

A large, light blue circle with a thick yellow border, centered on the page. Inside the circle, the title 'Fact Sheet: Bereavement by CJD' is written in a dark blue, sans-serif font.

# Fact Sheet: Bereavement by CJD



## About the CJD Support Network

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

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

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

Admin and general enquiries – [admin@cjdsupport.co.uk](mailto:admin@cjdsupport.co.uk) or +44 (0)7494 211476

Support – [support@cjdsupport.co.uk](mailto:support@cjdsupport.co.uk) or 0800 774 7317

Website – [www.cjdsupport.co.uk](http://www.cjdsupport.co.uk)

Post - PO Box 3936, Chester, CH1 9NG

Registered charity no. **1097173**

## Acknowledgements

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**Fact sheet: Bereavement by CJD – information for families and professionals**

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## Introduction

Being bereaved can bring up a whole range of feelings and emotions. The feelings people might experience vary a lot from one day to the next and one person to another. People can experience shock (feeling numb or being “in a daze”), overwhelming sadness and hard to control crying, tiredness or exhaustion, anger and guilt.

In this fact sheet, we will cover the kinds of experiences a person may have when they are bereaved, including some of the factors which may be particularly relevant to being bereaved by CJD, though we acknowledge that any of the experiences described may be relevant to different types of loss. This fact sheet is designed to support people who are bereaved and also act as a resource for counsellors and other professionals who are working with people who are bereaved by CJD. The aim is to cover the broad range of experiences and emotions that might be expected in bereavement and so not everything in this factsheet may apply to everyone. Equally, many people may experience things which are not covered here.

Quotes of people  
who have  
experienced rapid  
neurodegenerative  
disease in a loved  
one:

“This should have  
been a nice time  
of life,”

“I miss the  
companionship of  
shared parenting; my  
children have a sadness  
that he won't know their  
children”

“Even when you  
have close  
friends, they can't  
quite understand  
what you're going  
through”

“You experience  
different losses  
along the journey,  
very quickly, one  
after another.”

“There are times I  
feel very angry that  
this has happened,  
and times where I try  
to look for a reason  
why”

## What might we experience when we are bereaved?

Experiencing any kind of significant bereavement can impact every part of a person's life and affect them in far-reaching ways. Some of the ways that a major bereavement can impact a person include:

- **Intellectually** – *our understanding of the world can be threatened. Bereavement can challenge our belief that the world is a generally safe place in which things happen in a predictable way.*
- **Psychologically** – *our sense of self, who we are and what our life is about, may be thrown into question or threatened.*
- **Behaviourally** – *We may have to do things differently, be unable to do things that we did before or have to take on different roles and responsibilities.*
- **Spiritually** – *our sense of the meaning of life may be challenged or we may experience a crisis of faith. Alternatively, we may find ourselves moving closer to our spirituality.*
- **Physically** – *the stress and strain of a significant loss may take a toll on us physically, we may find that we have lower energy, have difficulty with sleep, or experience physical symptoms of anxiety.*
- **Emotionally** – *we may experience a wide range of emotions from disbelief, to shock, to anger, fear, sadness, guilt about things said and done or not said and done, relief, loneliness, numbness, and many other emotions. There may be times when we feel our emotions are out of control.*
- **Practically** – *We may have to take decisions and make changes to how we live our lives practically which we may never have anticipated having to make.*
- **Socially** – *A loss can affect how we interact with the people around us, the social roles we play and our capacity for engaging with others.*

**There is no road map for grief.** Every experience of bereavement is as unique as the relationship with the person who has died. You may experience any or all of the impacts listed on the previous page, and there may be things that you are or have experienced that are not included here. We encourage you to give yourself time and space with whatever you are experiencing, and try to be kind to yourself on this journey. Sometimes we may hear phrases like 'time heals', but it may be more helpful to consider things in term of 'time accommodates'. When someone dies, we carry this with us and time can help us to accommodate this loss into our life.

