



## 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:

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

Nine US researchers provide updates on the latest PSP and CBD research. 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. This conference, co-organized by Brain Support Network and UCSF, was held in late October 2017. Links to conference recording, handouts, and notes are here:

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

### **Diagnosing Progressive Supranuclear Palsy**

This webinar features Dr. Kathleen Poston, describing the new diagnostic criteria for PSP. Her focus is Richardson's syndrome, PSP-parkinsonism, and pure akinesia with gait freezing. The webinar, produced by Stanford University and Brain Support Network, was held in September 2017. Notes and a link to the recording are here:

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

### **PSP: Some Answers**

12-page document from CurePSP was last updated in October 2017.

[psp.org/wp-content/uploads/2017/09/PSP-Some-Answers-\\_WEB\\_PAGES-9.15.17.pdf](https://psp.org/wp-content/uploads/2017/09/PSP-Some-Answers-_WEB_PAGES-9.15.17.pdf)

### **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)

### **Treatment of and Research on PSP**

Dr. Adam Boxer, a leader of worldwide clinical trials in PSP, speaks for about 40 minutes in the PSP break-out session at the October 2012 atypical symposium, organized by Stanford University and Brain Support Network. Before Dr. Boxer's talk, Dr. Irene Litvan, one of the world's top experts on PSP, gives the keynote.

[youtube.com/watch?v=bHy7yEgS0qk&list=PLrukR7WKf08Q1nQygYxFLXu0hVP-1ukUw&index=4](https://youtube.com/watch?v=bHy7yEgS0qk&list=PLrukR7WKf08Q1nQygYxFLXu0hVP-1ukUw&index=4)

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

The first section of this excellent 110-page introduction to PSP and CBD focuses on symptoms such as cognition/mood, mobility/falls, fatigue/sleep, pain, swallowing, vision, and bladder/bowel. Published August 2013 by The PSP Association (UK).

[pspassociation.org.uk/app/uploads/2017/01/Personal-Guide-to-PSP-Section-1.pdf](http://pspassociation.org.uk/app/uploads/2017/01/Personal-Guide-to-PSP-Section-1.pdf)

### **Guidebook**

This 156-page resource on PSP (mostly), CBD, and MSA was updated by CurePSP in January 2018. Topics include incontinence, constipation, dry eyes, and visual issues.

[www.psp.org/wp-content/uploads/2018/01/2018-GUIDEBOOK\\_web.pdf](http://www.psp.org/wp-content/uploads/2018/01/2018-GUIDEBOOK_web.pdf)

### **CurePSP Archived Family Conference Recordings**

Some of CurePSP's family conferences are recorded and available online.

[www.youtube.com/user/CurePSP/playlists](http://www.youtube.com/user/CurePSP/playlists)

### **UCSF PSP/CBD Research Update**

This February 2014 conference, organized by UCSF and Brain Support Network, features Dr. Adam Boxer among other UCSF Memory and Aging Center clinicians. Dr. Boxer addresses new therapeutic approaches. Dr. Michael Geschwind talks about a genetics study in familial PSP. Dr. Christine Walsh discusses sleep issues in PSP. Most of the talks are about 14 minutes in length.

Boxer: [youtube.com/watch?v=9GmSEMiUHp0](https://www.youtube.com/watch?v=9GmSEMiUHp0)

Geschwind: [youtube.com/watch?v=ZOqWmYQ-wDU](https://www.youtube.com/watch?v=ZOqWmYQ-wDU)

Walsh: [youtube.com/watch?v=XNCs\\_I8USF8](https://www.youtube.com/watch?v=XNCs_I8USF8)

### **A Physician's Guide to PSP**

Though this video was produced in 2007 for MDs, most of it is understandable to laypeople. This 18-minute video by CurePSP and the PSP Association features some of the world's top experts in PSP including Dr. John Steele and Dr. Lawrence Golbe.

[youtube.com/watch?v=IXMv919LOWE](https://www.youtube.com/watch?v=IXMv919LOWE)

Notes on video: [brainsupportnetwork.org/physicians-diagnostic-video-on-bsp/](http://brainsupportnetwork.org/physicians-diagnostic-video-on-bsp/)

### **National Institute of Neurological Disorders and Stroke Fact Sheet on PSP**

NINDS is part of the NIH. This web page was last updated in September 2015.

[ninds.nih.gov/disorders/psp/detail\\_psp.htm](http://ninds.nih.gov/disorders/psp/detail_psp.htm)

### **PSP: A Primer for the Newly Diagnosed**

14-minute video full of facts from PSP expert neurologist Dr. Larry Golbe, and full of hopeful messages from a person with PSP, his wife, a volunteer, and Dr. Golbe.

[youtube.com/watch?v=eAILKni9K9E](https://www.youtube.com/watch?v=eAILKni9K9E)

Notes on video: [brainsupportnetwork.org/psp-a-primer-for-the-newly-diagnosed-video/](http://brainsupportnetwork.org/psp-a-primer-for-the-newly-diagnosed-video/)