GP 05

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Community Infection Prevention and Control Policy for General Practice

(also suitable for adoption by other healthcare providers, e.g. Dental Practice, Podiatry)

CJD (Creutzfeldt-Jakob disease)

CJD

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GP 05

CJD

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This document has been adopted as a Policy by:

Organisation: ..... …

Signature: ..... Name: .....

Job title: .....

Adoption date: .....

Review date: .....

Any variation to this Policy should be risk assessed, evidence-based, authorised through local governance channels and documented below. The Community Infection Prevention and Control (IPC) Team, Harrogate and District NHS Foundation Trust, cannot endorse or be held responsible for any variations.

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CJD (CREUTZFELDT-JAKOB DISEASE)

1. Introduction

Creutzfeldt-Jakob Disease (CJD) is one of a group of diseases called Transmissible Spongiform Encephalopathies (TSEs) which can occur in people or animals. The transmissible agent is an abnormal protein known as a prion. TSEs are characterised by degeneration of the nervous system and are fatal.

CJD has a long incubation period and may not cause symptoms for many years. Clinical features vary depending on the regions of the brain affected, but all patients experience a very rapid deterioration following onset of symptoms. There are no simple non-invasive tests available to diagnose CJD before symptoms develop, diagnosis can only be confirmed on the death of a patient by a brain biopsy.

In this Policy, the term CJD encompasses sporadic CJD, variant CJD (vCJD), familial CJD, and other TSEs. There are several types of CJD:

- **Sporadic**: commonest form caused by a mutant gene. Usual age of onset is late middle age. Most patients present with rapidly progressive dementia with focal neurological signs including ataxia, myoclonus, visual disturbances and rigidity. Death occurs within 4-6 months of clinical onset
- **Familial:** approximately 15% of cases are inherited and caused by a gene mutation
- **Iatrogenic**: about 1% are transmitted by medical or surgical procedures including pituitary hormone injections, dura mater grafts, and rarely by neurosurgical instruments. The incubation period can range from 1-2 years for neurological routes of transmission and up to 30 years in some pituitary hormone recipients
- **Variant CJD** (vCJD): thought to be as a result of eating contaminated bovine food products (same agent responsible for BSE in cattle). Whilst the numbers of vCJD cases remain reassuringly low, concerns remain over the possible appearance of new vCJD cases in other genetic cohorts and the numbers of asymptomatic individuals in the population harbouring vCJD infectivity. Tends to affect young adults, with the clinical illness lasting an average of 14 months. Symptoms may include both psychiatric and sensory abnormalities, which are followed by ataxia, myoclonus and other movement disorders and dementia

2. Transmission

How TSE's are transmitted is uncertain, but there is no evidence that they are spread from person-to-person by close contact. It is, however, known that

transmission of sporadic CJD can be associated with medical intervention, e.g. administration of hormones prepared from human pituitary glands, dura mater preparations, corneal grafts and recently from blood transfusions. CJD/vCJD has also been reported following brain surgery due to inadequately decontaminated instruments (prion proteins are resistant to decontamination processes).

The Advisory Committee on Dangerous Pathogens has suggested that in people with sporadic CJD, certain tissues have high, medium or low infectivity. There is evidence that the distribution of the abnormal prion protein in tissues is more widespread in the body in patients with vCJD, than in patients with sporadic CJD.