## Factors which may be particularly relevant in CJD

Though any bereavement can impact a person in many different ways, and all bereavements are unique, some of the common experiences in CJD can impact on how we grieve. The following section capture some of the elements of bereavement by CJD which may be relevant.

### Anticipatory grief

As CJD progresses, people can feel that there are fundamental changes in their relationship with the person due to the nature of the symptoms of the disease. They may feel that they are losing or lose the person before they die. It can be common for people to feel guilty about having these feelings whilst the person is still living, and it may be that the losses we can experience before the person dies are not recognised or understood as well by others. Research indicates that between 47 and 71% of carers experience grief whilst caring for their loved one. Anticipatory grief may change the way bereavement is experienced which sometimes makes it difficult to understand for family and friends.

### Speed and course of the illness

The course of CJD is often rapid with changes happening from week to week, day to day or even hour to hour. This rapid and ever-changing picture can be traumatic and impacts on carers' ability to adjust and process what is happening at the time, meaning that they may need more time to process things after their loved one has died before they are able to begin once again remembering the person as they were before they became unwell.

### The diagnostic process

As the initial symptoms of CJD are often non-specific and can mimic many other, more common, diseases and disorders, the diagnostic process can take some time and this can be extremely challenging for both the person who is unwell and their loved ones. Patients and loved ones may feel helpless, powerless, and uncontained during this process. They may feel that they are not being taken seriously, listened to, or believed by professionals about the symptoms they are reporting, particularly if tests that are undertaken come back 'clear'. Symptoms may be mislabelled, sometimes as something treatable which can give hope which is later lost. All of this contributes to the range of emotions that can precede final diagnosis; confusion, anger, frustration, fear, hope, sadness and many more. Those who are bereaved by CJD may continue to feel a sense of anger, frustration or regret.

### Beliefs about the world

We live in a society in which - for many diseases - there are now treatments which can slow, stop or reverse their course. Once a diagnosis of CJD is received, patients and carers are faced with the reality that there is currently no treatment and, particularly in sporadic disease, that there is no particular 'cause'. This, along with the progression of symptoms, can shatter the assumptions we may have about the world as being a place which is generally safe, and where things that happen are explainable and predictable. Those who are bereaved by CJD can feel that the way they view the world has been changed; thoughts about the world being an unsafe, unpredictable place can lead to feelings of hopelessness, fear, and many others. People who are bereaved by sporadic disease, though also in other forms, may find themselves searching for reasons 'why', particularly in the initial period after diagnosis and loss.

## Factors which may be particularly relevant in CJD

### Knowledge and awareness

As CJD is extremely rare, medical and care professionals may never have come across a person with this disease in their career and may have a lack of knowledge and understanding of the disease. This can impact on our beliefs, expectations and trust of those in such roles. It can also mean that we have to expend more energy and time advocating for our loved one. This can lead to different emotions including resentment and a lack of trust, as well as further feelings of not being appropriately supported by those whose role it is to support us.

Though many other people whose lives have been touched by other diseases may be able to relate in different ways and we would always encourage people to reach out to those around them, the rarity of CJD can mean that people bereaved by the disease may have greater difficulty accessing peer support in their immediate networks. People bereaved by CJD may find themselves having to educate those around them about the disease which can feel isolating and exhausting.

### Stigma and misunderstanding

The BSE epidemic means that many people's only frame of reference for CJD – if they have heard of it – is 'Mad Cow Disease'. This term may be very upsetting to those who have lost someone affected by variant CJD and any other form of the disease. People may have invasive and misguided questions asked to them 'how did they catch that?', and they may feel shame or reluctance to share the diagnosis for fear of this stigma. There can sometimes be misunderstanding about the infectivity of prion diseases despite the fact that CJD cannot be transmitted through regular methods of care and contact, even intimate contact. This stigmatisation and 'othering' can lead to feelings of anger, resentment and injustice, and isolation.

