

PROGRESSIVE SUPRANUCLEAR PALSY (PSP)

CAREGIVING CHALLENGES

Many of the concerns faced by family caregivers of people with PSP are due to the motor complications of this disease. Patients with PSP typically have poor balance, slowed movement, and eye movement problems which can result in falling.

Patients may also experience difficulty swallowing which can lead to aspiration, or the passage of food into the airways. This can result in pneumonia.

Visual disturbances include weakness, or palsy, of eye movements especially in the downward direction. Other visual disturbances may include blurred vision or difficulty focusing. These visual changes affect reading and eye-hand coordination as well as walking.

Patients with PSP may also experience behavioral and emotional changes. They may exhibit irritability, mood swings, sleep disturbances, impulsivity and apathy. Cognitive changes may include slower thinking and trouble organizing information.

STRATEGIES FOR COPING

Exercise is recommended to increase strength and balance. Patients may prefer to work with a Physical therapist or Personal trainer. A Physical therapist can evaluate the need for assistive devices such as canes or walkers. Increased supervision may become necessary, especially if the patient is demonstrating impulsivity and poor judgment.

A speech therapist can teach safer swallowing techniques to help prevent problems with choking and aspiration. Foods can be prepared in a way to minimize choking and aspiration. For example, cutting food into small pieces and drinking thick liquids can be helpful for some patients.

Alternative communication devices are helpful for some people and can be discussed with a speech therapist.

The visual changes impact on patient safety and quality of life. Books on tape, music and other activities that rely less on visual abilities can be encouraged. Modifications to the home environment may be necessary and are discussed below.

Please refer to the FTLD caregiving section for information on dealing with the behavioral and personality changes.

SAFETY AND ENVIRONMENT

Home safety can be fostered by keeping pathways clear of objects such as low furniture, cords and area rugs that are difficult to see without looking down. An Occupational therapist can perform a home safety check to make recommendations for assistive equipment and modifications.