CHAPTER 1

Do Not Disturb!

> Things are good right now,
> Really good.
> So if you find a
> "Do Not Disturb" sign,
> Hang it outside
> The door to my life.
>
> —*Lois Wyse*, I Am So Glad You Married Me

Life was beautiful in 1978. My marriage was solid, and my husband and I felt better than ever about our relationship. We were pleased with our children, now grown and married to individuals whom we loved dearly. My career as an educator was at its peak, and I felt very productive. I was forty-seven years old. Physically, I had never felt better. I had wonderful friends and relatives. I had a lovely home in Maine. Is it any wonder that I did not want anything to disturb my life?

I was born Glenna Wotton in 1931, in a small community in northern Maine. I grew up during the Depression years, surrounded by relatives who were short on money but never short on love and caring for one another. Mine was a secure world, where life revolved around the one-room school, the church, and my family. Eventually, when I left home to become a teacher, I was armed with faith and the values with which I had grown up.

At the University of Maine in Farmington, I earned my B.S. in Home Economics, and I met Blaine Atwood, who was also preparing to teach. We married and settled in Hampden, not far from Bangor, and near Orono, where we could continue our education while we taught school. Eventually, I became a teacher and then the chairman of the Home Economics Department of Hampden Academy.

Those were active, exciting years. I expanded the home economics program to include courses in consumer education, independent living, family life, and child development, and I started a nursery school within the department. The Maine Department of Education was using some of my courses as models, and other school systems in Maine, other states, and even other nations, were adapting my course, "Independent Living." It was a good feeling to be contacted by people who wanted to use my ideas. In 1975, I was named Maine's "Home Economics Teacher of the Year."

I looked forward to a blissful future. There were so many things to enjoy and accomplish. For one thing, I assumed we would have grandchildren. I planned to be the happiest, peppiest grandmother: my grandchildren would never have to deal with a grumpy, pokey old lady. I would retire early from the school system and embark on an enterprise of my own. I considered many possibilities. I could run my own school, where there would be no bells to require my students to jump up and leave before they were ready. I could start a day-care center based on ideas I believed in. I had ideas for at least fifty pursuits, but I hadn't made a choice. I felt that, eventually, God would help me choose.

Was it on July 3, 1978, on December 24, 1979, or on some other date that I first felt a change? I really can't say. I do know that "it" sneaked up on me as I went on my way. Once in a while, my right arm felt clumsy as I walked or stood, as if I didn't know what to do with it. But I ignored it. Doesn't everyone feel a bit awkward once in a while? At times, Blaine lost patience with my pace when we were walking and asked me to speed up. He complained that if he slowed down for me, I would slow down even more. I assumed that this was Blaine's problem, not mine: he was always in a hurry.

Then one day in the summer of 1980, while I was writing a letter to my daughter, Susan, my fingers became balky. The smooth flow of my writing was lost. I was annoyed but said nothing. This feeling in my hands did not go away, and it took me longer and longer to write anything. Sometimes I had to draw the letters or print. My letter-writing habits began to change: I wrote shorter and shorter letters. But I thought, "Ignore this change! Eventually, it will go away."

School reopened, and things were almost back to normal, yet I continued to be nagged by physical problems: Why was I getting so tired? Why was I really dragging by noon? What were the weird sensations I felt from time to time? My legs especially seemed to feel strange and heavy: they jerked or felt as if a rubber band were around them. But I felt that I must not complain; if I didn't tell anyone, these sensations would go away. I remembered the time, many years ago, when I learned that my fifteen-month-old niece had been struck and killed by a car, I had *screamed*, telling myself that if I screamed loudly enough, the news would not be true. This time I hoped that silence would work. Although I had spent years teaching students to be open about their feelings, I kept all this to myself.

Early in 1981, I caught the flu. My recovery was very slow, and finally my daughter, Susan, and my husband, Blaine, insisted that I go to a doctor. Coincidentally, I had just been reading a medical column in the daily newspaper, in which a reader had asked about the symptoms of Parkinson's disease. The doctor's answer described my symptoms: "The earliest signs are apt to be a difficulty in handwriting, a slight trembling of the hand, and a jackknife effect when you put two fingers together." Overcome by anxiety, I knew, but I still didn't tell anyone about my symptoms. I still hoped I was wrong. Yet I knew the time had come to see a doctor. Without telling my family, I admitted to myself that the problem was bigger than a simple case of the flu. One thing at a time.