### Interruption of life course

CJD can occur at a young or relatively young age. This can have a significant impact on the current and future life plans of both the individual with CJD and their loved ones. There may be responsibilities such as financial, work, child care and others, which the person is tied into and which others are left to manage. There may be plans and hopes for the future – retirement, 'bucket list' activities, seeing children get married, grandchildren be born – which cannot be realised. This can leave loved ones grieving not only the person they have lost and the life they had, but also their future.

### Genetic testing

A diagnosis of CJD always brings up the possibility that the illness may have a genetic cause, even when the clinical syndrome appears classical. The decision of whether or not tests should be undertaken where this is possible can be challenging and add further stress for the patient and family. The rapidity of the disease and timeframes for testing may mean that genetic test results are not available until some time after the person has died and, as such, uncertainty around the outcome may impact on grief. Where a genetic test result comes back as positive, there are then additional stresses and decisions to be made for those in the family such as whether they should be tested and how this may all impact on children and the wider family.

## Summary

As we have already mentioned, no two experiences of bereavement will be the same. Everyone is an individual and there are many factors which will impact on our journey with grief. However, we hope that the information in this fact sheet may help some people make sense of some of their own and others' experiences. The most important things are to try and be kind to yourself and how you are coping, and to reach out for support if you need it.

It is usually good to be open and talk about whatever you are experiencing. People will seek support and guidance in a number of ways, for example from their friends and family. If you or those close to you feel, however, that you are experiencing persistent, severe symptoms which are not changing over time or are getting worse it may be that you need more than this, particularly if feelings are becoming overwhelming and impacting on work, day-to-day activities or care duties. If you would like to explore options for speaking to someone outside of your immediate network, please refer to our factsheet on Talking Therapies, which can be found on the fact sheets page of our website.



## Further information and contacts

Further information about CJD may be found on the CJD Support Network website at [www.cjdsupport.net](http://www.cjdsupport.net)  
our fact sheets are also available by post on request to the Network.

Support and information may be obtained from the organisations below:

### **CJD Support Network**

Address – PO Box 3936, Chester, CH1 9NG  
Website – [www.cjdsupport.co.uk](http://www.cjdsupport.co.uk)  
Phone – 0800 774 7317  
Email – [admin@cjdsupport.co.uk](mailto:admin@cjdsupport.co.uk) or [support@cjdsupport.co.uk](mailto:support@cjdsupport.co.uk)

### **National CJD Research and Surveillance Unit**

Address - Western General Hospital, Crewe Road, Edinburgh EH4 2XU  
Website - [www.cjd.ed.ac.uk](http://www.cjd.ed.ac.uk)  
Phone - 0131 537 1980  
Email - [contact.cjd@ed.ac.uk](mailto:contact.cjd@ed.ac.uk)

### **UK National CJD Nursing Service & National Care Fund**

Address - Department of Clinical Neurosciences, Clinical Offices, 2nd Floor  
50 Little France Crescent, Edinburgh Bio-Quarter, Edinburgh, EH16 4TJ  
Website – [www.cjd.ed.ac.uk](http://www.cjd.ed.ac.uk)  
Phone - 0131 312 0193 / 0131 312 0192  
Email - Terri Awe (primary contact) - [Terri.awe@nhs.net](mailto:Terri.awe@nhs.net) , Juli Jose (additional contact) [juli.jose@nhs.net](mailto:juli.jose@nhs.net)

### **National Prion Clinic**

Address - National Prion Clinic, Institute of Prion Diseases, Courtauld Building,  
33 Cleveland Street, London, W1W 7FF  
Website - [www.ucl.ac.uk/national-prion-clinic](http://www.ucl.ac.uk/national-prion-clinic)  
Phone - 020 7679 5142 / 020 7679 5036  
Email - [uclh.prion.help@nhs.net](mailto:uclh.prion.help@nhs.net)