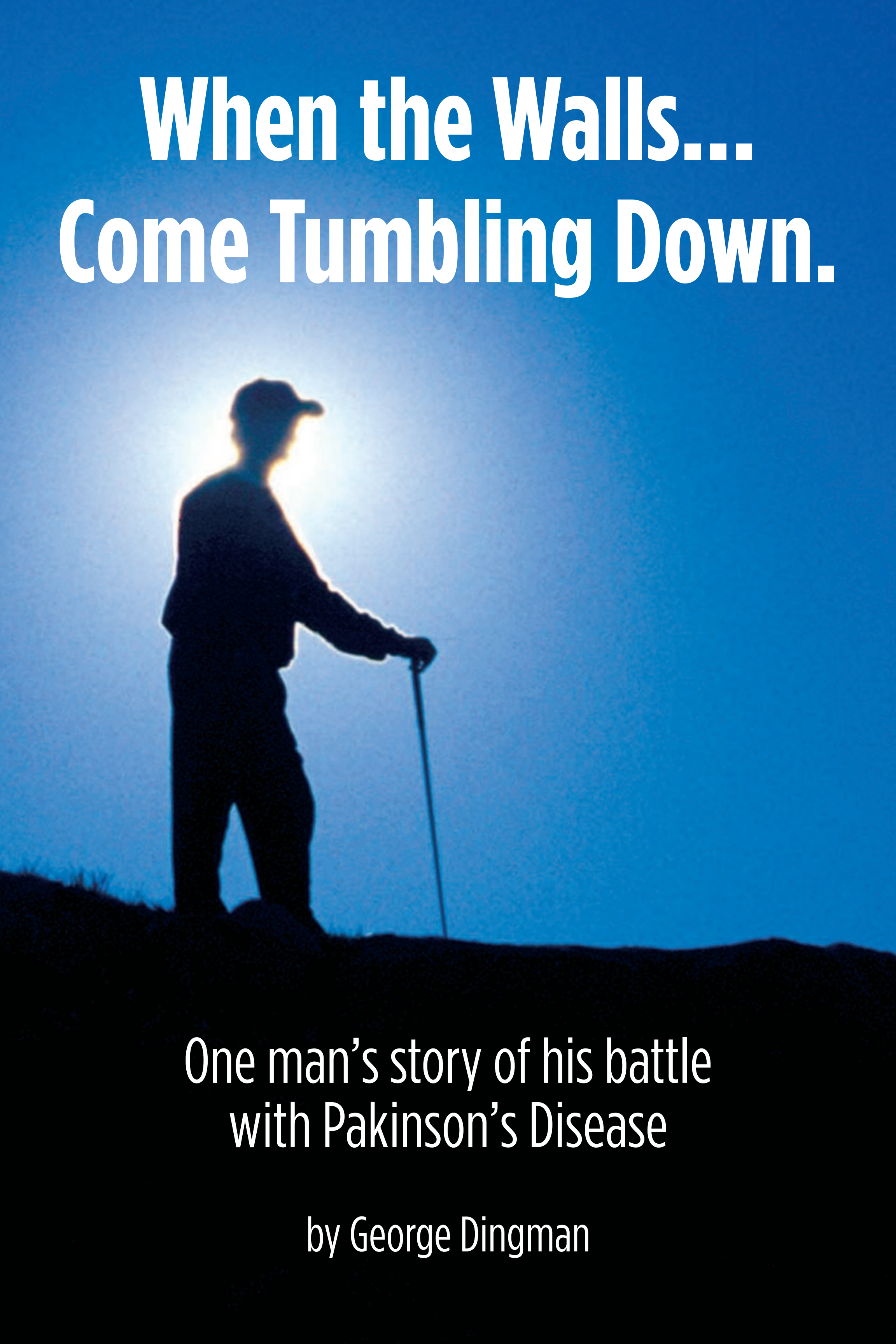

When the Walls...
Come Tumbling Down.

One man's story of his battle
with Pakinson's Disease

by George Dingman

When the Walls...
Come Tumbling Down.

By
George Dingman
With Ralph Wintrob

2nd edition

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Editing - Shawna (Hord) Dingman

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1. Forward

Broad-shouldered, tall and now past 60,
Weathered like a sea captain (Maybe it is the beard)
George Dingman has what actors call "presence".

To meet George is to remember him,
The kind of guy a son or daughter would say,
"My Dad is that tall guy over there".
You just knew that George was going to be special
in whatever field of work he was in.

Most people have heard of Parkinson's (Michael J. Fox has it).
Maybe a few of you know someone with it.

George doesn't cry about it,
but tells you in a matter-of-fact way how it has affected him.

His story tells of one man's struggle to deal with this
horrible disease and gives you an insight,
not only into the disease itself,
But a reflection of what character and strength of mind
can do in the face of adversity.

It is always with great pride when I say to others,
"I'd like you to meet my friend George Dingman".

Peter Calvert

2. Acknowledgements

Without an active and elaborate support system, a Parkinson's patient could not survive, physically or psychologically, and this book could not have been written.

Special thanks to my very kind friend Ralph; without his friendship and sensitivity this book would not have happened.

The following people give me reason for being. They give me purpose. They give me strength. I want them to know how important they are to me and to my journey.

Linda, Chris, Masami, Craig, Shawna, Marni, Drew, Kai, Reina, Jackson, Jenna, Jasmine, Taylor, Howard (Pop) (I miss you), Betty (Mom), Pat, Les, Liz, Art.

Bob and Barb, Peter and Joan, Ted and Jean, John and Brenda, Bob and Marg, Uwe and Lyn, Sid and Mabel.

Roy and Peg, Craig, Shirley and Drew.

Tom, Maggie, Peter, Ben and Pat, John and Carol, Lois and Hector, and Dick (I miss him every day).

Dr. Richard Gladstone, Dr. Robert Williams, Dr. Janet Myasaki.

I am blessed. There are many other people who are a part of my support system. Please do not feel slighted if I did not mention your name. You are in my heart. Thank you.

