

National Referral System: Patient Information Leaflet

last updated April 2012

PATIENT / CARER INFORMATION SHEET

WHY HAVE I RECEIVED THIS INFORMATION?

You are being given this information because the possibility of Creutzfeldt-Jakob Disease (CJD) or another form of prion disease is being considered. Two major, publicly funded, specialist teams work in the UK on these diseases. With your consent, someone from each team would like to visit you/the patient and discuss how they can help and also discuss important research they are doing into the causes of, and treatments for, prion diseases.

Some people referred to these teams will turn out not to have prion disease. Whatever diagnosis is confirmed, your/the patient's care will be led by your local clinical service. Involvement in any research is entirely voluntary and refusal to participate will not affect your care in any way.

WHO WILL BE APPROACHING ME?

1. The National CJD Research & Surveillance Unit team,
Western General Hospital, Edinburgh
Tel: 0131 537 2128
<http://www.cjd.ed.ac.uk/>

The National CJD Research & Surveillance Unit (NCJDRSU) is funded by the Department of Health to identify, classify and investigate prion diseases in the United Kingdom. The NCJDRSU team will want to visit to make sure that it is a prion disease and also to identify what type of prion disease may be affecting you/the patient. They will also wish to discuss other research projects. The team consists of a doctor and a nurse who will travel to see you/the patient and to discuss things with the local clinicians. They can provide advice, guidance and diagnostic tests to help the doctor looking after you/the patient both in making the diagnosis and in giving care. A National Care Team is based at the NCJDRSU. If you and the local clinicians wish, a care co-ordinator from the National Care Team will visit later to assess your/the patient's care needs and to help you and the local doctors to identify ways to meet these needs if they are not already met.

2. The National Prion Clinic and MRC Prion Unit team
National Hospital for Neurology and Neurosurgery, London
Tel: 0203 448 4037
<http://www.nationalprionclinic.org>

The National Prion Clinic (NPC) offers specialist in- and out-patient services including diagnostic facilities which are available to help support your doctors, if they wish, in choosing the best type of care for you as well as providing specialised advice and counselling.

A major, long-term, research effort is underway at the MRC Prion Unit in London to find new treatments for prion disease and to study if these treatments benefit patients (the National Prion Monitoring Cohort (NPMC)). We need to understand better how these rare diseases progress in everyone, not just those taking a new drug(s), in order to make real progress towards an effective treatment. Therefore, the NPMC has been designed to allow all patients that want to participate to do so, irrespective of whether or not they want to try the drug being tested at that time, or what form of prion disease they might have. The Department of Health has made a major financial investment in the trial and asked the Medical Research Council, which has over 50 years experience running trials, to find the best treatments for these diseases. The team would like to visit you to discuss the NPMC trial and other research projects aimed at tackling these diseases.

IS THERE ANYONE ELSE I CAN TALK TO?

Many patients and carers find it helpful to talk to others with experience of the same diseases. The UK CJD Support Network is a UK charity for patients with prion disease and their families and carers. It has a confidential helpline, offering support and practical information. It also has a website, and regular newsletters, with lots of useful information.

Because these diseases are very rare, many local medical and care services have no experience of them. But you are not alone. The support group, together with the specialist centres, are committed to making sure you don't miss out on whatever help is available. You don't have to wait until you have a firm diagnosis - support is there, if you want it, from the moment you have to consider the possibility of prion disease.

Helpline: 01630 673973

<http://www.cjdsupport.net/index.html>