

Sometimes I Don't Remember I Have Parkinson's An Interview with Alison Wood

by Ruth Rootberg

In September 2016 I attended the 4th World Parkinson Congress held in Portland, Oregon, along with a group of 18 volunteers and several local teachers as part of the Poise Project team (www.thepoiseproject.org). This non-profit organization was founded in 2016 by Alexander Technique teacher Monika Gross with the purpose of bringing the principles of the Alexander Technique to a broader population. In realizing its mission, it hopes to create jobs for teachers beyond our current private practice/private pay economic model. Its first targeted population is people with Parkinson's disease (Parkinson's or PD).

At the Congress, we met people living with Parkinson's disease, care partners, physicians, neuroscientists, and a broad range of health professionals including physical therapists and speech language pathologists. Many people we spoke with and gave hands-on turns to left inspired and hopeful, taking with them information on how to find a local Alexander Technique teacher.

I left Portland wishing for more detail about how an individual with PD could use Alexander skills to thwart symptoms of this degenerative disease.

Team member Alison Wood was a 49-year-old school teacher in 2003 when she was diagnosed with young onset Parkinson's disease, but, as with many people living with PD, Alison now realizes that symptoms appeared well before she was diagnosed. In 2007 Alison met Candace Cox, a Canadian, STAT-trained Alexander Technique teacher, and began taking lessons. Since then, her quality of life has improved enormously, which she attributes to skills learned during her lessons.

Alison's independence, passion to help people understand what it is like to live with this debilitating disease, and sense of humor impressed me throughout the week, and I arranged to interview her by phone and e-mail.

OFF, ON, and Dyskinesia

As our first phone interview begins, Alison needs to rise from her chair to get something from across the room.

Alison Wood: Push, push, push, push. I'm OFF.

Ruth Rootberg: What does that mean, you're OFF?

AW: OFF means my pills are not working, or they've stopped working, or are still not working. ON means my medication is working.

RR: Are those your personal terms?

AW: Most people who live and/or work with PD use the words OFF and ON. Every person with PD is different and experiences OFF and ON in a unique way. But when someone tells you he or she is ON, it means the pills are working, and the person is feeling his or her best at that moment. When someone says he or she is OFF, it means the pills aren't working. Then doing *anything* is going to be very difficult.

Parkinson's Disease

Parkinson's disease is a progressive, neurodegenerative movement disorder with symptoms that may include tremor in the hands, arms, legs, jaw, and face; rigidity and stiffness; slowness of movement; difficulty in initiating movement; and impaired balance.¹ It is generally considered a disease of late middle age with average onset at around age 60.² The symptoms generally come on slowly over time. Parkinson's patients typically develop a stooped, head-down, shoulders-drooped stance with a tendency to lean unnaturally forward or backward, and they tend to walk with a distinctive unsteady shuffling gait.³

There is no known cure for Parkinson's disease. Medical treatment involves powerful medications that act to reduce the symptoms and hopefully slow the pace at which the disease progresses. However, these powerful medications may produce side effects, including REM sleep disorder, nightmares, compulsive behaviors, and the continuous, uncontrollable movements known as dyskinesia, so care must be taken in regulating and changing dosages as conditions warrant.⁴

The earliest research indicating the Alexander Technique could be useful for people living with Parkinson's was published by Alexander Technique teacher Chloe Stallibrass in 2002.⁵ She followed up with another study in 2005.⁶ In 2015, Dr. Rajal Cohen, Alexander Technique teacher, researcher, and Poise Project team member, who has been researching Parkinson's disease for several years, published a single-session study applying concepts from the Alexander Technique with a Parkinson's population.⁷ The abstract from Candace Cox's presentation at the 3rd World Parkinson Congress⁸ in 2013 and the poster sessions presented by team members from the 4th World Parkinson Congress⁹ in 2016 also contribute to the literature.

RR: What is your experience of being OFF?

AW: Without PD medication there is no real life. When I'm OFF, my whole body shakes with tremors, and walking becomes difficult. At times I have what some call *freezing*: I want to walk, but my feet feel like they are stuck to the floor. Before learning the Alexander Technique, I could be stuck and unable to move off my spot for close to 5 minutes, sometimes 10. With the Alexander Technique, I can get going in seconds. Some people don't have the tremor, but freeze to the point of complete immobility until someone gives them their medications.

RR: Are you OFF only when your medications have worn off?

AW: There are days when the pills don't work; not all of my medications are predictable. They tend not to work when I'm

sick or under stress. The more stress, the worse it is for me.

