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MARKET RESEARCH

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## The Difficult Lives of Patients with Parkinson's Disease

- 75% of patients report a daily three-hour average when the effects of medication "wear off" and significant symptoms of their Parkinson's disease (PD) return.
- While PD is usually characterized by motor complications (e.g., tremor), this survey reveals that two of the top three most disabling symptoms are non-motor symptoms, including loss of energy and pain.
- Cumulative effects of increasing non-motor symptoms in PD patients are more strongly related to negative emotion than the cumulative effects of increasing motor symptoms.
- On average, PD patients report taking 19.25 pills per day (range: 3 to 100) and most (59%) report having difficulties swallowing.
- An ideal PD medication, PD patients say, would result in fewer side effects, a more predictable response, and improvement in daily "off" time.

A new survey of 228 patients with Parkinson's disease explored the disabling aspects of their disease, and how they are affected physically, psychologically and emotionally in their daily lives. The results are not reassuring. While their medications can improve some of their symptoms, they do not control the symptoms all the time. The period of time when symptoms are uncontrolled in between medication doses is known as "wearing off" or "off" time. It is during this "off" time that patients make accommodations to their daily activities, significantly affecting their quality of life.

This survey was sponsored by WE MOVE (Worldwide Education and Awareness for Movement Disorders) and funded by Amarin Pharmaceuticals, a specialty pharmaceutical company focused on bringing treatments to market for patients with movement disorders including Parkinson's disease and Huntington's disease.

### What is Parkinson's Disease?

Parkinson's Disease (PD) is a chronic, progressive disorder of the nervous system that occurs most commonly in the middle-aged and elderly; only 10% of sufferers are under the age of 40. An estimated one million Americans are believed to suffer from PD, and approximately 50,000 new cases are reported annually.

Parkinson's Disease occurs when neurons in the substantia nigra die or become impaired. The loss of these neurons results in a reduction in dopamine, a neurotransmitter implicated in coordinating nerve and muscle cells involved in movement. Consequently, PD patients suffer from a variety of motor symptoms including tremor, rigidity, freezing, and difficulty swallowing (*dysphagia*). In addition, a variety of non-motor symptoms frequently occur among PD patients, including anxiety, depression, sleep disturbances, and sexual difficulties.

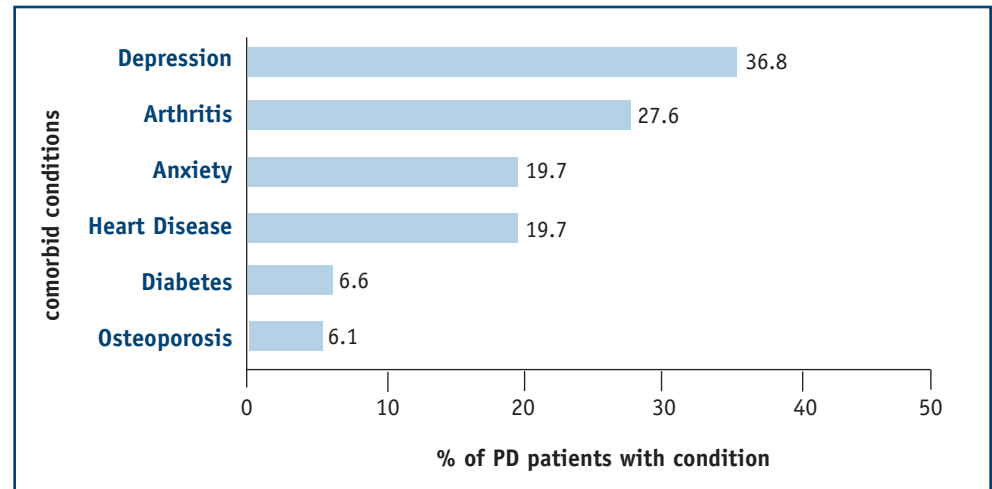
### Disease History and Comorbidities

The majority of Parkinson's disease patient respondents in this survey had been diagnosed with Parkinson's disease for just over 10 years, but some have had the diagnosis for much longer – up to 30 years. In addition, all survey respondents had been diagnosed with Parkinson's disease for a minimum of five years, as a requirement of participation in the survey.

