

Table S1. Categories/Themes From Free-Text Descriptions of Experiences During OFF Periods (N=2110)

General category or theme	Specific category or theme	Description of category or theme	Verbatim sample text for each (limit to 2–3)	n (%)
Motor symptom	tremors / tremulousness	Internal and external tremors and shakes	constant tremor in lower legs I get internal tremors that I do not experience during on times.	1038 (49.2)
	gait and freezing	mention of gait, freezing, shuffling, walking, dragging leg, falling, trepidation about falling, legs wobbly, initiation of walking, gait is sluggish	During off periods I have significant trouble ambulating. I shuffle my feet and my posture is not good. unable to step forward when standing frozen in place	535 (25.4)
	stiffness / rigidity	mention of stiffness, rigidity, tightness, physical tension in body	I start to stiffen up – especially neck and back. My hands are more rigid and my muscles stiffen.	430 (20.4)
	slowness	slow movement, mention of slowness (but not slow cognition), sluggish movements	feels like I'm moving in slow motion I feel draggy and slower to perform tasks.	358 (17.0)
	balance	balance issues, imbalance, unsteady, lose balance	My balance is compromised and I feel precarious. My balance is very unsteady, exhibited as some hesitation when walking a straight line.	320 (15.2)
	coordination / motor control	related to lack of control of movements, not moving well (nonspecifically stated), controlled movement, clumsy, movements not as smooth, fluid (in relation to movements)	Fine motor skills are slower, more awkward, less controlled. I cannot control my left arm and my right toes, it feels awkward almost painful.	258 (12.2)
	dystonia	toe curling, use of word dystonia, pulling, curling, foot twisting?	get major dystonia [sic] in one leg – leg contractions every 6 seconds or so and foot cramp Toes on my right foot curl when I am tired or at the end of my medication dose.	106 (5.0)
	dyskinesia	Head bobbing?	trouble with gait and more dyskinesia [sic] and head bobbing I have a lot of twisting (dyskinesia [sic]) of my legs especially the right side.	58 (2.7)
	posture	Hunching, postural stability, can't straighten up	may shuffle and tend to lean forward and have to concentrate more to maintain my posture posture is more slumped, feels like there is no core strength	48 (2.3)
Nonmotor symptoms	fatigue	energy drops, low energy, tired, drained, tiredness, I feel sluggish, I get sluggish	I feel like I am weighted down, tired, and I get fatigued quickly. tiredness that leaves me feeling on the verge of exhaustion, this usually occurs after strenuous activities	397 (18.8)
	mood / anxiety	anxiety, blues, unmotivated, depression, quiet/withdrawn, nervous agitation, moody or mood swings, heightened emotions	The anxiety is very uncomfortable. I get more emotional, cry more easily.	318 (15.1)
	cognitive symptoms	trouble focusing, attention, concentration, brain fog, not sharp, feel dumb, memory, slow thinking, brain feels sluggish	inability to focus slow cognitive processing I have trouble processing information.	327 (15.5)
	pain / ache / cramping	cramping, headache, muscle spasm	I get cramps in my left leg and foot after a while. The muscles in my back spasm sometimes for an hour or more. I also have pain in my lower right back and have trouble walking while off.	303 (14.4)
	mouth, speech, face symptoms	speech related, low voice, soft voice, drooling, mention of saliva, speech slurred, hoarse voice, facial movements, difficulty swallowing	facial masking, changes in speech volume frozen face with drooling	221 (10.5)
	sensory symptom (excluding pain)	burning sensation, RLS, restlessness, hands go numb, fidgety, jittery, twitching, tingling, feel cold, heaviness, paresthesia, jerking	can't feel the bottom of my feet, I'm cold and shivering minor loss of feeling in tips of fingers on right hand, sensation of reduced feeling in soles of feet a heavy or weighted feeling in arms and legs	140 (6.6)
	dizziness	dizzy, dizziness, light-headed	dizzy and unstable when walking start to feel dizzy/lightheaded (not vertigo)	50 (2.4)
	other symptoms	pounding in ears, teeth clenching, nausea, sleeplessness, insomnia, incontinence, hot flashes, appetite, difficulty breathing, malaise/general discomfort, swaying, bladder issues, uneasy feeling, noise sensitivity, psychosis, night terrors, floating, claustrophobia, swelling, nonspecific Parkinson's symptoms, tachycardia, vision	constant swaying of upper body I also have a systemic feeling of slight illness. some nausea and upper forehead sweating	203 (9.6)
Phenomenon of fluctuation	time / timing	mentioning time, including how long meds last, time of day, diurnal variations, schedule, randomly, time of triggering events, timing of meds	Wake up ON, take morning meds ON, then comes an OFF period for 15 minutes to half-hour. I have one or two a day, usually in late afternoon. I am learning that previously small amounts of stress now can dramatically affect my OFF periods.	356 (16.9)
Functional consequences	functional consequences (not including walking)	trouble with ADL such as difficulty dressing, reading, difficulty typing, handwriting changes, difficulty screwing small screw, writing, applying makeup, brushing teeth, using silverware, small penmanship, standing from chair	As for typing or using a fork to eat, it is slow and frustrating. Forget about using a knife! difficulty with shaving and brushing my teeth	184 (8.7)
Not classifiable		nonspecific response such as "physical" or "emotional" without further description		23 (1.1)

ADL, activities of daily living; RLS, restless legs syndrome.