As we began this call, my medication had not yet become effective. During these 5 to 10 minutes when I'm still OFF, I can walk because I'm using Alexander Technique-thinking. After that, I can walk without thinking about it. Mobility is so difficult for people with Parkinson's; to overcome the freeze is a real gift. Blair (another person with Parkinson's on the team) can get himself moving this way, too; he's had enough lessons. But people who have had just a few lessons don't remember to think in this way.

RR: Is freezing your only movement problem?

AW: My present OFF symptoms also include violent shaking in all limbs, cramping, overheating, excessive sweating, bradykinesia (slowness of movement), and absolute exhaustion when I finally finish and am once again ON. If I didn't take levodopa (the primary medication used to stop Parkinsonian tremor) at this point in my journey, I would shake so violently that I would be covered in sweat and weigh about 90 pounds or less (from the problems of trying to get food into the moving object called my mouth and also the exercise every part of my body gets when moving that fast as I shake). At church when I am OFF and sitting in a pew, everyone in that pew feels it, and many have to get up because they feel sick. It's the same when I sing in the choir. Now when the tremor happens, my limbs cramp (dystonia). When I am that OFF, even the thought of needing the bathroom will make me stuck again. It can take two hours to put a pair of stockings on. I can't track print, so reading is out of the question. Any activity except watching TV or listening to the radio is impossible.

RR: What are the side effects of the medications?

AW: I have been dealing with a variety of side effects since my diagnosis, including edema, insomnia, inability to move in bed, and bad dreams. *Dyskinesia*, which is the word for unwanted movements, is a side effect of the medication I take. That is now my worst symptom, but I only got it in the last two years. What makes it the most stressful side effect at the moment is that Candace and I haven't thought yet of a way that the Alexander Technique can overcome it.

RR: Dyskinesia has something to do with the cycle of the medication, is that correct?

AW: The dopaminergic medication (levodopa) must first pass through the blood-brain barrier, which occurs after it has been absorbed in the first 18 inches of the small intestine. If it becomes dopamine in the stomach, that is too soon, and it can't pass the blood-brain barrier; the person will be OFF despite having taking medication. When it is absorbed correctly, it goes through peaks and valleys within its dosage time, and when it peaks—usually about a half hour after you take it—you feel like yourself again. But overmedicating can lead to the large, uncontrollable, repetitive motions of dyskinesia. Most people

with PD, especially those with young onset, develop dyskinesia after about five years of taking dopaminergic drugs. Michael J. Fox's movements as seen on television are a good example of dyskinesia; when he's ON, he moves all over the place.

RR: Can you predict your dyskinesia?

AW: My movements come as a shock to me. I'm aware when it's happening, but not when it's about to happen. When I become aware of it, I can think.

RR: Would you describe your movement when you have dyskinesia?

AW: My right leg goes 90—even 180—degrees away from my left leg. When that happens, especially if I'm already up and walking, I start to get a little nervous, but I keep concentrating so I don't fall.

RR: Are your legs the only body parts affected?

AW: Recently my head bobs and my teeth slam together in a continuous motion. If I hold my face still with my hands, I can read a sentence or two, but the minute I let go, the bobbing starts again with no relief. On October 10, [Canada's] Thanksgiving Day, I chipped a tooth because of the violent, dyskinetic slamming of my teeth. The same thing happened on my way to Calgary last week, and I needed emergency dental work, because the force broke a molar and pieces of crown. Filling and tooth wedged themselves on top and in the back of the rest of the tooth, threatening to split it like pioneers used to split logs!

RR: What is it like when you are ON?

AW: Most of the time when I'm ON, I don't even remember I have Parkinson's! Although I haven't figured out how to stop the dyskinesia, I have been able to reduce much of it. I walk like I used to walk. I drive—but have to time it to the middle of my pill schedule.

RR: How long do you wait after taking the meds before you drive, and how long would you allow yourself to drive before wanting to be parked and out of the car?

AW: I can never be sure how long it will take to go ON, so I can't give you a time in minutes. It could be 10 minutes if I am lucky, 6 hours if I'm not. I don't drive until all tremor has stopped, except perhaps in my left hand, because I don't need my left hand to drive. When it is just the left hand that is still tremoring, I know that it will subside in minutes.

I value my independence but not at the expense of public safety or my own punctuality. I know I could drive for 15 minutes after I start to go OFF, but I drive routes that have lots of stores and coffee shops on the way, and if OFF happens earlier than it is supposed to, I pull into a parking lot and go for a walk or sit down for a coffee with a lid. If I were a freezer, I would not be still driving.



Ruth Rootberg

When I'm ON, I don't think about how long the medication will last for any other activity. That's really unusual for people with Parkinson's. Most people will have constant motion of a shoulder or leg without any awareness that it is occurring. I think I'm in a better situation than others who have also been living with the disease for 13 years. It is one of many things I attribute to the Alexander work.

