

Resources

8

CurePSP (North America)

- www.curepsp.org
- 1-866-457-4777
- *Guide for People Living with PSP and CBD*

PSP Association (Europe)

- www.pspeur.org

Parkinson Canada

- www.parkinson.ca
- PSP caregiver group 1-800-565-3000 ext.

Canadian Movement Disorder Group

- www.cmdg.org for links to regional centres

Mindfulness Meditation

- www.umassmed.edu/cfm/mbsr

Imagery

- www.healthjourneys.com
- 1-800-800-8661

Therapeutic Touch Networks of Canada

- <http://ttnc.ca> for links to regional networks



Getting Help for Progressive Supranuclear Palsy: A Guide for Patients and Families

Progressive Supranuclear Palsy (PSP) is an uncommon neurological disease. It is caused by damage to nerve cells in specific areas of the brain. It is most often diagnosed when a person is in their 60's. Early symptoms include loss of balance, stiffness of the neck, and unexpected falls (often backwards). As the disease progresses these symptoms worsen and difficulties with eye movements, speech, swallowing, and thinking occur.

People with PSP and their family members face many challenges and these challenges change over time. This brochure lists potential challenges as well as options that some patients and families have found helpful for improving their quality of life. While everyone's experience is different, the challenges are listed in the approximate order in which they may occur. You may decide that you only want to read the first section now.

The brochure is intended to be a *starting point** for discussions with your health care team. When you encounter or anticipate a specific challenge, we encourage you to talk to your health care team about whether one of the options listed would be right for you. If possible, this team should include a movement disorder specialist.*

*Anytime you see this symbol, you will find one or more resources listed on the back cover.

If/When

- Slowness of thinking occurs
- Financial assistance is needed
- It becomes more difficult to care for the person at home
- The end of life is approaching

Options May Include

- Allow time for the person to respond
- Present one idea at a time
- If the change is sudden, search for other causes
- Discussion eligibility for various disability benefits with social worker
- Contact local charities for possible assistance
- Discuss options with social worker. These may include: in-home or external respite programs, day programs, retirement homes or nursing homes
- Discuss with the health team your care wishes, eligibility for hospice or palliative care, and availability of grief counselling

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If/When**Options May Include**

- Falls occur often and/or it becomes more difficult to move
 - Referral to a physical or occupational therapist who may recommend walkers, wheelchairs, equipment, exercises, home adaptations or other strategies
 - Referral to a rehab program
 - A personal care provider at home*
 - Medications for muscle stiffness and slow movement
- It becomes difficult to look down
 - Avoid bifocals
 - Prism glasses to redirect gaze
 - Mirror on a swivel base
 - Raise plates and books
- The neck is stiff
 - Massage or prescribed stretches
- There is coughing or choking with food or fluids
 - Referral for a swallowing assessment, which may lead to suggestions for changes in head position, food texture, or utensils or use of reminders or thickened fluids
 - Monitor for pneumonia
 - In later stages, discuss with team the pros and cons of feeding tubes*

If/When**Options May Include**

- There is excess saliva or drooling
 - Chew/suck on gum or candy (if safe to do so)
 - Atropine drops under the tongue (by prescription)
 - Botox injected into salivary glands
- Eye irritation or sensitivity occurs
 - Artificial tears or lubricating drops
 - Omega-3 supplement/foods
 - Sunglasses
- The eyes become difficult to open
 - Botox injected around eyes
 - Reduction in medications
- Constipation occurs
 - Adequate fluid and fibre
 - Time and privacy (if safe) on toilet
 - Reduction in medications
 - Laxatives
- The urge to void is frequent and/or sudden
 - Urine culture to rule out infection
 - Prompt toileting
 - Routine toileting
 - Medications
 - Spill-proof urinal or bedside commode
 - Condom catheter
 - Incontinence briefs

If/When	Options May Include
<ul style="list-style-type: none"> • Sustained muscle contractions occur (dystonia) 	<ul style="list-style-type: none"> • Start or adjust medications • Botox injections to muscles • Relaxation techniques* • Referral to a pain specialist • Equipment from a therapist
<ul style="list-style-type: none"> • Sleep is disturbed 	<ul style="list-style-type: none"> • A short nap after lunch • Limit stimulating fluids, foods, and medications • Toileting strategies (see previous page) • Relaxation techniques* • Sedatives
<ul style="list-style-type: none"> • Apathy, depression, irritability, or mood swings occur 	<ul style="list-style-type: none"> • Counselling to support the caregiver, identify triggers, and find ways not to take the behaviors personally • Medications • Exercise for mental, physical and social wellbeing
<ul style="list-style-type: none"> • Travel becomes difficult 	<ul style="list-style-type: none"> • Discuss driving safety • Review transfer equipment or techniques with therapist • Handicapped parking permit • Accessible transit services

If/When	Options May Include
<ul style="list-style-type: none"> • You or others have questions 	<ul style="list-style-type: none"> • Discussions with your health care team • CurePSP literature, office and website* • PSP Association (Europe) literature and website* • Discussion with a Parkinson Canada staff member *
<ul style="list-style-type: none"> • You feel anxious, isolated, or overwhelmed 	<ul style="list-style-type: none"> • Support and counselling from a social worker in the community or clinic • On-line CurePSP support group* • Parkinson Canada PSP caregiver group* • Relaxation techniques, such as meditation, Therapeutic Touch™ or imagery* • Talk with family and friends • Ask the health team about any research opportunities
<ul style="list-style-type: none"> • Speech is affected 	<ul style="list-style-type: none"> • Use yes/no questions, writing, or hand/eye signals • Referral to a speech language pathologist for therapy and/or devices • Ensure others are aware of your financial, legal, and end of life care wishes