3. Dedication

This book is dedicated to all those who fight the good fight. Soon, I believe the war will be over. They will finally find a way... The following is paraphrased from a card written by Ed Cunningham and sent to me by my then principal, Jan Stewart, just when I needed it most.

Meanwhile, remember:
There are sad, lonely, down times for all of us
I know you are having one now.

Nothing I can say will make it go away completely
or make it easier for you to cope.

So let's talk about what really matters,
about a wonderful person... YOU.

I know that whatever life hands you,
you will be strong and carry on.

Whatever the obstacles in your path, you will
be tough, and get the better of, whatever choices you
have to make, you will make them.

4. Prologue

Doctors will tell you that the cause of Parkinson's disease may be genetic, or metabolic, the result of a deficient protein enzyme, or an inhibited molecule. As I write, researchers are laboring away trying to pin down the cause and find a therapy that will prevent, arrest, or cure the disease without painful side effects.

Well, good luck to them. One day, hopefully, stories like mine won't have to be written.

I can't tell my story as a professional would. For me, and my fellow Parkinson's sufferers, it's more an emotional roller coaster ride rather than a clinical one. It's more about getting diagnosed, learning to cope and dealing with the fallout.

In short, it's a human story.

Because stress makes the symptoms worse and the disease harder to control, this is the story of one person's up and down struggle to control the stress factor. For me, it's what Parkinson's has been all about. It's a story that I have been bursting to tell. I need to tell it to help my family understand, to help Parkinson's victims like me understand, and to help me get it right in my own mind.

It's the story of what happens When the Walls Come Tumbling Down, or maybe better, when you try as hard as you can to put yourself back together, all the while knowing deep down that you can't.

It's a story about trying to recreate myself in a new shell and how it changes everything, for me, for my vocation, and for those who are most near and dear.

5. Shawna

I first met George in the summer of 1997. What is really remarkable about our first meeting is that it was completely unremarkable. George's son Craig, my husband, had just bought a student house with a friend when we were in Chiropractic College. At the time, Craig and I were just friends, and I was renting a room from him. Craig's family is very close, and they were down in the city helping him renovate the basement. I couldn't tell you what day we met, what they were doing or even what I was doing that day; I just remember coming up the porch steps and in the front door, and there they were. George and Linda were sitting on the couch having a visit with Craig. I was introduced to them, shook their hands, made a little small talk and then disappeared upstairs to my room to resume whatever it was I had come in the house to do.

That was it. That's all I can remember about meeting George. I had no idea that he suffered from a debilitating neuromuscular disease. He was simply Craig's dad.

I can't really remember much more about George until the spring of 1998. By that time, I knew that he suffered from Parkinson's disease, but I didn't really know anything about the disease except what I had read in my textbooks. The truly amazing thing is that at that time, I would not have known that George had Parkinson's if Craig hadn't told me, despite the fact that he had been suffering from it for over 25 years.

Craig and I began dating in the spring of 1998. I remember stopping in at their home on the way back from our family cottage in May. It was the first time I had really been able to sit and get to know them on a personal level. They are the loveliest people you will ever meet. That was most likely the first time I noticed George's dyskinesia. In my naive mind, it didn't seem to affect his day-to-day life much, and I didn't give it much more thought than that.

George's Parkinson's disease became a real entity for me later that year. In our third year of Chiropractic College, we studied neurological diseases. As you can imagine, Parkinson's disease is a must-know for chiropractors because it is disease of the motor system. I can remember sitting beside Craig in class as we were learning about details of this devastating disease, about the drugs and about the psychosocial effects on those suffering from it. I could feel Craig's emotion as we sat in the lecture hall. At that point in my life, I knew that I wanted to spend the rest of my life with Craig. All of a sudden, it dawned on me that Craig could suffer the same fate as his father, and I would be in the same position as his mother. That was something I didn't know if I could handle. I felt like I was going to suffocate sitting next to him with these thoughts going on in my head.

So, I did the thing any insensitive smuck that can't wait until the end of the lecture to ask a private question would do. I raised my hand and asked if there was any research indicating that this disease was hereditary. I couldn't stop myself. I'm sure that Craig wanted to either slap me or sink right into his chair. I sat on the edge of my seat waiting for our professor's answer. Oddly enough, I can't really remember what he said. I think that on some unconscious level, I decided in the split second it took him to respond that the research is most likely inconclusive on this subject anyway, and it didn't really matter to me what the answer was. I loved Craig and that was that.

From that point on, understanding "the Parkinson's" as his family calls it became a huge part of getting to know his family. "The Parkinson's" is like an honorary member of the family - unfortunately, you can't have one without the other. I learned the personal side of this disease. Quite frankly, it's a side we all would rather read about in someone else's book. Parkinson's disease is a paradox in itself. It gives the body movements it cannot control, and yet overall, it takes away movement. It is fascinating the way it can ebb and flow through the body. One second, George can be walking next to me, and the next second, he can be pitching forward because his legs have stopped moving. When his medication is working well, he functions quite normally from the outside, but when his medication is off, he can't move at all. George learned quite awhile ago that when he freezes, he can move again if you give him something to step over. He created the "Dingman Device", a funky little add-on to his cane that allows him to step over it in case he does freeze. Luckily, just about anything can be a Dingman Device. I remember at one of our Father's Day barbecues a few years ago, George was coming down the stairs and froze just as he stepped onto the lower deck. I happened to be standing next to him, and he reached out to my shoulder to steady himself. It was a very hot day, and someone had discarded his t-shirt over a nearby chair. I grabbed the t-shirt and threw it down on the deck in front of his feet to step over. That was all it took. He stepped over the shirt, and I'm not sure if anyone else noticed. Over the years, I'm sure the family has come up with a number of handy devices like the shirt. Feet work well. Kleenex boxes and skipping ropes also do the trick. Now George has a special cane that has a laser light. When he needs a Dingman Device at night, he simply pushes a button, and a line of red light flashes through the darkness to provide that visual input to the brain, allowing him to move forward without falling. He has a special walker with the same mechanism.