Early Symptoms, Diagnosis, and Treatment

RR: What symptoms did you have before you were diagnosed in 2003?

AW: In April 2000 I was in a car accident and a couple months later got bronchitis. I was given an inhaler for the bronchitis and seemed to shake any time I used it, but eventually became accustomed to it. Then during the summer break that year, new carpets were installed in our school, including the portable buildings where I taught.

That fall eight members of the staff, including me, reacted to the air quality in the buildings. I was in a portable building, which was unable to off-gas the glue smell from the carpeting. I fainted one day in front of the class. I was told not to come back without a doctor's note, and it took six weeks before my doctor thought I was better. This time while I used an inhaler, I developed a tremor in my left hand that got worse with every puff. After I stopped using the inhaler and still had a tremor, I sought specialists in January 2001, first a pulmonologist and then a neurologist. Parkinson's was ruled out at that time; the only symptom I had at first was the tremor, and the neurologist was looking for other symptoms such as a masked face, bradykinesia, and stiffness, none of which I had. I was sent to a movement disorder clinic. For the next two years until January 2003, I was seen regularly, and eventually I was given essential tremor medications, but they didn't help.

In January 2003, the day before my Dad's quadruple bypass, my neurologist started seeing more symptoms. He wanted to start me on PD meds and told me I shouldn't work while getting used to those drugs, because side effects include falling asleep while standing. I arranged a leave of absence from work.

I started the drugs in February, and, because they made a difference, he diagnosed me on May 6. It took three years to diagnose PD. I was 49 years old, but I was 46 when I started going to neurologists for symptoms, so I am considered young (or early) onset.

There were also earlier symptoms that I only realized recently were indicative of PD. I had been a regular walker until about 1998, but developed numbness in my left arm within minutes of leaving the house, followed by chest and back numbness, followed by unbearable chest pains that required weird positioning of my arm to get home. These symptoms lasted two years. It wasn't until 2013 at the World Parkinson Congress in Montreal that I discovered that what I thought were heart problems are now considered indicative of PD.

RR: What was it like to live with PD before you began Alexander Technique lessons?

AW: I started a regimen of Parkinson's medications, but the drugs worked only sometimes, so I still had a tremor. That was a problem as a school teacher: I couldn't control my handwriting.

Perhaps it was because I was getting used to the medications, but I would fall asleep at odd times. Sometimes I would fall asleep in the afternoon at my computer; I just fell off the chair!

I tripped a lot; my balance was getting very bad. I had the typical stooped posture, which might have not been just from the Parkinson's—from grade eight on I had bad posture.

The only time there was no tremor was when I slept, and people with Parkinson's don't tend to sleep well.

RR: What kind of treatment, other than medications, were you offered?

AW: When I was diagnosed in 2003, Alberta Province paid

for 15 sessions that combined 60 minutes of exercise and 30 minutes of instruction for people with PD. I have also had physical and occupational therapy, Tai Chi, personal training, chiropractic, acupuncture, and classes called "Living Well with Parkinson's."

I also started singing lessons to help

my breathing. While engaged in one of the various recommended exercise programs, I tore the meniscus in my left knee using an exercise machine. I was in a lot of pain.

I was diagnosed with arthritis in my knee. I started using a cane, but because of the extreme movement in my leg when the tremor began when I was OFF, I would kick the cane away. Eventually I started using a walker.

RR: Did you also use a wheelchair?

AW: Yes, after I had meniscus surgery in January 2007. The surgery was not a complete success. Whenever I tremored, the bones would rub against each other, which eventually destroyed the remaining meniscus. After surgery I used a wheelchair quite a bit at home, but not when I taught school. Instead I used a walker or cane.

RR: You contended with many challenges.

AW: Although I made some improvement with other methods, nothing equaled the relief I gained when I began regular Alexander Technique lessons with Candace Cox.

Learning the Alexander Technique

RR: Had you heard of the Alexander Technique before meeting Candace?

AW: I heard about it as early as 1988, but thought it was just a performance thing. My thoracic back hurt while playing handbells. An organist I met on a handbell tour of England told me about the Alexander Technique. I wished to find a teacher, but couldn't until 1991, when I took a workshop with Annette Dieb in Edmonton. She kept talking about leading with the head. I thought, *What is she talking about?*

The next day I brought some bells to the workshop. As I was reaching for the box of bells, Annette said to me, "You have no idea how much power those things have over you, do you? The minute you looked toward them, your whole body changed." We hired her to present a workshop at the Fifth International Handbell Symposium held in Edmonton in 1992. Her work was very well received, but unfortunately, she moved away soon after.

RR: When did you meet Candace?

AW: You know the saying "When God closes a door he opens a window"? I found Candace like magic at my church.

