



Corticobasal Degeneration/Syndrome *TOP RESOURCES*

Brain Support Network has reviewed most of the resources available on Corticobasal Degeneration/Syndrome. 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-psp-and-cbd-conference/

Treatment of and Research on CBS/CBD

Dr. Irene Litvan, one of the world's top experts on CBD, gave an excellent hour-long update at the October 2012 atypical parkinsonism symposium, organized by Stanford University and Brain Support Network. The event was held in Burlingame, California.

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

UCSF Memory & Aging Center Overview of CBS

This webpage offers a good overview of the signs and symptoms of CBS.

memory.ucsf.edu/corticobasal-syndrome

The AFTD Overview of CBS

Published by The Association for Frontotemporal Degeneration, this webpage provides an overview of three categories of clinical features of CBS.

theaftd.org/understandingftd/disorders/corticobasal-degeneration

CBD: Some Answers

This 8-page document from CurePSP was last updated in October 2017.

psp.org/wp-content/uploads/2017/09/CBD-SOME-ANSWERS_WEB_PAGES-9.19.17.pdf

Understanding Corticobasal Degeneration

This 14-minute overview of CBD was given by Dr. Suzee Lee at the February 2014 UCSF Memory and Aging Center/Brain Support Network PSP/CBD Research Update in San Francisco.

[youtube.com/watch?v=-5N3o1IKDZO](https://www.youtube.com/watch?v=-5N3o1IKDZO)

New Therapeutic Approaches to Tau-Related Neurodegeneration

This 14-minute overview of new approaches to the treatment of PSP and CBD was given by Dr. Adam Boxer at the February 2014 UCSF Memory and Aging Center/Brain Support Network PSP/CBD Research Update in San Francisco.

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

Your Personal Guide to PSP (and CBD)

The first section of this 110-page booklet has an excellent introduction to PSP and CBD, with a focus on symptoms such as cognition/mood, mobility/falls, fatigue/sleep, pain, swallowing, vision, and bladder/bowel. Published April 2013 by The PSP Association (UK). The group uses the term “PSP” as shorthand for both conditions.

pspassociation.org.uk/app/uploads/2017/01/Personal-Guide-to-PSP-Section-1.pdf

Update on PSP and CBD

This update was given by neurologist Dr. Rajeev Kumar at the CurePSP family conference in Denver in October 2013. Recorded presentation is available online.

[youtube.com/watch?v=h6cRgTiy03s](https://www.youtube.com/watch?v=h6cRgTiy03s)

Challenges in the Management of CBD

This October 2010 update on CBD was given by Dr. Litvan, one of the world’s top experts on CBD. In this CurePSP webinar, Dr. Litvan reviews the three common clinical presentations of CBD. The recording is no longer available.

Notes on webinar: brainsupportnetwork.org/dr-litvan-webinar-on-cbd-notes/

Behavior/Cognitive Issues with PSP, CBD & FTD

This CurePSP webinar was presented by Dr. Brad Boeve, one of the US’s experts on CBD, in April 2010. Dr. Boeve examines how various CBD symptoms are managed.

https://web.archive.org/web/20120710092950/http://www.psp.org/file_download/81337c8a-84ff-4873-8f62-ad874ecbf9c8

Notes on webinar: brainsupportnetwork.org/notes-from-boeve-webinar-cognitivebehavioral-aspects/

Guidebook

This 156-page resource on PSP (mostly), CBD, and MSA was updated by CurePSP in January 2018. Topics include dry eye syndrome, oral hygiene, swallowing problems, aspiration pneumonia, communication, managing cognitive changes, and managing difficult behaviors.

www.psp.org/wp-content/uploads/2018/01/2018-GUIDEBOOK_web.pdf

Finding Meaning with Charles

Book by Janet Edmunson, whose husband Charles had CBD.

www.findingmeaningwithcharles.com