



What to Do About... Corticobasal Degeneration

While often misdiagnosed as Parkinson's disease based on their similar pathological symptoms, corticobasal degeneration (CBD) is a distinct condition that can cause muscle rigidity, spasms, and contractions, often on just one side of the body. (Corticobasal syndrome, or CBS, is its most common presentation.) Its largely movement-based symptoms can make for an especially frustrating experience for persons diagnosed, who lose the ability to perform movements that once came naturally to them. Below are strategies for persons diagnosed, care partners, and health professionals to use when facing CBD.

Strategies for Persons Diagnosed and Family Care Partners

- Pay attention to signs and symptoms of a possible movement disorder or atypical Parkinsonism such as rigidity or stiffness, difficulty completing common movements or gestures, and falls.
- Notice if symptoms affect one side more than the other. A greater impact on the left side could be a sign of corticobasal syndrome (CBS).
- Monitoring the effects of prescriptions such as carbidopa-levodopa, which is commonly used in Parkinson's disease, may help to determine an accurate diagnosis.
- Visit a movement disorder specialist familiar with atypical Parkinsonism so they can thoroughly evaluate movement and establish a baseline for treatment.
- Include physical, occupational, and speech therapies to help manage CBS symptoms and improve quality of life.
- Relax the expected standard of performance of the person diagnosed, rather than rushing them or arguing that they are doing something too slowly or incorrectly. What is most important is that the person diagnosed is engaged in the activity and feeling positive.
- Consider adaptive equipment like large eating utensils, stabilization devices, bathtub seats, or adaptive clothing.
- Use affirming statements (e.g., "Take your time," "I'll wait," "Would you like help?").
- Foster adapted communication. Provide simple, one-step directions and allow enough time for the person to process what you are saying and respond accordingly.
- Monitor for depression and apathy. People with CBS experience frustration and loss over their diminishing movement and communication capabilities, and are at greater risk of apathy and depression.
- Care partners should also seek a support group to learn strategies from other caregivers and learn more about the disease. Support groups can help families and those diagnosed realize they are not alone.
- Create a support team to provide support and guidance throughout the disease process.
- Consult the Penn Memory Care website for resources about driving and dementia: pennmemorycenter.org/driving-and-dementia.
- Discuss care preferences in advanced illness with loved ones, and complete related legal and financial planning documents. Visit AFTD's website for more information: theaftd.org/living-with-ftd/legal-financial-planning.

Guidance for Medical Health Care Teams

- Know the signs and symptoms of atypical Parkinsonism to facilitate accurate diagnosis, treatment and support for those affected.
- Refer families to multi-disciplinary specialty centers with experience in CBS for a comprehensive evaluation and care planning. Encourage them to get more information by contacting the AFTD HelpLine (866-507-7222, info@theaftd.org).
- Refer families to support groups for emotional support and reassurance that they are not alone in this journey. Point them to the AFTD website: theaftd.org/living-with-ftd/aftd-support-groups.
- Encourage referrals to physical, speech, and occupational therapy to design care strategies to maintain independence in activities of daily living, assess the need for assistive devices for gait and balance, and monitor for problems with swallowing.
- Ataxias can be embarrassing for those with CBS, causing them to self-isolate and shrink away from social environments. Create an environment of acceptance to help them feel more comfortable and open to try new things.
- Encourage the person diagnosed and their care partner to learn about research, clinical trials, emerging therapies and compensatory tools.
- Encourage family participation in therapy sessions to train caregivers in how to help maximize their loved one's independence and lead sessions at home.
- Consider referring the person diagnosed for a palliative care consultation. Initiating hospice services early can ease the transition and provide support in the home.
- Watch the AFTD Educational Webinar on CBS and CBD, featuring Dr. Melissa Armstrong of the University of Florida: www.theaftd.org/webinar-corticobasal-syndrome-corticobasal-degeneration-basics-what-you-need-to-know.
- Listen to needs of the person diagnosed and their families. Many people with an FTD diagnosis develop depression; encourage both them and their close family members to consider talk therapy for support.

ADDITIONAL RESOURCES

- Visit AFTD's website for more information on CBS and CBD, including a downloadable fact sheet you can print out and present to health professionals who may be unfamiliar with the condition, as well as a link to a recent AFTD Educational Webinar on CBS and CBD: theaftd.org/what-is-ftd/corticobasal-syndrome
- Other organizations that can provide information on CBS and CBD include CurePSP and the Brain Support Network.
- Janet Edmunson, a former board chair of CurePSP and a guest contributor to this issue of Partners in FTD Care, has written a book about her and her late husband's journey with CBS/CBD, *Finding Meaning With Charles*, published in 2006.
- If you have specific questions about CBS and CBD, do not hesitate to contact the AFTD HelpLine at info@theaftd.org or 866-507-7222.