

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Interventional Procedures

Patient Organisation Submission

IP1553 - Patient safety and reduction of risk of transmission of Creutzfeldt–Jakob disease (CJD)

Thank you for agreeing to give us your views on this topic, to help us develop NICE guidance. Patient and carer organisations can provide a unique perspective that is not typically available from other sources. We are interested in hearing about:

- the experience of having CJD, or caring for someone with CJD
- the experience of people knowing they are at increased risk
- any practical impacts on healthcare for those people at increased risk

To help you give your views, we have provided this template. You do not have to answer every question – they are there as prompts. The text boxes will expand as you type, the length of your response should not normally exceed 10 pages.

Please note, all submissions will be published on the NICE website alongside all evidence the committee reviewed. Identifiable information will be redacted.

About you	
1. Your name	XXXXXXXX XXXXXX
2. Name of organisation	CJD Support Network
3. Job title or position	XXXXXXXXXX XXX XXXXXXXXXXXXX
4. Brief description of the organisation (e.g. who funds the organisation? How many members does the organisation have?)	<p>Support group for patients, families, carers and professionals affected by all types of CJD or told they are at heightened risk of CJD.</p> <p>Established in 1996.</p> <p>Funded by private donations.</p> <p>501 members.</p>
<p>5. How did you gather the information about the experiences of patients and carers to help your submission?</p> <p>(For example, information may have been gathered from one to one discussions with colleagues, patients or carers, telephone helplines, focus groups, online forums, published or unpublished research or user-perspective literature.)</p> <p>I man a 24hour telephone helpline and so speak to patients, families, carers ,professionals and worried well affected by CJD, on a regular basis.</p> <p>We hold an annual family support meeting where I meet many of these people face to face.</p>	

Living with CJD

6. In your experience of working with families affected by CJD, what have they told you it is like to have CJD, and what have carers told you about their experience of caring for someone with CJD?

Experiences vary greatly, but I mainly hear that they feel isolated, they emphasise the devastating effect of CJD on the patient and the equally devastating effect on family members and carers. Some families have been torn apart through the experience of CJD, whilst others cope relatively well. This largely depends on whether at least one professional involved has had experience of caring for someone with CJD before - many have not.

They tell me about the practical implications and difficulties of caring for a loved one, as well as the psychological effects on carers and families. For many it becomes a 24/7 task, until the death of the patient, when carers often find it difficult to re-adjust to "normal" life.

Living with knowing you're at increased risk of CJD

7. From listening to those who have been told they are at increased risk of CJD, but have no symptoms or signs of the disease, what have they told you about what this is like?

(For example, impact of mental health, anxiety, impact on daily living)

Some think about it all the time and fear the worst when they are not well, hence becoming a member of the worried well. Some try to forget it and hold their secret to themselves causing family friction. They are often worried about their employer or mortgage or insurance company etc. finding out. They ask questions about the risk (which is not quantifiable) and the effects of being at risk has or may have on their future daily lives.

Impact of being at heightened risk of CJD

8. For individuals at increased risk, what have they told you about any impact this has had on their healthcare (including such things as dentistry) and social care?

(For example, any practical implications, discrimination, or other impact on their daily living not covered in Question 7)?

Many people who fall into this category, often have difficulties when attending the dentist, taking out insurance, needing an operation, completing a pre-op form, or having to stop giving blood when they have done so for many years. Difficulties also arise with the Funeral Directors, refusal of being able to view the body after death.

On the helpline, we have had examples of people who have been refused dental treatment because the fear of contaminating the dental equipment. We have had examples of cases when a patient declares their at risk status on their pre-op form, resulting in postponement or cancellation of the operation. All these issues have been due to lack of professional understanding about CJD and is of course, very upsetting for the patient.

Equality

9. Are there any potential [equality issues](#) that should be taken into account when considering this topic?

I have not come across any major equality issues.

Other issues

10. Are there any other issues that you would like the Committee to consider?

A program of CJD education with professionals who administer the pre-op forms and blood transfusion forms etc.

Ensuring the correct questions are asked. For example people are asked:

"Have you had one family member die of CJD" or sometimes:

"Have you had more than one family member die of CJD"

People find these confusing. The correct question should be drafted and used consistently.

Key messages

11. In no more than 5 bullet points, please summarise the key messages of your submission.
 1. It is important than when CJD is involved that healthcare staff fully understand the practical and psychological issuesof that the disease poses to all those involved.
 2. That professionals have access to and use, up to date information, to make informed decisions regarding care and treatment.
 3. Clarity and consistency of questions asked on forms, so responses are valid and reliable.
 - 4.
 - 5.

Thank you for your time.

Please return your completed submission to ip@nice.org.uk