



Department  
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Social Care

# CREUTZFELDT-JAKOB DISEASE: GUIDELINES FOR SOCIAL WORKERS IN ENGLAND

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# Foreword

**Lyn Romeo, Chief Social Worker (Adults), Department of Health and Social Care**

Most of us will not work with people with CJD or their families. It is a rare condition. But for those social workers who work with a person affected by CJD this set of guidelines provides invaluable information about the needs and circumstances of people affected by CJD.

Social work practice is enabled by guidelines and the profession has long recognised that accurate information and advice are empowering. This is keenly felt by those social workers who encounter people whose health conditions require specialist consideration. While each person is unique; those affected by CJD receive specialist diagnosis services, nationally co-ordinated health support and may have legal entitlements unique to this condition.

It is empowering for social workers to be equipped with knowledge and skills when they encounter, likely for the first time, a person affected by CJD. They can use these when working with the individual and their family, but also in their communications with other agencies. The information in these guidelines will equip social workers with a clear picture of the law in an area of practice where social workers should be expert.

The guidelines do not create expectations for social workers to 'step in' to this area of practice without due consideration of their role. Their impact may be more effective if it is supportive of other professionals although in some instances their role may be effective as co-ordinator or service navigator.

In my role as Chief Social Worker for Adults at the Department of Health and Social Care, I have increasingly advocated for practice frameworks to take a strengths based approach. As this document shows this is highly applicable to working with people affected by CJD, both individuals and their families and the national support groups. Strengths too lie in those NHS professionals who have world-leading expertise in this area of healthcare.

The authors of these guidelines note that they build on an earlier set of guidelines – published in 2003. I would like to pay belated tribute to their author Derek Biggs, a pioneer in practice development in this area. These present guidelines are a much-needed update but also take the guidelines further in linking them to resources and contemporary practice. I am most grateful to the authors who combine practice wisdom, research intelligence, and CJD expertise in a unique collaboration.

Consultation with individuals directly affected by CJD confirms these guidelines as a resource not only for practitioners but also individuals and families. I look forward to hearing of their use.

# 1. Introduction

These guidelines are written for social workers and other social care professionals who work with people with Creutzfeldt-Jakob disease (CJD) and their families. They aim to enhance awareness and understanding of this disease, and thereby improve social care for this specific group of people who often have very complex and rapidly changing needs.

The first set of good practice guidelines for social services professionals working with people with CJD were produced in 1998 by Derek A. Biggs, then Operations Manager at Cambridgeshire Social Services. These were published in conjunction with the CJD Support Network and the Association of Directors of Social Services in response to a CJD Support Network survey that identified a lack of awareness, knowledge and understanding of the condition amongst social workers. In 2000, the Department of Health published 'Guidance on CJD for Health Workers' to complement these guidelines. The Social Services Guidelines were subsequently amended and re-published in 2003. Improvement in health and social care services for people with CJD since that time has been reported ([Body and Glasson 2005](#)). However, the legal and policy framework for adult social care in England has changed significantly since the publication of the amended version of the guidelines, most notably as a result of the Care Act 2014 and increased personalisation. The guidelines here update the 2003 version both in response to these changes and in recognition that the rarity of the condition means that it will often be outside the experience of most social workers. While written in the context of legislation in England some content may be helpful to social workers in other parts of the UK.

These guidelines should be placed in the context of:

- The Care Act 2014
- The Care and Support Regulations
- The Care and Support Statutory Guidance
- The Mental Capacity Act 2005
- The Mental Capacity Act 2005 Code of Practice
- The National Framework for NHS Continuing Healthcare & NHS Funded Nursing Care 2012
- From 1st October 2018, the National Framework for NHS Continuing Healthcare & NHS Funded Nursing Care 2018
- The National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012
- The Human Rights Act 1998

## 2. What is Creutzfeldt-Jakob Disease?

Creutzfeldt-Jakob disease (CJD) is a rare, degenerative and invariably fatal condition that affects the brain. The causative agent of CJD or “prion” is thought to consist of abnormal forms of a naturally occurring protein found in the brain. Approximately 100-130 people are newly diagnosed with CJD every year in the UK.

### The Different Types of CJD

CJD can be classified by aetiology (the cause of the disease): as sporadic (unknown cause), inherited and acquired (transmitted between humans or animals), including variant CJD.

#### Sporadic or Classical CJD

Sporadic CJD (sCJD) is the most common form of CJD, accounting for about 80-90% of all cases. Adults of any age can be affected but the condition is most frequent in late middle age and older people.

Classical sporadic prion disease is recognised as a rapidly progressive dementia affecting many aspects of a person’s functioning. Typically the illness will last for only 4-6 months until death, although some people survive over a year or more.

Common features of CJD are summarised in the Department of Health (2000) Guidance for Health Workers, and include:

- Changes in personality and behavioural change
- Psychiatric symptoms
- Cognitive impairment
- Neurological deficits, including sensory and motor impairments such as abnormal balance
- Myoclonic jerks (sudden involuntary jerking of a muscle or group of muscles), or, less frequently, chorea (involuntary movements of the feet or hands) or dystonia (sustained or repetitive muscle contractions)
- Difficulty recognising people
- Rapid deterioration in condition
- Increasing difficulty with communication, mobility, swallowing and continence.

Diagnosis of probable sporadic CJD can be made by taking a thorough clinical history, CSF (cerebro-spinal fluid) analysis, neurological examination and an MRI (brain) scan. Note that the term probable in this context indicates 95%-100%, or near certainty. Definite diagnosis of sporadic CJD can only be made through examination of brain tissue, usually at post mortem examination.

## Inherited or Familial Prion Disease

Inherited prion disease (inherited CJD or genetic CJD) is a familial or inherited disease caused by mutation of the prion protein gene. It is inherited in an autosomal dominant way (meaning that it does not usually skip generations and typically is passed on to 50% of children of an affected person); it is responsible for 10-15% of the incidence of prion disease. Many mutations have been identified; different mutations are associated with different illness patterns, such as age of disease onset, rapidity of disease progression and characteristic symptoms.

Inherited prion disease symptoms and rates of progression can look exactly like sporadic CJD, but often the rate of progression after symptom onset is much slower and total durations of 10 years or more are not unusual.

In these very rare cases there is usually a suggestion of an inherited disease pattern based on the causes of death of previous generations; however, cases have been identified where there is no obvious family history, particularly when information about the family is limited by early death of a relative or adoption.

## Acquired or Iatrogenic CJD

Iatrogenic CJD is a rare form of the disease. This form arises from medical treatments contaminated with human tissue from an infected person, usually as the result of a specific medical procedure (e.g. the use of growth hormone preparations derived from cadavers (corpses) prior to 1985, or the use of brain membranes from cadavers in neurosurgery).

## Variant CJD

Variant CJD (vCJD) is a rare type of acquired prion disease and was initially named new variant CJD. It was first recognised in 1995 and affects younger people than sporadic CJD. vCJD is caused by dietary exposure to Bovine Spongiform Encephalopathy (BSE), a prion disease found in cattle; the suspected link between vCJD and BSE was announced in the House of Commons in March 1996, by the then Health Secretary Rt. Hon. Stephen Dorrell MP. vCJD is always fatal, but has a longer duration period than sporadic CJD, typically lasting approximately 14 months. Early symptoms include changes in personality and psychiatric symptoms, such as depression and social withdrawal. vCJD has been transmitted by blood transfusion.



### 3. People with CJD and Contact with Adult Social Care

Diagnosis of CJD is not straightforward (Barnett and McLean 2005). People who have a range of CJD related signs and symptoms, but no formal diagnosis of the condition, may be referred to local authority adult social care departments. Others with the condition may have been misdiagnosed: older people with sporadic CJD may have an initial diagnosis of 'dementia', while younger people with variant CJD may have a diagnosis of depression or other mental health conditions.

It is important that the signs of CJD are not overlooked, dismissed or assumed to be manifestations of 'self-neglect'. Social workers should always encourage people to seek advice from their doctor where symptoms are present. However, eligibility for adult social care services is not dependent on a formal diagnosis, but rather on the assessment of the Local Authority against the criteria outlined in the Care and Support (Eligibility Criteria) Regulations 2015. As noted in the Care and Support Statutory Guidance, in interpreting the eligibility criteria:

*The authority should base their judgment on the assessment of the adult and a formal diagnosis of the condition should not be required (Department of Health 2016: para. 6.104)*

When people with CJD come into contact with health and social care services the condition may already be very advanced (Barnett and McLean 2005). Services therefore need to respond without delay. Referrals will often be received by 'initial intake' or 'initial assessment teams' or 'single access points', so staff involved in these first contact processes should ensure that they do not overlook the complexity and need for urgency. Personal contact by an individual or their family may need reinforcement by their health care professional. These guidelines can be cited as giving relevant information about the need for urgency as it has the backing of The Chief Social Worker for Adults for England, the NHS National Prion Clinic, the National CJD Research & Surveillance Unit and the CJD Support Network.

The average age of onset and illness duration varies depending on type. The average age of onset of sporadic CJD is 66 years of age, with duration of 6 months from onset; both familial and iatrogenic CJD have a younger average onset age and longer duration; variant CJD has an average onset age of 28 years and average duration of 14 months. Presenting problems may also vary. Those with variant CJD generally experience psychiatric or mental health problems before neurological difficulties (Barnett and McLean 2005), while the initial symptoms of sporadic CJD are cognitive or neurological; others may first present with visual impairment (Freeman et al. 2010). Owing to this variation in both presenting need and age of onset, there is a risk that people with CJD 'fall between the cracks' in adult social care services (Das et al. 2012). Prompt decisions should be made in relation to which adult social care team will respond to a referral; this may be services for older people, physical and sensory disability teams, or the community mental health team.

