

*em*Powered!®

Communication Tool



PMD Alliance

Parkinson & Movement Disorder Alliance

©PMD Alliance 2020





What PMD Alliance is All About

We bring an arms-open, hand-in-hand, “Yes, and...!” mentality to every aspect of our work. We believe that no breakthrough exists in a vacuum, and no person with a movement disorder ever rides the wave of this journey alone.

We’re a partnership-based organization wholly devoted to exuding inspiration - for those with a movement disorder, their care partners, adult children and the ecosystem that supports us all. It’s about listening and engaging in a people-powered conversation. We will inspire you to take new leaps and strengthen your personal care team.

To our core, PMD Alliance believes that no one with a movement disorder truly thrives by him/herself. Going forward, movement and connections become like manna that nourishes your best life. Every day becomes a team effort, and we want to be part of your team in three ways: through in-person events, community-based support, and online opportunities.

Using our continuum of services and programs (based on the Movement Disorder Care and Support Ecosystem© - found on the last page), you will always be close to PMD Alliance and our free (yes, FREE!) resources, no matter the distance. With hundreds of programs designed just for you, we hope you take time to connect.

How We Work

We see our job as providing tools (like this one), information, resources, and connections that give you easy access to information and inspiration. We want you to live with Parkinson’s, not for it, so our tools help you effectively focus on PD, then get on with living!

What We Believe

People are more than their disease.
Transparency is a cornerstone of trust.
Partnership offers collective success.
Sustainability is the essence of organizational health.
Stretching and risk taking are imperatives.

Connect with Us

www.PMDAlliance.org • info@pmdalliance.org
(800) 256-0966



SYMPTOMS TOOL

adapted from Bunch's Symptoms List

NAME: _____

Nothing is more important than communication when navigating Parkinson disease. At first glance, this emPowered!® booklet may look like it's a symptoms checklist, but it's really much more. It's a tool to help families, loved ones, and physicians communicate effectively with each other. With clear communication, it's much easier to navigate the ups and downs and physicians can more effectively address your concerns.

It should take no more than 10 minutes to complete each use of this tool. We strongly encourage every person to complete the checklist separately (person with Parkinson's, care partner/spouse, adult children, family/ friends). Once completed, meet together and discuss what each of you have noticed. After completing your discussion, fill out the Snapshot Tool and forward it to your doctor. Everyone will be on the same page. Ideally, you will complete this tool quarterly and have shared discussions at those times.

How to complete the tool

- + Review the various symptoms.
- + Place an **X** asterisk if you experience the listed symptom some of the time.
- + Place an **A** mark if you experience the listed symptom nearly all or all of the time.
- + Leave the box empty if you experience the listed symptom rarely, never, or it does not bother you.

The goal is to surface a handful of issues that present significant challenges impacting your quality of life. Care partners, your input is important too. Please fill out a separate document to identify which symptoms impact your quality of life or what concerns you the most.

Once each person has completed their list, sit down together and talk. When you recognize issues and challenges noted by one or more of you, it strengthens your "personal team" and improves your interaction with the rest of your care team.

Effective communication is transformative!

Let's DO this!

ACTIVITIES OF DAILY LIVING (ADL)

Date Date Date Date

Blank = rarely, never, or not bothersome • X = sometimes, somewhat bothersome
A = frequently, always, very bothersome

