

## About the CJD Support Network

The CJD Support Network (charity no. 1097173) is the only UK charity dedicated to providing emotional and practical support for those affected by all forms of Creutzfeldt-Jakob Disease (CJD) and related prion diseases. Established in 1995 by relatives of people with CJD, and achieving independent charity status in 2003, the network supports patients, families, carers, and healthcare professionals across the UK. The charity is governed by a dedicated Executive Committee who meet quarterly, and is run operationally by a part-time National Coordinator.

**Our Vision:** An informed, supported, and connected UK prion diseases community.

### Our Mission:

- Provide accessible, accurate, and trustworthy information about CJD and prion diseases.
- Offer emotional and practical support to patients, carers, healthcare professionals, and those at increased risk.
- Connect people with personal experience of prion diseases.
- Promote high-quality care and encourage interagency cooperation.
- Represent people with lived experience and support prion disease research.

### Our strategic aims:

<b>Inform</b> Providing accessible, plainly written information about prion disease to patients, carers, healthcare professionals, and those at risk, by:  Maintaining our website and social media presence  Creating and regularly updating fact sheets  Providing information via email and our helpline  Quarterly newsletter with research, network and other updates  Arranging speakers for our annual conference and sharing talks online	<b>Support</b> Offering emotional and practical support to patients, carers, healthcare professionals, and those at risk of all forms of prion disease- and where possible supporting research – via our:  Providing financial care grants  National helpline and email support  ‘Out-reach’ and regular call back service  Providing research grants	<b>Connect</b> Promoting high quality care and interagency cooperation, and connecting people with personal experience of prion diseases by:  Maintaining links with national centres and other relevant organisations  Providing an online Facebook community  Linking professionals and families  Providing regular online peer support groups  Providing an annual in person conference
--	--	---

## Job Description: National Coordinator

**Location:** Home-based (*occasional UK travel*)

**Salary:** £35,000 per annum (*pro rata; reviewed annually*)

**Hours:** 0.4-0.6 FTE (*negotiable, approx. 2-3 days per week*)

**Reporting to:** Chair of the Executive Committee (*Current Chair - Professor Richard Knight*)

**Accountable to:** Executive Committee

**Role Overview:** The National Coordinator is responsible for daily direct provision and management of support services and activities, acting as first point of contact for those engaging with the charity. In this varied role, the Coordinator provides compassionate support, manages communications, organises events, facilitates administrative and committee functions. Scaffolded by a supportive management and governance structure, the role offers the opportunity to meaningfully help shape the future of support for the prion disease community.

### Key responsibilities

#### *Information and Communications*

- Administering and updating the charity website
- Maintaining the charity's social media presence
- Coordinating the regular review of the various fact sheets provided by the charity
- Answering informational queries received via telephone or email, seeking input from specialist clinicians and researchers as appropriate
- Publishing quarterly email newsletters with network and other updates

#### *Support Services and Grants*

- Answering, returning and making helpline calls, providing listening support and information.
- Coordination of the Care Grant process – sharing requests with Trustees, communicating decisions to applicants and coordinating payment of grants
- Coordination of the Research Grant process –sharing applications with Trustees and external reviewers as appropriate, communicating decisions to applicants and coordinating payment of grants
- Ensuring that all appropriate information relating to service users is correctly recorded in accordance with operating protocols/policies
- Responding appropriately to safeguarding concerns relating to both child protection and vulnerable adult issues

#### *Community and Professional Engagement*

- Building and maintaining links with specialist clinicians and researchers nationally
- Collaborating with national and international support associations
- Administering the charity's closed Facebook community
- Coordinating and facilitating regular online peer support groups
- Coordinating an annual in person Support Conference
- Representing the Charity to Governmental and Parliamentary bodies, and other public policy makers

## **Job Description (cont'd): National Coordinator**

### *Governance, Administration and Fundraising*

- Management of charity memberships and mailing list membership
- Supporting administration around annual general meetings (AGMs)
- Scheduling, attending and reporting to Trustees at quarterly meetings (either in person or online)
- Supporting fundraising through promotion, provision of information and resources to fundraisers
- Maintaining 'Donations in Memory' memorial roll and sending acknowledgement of donations
- Coordinating the management of charity merchandise
- Providing accurate and timely performance information for internal and external use
- Representing the charity at events and conferences

This job description serves to illustrate the type and scope of the duties currently required for the above post and to provide an indication of the required level of responsibility. It is not a comprehensive or exhaustive list and duties may be varied from time to time, but will not however change the general character of the job or the level of responsibility entailed.