As I mentioned, "The Parkinson's" is a not-so-invisible family member. It is a very selfish family member. It takes and takes and takes some more. First and foremost, it takes away George's comfort. I remember going to see him speak to the College of Pharmacy at the University of Toronto. Their college brings in people who suffer from various conditions and diseases so that their students can see first-hand how these conditions manifest themselves. They put a face to the disease in the hope that it will allow future pharmacists to help their clients in the most effective way possible. After all, people like George have a very personal relationship with their pharmacists.

Anyway, one of the students asked George what it felt like to have this disease dwelling inside you. Being a former teacher, he knew that a demonstration would be much more effective than simply using words. He asked the entire auditorium to stand up. We did. Then, he asked us to try to contract every muscle in our bodies. Then, he asked us to bend over while holding the contraction. "Now", he said, "try to move. That's what Parkinson's feels like all the time."

George is in constant pain. He takes Advil like candy to help dull the pain. Interestingly enough, he began having problems with his kidneys in the summer of 2005. This was most likely due to such a large consumption of pain relievers. He stopped taking Advil and has not found that he feels much worse. It's difficult for all of us to watch him go through so much pain. He often has what he calls "traveling pain". There is always a localized area of his body that is excruciatingly painful. At times, it has been his shoulder, his pelvis, his knee, or his elbow. This pain can be there for months, and then it just moves. There is often no rhyme or reason for it. It's difficult to know what to do to help him. You just never know how much of it is biomechanical correctable or how much of it is "The Parkinson's" settling itself for a long winter's nap in that area of the body.

I know that this has been particularly frustrating for both Craig and I as his chiropractors. Let's back up a bit, first. George first started seeing a chiropractor decades ago. He was coaching Craig's hockey team when Craig was 10. Craig injured his Achilles' tendon and was not able to play for a time. One of the other hockey dads was Dr. Tom Offen, a chiropractor. He asked why Craig was not able to play and offered to help. Dr. Offen adjusted Craig's spine in order to allow his nervous system to work better. When the nervous system does its job correctly, the whole body works the way it should. Craig was back playing hockey in no time.

George began seeing Dr. Offen in order to get his body working as well as it could give the physical limitations of his disease. He found that chiropractic helped him keep moving and playing sports; he could manage the disease much better. It is my belief that his diligent chiropractic care is one of the many things George has done that has allowed him to become such an anomaly with Parkinson's. There is no one in Canada who has had the disease for so many years and remains so functional.

Dr. Offen has since retired, and George gets adjusted at our office. There are times when he comes in and his spine adjusts like butter. There are other times when it's like trying to move a cement wall. There are also times when he simply can't get out of the car to come inside. George is probably our single biggest challenge in clinic.

We are used to people getting better. In our office, we offer what is called "wellness care" to our patients. That is to say, people generally choose our care when they don't simply want to relieve their pain, they want to fix the source of their problem and make sure it stays fixed for the rest of their lives. When people commit to this kind of care and follow their recommendations, they almost invariably get better. In fact, most people achieve results they never dreamed would be related to chiropractic care. We see this day after day. We expect this.

George is different. We know that the regular adjustments help his body work better, help his mind and body communicate as effectively as possible, and help to get him to the next round of golf. There are a lot of set-backs, though. Techniques that work for most people don't always work for him. Sometimes, working on one area of his body will aggravate another area. "The Parkinson's" has changed the way he moves and the way he walks. He has had to adapt in order to function. That presents challenges that are totally atypical. There are times when we wrack our brains to figure out what the hell is going on in his body to create the symptoms he is experiencing. And then all of a sudden, it can be gone and we haven't learned a damned thing from it to help him the next time. My mission in this chapter is to explain how George's Parkinson's disease affects my life. Well, I can tell you that from a professional standpoint, it sure has challenged me to say the least. Craig usually adjusts his dad. I feel much less effective as George's chiropractor than Craig does, so I defer to him when it comes to his father's care. Perhaps it is the mother in me, but I have a very difficult time detaching my personal feelings for my father-in-law from his care. It is too painful for me to watch him suffering as he does because I feel that, as his chiropractor, I should be able to take more of his suffering away. I take it very personally that I can't do more for someone who means the world to me. Craig is much better at knowing that it is what it is, and there is only so much we can do. He is better at accepting the fact that chiropractic helps his dad tremendously, and that George likely would have progressed much quicker if he wasn't getting that constant reminder to his nervous system in the form of years of adjustments. Craig is just better at being a really good chiropractor for his father.

Pain is a funny thing. Most people are motivated by lack of pain. I often wonder what suffering from pain on a constant basis does to change your motivation. If "The Parkinson's" has taken George's level of comfort away from him and given him pain instead, I can also say that it has given him a kind of motivation that few of us are privileged to have. George is one of the most positive people I have ever met. He has to be, suppose. Why else would you bother getting up every day? He figured out years ago that his mental state really affects the manifestation of the disease. Stress and negative emotion make the symptoms worse. Happiness and positive thoughts make the symptoms better. George has had to train himself to stay positive and avoid stress (positive and negative) whenever possible. He has been an incredible role model for Craig and I and our kids. For the whole family, really. He reminds me of Dory, the little fish in Finding Nemo. There is a part where she sings "Just keep swimming, just keep swimming. What do we do? We swim". Well, that's life for George. "The Parkinson's" isn't going to go away, so he finds a way to just keep on swimming. Luckily, he has a much better memory than Dory (selectively, of course).

The whole concept of avoiding stress brings a very interesting family dynamic to the table. Keeping stressful events from others in the family is a very popular pastime in the Dingman household. This was an entirely new concept for me. You see, Craig's family are really the nicest group of people I have ever met in my life. My family is... different. Don't get me wrong, my family is very nice, too, but not in the same way that the Dingmans are. When something needs to be said, it just gets said, and feelings can get hurt. Eventually, we all kiss and make up. When something needs to be said in Craig's family, there is a lot of stewing and figuring going on. Often, bad news is kept from certain members so that people aren't upset. Poor Craig. Meeting my family was like throwing a lamb into a den of wolves. I'm surprised at times that we ended up marrying. Maybe that's a testament to how nice a guy he is.