People with CJD experience physical and mental health difficulties, and the complexity of the condition and its rapid progression can make care provision problematic. People may need assistance with personal care, mobility, continence, communication, and managing and maintaining nutrition. As the condition progresses, people usually need 24-hour care until they die (Freeman et al. 2010). The actual support provided should reflect the outcome of an individual's needs assessment; social workers should avoid the use of standardised care packages and recognise the role that families, communities and the adults' own strengths and assets can play in meeting needs.

CJD, particularly variant CJD, has attracted substantial media attention, much of which has been unwanted by people with the condition and their families. De Vries et al. (2003) observed that such attention might adversely impact on people's wellbeing. Social workers should therefore pay particular attention to the general duty on local authorities, in exercising their adult social care functions, to promote individual wellbeing (Section 1 Care Act 2014).

## 4. Providing Advice and Information

Adults with CJD, their families and carers, and professionals have all identified a need for high quality information (Biggs 2003, Das et al. 2012), particularly at the point of diagnosis and as the condition progresses (Rentz 2008). In addition to requiring information on the nature of the condition, prognosis and symptom management, people may also need information on the following:

- How to access adult social care
- The type of services available
- Financial questions relating to the use of adult social care.

Local authorities have a general duty to establish and maintain a service that provides people in their area with information and advice relating to care and support; the service or services offering this provision must offer information and advice on the matters noted above (Section 4 Care Act 2014).

People with CJD will undoubtedly need advice on financial matters, particularly as certain exemptions on charging for social care apply (see section in these guidelines titled Funding and Charging Arrangements). Local authorities should therefore ensure sufficient information on these matters is available as required by s4 (3) (b) Care Act 2014. Somerset County Council is one of the few providing online information on adult social care specifically for people with CJD:

<http://www.somerset.gov.uk/adult-social-care/disability/cjd/>

This is a model other local authorities may wish to adopt, though they must remain mindful that the Section 4 duty will not be discharged by the provision of online information alone (Department of Health 2016: para 3.29).

### Sources of Specialist Advice and Information

The National CJD Research & Surveillance Unit (NCJDRSU) care team and the National Prion Clinic can provide specialist information and advice for people with CJD and their families and carers, and also for the multi-disciplinary teams supporting them. The CJD Support Network is a charity that was established by the relatives of people with vCJD during the 1990s. It provides information and financial support to people with CJD and their families.

The contact details for all three of these organisations are in the final section of these guidelines.

## 5. Urgent Responses

Many CJD symptoms are not unique to the disease and are present in other conditions. However, what makes CJD different is its short duration after the onset of symptoms and the experience of rapid deterioration, particularly in relation to cognitive impairment (Barnett and McLean 2005, Freeman et al. 2010). Adults with CJD ordinarily experience sudden decline in their condition, with a consequent rapid change in health and social care needs. Rapidly increasing impairment is predictable, as nobody has ever recovered from CJD. The need for social care services to respond quickly has therefore been repeatedly emphasised (Biggs 2003), and in many cases an urgent, same day response will be required. In such instances, social workers should consider the role of the NHS Continuing Healthcare Fast Track Pathway and the power to meet needs appearing urgent under section 19 (3) Care Act 2014.

### NHS Continuing Healthcare: Fast Track Provision

As outlined in the 2012 National Framework for NHS Continuing Healthcare and NHS Funded Nursing Care (Department of Health 2012), and in the 2018 revised version, to be implemented from 1st October 2018 (Department of Health and Social Care 2018), the Fast Track Pathway Tool is used in situations where an individual has a rapidly deteriorating condition that may be entering a terminal phase, and may need NHS continuing healthcare funding to meet their needs urgently.

The Fast Track Pathway Tool should be completed by an 'appropriate clinician': this may be a consultant, registrar, GP or registered nurse who is responsible for an individual's diagnosis, treatment or care and who are medical practitioners. By completing the tool, the 'appropriate clinician' confirms that the individual has a primary health need, and therefore no other test for eligibility is needed (The National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012). As such, social workers will not be involved in assessment processes using the checklist or Decision Support Tool (DST). However, social workers may have a role in identifying potential use of the Fast Track Pathway (Department of Health and Social Care 2018: para. 223), particularly as other professionals may be unfamiliar with CJD and the associated rapid deterioration, owing to the condition's rarity (Morris 2010).

Social workers should liaise with 'appropriate clinicians', some of whom will be based in The National CJDRSU Care Team and/or the National Prion Clinic (see later sections in these guidelines), who have the necessary knowledge and experience of CJD, and can comment on whether the individual's condition is likely to deteriorate rapidly. Although diagnosis of CJD in and of itself is not sufficient to indicate eligibility for the Fast Track Tool, in advocating for its use where appropriate, social workers should be aware of the following matters, outlined in both the 2012 and 2018 revised version of the National Framework for NHS Continuing Healthcare and NHS funded Nursing, which may be relevant to individuals with CJD:

## Urgent Responses

- The decision to use the tool should not be based solely on an individual's life expectancy.
- The term 'rapidly deteriorating' should not be interpreted so narrowly as only meaning an anticipated specific or short time frame and could reasonably apply to most patients with CJD.
- It may be appropriate to use the tool with an individual currently demonstrating few symptoms where it is clear that rapid deterioration is to be expected before the next planned review.
- Strict time limits that base eligibility on some specified expected length of life remaining should not be imposed.

The 'appropriate clinician' determines that the individual has a primary health need in fast track cases. Therefore, when a Clinical Commissioning Group (CCG) receives a completed Fast Track Pathway Tool recommending an urgent package of care, it must decide that the individual is entitled to NHS continuing healthcare and action implementation of the care package without delay (The National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012). The time period for implementing the care package should preferably not exceed 48 hours; to facilitate such timely provision, the 2012 and 2018 revised version of the National Framework for NHS Continuing Healthcare and NHS funded Nursing suggests that CCGs consider having staff dedicated to fast-track care package provision, who work closely with end of life care teams.

## Section 19 (3) Care Act 2014: Power to Meet Needs Appearing Urgent

Where the person is not entitled to NHS continuing healthcare via the Fast Track Pathway Tool, but the person's condition is deteriorating rapidly, social workers should be mindful of the power of the local authority, under section 19 (3) Care Act 2014, to meet urgent needs, without having yet completed an assessment or made an eligibility determination. Under this provision, the local authority can meet needs regardless of the adult's ordinary residence and also the needs of those present in their area but of no settled residence. A more detailed needs assessment should be completed following the initial response to meet urgent needs (Department of Health 2016: para. 6.26).

The power under Section 19(3) Care Act 2014 can also be used to provide urgent care and support to those people subject to immigration control, who have no access to public funds (as described in Section 115 Immigration and Asylum Act 1999), **but only where their need for care and support is not solely on account of being destitute**; this could include those adults who have care and support needs as a result of CJD. The Section 19 power could also justifiably be used to avoid a human rights or EU treaty rights breach, in relation to those people otherwise prohibited from receiving Care Act support as a result of Schedule 3 Nationality, Immigration and Asylum Act 2002. Further information on providing care and support for adults without recourse to public funds can be found on the No Recourse to Public Funds Network website: <http://www.nrpfnetwork.org.uk/Pages/Home.aspx>

Social workers should also seek guidance from their local authority legal team.

## 6. Multi-disciplinary and multi-agency Responses

### Health and Social Care Support: A Multi-Disciplinary Approach & The Keyworker

Section 3 Care Act 2014 requires local authorities to carry out their care and support functions with the aim of integrating services with those provided by the NHS or other health-related services. Section 6 Care Act 2014 requires local authorities to co-operate with their 'relevant partners', including health services, in carrying out their care and support functions. Such statutory duties are highly relevant to the provision of care and support to adults with CJD, for whom a multi-disciplinary approach is likely to be necessary. The features of CJD, including physical and mental health difficulties, are such that both health and social care professionals will need to be involved; positive team working amongst these professionals has been observed as key to the effectiveness of care and support (Barnett and McLean 2005).

Professionals working with an individual and their family may include General Practitioners, Community Mental Health Nurses, physiotherapists, occupational therapists, dieticians and community nurses. Social workers are also typically part of the team or network, and should have knowledge of local health, housing and social care services and other helping organisations within their communities. And, of course, home care workers may be the staff doing most of the day-to-day care and support.

### The Key Worker Role

As several professionals and services/agencies will be involved in the care and support of adults with CJD, effective organisation and co-ordination are essential (Das et al. 2012). A **key worker** should therefore be agreed upon and appointed locally, at a very early stage and irrespective of care setting, in order to co-ordinate a timely, multi-disciplinary response. The key worker position is not the sole responsibility of one profession, but could be allocated to any member of the care and support team, including nurses or an occupational therapist. However, social workers are very well placed to undertake this role owing to their professional skills in care co-ordination and relationship building.

The key worker's core function is to be a point of contact for the adult with CJD, their family and carers. They should also take responsibility for:

- Setting up multi-disciplinary team (MDT) meetings and co-ordinating agency interventions
- Co-ordination of assessment, carers' assessment and reassessment
- Co-ordination of timely care and support reviews

## Multi-disciplinary and multi-agency Responses

- Advocating for resources to meet care and support needs
- Co-ordination of information sharing, in line with data protection and confidentiality requirements.

