National Creutzfeldt-Jakob Disease Research & Surveillance Unit
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Concerns/complaints
Direct concerns/complaints to the
Clinical Lead and Director.
Or visit:
www.ed.ac.uk/university-secretary-group/
complaint-handling-procedure/about
National CJD Surveillance Unit

The National CJD Research & Surveillance Unit was established at the Western General Hospital, Edinburgh in 1990.

The aims of the unit are to monitor the incidence of CJD throughout the United Kingdom and to identify the causes of the disease.

The unit has brought together clinical neurologists, a neuropathologist, scientists, specialist nurses and others to undertake research into this disease. In addition, through the national care co-ordinator, we aim to improve care for those with CJD.

Initial Contact with you

With your clinician considering the possible diagnosis of CJD, staff from the Unit, usually a research registrar, will travel to see you and your family, with your consent.

The purpose of this visit is to perform a clinical examination, take a history of the illness and complete a detailed questionnaire. We hope the information gathered will lead to a greater understanding of the cause of this disease. We will endeavour to answer any questions you may have at this time.

The national care co-ordinator, with your permission, will liaise with your General Practitioner and the other professional carers involved to try to identify in what capacity, if any, they can help with any care needs you and your carers may have.

National CJD Care Team

The National CJD Care team is based within the National CJD Research & Surveillance Unit and was formed in response to concerns regarding the care of CJD patients. The team consists of two national care co-ordinators who are senior nurses and a senior administrator.

National Care Co-ordinators

A national care co-ordinator will work alongside you, your carer, the professionals and other organisations involved in your care and will be available to provide advice, information and support. Information will also be given to you about charitable organisations dedicated to helping people affected by CJD. The co-ordinator will be available on an ongoing basis by telephone and can travel to your destination to provide assistance. The Care Team are supported by neurologists from within the National CJD Research & Surveillance Unit.

Since October 2000 a care package has been set up for people with CJD to ensure that shortfalls in care provision are met. The co-ordinators and neurologists also liaise closely with the Department of Health and will monitor care in order to identify areas for improvement.

National Care Team aims

- To provide emotional and practical support for people whose lives are or have been affected by CJD.
- To be available for you to talk to someone from 9am – 5pm, Monday – Friday, in confidence.
- To meet with the patient and the family on a regular basis, if required.
- Attend case conferences to help review care needs.
- To provide advice, education and information to families and care providers.
- To be completely confidential with all information regarding the patient and their family.
- To liaise with other organisations involved in research in this disease and in the care of persons with CJD.
- To liaise with national and international family support agencies.
- Provide support in palliative care and end-of-life decisions.
- Provide access to CJD Care Package - a sum of money accessed through the national care co-ordinators to assist with the care of individuals affected by CJD. The care package may provide funding in addition to local health and social service provision in order to optimise care.

Creutzfeldt-Jakob Disease (CJD)

A progressive brain disease, which causes a relentless deterioration in the ability to function physically, mentally and emotionally.