I'm not very good at keeping my mouth shut. It's a very difficult thing for me to not just say what's on my mind. I think that my lack of finesse in this department was a bit of a shock for George and Linda. I remember years ago having a conversation with Craig about people choosing partners that are like their parents. Craig is very much like my father in some respects and drastically different in others. I asked Craig if I was like his mother. His reply was quite simply, "Good Lord no! She's the nicest person you'd ever want to meet!" I still don't know whether or not to be offended by this. Nonetheless, I have tried over the years to watch what I say and how I say it. I'm pretty sure I've failed miserably. I am getting better, though, because I can see how stress affects George. If stress-avoidance is a means of prolonging his health, then we have all learned to take life a little less seriously. This is not such a bad thing after all.

As I have mentioned, Craig and I have children. Our son, Jackson, was born in 1999, and our daughter, Jenna, was born in 2004. People often ask me how Jackson reacts to his Grandpa's Parkinson's. Well, he doesn't really react at all. We've never hidden it from him, so he's known about it right from day one. He doesn't see "The Parkinson's"; all he sees is a grandpa whom adores him and who he adores in return. He sees the twitchy legs and the other things that go along with the disease, but that's just grandpa to him. It's all part of the package. If only everyone could see George through his eyes.

Having the children has brought up issues around "The Parkinson's" that have caused grief over the years. I remember when Jackson was born, George would only hold him if he was sitting in a chair with arm supports. He was afraid of dropping him. So was I. There is almost five years difference in age between Jackson and Jenna. When Jenna was born, I don't remember George holding her very much at all. I think that his Parkinson's had progressed quite a bit in those five years, and he just did not feel comfortable holding his infant granddaughter. Driving is also an issue. George still has his license and is a very good driver. However, I don't feel comfortable with him driving my children. What if something happened and he froze while driving? It's never happened, but I don't want to take the chance. I've never expressed this to him, but he shares the same concern because he lets Linda drive whenever the children are in the car. It's difficult, though. I feel guilty about questioning their safety with him. I know he would never intentionally do anything to harm them. Blame it on "The Parkinson's" again.

George and Linda live with us now in our home during the warm months of the year. It has worked out to be a beautiful arrangement for all of us. The children get to spend so much time with their grandma and grandpa while they are here, and the moments they share are priceless. I think I can say that if it wasn't for "The Parkinson's", they would not have sold their home, rented a place in Florida for six months, and moved in with us. During these six months, I feel so blessed to have the benefit of our three generations living under the same roof. Often, there are four generations in our home as Linda's mom, Betty, spends a lot of time with us. There are not many families who can share care of each other the way we do.

And we really do all take care of each other. The older people (Craig and I, George and Linda) take care of the kids. George and Linda help to take care of Craig and me in so many ways. We can put the kids to bed and give them the baby monitor and go for a walk together. We can go away for business trips and leave the children with their grandparents in their own home. There are many nights when we come home from work and dinner is waiting for us on the table. We share many meals and many moments together as a family. And, of course, we all help take care of George and Linda when they need it. Craig is a rock for his parents, and I know they feel blessed to be such an integral part of his life.

This chapter has not unfolded the way I thought it would. When I think of "The Parkinson's", I think of the woes it has brought to George's life. In writing about our lives, it has brought to light once again how lucky we are in so many ways. I guess that's easy for me to say since "The Parkinson's" is not my cross to bear. Or perhaps it is George's positive influence on my life. I know that I would not be alone in feeling that if I could take away the pain of this disease from George, I truly would. He has suffered long enough and deserves a break. Any member of his family or his large circle of friends would agree with this.

I asked Linda once before I married Craig whether or not she would choose George again if she had known that more than half of her life would be spent caring for a man with Parkinson's disease. Knowing what you now know about George and Linda, it will be no surprise to hear that her answer was "yes". She would undoubtedly choose George again. He is more than the sum of his Parkinson's. He is a loving, patient, kind, supportive, courageous, wise man, friend, love, husband, father, son, brother and grandfather. He has taught us all strength, grace and love of life and family. His life - the good and the bad - is a gift for all of us to share.

I love you, Dad.

6. We are as we are made

Born in 1943, I was a wartime child. My mother was 23, my dad just 19. He wasn't even there at the time. Barely past their honeymoon, he left my Mom when was he called up to fight with the Canadian forces in Europe.

I was two years old when I first laid eyes on him. He came home wounded, shell-shocked, and with a bad case of DT's from fighting in the invasion of Europe in 1944. He was barely out of his teens. Although he had grown up in a downtown Toronto slum area, his experience as a soldier turned him inside out. It took him a long time, my mom told me later, to get him back together. I didn't catch on at the time. How could I? I just thought he was moody and I'd best keep out of his way.

He'd had a rough childhood I found out later, brought up in a string of foster homes. He never got past Grade 7.

When he was called up my mom went back to the family farm near Newmarket. She wasn't much better off scholastically. After Grade 11, legal school-leaving age then, she helped her folks full time on the farm. She never ceased telling me that my dad was her first and last beau.

On the farm, I was surrounded by aunts, uncles, and doting but firm grandparents. I spent my early childhood romping with the calves, or tied to a front yard tree waiting for my Grandpa to come up the laneway and release me to climb up on the hay wagon and ride beside him.

My sister is three almost four years younger than me; we were the apple of our grandparents' eyes. They dreamed of our success and did everything they could to make it happen. We only had to ask for something and if they could provide it, it was ours.

When my grandmother was still living, Christmas was the most special time. The whole family would descend on the house all at once. There was a feast of food, fun, and games. It was the best of times.

My grandfather had his peculiar ways. He had quite a temper and there were times in anger, frustration and jealous rage I was a bystander to some explosive behaviour. One time he held a knife to my grandmother's throat; my mom had to break a chair over his back to get him to remove the knife

He had his harsh ways too. He believed kids had to learn the realities of farm life early. I still remember when he made me watch him put a bullet through the head of our Collie when it came down with distemper. This was a horrifying experience to a six year old. I was so full of childish rage.

