

# CHANGING THE CONVERSATION: DISCUSSING PARKINSON'S SYMPTOMS

## WHAT IS PARKINSON'S DISEASE?



PARKINSON'S DISEASE IS A PROGRESSIVE NEURODEGENERATIVE DISORDER THAT CURRENTLY HAS NO CURE<sup>1,2</sup>

APPROXIMATELY

**4-5**

MILLION PEOPLE WORLDWIDE

**1**

MILLION PEOPLE IN THE U.S.

ARE LIVING WITH PARKINSON'S<sup>3-5</sup>

**60**



IS THE AVERAGE AGE OF ONSET<sup>3</sup>

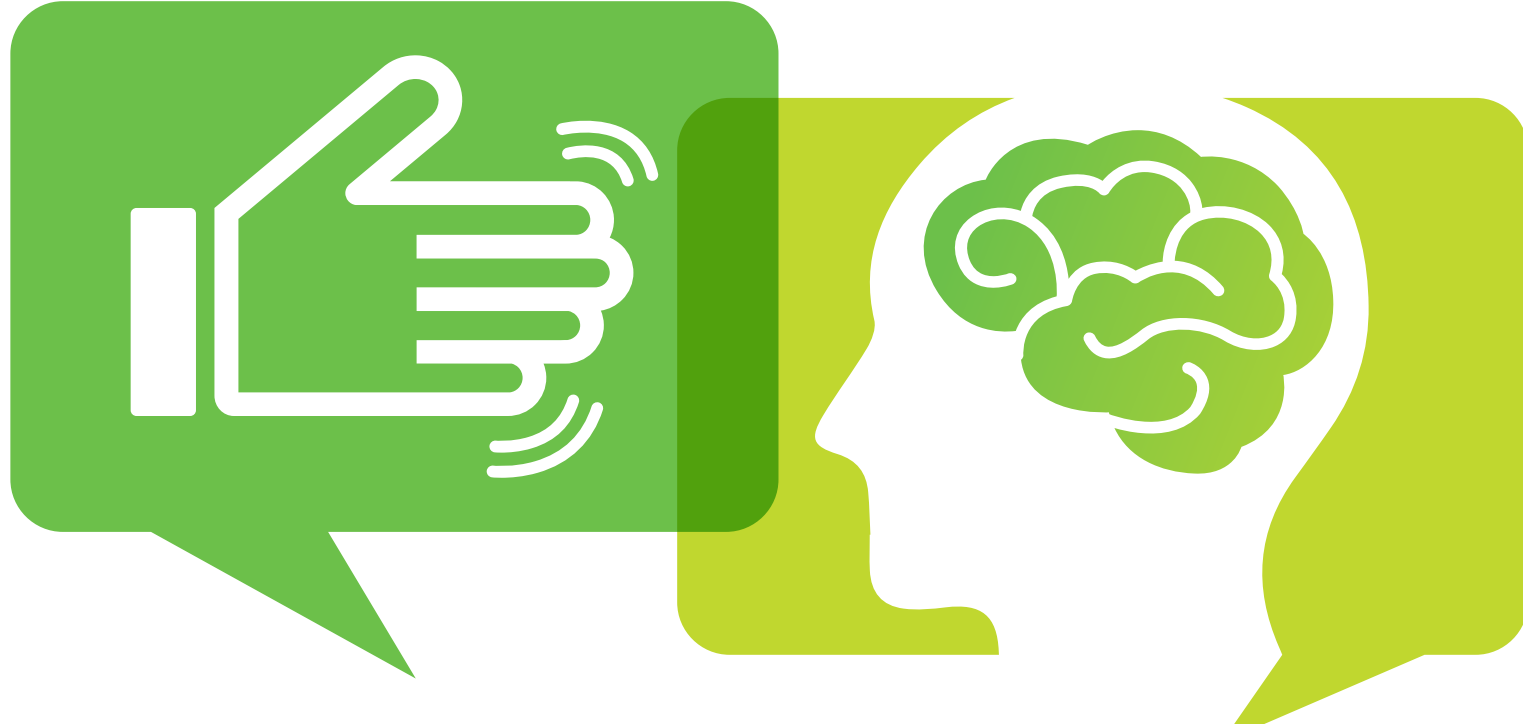
## WHAT ARE OFF PERIODS?

APPROXIMATELY

**350,000** PEOPLE LIVING WITH PARKINSON'S IN THE U.S. EXPERIENCE OFF PERIODS<sup>5-7\*</sup>

\*THE PERIODS IN WHICH PARKINSON'S SYMPTOMS RE-EMERGE<sup>3,8</sup>

SYMPTOMS CAN VARY ACROSS A BROAD RANGE OF MOTOR SYMPTOMS AND/OR NON-MOTOR SYMPTOMS<sup>2,9,10</sup>



**MOTOR SYMPTOMS:**

- IMPAIRED MOVEMENT
- MUSCLE STIFFNESS
- TREMORS

**NON-MOTOR SYMPTOMS:**

- ANXIETY
- FATIGUE
- PAIN
- DEPRESSION



## CURRENT UNMET NEEDS

RESEARCH REVIEWED AS PART OF "LIVE WELL. DO TELL." REVEALED SEVERAL GAPS IN THE SUPPORT OF PEOPLE WITH PARKINSON'S WHO EXPERIENCE OFF PERIODS:



