



# A Patient's Guide to Progressive Supranuclear Palsy (PSP)

This material is provided by UCSF Weill Institute for Neurosciences as an educational resource for patients.



UCSF Weill Institute for Neurosciences

Memory and Aging Center

## What is progressive supranuclear palsy?

Progressive supranuclear palsy (PSP) is a condition that causes changes in movement, language, and behavior. In its typical form, PSP causes difficulties with balance that lead to frequent falls. Eye movement problems are also a characteristic symptom of PSP, although these are often discovered when a doctor examines a person with PSP. Slowed movement, stiffness, and difficulty walking are common. People with PSP may also have changes in speaking, thinking, or behavior.

### What causes PSP?

The cause of PSP is unknown. Scientists know that in PSP 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. As more and more proteins clump in the nerve cells, the cells lose their ability to function and eventually die. This causes the affected parts of the brain to shrink.

### How is age related to PSP?

Most people with PSP start having symptoms after age 60, although some people have shown signs earlier or later.

### What happens in PSP?

The most common first sign of PSP is trouble with balance. Because of their balance problems, people with PSP may have trouble walking and may fall. Frequently, people with PSP feel stiffness in the neck and back, and their movements may be slowed. A person with PSP will begin to experience eye problems, such as difficulty opening and closing their eyes, blinking, blurry vision, or moving their eyes side to side or up and down.

Later in the disease, people with PSP may feel increasing weakness in their limbs. Their balance may get worse and they may fall more often while walking. Eye problems, such as keeping eye contact with another person, will get worse. PSP can also affect a person's ability to speak, and their voice may become soft and weak. Mood and behavior changes may occur. People with PSP may become irritable, forgetful, or depressed, and they may become less interested in things. They may also become more impulsive in their decision-making.

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

#### Are there medicines to treat PSP?

Though there is no cure for PSP yet, there are medications that help manage the symptoms. Movement symptoms may be treated with medications used for Parkinson's disease, such as levodopa, although the effect of these medications in PSP is debated.

# What other things help?

Speech therapy may be helpful for people with PSP who have problems with speaking and expression. Physical therapy and stretching exercises may help strengthen stiff muscles and improve some movement difficulties. A professional should evaluate fall risks at the home of the person with PSP and make changes as necessary, such as installing rails, removing carpets, or adding a shower chair.

In addition to medications, there are various ways to help a person with PSP. 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 brain 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

PSP Association: pspassociation.org.uk

The Association for Frontotemporal Degeneration: <u>theaftd.org</u> National Organization for Rare Disorders: <u>rarediseases.org</u> Family Caregiver Alliance: <u>caregiver.org</u> National Institutes of Health: <u>nih.gov</u>

Research: clinicaltrials.gov

