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TOM GRABOYS, M.D.: RELUCTANT CHRONICLER OF HIS DUAL ILLNESSES

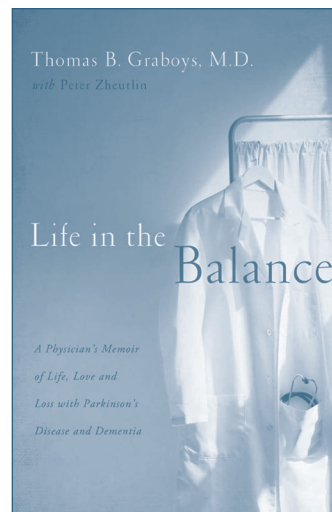
There are many people who put in decades at their jobs and eventually look forward to their retirement and ensuing golden years. But Tom Graboys was not one of these people. A renowned Boston cardiologist and a Clinical Professor of Medicine at Harvard Medical School who had more than 160 papers and abstracts with his name on them, he was at the pinnacle of his medical career and envisioned many more years of interesting work.

But then Parkinson's disease and the attendant slowed physical movements and tremors suddenly struck him. But there was more medical mayhem awaiting. Dr. Graboys was also diagnosed with dementia with Lewy bodies, an ailment akin to Alzheimer's disease and Parkinson's disease.

Although the final diagnoses were life altering and difficult to accept, they did not come as a total surprise. Long before he was eventually diagnosed, Dr. Graboys was having horrific nightmares and oftentimes found himself flailing in bed or else on the floor next to his bed the next morning. He was also having trouble with his memory and found it difficult to concentrate. Both of his parents had died of Alzheimer's, and since he had always feared a similar fate, he made sure to downplay his symptoms to his wife.

While he instinctively knew something was not right with himself, he chose not to acknowledge these extreme medical issues or do anything about them. He always wanted to be in complete charge—even now, when confronted by an illness that could possibly force him to cede over control of his destiny.

Dr. Graboys's longtime office assistant noticed early on that something was not right, that the doctor seemed to have slowed down and could no longer keep up the high-speed physical and psychological pace he had adhered to over the three decades that they had worked together. She also observed the uncharacter-



istic fatigue that had come over him and the many naps he would take behind closed doors. She instinctively began to cover up for him when dealing with patients and his partners in their medical practice, and she did so admirably for quite some time until his colleagues eventually realized something was definitely amiss.

In 2005, Dr. Graboys finally wrote to his hundreds of patients announcing his retirement and that he could no longer care for them. A few years later his memoir, *Life in the Balance: A Physician's Memoir of Life, Love, and Loss with Parkinson's Disease and Dementia* (Union Square Press, 2008), was published and in it he detailed what life was like shortly before his illnesses and how it was since. He writes:

"Today I can no longer see patients or give rounds. My face is often expressionless, though I still look younger than my 63 years. I am stooped. I shuffle when I walk, and my body trembles. My train of thought regularly runs off the rails. There is no sugarcoating Parkinson's. There is no silver lining here. There is anger, pain, and frustration at being victimized by a disease that can to some extent be managed but cannot be cured."

His is a beautifully written, no-holds-barred account of how illness, especially one that scrambles the synaptic links in the brain and gums them up with plaque deposits, can affect how you go about your daily routines. He points out, too, that if you are going to strive for a fulfilling life in spite of these ailments, you need to scrap any plans you might have made for the future, reassess, and then come up with a modified blueprint for achieving your new goals and putting some quality back into your life.

As can be imagined, with two ailments to deal with daily and an uncertain future, some days are good for Dr. Graboys and some, not so good. Even so, he does all that he can to put life back into his life, bit by tiny bit. He takes a one-hour spinning class several times a week and has a trainer that comes to his home. He has a loving wife, daughters, and grandchildren, and he dotes on them. He is a battler who still fights his hardest every day to get what he can out of his life, so he can add back the density, richness, and texture that the ailments have stolen from him.

No longer a physician seeing patients in his office, Dr. Graboys nonetheless feels that he is still a doctor, one who can offer important advice for people who may have lost hope because of dementia or Parkinson's. At a prearranged time, a telephone call was placed from *Memory Disorders* to Dr. Graboys. Several days before he had been sent a list of questions that he would be asked. He had requested extra time to prepare his answers in advance. He wanted to make sure that he did his best to continue with the flow of words, so he could deliver them from the part of the brain where ideas are formed to the other part that regulates speech. So many times, he had been the victim of synaptic breakdowns that

had put unexpected roadblocks in his conversations, leaving him embarrassed and unable to complete his thoughts.

For starters, he was asked if he had been able to accept the “new” Tom Graboys and whether or not the “old” Tom Graboys still played a part in his life.

“The ‘old’ Tom Graboys is like the word. It’s old and in the past,” he said. “That’s the reality and I have come to accept it.” Once you are able to do that, he believes that you can stop the whining, the complaining, the mourning for the person you used to be.