I was the church handbell director at Riverbend United Church for 10 years, from 1998 until 2007. When I was diagnosed, I suggested that the bell choir find another director, since my hands shook too much, but they wanted me to continue and said, "You have a way of explaining that's really great; please stay." I did, but as the disease progressed, I knew I couldn't continue.

By spring 2007 the time to resign had come, and I told them Easter would be my last Sunday. After we had played our last piece, the tremor was so strong that I was jumping up and down and couldn't do anything to stop it. My dad even tried to hold me down but couldn't, even though he was a big guy. I returned to a pew when the sermon was about to start, still shaking. Then there was a little tap on my shoulder. "Can I try something?" "Sure," I said. The woman put fingers around my shaking wrist. She stretched my arm out along the pew railing, and my arm stopped shaking. My dad looked at me and then at her. "How did you do that?" he asked. She answered, "I'll tell you after church." The sermon was about to start.

After church Candace said, "This is going to sound strange, but the group with which I am associated is starting to work with people living with Parkinson's disease. We are looking for ways to deal with symptoms." I asked, "What is your group?" She replied, "It's teachers of the Alexander Technique." That really excited me, because of my initial experience with Annette. Candace was surprised I had heard of it. She said she would love to show me what she thought might help and offered to give a couple of workshops to the local Parkinson's support group for free.

About 18 people attended the first workshop. Candace asked us what kinds of movements we were having trouble with. One woman said, "My husband drives a sports car; can I learn how to get out of it?"

Candace talked about equal and opposite reaction—one thing goes forward and one goes back. That night we learned how to get in and out of all sorts of chairs. That was a big thing to accomplish without pain, and we learned how to do it in a

very controlled way. It works getting out of anything, from a really low sports vehicle to low stools and chairs with all varieties of support. You reach your arms and torso forward, leading with your head, and lengthen the spine from the head all the way down to the tailbone so the tailbone and head separate as much as possible. It's done with complete control.

RR: Do you still reach with your arms to get out of a seated position?

AW: It depends on the day; if I need my arms, I use them. I never need help from another person anymore, although some people like to help (but really just get in the way). This autonomy of movement is what has kept me independent these last eight years.



Alison Wood before her Alexander Technique lesson

Alexander Technique and Knee Replacement Surgery are Helpful

RR: After that first group class, did you begin private lessons?

AW: I had a few private lessons, but in the first year I had to limit them to holidays because of problems with my school situation.

In June 2008, a year later, I retired from teaching after 32 years. I was under duress; my knee was incredibly painful, and even when I lay down, I could feel the bones rub against each other when I was OFF and trembling.

In July 2008, I traveled to Florida. I had responsibilities to fulfill in my volunteer position as Executive Director of the International Handbell Committee. I was housed in a palatial hotel room, and it was lovely, like a small apartment, but I couldn't walk from one end of it to the next without excruciating pain. And that was really difficult when I had to go to the bathroom! My sister rented me a scooter. When I returned home

from Florida, I stopped using the scooter; I was afraid I would get to like it too much.

When I returned, I saw Candace every week for a month. I also consulted with a new surgeon about my knee, because the surgeon who had performed the meniscus surgery had advised

me to wait several years before considering a knee replacement. I knew I needed something much sooner than that or I would be in a wheelchair for the rest of my life.

After the second surgeon spoke with the first, I received a promise to get knee replacement surgery as soon as there was an opening.

Then Candace announced that she, her husband, and children planned to travel the world. I was very disappointed. She introduced me to a couple of local teachers, and I did have a few lessons.

In October my mother died, and in November I had knee replacement surgery. I spent time in extended care, because my blood pressure dropped severely.

"I arrive at the first lesson almost folded over with my head completely down..."

In February my dad's health started deteriorating rapidly but that was also when Candace returned early from her world travels because of problems with her house. That was lucky for me.

In April my dad died. After knee surgery, because of adjustments they made to that leg, my left leg was at least one inch longer than my right leg. The surgeon suggested putting a lift in my right shoe. I tried it for a while. Then in May 2009, I started regular lessons with Candace (with some interruption for travel). She taught me to walk without the lift. In January 2010, at my one-year post-op visit to the surgeon, the doctor was impressed; he said he had never seen anyone walk without a limp within one year of surgery.

RR: What an inspiring story! Did you continue with Candace after seeing the doctor?

AW: I continued regular lessons until she and her husband moved to Ontario in July 2011. Candace taught two teachers her methods of adapting the Alexander Technique so that the Edmonton people living with Parkinson's could continue to have regular lessons. Unfortunately, one teacher moved back to Switzerland just a few weeks after I started with her. The other, Daisy Kaiser, had to stop teaching temporarily. For a while I just waited for Candace's return trips; she still comes back about every eight weeks, sometimes more frequently, and teaches for five or seven days. I have three to five lessons with her when she comes.

