Introduction

The CJD Support Network (CJDSN) is dedicated to supporting individuals affected by Creutzfeldt-Jakob Disease (CJD), and all human prion diseases, and their families. As part of this commitment CJDSN offers 1-1 support. This can take place via telephone, email or online meetings.

1. Purpose

This policy outlines the principles, boundaries, and procedures for 1-1 support provided by the charity's national coordinator or cover personnel. It aims to ensure that support is delivered compassionately, consistently, and within safe and sustainable limits for both staff and service users.

2. Scope

This policy applies to all support interactions initiated or received by the national coordinator. It does not apply to peer-to-peer support groups.

3. Nature of Support

Support is non-clinical, non-therapeutic, and provided by staff members or volunteers without formal mental health qualifications.

It is intended to offer emotional reassurance, practical guidance, and signposting to appropriate services.

Support is available to individuals affected by CJD, their families, and carers.

4. Boundaries and Duration

At times of high demand, support is offered on a short-term basis, typically during periods of acute distress, diagnosis, or bereavement.

At times of high demand, the coordinator may offer up to six scheduled contacts per individual, with flexibility based on need.

Ongoing or frequent contact beyond this may be reviewed and limited to protect staff capacity and ensure equitable access.

5. Referral and Signposting

Where appropriate, individuals may be referred to:

- Clinical professionals
- Mental health services
- Bereavement support organisations
- Peer support groups facilitated by the charity

- Other charitable organisations or organisations as appropriate

The coordinator will document any referrals or signposting offered.

6. Review and Escalation

If a service user’s contact becomes excessive, repetitive, or clinically inappropriate, the coordinator will:

1. Discuss the case with their line manager
2. Document the concerns and consultation
3. Agree on a course of action, which may include limiting or ending support

All decisions will be made compassionately and communicated clearly to the individual.

7. Safeguarding and Risk

Any concerns about a service user’s safety or wellbeing will be escalated in line with the charity’s safeguarding policy.

The coordinator is not responsible for clinical assessment or crisis intervention.

8. Documentation and Confidentiality

Brief notes will be kept for each call, including date, duration, and key points discussed.

Records will be retained for six years in accordance with data protection and clinical governance standards. All information will be handled confidentially and securely.

9. Complaints and Appeals

If a service user disagrees with a decision to limit or end support, they may submit a written appeal to the Chair of Trustees.

The charity will respond within 14 working days.

10. Review and Amendments

This policy will be reviewed annually or sooner if required.

Amendments may be made based on staff feedback, service user needs, or legal guidance.