

Living with Parkinson's: A Jeckyl and Hyde Existence

February 23, 2006 - "I live a strange double life," said 37-year-old Tom Isaacs, who was diagnosed with Parkinson's disease (PD) ten years ago and is a co-founder of the Cure Parkinson's Trust in the United Kingdom. "I am both Dr. Jeckyl and Mr. Hyde."

As Dr. Jeckyl, when his medication is working, he describes himself as confident, opinionated, and driven to fight the ravages of his disease. As Mr. Hyde, without medication, it is as if he is "trapped in a washing machine on the spin cycle," or, alternatively, "locked in a fridge, trapped in my own body."

At this week's World Parkinson Congress in Washington, D.C., the first-ever international forum on PD, Mr. Isaacs and others discussed the challenges of living with PD and effective strategies for coping with this disabling disease.

PD is the second most common neurodegenerative disorder, affecting more than one million Americans. There is no known cure. Its symptoms, some of which include tremor, rigidity, and gait disturbance, worsen over time.

However, as David Heydrick, M.D., a neurologist and a Parkinson's patient, explained, "Through use of medication, nutrition, and exercise, patients can control their symptoms and potentially the progression of the disease."

Dr. Heydrick runs daily, practices tai chi, and lifts weights. In addition to exercise and a healthy diet, he also manages his stress level. He emphasized that PD patients have a lower threshold for stress, so stress management is absolutely critical.

Dr. Heydrick has also received a surgical therapy, deep brain stimulation (DBS), in which electrodes inserted into the brain are used to help control the motor (movement-related) symptoms of PD. Other symptoms are less responsive to DBS, and to levodopa, the primary medication for PD, as the disease progresses.

According to Anthony E. Lang, M.D., a neurologist at the University of Toronto, "Symptoms such as difficulty speaking, swallowing, walking, and maintaining one's balance worsen over time and become resistant to medication."

Non-motor symptoms of PD, such as depression and anxiety, can have a greater impact on a patient's quality of life than motor symptoms, said Laura Marsh, M.D., a psychiatrist at The Johns Hopkins University School of Medicine.

Approximately 50 percent of PD patients develop depression, and 25 to 40 percent have anxiety. Many suffer from both problems at the same time.

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“The good news is that depression and anxiety in PD are treatable,” said Dr. Marsh. “These disorders must be recognized and diagnosed so that we can reduce the negative impact.”

While the hallmark of PD is the loss of dopamine-producing neurons, non-motor symptoms, such as those discussed by Dr. Lang and Dr. Marsh, are thought to result from damage to other parts of the brain.

“We are now realizing that PD is not just dopamine — other areas of the brain are affected,” says Dr. Lang. “Our challenge is to understand these other areas and develop effective therapies.”

Until these therapies are developed, patients with PD, like Mr. Isaacs and Dr. Heydrick, say that patients must take a proactive approach to managing their disease and to educating others about it.

“There are only three things Parkinson’s hasn’t kidnapped from me: my sense of humor, my spirit, and my sense of worth,” said Mr. Isaacs. “I want to be able to say I used to have Parkinson’s disease.”

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The World Parkinson Congress is a unique international event bringing the Parkinson’s community together, and is organized by the World Parkinson’s Congress, Inc. The Congress is supported by The Movement Disorder Society, The National Institutes of Health, the U.S. Army Medical Research Acquisition Activity, and professional and patient voluntary organizations. For more information, please visit www.worldpdcongress.org.