As the PD gets worse, I have good times—I have traveled the world to the World Parkinson Congresses and to the Galapagos—and bad times, but whenever Candace comes, it turns into a good time. I arrive at the first lesson almost folded over with my head completely down, and then after the lesson I am straight again. I learned what the headrest was for in the car!

But without regular lessons, I can't remember how to get my back into the right place, and it's taking longer for Candace to get me soft again. She recommended that I have lessons more frequently, so in 2014 when Daisy was teaching again, I started working with her.

Skill Building

RR: What are some of the specific skills you've learned through lessons?

AW: The most important early lesson was learning how to sit down and stand up as Candace taught in that first workshop. Even when my knee was bad before surgery, it felt totally safe. I've even been able to teach it to others. I helped a lady out of a wheelchair, something her six strong family members couldn't do!

RR: How did you manage that?

AW: I stood in a *monkey* in front of the lady and put my hands out, reaching for her. "Don't grab, just reach for me; I'll be there to catch you if you fall," I said. "Keep reaching." I

backed up as she continued to reach, and she got right out of her chair!

RR: That's wonderful!

AW: I also learned to stand with my weight more evenly distributed instead of standing with the weight on one foot. And as I mentioned, Candace really helped me with walking. By the time she moved away in 2011, I had stopped using a wheelchair except when I needed to move swiftly at an airport.

RR: No walker or cane, either?

AW: That's right.

RR: What kind of help with walking do people with Parkinson's need?

AW: Some people with PD lean forward a lot, and their gait is almost a run with little teeny steps. The feet have to go quickly to keep up, because the torso is so far forward. But if they lean back, they fall backward.

The main thing people do is shuffle. I still shuffle if I don't think about it. When I start thinking, I have to push off with each step so my foot goes up a little higher. Most people can't correct the shuffle, because they haven't had lessons.

RR: Were you given instructions in walking after your diagnosis?

AW: A physical therapist taught me to kick out with my front foot and launch myself with big steps, winding up with a model's walk, tucking my tail. The Alexander way is completely different. I roll through each foot. That is good for the edema that arises from taking all the medications. And the push-off idea is great. I think of three points to push off from—the heel and two points on the ball of the foot. When I push off with my back foot, my other foot is still in the air, and I can choose to land it right under me, so that it gives me total support to my whole body. I'm always in contact with the earth below. That is so important for people with PD.

Using Candace's instructions, I began to feel really, really safe, but I have to start thinking consciously all the time to guarantee that safety. It takes some effort, but it's worth it.

RR: You mentioned using a monkey to help a woman out of her chair. Do you work on monkeys frequently?

AW: Yes. That's something I love. Candace has me practice setting the table in a monkey. I get to stretch while practicing lengthening my back, separating my tailbone, etc. When I was first learning the Alexander Technique, I told my singing teacher about the lessons. She started taking lessons with



*Alison Wood after
Alexander Technique
lesson*

**"...and then after the lesson I am
straight again."**

Candace! She does monkeys all the time in my singing lessons. When she wants me to lighten up, she says: "Think of Candace!" That always works. If she tells me something in an Alexander Technique fashion, I get it really fast.

RR: You have learned to think consciously. Would you say more?

AW: During the first couple of lessons, I didn't know I would be involved. It was kind of nice to lie there and just be. At the end of the second lesson, my back was straight. I couldn't believe it! Two days after, I asked myself whether I could lengthen my back on my own. I could, and that was so cool! My thoracic back rarely even hurt again. My body learned first, and then I followed up with my thinking.

Candace taught me—this was huge—to always think UP. *Oh yeah, that's malarkey*, I used to say to myself at first. But I tried, and it works. When my head goes up, it takes a lot of pressure off my hips and knees; everything feels light and airy. I'm not trying to lift off the planet, but if my head is up, I'm not putting pressure on the joints nearer the ground. It's almost like losing weight! That's another real gift of the Technique: If you are starting to hurt, you can stop and think. It's a real blessing.

RR: Was it easy to learn this thinking?

AW: Learning to think was hard. The brain is my favorite organ, but my thinking process had always been very cerebral and didn't have much to do with my body. At first I didn't want anything to change; I didn't want to feel different from how I knew myself. But the way Candace and Daisy talk to me, I'm making the connection between mind and body.

It's taken me awhile to realize what Candace and Daisy are offering me. One time I arrived for my lesson with Candace and actually wasn't late (the symptoms when I'm OFF make punctuality very challenging), but she was late for me. I felt really blue having to wait; I had been so excited to be on time for once. I started to cry. "I'm sorry I am crying; I haven't cried since I was diagnosed," I told her. Candace replied, "Maybe we should just skip this lesson and go have a drink instead." I said, "I don't do that. I never participate in activities that would make me lose control of my body." Then it hit me. The last thing in the world a person with PD has is control of the body! We laughed and laughed. Candace replied, "In another lifetime, you might want to rethink that decision!"