The key worker should also liaise and work closely with the national CJD services: The National Care Team and staff at the National Prion Clinic.

## The National CJD Care Team & The National Prion Clinic Specialist Nurses

Owing to the rarity and unique features of the disease, adults with CJD and the local social care services supporting them may benefit from specialist support and advice from the national services. In the UK, specialist expertise related to prion diseases is concentrated in two locations: the National CJD Research and Surveillance Unit in Edinburgh and the Institute of Prion Diseases at UCL (University College London) and the affiliated National Prion Clinic in London. In order to coordinate specialist care and research priorities, a National Agreement (made in 2004) specifies certain roles and responsibilities and that both organisations are involved in the assessment and care of all people suspected to have prion disease in the UK. Although specialist nursing care and case coordination are joint responsibilities between the two teams, in each individual case, one team usually takes a leading role. The level of involvement of each team will be determined by multiple factors, including the needs of the person with CJD assessed directly during a visit, by telephone assessments with the person with CJD, carer or other professionals, and by coordination meetings and telephone calls between the specialist teams. Anyone can make referrals to specialist teams, including social workers.

## The National CJD Care Co-ordinators

The National CJD care co-ordinators, who are both senior nurses supported by clinical neurological and administrative staff, provide specialist expertise in the condition and act as an information resource for local health and social care professionals. They provide a UK wide service to all families affected by all types of CJD, and are available to travel throughout the UK to attend home visits, multi-disciplinary team meetings and any professional meetings relating to the care of the adult with CJD. The care co-ordinators provide emotional and practical support, and also act as an advocate on behalf of adults with CJD and their families. As the condition is so rare, they also offer education to all agencies involved in care provision. The care co-ordinators often, if necessary, remain involved for the lifetime of the person with CJD.

The care co-ordinators also help people with CJD and carers access CJD Care Package funding (see section in these guidelines on funding and charging arrangements).

## The National Prion Clinic: Specialist Nurses

The National Prion Clinic in London offers a UK wide comprehensive investigation and assessment service in order to provide diagnosis and care for people with all types of suspected CJD. People referred to the clinic are contacted on the day of referral and the service aims to provide a joint medical and specialist nurse review within a week. Each person is allocated a named nurse, who manages their care throughout the duration of their contact with the clinic. These specialist nurses offer support via telephone or email, will attend home visits and outpatient appointments, and can also attend case conferences. They can also offer counselling for both the adult with CJD and their families and can provide information on disease progression and symptom management. The National Prion Clinic Specialist Nurses typically do joint assessments with a neurologist to coordinate responses to nursing and medical needs and give advice to local clinicians.

The nurses also act as a specialist resource for local health and social care services and will liaise closely with the National CJD care co-ordinators and support the locally appointed named key worker.

## Community Mental Health Teams, Counselling Services & Palliative Care

Some people with CJD, particularly those with variant CJD and young people with sporadic CJD or inherited prion disease, have mental health or psychiatric symptoms. They may be low in mood or distressed (de Vries et al. 2003) or experience a range of psychotic symptoms, including delusions or be sexually disinhibited or unusually aggressive (Department of Health 2000). Social workers should therefore facilitate access to community mental health services if they are not already involved, where appropriate, particularly when they are taking on the key worker role.

The National CJD Care Team can secure funds to pay for the cost of counselling services and mental health support where only private sector counselling is available. The National Prion Clinic specialist nurses may also be able to provide psychological support directly or assist local services.

CJD is an invariably fatal condition, although the average time from onset to death varies depending on type. In cases of sporadic CJD, death usually occurs within 4-6 months, while the average time from onset of symptoms to death in cases of variant CJD is 14 months. A move to palliative care settings may therefore be considered (Biggs 2003), particularly as the person enters the end of life phase. Transfer to hospice care or a care home with nursing provision may be positive in some ways (de Vries et al. 2003), and in such cases social workers should try to identify provision that meets the person's needs as far as possible, such as being close to the person's family and appropriate to their age. The National Prion Clinic specialist nurses, National CJD care coordinators and CJD Support Network can assist in finding such services.



## 7. Care and Support Needs Assessment

The low threshold for triggering the duty on local authorities to assess (the appearance of care and support needs) is highly likely to be met where referred adults have suspected or probable CJD. As outlined in section 9 Care Act 2014, a needs assessment must be undertaken irrespective of the local authority's view of the adult's financial resources and must cover the following:

- The impact of the adult's needs for care and support on well-being
- The outcomes that the adult wishes to achieve in day-to-day life
- Whether, and if so to what extent, the provision of care and support could contribute to the achievement of those outcomes
- Whether, and if so to what extent, matters other than the provision of care and support could contribute to the achievement of the desired outcomes
- Whether the adult would benefit from the provision of preventative services, advice and information, or of anything which might be available in the community.

As with all needs assessments, the person with CJD, their carer(s), and anyone who they ask the local authority to involve must be involved in the needs assessment process. Where the adult with CJD lacks capacity to ask the authority to do so, any person who appears to the authority to be interested in the adult's welfare must be involved. Such involvement is essential, as it recognises that people are experts in their own lives and situations (Department of Health 2017). It also ensures that assessments acknowledge existing resources and resilience, even for those with complex conditions such as CJD, and facilitates the identification of any support that is available within families, communities and wider social networks (Department of Health 2017). As the condition may be advanced and rapidly deteriorating by the time contact is made with social care services, adults with CJD may have substantial difficulty being involved in the assessment process. Social workers must have regard to how the condition may result in the experience of substantial difficulty, and be mindful of the section 67 Care Act 2014 duty to involve independent advocates for those experiencing such difficulty who have no one appropriate to represent and support them.

As outlined in the previous section, a multi-disciplinary approach is crucial; as such, consideration should be given to the completion of an integrated assessment as outlined in the Care and Support Statutory Guidance, Chapter 6, paras. 6.75-6.79. The key worker should take responsibility for co-ordinating this assessment.

Local authorities must offer adults with CJD a supported self-assessment, where they or their carer are able and willing and have capacity to undertake it. However, social workers should pay careful attention to the rapidly deteriorating nature of CJD and associated change in needs; self-assessment will not therefore always be appropriate.

## Skills, knowledge and competence: Consulting those with Expertise

Although a range of professionals may undertake needs assessments, social workers are well placed to complete these, particularly where the adult presents with complex and multiple needs. However, owing to the rarity of CJD, working with people with the condition is often outside the experience of most social workers. If social workers do not have the necessary knowledge of CJD, they must consult someone with relevant expertise (see The Care and Support (Assessment) Regulations 2014 section 5 and The Care and Support Statutory Guidance, Chapter 6, para. 6.88). The care co-ordinators from the National CJD Care Team or the specialist team based at the National Prion Clinic would be particularly appropriate professionals with whom to consult. Consultation can take place before or during the assessment process.

## Eligibility for NHS Continuing Healthcare

A diagnosis of CJD is not in itself a determinant of eligibility for NHS continuing healthcare. However, owing to the nature of the condition and its rapid progression, eligibility for NHS continuing healthcare should always be considered. In situations where an individual with CJD may be entering the terminal phase, use of the Fast Track Pathway Tool should be considered, as outlined earlier in these guidelines.

When undertaking a 'needs assessment' under section 9 Care Act 2014, social workers should be mindful of the obligation on local authorities to refer adults to the relevant NHS body, where it appears that they may be eligible for NHS continuing health care (Care and Support (Assessment) Regulations 2014 Section 7(1)). Completion of the NHS continuing healthcare checklist can help social workers identify where an adult with CJD needs consideration for full assessment for NHS continuing healthcare.

As the 2012 and 2018 revised version of the National Framework for NHS Continuing Healthcare and NHS Funded Nursing Care (Department of Health 2012, Department of Health and Social Care 2018) recommends the involvement of both health and social care colleagues in eligibility determination processes, social workers may be involved in the completion of the 'Decision Support Tool' (DST) when working with adults with CJD. This is important, as there is a statutory requirement to consider the 'local authority limits test' in every NHS continuing healthcare assessment and only the local authority representative can assess if the adult's care needs are beyond local authority limits. The National Framework also notes that best practice requires the involvement of individuals with specialist knowledge of particular conditions and that the assessment process should make use of existing specialist assessments (Department of Health 2012: paras. 61 & 80, Department of Health and Social Care 2018: paras. 28.1, 126 & PG22). The national care co-ordinators and/or clinical colleagues from the National Prion Clinic are well placed to provide these assessments and social workers, particularly those in the role of key worker, should liaise closely with them.

## Fluctuating Needs

When undertaking 'needs assessments' under section 9 Care Act 2014, social workers must consider whether the presenting 'current level of need is likely to fluctuate and what their ongoing needs for care and support are likely to be' (Department of Health 2016: para. 6.58). This is particularly relevant when working with adults with CJD whose needs may change rapidly as the condition deteriorates (Department of Health 2000). Fluctuation in need must also be considered when determining eligibility for publicly funded adult social care (Care and Support (Eligibility Criteria) Regulations 2015, Section 2(4)).

## Whole Family Approach

CJD has been described as having 'devastating consequences for both the patient and their family' (Barnett and McLean 2005: 117). The rapidly deteriorating nature of the disease and some of the possible presenting symptoms, including personality changes, aggressive behaviour and sexual disinhibition will undoubtedly impact on family members providing care and support. Social workers must therefore adopt a 'whole family approach' to needs assessment, as outlined in Chapter 6 Care and Support Statutory Guidance (Department of Health 2016: para: 6.65-6.67). This involves identifying how the adult's care and support needs impact on other family members, determining if they would benefit from any information and advice, and signposting them to appropriate support services. Those family members identified as providing care to the adult with CJD and appearing in need of support themselves, should be offered a carer's assessment under section 10 Care Act 2014 (see section in these guidelines titled Support for Carers).