Respondents reported a number of concomitant diagnoses along with their Parkinson's disease, including depression (37%), arthritis (28%), anxiety (20%) and heart disease (20%), and significant but much smaller percentages have been diagnosed with diabetes (7%) and osteoporosis (6%).

## Disease History

On average, survey respondents have been diagnosed with Parkinson's disease for 10.4 years (range: 5 to 30 years), and have been taking prescription medication to treat their PD for 9.9 years. The most common comorbid condition is depression, followed by arthritis.



## “Wearing-off” Symptoms and Effects

A major problem with current medications for Parkinson's disease is that they do not control the symptoms all the time. Seventy five percent of these patients experience an average of three hours a day in which the effects of their medications “wear off” and symptoms of their disease return.

Although they are not the most frequently occurring symptoms, loss of energy, walking problems and pain are the most disabling symptoms these PD patients experience during their “off” time.

Increases in both motor symptoms (e.g., handwriting problems, overall slowness and falling) and non-motor symptoms (e.g., loss of the sense of smell, sleep disturbances and anxiety) are associated with higher levels of “negative emotions”, such as depression, hopelessness and anxiety. Increases in non-motor symptoms are more strongly associated with increases in “negative emotions.”

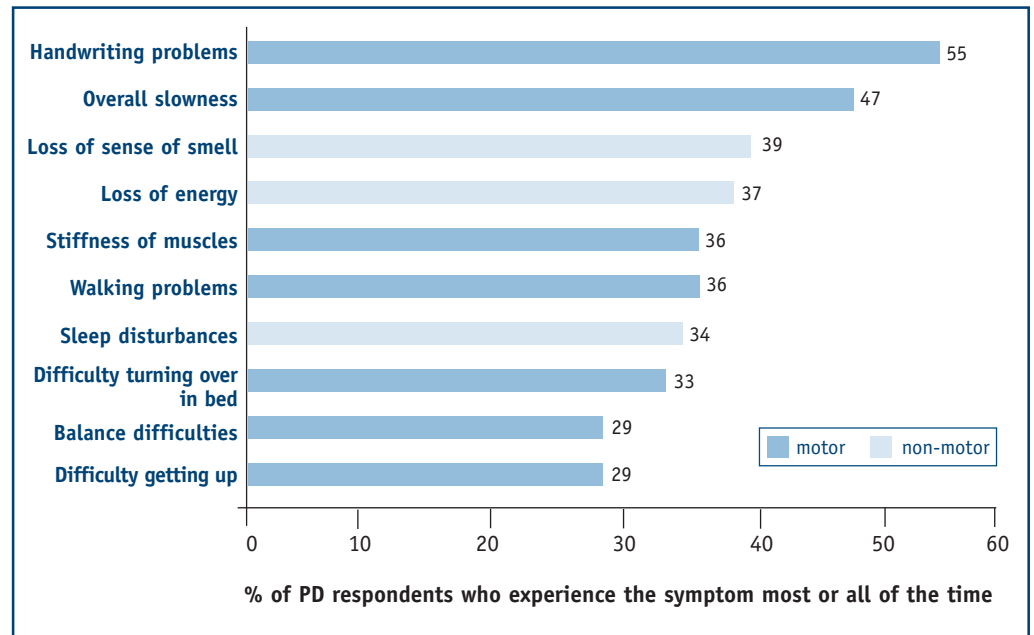
Nearly 60% of PD patients report that they have difficulty swallowing and 44% have difficulty swallowing their medications. This is important because PD patients take an average of 19 pills per day and in order to cope with their swallowing difficulties, patients report having to crush their pills, dissolve them in liquid, or skip taking their medications altogether.

Most commonly, PD patients cannot work or walk as well during “off” time, they limit their driving, and they cut back on daily activities, such as cooking and reading.

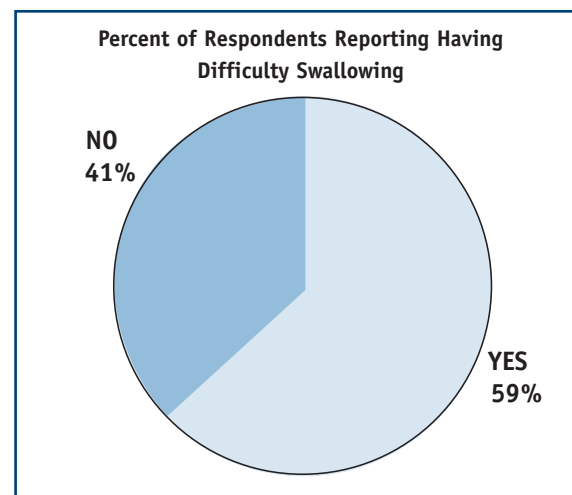
Seven of the top 10 most frequently experienced symptoms are motor systems. Three (loss of energy, sleep disturbances and loss of sense of smell) are non-motor symptoms.

## What symptoms are most frequently experienced during “off time”?

Seven of the top 10 most frequently experienced symptoms are motor symptoms. Three (loss of energy, sleep disturbances, and loss of sense of smell) are non-motor symptoms.



## Swallowing Difficulties In Parkinson’s Patients



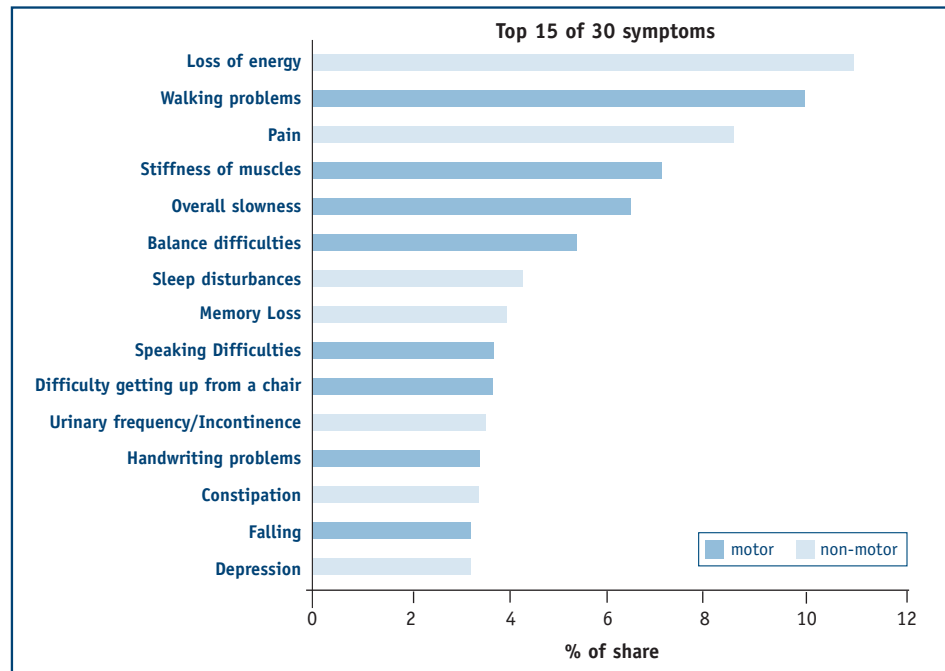
## Which symptoms are most disabling?

When asked to rate their symptoms according to how disabling they are, a different picture emerges. The most disabling symptoms are not the same as the most frequent.

Loss of energy, ranked fourth in frequency, emerges as the most disabling symptom. Handwriting problems, experienced most frequently during “off” time ranked only 12th in terms of being disabling.

Pain and memory loss were ranked third and eighth in terms of being disabling, but were not among the 10 most-frequently experienced symptoms.