I made an appointment for March 30 with my family doctor. After the usual physical examination and discussion of my symptoms, my doctor said he suspected I might have Parkinson's disease. He happened to have a young student doctor in his office who was preparing to specialize in neurology. My doctor called him in, told him my symptoms, and said he suspected Parkinson's. The student observed my tremor and asked me to walk. My walk was awkward, and my arm swing was almost nonexistent. His statement was cold and brief: "That isn't Parkinson's. The tremor is too fine. I'd say it's more likely to be a tumor on the brain." With that, he left. I do not know his name, but whoever he is, and wherever he is, I hope he has learned a great deal more about diagnosing Parkinson's and about dealing with patients.

In the absence of any definitive diagnostic test for Parkinson's, my doctor called to make an appointment for me with a neurologist in Bangor. But this was March, and the neurologist couldn't give me an appointment until July. After all, what's a three- or four-month delay when you are waiting to hear whether you have Parkinson's disease or a brain tumor?

Blaine and I were thankful that my doctor did not want to wait until July. He offered to contact a neurologist in Boston, if we were willing to travel that far. We were, and an appointment in Boston was made for the following week.

During that week, we tried to go on as usual, to work, to sleep, and to eat. At the time, one of our very dear friends was dying of a cancerous tumor on the brain, and our anxiety about the possibility of a tumor on my brain was almost unbearable.

Blaine and I took Friday off and journeyed to Boston to see my first neurologist. This doctor was a mature man and had no doubt seen many people with Parkinson's in his day. He was kind, gentle, and unhurried. We sensed that he was reluctant to tell us his diagnosis. At last, he told us that I was in the mild stages of Parkinson's disease and that it would take about ten years for me to enter the advanced stages. He advised me to go home, go back to work, and tell no one; no one would know. He told me nothing about medication, about what I would look and feel like in ten years, or about where I might get more information. And he did not explain why I should keep the diagnosis a secret.

Actually, we paid little attention to those mysteries at the moment. Blaine and I were too happy that the diagnosis was Parkinson's and not a brain tumor. At least Parkinson's wouldn't kill me. We wept with relief.

In the next weeks, I underwent CAT scans and other diagnostic tests to rule out other medical problems. At last my family doctor, who reviewed the tests, said that the results supported the neurologist's diagnosis. He agreed with the neurologist that I should exercise, keep up my good attitude, and keep on working. He, too, felt that I should tell no one and that no one need know.

I should have asked for more information, but my generation had been conditioned not to question the doctor; we'd learned to sit and agree to do what the doctor tells us to do. One thing I would have liked to know was why I shouldn't tell anyone. I realize that some patients really may not want to know any more than what the doctor tells them, but I was anxious to educate myself about this illness that had taken up residence in my body. I knew that it was progressive and that there was no cure. I knew a little about how the tremor acted, how one muscle worked against the other, how a person looked shuffling along all bent over. But that was all I knew.

I soon discovered that it would be difficult to educate myself: very little information was available, and I didn't know anyone else who had Parkinson's disease. Finally, Blaine learned of Merle Watson, a Parkinson's patient who lives in a neighboring town. I called Merle's wife, Barbara, and she gave me the addresses of the four national organizations concerned with Parkinson's disease. Their free materials, which I obtained in the mail, seemed to be the extent of the information available to patients in 1981. These depressing materials contained pictures of people with frozen facial expressions and thin, bent-over figures. Very little in the materials could give me much hope that I might live in reasonable comfort, as I later learned to live. However, I was now on several mailing lists, and soon newsletters began to appear. Within a year, more was being written, and what was written was more positive. (Although Parkinson's was not at the top of the researchers' lists when my disease was diagnosed, a renewed interest in Parkinson's generated much more research in subsequent years.)