# 8. Care and Support Planning

## Care Co-ordination and Provision

If an adult with CJD is eligible for NHS continuing healthcare, the CCG is responsible for care planning, commissioning services, case management and undertaking regular reviews (Department of Health 2012, Department of Health and Social Care 2018: paras. 165 & 167). This involves management of the whole care package, not just those aspects considered healthcare. In some areas, social workers are employed by or commissioned by CCGs to undertake this care management role.

If an adult with CJD is eligible for local authority funded and/or arranged adult social care, social services professionals, including social workers, will undertake the care co-ordination and management role. In such cases, it may be useful for the social worker to be appointed as the key worker (see earlier section in these guidelines).

Local authority Care and Support plans must be prepared in accordance with section 25 Care Act 2014 and a copy of the plan must be given to the adult with CJD, their carer if they have one, and anyone else whom the adult with CJD asks the local authority to give a copy. In preparing the plan, social workers must involve the adult with CJD, their carer if they have one, and anyone else whom the adult with CJD asks the local authority to involve.

Morris (2010) observes the potential usefulness of family meetings and case conferences in co-ordinating care for adults with CJD; the key worker should take responsibility for arranging these, and should also remain in personal contact with professionals from the National Care Team and National Prion Clinic, where they are involved.

Adults with CJD may need assistance with personal care, support with domestic tasks including laundry, continence support, aids and equipment. However, care and support needs will vary and therefore services will differ. There is no 'standard CJD care package' and actual provision will depend on assessed eligible needs. Adults with CJD consulted for the 2003 guidelines wanted services that were appropriate to them as unique individuals and requested that professionals be sensitive and ask how they wish their needs to be met (Biggs 2003). Social workers should work positively and collaboratively with people with CJD and their families to determine their desired outcomes. In addition to co-ordinating commissioned care and support, social workers should co-design support packages that draw on people's own capabilities and resilience, and connect people to support available from wider social networks (Department of Health 2017). Reflecting this strengths-based approach, social workers must be mindful of the statutory duties on local authorities as a result of section 1 Care Act 2014. This includes having regard to:

- the importance of beginning with the assumption that the individual is best-placed to judge their well-being;
- the individual's views, wishes, feelings and beliefs.

## Care and Support Planning

Owing to the rapid deterioration and consequent change in need experienced by adults with CJD, care and support plans should include contingency planning, pre-empting an increase in need. Social workers should be innovative and creative in care and support planning to address such complexity, drawing on their knowledge of local services and resources, and the expertise of the national services. Use of direct payments may be a positive way of responding to fluctuation in need (see next section).

In some situations, care home accommodation may be required. Social workers must pay careful attention to the Care and Support and After-care (Choice of Accommodation) Regulations 2014. The CJD Support Network, Care Co-ordinators and National Prion Clinic nurses can assist in identifying suitable accommodation as they have experience of finding such services with capacity to offer quality care. Specific consideration must be given to the age of the adult with CJD, as particular concern has been raised about the paucity of age appropriate services for younger adults with CJD (Biggs 2003) but other factors may be just as important, such as language provision and proximity to family.

Whether support is residential or non-residential, services should be put in place as soon as possible. In some situations, adults with CJD may move geographical location, perhaps to be nearer to family. In such cases, social workers must ensure continuity of care as outlined in section 37 and 38 Care Act 2014, passing information to the “second local authority” in a timely fashion.

Social workers will need to work closely with care and support providers, for whom working with adults with CJD may be unfamiliar. Rentz (2008) notes that care workers may fear that CJD is contagious and will thus need reassurance that it cannot be transmitted by direct contact (this need for reassurance may of course apply to other people). Social workers can refer care providers to Section 4 of the Department of Health (2000) CJD Guidance for Health Workers. This advises care workers to adopt standard infection control practices applicable in any care context and notes that normal social and routine clinical contact does not pose a risk of CJD transmission to staff. Advice and guidance can also be sought from the specialist nurses at the National Prion Clinic and/or the Care Co-ordinators based in the National Care Team.

## Direct Payments

Owing to the rapidity of deterioration and consequent change in need common to CJD, care and support packages should be flexible and sufficient funding quickly made available. The 2000 Department of Health CJD Guidance noted that some adults with CJD develop a fear of strangers; as such, continuity of care workers and other staff such as nurses is key. The need for flexibility and continuity of care worker can be addressed through the use of direct payments to employ consistent care workers or personal assistants (McGuigan et al. 2016, Simcock and Castle 2016). Where the legal conditions are met (see section 31-33 Care Act 2014 and The Care and Support (Direct Payments) Regulations 2014) direct payments must be offered to adults with CJD and their carers.

The systems and processes accompanying local authority direct payments must be co-ordinated with those relating to any direct payments the adult with CJD receives from the NHS under section 12A National Health Service Act 2006. This will reduce any administrative burdens on the adult or their nominated or authorised person.

Although direct payments must be offered where the conditions are met, adults are not required to accept them as a way of meeting their needs (Department of Health 2016: para. 12.5). This is particularly important in relation to adults with CJD; owing to the rapid deterioration inherent in the condition, adults with CJD and their families do not always have time to explore care options and make all the required arrangements (Wickenden 2006, Rentz 2008). In such situations, local authorities should directly provide or commission care and support without delay.

## Aids, Equipment and Home Adaptations

Aids, equipment and home adaptations are reported to improve health and well-being, enhance service users' and carers' quality of life, and promote independence (Heywood and Turner 2007, Care & Repair England 2015, Clements 2017). For adults with CJD, the provision of such aids and adaptations may be an essential part of the care and support package (Barnett and McLean 2005, Body and Glasson 2005).

Barnett and McLean (2005:116) observe that the equipment required by adults with CJD is ordinarily 'similar to that for any [adult] with a progressive neurological disorder': this includes incontinence products, bedside tables, rise recliner chairs, stair lifts and wheelchairs with built in neck and body support (Barnett and McLean 2005, Rentz 2008). Some equipment may need specific modifications in order to meet individual need (Barnett and McLean 2005). Social workers should seek advice from occupational therapists and the specialist clinicians at the National CJD Care Team and the National Prion Clinic in relation to such modifications.

Examples of home adaptations that may be required include bathroom modifications or property extensions to enable the adult with CJD to be cared for at home (Barnett and McLean 2005).

## Provision of Equipment

The care and support needs of adults with CJD may in part be met by the provision of equipment following a local authority needs assessment and eligibility determination. However, social workers should be mindful of the section 2 Care Act 2014 duty to provide or arrange for the provision of services, facilities or resources, which it considers will contribute towards preventing or delaying the development of care and support needs; the Care and Support Statutory Guidance clarifies that the provision of equipment is considered such a service (Paras. 2.8-2.9). Access to equipment may therefore be available to adults with CJD, pre-eligibility determination; such provision can be facilitated through Integrated Community Equipment Services.

## Care and Support Planning

Adults with CJD may wish to make use of direct payments to purchase equipment in order to have greater flexibility and choice. The CECOPS website offers further information and guidance on using direct payments for equipment: [www.cecops.org.uk](http://www.cecops.org.uk)

Under the Care and Support (Charging and Assessment of Resources) Regulations 2014, adults cannot be charged for community equipment (or minor adaptations up to £1000).

## Provision of Adaptations

Home adaptations are also listed as a preventative service in the Care and Support Statutory Guidance (para. 2.8). Where social workers identify either an opportunity for a preventative response or an eligible need during a section 9 Care Act assessment that should be met through home adaptations, where appropriate, adults with CJD should be supported to make an application to the housing authority for a Disabled Facilities Grant (DFG). Provided under the Housing Grants, Construction and Regenerations Act (HGCRA) 1996 (Part 1, section 23), DFGs are available for adaptations not only within the property, but also in the communal areas of accommodation such as blocks of flats and in order to make a garden accessible. DFGs are also 'tenure neutral', so are available not only to owner-occupiers, but also those in rented accommodation and in some circumstances people living in mobile homes, caravans and houseboats (Clements 2017).

In order to be eligible for a DFG, the adult with CJD must have been assessed as needing the adaptations, and the work must be considered 'appropriate' or 'reasonable and practicable' (HGCRA 1996). Social workers can find further guidance on both good practice and eligibility for a DFGs in the 2013 Home Adaptations Consortium (HAC) publication 'Home adaptations for disabled people: a detailed guide to related legislation, guidance and good practice' (this document was updated in 2015 to reflect the implementation of the Care Act 2014) (Home Adaptations Consortium (HAC) 2013).

