

The Parkinson's Disease Composite Scale



My PD Journey has developed a new Parkinson's Disease Composite Scale (PDCS) which measures the severity of symptoms experienced by people with Parkinson's in a timely way. It combines motor symptoms, non-motor symptoms, treatment-related complications and disability. Designed to complement existing scales, the PDCS is simple and relatively fast to use.

The rater-based, 17-item Composite Scale assesses the severity of the most frequent and burdensome manifestations of Parkinson's disease. They are grouped into four dimensions:

- motor signs;
- non-motor symptoms;
- therapy complications;
- disability.

Motor symptoms

Bradykinesia:	Score	(Total of finger tapping, alternating hand movements, legs agility, total impression of body bradykinesia)
Absent	0	Symptom not present.
Mild	1	Minimal slowness, giving movement a deliberate character; could be normal for some persons. Possibly reduced amplitude.
Moderate	2	Mild degree of slowness and poverty of movement which is definitely abnormal. Alternatively, some reduced amplitude.
Severe	3	Moderate slowness, poverty or small amplitude of movement.
Very severe	4	Marked slowness, poverty or small amplitude of movement.

Tremor:	Score	(Total of four limbs)
Absent	0	Symptom not present.
Mild	1	Slight and infrequently present.
Moderate	2	Mild in amplitude and persistent. Or moderate in amplitude, but only intermittently present.
Severe	3	Moderate in amplitude and present most of the time.
Very severe	4	Marked in amplitude and present most of the time.

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Gait:	Score	
Absent	0	Symptom not present.
Mild	1	Walks slowly, may shuffle with short steps, no festination or propulsion.
Moderate	2	Walks with difficulty, little or no assistance, some festination, short steps or propulsion.
Severe	3	Severe disturbance, frequent assistance.
Very severe	4	Cannot walk.

Balance/postural stability:	Score	
Absent	0	Symptoms not present.
Mild	1	Walks without help, recovers unaided at pull test.
Moderate	2	Walks with help, would fall if not caught at pull test.
Severe	3	Walks with help, falls spontaneously at pull test.
Very severe	4	Wheelchair bound, unable to stand.

Freezing:	Score	
Absent	0	Symptom not present.
Mild	1	1-2 seconds – very rarely.
Moderate	2	3-10 seconds – rarely.
Severe	3	11-30 seconds – often.
Very severe	4	≥31 seconds – always.

Nocturnal akinesia:	Score	
Absent	0	Symptom not present.
Mild	1	Mild loss of the ability to move (10-20% of the night).
Moderate	2	Moderate loss of the ability to move (21-40% of the night).
Severe	3	Severe loss of the ability to move (41-60% of the night).
Very severe	4	Very severe loss of the ability to move (61-100% of the night).

Non-motor symptoms (in the past 2 weeks)

Fatigue:	Score	
Absent	0	Symptom not present.
Mild	1	Fatigue interferes very rarely with physical functioning/carrying out duties/responsibilities.
Moderate	2	Fatigue interferes rarely with physical functioning/carrying out duties/responsibilities.
Severe	3	Fatigue interferes often with physical functioning/carrying out duties/responsibilities.
Very severe	4	Fatigue interferes always with physical functioning/carrying out duties/responsibilities.

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Urinary:	Score	
Absent	0	Symptom not present.
Mild	1	Very rarely urgency and frequency day/night.
Moderate	2	Rarely urgency and frequency day/night.
Severe	3	Often urgency and frequency day/night, rarely loss of urine.
Very severe	4	Always urgency and frequency day/night, frequent loss of urine.

Cognitive impairment:	Score	
Absent	0	Symptom not present.
Mild	1	Occasional forgetfulness with partial recollection of events and no other difficulties.
Moderate	2	Moderate memory loss, with disorientation and moderate difficulty handling complex problems. Mild but definite impairment of function at home with need of occasional prompting.
Severe	3	Severe memory loss with disorientation for time and often to place. Severe impairment in handling problems.
Very severe	4	Severe memory loss with severe spatio-temporal disorientation. Unable to make judgments or solve problems. Requires much help with personal care. Cannot be left alone at all.

