



## Progressive Supranuclear Palsy *TOP RESOURCES*

Brain Support Network has reviewed most of the resources available on progressive supranuclear palsy (PSP). In our opinion, these are the most helpful family resources.

### **Your Personal Guide to PSP**

The first section of this excellent 108-page introduction to PSP and CBD focuses on symptoms such as cognition/mood, mobility/falls, fatigue/sleep, pain, swallowing, vision, and bladder/bowel. Published February 2024 by The PSP Association (UK).

> [pspassociation.org.uk/wp-content/uploads/2024/02/Personal-Guide-to-PSP-Updated-address.pdf](https://pspassociation.org.uk/wp-content/uploads/2024/02/Personal-Guide-to-PSP-Updated-address.pdf)

### **PSP: Some Answers**

12-page document from CurePSP was last updated in 2023.

> [psp.org/assets/resources/items/65d60040c6d15PSP-Some-Answers-2023\(1\).pdf](https://psp.org/assets/resources/items/65d60040c6d15PSP-Some-Answers-2023(1).pdf)

### **Treating PSP, MSA, and CBD – What can be done?**

Dr. Brent Bluett describes symptomatic treatments possible for PSP that can improve quality of life. His message is that each treatment may be minor, but in sum they can make a significant difference. There is always hope! February 2019 webinar, co-hosted by Brain Support Network and Stanford University.

> [brainsupportnetwork.org/treating-psp-msa-and-cbd-webinar-notes-recording-resources](https://brainsupportnetwork.org/treating-psp-msa-and-cbd-webinar-notes-recording-resources)

### **Updates on PSP and CBD, a Tale of Two Cousins**

Dr. Nicholas McFarland discusses the commonalities and differences of PSP and CBD, advances in imaging biomarkers, treatment options, and emerging treatments. October 2023 talk, hosted by CurePSP.

> [youtube.com/watch?v=ocS6FLBseTY](https://youtube.com/watch?v=ocS6FLBseTY)

### **Falls and Dysphagia in PSP**

This excellent 6-page report was published for healthcare professionals in Summer 2015 by The Association for Frontotemporal Degeneration. The composite story of “Jackie Riddle” is actually an amalgam of two BSN volunteers’ loved ones.

> [theaftd.org/wp-content/uploads/2015/07/PinFTDcare\\_Newsletter\\_summer\\_2015.pdf](https://theaftd.org/wp-content/uploads/2015/07/PinFTDcare_Newsletter_summer_2015.pdf)

### **Sleep in MSA, PSP, and CBS**

Neuroscientist Dr. Christine Walsh reviews the current understanding of sleep/wake disruptions, a clinical trial on sleep in PSP, and sleep hygiene. May 2022 webinar, by CurePSP.

> [youtube.com/watch?v=2KDgP5qFJvA](https://youtube.com/watch?v=2KDgP5qFJvA)

## **PSP/CBD Research Update and Practical Conference**

In the practical sessions, we hear from a neurologist, a neuro-ophthalmologist, a social worker, a physical therapist, a speech therapist, someone with CBD, someone with PSP, and a caregiver to someone with PSP. Plus, nine US researchers provide updates. October 2017 conference, co-organized by Brain Support Network and UCSF. Recordings, handouts, and notes are available.

> [brainsupportnetwork.org/2017-1028-psp-and-cbd-conference/](https://brainsupportnetwork.org/2017-1028-psp-and-cbd-conference/)

## **Brain Support Network's PSP blog**

Recent blog posts include poetry by those with PSP. Our website offers a list of top resources on PSP, the latest diagnostic criteria, and a short overview of the disorder.

> PSP Blog: [brainsupportnetwork.org/category/psp/](https://brainsupportnetwork.org/category/psp/)

> PSP Info: [brainsupportnetwork.org/education/progressive-supranuclear-palsy](https://brainsupportnetwork.org/education/progressive-supranuclear-palsy)

## **PSP, CBD, and FTD Brain Donations: Who, What, Where, When and Why?**

Brain Support Network's Robin Riddle addresses the brain donation process, noting the crucial need for brain donations to advance science. A UPenn neurologist explained the value of brain donations for research. A wife discusses donating her husband's brain. March 2023 webinar, co-hosted by the Association for Frontotemporal Degeneration and the FTD Disorders Registry.

> Brain Support Network's talk: [youtube.com/watch?v=\\_WG1ksEbWxY](https://youtube.com/watch?v=_WG1ksEbWxY)

> Full webinar recording: [youtube.com/watch?v=F4FcQZjacEY](https://youtube.com/watch?v=F4FcQZjacEY)

## **Guidebook**

This 140-page resource on PSP (mostly), CBD, and MSA focuses on incontinence, constipation, dry eyes, and visual issues. Updated 2020, by CurePSP.

> [psp.org/assets/resources/items/65d6012f381852020-GUIDEBOOK\\_web.pdf](https://psp.org/assets/resources/items/65d6012f381852020-GUIDEBOOK_web.pdf)

## **Care Partner Guidebook**

This 76-page booklet addresses advance healthcare planning (including a feeding tube), Social Security's Compassionate Allowances program, driving, hospice, keeping families strong, and the emotional aspects of caregiving. The last section offers specific advice from PSP caregivers. Updated 2020, by CurePSP.

> [psp.org/assets/resources/items/65d6015de072b2020-CAREPARTNERS-GUIDEBOOK\\_web.pdf](https://psp.org/assets/resources/items/65d6015de072b2020-CAREPARTNERS-GUIDEBOOK_web.pdf)

## **Last Dance at the Savoy: Life, Love and Caring for Someone with Progressive Supranuclear Palsy, by Kathryn Leigh Scott**

In this book, Scott shares her insights on daily caring for her husband Geoff Miller with PSP. Miller, the founding editor of Los Angeles magazine, lived life fully despite PSP. Scott recommends working with BSN for brain donation arrangements!

> [kathrynleighscott.com/marketplacebooksphotos/p/lastdance](https://kathrynleighscott.com/marketplacebooksphotos/p/lastdance)

## **Diagnosing Progressive Supranuclear Palsy**

Dr. Kathleen Poston describes the new diagnostic criteria for PSP, including Richardson's syndrome, PSP-parkinsonism, and pure akinesia with gait freezing. September 2017 webinar, co-hosted by Stanford University and Brain Support Network.

> [brainsupportnetwork.org/recording-notes-from-diagnosing-psp-webinar-august-2017/](https://brainsupportnetwork.org/recording-notes-from-diagnosing-psp-webinar-august-2017/)