DFGs are only payable when the applicant lives or intends to live in the property as their main or sole residence throughout the grant condition period (a period of five years) (s21-22 HGCRA 1996). However, the HGCRA 1996 refers to an alternative shorter period 'as health and other circumstances permit', which is of significance for those with sporadic or variant CJD, who are likely to have limited life expectancy. While the HAC 2013 guidance states that 'where an applicant's prognosis implies that degeneration in the short term will occur, then this should be taken into account when considering the eligible works' (para. 35 Annex C), social workers should be aware of the following HAC guidance provisions, if needing to support a DFG application from an adult with CJD:

*A relatively limited period in which a particular adaptation is appropriate should **not be regarded as a sufficient reason for delaying or withholding its provision** (Para. 7.34)*

*Where it appears to the person carrying out the assessment or the person evaluating the application for the grant, that the applicant may not continue to occupy the adapted property for*

*a period of five years or more they should consider the circumstances. If the reason for suspecting this is a prognosis of a **deteriorating condition or possible imminent death of the applicant, this should not be a reason for withholding or delaying grant approval** (Para. 7.70).*

Clements (2017) observes that not all individuals are eligible for DFG monies, that the funds may not cover the type of adaptation required, or that the cost of the adaptations required exceeds the DFG maximum mandatory grant (£30,000 in England). Further details on the DFG means test can be found in the Renewal Grants Regulations, which are amended annually. Where the DFG does not cover the full cost of the adaptations, the Housing Authority can use its powers under the Regulatory Reform (Housing Assistance) (England and Wales) Order 2002 to cover the shortfall, or the Adult Social Care Department can do so under the Care Act 2014. Where the adult with CJD has NHS Continuing Healthcare funded care and support, the CCG also has the power to provide additional support, where the DFG monies are insufficient (Department of Health 2012: para. 79.3, Department of Health and Social Care 2018: para. 56.4).

Social workers must remain mindful of the duty to meet assessed eligible needs under the Care Act 2014, which may include the provision of adaptations; this duty is separate from the processing of DFG applications and it would be considered maladministration for the Adult Social Care Department to fail to meet assessed eligible need by way of adaptations, even where a DFG application has been unsuccessful (Clements 2017). Care & Repair England (2015) notes that home adaptations may certainly be an appropriate way of meeting need in relation to various eligibility outcomes: managing toilet needs; maintaining an habitable home; being able to make use of the home safely. Where adaptations are provided under the Care Act 2014, there is no requirement that they be 'reasonable and practicable', as under the HGCR 1996. Some local authorities are making use of part of adults' personal budgets to cover adaptation costs (College of Occupational Therapists 2016).

Funds from the National CJD Care Package can also be used to cover the cost of both specialist equipment and adaptations. See the section in this guidance titled 'Funding and Charging Arrangements'.

## Preventing Delay in the Provision of Equipment and Adaptations

The Department of Health (2000) emphasized that equipment and adaptations must be provided to adults with CJD without delay, owing to the rapid progression of the condition. However, there is evidence of significant delay in the provision of equipment and adaptations overall (Leonard Cheshire Disability 2015, Clements 2017) and this has been identified as a particular concern for those with CJD (Barnett and McLean 2005).

To prevent delay, Biggs (2003) and CECOPS (2015) recommend pre-empting need by way of anticipatory assessments and providing equipment immediately so that it is available when required. The College of Occupational Therapists (2016) also suggests that basic equipment



## Care and Support Planning

and minor adaptations can be provided by appropriately trained support staff, thus provision through the involvement of qualified occupational therapists is not necessarily required.

Where funds from the National CJD Care Package are being used, Barnett and McLean (2005) recommend inviting budget holding managers from the CCG and local authority to initial case conferences, so that responsibility for invoicing in relation to reimbursement is made clear, thus also preventing delay.

Delays in the provision of major home adaptations can be associated with the processing of a DFG application. Clements (2017) suggests that social workers assist those experiencing such delay by intervening in this process. When working with people with CJD, social workers can do this by referring to the timescales noted in the HAC (2013) guidance, paying particular attention to para. 7.33; this notes that those with deteriorating conditions should have their applications processed 'as fast as possible' and that consideration be given 'to expedited procedures and interim solutions'. Social workers can also refer to the College of Occupational Therapists Housing Corporation (2006) guide 'Minor adaptations without delay - A practical guide and technical specifications for housing associations', endorsed by the Association of Directors of Adult Social Services (ADASS); this stresses that those with life-limiting conditions should have a faster response in relation to DFG delivery. Reference to local authorities' positive obligations under the Human Rights Act 1998 may also be helpful; Clements (2017) observes that these obligations have been referred to by the Local Government Ombudsman in investigations relating to complaints about delayed DFGs.

Section 36 of the HGCR 1996 does allow for a maximum of 12 months delay in the payment of a DFG, from the date of application. Therefore, in addition to intervening in the process, social workers working with adults with CJD, may also request that the housing authority make use of their wide ranging power under the Regulatory Reform (Housing Assistance) (England and Wales) Order 2002. The HAC (2013) notes that assistance under this order can be used **'to deliver a much quicker remedy for urgent adaptations' by 'avoiding the procedural complexities of mandatory DFGs'**.

A third option to avoid delay in the provision of adaptations associated with DFG application processing is to provide the required work under the section 18 Care Act 2014 duty to meet assessed eligible need. Clements (2017: 219) highlights that 'it would be unlawful for a social services authority to refuse to address a person's needs for an adaptation under the Care Act 2014 on the ground that it was possible that at some time in the future that a DFG might be awarded'.

## Direct Social Work Support

Diagnosis of CJD can be devastating for individuals and their families, who may face a range of emotions and reactions associated with living with life-limiting illness (Rentz 2008). While for some adults formal counselling and therapy may be appropriate, Morris (2010) observes that family support and talking can be more effective. Social workers are well placed to offer this support, but will need to go beyond their care management function in doing so. This should be discussed in supervision and acknowledged in caseload management.

## 9. Funding and Charging Arrangements

Professionals need to establish, without unnecessary delay, which agency is responsible for funding the care and support provided to individuals with CJD. Disagreement between agencies as to financial responsibility should not result in the delay of provision and individuals should not be left without support while disagreements are resolved. Social workers should refer to the National Framework for NHS Continuing Healthcare and NHS Funded Nursing Care (Department of Health 2012, Department of Health and Social Care 2018: paras. 196-207) and Section 4 of the Care and Support (Provisions of Health Services) Regulations 2014 for guidance on dispute resolution between the NHS and local authorities concerning funding.

Funding for care and support for adults with CJD may come from the NHS, the local authority, or in many cases both of these bodies. Individuals may also self-fund their care and support. In addition to these funding streams, social workers must also be aware of the National CJD Care Package and the variant CJD Compensation Trust described below.

### NHS Continuing Healthcare Funding and Jointly Funded Packages

An adult with CJD may be eligible for NHS continuing healthcare funding via either the Fast Track Pathway or based on recommendation following completion of the Decision Support Tool. Where eligible, the CCG is responsible for funding and care managing the whole care and support package. The CCG can commission services from care and support agencies or make use of personal health budgets, provided as a direct payment, where clinically and financially appropriate.

In some cases where an adult with CJD is not eligible for NHS continuing healthcare, the Decision Support Tool may have identified needs that are not of a nature that the local authority can solely meet. In such instances, the CCG should work in partnership with the local authority to fund and co-ordinate a 'joint package of care' (Department of Health 2012, Department of Health and Social Care 2018: paras. 263-269). Joint packages of care may include NHS funded nursing care and other NHS services. Joint packages of care may be provided in both residential and non-residential settings.

### Local Authority Funding: Exemption from Charging

Where the local authority is meeting needs under section 18, 19 or 20 Care Act 2014, it has a power to charge under section 14, subject to financial assessment under section 17. However, the local authority **must not make a charge** for meeting needs under this section, where the care and support is being provided to an adult **with variant CJD** (see Care and Support (Charging and Assessment of Resources) Regulations 2014 Section 4).

## The National CJD Care Package

Established in October 2000, the National CJD Care Package provides funding for care needs that cannot be covered by the local authority or CCG. It does not replace local health and social care funding arrangements and responsibilities, but rather supplements them to cover any identifiable shortfalls.

Advice on the fund is available from the care co-ordinators in the National CJD Care Team, who also process applications. Funding is available to people with all types of CJD, once agreement is reached with the care co-ordinators about shortfalls in provision. Funding is provided on a reimbursement basis: the local authority or health authority (CCG) should arrange and directly fund the additional care or equipment required and these bodies will then be reimbursed accordingly.

The aim of the National CJD Care Package is to facilitate the timely implementation of a flexible care and support package that can meet the rapidly changing needs of adults with the condition. Funding has been used, for example, to cover the cost of:

- Specialist equipment and adaptations, including raiser-recliner chairs and wet rooms
- Additional nursing and social care input, often enabling people to remain at home
- Alternative therapy
- Top up fees for those in care homes.

## The variant CJD Compensation Trust

The variant CJD Compensation Trust was established in 2001 following the report into the BSE inquiry (see Department of Health 2012: paras. 113-117, Department of Health and Social Care 2018: paras. 263-269). Payable only to those with variant CJD and their families, the monies are used to compensate for emotional distress; the funds are not for the use of paying for care services or adaptations.

(Body and Glasson 2005) identify the four categories of award:

- 1. The experience of vCJD for the patient: a sum awarded as a Basic Sum to reflect the experience of vCJD for the family.*
- 2. The experience of vCJD for the patient's immediate family and/or carers: A sum of up to £15,000 made for the experience of looking after a vCJD 'victim'. A further discretionary award may be made for psychiatric injury causing 'particular hardship'.*
- 3. Costs incurred by the patient and their family as a direct result of the patient suffering from vCJD: funeral expenses up to £3,000, reasonable capital expenditure on equipment purchased to improve patient's life during illness. For pre-National Care Package Families (i.e. pre October 2000), a payment of the cost of gratuitous care.*

*4. Future losses caused to the patient's dependents as a result of his/her death from vCJD: calculation broadly similar to conventional personal injury award. It is assumed that all children's dependency runs to 21 years.*

Applications to the variant CJD Compensation Trust are processed by the National Care Team care co-ordinators. An interim payment is made initially, followed by a further payment dependant on the particular circumstances.