RR: Can you give another example of how thinking has helped you?

AW: I am not someone who sits to relax very often, in part because I don't know how. Any time I'm sitting, supposedly relaxing, I realize I'm still very tense. I used to feel as if I was

trying to suspend myself from the chair so that I wouldn't hurt it, but I'm changing. During a lesson when I'm lying on the table, Candace or Daisy will say, "Let me have your leg." I had a real a-ha moment when I figured out what they meant and could go soft.

RR: You've really regained some control by using Alexandrian thinking.

AW: I continue to nudge myself to figure out what my body is doing. I realize that I have to actively engage with the table and with what's happening during a lesson. I can figure out more and more what either teacher is doing as she moves me. That is



Alison Wood practices monkey.

true whether I am supported by the table or by the floor when standing. Of course, I lose a lot when not taking lessons, and I am still not always present in the moment during a lesson. Candace and Daisy remind me to come back.

Coping Strategies

RR: Although you have learned so much, you are facing a degenerative situation. What else can you say about your present conditions and how the Alexander Technique helps you to cope and remain independent?

AW: I have trouble in the morning; I wake up gasping for breath. I bought a massage table for lying down (if I can keep stuff off it), and I lie on it in the morning and then again in the afternoon, if I am able

to move myself onto it. My knee still kicks up a fuss once in a while, and when it does, I spend more time on the table. When I lie down, I get more information. Because of the Alexander

Technique, I can observe how I'm using my knee.

If I am shaking, I am very uncomfortable and I sit down, because I know that things will start to fall apart if I don't. I am considering trying to lie on the table, but at this point I often feel it is too far away to risk the effort or that I may shake myself off the table once I'm on it.

When I look at my neck in the mirror, it appears dropped forward to about 45 degrees. I don't like the way it looks and know it's important for my whole system to raise my head if I can. I have to remind myself that I must move it higher. At least it's no longer sunken onto my chest! That is an improvement I have not seen in others, unless they've been studying the Alexander Technique.

My proprioception is out of whack because of the PD. I'm at a stage where I don't have a perception of where I am in space. I don't know my trunk is listing to the left unless somebody tells me. The asymmetry brings me out of balance, and I might not walk a straight line. Candace, Daisy, and I are working on lengthening my torso on the left side. Now I can feel when I'm about to walk in a diagonal line, and I can fix it.

OFF periods and freezing are regular challenges. I freeze turning corners or when I approach a doorway. It also occurs

"When she said, 'You can't do that.' I said, 'Try me.'"

when I am in a crowd and people are in my way. The worst is when I've fallen asleep in a strange position, maybe in a chair, not supported by anything. I'm so stiff, I feel I can't move. I may start to panic, especially if I have to go to the bathroom. But I tell myself, *You can do this. Just calm down, you've done it before, you can do it now.* I'm very lucky that my Alexander skills help me to get myself going again; some people have to wait for a caregiver to bring them their pills.

I pull myself to a position so that I can get up from the chair. Two years ago I realized that if I skip raising my head up, I'll have trouble taking more than one or two steps once I'm standing. But sometimes it's easier to *know* what to do than to *do* it. So sometimes I put my hands on my head to remind myself of the lift of the head or even use my hands to move my head as I've seen my teachers do on me. It's the opposite of pushing down on the cap of a childproof medicine bottle. That gives me the space I need to get my body going. Once I perceive my head is up off my chest and higher than the shoulders, I say, "Now it's time." Then I say, "Push, push, push," and all of a sudden I can move.

Then I push on the floor so I can get some leverage, stand, and continue towards the bathroom. When I'm no longer worried about the bathroom, in a count of 10 I can get into a gait and don't have to think about making myself walk. But until the medication has progressed to the starting-to-go-ON moment, every thought and fiber of my body must concentrate on how to move. I can't talk to someone else and think the Alexander Technique in the same moment. I say, "I'm sorry, don't talk to me; I have to work on this." As long as nobody is talking to me, I can overcome anything. And I try not to have anything in my hands until I'm more steady. Usually in quick order, but not without difficulty, I can manage. After a while, my body takes over and I don't have to think so much.

RR: Do you always say the same thing, "Push, push, push"?

AW: It works for me. A lot of people would say: "Up, up," but I say "Push, push." Candace thinks I choose that word because it helps me connect to the floor. I push down to go up. It starts a song going in my head. If my head is down, within the next two steps my head goes up a little higher.