“I tell people now that I am clearly feeling better than I was before. There is no cure for the disease that I have, but it can be managed. I am a testament to that,” he said. “I’m on a very good drug program.”

In addition to the medication he takes for Parkinson’s, Dr. Graboys takes an antidepressant along with Namenda (memantine), a medication approved to treat AD that some clinicians also seem to think helps people with dementia with Lewy bodies. This has not yet been shown to be the case, however.

“These drugs really do need time to work. You have to be patient,” he said. “You also have to be very careful with the dosing. Once you start adding additional medication to this cocktail, you have created a new drug and the body has to deal with the side effects.”

Dr. Graboys admitted that he sometimes still ruminates about his past life. “But it’s a complete waste of energy,” he added. “That leads to whining, and I don’t like whining. I do my best to focus on the positive.

“What amazes me every day is how slow I am. The inability to do even simple things is also amazing. If I am going to go out and eat, I have to begin preparing an hour or more before. It’s the new reality that has to be addressed. I have to face it, not be passive and not think that the sky is falling. I choose to be positive and take a step forward. I don’t want to whine.”

Help in getting through the day, from morning to night, is always needed and Dr. Graboys is grateful and happy that he has Vicki, his loving wife, and a team of helpers in place who assist him, whether it be getting dressed, being reminded to take his medications, or being driven to and from his spinning classes.

“Do the best you can to manage your situation. People also need an action plan that includes medication, physical activity, diet, and support,” he said. “You also need a coach to help lay out this plan. This person doesn’t have to be a Nobel prize winner, but someone who is interested and concerned. This will all help you get some control back in your life.”

DEMENTIA WITH LEWY BODIES

Dementia with Lewy bodies, or DLB, is a newly recognized form of dementia that may account for about 15% to 20% of all dementia cases. It is now believed to be the second or third most common cause of dementia after AD and perhaps vascular dementia. Lewy bodies—named for Frederick Lewy, M.D., the physician who first identified them in 1912 while working in the laboratory of Alois Alzheimer, M.D.—are tiny, spherical deposits of a protein called alpha-synuclein that are found in the brains of patients with this disorder. The presence of Lewy bodies throughout the brain disrupts the brain's normal functioning.

There is considerable overlap between DLB and

two other disorders: AD and Parkinson's disease. In DLB, there is a loss of dopamine-producing nerve cells similar to that seen in Parkinson's disease. There is also a loss of acetylcholine-producing nerve cells that resembles what occurs in AD. Patients with DLB often experience cognitive problems associated with Alzheimer's, such as memory loss, spatial disorientation, and communication difficulties. They may also develop Parkinsonian symptoms such as muscle rigidity, a blank facial expression, soft voice, tremor, poor balance, and gait disturbances. Some patients initially diagnosed with Parkinson's disease later go on to develop a dementia that closely resembles DLB.

There are certain symp-

toms that are characteristic of DLB and help to distinguish it from AD as well as from other forms of dementia. For example, unlike people with AD, Lewy body patients may experience detailed and extremely vivid visual hallucinations, often of people or animals. People with this disorder also tend to show marked fluctuations or variability in their cognitive abilities and alertness from day to day and even during the same day. In addition, they tend to fall asleep very easily during the day and have restless, disturbed nights marked by confusion and nightmares.

Some individuals who have DLB report developing vivid nightmares or are reported by their partner to have been restless and agi-

tated when sleeping even 10 years before the first symptom. This condition, called REM sleep behavior disorder (RSBD), may thus be an early precursor of DLB; however, we do not know how many people with RSBD never develop DLB.

Recognition of these characteristic symptoms leads to an accurate diagnosis of DLB. A correct diagnosis is particularly important because the medical management of patients with DLB presents special challenges. The drugs that are normally used to treat some of the symptoms in these patients can aggravate other problems and cause potentially serious adverse reactions. In particular, antipsychotic (neuroleptic) drugs can provoke danger-

ous side effects and must be used very cautiously, if at all, in these patients. In addition, levodopa, a drug normally used to treat Parkinsonian symptoms, may cause worsening of hallucinations, and its dose needs to be carefully adjusted in patients with DLB.

Not all patients with DLB display these characteristic symptoms, however, and diagnosis is sometime difficult in the early stages of the disease. Fortunately, several tests are helpful in such cases. Tests to assess the patient's visuospatial ability as well as new imaging tests that measure certain characteristic brain abnormalities may help pinpoint the diagnosis of DLB.

Finally, there is some very good news. Cognition is often fairly well preserved

early in Lewy body disease, and many patients show an especially strong response to the cholinesterase inhibitor drugs (Aricept [donepezil], Exelon [rivastigmine], and Razadyne [galantamine]) that are used to treat Alzheimer's disease. Such drugs can improve cognition and may reduce hallucinations in these patients. Early identification of the disorder can also lead to a comprehensive approach to treatment that addresses the diverse problems affecting these patients, including cognitive, neuropsychiatric, motor, sleep, and autonomic symptoms. Such an approach can lead to significant improvement, and many patients do very well, with a good quality of life, for many years after diagnosis.