## Person Specification: National Coordinator

Qualifications and Training	
<p><i>Essential</i></p> <ul style="list-style-type: none"> <li>No specific formal qualifications are essential. A relevant degree or training in health, social care, charity management, counselling or related fields would be beneficial.</li> </ul>	<p><i>Desirable</i></p> <ul style="list-style-type: none"> <li>Training in bereavement or mental health support, counselling skills, or safeguarding.</li> <li>Training in charity management, communications or health advocacy.</li> </ul>
Experience and Knowledge	
<p><i>Essential</i></p> <ul style="list-style-type: none"> <li>Experience coordinating charity activities, support services or project management.</li> <li>Experience supporting people in emotionally challenging situations.</li> <li>Experience maintaining communication platforms such as newsletters, websites and social media.</li> <li>Experience working remotely and independently.</li> <li>Experienced and confident in liaising with a variety of stakeholders.</li> <li>Knowledge of issues relating to safeguarding.</li> </ul>	<p><i>Desirable</i></p> <ul style="list-style-type: none"> <li>Experience supporting those affected by neurological or rare conditions.</li> <li>Understanding of prion diseases.</li> <li>Knowledge of UK health &amp; social care systems.</li> <li>Experience in fundraising, donor engagement, or events.</li> <li>Experience supporting or facilitating peer groups or conferences.</li> <li>Familiarity with charity governance and relevant legislation e.g. GDPR.</li> <li>Experience of drafting and updating policies.</li> </ul>
Skills and Abilities	
<p><i>Essential</i></p> <ul style="list-style-type: none"> <li>Ability to exercise good judgement, recognise the limits of one's own competence and seek input from others appropriately.</li> <li>Excellent written and verbal communication.</li> <li>Ability to demonstrate empathy.</li> <li>Strong organisational and time management skills.</li> <li>Ability to use digital tools (Mailchimp, Zoom, social media, MS Office etc.).</li> <li>Ability to create graphics and posts for social media, adapting messages for different platforms and audiences.</li> <li>Ability to maintain appropriate levels of confidentiality.</li> </ul>	<p><i>Desirable</i></p> <ul style="list-style-type: none"> <li>Public speaking or advocacy skills.</li> </ul>

## Benefits

Working for the CJD Support Network offers the opportunity to make a meaningful difference within a small, supportive charity environment. The role is designed to be flexible, empowering the postholder to shape their working approach while supporting an important cause.

**Salary:** £35,000 per annum (*pro rata; reviewed annually*)

**Holiday entitlement:** 5.6 weeks of paid holiday per year (*pro-rata, based on negotiated hours*)

**Pension:** In accordance with Part 1 of the Pensions Act 2008.

## Equal Opportunities and Accessibility

The CJD Support Network is committed to promoting equality, diversity and inclusion. We welcome applications from all individuals and strive to ensure that no applicant or employee receives less favourable treatment on the grounds of age, disability, sex, gender reassignment, race, religion or belief, sexual orientation, marriage or civil partnership, or pregnancy and maternity — in line with the Equality Act 2010. We are committed to ensuring that our recruitment process is inclusive and accessible. If you have any access needs or require reasonable adjustments at any stage, please let us know when applying. We will do our utmost to accommodate your requirements.

## How to apply

To apply, please send your CV and a cover letter explaining your interest in and suitability for the role to: [admin@cjdsupport.co.uk](mailto:admin@cjdsupport.co.uk).

**Application deadline:** Applications will be reviewed on a rolling basis, and the position may close once a suitable candidate is appointed. Early applications are encouraged.

## Interview process:

**Shortlisting** – Applications will be reviewed against the person specification. Shortlisted candidates will be invited to an online interview.

**Online Interview** – This will be held over Zoom with a small panel, including members of the Executive Committee. The interview will include competency and scenario-based questions, and time for your questions about the role or organisation.

If you would like to discuss the role or ask any questions before applying, please contact the current National Coordinator, Beth Marsh, on 0800 774 7317 / [admin@cjdsupport.co.uk](mailto:admin@cjdsupport.co.uk).

## Please note

- *This vacancy may be closed early if we receive sufficient applications for the role. Therefore, if you are interested, please submit your application as early as possible.*
- *An offer of employment will be subject to satisfactory references and an enhanced Disclosure and Barring Service (DBS) check. As the role involves contact with vulnerable individuals, safeguarding is a priority. This post is exempt from the Rehabilitation of Offenders Act 1974.*
- *The successful candidate will be offered the position subject to a probation period (length to be agreed), during which support and performance will be reviewed.*
- *We will process your personal data solely for recruitment purposes, in accordance with UK GDPR and our privacy policy, which can be found at [www.cjdsupport.co.uk/privacy-policy](http://www.cjdsupport.co.uk/privacy-policy). Your data will be used only by those directly involved in the recruitment process and will be retained only as long as necessary for this purpose.*