

Supplementary Material

People with Parkinson's Disease: What Symptoms Do They Most Want to Improve and How Does This Change with Disease Duration?

Supplementary Table 1. Scheme for interpreting survey responses. Table shows in the right hand column the free text terms used by respondents to describe symptoms or issues and how these were interpreted and recorded in the left hand column.

Symptom	Terms used by survey respondents
Movement	movement, mobility, fluid movements, move freely, move normally, getting out of chair, motor function, moving in confined spaces, flexibility, upper limb movements, control of my legs, hanging arm, right leg, restricted movement, lack of foot dorsiflexion, overgripping, body control
Moving in bed	turning/moving in bed
Walking	walking, scuffing feet, shuffle, gait, dragging foot, step, stumble, arm swing, limping, trip, natural arm swing while walking/running
Slowness	slowness of movement, bradykinesia, speed, faster, faster pace, quicker
Stiffness	stiffness, rigidity, seizing up
Posture	posture, leaning, neck position, pisa syndrome, head drop
Fitness	stamina, body fitness, ability to exercise, ability to walk a (reasonable) distance / further, swimming, tennis, hike, athletic ability, riding a bike, *specific mention of ability to do other exercise-based activities*, dog-walking
Weakness	weakness, loss of power, loss of strength, muscular problems
Freezing	freezing, freezing of gait, festination, hesitation, feet sticking, able to move feet
Balance	balance, stability, unsteady, wobbly, ability to descend stairs in safety, coping with uneven surfaces
Falls	falls, falling, fear of falling
Dexterity	dexterity, fine movement, hand movement, typing, handwriting, motor function in hand, (loss of) hand control, handle clothing / cutlery, clumsiness, motor skills

Facial expression	facial expression, smiling, masking, lop-sided expression, facial spasm, facial stiffness, facial movement
Coordination	coordination, controlled movement
Tremor	tremor, shaking, trembling, internal shaking, nodding head/chin, quivering lips
Fatigue	Fatigue, fatigue of muscles, muscle fatigue, dullness and heaviness of limbs
Tiredness	tiredness, tired, drowsiness, weariness, tiredness after exercise, tired legs, tired and weary legs
Lack of energy	lack of energy, exhaustion, lethargy
Sleep	sleep disorders, insomnia, deprivation, quality, vivid dreams, disturbed nights, thrashing around in bed, sleeplessness, disturbed sleep, night disturbance, stop dreams, lack of sleep at night
Daytime sleepiness	falling asleep unexpectedly / when you don't want to, sleepiness as a side effect of medication, fall asleep within minutes of sitting down, ability to stay awake during the day, doziness, sleepiness
Cognitive impairment	cognitive ability, (loss of) concentration, clarity of thought, mental fog, slowness of thought, confusion, alertness, speed of thought, executive function, recall, coordination (mentally), not being able to think of the right words
Memory	memory, forgetfulness, remembering things
Dementia	dementia
Speech	speech, articulation, voice, communication, voice, when talking to others, confusion of speech, difficulty holding a conversation
Eating and Swallowing	swallowing, choking, (difficulty) eating, food, feeding
Saliva problems	drooling, dribbling, dry mouth, discoloured (yellow) saliva
Incontinence	incontinence, continence
Bladder	nocturia, bladder control, urinary problems, hold to get to the toilet, urinary symptoms, urinary urgency, overactive bladder, urinary tract infection, poor and messy passing
Bowel	constipation, bowel normality, bowel movements, digestive problems, crashing because of constipation meds not working

Pain	pain, ache, pain relief, discomfort, muscular pain, ear-ache
Dystonia	dystonia, cramps, spasm, twisting, foot turning over, night cramps
Unpleasant sensation	numbness, pins and needles, burning sensation, creepy crawlies, restlessness
Restless legs	Restless leg, able to sit still
Depression	depression, emotionally down,
Mood	(change in) mood, low mood, positive outlook, grumpiness, mood swings, anger, frustrated, feel normal, feeling that life's passing me by,
Apathy	apathy, lack of motivation, disinterest, failure to carry out tasks, loss of enthusiasm
Psychological impact	psychological impact, personality changes, accepting diagnosis, embarrassment, people to stop thinking you are incapable because you have Parkinson's, self-conscious, worrying / fear about the future, being less focused on small details, worry about my ability to care for myself in the future, fear of deterioration
Anxiety	anxiety, stress, nervousness, panic attack, stress levels, cope with stress, nervousness, rumination,
Confidence	loss of confidence, confidence, self-worth
Hallucinations and Psychosis	hallucinations, paranoia, delusions
Side effects of medication	side effects, nausea, rash / itchiness, sleepiness as a side effect of medication (also captured in daytime sleepiness), apraxia of the eyelid opening from sinemet
Dyskinesia	dyskinesia, jerky movements, uncontrolled movements, involuntary movements, be able to sit still
Impulsive and compulsive	impulsive and compulsive behaviour
Medication wearing off	medication wearing off, off periods, improved 'on' time, coming down, variability, unpredictability, fluctuations
Eyes and Vision	blepharospasm, eye sight, vision, double vision, focussing *in relation to vision*, opening eyes,
Sense of smell	smell, sense of smell

Thermoregulation	Body-burning up, feeling cold, temperature control, sensitivity to cold, overheating, sweating
Sexual	ED (erectile dysfunction)
Skin	eczema
Breathing	breathing, improving my breath control
Nose	runny-nose
Heart and blood pressure	Blood pressure, heart-rate, dizziness, lightheadedness

Other, out-of-scope, responses

Uncategorised	Unclear/vague responses
Cure	Cure, stop/halt/reverse progression, not have Parkinson's anymore
Better treatments	Better, longer lasting treatments, fewer side effects, more effective
Better care	Improved diagnosis / management, access to nurses/therapists, dietary advice/management
Maintaining independence	Independence, ability to work, ability to drive, ability to take care of myself, reliant on others, loss of independence