Depression/anxiety:	Score	
Absent	0	Symptoms not present.
Mild	1	Periods of sadness or anxiety greater than normal, never sustained for days or weeks.
Moderate	2	Sustained depression or anxiety (1 week or more).
Severe	3	Sustained depression with vegetative symptoms (insomnia, anorexia, weight loss, loss of interest) or sustained anxiety.
Very severe	4	Sustained depression with vegetative symptoms and suicidal thoughts or intent.

Symptomatic orthostatic hypotension:	Score	
Absent	0	Symptom not present.
Mild	1	Very rare dizziness/high headedness/feeling faint/generalised weakness.
Moderate	2	Rare dizziness/high headedness/feeling faint/generalised weakness.
Severe	3	Often dizziness/high headedness/feeling faint/generalised weakness and occasional loss of consciousness.
Very severe	4	Always dizziness/high headedness/feeling faint/generalised weakness and frequent loss of consciousness.

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Hallucinations or thought disorder (due to drug intoxication or dementia): **Score**

Absent	0	Symptoms not present.
Mild	1	Vivid dreaming or hallucinations.
Moderate	2	“Benign” hallucinations with insight retained.
Severe	3	Occasional to frequent hallucinations or delusions; without insight; could interfere with daily activities.
Very severe	4	Persistent hallucinations, delusions or florid psychosis. Not able to care for self.

Treatment complications: (in the past 2 weeks)

Dyskinesia: **Score** (or if present, rate the severity of camptocormia and/or Pisa syndrome)

Absent	0	Symptom not present.
Mild	1	Dyskinesia present $\leq 25\%$ of on-time, or more but not interfering with daily activities .
Moderate	2	Dyskinesia present 26-50% of on-time, mildly interfering with daily activities.
Severe	3	Dyskinesia present 51-75% of on-time, or less but interfering with daily activities.
Very severe	4	Dyskinesia present $\geq 76\%$ of on-time and interfering with daily activities.

Dystonia: **Score**

Absent	0	Symptom not present.
Mild	1	Dystonia present less than 30 minutes a day.
Moderate	2	Dystonia present less than 60 minutes a day.
Severe	3	Dystonia present less than 2 hours a day, with pain.
Very severe	4	Dystonia present more than 2 hours a day, with severe pain.

ON/OFF: **Score**

Absent	0	Symptom not present.
Mild	1	Time spent in the OFF state: $\leq 25\%$ of waking day; fluctuations impact on a few activities.
Moderate	2	Time spent in the OFF state: 26-50% of waking day; fluctuations impact on some activities.
Severe	3	Time spent in the OFF state: 51-75% of waking day; fluctuations impact on many activities.
Very severe	4	Time spent in the OFF state: $\geq 76\%$ of waking day; fluctuations impact on all the activities.

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Dopamine dysregulation syndrome:

Score

Absent	0	Symptom not present
Mild	1	Very rare auto-medication/mood disturbance/violent behaviour/compulsive behaviour.
Moderate	2	Rare auto-medication/mood disturbance/violent behaviour/compulsive behaviour.
Severe	3	Often auto-medication/mood disturbance/violent behaviour/compulsive behaviour.
Very severe	4	Always auto-medication/mood disturbance/violent behaviour/compulsive behaviour.

Disability

Disability level: Score

Absent	0	Able to perform daily activity without problems.
Mild	1	Limitations to perform exigent or instrumental daily activities.
Moderate	2	Limitations to perform basic daily activities.
Severe	3	Needs help to perform some basic daily activities.
Very severe	4	Dependent of other persons to perform all basic daily activities.

If you are a healthcare professional and you have used the Parkinson's Disease Composite Scale (PDCS), we would kindly ask you to complete a short survey here: www.surveymonkey.com/r/PDCSfeedback

The answers to this survey will provide the European Parkinson's Disease Association (EPDA) with valuable feedback which will be used to further develop the PDCS.

