

PSPA

CREATING A BETTER FUTURE FOR
PEOPLE LIVING WITH PSP & CBD



JOB APPLICATION PACK

Helpline Care Navigator

PSPASSOCIATION.ORG.UK

PSPA is the only UK charity dedicated to creating a better future for everyone affected by PSP & CBD.

WHO WE ARE

- PSPA is the UK's leading centre of knowledge, experiences and support for people living with PSP or CBD and their families.
- Our people have experience and knowledge to help individuals understand the conditions and support available to them.

WHAT WE DO

We work to ensure the 10,000 people with PSP or CBD receive support and care that is co-ordinated, has continuity and is compassionate.

WHY WE EXIST

- Our work is important because people with PSP & CBD do not receive timely diagnoses or adequate support and care.
- For one in three people, it takes over one year to be referred to a neurologist by their GP
- 60% of people living with PSP or CBD initially receive a misdiagnosis.

OUR CALL TO ACTION

Together we can improve diagnosis for the 10,000 people living with PSP & CBD, saving time, resources and helping patients get the care they need faster.



Dear Candidate,

Don't be put off from applying for this role by how hard it is to pronounce Progressive Supranuclear Palsy or Corticobasal Degeneration, I remember being terrified at my interview I might get it wrong. Now it is over two years since I was appointed CEO at PSPA and as each month passes my ambition for what I want PSPA to achieve grows. The charity's work is deeply satisfying and every member of the team is committed to creating a better future everyone affected by PSP & CBD.

This year we have set out our new strategy and we are expanding our team to reflect our growing ambitions. Our Helpline remains at the core of the support we provide to people living with PSP, CBD, their families and Health and Social Care Professionals and we are looking for a compassionate and caring person to join the helpline team.

Being the only charity in the UK to provide support, raise awareness and fund research for people living with PSP or CBD we are in the unique position of being the voice of those affected across the UK. We provide a great range of support services, a growing programme of research grants and want to expand our impact in raising awareness to improve diagnosis, so we can make progress towards finding treatments and a cure.

Our 2022 patient survey showed that 60% of people with PSP or CBD are initially misdiagnosed and the average time to a diagnosis is three years. For conditions where there are no treatments and no cure it is our drive and ambition to forge partnerships that can change the landscape for people with PSP or CBD. We know together we can improve diagnosis for the 10,000 people living with PSP & CBD. That's why we have hybrid working arrangements which allows flexibility of working at home, alongside some time with colleagues in the office at least once a week to collaborate and innovate for the benefit of everyone affected by PSP or CBD.

I hope you will consider coming to join us. If you have any questions, please get in touch with our Helpline Manager , Jules Brown - juliabrown@pspassociation.org.uk

Best wishes,



Rebecca Packwood
PSPA CEO



DIRECTOR OF POLICY AND INFLUENCING

Job Title	Helpline Care Navigator
Salary and benefits	<p>£28,544</p> <p>Employer contribution to the workplace defined pension scheme.</p> <p>Employee Assistance Programme with UK Healthcare.</p>
Hours of work	<p>35 hours per week</p> <p>This may include working some unsociable hours, including evenings and weekends.</p>
Annual leave	28 days plus bank holidays
Location	The role covers Greater London, Kent, Surrey and Essex; our offices are in Milton Keynes with Hybrid working , 1 day per week in the office
Contract type	Full Time, permanent.
Reporting to	Helpline Manager
Experience/Qualifications	<ul style="list-style-type: none"> • Previous experience of working in a similar role with a charity or a health or social care setting • Excellent listening and interpersonal skills • Empathetic and non judgmental approach

About the Role

Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD). are rapidly progressing neurological conditions caused by the premature loss of nerve cells in certain parts of the brain, and like many other chronic conditions, there is currently no cure. However, many of the symptoms can be managed, and our mission is to provide everyone affected with PSP & CBD with information and support to enable them to lead the best possible life they can.

Our Helpline is part of our core service provision, which is a mix of employed staff and volunteer supporters in the evening. We are currently in touch with approximately 2,000 people living with PSP & CBD, and in addition, approximately 12,000 others registered as health & social care professionals, carers, supporters, volunteers, or fundraisers.

There are two key elements to the role:

- To be the 'first port of call' for people with PSP & CBD, their carers, and families through our Helpline. Providing people with support and information over the phone and via email.
- To raise awareness of PSP & CBD through attending neurological clinics and providing briefings/education sessions for Health and Social Care professionals.

Key duties and responsibilities

- To provide accurate information in all aspects of PSP & CBD in response to enquiries and signpost onto other organisation where appropriate
- Ensure a maximum response to all helpline calls, emails, and enquiries
- To keep clear and accurate records and statistics of enquiries received and actions taken
- To carry out a maximum number of proactive calls to people affected by PSP & CBD within your region as directed by the Helpline Manager
- Develop and maintain a database of key health and social professionals and regional services
- To deliver awareness and learning sessions to HSCP's within your region
- Attend outreach events to build the profile of PSPA services among health professionals
- To signpost to PSPA Support Groups and services
- Liaise with external services to signpost to local support
- Take an active part in the delivery and planning of information and support events, which may include the possibility of overnight stays and weekends
- Liaise with the fundraising team to signpost to fundraising activities
- To attend and contribute constructively to team and other meetings as required
- To ensure the implementation of policies, procedures and quality standards as defined by PSPA
- To recognise the importance of, and actively participate in, training offered locally and nationally and occasionally outside of normal working hours
- Contribute to the development of literature and articles for PSPA Matters
- To undertake any other tasks, by agreement, as required, in support of the work of PSPA.

Person Specification

	Essential	Desirable
Experience in delivering helpline and/or information and support services	x	
Excellent listening and interpersonal skills, with the capacity to listen actively understanding different points of view	x	
Ability to keep accurate records	x	
Willingness to undertake training and continuing personal development	x	
Experience of and sensitivity to communicating with audience from a range of backgrounds	x	
Strong IT skills, with experience in MS Office products and customer relationship management software	x	
Flexible and reliable attitude and the ability to self-organise and to work without direct supervision	x	
Good communications skills, both oral and written and excellent telephone manner	x	
Ability to manage difficult questions, emotions and situations in a calm and confident manner	x	
Knowledge of PSP & CBD or other neurodegenerative diseases and/or experience in working in the NHS		x

IN APRIL 2023, WE LAUNCHED A NEW STRATEGY FOR PSPA

This three year strategy, sets out our purpose, goals and priorities to help create a better future for everyone affected by PSP & CBD.

Since PSPA's 30th birthday will take place in 2024, we wanted to ensure we set a bold vision, honouring the vision Michael Koe set out in memory of his late wife Sarah.

In this strategy, our goals are:



SUPPORT & INFORMATION

Enabling people to live the best life possible



RESEARCH & AWARENESS RAISING

Improving quality of life



INVOLVEMENT

Putting people living with PSP & CBD at the heart of what we do

OUR COMMITMENTS

Our commitments apply to everything we say and everything we do.

- To be courageous in making sure the voices of people living with PSP & CBD are heard. Standing up for a better life for people and having a tenacious commitment to change, even in the face of setbacks.
- To be ambitious - to be the leaders in the field of PSP & CBD in the UK. To be willing to listen and learn and to strive for excellence and impact.
- To work collaboratively, to inspire people externally and internally, to bring their individual talents together to improve outcomes.
- To respect, value and recognise everyone's contribution. Empowering people and building a team which champions Equality, Diversity, and Inclusion.