By 1982, I knew I was going to retire from teaching. I had shared my "secret" of Parkinson's disease with my students and colleagues, as well as with my family and friends, and they were all very helpful. But it was not fair to have others do my work. Also, no matter how much they did, they could not take away the pain in my hips that made me limp, the all-over aching, and the extreme tiredness that kept me on the couch from the time I got home until bedtime.

It was frustrating that no one seemed to understand Parkinson's disease. The feeling kept growing in me that I needed to find an expert in the field. I learned the name of another neurologist, and in February 1982, I visited my second specialist. He, too, was helpful and understanding, and I certainly could not find any fault with him. But what I was really looking for was a specialist who lived and breathed Parkinson's disease. My family doctor and the neurologist had so many other illnesses to deal with. The question kept recurring in my mind: how much time do they really have to keep up with the latest findings on one disease—Parkinson's?

Finding my specialist in Parkinson's disease happened in a roundabout way. Blaine and I began thinking that we might start a Parkinson's support group in our area. We needed to talk to others with Parkinson's and felt that people in our area must have the same need. One person we talked to was Mary Dike of Gardiner, Maine, whom we contacted after reading about her in a newspaper article. Mary was also interested in starting a support group in her area. A home economics teacher a few years younger than I, Mary was about to leave teaching because of Parkinson's disease. She told us about her doctor, Robert Feldman, a Parkinson's specialist at Boston Medical Center. Listening to Mary, I felt that I had found the specialist I was looking for.

We made an appointment, and on April 2, 1983, I saw my third neurologist, Dr. Feldman. We were not disappointed. We found him and his multidisciplinary team to be experts whose aim was to educate the patient about Parkinson's disease and who knew how to treat the disease. They drew Blaine, me, and our family doctor into the "team." During that visit and at subsequent visits every six months, Dr. Feldman, Blaine, and I talked together until we agreed on a course of treatment that was satisfactory to all of us. Then Dr. Feldman wrote to our family doctor advising him of the results of our meeting. This is the pattern we still follow. Thus, I have the security of knowing that if I have any immediate problems, my family doctor, close by, knows my status.

I had come a long way since I first responded to my symptoms in 1980. I learned that I needed to take the responsibility of keeping myself as healthy as possible and to ask questions in the doctor's office. I learned that doctors, too, are human: some find it difficult to say, "I don't know," when they can't diagnose an illness. Some find it difficult to tell the patient when they do know. Some are insensitive. All doctors are different, just as all patients are different. It's important to find the right combination.

I feel that our persistence in looking for the right specialist has paid off. We feel good about our team.

Parkinson's is a progressive disease, but in most cases it progresses so slowly that it's easy to ignore the first symptoms. What are the first symptoms? They differ from person to person, but the ones I hear about most often are these:

- Fatigue
- Aches and pains that may be vague or may be severe enough to cause limping or all-over discomfort (they disappear when you rest for a while)
- Slow movement: this makes you feel like you are in a slow-motion segment of a movie or are walking through water
- Loss of the natural swing of your arms when you walk
- Poor balance and falling (a feeling of awkwardness)
- Tripping, caused by not lifting the feet sufficiently
- Dragging a foot
- Cramps or other weird sensations in the legs or the feet
- Difficulty with handwriting: sometimes you feel that each letter must be drawn painstakingly. The writing may get smaller and smaller as you progress, and sometimes the lines of your writing slant downhill. If you experience a tremor, your handwriting may be shaky.
- A jackknife effect when you touch your forefinger and middle finger together
- Difficulty with small objects requiring manual dexterity: buttoning clothes or fastening jewelry
- Symptoms that are more pronounced on one side of your body than on the other
- A vague feeling that something is not quite right

If you suspect that you have Parkinson's, knowing for certain will be much better than uncertainty. If your suspicions are confirmed, you can deal with your fears and find a Parkinson's specialist who will start you on a program of treatment. Educate yourself about the disease. Go to the library, write to the national organizations concerned with Parkinson's disease (see the names and addresses in the appendixes to this book), and join the nearest Parkinson's support group. Enlist the support, the confidence, and the involvement of your spouse, close relatives, or close friends from the beginning. You deserve the best!