

# Prologue: The News

Do you remember where you were when . . . ?

That sentence usually ends with some event that made history: an invasion, an assassination, a natural disaster. But it can also end with a personal event: one that nobody outside your circle of friends or family will ever hear of or care about, but one that wrenches your life onto a track you never even knew existed.

My wife, Sandra, and I were strolling toward a path called Rhododendron Walk in Central Park near our home in Burnaby, British Columbia. She had been quiet, had said little for almost a week, which was unusual for her. I was about to find out why.

She tightened her grip on my hand and said, “I went to see a doctor yesterday. He told me I have Parkinson’s disease.”

Looking back, I don’t recall having any kind of emotional reaction to what she said. I’d heard of Parkinson’s, of course. I knew it had something to do with tremors. I’d seen film clips of people who were afflicted with the disease frozen as they tried to cross a room. But her words didn’t seem to sink in. Maybe it was because I couldn’t reconcile these images of infirmity with this woman who was always one step ahead of me. Maybe it was because I had no idea what this diagnosis meant for her and for our lives. Or maybe it was because I just needed time for information like this to register. Whatever the reason, based on my reaction, she might just as well have announced that her hairdresser said she needed to get a haircut.

Still, I remember exactly where I was when she told me.

## Digression

I haven't written an introduction to this book because I don't like reading them, but it will be helpful for you to understand how I've laid it out.

Part I has six chapters. Each chapter in Part I has two sections. The first section tells about Sandra and me from the time we met to when Sandra was diagnosed with Parkinson's. The second section describes aspects of Parkinson's: what it is, its symptoms, and its treatments.

Part II tells of Sandra's journey from her diagnosis to now. It's roughly chronological.

Part III deals with caregiving and the things I've learned. I hope it's useful to you. The book also has some appendices, one of which is Sandra's chronology. It identifies the chapters in which I describe the events that marked her journey.

**Part I**

# **Prelude**

## First Contact

I first saw Sandra at an outdoor party at the student nurses' residence of the Calgary General Hospital in Calgary, Alberta. She was sitting beside a campfire with several of her classmates, and as if ignoring the laws of optics, the light from the fire shone only on her; her friends were in shadow. She was laughing, her face aglow with life. I would learn that was part of her personality.

I was entranced. The song "Some Enchanted Evening" from *South Pacific* played in my mind. I wanted to "fly to her side" and if not make her my own, then at least get to know her. But I had a problem: I had awakened with a tickle in my throat and a trickle in my nose. That was the best I'd feel all day. By the evening, I had the pallor of a parsnip, and I feared that if I fell down at the hospital, some earnest intern would perform an autopsy on me before I could protest. I should have stayed in bed, but my roommate had insisted we go to the party to meet new women because, as he lamented, we'd both struck out with the ones we knew.

While I longed to approach this woman who had so captivated me, I didn't want her first reaction to me to be "Oh, no. Another patient." So I backed away, got in my car, and drove home. I knew I'd see her again. I knew where she lived.

"Again" came sooner than I'd expected when, a couple of days later, my roommate announced he was bringing his new girlfriend over to the apartment. I wasn't sure why. His hobby was rebuilding the motor of his sports car, and since he didn't have a garage, he was using our living-room floor. As centerpieces go, it was unique, although I doubted it would appeal to a

woman who wasn't interested in spark plug gaps or ignition timings. But I didn't care; where he took his dates was none of my business.

Then he walked in with her, and I was slammed with three emotions: delight at seeing her again, envy at my roommate, and frustration at the code that says you don't poach your friends' girls.

I wanted to say something pithy, something memorable, something that would let her know I wasn't just another grunt. I wanted to make an impression, but in the stew of my emotions, spiced by the remnants of my cold, the best I could do was to point to the pedal pushers she was wearing and ask her why she didn't have clothes that fit.

Her scowl told me I had made an impression.

It would be a couple of weeks before I saw her again, this time at a disco where a group of us had agreed to meet, along with some of the student nurses. I found out later that she came only because she'd learned that my roommate, with whom she'd had an emphatic breakup (yes!), was out of town. However, she did ask her friends to keep me away from her.

No way. My cold was gone and my judgment was as good as it ever gets, and this time I wasn't going to miss the chance to get to know her.

