Fact Sheet: Aggressive behaviour in CJD

About the CJD Support Network

The CJD Support Network is the leading care and support charity for all forms of CJD. The CJD Support Network:

- Provides practical and emotional support to individuals, families and professionals concerned with all forms of CJD
- Provides emotional support to people who have been told that they are at a 'higher risk' of CJD through blood or surgical instruments
- Links families with similar experiences of all forms of CJD
- Offers financial support for families in need
- Provides accurate, unbiased and up-to-date information and advice about all forms of CJD
- Provides a national helpline on all forms of CJD
- Promotes research and the dissemination of research findings
- Promotes good quality care for people with all forms of CJD
- Encourages the development of a public policy response for all forms of CJD
- Provides support, education and training to professionals concerned with CJD

For more information about the activities of the CJD Support Network, contact:

Admin and general enquiries - admin@cjdsupport.co.uk or +44 (0)7494 211476
Support - support@cjdsupport.co.uk or 0800 774 7317
Website - www.cjdsupport.co.uk
Post - PO Box 3936, Chester, CH1 9NG

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Fact sheet: Aggressive behaviour in CJD
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If you are caring for someone with Creutzfeldt-Jakob disease (CJD) you may find they behave in an aggressive way which is uncharacteristic of their usual personality. You may be surprised, upset and wonder how best to cope.

If a person with CJD reacts with aggression, it is probably because they feel frightened, humiliated or frustrated by what is happening to them. Since CJD is such a rare condition it may be that the person affected picks up on the confusion of their carers, who may not realise what is happening.

Because CJD affects the brain, judgment and self-control may be eroded. The person affected may forget all about their normal habits of good behaviour and manner learned in childhood. They might completely over-react to any criticism or comment you make – however mild – of their altered behaviour. Obviously, it's upsetting for carers to be attacked verbally, or even physically, in this way. But it's important for you to remember that the aggression is not directed to you personally. In fact, the person with CJD will probably forget the incident much faster than you do.

Triggers for aggression

There is often a trigger for aggressive behaviour. If you are caring for someone with CJD, you may find it worthwhile to keep a diary of events. This is a useful way of learning what upsets the person affected which, in turn, makes it easier for you to plan a strategy to prevent it happening. Some pointers to watch out for are:

- Feelings of frustration or humiliation because the person can no longer cope with everyday life. Since people with variant CJD are often in the younger age-groups, there may be a very marked contrast with their usual lifestyle.
- Concerns about loss of privacy and independence as others take over intimate functions like washing, dressing and going to the toilet.
- Worries that they are being judged or criticised because they have forgotten something or made a mistake. Before diagnosis, this may be a particular problem.
- Caring for someone with CJD often involves many different professionals. It may be that too much noise or the presence of 'strange' people creates feelings of agitation.

As CJD progresses, the person may become unable to recognise familiar people or places. This is likely to add to their feelings of anxiety and confusion – and may express itself as undue aggression. Symptoms like pain, thirst or boredom may also be communicated with angry gestures if the person finds it hard to communicate in the usual way.

Prevention

A carer's diary is probably the best way to prevent aggression in the person with CJD. If you can see a pattern, you may be more than halfway to preventing unwanted behaviour.

You may find it helpful to:

- Reduce the usual demands on the person if they are not coping and create an unhurried and stress-free routine as far as you can.
- Explain things slowly and carefully. Aggression can often be due to an inability to appropriately communicate need. Remember that the person may take longer to respond to you than when they were well.
- Find ways to help them, without seeming to take charge. For instance, break everyday tasks down into manageable steps and find ways of prompting the person.
- You may feel irritated, but try not to comment or criticise if the person you are caring for gets uncharacteristically angry. A calm attitude on your part will help defuse any problems.
- Try to avoid sudden sounds and movement, which may agitate the person.
- Make sure you are in regular contact with your doctor – sometimes aggression has a physical cause, such as urinary tract infection or constipation, which can be treated.

How to cope

If a confrontation occurs, try to keep calm, even if you feel upset. Leave the room if necessary. If you look anxious or angry, it will probably only increase the person's aggression. Should the person become physically violent, give them plenty of space and do not try to restrain them – unless you absolutely have to. It's important always to have available the contact numbers of those who can help available – the GP, social worker, district nurse and so on. If you have a mobile phone, programme the numbers into the database and take the phone with you if you are out with the person you are looking after.

Your own feelings

The aggression of the person with CJD may well be directed at you, but you should realise that it is not personal. It's hard when the person was formerly a loving family member, but it's important to understand that their anger is a product of their illness. You may find it helpful to chat with a family member or friend after an incident. Some people find it easier to spend some quiet time alone. Should you lose your temper, it's quite understandable and you should not feel guilty. But do take the opportunity to discuss your situation with another carer or a health professional if you feel unable to cope. You will find information on where to get support on the next page. Please do not hesitate to get in touch.

Further information and contacts

Further information about CJD may be found on the CJD Support Network website at www.cjdsupport.co.uk our fact sheets are also available by post on request to the Network.

Support and information may be obtained from the organisations below:

CJD Support Network	Address – PO Box 3936, Chester, CH1 9NG Website – www.cjdsupport.co.uk Phone – 0800 774 7317 Email – admin@cjdsupport.co.uk or support@cjdsupport.co.uk
National CJD Diagnostic Advisory Service	Based in Royal Infirmary of Edinburgh Website page with contact information - www.cjd.ed.ac.uk Email - loth.securecjd@nhs.scot
UK National CJD Nursing Service & National Care fund	Address - Department of Clinical Neurosciences, Clinical Offices, 2nd Floor 50 Little France Crescent, Edinburgh Bio-Quarter, Edinburgh, EH16 4TJ Website – www.cjd.ed.ac.uk Phone - 0131 312 0193 / 0131 312 0192 Email - Terri Awe (primary contact) – terri.awe@nhs.scot, Juli Jose (additional contact) juli.jose@nhs.scot
National Prion Clinic	Address - National Prion Clinic, Institute of Prion Diseases, Courtauld Building, 33 Cleveland Street, London, W1W 7FF Website - www.ucl.ac.uk/national-prion-clinic Phone - 020 7679 5142 / 020 7679 5036 Email - uclh.prion.help@nhs.net