



Fact Sheet:

Progressive Supranuclear Palsy (PSP)

Definition

PSP is a rare, degenerative brain disorder related to Parkinson's disease. It strikes middle age adults and the elderly, slightly more men than women and affects 1.4 in 1,000,000. Its cause remains a mystery, and although there is no cure, symptoms can often be helped. There are estimated to be 20,000 people with PSP in the United States, but only 3,000 to 4,000 have been diagnosed. In 1963, Dr. John C. Steele, Dr. J.C. Richardson and Dr. J. Olszewski identified PSP as a distinct neurological disorder.

What does Progressive Supranuclear Palsy mean?

- **Progressive** means that the disease gets slowly worse over time, from diagnosis to late stages, typically three to ten years.
- **Supranuclear** means that the area of the brainstem that controls up and down eye movements.
- **Palsy** means a weakness, referring to the palsy of moving the eyes.

Symptoms

Early symptoms include falling, difficulty walking, imbalance, and slow movement, similar to Parkinson's disease. People with PSP experience vision problems such as double and

blurred vision, as well as difficulty with speech and swallowing. There may also be changes in mood and behavior. In its advanced stages, persons with PSP are bedridden or in wheelchairs and require fulltime care.

Diagnosis

PSP is usually diagnosed by a neurologist. There is no diagnostic test other than the clinical evaluation. Typical findings include features of Parkinson's with limb stiffness, slowness, imbalance and trouble walking with limitation of upward and downward eye movements.

Because PSP is a rare disease, there is often a delay before the diagnosis is made. Without an early diagnosis and adequate information, families cannot anticipate the future course of the disease and therefore, are unable to plan. Furthermore, people with PSP may live hundreds of miles from each other and knowledgeable health care professionals, causing feelings of loneliness and isolation.

People with PSP die from complications of immobility and the inability to swallow, including pneumonia and aspiration.

Treatment

At present, there is no treatment that can reverse the effects of this disease. Yet, a variety of medications and other

forms of therapy can help the symptoms.

Credits

Progressive Supranuclear Palsy: HL Klawans; United Parkinson Foundation, 1981.

Accuracy of Clinical Criteria for the Diagnosis of Progressive Supranuclear (Steele-Richardson-Olszewski Syndrome). I. Litvan, MD et al.; Neurology (April 1996;46). Pp. 922-30.

Clinical Research Criteria for the Diagnosis of Progressive Supranuclear (Steele-Richardson-Olszewski Syndrome). I. Litvan, MD et al.; Neurology (June 1997; 47). Pp. 1-9.

Characterizing Swallowing Abnormalities in Progressive Supranuclear Palsy. I. Litvan, MD et al.; Neurology (June 1997; 48). Pp. 1654-1662.

Resources

Southern Caregiver Resource Center
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Southern Caregiver Resource Center offers free support services to caregivers of adults with chronic and disabling conditions in San Diego and Imperial counties. Services include information and referral, needs assessments, care planning, family consultation, case management, individual counseling, legal and financial consultation, respite care, education and training, and support groups.

CurePSP

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