

DIRECTIONS FOR PATIENTS & FAMILIES

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

This 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 individual care needs

PATIENT INFORMATION

Patient Name:

Address:

City:

State/
Province:ZIP/
Postal Code:

Date of Birth: / /

Phone:

Diagnosis:

- ☐ Progressive supranuclear palsy (PSP) ☐ Corticobasal degeneration (CBD) ☐ Multiple system atrophy (MSA)
☐ other _____

Year of Diagnosis:

Year of Symptom Onset:

Primary Care Physician Name:

Phone:

Neurologist / Specialist Name:

Phone:

IMPORTANT CONTACT INFORMATION**Healthcare Power of Attorney or Primary Emergency Contact:**

Name:

Relationship to Patient:

Phone:

Alt. Phone:

Alternate Emergency Contact

Name:

Relationship to Patient:

Phone:

Alt. Phone:

Does Patient Have Advance Care Directive? YES NO *If YES, please provide a copy to care team*

Current Medications (Prescribed, over-the-counter, supplements)	Dosage (Tablet size/liquid volume)	Times taken
①		
②		
③		
④		
⑤		
⑥		
⑦		

Medication allergies, sensitivities or known interactions:

(Attach page(s) if needed to list additional medications)

MEDICAL HISTORY

Patient is engaged in an experimental drug trial:

YES NO *If YES, please provide additional info:*

.....

.....

.....

.....

Recent hospitalizations, surgeries or significant medical events:

.....

.....

.....

.....

.....

Additional medical information (e.g., implanted devices, chronic health conditions):

.....

.....

.....

.....

Medication Precautions for PSP, CBD and MSA

Do not abruptly increase or reduce levodopa or amantadine.

To avoid:

- Pimavanserin, quetiapine and clozapine—Can be used in brief, emergency situations but can cause aggravation of slowness and stiffness
- Benzodiazepines (clonazepam, temazepam) and benzodiazepine receptor agonists (zolpidem, eszopiclone)—Can increase risk of falls, but can be used if person is chairbound and hypotension is not a risk

To use with caution:

- Haloperidol, olanzapine, aripiprazole and risperidone—Can dangerously aggravate stiffness and slowness and cause severe sedation
- Amitriptyline, benztropine, trihexyphenidyl, oxybutynin, tolterodine, fesoterodine, paroxetine and most tricyclic antidepressants—Can worsen mobility
- Diphenhydramine, an antihistamine with anticholinergic effects—Can worsen mobility
- Memantine—Can cause nausea, dizziness and sedation
- Metoclopramide and prochlorperazine; For nausea/vomiting, instead use ondansetron, trimethobenzamide or granisetron

For MSA:

- Dopamine agonists—Can cause dystonia
- Alpha-blockers for bladder dysfunction and beta blockers for anything—Can cause sudden hypotension

MEDICAL HISTORY *(continued)*

Current symptoms <i>(check if applicable)</i>		Comments
Thinking / Memory	<input type="radio"/>	
Impulsivity	<input type="radio"/>	
Visual difficulty / Light sensitivity	<input type="radio"/>	
Difficulty swallowing liquids and/or solids	<input type="radio"/>	
Changes to speech / voice	<input type="radio"/>	
Gait / Balance / Prone to falls	<input type="radio"/>	<i>Note use of any ambulatory equipment and typical direction(s) of falls</i>
Difficulty with coordination / motor skills	<input type="radio"/>	
Hallucinations	<input type="radio"/>	

MEDICAL HISTORY *(continued)*

Current symptoms <i>(check if applicable)</i>		Comments
Urinary changes/ constipation	<input type="radio"/>	
Sleep	<input type="radio"/>	
Blood pressure regulation	<input type="radio"/>	
Breathing	<input type="radio"/>	

Additional notes about symptoms or care needs: