Infection. Prevention. Control.
You're in safe hands

NHS

Community Infection Prevention and Control Policy for Care Home settings

CJD

(Creutzfeldt-Jakob disease)

Version 4.00
May 2025

07

CJD

Please note that the internet version is the only version that is maintained. Any printed copies should, therefore, be viewed as 'uncontrolled' and as such, may not necessarily contain the latest updates and amendments.

This Policy has been adopted by:

Organisation: .....

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

Job title: .....

Adoption date: .....

Review date: .....

Any variation to this Policy should be risk assessed, evidence-based, authorised 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.

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

Contents Page

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 invariably 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 following onset of symptoms a very rapid deterioration occurs. There are no simple non-invasive tests available to diagnose CJD before symptoms develop, diagnosis can only be confirmed on the death of a resident 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 cases 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 rare, there has been a gradual increase in numbers of people being diagnosed. 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 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 residents with vCJD, than in residents with sporadic CJD.

3. Care of a resident with CJD

Normal social or routine clinical contact with a resident with CJD or related disease does **not** present a risk to staff, relatives or the community. Isolation is not necessary and they can be cared for in a care home setting. No special measures over and above 'Standard infection control precautions' (SICPs) are required for caring for CJD or vCJD residents in a community setting, as it is **unlikely** that a procedure will be undertaken that involves contact with high or medium risk tissues, e.g. brain, spinal cord.

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 residents who are confirmed, suspected or at risk of developing CJD or related disorders.

Care of a resident with CJD	
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 resident may be cared for in a care home 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	Body secretions, body fluids, including saliva, blood, and excreta, are all low risk for CJD. It is, therefore, likely that the majority of samples taken will be low risk. Blood and body fluid samples from residents with, or 'at increased risk' of, CJD should be treated as potentially infectious and handled with SICPs as for any other resident. All specimens from a resident with a definite, probable or possible, diagnosis of CJD, must be labelled as 'infection risk'
PPE	Disposable apron and gloves should be worn when performing any procedure which involves handling body tissue, blood or body fluids and face protection worn if splashing is anticipated

Care of a resident with CJD	
Disposal of faeces/urine	No specific precautions are required. Residents may use the toilet, provided good personal habits are maintained
Disposal of clinical waste	Clinical waste should be disposed of as per local policy
Cutlery and crockery	No specific precautions. Disposable items are not required
Medical equipment	No specific precautions are required. Standard infection prevention and control cleaning and disinfection measures should be applied. Refer to the 'Safe management of care equipment Policy for Care Home settings'
Linen	No special requirements, linen and clothing should be laundered as usual. Refer to the 'Safe management of linen, including uniforms and workwear Policy for Care Home settings'

4. Spillages of blood and body fluids

SICPs should be followed to clear up spillages of blood and body fluids from residents with, or 'at increased risk' of, CJD. Spillages should be cleared up as quickly as possible. Refer to the 'Safe management of blood and body fluid spillages Policy for Care Home settings'.

5. Sharps injury and blood or body fluid splashes

Contact with small volumes of blood, including sharps injury, is considered low risk. 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 'Safe management of sharps and inoculation injuries Policy for Care Home settings' and reported immediately to the Occupational Health Department/GP Practice/Emergency Department, who will discuss the case with a Consultant Microbiologist.

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

- Prior to a resident's transfer to and/or from another health or social care facility, an assessment for infection risk must be undertaken. This ensures appropriate placement of the resident.
- Transfer documentation, e.g. a patient passport or an 'Inter-health and social care infection control transfer Form' (available to download at www.infectionpreventioncontrol.co.uk), must be completed for all transfers, internal or external and whether the resident presents an infection risk or not. Refer to the 'Patient placement and assessment for infection risk Policy for Care Home settings'.

- The resident'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.
- The ambulance/transport service and receiving area must be notified of the resident's infectious status in advance.

7. Death of a resident

Inform your local Community IPC or UKHSA Team. 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 resident'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.

Refer to the 'Care of the deceased Policy for Care Home settings'.

8. Infection Prevention and Control resources, education and training

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

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

- 30 IPC Policy documents for Care Home settings
- Preventing Infection Workbook: Guidance for Care Homes
- IPC CQC inspection preparation Pack for Care Homes
- IPC audit tools, posters, leaflets and factsheets
- IPC Bulletin for Care Homes

In addition, we hold IPC educational training events in North Yorkshire.

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

9. 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 (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*

NHS England (Updated 2025) *National infection prevention and control manual (NIPCM) for England*