Payments made from the Trust are considered a capital to be disregarded when the local authority is undertaking a financial assessment (see the Care and Support (Charging and Assessment of Resources) Regulations 2014. Schedule 2: 27).

Should a family member receive payment from the Trust, and subsequently themselves need local authority care and support, the monies must be disregarded when determining their financial contribution to the cost of care for two years from the date of death of the relative with CJD (or from the date of payment from the Trust if later). In the case of a dependent child or young person, the monies should be disregarded until they turn 18 (See the Care and Support Statutory Guidance Annex B, Paragraph 49).

## **CJD Support Network Care Grants**

The CJD Support Network can offer financial support in the form of 'care grants' to those families experiencing financial need as a result of caring for relatives with any form of CJD. These care grants are only available to meet needs not covered by NHS or local authority social care services.

Social workers should signpost those in need to the CJD Support Network. They should also provide a letter confirming financial need, which is required in addition to both the application and a doctor's letter confirming a CJD diagnosis.

# Review and Revision to Care and Support Plans

## Frequency of Review

Under section 27 Care Act 2014 local authorities have a duty to keep care and support plans under review generally or on reasonable request by or on behalf of the adult or carer. No specific timescales are given except for direct payment care packages, which must be reviewed within the first six months and then annually (section 7 Care and Support (Direct Payment) Regulations 2014). However, as outlined in the Care and Support Statutory Guidance, the expectation is that reviews should be no less frequent than annual and a review soon after services commence is recommended.

Care and support plan reviews for adults with CJD need to occur at much shorter intervals and more frequently than that described above, owing to the speed of deterioration and sudden alteration of care needs (Body and Glasson 2005: 19); such changes may occur within one or two weeks. As the level of deterioration may render a current care plan ineffective, social workers may need to revise the existing plan or reassess the adult's needs under section 9 Care Act 2014. Consideration should be given to whether the adult's needs now appear to be eligible for NHS continuing healthcare (Care and Support (Assessment) Regulations 2014 Section 7(1)).

## Nature of Review

Social workers should see reviews an opportunity to determine whether the care and support plan is meeting the adult's needs, paying attention to the broad elements outlined in para. 13.12 Care and Support Statutory Guidance. Reviews are also an opportunity to determine whether any equipment provided continues to meet need or whether it needs to be repaired or replaced (Department of Health 2000).

The review may identify the need for a care and support plan revision or a complete change, particularly where there has been sudden and drastic deterioration. However, as noted earlier, care and support plans should include contingency planning, pre-empting an increase in need.

Adults with CJD, their carers and others requested by the adult with CJD, must be involved in review and revision processes. Where the adult would have substantial difficulty in being involved, social workers must be mindful of the section 67 Care Act 2014 duty to involve independent advocates for those experiencing such difficulty who have no one appropriate to represent and support them.

# 10. Mental Capacity, the MCA 2005 and CJD

## CJD and Mental Capacity

A common feature of CJD, particularly sporadic CJD, is the rapid onset and progression of dementia. As such, adults with the condition usually lack capacity to make decisions about their care and support as the disease progresses. Social workers should advise people of their options under the Mental Capacity Act 2005 to 'plan ahead' and act quickly to support those interested in these options to make the necessary arrangements. Such options include setting up a Lasting Power of Attorney (LPA) under section 9 Mental Capacity Act 2005 and the making of 'Advance Decisions to refuse treatment' under section 24 Mental Capacity Act 2005.

Doubts may be raised about the capacity of an adult with CJD to make a specific decision about their care and support, owing to their behaviour, their circumstances or as a result of concerns raised by others. In such situations, social workers should assess the adult's capacity to make the specific decision in accordance with section 2 Mental Capacity Act 2005 and in line with the five principles of the Act, as outlined in section 1 of the Act and Chapter 2 Mental Capacity Act Code of Practice:

1. A person is **assumed to have capacity** unless a lack of capacity is clearly established
2. No one treated as unable to make a decision unless **all practicable (reasonable) steps** to help them have been exhausted and shown not to work
3. A person is not to be treated as unable to make a decision merely because he makes an **unwise decision**
4. If it is decided that a person lacks capacity than any decision taken on their behalf must **be in their "best interests"**
5. Any decision taken on behalf of a person who lacks capacity must **take into account their rights and freedom of action.**

## Involvement of Independent Mental Capacity Advocates

Social workers should be mindful of the duty on the NHS and local authority to involve Independent Mental Capacity Advocates (IMCAs) under sections 35 – 36 Mental Capacity Act 2005, where the adult with CJD is 'unbefriended' and the decision concerns a change of accommodation or serious medical treatment, or a Deprivation of Liberty application. The power to involve IMCAs during placement reviews or safeguarding procedures (even where the adult with CJD is not unbefriended) should also be considered where appropriate.

## Particular Treatments for CJD and Best Interests

Where adults with CJD lack capacity to make a specific decision about their care and support, the decision should be made in their best interests in the way outlined in the Mental Capacity Act and Code of Practice. Social workers will be familiar with the 'Best Interests Checklist' detailed in section 4 Mental Capacity Act 2005, and must refer specifically to this.

Although medical treatment decisions will not be taken by social workers, they should be aware of the specific provision relating to treatment for CJD in the Mental Capacity Act 2005 Code of Practice:

*Unless the adult has previously made an LPA appointing an attorney to make healthcare decisions for them, or they have made a valid advance decision to refuse the proposed treatment, the **Court of Protection** must be asked to make decisions relating to: cases where there is a dispute about whether a particular treatment will be in a person's best interests. This includes cases that introduce ethical dilemmas concerning untested or innovative treatments, for example, **new treatments for CJD**.*

# 11. Support for Carers

## Carers' Needs and CJD

Social workers must identify how the care and support needs of an adult with CJD impact on family members and friends, and recognise that some may be acting as carers: the legal definition of a carer under section 10 (3) Care Act 2014 is broad and inclusive:

*“Carer” means an adult who provides or intends to provide care for another adult.*

Providing care and support for adults with CJD can be stressful, complex and demanding (CECOPS 2015). For family members and friends undertaking a caring role, certain features of CJD, such as personality changes, psychotic or florid symptoms and aggressive or sexually disinhibited behaviour, may be particularly distressing and challenging. Social workers should recognise that carers may have unmet support needs themselves, and offer advice, information and directing to support services such as the CJD support network. Carers of adults with CJD may need:

- Information about CJD, symptom management and prognosis
- Support with financial matters
- A break from their caring responsibilities
- Emotional and psycho-social support

Where it appears to a local authority that a carer of an adult with CJD may have needs for support (at the current time or in the future), they must undertake a carer's assessment (section 10 Care Act 2014). The duty to assess applies irrespective of the local authority's view of their support needs or the carer's financial resources.

## Carers' Assessment and Meeting Carers' Needs

As outlined in section 10 Care Act 2014, a carer's assessment must cover the following:

- Whether the care is, and is likely to continue to be willing and able to provide care for the adult
- The impact of the support needs on their well-being
- The carers' desired outcomes and whether, and if so to what extent the provision of support could contribute to the achievement of those outcomes
- Whether the carer works or participates in education, training or recreation or wishes to do so.



## Support for Carers

Eligibility for local authority funded support for carers is determined by assessment against the Care and Support (Eligibility Criteria) Regulations 2015, section 3. A duty is placed on local authorities under section 20 Care Act 2014 to meet carers' eligible needs for support. Carers' needs may be met by direct provision, commissioned services or direct payments. Carers of adults with CJD may have very particular needs as outlined above. However, they must not be required to have a direct payment to meet their support needs; where this is not the preferred option of the carer, the local authority should still offer individualised services to meet their needs, rather than referral to services for all carers.

The availability of respite or short-break care, offering carers a break from their caring responsibilities, has been identified as particularly important (de Vries et al. 2003, Barnett and McLean 2005). However, respite care is not the only option for facilitating a break for carers. Social workers should be mindful of the power under section 10 (7) Care Act 2014 to meet a carer's support needs, by meeting the non-eligible needs of the adult with CJD.

Where the adult with CJD is eligible for NHS continuing healthcare and their care and support are thus funded by the CCG, the CCG should consider meeting any training needs that their carer may have. The CCG should also provide additional care for the adult with CJD to enable the carer to have a break from his/her caring responsibilities (Department of Health 2012: para. 89.1, Department of Health and Social Care 2018: paras. 291 & 327).

Those providing care for an adult with CJD may need support not only whilst undertaking their caring role, but also after the adult has died (Department of Health 2000, Biggs 2003). Rentz (2008) observes that carers may have unresolved issues of loss owing to the intensive nature of caregiving during the progression of the disease. Furthermore, Rentz (2008) highlights that 'the public health issues surrounding CJD can intensify and prolong the grieving process for affected families'. Social workers should therefore ensure that support is available for families and carers into the bereavement period. The CJD Support Network can offer such support.

## 12. Sources of Support & Information

### National CJD Research & Surveillance Unit

Western General Hospital

Crewe Road

Edinburgh

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The National CJD Surveillance Unit monitors the incidence of CJD in the UK. Two case co-ordinators are also based at the Unit in the National Care Team, whose role it is to co-ordinate a care package for people with any form of prion disease. The National Care Team also provides access to the National CJD Care Package funds.

