

## CREUTZFELDT-JAKOB DISEASE

### GOOD PRACTICE GUIDELINES FOR SOCIAL SERVICES PROFESSIONALS

AMENDED VERSION – JUNE 2003

#### 1.0 BACKGROUND

- 1.1 A recent survey conducted by the CJD Support Network amongst carers of people who have contracted CJD or died from the disease shows a lack of knowledge and understanding by the Social Services personnel in relation to supporting and working with sufferers and with their carers and family. This view was also expressed of other professionals from other disciplines. **However, it should be noted that response times and services have improved.**
- 1.2 In view of this, the CJD Support Network in conjunction with the Association of Directors of Social Services have agreed to produce these guidelines in order to support staff, many of whom are working for the first time with people who have contracted the disease. As it is still fairly rare in this country there is **still** a big gap in awareness, knowledge and understanding of the needs of this specific group of service users.
- 1.3 Many of the comments received from carers were to the effect of “too little too late”, “professional workers were well intentioned but had very little knowledge and understanding of our situation”. Services **have been** offered and plans put in place to cover general care rather than specific needs of people with CJD.
- 1.4 Another comment was a lack of information to people who did not know how to access services, what services could be available and also on how to respond and make their feelings known.
- 1.5 Coupled with this is a clear feeling by workers who contact the CJD network, of a feeling of isolation and concerns about their practice and whether it is appropriate or not.
- 1.6 Working with sufferers of CJD and their carers is outside most practitioners and service provider’s experience. It takes time for experience to be built up and first referrals are **still** just being received in some authorities.
- 1.7 There has to be recognition that someone has got CJD. All sufferers have the same symptoms but not always in the same order. Individuals do have a different understanding of the disease and one needs to be aware of this and not jump to conclusions that someone is suffering from mental illness or is “not genuine”.
- 1.8 Services offered need to dovetail in with that of the Health Services and run along side other agencies. There is a lack of knowledge in relation to this disease and what is required is a central source providing information, which could be drawn upon and is well published. It is felt that this would help people. There are often different perceptions of where referrals would go to and within the Social services

Department who will receive the referral, i.e. Mental Health Team, Physical Disability or Elderly Persons' Team.

- 1.9 What is required is identification of a key worker with understanding to assess needs, both of the patient and the carers, and follow the case through. Professionals can and do respond appropriately if they know what they are responding to.
- 1.10 Please see Appendix 1 for background information on CJD.
- 1.11 Current Position Statement as at **5 August 2002**.

The current number of people known to the CJD Network who have been diagnosed as having new variant CJD is **115**. However, precise numbers are difficult to ascertain as CJD is not totally confirmed until a post mortem is carried out after death and this can take up to six months to undertake.

It generally is expected to affect one in a million of the population.

## 2.0 ACKNOWLEDGE NEED

- 2.1 It needs to be stated from the onset there **is** a clear need to respond quickly and effectively to service users, their carers, families and to respond appropriately. Social Services Departments need to own their responsibility and one recommended way forward is that a key worker, usually a Social Worker/**Care Manager** takes responsibilities for co-ordinating plans and service delivery to service users.
- 2.2 It is felt very important that for each individual service user and their families that there is a "key worker" role. This is important for professionals as well as the service users and carers. By "key worker" we mean the person (and agency) who will take responsibility for the assessments and care plan and who will co-ordinate services and information sharing.
- 2.3 A blanket approach to service users is not suitable due to the uniqueness of each situation.

- 2.4 Appendix 2 can be used as a checklist to some main points in these guidelines.

## 3.0 RAISE AWARENESS

- 3.1 All professionals need to be aware of the disease it's implications and users specific needs particularly when responding to referrals. Once clinical symptoms are apparent, all strains have rapid onset of dementia.
- 3.2 Professionals need to be aware that there is available literature to help and support them. Awareness training is also vital for workers in order for them to best support the person and their carers.

3.3 Please refer to Appendix 3 on sources of information.

#### 4.0 RESPONDING TO REFERRAL

Please refer to Appendix 4 for list of legislative framework under which Social Services personnel work.

#### 4.1 Response Times

Social Services Department generally have response times and standards. However, the need to respond quickly is vital due to the sudden deterioration of most people suffering from the disease who within a matter of two months can move from being a very health person to death. The need for a quick response cannot be emphasised enough.