## What symptoms are most *disabling* during “off time”?

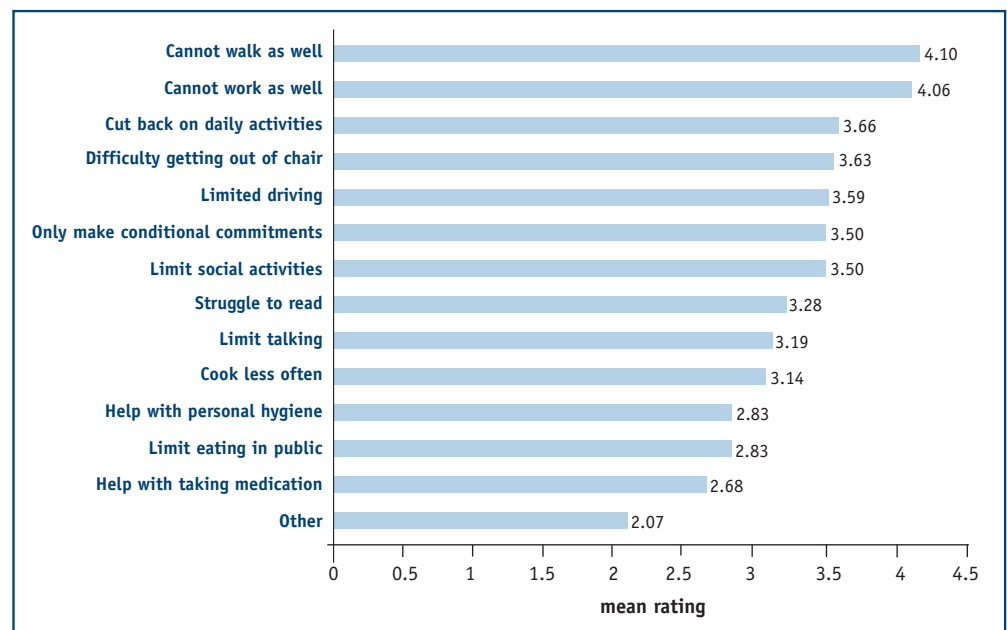


## The impact of “wearing off” symptoms on Parkinson’s disease patients

“Wearing off” changes the way Parkinson’s patients live their lives and alters their daily routines. Patients report they cannot walk or work as well as they would like. Also, patients cut back on their daily activities, have difficulties getting into and out of chairs and limit their driving.

Pain and memory loss were ranked third and eighth in terms of being disabling, but were not among the 10 most-frequently experienced symptoms.

## The impact of “wearing off” symptoms on PD patients, and the accommodations they make



## Current and future treatment of Parkinson’s disease

On average:

- These patients take 19 pills every day.
- 60% of these pills are for Parkinson’s disease and the other 40% are taken for other conditions.
- These patients take medication for Parkinson’s disease 4.5 times a day.

However, these averages are based on a very wide variation in the numbers of pills, and the frequency with which they are taken. Some patients take up to 100 pills a day, and some take Parkinson’s disease medications 12 times a day.

Most (68%) of these patients sometimes forget to take their medications. Two out of five (41%) do so once a week or more often.

Most of these Parkinson’s disease patients are at least slightly satisfied with their treatments; 58% rate them 5, 6, or 7, where 7 is completely satisfied. Only 22% rate their treatments 1, 2, or 3 where 1 is completely dissatisfied.