Sometimes I say: "Push one, two; push one, two." Either connects me to my feet, head, and body, eventually. Anybody with PD knows freezing is horrible; the feeling of being stuck to the floor is horrible. My way of getting unstuck, as long as I can remember that I already know what to think, works almost all the time.

For example, once I was about to introduce a speaker whose topic was stem cell therapy, and just as I was about to make the introduction, I went OFF, started to tremor badly, and became hunched over. My head went completely down. I pushed my head up with my hands, took a deep breath, and said, "Push, push, push." I lengthened my torso, walked across the stage with my arms swinging and my head up. The audience was astonished at the transformation; their jaws dropped. Later people approached me to find out what I was doing. Some signed up for lessons!

RR: Many people who study the Alexander Technique silently say, "Neck free, head forward and up, back to lengthen and widen." Do you?



Alison Wood walking fluidly after lessons

AW: My sequence is: "Stop. Think. Get your head up." Then the rest. I don't begin with "Neck free" yet, but my neck is getting kind of stuck. My other words are "Open" to remind myself to open my chest, and "Soften," which is what I use when my teacher asks me to let go.

RR: When we were in Portland, did I hear you say that you keep moving your hips around to prevent them from locking? I thought what I had observed was dyskinesia.

AW: That is exactly what I said. It does *look* like dyskinesia, and I have had a variety of people assume it is that, but the PD nurse and neurologist confirmed my assertion that, in my case, it is not. When I started with Candace, I used to have to remind myself to move my hips, because if I didn't do it, I would be stiff and couldn't move fluidly! Now I move my hips without thinking about it and

don't mind that it has become a bit automatic; it is really hard to think about everything I need to think about, like lead with the head; elongate the spine and limbs in the equal and opposite directions; roll the feet; feel the floor....

Now that I do have dyskinesia from time to time, I absolutely *know* that my hip movement is not that. Dyskinesia is exhausting and causes cramping that really hurts, whereas hip loosening makes me feel much better and takes pain away.

"I went OFF, started to tremor badly, and became hunched over. My head went completely down. I pushed my head up with my hands, took a deep breath, and said, 'Push, push, push.' I lengthened my torso, walked across the stage with my arms swinging and my head up."

Movements caused by my dyskinesia cannot be controlled, but I can stop immediately when someone says something like, "You have dyskinesia now, don't you?" Stopping immediately proves that it isn't due to dyskinesia. I try to remember

to stop at my neurologist appointments so as not to confuse the issue! Although when it is time to stand and walk or hold my balance when the doctor pulls me from behind, I automatically move my hips to warm myself up for the test.

RR: You said Candace adapts the Alexander Technique. What do you mean?

Alexander Technique Adapted for Parkinson's

AW: Candace doesn't work in a certain order; she'll go first to the area that's shaking. When I'm trembling, she takes my arm and does the stretch thing (lengthening) she did at church that first day. The tremor goes through her to the floor like a lightning rod.

It is not unusual when she works with me for her to be standing straight and lengthening my arm to get rid of tremor. Then my leg starts, and if my arm hasn't stopped, she lifts her knee to her ear so she can put her foot on top of my ankle. If something else starts to move, she lowers her head onto that body part, and we breathe. If I have the energy to look at her, you can bet her spine from head to tailbone will be in alignment when she is doing all that. I would bet that only part of that would be in an Alexander book.

Spreading the Word

RR: I imagine you have let your medical professionals and other people living with Parkinson's disease know about the Alexander Technique.

AW: Of course! My general practitioner has marveled for years. She saw the improvement immediately. I looked pretty "PD-ish" by the time I met Candace. Now when I am ON, even my neurologist has trouble finding something that looks like PD.

The exercise class I took early after my diagnosis was taught by a physical therapist, Chris, who worried about my posture. I was given a bunch of before-and-after tests at the movement disorder clinic. One of the tests was to time me while I picked something up off the floor. I couldn't perform the test before my knee surgery, and Chris thought there was no point in conducting it after my surgery. But that appointment was also after I had begun Alexander Technique lessons.

When she said, "You can't do that." I said, "Try me." So she dropped her stopwatch onto the floor. I looked down and immediately picked it up and said, "You mean like that?" I bent and stood up several times. Chris was totally shocked. She recommended I continue my lessons! That was six years after having been diagnosed with PD and about a year after surgery. A newer physical therapist and some occupational therapists have also become interested. People started to pay a lot of attention.

I mentioned before that my surgeon had never seen anyone walk without a limp so soon after surgery. His nurse was also very impressed. She had another patient with PD and phoned me after an appointment to find out more about the Alexander Technique.

At my PD society, they asked what the Alexander Technique had done for me. I demonstrated how I could walk and touch the floor. Four people signed up for lessons immediately. Private lessons are cost prohibitive for many, but people sign up for workshops.