#### 4.2 Assessment/Care Plan

4.2.1 Workers need to be aware of the individual circumstances/cultural needs/background of the situation and the individuals involved. Each individual situation is unique. Professionals need to recognise the signs of people suffering from CJD and not put it down purely as “self neglect”. They need to look at the past and **at** the presenting problem. There is a need to keep an open mind as mis-diagnosis had often occurred in the past, e.g. service users being regarded as mentally ill or suffering from dementia as the effects of CJD have not been recognised.

4.2.2 In relation to individual circumstances it is felt that people living alone are in some respects more vulnerable and will certainly need a care plan that takes account of their own individual living circumstances. If a person is clinically diagnosed with CJD, it would be dangerous for them to be living alone. It may be appropriate to consider the use of and need for an advocate to act on their behalf.

4.2.3 One must be aware of people who normally fall through “the gap” and there is concern in relation to homeless people who may have contracted the disease.

4.2.4 Service users and carers need to understand clearly the assessment and care plan procedure. They need to know what it is, what does it mean, its use and its purpose. In carrying out an assessment, a holistic approach should be taken looking at all parties’ short and long term needs. Key workers should co-ordinate and hold case responsibilities and they should ensure that not too many individuals are involved.

4.2.5 It is important and essential that professionals note their own personal assumptions and values and do not impose these on others.

4.2.6 Communication should be as open as possible with clarification that everyone understands each other’s expectations. Establish commitment to early identification, rather than crisis management.

- 4.2.7 Workers need to be clear about their role, establish aims and objectives, and clarify timescales and long term needs.
- 4.2.8 Feedback received from **professionals** who have supported CJD victims and their carers suggest that the case should not only be case/care managed, but social work casework and counselling is often required.
- 4.2.9 Timing is crucial and all agencies must appreciate the importance of prompt action. Social Services must be aware of need for initial urgent responses, e.g. same or next day.
- 4.2.10 Consider if a “fast track” approach is required on occasions, e.g. if request is for a **Blue** Badge, why go through a long delay and bureaucratic system if the need is obvious?
- 4.2.11 Be astute and open to what sufferers need, e.g. help with lifting, **specific** beds, and hoists.
- 4.2.12 The speed of deterioration of an individual sometimes renders existing plans inoperable. Thus, the requirement for a frequent review of plan.**

#### 4.3 Changing Needs

- 4.3.1 One of the essential reasons why good and frequent contact and communication is important is because of **frequent** sudden changes and deterioration of the condition. There needs to be a trigger, particularly by carers to professionals for them to respond, as there can be drastic changes in someone’s independence in a very short timescale, e.g. one to two weeks. This happens rapidly and is now unlike many other situations. At certain times a high level of support may be required. CJD is a terminal disease.
- 4.3.2 All responses by professionals should be sensitive to the people we support.

#### 4.4 Revision

- 4.4.1 In conjunction with changing needs, care plans need to be flexible and to be revised continuously at a much shorter frequency than normal departmental review procedures. The role of carers is crucial in this in triggering review and revision periods.

### 5.0 MONITORING ASSESSMENT AND CARE PLANS

- 5.1 Everyone involved, including the service users and carers as well as professionals need to ask themselves, “is the care plan working, and are the services being offered appropriate”? If the answer to these are no, then further review and exploration needs to be implemented.
- 5.2 Shared information can be helpful, e.g. what have other people experienced. See Appendix 5 for an example of good practice.