### National Prion Clinic at the National Hospital for Neurology & Neurosurgery

Queen Square

London

WC1N 3BG

Email: [s.macleod@prion.ucl.ac.uk](mailto:s.macleod@prion.ucl.ac.uk)

Website: <http://www.prion.ucl.ac.uk/clinic-services/>

Telephone (Switchboard): 020 3456 78990

Telephone (Helpline): 020 3448 4037 / 020 3448 4038

The National Prion Clinic performs comprehensive investigations and assessment to provide diagnosis and care for all forms of suspected prion disease: Inherited/Familial, Iatrogenic, Sporadic and Variant. People are allocated a named doctor and nurse who will manage their care for the duration of their involvement in the clinic.

## Sources of Support & Information

### The CJD Support Network

P.O Box 346

Market Drayton

Shropshire

TF9 4WN

Email: [support@cjdsupport.net](mailto:support@cjdsupport.net)

Website: <http://www.cjdsupport.net>

Telephone (Admin): 01630 673 993

Telephone (Helpline): 0800 085 3527

The CJD Support Network is the only UK based charity providing emotional and practical support for people with all strains of CJD and for those who are at greater risk of CJD. In addition to providing support to people with CJD, their families and carers, the Support Network also provides information, advice and training to professionals and links them to others with more experience of providing CJD care.

## 13. Case Studies

These case studies are based on people who were seen by the National Prion Clinic team (NPC) and were followed up for the duration of the disease. The cases illustrate the various matters that may arise when supporting people with CJD and highlight the challenges of accessing both relevant care and associated funding in a timely manner. Such challenges may be the result of a lack of information about CJD and limited experience of supporting people with this very rare disease. Details have been changed to protect anonymity and confidentiality.

### Case study 1: Albert

Albert was an 80-year-old man who lived with his wife of 50 years. He was an avid gardener (spending most days outdoors) and had been well all his life.

Over a six-month period, Albert experienced memory loss and difficulty in doing day-to-day activities. His wife believed he had not been his 'usual self' and that his personality had changed. Albert later developed severe balance problems, his mobility deteriorated and he was no longer able to walk independently. His older brother had experienced similar symptoms ten years ago and had been diagnosed with the inherited form of CJD.

Albert's GP quickly referred him to a specialist service where his diagnosis of inherited prion disease was confirmed. With Albert's consent, the Clinical Nurse Specialist (CNS) from the National Prion Clinic made a referral to the Local Authority Adult Social Care Department, alerting them to his diagnosis.

Albert's wife found it increasingly difficult to look after him on her own over the following weeks. Someone from the local authority wrote to him and his wife advising that a social worker would visit to conduct a needs assessment in four weeks' time, but if his condition worsened, the GP and local Community Nursing Team should be contacted.

Albert's condition accelerated over two weeks. His wife and daughter both made several attempts to contact the Local Authority Adult Social Care Department to organise crisis care, without success; they did however manage to get the District Nursing team to provide a profiling bed for downstairs. As a needs assessment by the local authority had not yet taken place, the family decided that self-funding some interim home care in the morning was the best and only option. Following the social work needs assessment, a care and support plan consisting of care worker visits four times a day was implemented, and the family no longer had to self-fund support. However, Albert's symptoms progressively worsened, particularly during the night, suggesting the need for a night-sitting service; he had made several attempts at getting out of bed and had fallen. A request for such a service was made to the social worker. However, the local authority hesitated to fund this and instead asked Clinical Commissioning Group (CCG)

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clinicians to undertake a joint visit; as Albert's needs were increasing, it was felt that he may be eligible for NHS continuing healthcare.

The social worker mistakenly thought that this meeting indicated that the CCG had immediately taken responsibility for funding and arranging care for Albert. As such, when the family requested additional care in the following weeks, she said that the CCG was responsible for providing this care. However, the CCG stated that it was still the responsibility of the local authority, as eligibility for NHS continuing healthcare had not officially been agreed, despite the verbal agreement that had been made.

Discussions between NPC, social worker and CCG clarified the situation. The most appropriate care package for Albert was agreed and implemented, and the family was given reassurance that Albert would be cared for at home for as long as possible.

The case illustrates the need for the following:

1. Much greater clarity over funding responsibilities and arrangements for care and support for adults with CJD.
2. Early discussions over funding which should not delay the provision of care nor give rise to consequent stress among people with CJD and their families.
3. Referrals to the local authority should be followed up by the National Prion Clinic where there is a delay in response.
4. Greater priority to be given by the Local Authority Adult Social Care Department to referrals relating to adults with CJD.

## Case Study 2: Dalton

Dalton was a 44-year-old man, who lived with his wife and two children. He managed a successful business and worked mainly from home. Dalton's wife noticed that he began struggling to do his accounts and was forgetting important passwords. His eyesight had deteriorated and he was also experiencing insomnia.

After being taken to A&E by his wife, hospital staff admitted Dalton onto a neurology ward for further investigations. A week-long series of investigations was carried out and CJD was diagnosed. His mobility deteriorated during his stay in hospital and he was discharged home with a wheelchair. Dalton was unable to walk or transfer without assistance and his eyesight continued to deteriorate. A care and support package was not organised on discharge, because Dalton's wife said that she could manage at home with some help from her mother.

Dalton's condition rapidly progressed and his wife called the GP for help to set up some care services at home. The GP made a referral to the local authority adult social care department; the referral was received and the GP was advised that Dalton would be contacted as soon as

possible. At this time, Dalton required the assistance of two people to transfer from bed to chair and he had become severely sight impaired.

Two weeks passed and there had been no contact from the adult social care department. Dalton's wife became very anxious about the situation and started to panic; she called the GP again for help and advice. Following this contact, a social worker made contact to organise an appointment for the following week.

Prior to this appointment, the situation reached a crisis point as Dalton's wife felt she could no longer cope with looking after him at home. The NPC team visited Dalton at home and the Clinical Nurse Specialist spoke with the local district nursing team who made use of the NHS continuing healthcare Fast Track Pathway Tool.

The case illustrates the need for the following:

1. Earlier consideration by health and social care staff (the hospital discharge team, GP, the District Nurse, and the local authority) of use of the NHS continuing healthcare Fast Track Pathway Tool.
2. Speedier responses from Local Authority Adult Social Care Departments to referrals relating to adults with CJD; if appropriate this could have been earlier consideration of the Fast Track Pathway or use of the power under Section 19(3) Care Act 2014.

### Case study 3: Balraj

Balraj was a 37-year-old man diagnosed with inherited prion disease. He was admitted to hospital after falling down stairs at home and injuring himself. The Occupational Therapist at the hospital referred Balraj to the Local Authority Adult Social Care Department, when he was an inpatient, for a needs assessment and possible care and support services. Balraj was told that he would hear from them within two weeks of discharge from hospital.

There was no contact from the local authority after three weeks, which caused his partner great distress. The Clinical Nurse Specialist from the NPC re-referred to the Adult Social Care Department, emphasising the presence of a stressful home environment and also highlighting the expected disease progression. The duty social worker stated that she considered this an 'urgent case', but, two weeks later, there was still no follow up. The CNS therefore persisted with the Adult Social Care Department, stressing the need for an urgent assessment and for a social worker to be allocated. The CNS suggested a joint home visit, with the social worker and OT; a date was agreed and the visit was undertaken a week later.

A needs assessment was completed during the home visit, and this identified that Balraj had increasing difficulty completing both his activities of daily living and instrumental activities of daily living, including doing the shopping and managing his finances. Balraj told the social worker and OT that he regularly got lost when out alone in his local area and that the police had

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been contacted by his partner several times in order to locate him. It was agreed during the home visit that Balraj needed supervision and support. One of his main desired outcomes was to remain as independent as possible, but to have care and support available, the amount of which could be increased as required, owing to the progressive nature of CJD. Recognising both current and potential future need, the Local Authority Adult Social Care Department offered Balraj a place in supported living accommodation, local to his area at his request. They also provided a befriender who assisted with some of the day-to-day tasks and kept a 'friendly eye' on him.

Following a move to the supported living accommodation, Balraj's condition deteriorated further as expected, and, consequently, his social care needs increased. The deterioration in his condition also led to expressed concern about his mental capacity to make decisions about his care and support. As such, a capacity assessment was undertaken under the Mental Capacity Act (MCA) and it was determined that Balraj lacked capacity to make a decision about his care and support. A best interests decision was taken by the multi-disciplinary team to increase the level of care and support available; this reflected Balraj's earlier expressed wishes to have additional support when his condition deteriorated. Concerns about his safety if and when leaving the supported accommodation to go out into the local area were considered a priority, but application of the MCA 'least restrictive' principle was essential. The care and support plan therefore included support to enable Balraj to leave the accommodation and access the local community safely, but it was not increased to the point of being continuous supervision.

This case illustrates the need for the following:

1. Speedier responses from the Local Authority Adult Social Care Department to referrals relating to adults with CJD; people with this specific inherited CJD condition can have difficulty in temporarily holding information, reduced fluency of speech, apathy (lack of emotion, interest, and concern), inattentiveness, delayed responses to questions, and a striking lack of inhibition, including socially inappropriate behaviour.
2. Multi-disciplinary assessment and care and support planning.
3. Consideration of future needs, related to the expected disease progression, in needs assessments and care and support planning.
4. Referrals to the local authority to be followed up by the National Prion Clinic where there is a delay in response.
5. Application of both the Mental Capacity Act 2005 principles and the provisions related to assessment and best interests decision-making.

## Case study 4: Jenny

Jenny was a 28-year-old woman, diagnosed with inherited prion disease by the National Prion Clinic team.

