My Auto-Pilot Has Been Compromised:
Tips and Tricks for Dealing with Dysautonomia

PD Dysautonomia Q&A:

Who: > 80% w/ Parkinson's disease have symptoms of autonomic dysfunction. The most common is constipation.
What: Dysautonomia is dysfunction of the portion of nervous system which controls automatic body functions like blood pressure, heartbeat, temperature and digestive processes.

Symptoms: constipation, orthostatic lightheadedness, urinary problems, heat or cold intolerance, sweating problems, drooling, swallowing problems

When: dysautonomia occurs in all disease stages
Where: sympathetic (fight or flight), parasympathetic (rest & digest) and enteric nervous systems (gut motility)
Why: misfolded α-synuclein forms Lewy bodies and Lewy neurites impairing function in autonomic neurons

How to manage symptoms of dysautonomia:

1) First recognize presence of non-motor fluctuations: pay attention to timing of the symptom and target PD medication adjustments first.

Autonomic	Light-headedness	OFF > ON[a]
	Limb edema	OFF > ON
	Abdominal pain	OFF
	Abdominal bloating	OFF > ON
	Constipation	OFF > ON
	Nausea	OFF > ON
	Pyrosis	OFF > ON
	Hunger	OFF
	Sexual disorders	OFF > ON[a]
	Drenching sweats	OFF > ON[a]
	Facial flushing	OFF > ON
	Bladder dysfunction	OFF > ON[a]
	Belching	OFF > ON
	Drooling	OFF > ON
	Swallowing trouble	OFF > ON
	Chilling	OFF > ON
	Cough	OFF > ON
	Stridor	OFF
	Visual disorder	OFF > ON

2) Then utilize nonpharmacologic and pharmacologic interventions specific to the symptom

Orthostatic Hypotension:

A) Abdominal compression: wear when out of bed

B) Bolus of water: on bad days drink two 8-ounce glasses of cold water prior to prolonged standing.

Bed up: sleep with head of bed elevated 4 inches

C) Counter maneuvers: contract muscles below your waist for 30 seconds at a time to raise blood pressure before standing, during prolonged standing or when symptomatic

D) Drugs: work with your doctor to reduce or eliminate medications that lower blood pressure. If BP still too low on standing your doctor may use midodrine, fludrocortisone, droxidopa (Northera) or pyridostigmine to raise blood pressure

E) Education: Recognize situations which lower BP (like heavy meal, positional changes, heat, exercise, or a hot bath and avoid/change behaviors to avoid lowering BP). Avoid: Alcohol except in evening before bed, carbohydrate heavy meals and straining during urination and defecation.

Exercise: avoid inactivity (recumbent bike, rowing machine or pool exercise is best)

F) Fluids and Salt: Get plenty of both. Eight 8-ounce glasses water per day minimum. Take one 2 g salt tablet three times per day or increase salty foods significantly (caveat: if you have cardiac conditions discuss salt increase with cardiologist before increasing salt)

Constipation:

Step 1: Lifestyle/Dietary Modifications:

Water and Fiber:
Drink 8, 8 oz glasses of water/day

Diet: Add probiotics, extra virgin olive oil, fish oil

Increase foods rich in fiber include:
bran fiber
whole wheat products
lentils and beans
prunes or prune juice
dried apricots
chia Seeds

Rancho Recipe:
Recipe: Mix together one cup each of bran, applesauce, and prune juice
Instructions: take 2 tablespoons every morning; the mixture can be refrigerated for one week then discarded.

Remove Aggravating Factors: opioids, etc

Exercise: Do moderate exercise most days of the week

Set a Routine: schedule a time to sit on the toilet every day for a bowel movement. Even if one does not occur, the routine improves regularity.

Gain mechanical advantage: Elevate your legs using a stool when you sit on the toilet (squatty potty)

If constipation persists after Lifestyle/Dietary Modifications, continue those measures and move on to Medication Steps. Continue each medication for 2-4 weeks minimum. If somewhat helpful but constipation persists, add medicine from next category. If a category is not helpful at all, then stop that type of medication and start one from next category.