Nevertheless, he had his good side too. I remember him taking me to the Canadian National Exhibition every year, known locally as the Ex. We had a great time together. He always bought me an ice cream waffle and introduced me to the Ferris Wheel.

When Hodgkin's disease took hold of him, my grandparents sold the farm and we all moved into a big house in what was then Lansing, known today as Sheppard and Yonge, so he could be near a hospital for treatment. We all lived in the big house on Bogart Ave. until I was 14 years old.

My grandmother had a tremendous influence on me during those first fourteen years. My dad worked at two or three jobs to keep us going. From the time my grandfather died until I was 12, I used to sleep in the same room with my grandmother.

When I was 14, my world started to fall apart. First, my grandmother died, taking part of me with her. I was closer to her than I was to my own parents. In those days when a person died, he/she was laid out in the front parlor for visitation. My mom wanted me to take grandmother's hand and hold it as a parting gesture. I just couldn't do it. The warmth in those hands had meant everything to me.

Strangely, when my grandma died, my parents didn't inherit the house. It went to the whole family so we had to move. My parents found a house not too far away from Bogart Ave. on Anndale Drive. It was mortgaged to the hilt; it took a lot of work and worry to keep it.

All the turmoil in his life triggered my dad's quick temper. He was strict. He never just scolded. He hit. In fact, he believed in using a belt "to keep me in line." I was terrified of his explosions before I learned to appreciate that deep down he was good and caring. I came to understand what had made him so explosive.

I just couldn't handle the stress of the loss of my grandmother. It affected my schoolwork. All through elementary school, I just coasted along, getting good marks without even half trying.

Within a few months after entering high school I was in academic trouble. I had great difficulty with French, had major run-ins with my strings teacher. No one was going to dictate to me. I wore a huge chip on my shoulder. My grades started to slide. After I failed and had to repeat Grade 9, I stumbled and bumbled through another two years. Then in Grade 12, I wiped out again, and had to repeat that grade too. My guidance counsellor told me I should learn to drive a truck because the way I was going, that's all I'd be good for.

I was supposed to take make up courses in Summer School, but I told the guidance counsellor that I had to work. My parents couldn't afford to send me to summer school. I wasn't lying. Since the age of 11 I'd been working summers and weekends at a golf course and elsewhere. I'd be up before six, and many days I wouldn't get home until after dark. My folks expected so much from me... to be what they never had the chance or the skill to be themselves. I was trying to make it on bravado alone, but inside I felt crushed. I was messing up and I didn't see any way out. I was ashamed for them, and for myself.

Then I met Linda. I was hooked.

I was determined to marry her, but first I had to find something worthwhile that I could do to make a living. I applied to Teachers' College and to my utter amazement; I was accepted into the two-year certificate program. In those days, there was a huge market for teachers, but I still had to prove myself. And I did. I even surprised myself, considering my high school record. I even made the honor role and landed a job, no trouble, teaching Grade 5.

I was in heaven. We married and moved into a tiny apartment to begin what I was sure was going to be a steady path upwards.

7. The great humbler

Once I got into teaching, I thought I was jet propelled. I was sure I was going places. I loved the content. I loved the kids, and they seemed to respond to me. My life was coming up roses.

In my third year at the school, the vice-principal suggested I apply for a position at an Open Plan school, a new concept that was opening in the fall. I was interviewed, and wonder of wonders, I was hired to teach Phys. Ed. and I was part of a team that had first to create a curriculum and program in keeping with the concept. The only condition was that I complete my Phys. Ed. Specialist's Certificate by the end of the school year.

I was dancing on a cloud. My younger son was born that year so we moved into our own house in Aurora. At that time, I was working with a great bunch of guys to whom I could really relate. After four good years there, I decided to apply to become a Phys. Ed. Consultant.

I didn't get it. Well, I thought, I've only been at it for six years. I'll try again next year.

That year Marni my youngest, was born. I had just finished my undergrad degree work at York University part time. I was on another high.

We were at Marni's christening, standing at the altar, when it all began to fall apart. I had a sudden attack of the shakes, like nothing I'd ever felt before. I was trembling so convulsively I thought the earth was shaking underneath my feet. I had to hand Marni over to Linda while I tried to steady myself. I sat down. Soon, the tremors stopped and I relaxed.

I was shocked. How did I get so out of control? I was so ashamed and embarrassed. Had anyone seen me shaking so, I wondered?

A few weeks later, I was asked to be godfather to one of my best friend's new child. I was supposed to hold a candle at the christening ceremony, but I just couldn't do it. Again, I started shaking uncontrollably. The candle wax spilled all over my hand and gave me a nasty burn. I had to hand it off, find a seat, and get myself together.

This is crazy, I thought. What's happening to me? Am I going nuts? What am I going to do?

Eventually, the spells passed and did not return for quite a while.

The next spring, my academic requirements behind me, I applied for a consultancy again. I was sure I had what it takes to burn up the world of education. This time, I got it.

Now I was into peer coaching and curriculum development, and I felt I was making a difference already. So I thought, why not go for broke and apply for a vice-principalship. In those days, after a year or two as consultant, such a promotion was almost automatic but I didn't get it.

I was sure the interview had gone well, that I had come across confident and creative. The interviewer had noticed something that I had tried so hard to hide. My knees, my hands started shaking and I couldn't make them stop. He asked me why. "I guess I'm just excited," was all I could think to say.

His judgment was that I wasn't ready yet for such a major leap. It didn't bother me all that much that I didn't get the job since there were always plenty of admin openings every year.

Nevertheless, I was troubled by the sudden onset of the shakes, more so for not being able to control them.

I kept going and over time, I noticed that whenever I got an adrenalin rush, the tremors would reappear. What was all this about? I just had to find out.

