

Fact sheet: Talking Therapies

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.net or +44 (0)7494 211476

Support - support@cjdsupport.net or 0800 774 7317

Website - www.cjdsupport.net

Post - PO Box 3936, Chester, CH1 9NG

Registered charity no. **1097173**

Acknowledgements

The CJD Support Network gratefully acknowledges the assistance of Beth Marsh, Professor Simon Mead, Dr Edgar Chan and Rachel Williams of the UK National Prion Clinic in the preparation of this booklet.

Fact sheet: Talking Therapies

Version: 2

Date of review: 27th August 2024

Next scheduled review date: August 2026

Contents

| | |
|--|---|
| INTRODUCTION | 3 |
| TALKING THERAPIES | 3 |
| ACCESSING SUPPORT | 4 |
| THE CJD SUPPORT NETWORK | 4 |
| THE NATIONAL PRION CLINIC (NPC) AND UK NATIONAL CJD NURSING SERVICE | 4 |
| NHS | 4 |
| <i>GENETIC COUNSELLING</i> – | 4 |
| CHARITABLE ORGANISATIONS | 5 |
| <i>‘MIND’</i> – | 5 |
| <i>CRUSE</i> - | 5 |
| <i>CHILD BEREAVEMENT UK</i> – | 5 |
| PRIVATE PRACTICE..... | 5 |
| <i>BRITISH ASSOCIATION FOR COUNSELLING AND PSYCHOTHERAPY (BACP)</i> –..... | 5 |
| LIVING WITH A RISK OF OTHER FORMS OF PRION DISEASE | 6 |
| FURTHER INFORMATION AND CONTACTS | 7 |

Introduction

A diagnosis of prion disease can bring up a whole range of completely normal and expected feelings and emotions for the friends and family of a loved one. The symptoms 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.

It is usually good to be open and talk about whichever emotions you are feeling. People will seek support and guidance in a number of ways, for example from their friends and family. Sometimes people may feel like they need more than this, particularly if feelings are becoming overwhelming and impacting on work, day-to-day activities or care duties.

Talking Therapies

Talking therapies involve speaking with a trained professional about how you feel and how it relates to your thoughts and behaviours. Talking therapies are often referred to by different names such as counselling, psychotherapy and psychological therapy. Regardless of which form of talking therapy is accessed, the overall aim is always to improve the mental health and wellbeing of the individual. The different names relate to the training of the professional providing the treatment. There is good scientific evidence that talking therapy can help with managing psychological difficulties such as stress, anxiety and depression. Talking therapy can also support adjustment to disease diagnosis and bereavement.

You do not need to have a formal diagnosis to benefit from talking therapies. Sometimes, seeking help early can stop things from getting worse and give you the tools and resources you need to cope if/when things become more difficult in the future.

Accessing Support

The CJD Support Network

The CJD Support Network helpline is available on Tuesdays and Fridays from 8am-6pm (0800 774 7317). Please don't hesitate to contact us for emotional support and listening. If you would prefer to contact us via email initially, we can arrange to give you a call on a suitable day/at a suitable time. Whilst we are unable to offer formal counselling or psychological therapy, we can support you to identify locally available therapy or signpost you to relevant services and organisations.

The National Prion Clinic (NPC) and UK National CJD Nursing Service

At the both the **National Prion Clinic (NPC)** in London and **UK National CJD Nursing Service** have specialist nurses/care co-ordinators are available to provide information, signposting and ongoing emotional support. There are four nurses at the NPC and two at the UK National CJD Nursing Service in Edinburgh. The NPC aims to make available around a day each per week specifically for information and emotional support. If it is felt that more specialist therapy is required, they have a neuro-psychologist within the team who can provide help, or could also help you to access therapy in your local area. See page 6 for contact information.

NHS

Talking Therapies –

Wherever you live in the UK, your GP will have knowledge of local talking therapies services and will be able to refer you to access them. If you live in England and are registered with a GP, you can also self-refer to your local Talking Therapies Service (formerly known as 'IAPT' services - Improving Access to Psychological Therapies). Once referred, you will be contacted by the service and may be offered 1-1 therapy, group therapy, online therapy, or signposted/referred to a more suitable service depending on what they think would be most appropriate. To find your local Talking Therapies service, you can go here: www.nhs.uk/service-search/mental-health/find-a-psychological-therapies-service/

Genetic Counselling –

If you are concerned about the risk of inherited prion disease, it may be beneficial to see a genetic counsellor who will work in a Clinical Genetics team at a local NHS hospital. You can speak to your GP to discuss referral. Finding out whether you have a gene mutation which leads to prion disease is a complex and personal decision. Genetic counselling offers an opportunity for individuals who are at risk of inherited prion disease to find out about the possible implications of a positive or negative test result and weigh up the pros and cons of having a test. Follow up support and advice may also be available from these teams. The NPC have responsibility for inherited prion disease in the UK and are another source of support and information.

Charitable Organisations

'Mind' –

A large mental health charity organization that also provides free or subsidised talking therapy. They also have great online resources for learning about mental health difficulties and offer tips and strategies.

www.mind.org.uk

Cruse -

The UK's leading bereavement charity. They offer support through their website, national helpline, live chat, group, zoom, telephone or one-to-one in person support. Information on the support they offer, including availability of in person local support in different areas of the UK can be found on their website.

www.cruse.org.uk

Child Bereavement UK –

Helps children, parents and families to rebuild their lives when a child grieves or when a child dies. They support children and young people up to the age of 25 who are facing bereavement, and anyone affected by the death of a child of any age. They offer free, confidential bereavement support by telephone, video or instant messenger, wherever you live in the UK. www.childbereavementuk.org

Private Practice

British Association for Counselling and Psychotherapy (BACP) –

The BACP is the leading association for members of the counselling professions in the UK. All practising members of BACP must either be registered or working towards registration. In order to be registered, therapists must meet or exceed the BACP recommended minimum quality standards. These standards cover training, supervision, continuing professional development and a commitment to an Ethical Framework. You can find a register of BACP registered/provisionally registered therapist who offer therapy privately here: www.bacp.co.uk/search/Therapists

Living with a risk of other forms of prion disease

You may have been told that you have potentially been exposed to prions by a treatment or surgery in the past. The risks of developing the disease may be very low, but the thoughts of this possibility may be intrusive, provoke anxiety and/or have an impact on everyday life. Talking therapies may be helpful for providing a confidential space for talking about this and for learning strategies to better manage living with the risk.

Further information and contacts

Further information about CJD may be found on the CJD Support Network website at 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

Phone – 0800 774 7317

Email – admin@cjdsupport.co.uk or 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

Phone - 0131 537 1980

Email - 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

Phone - 0131 312 0193 / 0131 312 0192

Email - Terri Awe (primary contact) - Terri.awe@nhs.net , Juli Jose (additional contact) 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

Phone - 020 7679 5142 / 020 7679 5036

Email - uclh.prion.help@nhs.net