

A Research Study to Improve Support

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Objective: To understand the needs and resources, of people with PSP and their caregivers, and identify the priority need.

Background: Although PSP is the most common type of atypical parkinsonism, there is almost no data available on needs and resources from the perspectives of people with PSP or their caregivers.

Method: A situational assessment was conducted with data gathered from: a) focus groups with people with PSP and their family and professional caregivers; b) surveys of major organizations serving those affected by PSP; and c) surveys of Movement Disorder Centre staff.

Results: Four categories of challenges were identified: symptoms, services, research, and knowledge. Symptoms that were most often identified as challenging were falls, mobility, vision, mood or thinking, speech, and swallowing. The service challenges involved service access and interactions with physicians, community workers, private caregivers, and long-term care staff. The research challenges related to the lack of research and/or the failure of health care providers or PSP organizations to communicate research findings. The most common challenges in the knowledge category were lack of knowledge of PSP among community workers, physicians, patients, and family members. Knowledge challenges were identified as the priority need far more frequently than challenges in the other three categories. Many participants found help with these challenges from sources such as services, treatments, information, equipment, and family support.

Conclusions: The many challenges faced by people with PSP, their families, and other caregivers are diverse and evolving. Individuals find help with these challenges from many sources. However, these sources of help were frequently unknown, inaccessible, underutilized, or inadequate. Focus group participants were particularly clear about the priority need—dissemination of information about the disease and about diagnosis and care of the person with PSP. This information needs to reach doctors, long-term care staff, community workers, patients, families, and the general public. This need is currently being addressed in phase 2 of this project.