## 6.0 MAKING SERVICES AVAILABLE

- 6.1 Services must be sensitive to need **and should be the outcome of careful planning rather than a ‘knee jerk response’**. There is fear **of the** unknown of the disease, e.g. what are the risks, is it contagious?
- 6.2 Some of our current and long established services are appropriate but they must be appropriate to the individual and one concern of carers and service users is age related services, (e.g. young adult services often lacking). Whether services will be provided is a worry and it is devastating for carers to see people in a wrong setting.
- 6.3 What services are required **will** depend on specific needs. **Many** requests **for assistance** come in terms of daily help and personal care. Sitting services are also vital in order to give support and respite to the carers. In implementing services there needs to be trust and faith in the service and there is a strong plea to professionals to take the lead from service users and carers are often to do as carers wish and not to “take over”. Continuity of care is essential, e.g. try to avoid using different home care staff.
- 6.4 Continuity is especially vital where young families are involved. It cannot be emphasised enough how young children require the STABILITY/CONFIDENCE/TRUST, which would result from continuity of care of a young parent. The same continuity of care must also assist the home care staff to build up that TRUST/CONFIDENCE WITH ALL MEMBERS OF FAMILIES CONCERNED.
- 6.5 Most important is that whatever care is provided, it should be of a good quality and relevant to people’s needs. There is a role for day services and sometimes residential care but they need to be appropriate and there has been criticism of young people having to go into old people’s homes because no other service exists.
- 6.6 In offering services it is vital for professionals to draw on the skills and knowledge of other professionals and explore all the alternatives and support services available e.g. possible financial support for care and private nursing costs and Independent Living Fund.
- 6.7 For carers the cost of paying for services can be an issue. If they purchase equipment due to lack of availability remember it often will not be for a long-term need.
- 6.8 Imaginative and innovative care plans are often required and can be cost effective.
- 6.9 C.J.D. Care Fund**

**In response to the Report of the BSE inquiry the Government set up a ‘Care Fund’ to assist with funding care packages. Advice on assessing the Fund can be obtained from the Care Co-ordinators at the CJD Surveillance Unit. Please see Appendix 3.**

- 6.10 **Funding – Professionals will need to establish which agency pays for which service.**
- 6.11 **Charging – Local Authorities charge for services but, users of non-residential Social Services suffering from any form of CJD should not under go a charge assessment, but should be treated as automatically exempt. Please see Appendix 6.**
- 6.12 **On occasions it may be appropriate and possible to pre-empt need and have some services, e.g. equipment, available for when required.**
- 7.0 MULTI-DISCIPLINARY LINKS
- 7.1 A multi-disciplinary approach is essential to assist with both assessment of need and provision of the service. Other professionals need to be involved, e.g. GP, CPN, Physiotherapist, Occupational Therapist, Dietician (loss of swallowing reflexes) and Community Nurses. Often there will be a need to agree discharge procedures as a number of people wish to be at home rather than in hospital or residential care.
- 7.2 In engaging in a multi-agency approach there still must be an emphasis on speed. Links should not slow down the process or flow of information.
- 7.3 The role and input of other professionals needs to be defined. The key worker must take responsibility to inform user/carer of links, e.g. purpose of meetings, input to meeting.
- 7.4 **Joint care working may need access to specialist services, e.g. Mental Health input for support, use of palliative care services.**
- 7.5 **One advantage of joint working is to get the agencies and services required involved quickly to enhance life quality.**
- 8.0 CONSULTING USERS AND THEIR CARERS/FAMILIES
- 8.1 Those who care for people with **CJD** have a right to an assessment in their own right. It is essential that professionals do not neglect or forget the needs of carers who are often providing twenty-four hour care round the clock 7 days a week. A young husband/wife must be given the support/respite to fulfil other roles i.e. young dad/young mum!!
- 8.2 As many service users wish to be at home, and their families wish that to happen, it is essential that all people in the household are assessed and supported in order to undertake the care role. The assessment of carers is a statutory requirement.
- 8.3 One frequent concern and criticism from service users and carers is **that sometimes** professionals insist **that** things are done their way. Many people have their own individual ways of doing things and **therefore** request that professionals are sensitive and ask people how they wish the service to be delivered.

- 8.4 Professionals need to understand the nature of each individual disability and the implications on them and their families and to avoid making assumptions.
- 8.5 All information is vital. Sharing details and perceptions can assist in the support of individuals and carers. Keep it simple and ensure consistency across agencies. With this, develop a partnership approach to reach agreements between workers on general principles of support and practical tasks, e.g. discussions to involve people as to their preferred method.
- 8.6 The need for urgency must be emphasised. **Professionals need this awareness**, as they often may not have the same empathy to the sense of urgency.
- 8.7 Most important is that workers should identify which areas service users and carers feel are priorities and particularly where these differ to the worker's own perceptions.
- 8.8 Confidentiality must be respected within each setting. Respect the wishes of the individual.
- 8.9 **CJD sufferers moving geographical areas can present problems in their own right. Professionals need to be aware of the implications of this, the need for information to be passed quickly to the relevant agencies for continuity of services to be maintained.**
- 8.10 **From the carers point of view:**