I asked her to dance, and while the rest of our friends were jiving and bopping around the floor, we somehow slid into dancing the foxtrot. We got a lot of frowns and snickers, but to me they sprang from envy. I was, after all, the only man in the room holding a woman in his arms.

We discovered that we wanted to talk, but the blare of the disco made that impossible. So we went out into the night, next door to a twenty-four-hour coin laundry where we sat on tacky chairs and made up new uses for plastic garbage bags, none of which I recall except that some of them had to do with small furry animals.

I learned that her name was Doris Sandra Adell Johnson. Yes, that's how she spelled Adell; her father, when he registered her, hadn't known how it was normally spelled. I thought it was charming. When I asked her why she had three given names, she told me she had eight siblings, and she figured her parents thought that if they used up all the available names, they'd stop having kids. It must have worked because she was the second youngest.

She was from rural Saskatchewan. She'd come to Alberta to take the province's dual diploma program in psychiatric and general duty nursing. The general duty part, which would give her the RN certification, was at

the Calgary General, but the program was based out of the Alberta psychiatric hospital at Ponoka. When I got home that night, I looked up Ponoka on the roadmap. I had a feeling I'd be spending a lot of time traveling there and back.

## All about Parkinson's Disease

Parkinson's disease is named after the English doctor James Parkinson, not because he had it, but because he described it in his 1817 work, *An Essay on the Shaking Palsy*.<sup>\*</sup> Of course, the disease didn't first appear in 1817; it's described in records that go back to antiquity. For Dr. Parkinson, getting his name attached to it was just good timing.

Parkinson's disease, characterized by tremors and stiffness, results when neurons in an area of the brain called the substantia nigra fail to produce enough of the neurotransmitter dopamine.

Now, often when I read sentences like that last one, it means as much to me as if the writer had said something like “tIqjaj yInllj ‘ej bIcHepjaj.” (That's “Live long and prosper” in Klingon.) Since one of my goals in this book is to provide an insight into Parkinson's that may at times be irreverent, occasionally whimsical, but always accurate and clear, I need to decode that sentence.

So here it is again in its basics: Parkinson's disease results when neurons in the substantia nigra fail to produce enough of the neurotransmitter dopamine. Understanding this means understanding how the human brain works. This shouldn't take long.

The human brain is composed of gazillions of brain cells, or neurons, which are connected together into a vast number of massive networks. The networks are themselves interconnected, which makes things even more complicated.

A neuron receives a stimulus, usually from another neuron, and converts it into an electrical impulse that travels along the neuron to its end. There, the stimulus is passed on to other neurons, sometimes up to a thousand of them. A neuron's sole job is to receive a stimulus and pass it along,

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\* Parkinson. A note on my footnotes. Where I give a name, such as in this case, the complete reference is in the bibliography, which is in alphabetical order. Sometimes I have referenced the name in a comment. The name could also be that of a website or an organization, which I've also included in the bibliography.

like a member of a bucket brigade, although one that's fighting up to a thousand fires at a time.

But researchers discovered there's a gap between neurons that the signal can't cross. So how does it get to the next neuron? Here's what happens: When the electrical signal reaches the end of the neuron, it triggers the release of a chemical. Like a ferry crossing a river, that chemical crosses the gap to the receiving neuron. There, it triggers a new electrical signal. That new signal travels to the end of its neuron and stimulates the release of its chemical, which crosses over to the next one and so on and so on.

Because these chemicals transmit neurological signals, they're called "neurotransmitters." Researchers have identified about a hundred of them and similar chemical messengers.\* One of them is dopamine. A deficiency of dopamine leads to Parkinson's.

Dopamine is one of the so-called "feel good" neurotransmitters; an abundance of it is associated with feelings of euphoria and well-being.† On the other hand, levels that are too high are associated with schizophrenia.‡ So getting the level of dopamine right is a balance between voices in your head and tremors in your hand.

And that's it. Whether your brain is balancing your blood sugar or balancing you, whether you're composing a symphony or planning a genocide, it's all networks of neurons passing along electrical signals.

Okay, you may say, but what about this substantia nigra thing? "Substantia nigra" is Latin for "black substance," an example of how medicine—and law—love Latin words: they sound so much more impressive.