Tissue infectivity of CJD and vCJD

Tissue	Assumed level of infectivity	
	CJD other than vCJD	vCJD
Brain	High	High
Cranial ganglia	High	High
Cranial nerves, specifically the entire optic nerve and only the intracranial components of the other cranial nerves	High	High
Pituitary gland	High	High
Posterior eye, specifically the posterior hyaloid face, retina, retinal pigment epithelium, choroid, sub-retinal fluid, optic nerve	High	High
Spinal cord	High	High
Olfactory epithelium	Medium	Medium
Spinal ganglia	Medium	Medium
Adrenal gland	Low	Medium
Appendix	Low	Medium
Gut-associated lymphoid tissue	Low	Medium
Lymph nodes and other organised lymphoid tissues containing follicular structures	Low	Medium
Spleen	Low	Medium
Thymus	Low	Medium
Tonsil	Low	Medium
Anterior eye and cornea	Low	Low
Blood and bone marrow	Low	Low
CSF	Low	Low
Dental pulp	Low	Low
Dura mater	Low	Low
Gingival tissue	Low	Low
Peripheral nerve	Low	Low
Placenta	Low	Low
Skeletal muscle	Low	Low
Urine	Low	Low
Other tissues	Low	Low

3. Risk groups

When considering measures to prevent transmission to patients or staff, it is useful to make a distinction between:

- Symptomatic patients, i.e. those who fulfil the diagnostic criteria for definite, probable or possible CJD or vCJD; and
- Patients 'at increased risk', i.e. those with no clinical symptoms, but who are 'at increased risk' of developing CJD or vCJD, because of their family or medical history

It is the responsibility of the clinician to ensure that an assessment to determine risk is undertaken using the table below as guidance.

Risk groups	
Symptomatic patients	• Individuals who fulfil the diagnostic criteria for definite, probable or possible CJD or vCJD • Individuals 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
Asymptomatic patients 'at risk' from genetic forms of CJD	• Individuals who have a blood relative known to have a genetic mutation indicative of genetic CJD • Individuals who have been shown by specific genetic testing to be at significant risk of developing CJD
Asymptomatic patients identified as 'at increased risk' of CJD/vCJD through 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 dura mater graft and should be treated as 'at risk' unless evidence can be provided that dura mater was not used) • Individuals who have been contacted as potentially at risk and asked to follow public health precautions

4. Care of a patient with CJD

Normal social or routine clinical contact with a patient with CJD or related disease does not present a risk to healthcare staff, relatives or the community. Isolation is not necessary and they can be cared for at home or in a health and social care setting. Always use 'Standard infection control precautions' (SICPs) and, where required, 'Transmission based precautions' (TBPs), refer to the 'SICPs and TBPs Policy for General Practice'.

Although cases of CJD/vCJD have been reported in healthcare staff, there have been no confirmed cases linked to occupational exposure.

The following advice is for the care of patients who are confirmed, suspected or at risk of developing CJD or related disorders.

Description	Advice
Communication	Your local Community Infection Prevention and Control (IPC) or UK Health Security Agency (UKHSA) Team should be contacted in order to give appropriate advice
Type of isolation	Isolation is not required. A patient may be cared for in their own home or in a health and social care setting and can socialise and take part in normal activities
Main infection source	The main potential source of infection is from high risk tissues, especially brain, spinal cord, eye and cerebrospinal fluid (CSF) in sporadic CJD, contact with high risk tissues is unlikely in a community setting. There is no evidence of infectivity in saliva, body excretions or excreta. As the infectivity of other tissues in vCJD is less well understood, SICPs should be adhered to including covering cuts and abrasions with a waterproof dressing
Pathology specimens	All specimens from a patient with a definite, probable or possible diagnosis of CJD, must be labelled as 'infection risk'. Pathology specimens should only be taken if absolutely essential, and after prior consultation with your local Community IPC or UKHSA Team and the pathology laboratory
Personal protective equipment	Disposable apron and gloves should be worn when performing any procedure which involves handling tissues, blood or body fluids, and facial protection if there is a risk splashing to the face
Disposal of faeces/urine	No specific precautions are required. Patients may use the toilet provided good personal habits are maintained

<table>
<tr><th>Description</th><th colspan="3">Advice</th></tr>
<tr><td rowspan="5">Disposal of clinical waste from patients with, or ‘at increased risk’ of, CJD</td><td>Diagnosis</td><td>High or medium risk tissue*</td><td>Low risk tissue and body fluids**</td></tr>
<tr><td>Definite</td><td>Incinerate</td><td>Normal clinical waste disposal</td></tr>
<tr><td>Probable</td><td>Incinerate</td><td>Normal clinical waste disposal</td></tr>
<tr><td>‘At increased risk’</td><td>Incinerate</td><td>Normal clinical waste disposal</td></tr>
<tr><td colspan="3">* Refer to tissue infectivity of CJD and vCJD table on page 5
** Tissues and materials deemed to be low risk include body fluids such as urine, saliva, sputum, blood, and faeces. Blood from vCJD patients is considered to be low risk except when transfused in large volumes</td></tr>
<tr><td>Cutlery and crockery</td><td colspan="3">No specific precautions. Disposable items are not required</td></tr>
<tr><td>Medical equipment</td><td colspan="3">Single use equipment should be used, where possible, if in contact with body fluids and disposed of as infectious waste. Reusable medical equipment in contact with intact skin should be decontaminated with detergent and warm water, or ‘2 in 1’ detergent and disinfectant wipes, after use</td></tr>
<tr><td>Linen</td><td colspan="3">No special requirements, linen and clothing should be laundered as usual</td></tr>
</table>

5. Clinical and surgical procedures

The advice of your local Community IPC or UKHSA Team must always be sought before any clinical or surgical procedure on confirmed, suspected or at risk individuals.

6. Spillages of blood and body fluids

SICPs should be followed to clear up spillages of blood and body fluids from patients with, or ‘at increased risk’ of CJD in the community. Spillages should be cleared up as quickly as possible. Refer to the ‘Safe management of blood and body fluid spillages Policy for General Practice’.

Spillage kits may contain solidifying polymer granules. A National Patient Safety Alert issued in 2017, following a number of deaths and incidents related to patients ingesting the product, advises a risk assessment and procedures in place to ensure supplies are securely stored away from the general public.

7. Inoculation injury and blood or body fluid splashes

Any incident involving used sharps, splashes into the eyes, mucous membranes or contamination of abrasions with blood or body fluids, should be dealt with in accordance with the 'Safe management of sharps and inoculation injuries Policy for General Practice' and reported immediately to the Occupational Health Department/GP Practice/Emergency Department, who will discuss the case with a Consultant Microbiologist.

8. Contact lenses and ophthalmic devices

There have been no known cases of iatrogenic transmission of CJD/vCJD resulting from diagnostic examination or contact lens wear. Although contact with the corneas is considered as low risk in terms of iatrogenic transmission, further advice can be obtained from the Department of Health's 'Guidance from the ACDP TSE Risk Management Subgroup'.

The use of 'single use' instruments or contact lenses is recommended for use on those designated at increased risk of CJD or vCJD.

9. Referral or transfer to another health or social care provider

- If it is necessary to refer or transfer a patient to another health or social care provider, e.g. ambulance service, hospital, they should be informed of the patient's CJD status prior to the transfer. This will enable a risk assessment to be undertaken to determine the appropriate IPC measures to be taken, e.g. transported without other patients, isolated on admission.
- Staff preparing to transfer a patient to another health and social care provider should complete a patient passport or the Inter-health and social care infection control transfer Form (see Appendix 1, available to download at www.infectionpreventioncontrol.co.uk). This should accompany the patient. Refer to the 'Patient placement and assessment for infection risk Policy for General Practice'.
- The patient's 'at risk' status must be included in any referrals for surgery as head and neck surgery may involve contact with tissues of high or medium infectivity, for which special infection control precautions will be required.
- SICPs and TBPs should be followed whenever transferring a patient, whether they have a confirmed infection or not.
- The completed transfer documentation should be supplied to the receiving health or social care provider and a copy filed in the patient's notes.

- Ensure that care equipment used to transfer the patient, e.g. wheelchair, is decontaminated in accordance with the 'Safe management of care equipment Policy for General Practice'.

10. Death of a patient

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

Funeral directors must be informed of the infection status. The deceased person's body should be placed in a cadaver bag prior to transportation by the funeral directors.

Under no circumstances must any tissue or organs be used for donation.

11. Infection Prevention and Control resources, education and training

The Community IPC Team have produced a wide range of innovative educational and IPC resources designed to assist your Practice in achieving compliance with the *Health and Social Care Act 2008: code of practice on the prevention and control of infections and related guidance* and CQC registration requirements.

These resources are either free to download from the website or available at a minimal cost covering administration and printing:

- 27 IPC Policy documents for General Practice
- Preventing Infection Workbook for General Practice
- IPC CQC inspection preparation Pack for General Practice
- IPC audit tools, posters, leaflets and factsheets
- IPC Bulletin for GP Practice Staff

In addition, we hold educational study events in North Yorkshire.

Further information on these high quality evidence-based resources is available at www.infectionpreventioncontrol.co.uk.

12. References

Department of Health and Social Care (Updated December 2022) *Health and Social Care Act 2008: code of practice on the prevention and control of infections and related guidance*

Department of Health (2012, updated November 2021) *Minimise transmission risk of CJD and vCJD in healthcare settings* www.gov.uk/government/publications/guidance-from-the-acdp-tse-risk-management-subgroup-formerly-tse-working-group

Department of Health (July 2003, revised and updated February 2015) *Transmissible Spongiform Encephalopathy Agents: Safe Working and the Prevention of Infection: Part 4 Infection Prevention and Control of CJD and Variant CJD in Healthcare and Community Settings* www.gov.uk/government/uploads/system/uploads/attachment_data/file/427854/Infection_controlv3.0.pdf

NHS England (2022, updated 2023) *National infection prevention and control manual (NIPCM) for England*

NHS England (2019) *Risk of death and severe harm from ingesting superabsorbent polymer gel granules Reference NatPSA/2019/002/NHSPS* www.england.nhs.uk/wp-content/uploads/2020/02/PSAlert_Polymer_28_Nov_2019_FINAL.pdf

13. Appendices

Appendix 1: Inter-health and social care infection control transfer Form

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Inter-health and social care infection control transfer Form

The *Health and Social Care Act 2008: code of practice on the prevention and control of infection and related guidance* (Department of Health and Social Care, updated December 2022), states that "The provision of suitable accurate information on infections to service users, their visitors and any person concerned with providing further social care support or nursing/medical care in a timely fashion". This form has been developed to help you share information with other health and social care providers. The form should accompany the service user and, where possible, a copy filed in their notes.

Service user name:..... Address: ..... NHS number: ..... Date of birth: ..... Service user's current location:.....	GP name and contact details:

Receiving facility, e.g. hospital ward, hospice: .....

If transferred by ambulance, the service has been notified: Yes ☐ N/A ☐

Is the service user an infection risk:
Please tick most appropriate box and give details of the confirmed or suspected organism

☐ Confirmed risk Organisms: .....

☐ Suspected risk Organisms: .....

☐ No known risk

Service user exposed to others with infection, e.g. diarrhoea and/or vomiting, influenza: Yes ☐ No ☐ Unaware ☐

If yes, please state: .....

If the service user has a diarrhoeal illness, please indicate bowel history for last week, if known, (based on Bristol stool form scale):

.....

Is diarrhoea thought to be of an infectious nature? Yes ☐ No ☐ Unknown ☐

Relevant specimen results if available

Specimen:				
Date:				
Result:				

Treatment information:

Is the service user aware of their diagnosis/risk of infection? Yes ☐ No ☐

Does the service user require isolation? Yes ☐ No ☐

If the service user requires isolation, phone the receiving facility in advance: Actioned ☐ N/A ☐

Additional information:

Name of staff member completing form: .....

Print name: .....

Contact No: ..... Date .....

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