Funeral arrangements after a CJD* death

Answers to some commonly 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, 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 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 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 people 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 Health and Safety Executive, the CJD Support Network and the Department of Health’s ACDP TSE Working Group to raise awareness of the guidance issued by HSE and DH regarding funeral arrangements. Funeral directors may find the following guidance document helpful:

*This guidance is intended to apply to all forms of human transmissible spongiform encephalopathy or prion disease.