The substantia nigra is a region of the brain that is responsible for, among other things, overseeing motor control and coordination. When it detects that you need some motor control or coordination, it sends out signals from its neurons to those in other areas of the brain. Like memos that a clerk is routing around an office, these signals stimulate other neurons until some of them trigger movements in the muscles that need to be moved. This system is what allows you to stand upright, jump up and down, catch a ball, and drink a cup of coffee without spilling it down your front. When there's not enough dopamine to carry the signals to other areas of the brain,

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\* Cherry.

† There are four others: serotonin, GABA (gamma-Aminobutyric acid), norepinephrine, and acetylcholine.

‡ Birtwhistle.

or even when there's not enough dopamine to transmit the signals within the substantia nigra itself, the system malfunctions and you have a loss of motor control and coordination. You have Parkinson's disease.

So there you have it. Parkinson's disease results when neurons in the substantia nigra fail to produce enough of the neurotransmitter dopamine.

I must note here that many references state that Parkinson's results when the dopamine-producing neurons in the substantia nigra die. I have a couple of problems with that. First, to speak of "dopamine-producing neurons" implies there is a repository of dopamine for other neurons to use. Not true: each neuron produces its own neurotransmitters. Second, if the neurons die, how would giving dopamine medications help? Dead neurons can't use them—giving them would be like tube-feeding a corpse—and live neurons don't need them. These neurons do die, but before they do so, they fail to produce enough dopamine to consistently carry the signals to other parts of the brain.

But there are a couple of nagging problems. One of the symptoms of Parkinson's is an abundance of movements you don't want, such as tremor, while another is an impairment of movements you do want, such as walking. Why? Why do the hands shake but the legs freeze?

Some intriguing speculation\* has suggested that perhaps freezing is a logical response of the brain. Different neurons use different neurotransmitters, but only 30,000 to 50,000 use dopamine.† (Neuroscientists refer to these neurons as "dopaminergic." From here on, I'll just call them "dopamine neurons.") With about a hundred billion neurons in the brain, that's the equivalent of 100 to 150 people in the entire United States—and they all live in the same town, probably somewhere in New Mexico. There may not be a lot of these neurons, but they reach to almost all areas of the brain, and in addition to motor control, they form part of the reward system.

Let's say you pass a storefront in the mall and you see something in the window that interests you. Do you go into the store to examine it or do you move on? It all depends. Do you have the money? Is there someone waiting for you at the coffee shop? Are you in a hurry? Do you really need, or want, whatever this is? The evaluation of each alternative—to go into the store or to move on—is one of the things the dopamine neurons provide. They help us choose.

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\* Montague, pages 156–158.

† Montague, page 106.

But what happens when the signals fail? In that case, there's nothing to tell the brain what to do. So, lacking direction, it does the logical thing: it waits—it freezes. When Parkinson's damages the dopamine neurons, it damages not only motor control but also the ability to value choices, one of the most important parts of our daily lives. Now, I must point out that this idea is speculative, and in watching Sandra, it doesn't always appear to be apt, but there are times when she struggles to choose between options that would not have given her a second's pause before the disease.

The second nagging problem is this: as researchers dig deeper into Parkinson's, they are finding out that it's far more complicated than a dopamine deficiency, despite the claims of most consumer information and websites. They've discovered that as the disease progresses, it damages not only the substantia nigra but also other areas of the brain, leading one researcher to suggest a novel hypothesis: that Parkinson's has six stages,\* each one occurring as the disease moves on to affect different parts of the brain. These stages occur in the same sequence for all Parkinson's patients. The substantia nigra isn't affected until stage 3, which implies that Parkinson's begins long before the typical symptoms start to appear.

But not all is sweetness and light in research-land. Some other researchers have said, in effect, "This is a crock."<sup>†</sup> (Their actual words were more genteel. At university, Sandra analyzed a theory she thought was nonsense, but instead of calling it nonsense, she wrote, "One has to question the assumption that . . ." Her professor, who also thought the idea was nonsense, was delighted.)

The researchers who question the idea of six fixed stages don't dispute that various parts of the brain are affected, nor do they question which parts. But since there's no relationship between these stages and the actual symptoms of the disease, they argue it's wrong to suggest it advances so systematically.

So who's right? I don't know. I'm not qualified even to have an opinion. But one thing is clear to me: this argument isn't about the extent to which Parkinson's affects different areas of the brain; it's a debate about how it progresses. So to me and probably to you, it doesn't matter. What does matter is that Parkinson's is far more complex than researchers had suspected and that it will be a long time before there's a cure on the horizon.

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\* Braak.

† Burke.