



Professor JW Ironside, Consultant Neuropathologist 0131 537 1980  
Elaine Lord, Administrative Coordinator 0131 537 3104  
Linda McCardle, Laboratory Manager 0131 537 3084  
Fax 0131 343 1404

National Creutzfeldt-Jakob  
Disease Research & Surveillance Unit  
Bryan Matthews Building  
Western General Hospital  
Crewe Road  
EDINBURGH  
EH4 2XU

## **GUIDANCE FOR UNDERTAKERS WHEN DEALING WITH PATIENTS WHO HAVE DIED WITH CJD\***

Enclosed with this letter is a summary document outlining the guidance for undertakers when dealing with a patient who has died with or “at increased risk” of any form of CJD, based on the existing guidance from the relevant Government Advisory Committee (ACDP/SEAC Joint Working Group on TSE). I would like to draw your attention in particular to points 2 & 4, since we are aware that these have caused considerable upset to relatives. Even if an autopsy has been performed on a patient with CJD, the body bag can be opened for viewing purposes and the body prepared for viewing after the autopsy. Similarly, the relatives should be allowed to view the body in the open bag and superficial contact with the body need not be discouraged, even after an autopsy had been performed. Point 5 reinforces the fact that the coffin does not need to be sealed in any particular way or constructed of any particular material.

I hope that this letter and the accompanying document are helpful and I would, of course, be happy to discuss any questions on an individual basis.

Thank you for your attention.

Yours sincerely

Professor James W Ironside CBE  
Professor of Clinical Neuropathology  
Honorary Consultant in Neuropathology

For further guidance, see “Transmissible Spongiform Encephalopathy Agents: Safe Working and the Prevention of Infection” ACDP/SEAC Joint Working Group on TSE:  
[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/156201/dh\\_116540.pdf.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/156201/dh_116540.pdf.pdf)



## GUIDANCE FOR UNDERTAKERS

### POST-MORTEM AND FUNERAL ARRANGEMENTS FOR PATIENTS WITH OR "AT INCREASED RISK" OF CREUTZFELDT-JAKOB DISEASE

**Current guidelines for post-mortem and funeral arrangements for patients with or "at increased risk" of Creutzfeldt-Jakob disease can be summarised as follows:**

1. The body should be enclosed in a body bag before and after autopsy. The body may be viewed prior to autopsy by opening the bag.
2. After the autopsy, the body bag can be opened for viewing purposes and the body prepared cosmetically for viewing.
3. Embalming is discouraged.
4. The relatives should be allowed to view the body in the open bag and superficial contact with the body need not be discouraged, even after an autopsy has been performed.
5. The coffin does not need to be sealed in any particular way or constructed with any particular material.
6. If the body is to be cremated, no special arrangements need apply.
7. If the body is to be buried, there are no special precautions that need to be taken with the coffin.

Any further questions can be directed to [Professor James Ironside](#) or [Linda McCardle](#) or [Elaine Lord](#) at the National CJD Research & Surveillance Unit, Edinburgh. ☎ **0131 537 1980**

For further guidance, see "Transmissible Spongiform Encephalopathy Agents: Safe Working and the Prevention of Infection" ACDP/SEAC Joint Working Group on TSE, [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/156201/dh\\_11654\\_0.pdf.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/156201/dh_11654_0.pdf.pdf)



## FREQUENTLY ASKED QUESTIONS

### **Are there any risks to relatives in viewing the body of a patient who has died with CJD?**

There is no evidence that CJD can be passed from one person to another by contact with the skin or hair. Therefore, the body bag can be opened to allow relatives to view the body, and, if they wish, to have contact with the deceased. The department of Health (DH) and the Health and Safety Executive (HSE) have both issued advice on this important matter (see link at the end of this guidance note).

### **If an autopsy has been performed, are there any additional risks to viewing the body of a patient who has died of CJD?**

No. As above, the body bag can be opened to allow relatives to view the body, and, if they wish, have to contact with the deceased with no additional risk to either staff or relatives.

### **Are there any risks to relatives in dressing the body and washing the hair of a patient who has died of CJD?**

As above, there is no evidence that CJD can be passed from one person to another by contact with the skin or hair. Therefore, the body bag can be opened to allow relatives to dress the body and wash the hair.

### **If an autopsy has been performed, are there any additional risks to relatives in dressing the body and washing the hair of a patient who has died of CJD?**

If an autopsy has been performed, dressing of the body and washing of the hair may be performed by relatives under the supervision of mortuary staff or a funeral director, using standard infection control measures to minimise risk.

### **Are there any risks involved in transporting the body of a patient who has died with CJD?**

Precautions are required for the transport of patients who have died with CJD. The body should be transported in a body bag to protect against accidental seepage of body fluids following death.

### **Following a CJD death, can the body be transported within the UK or abroad?**

No additional precautions are needed for transporting the body within the UK. However, if there is a need to transport the body internationally, it will be necessary to comply with the IATA Restricted Articles Regulations and any additional requirements of the individual carrier, which should be discussed on a case-by-case basis.

**Are special burial or cremation arrangements required for a patient who has died with CJD?**

No special arrangements are needed for burial or cremation of a patient with known or suspected CJD.

**What happens if I encounter problems with the funeral directors and others regarding funeral arrangements following a CJD death?**

We are aware that some problems have been encountered in the past with funeral directors and others misunderstanding the risks posed from a body of a patient who has died with CJD. We appreciate that this can be very upsetting and we hope the information here clarifies the situation. In addition, a joint effort has been made by the HSE, the CJD Support Network and the Department of Health's ACDP TSE Working Group to raise the awareness of guidance issued by HSE and DH regarding funeral arrangements.

Funeral directors may find the following guidance document helpful:

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/156201/dh\\_11654\\_0.pdf.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/156201/dh_11654_0.pdf.pdf)

*This guidance is intended to apply to **ALL** forms of human transmissible spongiform encephalopathy or prion disease, including patients with or "at increased risk" of any form of CJD.*