Step 2: Add daily Bulk laxative (fiber supplements: Fibercon, psyllium, Benefiber) -good water intake necessary for efficacy
Step 3: Add daily Emollient (lubricating laxative, like docusate)
Step 4: Add daily Osmotic laxative (polyethylene glycol) -good water intake necessary for efficacy
Step 5: Add stimulant laxative as needed (bisacodyl (Dulcolax), milk of magnesia or Senna *(these are rescue medications to be used if no bowel movement after 3-4 days (do NOT use regularly, will lose efficacy over time)*
Step 6: referral to gastroenterologist (GI) specialist for refractory constipation.

Dysphagia (swallowing problem)

Nonpharmacologic: position changes when eating, smaller amounts, slower, modify meal consistency. Swallow therapy and/or Lee Silverman Voice Technique (LSVT)

Gastroparesis: delayed stomach emptying →early satiety (feeling full too soon while eating), reduced appetite, weight loss

Step 1: Reduce medications that can worsen GI motility (opioids, anticholinergic medications)
Step 2: Discuss symptoms with your doctor. They may add domperidone (Canada), pyridostigmine, or another agent to improve motility.
Step 3: referral to a GI specialist

Dry Mouth: Dry mouth and drooling coexist in 30% of cases
Do: Work with your doctor to reduce or remove exacerbating medications.
Sip water frequently, let ice melt in your mouth, restrict caffeine intake, use a humidifier in sleeping area, suck on sugarless lemon drops or chew sugarless gum (sorbitol-based is good)
Don't: use mouthwashes with alcohol which can be drying

Saliva substitutes: Biotene, Xero-lube, Salivart, MoiStir and Orex, or Sodium carboxymethyl cellulose 0.5% aqueous solution: oral rinse used several times per day

Dry Lips:

Do: Use K-Y Jelly, Surgi-Lube or Hydrous lanolin (ask pharmacist) on lips to reduce dryness.
Don't: use petroleum or Vaseline based products which pull water from tissues making them dryer

Drooling:

Cause: reduced efficiency and frequency of swallowing
Nonpharmacologic: carefully swallow saliva at specific times, chew sugarless gum or use sugarless lemon drops to stimulate swallowing of saliva

Pharmacologic: Oral glycopyrrolate, sublingual atropine drops or ipratropium spray, Botulinum toxin injections (Botox) into the salivary glands are efficacious (Botox needs to be repeated every 3 to 6 months.

Urinary Dysfunction:

Do: Keep a bladder diary (~3 days): fluid intake, voiding frequency, time of each void, severity of urge to void, voided volumes, urine leakage episodes, pad usage. *A diary is helpful to document symptoms and monitor progress after behavioral changes / treatment*
Don't: Use anticholinergic medications (Oxybutynin (Ditropan), tolterodine (Detrol), solifenacin (Vesicare) in setting of cognitive/memory problems. Myrbetriq (mirabegron) is an effective alternative.
Nonpharmacologic: bladder training, fluid and diet management, pelvic floor therapy, biofeedback training, bedside commode or urinal for nighttime
Pharmacologic: multiple types of medication can be prescribed, the best one is based on your other medical problems.

Two for One Rx: duloxetine or milnacipran can be used to treat depression and has demonstrated efficacy for off label treatment of overactive bladder in PD.

Sweating

Drenching sweats occur predominately in *OFF* state or when *ON* with dyskinesias

Identify patterns: time of day, time since last dose of Parkinson's medication. Record and review with your Parkinson's provider as a dopamine medication change often helps reduce sweating episodes.

Lifestyle Modifications:
Identify: food or drinks triggers (i.e. alcohol, caffeine or spicy foods).
Use an antiperspirant
Avoid tight-fitting or synthetic (e.g. nylon) clothes.
Wear clothes made of natural fibers, such as cotton, or fabrics designed to absorb moisture.

Pharmacologic Treatments: Prescription antiperspirant with aluminum chloride (Drysol, Xerac Ac). Prescription creams. w/ glycopyrrolate. Antidepressants: amitriptyline helps, some SSRIs may worsen sweating.

NOTES: