

DIRECTIONS FOR PATIENTS & FAMILIES

Complete, remove and staple together the pages of this “Grab & Go” document and bring it with you to the emergency room, hospitalization or short-term stay in a skilled nursing or rehabilitation facility.

You can also bring the full Prepare to Care workbook, but the Grab & Go provides a short and quick reference for care teams to refer to, especially in more emergent situations.

Also remember to always bring a copy of the person’s medical insurance card(s) and advance care directives.

HEALTHCARE PROVIDERS, PLEASE READ

This patient has been diagnosed with a rare neurodegenerative disease which may cause symptoms such as:

- Loss of balance and difficulty with gait/ambulation
- Changes in cognition, including slowed processing and impulsivity
- Weakened eye movements and double vision
- Slurred or softer speech
- Difficulty swallowing
- Extreme changes in blood pressure when altering positions
- Stiffness or clumsiness in upper or lower extremities

Progressive supranuclear palsy (PSP), corticobasal degeneration (CBD; sometimes called corticobasal syndrome or CBS) and multiple system atrophy (MSA) are often misdiagnosed because of lack of familiarity among many healthcare providers and because initial symptoms may be mistaken for those of other conditions. The most common initial or misdiagnosis is Parkinson’s disease. However, these diseases, referred to as “atypical parkinsonism diagnoses,” must be treated differently from Parkinson’s and have unique considerations for care.

Important notes regarding the care of PSP, CBD or MSA:

- Provide medications as prescribed
- It is helpful if a neurologist (preferably their neurologist) and rehabilitation therapy are consulted for their care
- Closely monitor for falls risk, delirium, swallowing difficulty, urinary tract infections, blood pressure issues and other complications
- Prior to discharge, assess for adequate care set up in the home and family care partner needs as well as provide clear instructions
- It is important for this person to be spoken to in a respectful manner and that they are included in care decisions as much as possible, despite challenges with speech or cognition
- Read this document for important information on contraindicated medications for PSP/CBD/MSA as well as this person’s symptoms, medication schedule and unique care needs