If this is the case, please refer to the additional recommendations for high risk procedures in the guidance document above



Classification of Risk Groups

1	Symptomatic patients (Definite , probable or possible)	<p>1.1 Patients who fulfil the diagnostic criteria for definite, probable or possible CJD or vCJD</p> <p>1.2 Patients with neurological disease of unknown aetiology who do not fit the criteria for possible CJD or vCJD, but where the diagnosis of CJD is being actively considered</p>
2	Asymptomatic patients at risk from familial forms of CJD linked to genetic mutation	<p>2.1 Individuals who have been shown by specific genetic testing to be at significant risk of developing CJD or other prion disease</p> <p>2.2 Individuals who have a blood relative known to have a genetic mutation indicative of familial CJD</p> <p>2.3 Individuals who have or have had two or more blood relatives affected by CJD or other prion disease.</p>
3	Asymptomatic patients identified as potentially at risk due to iatrogenic exposure	<p>3.1 Recipients of hormone derived form human pituitary glands e.g. growth hormone, gonadotrophin. In the UK, cadaver –derived human growth hormone was banned in 1985 but use of human derived products may have continued in other countries.</p> <p>3.2 Individuals who have received a graft or <i>dura mater</i> (people who underwent neurosurgical procedures or operations for a tumour or cyst of the spine before August 1992 may have received a graft of <i>dura mater</i> and should be treated as at risk unless evidence can be provided that <i>dura mater</i> was not used)</p> <p>3.3 Patients who have been contacted as potentially at risk including individuals considered to be</p> <ul style="list-style-type: none"> <li>• at risk of CJD/vCJD due to exposure to certain instruments used on a patient who went on to develop CJD/vCJD or was at risk of vCJD</li> <li>• at risk of vCJD due to blood or blood components from 300 or more donors since January 1990</li> <li>• at risk of CJD/vCJD due to receipt of tissues/organs</li> <li>• at risk of vCJD due to the probability they could have been the source of</li> </ul>

		<p>infection for patients transfused with their blood who are later found to have VCJD</p> <ul style="list-style-type: none"><li>• at risk of vCJD because they have received blood or blood components from someone who has also given blood or blood components to a patient who went to develop vCJD</li><li>• at risk because of treatment with certain UK sourced plasma products between 1990 and 2001</li></ul>
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**CARE OF THE DECEASED**

- 1 On the death of a CJD patient (or patient at risk of developing CJD) the removal of the body from the ward, community setting or hospice, to the mortuary, should be carried out using normal infection control measures. It is recommended that the deceased patient is placed in a body bag prior to transportation to the mortuary, in line with normal procedures for bodies where there is a known infection risk. Full details of the proposed/confirmed diagnosis must be given to the undertakers concerned with the deceased prior to their handling of the body.
- 1.1 Following the death of a patient, their cultural/religious needs and wishes, which were expressed prior to death, will be carried out as far as possible. The dignity of the deceased person will be respected throughout the whole process. Staff should refer to the Trust's spirituality policy for guidance on meeting the needs of both the relatives/carers and the deceased, and if necessary ask the patient's faith representative to attend the ward.

**Post-Mortem**

- 1.2 Post-mortem examinations are required in order to confirm a clinical diagnosis and the cause of death in patients with suspected CJD or vCJD. Post-mortem examinations on CJD cases can be undertaken in any mortuary, provided that appropriate care is taken to minimise contamination of the working environment.

**Undertakers**

- 1.3 The undertakers should be informed of the known or potential CJD/vCJD diagnosis, prior to handling the body of the deceased. Concern about possible unknown CJD cases does not warrant a level of precaution for undertakers handling intact bodies other than those used generally for all work of this nature.

**Viewing the Deceased**

- 1.4 Relatives of the deceased may wish to view or have some final contact with the body. Such viewing and possible superficial contact, such as touching or kissing need not be discouraged.

**Environmental Concerns**

- 1.5 There is no need to discourage burial of a patient with known or suspected CJD or vCJD, and no special arrangements for burial are required. Similarly, there is no need for any extra precautions to be taken for cremation.

## **Transporting the Body**

- 1.6.1 No additional precautions are needed for transporting the body within the UK.
- 1.7 Please refer to End of life care policy (Incorporating Infection Prevention and Control of Deceased patients and Care of Patients in the Last Days of their Life) for any further guidance in relation to Last Offices.