Her father contacted the NPC for help, as he was concerned for her safety. She lived alone in what he considered an unsafe part of town and he suspected that she was being sexually exploited by men. The clinical nurse specialist arranged to visit Jenny at her home with a NPC Doctor and her GP to fully assess the situation. It was apparent that Jenny's cognitive function had declined and she was having difficulty with activities of daily living. The GP referred her to the local authority adult social care department, as he thought she needed a care worker to assist with getting washed and dressed every morning and someone to be with her during the day to ensure her safety. No care and support was arranged for the evening even though this was when she had a tendency to walk into town and put herself in danger. A week later her GP contacted the local authority for an update and was told that Jenny was not considered a priority as she was independent and still had some insight into her condition and situation. The GP suggested that the local authority contact the National Prion Clinic for further information about CJD and also about Jenny. Ten days later there was still no contact from the local authority. The NPC clinical nurse specialist contacted the social worker to whom the GP had initially spoken. She emphasised the urgency of this referral; the social worker requested some further information about CJD and a clinical letter from a NPC doctor and a letter of assessment from the NPC clinical counsellor.

The nurse suggested to the social worker that a meeting with Jenny's father could be beneficial. This meeting took place two days later and discussion focussed on Jenny's anticipated needs and her safety, as there had been several occasions where Jenny would walk into town in a way that placed her at risk of harm. Jenny's aggressive behaviour and lack of inhibition, including socially inappropriate behaviour, were also discussed. This was the main concern, especially for her father.

Following the multidisciplinary meeting, with agreement Jenny moved to a care home for younger adults living with dementia. This was considered by her father and the professionals to be the best way to meet her current and anticipated future eligible care and support needs.

This case illustrates the need for the following:

1. Speedier responses from Local Authority Adult Social Care Department to referrals relating to adults with CJD, recognising that in certain types of inherited prion disease the person's ability to walk independently can remain well-preserved for a long time (several years), even in the face of relentless cognitive decline.
2. Referrals to the local authority to be followed up by the National Prion Clinic where there is a delay in response, with additional information about the nature of CJD where appropriate.
3. Multi-disciplinary assessment and care and support planning.



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4. Use of the Mental Capacity Act 2005 and Deprivation of Liberty Safeguards will need to be addressed early on and subsequently.

### Case study 5: Gregory

Gregory was a 35-year-old man, diagnosed with inherited prion disease. He first experienced symptoms whilst working on a building site. His manager noticed he was unstable on his feet and that he could not remember how to use certain tools. Gregory was sent home and was advised to contact his GP.

The GP was aware of Gregory's family history, so referred him to the National Prion Clinic. He was seen by the consultant and clinical nurse specialist; the symptoms were predominantly memory and cognitive decline. Gregory's partner stated that he needed help around the house while she was at work; she also expressed her concern about him being left on his own in the home and when going outdoors. The CNS completed a referral to the local authority adult social care department, accompanied by a clinical letter from the NPC.

The CNS chased the referral a few days after it was sent; an appointment for a needs assessment had been scheduled for six weeks' time. However, Gregory and his partner were facing eviction due to late payments of rent and council tax; Gregory had always dealt with the household finances and his partner was unaware of the problems. This situation exacerbated the difficulties the couple faced. The NPC team who carried out the clinical assessment wrote a letter to the local housing authority office explaining Gregory's diagnosis and the reasons for non-payment of rent and council tax. A copy of this letter was also sent to the local authority adult social care department, with further information on Gregory's current condition and prognosis and consequent need for an urgent response.

The housing officer advised Gregory's partner to apply for housing benefit due to the circumstances and a multidisciplinary team meeting was arranged, attended by an allocated social worker, Occupational Therapist and the NPC team. This meeting was very productive: social care was arranged the following day enabling Gregory's needs to be met whilst his partner continued her job.

This case illustrates the need for:

1. Effective communication between professionals and multi-disciplinary working.
2. Holistic and whole family approaches to assessment, including matters such as debt and domestic financial arrangements.
3. Support for family and carers taking into account needs related to employment.

## Case Study 6: Meredith

Meredith was a 52-year-old woman who was referred to a specialist neurology hospital after her appointment at a local memory clinic. While at work she experienced confusion and some memory loss, which worried her colleagues. She was sent home on sick leave.

At home Meredith's condition continued to deteriorate; her husband began carrying her around the home because she was so unstable on her feet. Meredith underwent a series of tests including MRI and a lumbar puncture and was subsequently diagnosed with CJD. She was discharged from hospital without a package of care and support because her family wanted to care for her, whilst spending quality time together.

A few weeks after discharge, Meredith's condition deteriorated more quickly than her family expected and a decision was taken by the family to move her to a local care home for respite, whilst arrangements were made for more care and support at home.

Funding for this support had not been secured or agreed by either the local authority or the CCG. However, the National Prion Clinic nurse specialist was told by the CCG that the local authority should be paying for the care. The local authority arranged a date to carry out a needs assessment. The specialist nurse made contact with the relevant local authority team to explain Meredith's diagnosis and to discuss her situation. Letters were also sent from the clinical team. Meanwhile, Meredith's condition continued to deteriorate and she began to be cared for in bed. The CCG agreed to fund her place in the care home as it determined that she was eligible for NHS continuing healthcare.

The case illustrates the need for the following:

1. Earlier consideration by health and social care staff of use of the NHS continuing healthcare Fast Track Pathway Tool.
2. Greater clarity over the funding responsibilities and arrangements for care and support for adults with CJD.
3. Contingency planning with the family to explain that needs may change rapidly.

## Case Study 7: Walter

Walter was a 63-year-old man who had lived alone all his life. He was diagnosed with sporadic CJD by his local hospital. While Walter was in hospital he was assessed by a social worker from the local authority hospital social work team. The outcome of the assessment was that he did not have eligible needs for care and support. He was therefore discharged home without a package of care and support. Predictably, in light of the likelihood of rapid decline in CJD, three weeks after discharge, Walter's mobility deteriorated and he stayed in the downstairs living area, holding on to furniture to walk around his home. Walter's siblings visited him weekly,

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although they did not fully understand the implications of his diagnosis or prognosis; however, they did notice a drastic deterioration in Walter's memory, mobility and cognitive states. They also noticed that his living space was extremely cluttered, which was very out of character.

Walter was taken to A&E by his family and was subsequently admitted to a stroke ward. On reading his medical records, ward staff referred him to the National Prion Clinic (NPC). By the time he was seen by the NPC Walter was unable to walk and had lost speech. The Community Nurse Specialist (CNS) spoke with the hospital palliative care team advising them to make use of the NHS continuing healthcare Fast Track Pathway tool.

Walter's family were angry that he had been discharged from hospital after his first visit despite his diagnosis and associated prognosis and without informing them. The family wanted Walter to be moved to a hospice near their family home. He was transferred to this hospice within two days of funding being approved by the CCG.

The case illustrates the need for the following:

1. Earlier consideration by hospital staff, including social worker, of use of the NHS continuing healthcare Fast Track Pathway Tool when diagnosis of CJD is known.
2. To consider the rapidly progressive nature of CJD when completing needs assessments and making eligibility determinations.
3. Appointment of a key worker prior to hospital discharge.

## 14. Checklist

- Where there is no diagnosis but the person referred to adult social care is presenting with symptoms associated with CJD, have they been advised to seek urgent advice from their doctor?

### Advice and Information

- Is advice and information on adult social care for people with CJD available and accessible? Does this include contact details for the National CJD Care Team, the National Prion Clinic and the CJD Support Network?

### Urgent Needs

- Where the person is presenting with urgent needs has use of the NHS Continuing Healthcare Fast Track Pathway tool been considered?
- Is use of the local authority power to meet needs under section 19(3) Care Act 2014 appropriate?

### Assessment

- Has the needs assessment been undertaken in a way that is Care Act compliant, with involvement of the adult with CJD?
- Where knowledge of CJD is outside the experience of the assessor, have they sought advice from the National Specialist Services?
- Is an independent advocate needed to facilitate involvement in the needs assessment?
- Has eligibility for NHS Continuing Healthcare been considered? Where appropriate, has referral been made to the relevant health authority?
- Have both current and future needs been considered? Has the potential for rapid deterioration and associated change in care needs been assessed?
- Are assessments under the Mental Capacity Act 2005 required?
- Have carers supporting the person with CJD had carers' assessments?

### Care and Support Planning

- Has a key worker been identified?

## Checklist

- Has contact been made and maintained with the National Specialist Services where and as appropriate?
- Has the adult with CJD been referred to local mental health services or palliative care services where appropriate?
- Where the local authority is arranging and/or funding care and support, has the care plan been prepared in accordance with section 25 Care Act 2014? Has attention been paid to the adult's own strengths and assets? Has family, community and wider social network support been explored?
- Have the National CJD care co-ordinators been involved in the development of the care and support plan, where necessary?
- Are contingency plans in the event of rapid deterioration embedded in the care and support plan? Have plans been made for timely review?
- Has the potential of direct payments been explored and offered as required?
- Has the provision of aids, equipment and adaptations been considered? Where necessary has the adult with CJD been supported to make a DFG application? Have all options to prevent delay in the provision of such aids, equipment and adaptations been considered?

## Funding Arrangements

- Has the agency responsible for funding care and support been confirmed? Where there are disputes, is the adult with CJD receiving appropriate support whilst these are resolved?
- Where the adult has variant CJD and is receiving support funded by the local authority, have they been advised of the exemption from charging?
- Have other funding streams such as the National CJD Care Package, the variant CJD compensation Trust and the CJD Support Network Care Grants been considered, where appropriate?

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