



## Senior Manager of Support & Engagement

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### About us:

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Founded in 1990, CurePSP is the leading non-profit organization dedicated to the awareness, care and cure of 3 neurodegenerative diseases: progressive supranuclear palsy (PSP), corticobasal degeneration (CBD) and multiple system atrophy (MSA). As a catalyst for new treatments and a cure, we establish important partnerships and fund critical research. Through our advocacy and support efforts, we enhance education, care delivery, and quality of life for people living with PSP, CBD and MSA and their families. Science, community and hope are at the heart of CurePSP's mission and all of our services. CurePSP is a registered 501(c)(3) charity within the United States (Federal Employer ID Number: 52-1704978).

Our mission is to raise awareness, build community, improve care and find a cure for PSP, CBD and MSA. We accomplish this through our three pillars: Care, Consciousness and Cure.

### About the role:

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CurePSP seeks a Senior Manager of Support & Engagement to work as part of the Patient & Care Partner Advocacy Team, reporting to the Director of Clinical Affairs and Advocacy. This team primarily focuses on CurePSP's care and consciousness pillars and leads CurePSP's initiatives that include: direct interaction with people affected by PSP, CBD and MSA, a network of prestigious medical centers, educational resources and events for both community members and healthcare professionals, the Quality of Life Respite Program, support and volunteer programming, legislative and public policy advocacy, brain donation assistance and raising awareness. The goals of these efforts are to lead to earlier diagnosis, assessment and addressing of unmet needs, outreach for historically underrepresented communities, improved access to comprehensive care and support for people with PSP, CBD and MSA and increased coordination, funding and research around these diseases.

People impacted by rare neurodegenerative diseases often face a long and windy diagnostic journey, confusions around navigating medical systems, changing family dynamics, quickly progressive care needs, social isolation and complex decisions around health, safety, long-term care and end of life, all of which can be vulnerable experiences. Interacting with people "who understand," like CurePSP staff and volunteers, and getting plugged into disease-specific resources and a network can help to positively shape someone's disease journey and foster hope and meaning. CurePSP is looking to add a full-time team member to continue and enhance its ability to offer comprehensive and direct support to the community. The key role presents the opportunity to work alongside, and on behalf of people with lived experience with PSP, CBD and MSA, including diagnosed individuals, current and former family care partners, and volunteers, empowering them with education, connection and a sense of purpose.

The Patient & Care Partner Advocacy Team closely partners with the Marketing Team, Development-Events Team, Scientific Affairs Team, Chief Executive Officer, volunteer committees and Board of Directors to carry out responsibilities and priorities.

### Primary Functions:

1. Staff the CurePSP Hopeline (primarily phone; arrange as-needed video meetings) and respond to information email inbox – building a relationship with those who reach out, fielding questions,

- assessing needs and offering guidance, individualized support and connection to appropriate resources.
2. Reimagine and maintain CurePSP's volunteer programming, including:
    - a. Recruit, train, communicate with and track support group leaders, peer supporters, boots-on-the-ground educators, research participants and other volunteers
    - b. Lead Office Hour meetings (bimonthly) and the Community Advisory Committee (quarterly)
  3. Facilitate virtual psycho-educational programming, including:
    - a. Care Partner Video Club (coping skills program for families offered 1-2 times/year)
    - b. PSP/CBD/MSA 101 (educational support series for people who are newly diagnosed offered on a bimonthly basis)
  4. Manage intake and support for "Louder than Words: CurePSP Voice Program".
  5. Work with Associate Director of Education to track and manage inventory of education materials and to fulfill requests for materials received by community members, volunteers and healthcare professionals.
  6. Represent CurePSP and share resources at relevant educational and networking events.
  7. Other related duties as required.

**Required Experience and Skills:**

- Bachelor's degree in social work, psychology or related field
- 3-5 years of clinical and/or nonprofit experience is preferred, although what is most important is a passion for the CurePSP mission, the role and the community as well as a readiness to learn and jump in.
- Working understanding of clinical care, support and education in neurological and rare diseases, caregiving and volunteering.
- Compassionate as well as has outstanding listening, interpersonal and rapport-building, and written and oral communication skills.
- Highly-organized and innovative self-starter, with excellent attention to detail and time management skills to manage multiple projects at once and follow-through on tasks.
- Abilities and drive to both work within a collaborative team environment and to operate independently.
- Competency with software and other productivity tools that are part of the CurePSP toolkit, such as Microsoft Office products, Slack, Survey Monkey, Zoom and social media platforms.

**Location and Travel:**

- 100% remote role
- Approximately 15% travel to team meetings, community events, educational conferences or other in-person opportunities as required

**Salary and Benefits:**

- This position offers a salary range of \$65,000-75,000, commensurate with experience
- CurePSP offers a comprehensive benefits package that includes retirement, medical, dental and vision

**How to apply:**

Please send your resume and cover letter to: Jessica Shurer, MSW, LCSW, Director of Clinical Affairs and Advocacy, at [shurer@curepsp.org](mailto:shurer@curepsp.org).

*CurePSP, Inc. is an equal opportunity employer. We respect and seek to empower each individual and support the diverse cultures, perspectives, skills and experiences within our workforce.*