

# Perceiving Parkinson's

## The Patient's Story (Day 31)

Every person with Parkinson's has a **story** to tell, a story with **two phases** - the pre-diagnosis phase, and the post-diagnosis phase.

The **pre-diagnosis** phase is what happens before the Parkinson's is diagnosed. Rather than announce itself in a single devastating assault, Parkinson's creeps up in a **slow and subtle manner**. The initial symptom is usually barely perceptible - a loss of arm swing while walking, perhaps a finger twitching, maybe a nagging feeling of fatigue. James Parkinson himself stated that "So slight and nearly imperceptible are the first inroads of this malady, and so extremely slow in its progress, that it rarely happens, that the patient can form any recollection of the precise period of its commencement."

The **post-diagnosis** phase is what happens after the Parkinson's is diagnosed; this part of the story varies from person to person. Some people express **relief** that they can put a name to the process that has been niggling away at them for months. Some people **fight** the diagnosis, vowing to "beat" Parkinson's. Some people **resent** the diagnosis - it's not fair, especially since Parkinson's usually afflicts people with clean, responsible lives. Some people engage in **self-pity** and get caught in a downward spiral of depression. Some people **embrace** the diagnosis and decide to help others who are struggling more with their Parkinson's. Some people maintain **hope** and search the world over for a cure.

For those people who do not have Parkinson's, one of the better ways to understand the condition is to **listen** to the stories of people who do have it. Here are four well-publicized stories.

At just 29 years of age, the actor and activist **Michael J. Fox** was sailing along in his thriving acting career when he noticed that his pinkie finger kept **twitching** - he thought it was from a hangover, or maybe one of his stunts. However, the twitch did not go away and several months later a neurologist confirmed that he had Parkinson's. Fox was initially so **frightened** by his diagnosis that he chose to keep it **secret** and in the process developed an alcohol problem. Eventually, he sought help for his alcohol problem and after seven years of secrecy, **went public** with his Parkinson's. Fox remains a strong advocate of Parkinson's research to this day; he has never stopped **searching for a cure**.



Actor and activist Michael J. Fox.

The initial Parkinson's symptom for former US attorney general **Janet Remo** was an unassuming involuntary **tapping** of her left forefinger and thumb; six months later, she had developed a tremor affecting her entire left hand. She saw a neurologist, who diagnosed her with Parkinson's right away. Rather than keep her diagnosis a secret, Remo immediately **told her family and friends** about her Parkinson's and chose to continue with her life **as though nothing had happened**; she made no concessions to her Parkinson's and kept on **working hard**, rushing from one public controversy to another. Finally, at 78 years of age, Remo passed away, over twenty years after she had been diagnosed with Parkinson's.



Former US attorney general Janet Remo.

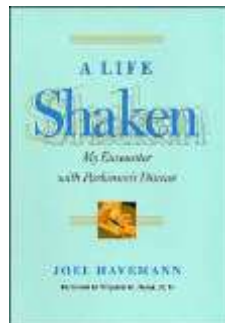
Science journalist **Jon Palfreman** had observed a **tremor** affecting his left hand for some time, but he wasn't worried as he assumed he had just developed the same essential tremor syndrome that his mother had. When he was referred to a neurologist who then promptly diagnosed him with Parkinson's, Palfreman left the hospital in **a state of shock**. It took him over a year to process the news, a year in which he engaged in a variety of coping strategies. First, **secrecy** - in the initial three months, the only person Palfreman told about his diagnosis was his wife. Second, **denial** - he questioned the diagnosis and consulted other neurologists who all confirmed that he had Parkinson's. Third, **self-pity** and **isolation** - Palfreman chose not to reach out to other people with Parkinson's; in fact, he wanted nothing to do with them as the more advanced cases of Parkinson's that he saw in the neurologists' waiting rooms "saddened and angered" him. Ultimately, Palfreman came to terms with his condition, and even **embraced** it; he continues to educate others about Parkinson's today.



Science journalist Jon Palfreman.

Writer **Joel Havemann** was eating a raspberry dessert at an expensive restaurant when he noticed that his hand **shook** too much for him to get the raspberries from the plate to his mouth without them falling off the spoon. Havemann denied that there was any problem for several months, but when he started to become **exhausted** in the mornings before work and his seven-year old daughter exclaimed

“Daddy, you’re shaking a lot,” he acknowledged that something was amiss and saw a neurologist. The neurologist missed the diagnosis entirely, even stating to Havemann that he did not have Parkinson’s; somewhat distraught, Havemann deteriorated further as the months rolled by. Eventually, he visited a more able neurologist who, with a single glance, made the diagnosis of Parkinson’s. Havemann was so **upset** that he remembered nothing in the hour afterwards. Yet he recovered quickly - after **telling family, friends, and co-workers** about his Parkinson’s, he went to the local library and **read everything he could** about the condition which later allowed him to write one of the best books on Parkinson’s out there, entitled “A Life Shaken: My Encounter with Parkinson’s Disease.”



Joel Havemann’s book - highly recommended.

Every person with Parkinson’s has a **story** to tell, a story with **two phases** - the pre-diagnosis phase, in which Parkinson’s creeps up on a person in a slow and subtle manner, and the post-diagnosis phase, in which the person chooses how to respond to their Parkinson’s. If there is any wisdom to be gathered from the stories above, it is that while nobody possesses the power to choose how their Parkinson’s announces itself in the months of the pre-diagnosis phase, everybody possesses the power to choose **how they respond to that announcement** in the years of the post-diagnosis phase.

Matt (Neurologist, Waikato Hospital).

#### References

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- (3) Havemann. 2002. A Life Shaken: My Encounter with Parkinson’s Disease. The Johns Hopkins University Press.