RR: Are you the exception to the rule, or have other people experienced rapid and long-lasting improvement?

AW: Candace offers workshops fairly regularly through the PD society in Edmonton. I know only a few people who have committed to private lessons because of the cost. Some people were involved in the studies, which included free lessons, and every person in those studies improved.

A friend with PD went from a 90-degree forward neck and head to an upright posture and could take up tennis again. Even after a hip replacement, his speaking, gait—everything—improved. His wife assisted by doing with him at home on the floor what she saw Candace do at the table during lessons.

Philippe, another student of Candace's who joined the team in Portland, has had PD for 12 years.

In a pre-learning work-up, it took him five minutes to get out of a chair. Within one class, all of a sudden, he was up and walking beautifully. His life changed from that one week of classes. His wife wrote a very impassioned thank you. At the latest workshop that we both attended, he demonstrated his ability to sit and stand in one fluid motion that took seconds. There were other participants at that workshop who did not have PD but had seen him at a previous workshop. They were all in tears. There was an eye doctor who said near the end of the class "Even if one arrives completely skeptical about this work, when you see these two people with Parkinson's do what they do, you have to believe that the Alexander Technique is effective."

There are people who see the effectiveness, but because they can't afford it, they dismiss it. Those whose spouses nag them to participate usually give up before they've taken enough time to experience benefit. But those who really commit improve.

Candace presented a case study based on her work with me at the 3rd World Parkinson Congress in 2013.¹⁰ It traced the progression of the disease until I started lessons and then showed that after lessons several of my test scores reversed. Then she gave a poster session in Portland of a study of six people who had fabulous improvement after one week of private lessons and group classes.¹¹ Now more people are signing up for private lessons.

Conclusion

AW: I remain committed to spreading the word about the value of the Alexander Technique for people living with Parkinson's disease. I know in my head and heart that I would be in huge trouble by now without it. I've watched friends who were diagnosed at the same time as I was and realize how much I've gained and how much they've lost. I've learned that the Alexander Technique helps all of me, not just my Parkinson's symptoms. Our bodies are not meant to be sore. It's what we do with them that causes them to be sore.

I have regained hope and quality of life, thanks to the Alexander Technique. I am blessed that Candace came into my life when she did and that she was willing to devote her time to learning about the illness, both from studying previous research by other Alexander Technique teachers and from working with me and adapting her teaching to my needs. I have hope, because I know she is committed to continuing her work with me. She taught me the skills I need to remain mobile and to live alone so long and so well.

People who live with Parkinson's disease as long as I have receive daily reminders that the disease is progressing. They have to deal each day with the increasing severity of symptoms, the extra non-motor complications, and the difficulties that affect even the ON periods. Most of them cannot forget that they have Parkinson's, even for a moment; they feel the disease all the time. I can forget for several hours at a time.

Parkinson's disease is presently receiving more attention as discoveries are made regarding what seems to be a spectrum of PD-related conditions. Although previous measures of the disease's progression are becoming a bit obsolete, we still use a five-stage definition of the progression. The difference between stage four and stage five Parkinson's is whether or not you can live on your own. That is another gift of the Alexander Technique. I remain independent. I have no caregiver. I still feel as if I don't have PD most of the time. My wish is for other people to have the help I have had, so that everyone has the same chance to enjoy life and live safely.

"I'm very lucky that my Alexander skills help me to get myself going again; some people have to wait for a caregiver to bring them their pills."

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11. Candace Cox, Daniel Kral, Monika Gross, and Rajal G. Cohen, "Thinking in Action: Alexander Technique for Parkinson's Disease." (Poster presented at the 4th World Parkinson Congress, Portland, Oregon, September 2016.) See also note 9 above for access date.

Ruth Rootberg (Alexander Technique School New England [ATSNE], 2003) is author of Living the Alexander Technique and the article "The Alexander Technique and Parkinson's Disease: A Case Study in Generating Hope for a Degenerative Condition" (AmSAT News, 83, Summer 2010). She is Chair of AmSAT's Professional Conduct Committee, writes frequently for AmSAT Journal, and has recently been appointed Associate Editor of AmSAT Journal after over 10 years volunteering on the team. Ruth teaches private lessons and group workshops in Amherst, Massachusetts and around the country.

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Endnotes

1. "Parkinson's Disease—a Unique Survey Launched," World Health Organization Press Release/71, October 14, 1998, accessed May 1, 2010, www.who.int/inf-pr-1998/en/pr98-71.html.
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What Was the Impact of the Poise Project?

Has anyone living with Parkinson's disease contacted you for lessons recently?
Please let Ruth Rootberg know at RRootberg@comcast.net.