				Acid Reflux/Heartburn/Indigestion
				Appetite: increased or reduced
				Chewing/Choking: difficulties keeping food moving toward the throat, aspirate food into lungs
				Communication: slow at finding/remembering the right word - Aphasia
				Cramping/Burning/Pins & Needles: toes, legs, neck, etc -Dystonia
				Daytime Sleepiness: excessive - EDS/Somnolence
				 Drooling: excessive saliva - Sialorrhea
				Dry Mouth: excessively dry, cheeks may 'stick' to your teeth - Xerostomia
				Fatigue: physical/mental weakness
				Freezing in Position: temporary, feet stuck to floor, hands won't release - Akinesia
				Light Sensitivity: pupillomotor, more sensitive to light - Photophobia
				Nasal Draining: unexplained, often in just one nostril
				Numbness/Tingling: generally arms and/or legs
				Pain: burning, scalding, stabbing, insects crawling on the skin
				Sexual Dysfunction: men & women, less desire for sex, lower testosterone levels
				Sleep/Insomnia: awoken often, can't fall/stay asleep
				Sleep Apnea: snoring/stoppage of breathing
				Sleep Problems: frequent awakening/early awakening
				Smell - Loss of: can diminish to zero - Anosmia/Hyposmia
				Speaking: soft or low volume - Hypophonia
				Speech: hesitant/monotone/slurred, difficult articulation - Dysarthria
				Swallowing: difficulty swallowing, risk of aspiration - Dysphagia
				Sweating: increased or excessive, "night sweats" - Hyperhidrosis
				Temperature Sensitivity: hot and/or cold
				Thirst: excessive/sporadic/constant and extreme "dry mouth" - Polydipsia
				Turning/Rolling Over in Bed: difficulty turning and moving in bed
				Urination: frequently, incontinence, urgency, frequently at night - Nocturia
				Vision: blurred/double, depth perception, dry eyes, eye strain, light sensitivity - Diplopia
				Vivid Dreams: may act out, may become dangerous to self or others
				Writing Smaller: difficult to read - Micrographia

Other symptoms that I have questions or concerns about:

MENTATION, BEHAVIOR, MOOD

Date Date Date Date

Blank = rarely, never, or not bothersome • X = sometimes, somewhat bothersome
A = frequently, always, very bothersome

Date	Date	Date	Date	
				Aggression: hostile or violent behaviors or attitudes toward others
				Anxiety: worry, concern, apprehension, angst
				Apathy: lack of interest (ennui), enthusiasm, concern
				Cognitive Function: diminished problem solving, decision making
				Comprehension: difficulty understanding
				Delusions: misconceptions, misbelief not backed by reality, faulty judgment
				Dementia: impaired mental ability impacting daily activities, memory and reasoning
				Depression: despondency, dejection
				Fear: alarm, panic, terror, fright, dread, distress
				Frustration: exasperation, annoyance, vexation, irritation
				Grief: deep sorrow, sadness, anguish, distress, heartache, woe, despair
				Guilt: sense of wrongdoing, misconduct, shame, regret
				Hallucinations: seeing/hearing/sensing something not present
				Impulse Control: compulsive spending, eating, sex, gambling, hoarding, etc
				Inappropriate crying/laughing: tearfulness, outbursts of laughter - Pseudobulbar Affect
				Insecurity: lack of confidence, self-doubt, nervousness, uncertainty
				Internal Restlessness/Tremor: difficult to sit still - Akathisia (not Dyskinesia)
				Irritability: short tempered, testy, ill humor
				Memory Changes or Loss: slower at recalling words/ideas
				Mood Swings: abrupt changes in temperament, emotional instability
				Panic Attack: acute and disabling anxiety
				Self Esteem, (low): less confidence in one's own worth or abilities, self respect
				Sexual Desire (less): lacking motivation, need, attraction, lust
				Startle Easy: very easily surprised - Hyperekplexia
				Suspicious Thinking: unfounded fears, distrust of others, conspiracy mindset - Paranoia
				Thinking: slow and deliberate, impaired - Bradyphrenia
				Time Perception: difficulty determining time spans
				Worry: overthinking, brood, panic, lose sleep, fret, stew

Other symptoms that I have questions or concerns about:

Motor

Date Date Date Date

Blank = rarely, never, or not bothersome • X = sometimes, somewhat bothersome
A = frequently, always, very bothersome