CURRENT RESOURCES ARE ONE-SIZE-FITS-ALL AND DON'T ACCOUNT FOR THE HETEROGENEITY OF PARKINSON'S

SIGNIFICANT BARRIERS TO COMMUNICATION ABOUT OFF PERIODS INCLUDE:

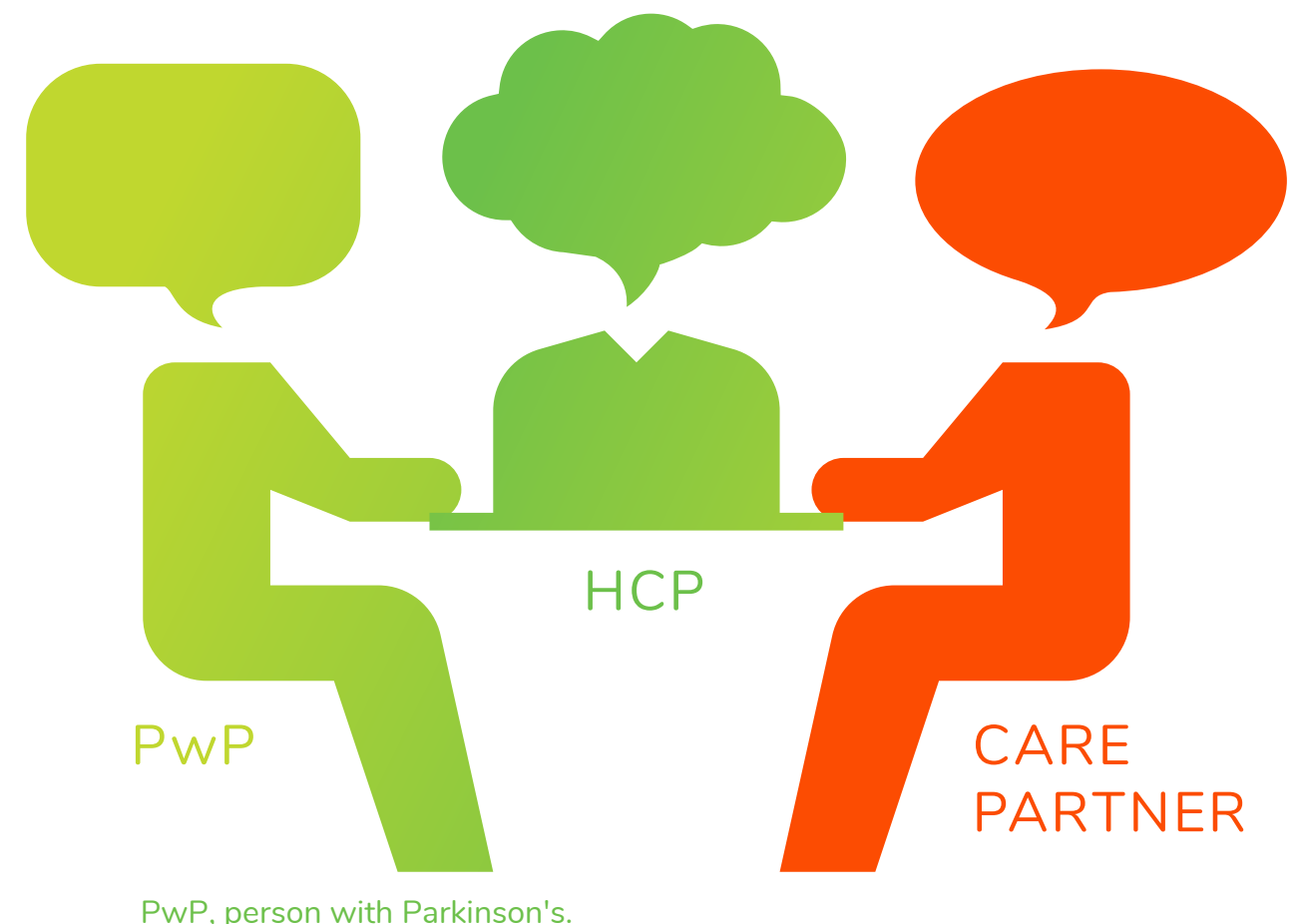


- FEAR OF DISEASE PROGRESSION
- UNPREDICTABILITY OF PARKINSON'S
- RATIONALIZATION OF SYMPTOMS

THERE IS NO WELL-DEFINED LEXICON FOR OFF PERIODS

COMMUNICATION IN CURRENT PRACTICE MAY NOT TAKE INTO ACCOUNT THE HOLISTIC IMPACT OF OFF PERIODS

CARE PARTNERS MAY HAVE A DIFFERENT POINT OF VIEW THAN PEOPLE WITH PARKINSON'S



LEARN MORE ABOUT WHAT CAN BE DONE TO ADDRESS THESE NEEDS AT [LIVEWELLDOTELL.org](http://LIVEWELLDOTELL.org)

**References**

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