8. Stiff upper lip... and the rest

After another year as program leader, I applied for an exchange that the Board ran with a school board in England. I really wanted to go. Neither Linda nor I had ever been far from home base, and this seemed like a golden opportunity to see the world without cost. I cautiously broached it to Linda and she thought it was a great idea, three little ones notwithstanding. What a surprise!

Double surprise. I was accepted for the program without hassle. I was paired off with Mary Gameson, a peripatetic special needs teacher based in Leicester in the English midlands. She was single and didn't drive so she didn't need our house or our car. We could rent the house. She did need accommodation, so I mentioned at a school I was visiting one day that I was looking for a place for an exchange teacher to live for a year. One teacher, originally from England herself, volunteered her house. The match was made. Coincidently, she taught me in grade 3, her name is Jean Fowler and she originally was from Melton Mowbray.

On August 12, there we were, two adults, three kids, 10, 6, and 2, and a pile of luggage at Toronto International Airport, with Marni enthusiastically awaiting her second birthday and Chris and Craig totally enthralled with the "hub-bub" of an international airport.. Linda and I were certainly filled with a plethora of emotions.

At Heathrow Airport in London, we were met by my new headmistress, a term I'd never heard before, together with her family.

Then we were off on this adventure of a lifetime, in a rented van, riding on the wrong side of the road. New home, new job, new friends. What was in store for us? Would we ever get used to it all?

After a three and a half hour drive, we were zombies by the time we arrived in Groby (pronounced "groo bee") a little village on the outskirts of Leicester. Pronounced "lester". We pulled up in front of a semidetached house that we had rented . The owner, Roy Light, was there to welcome us. Roy and his daughter Sally had prepared a light lunch for us. It turned out he was the deputy head of a large comprehensive school in Leicester. We hit it off right from the start so we carpooled together. Roy and Peg were there for us through that entire traumatic year. In fact, we're still friends to this day. I hold a very special place in my heart for Roy.

First things first, get in supplies. Roy took Linda out to acquaint her with the local supermarket while I helped the kids settle. It was still the old English money system, and neither Linda nor I could make sense of it. She just pulled out bills and coins and trusted the clerk or shop assistant to take the correct amount.

We had two weeks to get ourselves together before I had to start teaching. Learning about the students' range of disabilities made the prospect terrifying. The class was called Grade 6 Educationally Subnormal Severe (ESN-S). I never had to deal with students like this before. What was in store for me?

An ESN-S class means that the IQ of the students was 60 or less. Most, I was told, were in diapers and arrive in ambulance vans. Some have to be carried to a class cot because they can't walk. They were, in a word, helpless. It was my job to make sure they weren't hopeless.

The first day I came home a nervous wreck. "I can't do this," I confessed to Linda. "I don't know how to handle these kids. I've never seen kids like this."

There were 13 of them, all in their early teens. Some of them crawled on all fours to get around. Most could barely talk. One would suddenly turn animal wild. Two or three had Down's syndrome, snot forever running from their noses.

Now, decades later, I can still see their faces as clear as clear. Individually they were beautiful and I loved them. Together, they were a handful: what an ordeal!

My daily Saviour was my nursery assistant, Dorothy White. She came to my rescue mid-morning and afternoon every single day with a cheery, "George, I've made you a cuppa. Go have a cigarette and relax. I'll look after the class for you."

Back at 174 Leicester Rd., Linda had to fend for herself for six straight weeks without a break. We didn't have a car, so she had to walk Marni to playgroup and then on to the supermarket and back for whatever she needed. One day, Roy offered us his old spare car and we were finally mobile. Chris made the school soccer team and was happy. Craig learned to read in just three weeks at the 300-year-old infant school he attended. The teaching was that good.

Me? On the surface, I was O.K., but inside I was a complete wreck. I was so stressed out, trying to do my best for the school kids, that I had no strength left for home and family stresses. I was wiped out and getting worse by the day, and the school year had only just begun. The more agitated I became, the more I felt a stiffness growing all through my body. I felt very strange indeed.

Our landlord, Roy, took me to school and back every day, and looked in on us regularly to make sure we were O.K. He was the support system that would have been provided by family and friends at home. It made him a friend for life.

So how did I deal with the panic I felt growing in my head and in my body? Well, stiff upper lip was the name of the game, but stiff body it was not. I was determined not to use drugs to get me through. First thing, I flushed a vial of valium I had brought from home down the toilet. Each day I got edgier and edgier. I was utterly fatigued by the end of each day. I had no strength left to go anywhere or do anything. Moreover, the stiffness kept getting worse. Sometimes I'd come home after school and go straight to bed. That left Linda with all the work and worry, and me feeling more guilty with each passing day.

While I went to pieces, Linda seemed to gather strength. She took charge of the house, the kids and me as if she were made for the job. No complaints. I was amazed... and so grateful.

By midterm break, I couldn't face getting up, never mind going out and doing something. I couldn't walk across the street for a pack of cigarettes without shaking like a leaf. I holed up in the house for three full weeks. I thought I was dying.

After the break, I dragged myself back to work, determined to see the year through. I even volunteered to lead special programs and activities.

My colleagues could see I wasn't coping very well. They gave me incredible support; always there to give me a break when I needed it, commending me on the program I was running, helping me get through each day. I'm forever grateful to them for all they did to get me through, because I knew that my agitation and stiffness was getting more noticeable with each passing day.

At spring break, I felt well enough for us to tour the south coast. We even ventured over to The Channel Islands for a few days. We were both comfortable now driving on the left hand side.

Then, beyond belief, it was July; end of term and time to pack up and go home. We decided to return on a small Polish passenger freighter, the Stefan Batory. It took us ten days that turned into a lovely relaxed holiday. Both our families were there to welcome us when we docked in Montreal.

Out of that tumultuous year in England came one wonderful benefit. A new Linda. Up until then she had let me take the lead, but with me on so much downtime, she had to take on increasingly more family responsibility. The strength she developed was the only thing that would help me get through what lay ahead.