**It should be recognised that carers often have unmet needs themselves – anxiety, depression and isolation being the common ones. Consequently, when carrying out a holistic assessment it should be remembered that carers need practical (and domestic), psychosocial, financial and spiritual support. The physical and psychological stress on the carers are compounded by social factors such as the fragmentation of the family, increased social mobility and the diminished role of the extended family.**

**Carers are often reluctant to disclose their needs because they do not think it is acceptable to do so. The reasons for this include:**

- **Not wanting to put their needs before those of the person with CJD**
- **Not wanting to be judged inadequate as a carer**
- **Believing concerns and distress are inevitable and cannot be improved**

**The information that carers say they need is:**

- **The Diagnosis**
- **Causes, importance and management of symptoms**
- **How to care for a person with CJD**
- **Likely prognosis and how the person might die**
- **Sudden changes in persons condition**

- **Services available and how to access them**
- **Finances**

## 9.0 MINIMUM STANDARDS

9.1 Although, it is stated that each case is individual and workers should respond accordingly, there needs to be set minimum standards, which basically are the right to an assessment and a care plan. As part of the assessment and care plan approach standards, such as timing, should be clearly stated so that plans are implemented as quickly as possible. Please remember that you are responding to a disease, which can lead to a quick death.

9.2 The least acceptable minimum standards that sufferers and carers can expect are:

Assessment

Care Plan

Implementation

All with a sense of purpose and urgency.

## 10.0 AUDITING CURRENT SERVICES

10.1 The quality of the service, as in all our work, needs to be high and constantly maintained. It is helpful for quality standards to be set and in so doing essential for all professionals and providers of service to listen to service users and their carers. The whole service needs to be audited.

## 11.0 FOLLOW-UP SERVICE

11.1 When a person dies the need for a service does not end. Carers have needs after death, e.g. counselling. This can also be the opportune moment to reflect on an audit, e.g. how was the service? What was good? What should have been done differently?

## 12.0 IMPLICATIONS OF TRAINING

12.1 Awareness training is vital for workers in order for them to best support the person and their carers. Joint training across agencies will enhance workers ability to understand each other's perspective.

12.2 It is felt that training is often required in terms of professionals experiencing gaps in the skills, knowledge and understanding of the disease. Workers need to know the disease and understand its implications, particularly the rapidity of it. There needs to be an awareness of the family trauma, incorporated with the disease, who sees the rapid decline of people. Safety issues are paramount and with rapid onset on the disease safety needs to be high on the agenda.

12.3 One must understand that the disease does not discriminate and an understanding of it is essential. Workers need to gain a grasp and understanding of what they are actually dealing with.



12.4 **Support organisations, such as** the CJD network, will be pleased to contribute to training plans.

### 13.0 PLAN AND SECURE RESOURCES

13.1 In planning services one of the biggest gaps initially appears to be information and service users and their carers need to know how to access support.

13.2 For each Social Services Department a designated senior officer as a contact person is felt to be an appropriate way forward to help support their staff.  
**Managers need to understand the urgency of need.**

13.3 For plans to be effective, finance and resources are an essential requirement. Community Care plans should take account of the effect of CJD in service development and the need for resources in planning budgetary requirements.

13.4 Social Services Departments need contingency plans available, i.e. because the number of cases could increase considerably – this is an unknown factor.

13.5 **In order** to meet needs **you** are planning **a** specialised care package, which in **it's self** contains an element of an emergency plan.

### 14.0 VCJD TRUST

14.1 **Following the report of the BSE Inquiry, the Government responded by setting up a VCJD Trust. It is for sufferers of VCJD only. There is an interim payment initially followed by a further payment depending on circumstances. It is for family use and cannot be used for care services or adaptations. It is also not means tested. At present, it is not known how long this trust will exist. For information or access to it contact either the CJD Support Network or Human BSE Foundation (see Appendix 3).**

### 15.0 GAINING PUBLIC COMMITMENT TO SERVICES

15.1 Finally, there is a role for members of local authorities and health authorities to have an understanding and awareness of the disease and to offer support to their officers and staff in accessing the services in order to give the best at all times.

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