

# MY PD JOURNEY

POSITIVE PROGRESS FOR  
PEOPLE WITH PARKINSON'S



## THE PARKINSON'S DISEASE COMPOSITE SCALE

### WHAT IS MY PD JOURNEY?

My PD Journey is a European multi-stakeholder coalition bringing together umbrella healthcare organisations across Europe, together with high-profile Parkinson's neurologists, people with Parkinson's, carers and members of the multidisciplinary healthcare team under the lead of the European Parkinson's Disease Association (EPDA).

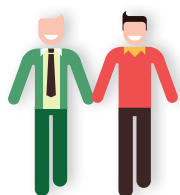
### WHAT IS THE PARKINSON'S DISEASE COMPOSITE SCALE (PDCS)?



The My PD Journey coalition has developed the Parkinson's Disease Composite Scale (PDCS) – a new and simple scale which measures the severity of symptoms experienced by people with Parkinson's in a timely way. The PDCS provides a comprehensive overview of motor and non-motor symptoms and enables clinicians to monitor the individual's condition.

### WHY DEVELOP A NEW SCALE?

Existing scales used by neurologists currently explore different aspects of Parkinson's, but do not offer a comprehensive overview of the individual's condition. The development of the PDCS was therefore needed as it combines motor symptoms, non-motor symptoms and treatment-related complications. Crucially, it is designed to complement – rather than replace – existing scales by offering a comprehensive view of Parkinson's. In addition, the scale grades the relative importance of particular symptoms, taking into account people with Parkinson's perspectives, which are critical in the delivery of timely and effective treatment and care.



### WHO LED THE DEVELOPMENT OF THE PDCS?

Developed by clinicians for clinicians, the development of the PDCS was led by Parkinson's specialist neurologists Pablo Martinez Martin (Spain), Fabrizio Stocchi (Italy) and Fabiana Radicati (Italy) in collaboration with the My PD Journey coalition.

### WHAT ARE THE BENEFITS OF THE PDCS FOR HEALTHCARE PROFESSIONALS?



The PDCS is designed as a tool to be used primarily by neurologists but also by other healthcare professionals working with people with Parkinson's. Conducted in roughly 20 minutes, it makes a consultation between the person with Parkinson's and their neurologist faster than is usually the case, therefore freeing up time within the consultation to discuss other critical aspects important to the person with Parkinson's.



### HOW SHOULD THE PDCS BE USED?

The rater-based, 17-item PDCS assesses the severity of the most frequent and burdensome manifestations of Parkinson's disease. They are grouped into four dimensions: motor (1) and non-motor (2) symptoms, therapy complications (3) and disability (4). Motor symptoms are examined at the time of evaluation by a healthcare professional. Non-motor symptoms and treatment complications are evaluated for severity based on the patient's experience over the two weeks prior to the assessment. Throughout the scale, each item is anchored by five severity levels: absent; mild; moderate; severe, and very severe. While a score of 0 is considered the absence of the specific symptoms, some items range from 0 to 4 and others from 0 to 7 to account for the different levels of impact each symptom has on the patient. A total score can be calculated for each domain by summing its component parts, and a total score for the PDCS can be calculated by summation of the domain scores.

### HOW AND WHEN WILL THE PDCS BE VALIDATED?

Work began on the PDCS in September 2014 with an initial pilot study and a first validation study completed in 2015. The first validation study indicated that the scale was a feasible, acceptable, reproducible, valid and precise instrument for a more comprehensive measurement of Parkinson's symptoms. A second and more extensive validation study, aimed at reaffirming the first study's findings, was completed in July 2018 and is currently awaiting publication. This study involved 22 centers and 700 patients across 14 countries. In parallel, My PD Journey is working with neurological and clinical bodies, policymakers, and patient organisations to promote the use of this new, innovative tool across Europe.



## HOW CAN I LEARN MORE?

My PD Journey is a first-of-its-kind multi-stakeholder project for people with Parkinson's in Europe, led by the EPDA. The Parkinson's Disease Composite Scale (PDCS) is a My PD Journey project, and as such belongs to the EPDA.

Visit [www.epda.eu.com](http://www.epda.eu.com) for more information about Parkinson's disease and the EPDA work programme. For more information on The Parkinson's Disease Composite Scale (PDCS), go to [parkinsonscompositescale.com](http://parkinsonscompositescale.com) or email [secretariat@mpdj.eu](mailto:secretariat@mpdj.eu).

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