A Patient’s Guide to Corticobasal Syndrome (CBS)

This material is provided by UCSF Weill Institute for Neurosciences as an educational resource for patients.
What is corticobasal syndrome?
Corticobasal syndrome (CBS) is a condition that causes changes in movement, language skills, or both. CBS may start with movement problems, such as stiff muscles on one side of the body involving the arm, leg, or both. People with CBS may describe having a hard time controlling their arm or leg. Some people with CBS have language problems first and may develop movement problems over time. Thinking and behavior changes may happen either at the beginning or later in the disease.

What causes CBS?
The cause of CBS is unknown. Scientists know that in some people with CBS, there is a large build-up of a protein called tau. Tau occurs normally in the brain, but we do not yet understand what causes it to build up in large amounts. Others may have a large build-up of amyloid plaques similar to those seen in people with Alzheimer’s disease. As more and more proteins buildup in the nerve cells, the cells lose their ability to function and eventually die. This causes affected parts of the brain to shrink.

How is age related to CBS?
Most people with CBS start having symptoms around age 60, although some people have shown signs earlier or later.

What happens in CBS?
The first sign of CBS is usually trouble with movement. The symptoms may begin in one hand, arm, or leg. The limb may feel stiff and might shake. A person with CBS may experience a slight change in the feeling of the limb and may have trouble making the limb move, or the movement may be slower than usual.

Later in the disease, language problems may begin. People may have increasing trouble finding the right word, naming objects and people, or just getting the words out. Their reading skills might also get worse, and writing might become especially difficult if the movement symptoms affect the hands.

Moving around might also get harder as time goes on. Symptoms that start in one limb or on one side of the body might move slowly to other limbs or to the other side of the body. In late stages of CBS, people may have some personality changes. They might become obsessive or impulsive, or say inappropriate things. Some people may also develop memory problems, such as misplacing objects or repeating questions.

A person with CBS can live many years with the disease. Research suggests that a person with CBS may live an average of 6–8 years with the disease, although this can vary from person to person.

Are there medicines to treat CBS?
Though there is no cure for CBS yet, there are medications that help manage the symptoms. These medications are called cholinesterase inhibitors, and they can help if a person with CBS is having memory problems, especially with CBS symptoms that look like Alzheimer’s disease. Some examples of these medicines are donepezil, rivastigmine, and galantamine. If a person with CBS has movement symptoms they may be treated with medications used for Parkinson’s disease, such as levodopa, although the effect of these medications is questionable.

What other things help?
There are various ways to help a person with CBS. Speech therapy may help improve communication between people with CBS and others. Physical therapy and stretching exercises may improve some movement difficulties.

Research has shown that physical exercise helps to enhance brain health and improves mood and general fitness. A balanced diet, enough sleep, and limited alcohol intake are other important ways to promote good health. Other illnesses that affect the brain, such as diabetes, high blood pressure, and high cholesterol, should also be treated if present.

Resources
Cure PSP: psp.org
The Association for Frontotemporal Degeneration: theaftd.org
National Organization for Rare Disorders: rarediseases.org/rare-diseases/corticobasal-degeneration
Family Caregiver Alliance: caregiver.org
National Institutes of Health: nih.gov
Research: clinicaltrials.gov