9. Down to the gates of hell

I came back to my program leader's job. The lack of a daily classroom routine made me believe I'd be all right. I thought I would be able to handle, even control, whatever anxious moments arose that I thought were the cause of those sudden attacks of shakes or stiffness that had plagued me in England. Oddly, in the classroom setting I never once seized up, although I was pretty tense and agitated there most days for sure. What did me in was having to deal with little things, like turnstiles, customs and immigration officers, waiting in line to check out in a supermarket, or in a theatre. My anxiety level spiked. I felt I was going to explode. Eventually, I stopped going to places that I thought would set me off.

I should have been back to myself again, but despite the safe, secure, unthreatening environment, I was constantly on edge wondering when the next panic attack would trip off the shakes. Then, I noticed that I would occasionally stumble and fall for no reason. What if I did it in front of my peers, or a group of kids to whom I was demonstrating something? They'd think I was out of control. It got to the point I didn't know what was worse: an attack, or fear of an attack.

One thing for sure, it was making life at home more difficult with each passing day. I was short tempered with Linda and the kids. Everything, everybody annoyed me or frightened me. I couldn't concentrate and finish what little I had to do. I wasn't interested in my work. I started walking into appointments cold, trying to wing it every step of the way.

I was beginning to think I was going off my rocker and everybody else, I felt, was thinking it too.

Now here I was, a typical North American male, with a philosophy of life that ran something like this:

– Keep personal issues to yourself.

– Keep feelings well hidden.

– Fix it yourself if something goes wrong.

In other words, "Play it cool". My whole self-image was bound by these constraints and there I was not doing any of them. It was making me depressed as well as moody and short-tempered. I was up one day, down the next, depending on how my body was functioning. Each day was a loop-the-loop or a roller coaster ride. In my head, I felt like a crazy mixed up teen, while physically I felt like an old crock.

I thought I was going crazy.

Maybe this was happening because I had come back to a job with different parameters from the one I'd left in England. I was learning to do a completely new job, on the job. No one bothered to explain to me exactly what I was supposed to do.

In addition, there were the stresses at home. Our house was too small for three energetic kids who were growing up fast. We had to upgrade but to where, how big, for how much?

A mountain of worries had me all fired up, even hyper. The freezing and shaking attacks had to be from all that tension. I was consumed with how to cover it all up.

Meanwhile, I wasn't eating or sleeping properly. There I was 34 years old, up to my ears in responsibilities. Questions plagued me. What was going to happen to all my hopes, dreams and ambitions?

At work, I had to keep taking breaks, even naps after lunch. I started missing workdays when I was too stiff or too shaky to face my day. I hurt. I was angry. I wanted to give up... just run away and hide somewhere as I had as a child.

Like a typical macho male, I tried to soldier on alone. I couldn't confess to anyone what was happening to me. Me, admit weakness or uncertainty? Never! My parents wouldn't understand. My bosses would fire me. My friends would think I was crazy and run.

I hated myself, especially my body, which I could no longer control. Trying to navigate a narrow aisle, a revolving door, or a crowded entrance made me freeze up. I couldn't control the panic attacks any more at all.

Then I thought, This never happened in the classroom in Leicester. Maybe I'm not busy enough.' I made up my mind to go back into the classroom full time, back into the open concept school I'd left for the program leader's job and what I thought was a sure path to a top job in education. I knew I couldn't teach Phys. Ed. now. I wiped out too quickly. Without stamina and control, there was no job there. My body was a solid mass of pain all the time now, but maybe the ticket was a classroom job teaching full days.

I applied to teach geography, history, math and ESL at my old school. I was hired without a hassle. It was like getting a second chance to make good, the way convicts must feel when they leave prison with a job. I started the school year high on hope and determination.

Meanwhile I bugged my family doctor for help. He was sure it was just nerves and prescribed drugs to calm me down. He even sent me to a psychiatrist who was so sure it was all in my head. Their message was always the same: I'm overstressed. I'll get over it. I was too young, they said, to have symptoms of anything worse than that.

I insisted that the problem was not in my head but in my body. It just wasn't working right and that was what was making me so depressed and dysfunctional. I explained that most of the time I was fine though my body ached from top to bottom, but I would get these sudden attacks of shaking or stiffness. That's when I panicked, I explained. They just kept assuring me that I'd get over it with drugs and therapy.

How did I know it wasn't all just in my head? Because I settled into teaching full time easily and comfortably, that's how. I liked the kids, and they seemed to like me. I didn't feel pressured or stressed there. I got on really well with the teachers in all my subjects. I volunteered for extracurricular programs, like excursions and field trips. I came to think of myself as a potential vice-principal again.

That was my dream... and to find out what was really bugging my body.

Then one day I crashed through the gates of hell itself, and there I was in the inferno.

10. Breaking through

One day, I drove up the driveway after work. When I stepped out of the car I couldn't straighten up, I crawled on all fours to the side door. I had snapped.

I went straight to the phone, still on all fours, and called my family doctor. "You've got to help me," I cried, in terror and in pain. "I can't move my muscles. Everything is frozen inside me. I feel like I'm dying. I can't go on like this."

"Okay, George. get you in to see a neurologist right away."

"I don't know what a neurologist is," I said, "but I've got to know what's happening to me. I know it's not in my head. When can I go?"

A week later, I was face to face with Dr. Richard Gladstone, head neurologist at North York General Hospital. His examination was swift. His first words to me afterwards were, "You're going into hospital for tests, just to make doubly sure. When can you come?"

Out of the depths of frustration and despair, I snapped "Tomorrow."

The next day I was admitted to the self-care unit of the hospital. Those were the days of big budgets and program initiatives. In the self care unit, I could wear regular clothes, and eat in the hospital cafeteria while the tests were performed. Then they sent me to the Toronto General for a CAT scan, a new technology at the time.

The diagnosis was swift and certain. "George, you have Parkinson's. The good news is it can be controlled. The bad news is we don't know yet how to cure it."

At 34 years old, to me it was still a sentence of death. What did I know? However, I liked and trusted Dr. Gladstone. I couldn't stand the pain and punishment anymore and he was throwing me a lifeline. From that moment on, I knew my life was going to change radically.