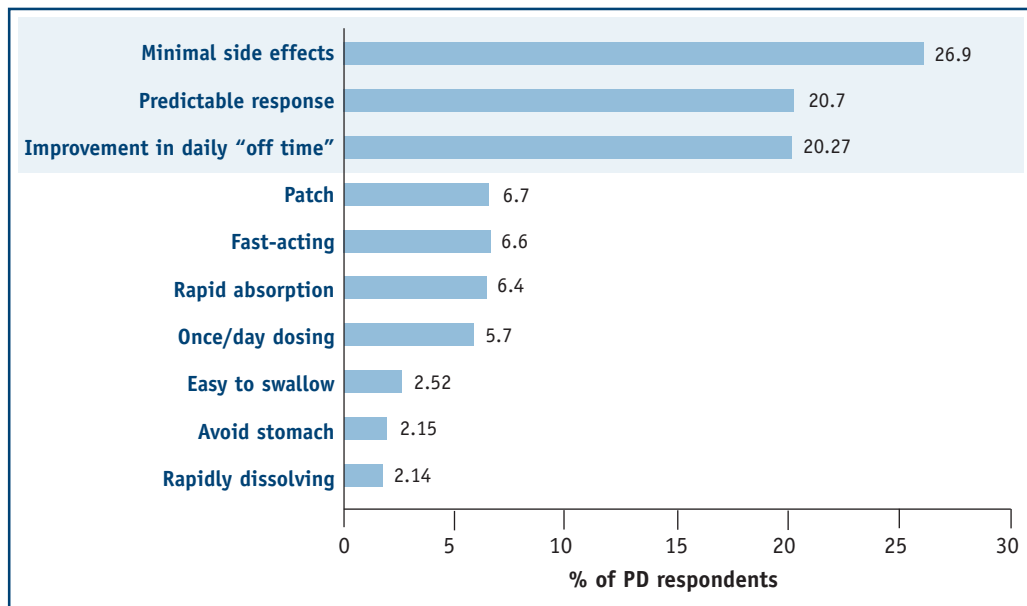
**Table 1**  
Current Parkinson’s Disease Treatment (On Scale of 1 to 7)

SCALE		%	
7	Completely satisfied	13%	} 58% satisfied
6		28%	
5		17%	
4	Neither satisfied nor dissatisfied	19%	
3		12%	
2		8%	} 22% dissatisfied
1	Completely dissatisfied	3%	

These Parkinson’s disease patients would welcome many changes and improvements to their current treatment. In particular, they would like to take fewer pills, take them less often, and have fewer side effects such as drowsiness and dyskinesias (involuntary movements). Furthermore when Parkinson’s patients are asked which characteristics they would choose for an ideal Parkinson’s treatment, there is a clear preference for a treatment with minimal side effects, predictable response and improvement in daily “off” time.

### What is an ideal PD medication?

The results of a pair-wise ranking exercise revealed clear preferences for the most important elements of an ideal PD medication: minimal side effects, predictable response, and improvement in daily “off time.” These three items were considered 3 to 4 times more important than the next elements in the list.



The full survey report may be obtained by emailing: [survey@amarinpharma.com](mailto:survey@amarinpharma.com)

### Methodology

This study was conducted online within the United States between August 19 and September 8, 2003 among a sample of 228 U.S. adults, aged 18 years and over, who have had Parkinson’s disease for a minimum of five years. Responses were weighted by age and gender using current U.S. epidemiological data.

Patients with Parkinson’s disease were recruited from four different sources. The largest number of survey respondents was provided through the People Living With Parkinson’s website. People Living With Parkinson’s is a nonprofit organization founded by two Parkinson’s disease patients, and dedicated to educating and supporting Parkinson’s disease patients. The content of the online questionnaire was developed from research gathered during a series of focus groups with Parkinson’s disease patients and with the help of medical advisors and WE MOVE, a nonprofit organization focusing on movement disorders, including PD.

In theory, with a probability sample of this size, one can say with 95 percent certainty that the results have a statistical precision of plus or minus 6.4 percentage points of what they would be if the entire population of those with Parkinson’s disease in the United States had been polled with complete accuracy. Unfortunately, there are several other possible sources of error in all polls or surveys that are probably more serious than theoretical calculations of sampling error. They include refusals to be interviewed (nonresponse), question wording and question order, interviewer bias, weighting by demographic control data and screening (e.g., for likely voters). It is impossible to quantify the errors that may result from these factors. This online sample was not a probability sample.

*These statements conform to the principles of disclosure of the National Council on Public Polls.*

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