Date	Date	Date	Date	
				Balance: movement loss, falling backwards - Retropulsion/Dysequilibrium/Ataxia
				Coordination: less coordination, especially fine motor - Ataxia
				Dyskinesia: involuntary movements, twitches, jerks, twisting, rocking
				Eyes: dry, decreased blinking, difficulty opening, blurred vision
				Facial Expression: "masked face," no expression - Hypomimia
				Foot and Toe Cramping: painful cramping - Dystonia possible
				Gait: Freezing of Gait (FOG) - sudden inability to move legs, small steps, can't move forward
				Muscle Jerks: muscle jerks or spasms - Dystonia
				Pill Rolling: rubbing the thumb with the forefinger - Pill Rolling Tremor
				Posture Instability: hunched, stooped over, problems standing/walking
				Restless Leg Syndromes (RLS) + Arms: constant moving of limbs
				Rigidity: less range of motion of arms, legs, and torso - Akinesia
				Rising from Seated Position: difficulty getting up, not in balance
				Slow Movement: slowness or limited range of movement - Hypokinesia/Bradykinesia
				Stiff Shoulder: frozen or painful shoulder
				Tremor (at rest): arms, face, hands, head, jaw, legs, voice
				Walking: foot drag usually on one side - no arm swing, shuffle, slow, stiff
				Weakness: arms and legs - Generalized Asthenia

Other Nonmotor

Date	Date	Date	Date	
				Allergies: increased number of allergies
				Back Pain (lower): pain from mild to severe aches, spasms
				Blood Pressure (low): BP drops when standing, dizzy, falls
				Bowels: incomplete elimination or absorption of nutrients, impaction
				Breath: shortness, shallow, panting, wheezing, hyperventilation - Dyspnea
				Constipation: bowel movement less than 3x/week or reduced frequency
				Digestion: difficulty fully digesting food - Gastroparesis
				Dizziness, Fainting, Lightheadedness, Vertigo
				Edema: swelling of legs, retention of excess water
				Heart Palpitations: heart races intermittently
				Nausea, Queasiness, Vomiting: with or without medication
				Neurogenic Orthostatic Hypotension: dizzy when standing
				Punding: continually taking something apart and putting it back together, repetitive
				Skin: dandruff, flaky, itchy, oily, rashes, red - Seborrhea, Shingles
				Tearing: excessive tearing for 20-40 seconds from only one eye or both

LET'S TALK ABOUT IT

Tips for communicating more effectively with your physician & medical team

It's not unusual to be slightly uncomfortable when talking with your doctor. In fact, research shows that many patients are often afraid to share concerns with their physicians out of fear that they will be perceived as a complainer. The tips below can help you and your loved ones communicate more fully and comfortably with your care team.

- + Most physicians find their greatest self-worth and value when they can help, but your doctor can't help you address issues that s/he doesn't know about. Telling the truth - good or bad - helps everyone get the most out of the visit, including your doctor.
- + Many people believe that their doctor will bring up all the issues that matter during an appointment. That may have been the case when a physician could spend 45 minutes or an hour with a patient, but it isn't the reality anymore. Doctors often need to rely on you to surface issues that they can then respond to.
- + Remember, it's a team effort. The person impacted by the disease, the care partner, adult children, and friends will all see different aspects of the disease. Getting and sharing input from a variety of sources can help a physician.
- + Synergy matters. It's important to develop a truthful, open connection with your physician. As in any long term relationship, trust and rapport make it easier to talk honestly to each other.
- + If you find it difficult to think of issues to talk about at your appointments, you can:
 1. Bring this booklet with you and use it as a talking guide.
 2. Make a copy of this booklet for your physician or ask the front desk staff to send the physician a note in advance of your appointment.
 3. Give a list of your concerns to the medical person that takes you to the exam room so your doctor is prepared when s/he comes in.
 4. Take notes while talking with the doctor. Later, when you want to recall the conversation, your notes will make it easier for everyone.
- + It's your health. You're in charge. You deserve reliable, trustworthy and responsive health care. Your part in that effort to openly share information about your condition, your concerns, your questions, and your goals.

Some phrases to get the conversation started:

- + Since my last appointment, these are the top three to five issues that have impacted my quality of life . . .
- + My number one thought/feeling/experience over the last three months has been . . .
- + Since my last appointment, these are three ways I've tried to bring more quality to my life . . .
- + My biggest worry since my last appointment has been . . .

MOVEMENT DISORDER CARE & SUPPORT ECOSYSTEM[©]

Parkinson & Movement Disorder Alliance (PMD Alliance), a nonprofit, independent organization, delivers high impact programs to the public, healthcare providers, and healthcare/residential facilities. With attention on the whole system, we re-ignite vitality, create resiliency, and strengthen connections.

