



Community Infection Prevention and Control Policy for General Practice

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

CJD

(Creutzfeldt-Jakob disease)

Version 4.00
March 2026

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Signature: Name:

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Adoption date:

Review date:

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Community Infection Prevention and Control
Harrogate and District NHS Foundation Trust
Gibraltar House, Thurston Road
Northallerton, North Yorkshire. DL6 2NA
Tel: 01423 557340
email: infectionprevention.control@nhs.net
www.infectionpreventioncontrol.co.uk

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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 TSEs 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 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).

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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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		
Disposal of clinical waste from patients with, or 'at increased risk' of, CJD	Diagnosis	High or medium risk tissue	Low risk tissue and body fluids*
	Definite	Incinerate	Normal clinical waste disposal
	Probable	Incinerate	Normal clinical waste disposal
	'At increased risk'	Incinerate	Normal clinical waste disposal
* 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			

Description	Advice
Medical equipment	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

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 was issued following a number of deaths and incidents related to patients ingesting the product. This advises a risk assessment be undertaken and procedures put 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 (available to download at www.infectionpreventioncontrol.co.uk/resources/inter-health-and-social-care-infection-control-transfer-form/). 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 assessment 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 (Updated November 2021) *Minimise transmission risk of CJD and vCJD in healthcare settings*

Department of Health (Updated March 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*

NHS England (Updated 2025) *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*