When I climbed into the car after that momentous pronouncement, Linda asked, "Well, what did he say?"

"He said I've got Parkinson's." Linda slammed on the brakes so hard I thought I was going through the windshield. "Oh my God," she wailed. "What are we going to do?"

"Don't worry," I tried to calm her. "I'm so relieved. I'm not scared now. He promised he'd see us through it. It can be controlled."

From that day on, I began a course of medication that had me feeling relatively normal within two weeks.

I was elated. It wasn't all in my head. "There's no such thing as a nervous breakdown anyway," Dr. Gladstone told me right off. "If you're nervous system really breaks down, you're dead."

I was alive. I was going to live. Best of all, I was going to beat back this devil. I knew it, because I believed in Dr. Gladstone. He became my lifesaver, my lifeline, and my mentor.

11. Learning to live with the monster

Nothing could have prepared me for learning to live with Parkinson's. I started out doing everything I could to hide the truth and the symptoms from the world. I told people I was suffering the effects of a chemical imbalance. I told myself I was going to be lord and master of my life no matter what.

Yet, I couldn't hide anything from anybody. I had to learn to be dependent for the first time in my life. In fact, I had to develop a network of support to keep me going. It was a completely new world.

How can I explain what living with Parkinson's is like? Try this. Bend your body into an L. Freeze in this position. Then tighten the muscles in your limbs until you start to shake. Then, still bent, walk forward, then backward a distance. Then return to normal. That's a mere taste of my life 24/7.

At least twice a day sometimes more my body starts to shut down. I can hardly walk or talk. The pain is excruciating. When it starts and how long it lasts depends a lot, so we're told, on metabolism, stress, fatigue, food intake (both quality and quantity; a lot of protein is tough on me), and exercise level. If I'm not meticulous about taking my medication, it won't work.

The general guide for an attack: Be patient. Rest. Be upbeat; talk to yourself: "George, it's going to be O.K. In an hour, you'll be back on track. Calm down. You've been there and back so many times."

Of course, I'm a walking pharmacy. I gobble pills, the dosage of which is being constantly readjusted. Dr. Gladstone is always fine-tuning and trying new drugs on me.

Right now, my medication regime is nine times a day starting at 6 a.m. and ending at 3a.m.

Not a day goes by without its special challenge, some pretty funny, but most not so. I've pitched forward carrying a bag of bottles and have stitch marks to show for it. To the chortles of all around, I've tripped and fallen trying to get out of a barber's chair. I've soiled myself when I couldn't get to the toilet in time. My shoulders and knees are battle scarred from falls, knocks and strain. To deal with muscle spasm I invented Dingman Device, a cane with an arm at the bottom to step over, get me going, and steady my gait. I avoid inclines or hills like the plague unless they have plank-like steps that will allow me to steady my pace.

I have to plan social events or shopping excursions to match the time my medication is working full blast. I have to avoid crowds or any places that make me feel claustrophobic.

In a new situation, I have learned to be up front right off so people won't panic if I freeze, fall or start to shake. Chat it up. Smile. Disarm them straight away. It works... most of the time.

What they don't know is that a trace of rigidity and a lot of pain are there all the time. Every once in a while, my body does seem to get in balance briefly and I feel almost normal, but then, without warning, the internal alarm system goes off and immediately my body starts to shut down on me. It can take 10 minutes or longer, it all depends on the toxins that are in my body, what I've eaten, and my anxiety level. I can have as many as five shutdowns a day. I depend on the drug regime to pump me back up.

Getting me together again can also take ten minutes or longer, even up to 40 minutes. In the beginning, the longer it took the more I would panic. Now I know from experience that there are so many variables at work going down and coming up that I just have to let my body do its thing. Overall, I figure I'm off 50% of my day and on the other 50%, although the off time gets longer as I get older and my body weakens.

The nights are the worst. Sleep induces stiffness because I'm off my medication routine. At first, I'd wake and hardly be able to move, never mind straighten up. I'd have to crawl on all fours to get to the bathroom and back, so I had to get used to sleeping in three to four-hour bouts. Taking medication during the night is not recommended because when the drugs kick in, I have a burst of energy with no outlet for it.

So every day is a battle with the demon Parkinson's. I'm now an expert on festination and dyskinesia, words I wish I'd never heard of. Festination is an involuntary pitching forward. This is so scary because I never know whether I'll be able to stop myself from falling. Dyskinesia is involuntary muscle spasm.

I have frozen in the middle of big box stores and supermarkets, especially when aisles are narrow or when kids are darting around me and I think I'll bump into them. Then I have to pop my pills and wait until the drug kicks in. A major survival strategy is to avoid malls. They're trouble.

My diet must be monitored carefully. Too much protein can really set me off. Sometimes food... quantity or quality... can override the medication and I shut down. Because of that, I'm often afraid to eat when I'm out. Countering that with the need to eat at regular intervals is another problem I face every single day.

It might not be Hell itself, but Purgatory it certainly is.

12. Learning to best the monster

No doubt about it, Parkinson's changed my life substantially. It humbled me!

Without the monster inside me, I would have tried the yuppie path to the top: top job, top of the line house, car and club. I saw life as a game and I personally had to win the Cup, the MVP award. I wanted it all.

Soon all that was out of reach. I had to redefine myself, my values, my hopes, my dreams. Each day became a gift, not just another marker on the road to success. I had to forget about that pot of gold at the end of the rainbow that I was so sure was mine for the taking. I had to learn to catch the joy as it flies, treasure it, and hope there'd be a tomorrow to grab another.

It wasn't easy.

I had to watch myself wash out at work. The worry of suddenly freezing, tripping or stumbling in front of a class was unbearable. Sometimes I couldn't speak above a whisper, or even not at all. I knew I had to hide any suggestion of weakness. If I didn't I was a goner, but I couldn't sit or stand for long periods without a spasm of some kind.

Just having to confront the fact of weakness in myself and admit it to my family, all expecting so much from me, was unbearable too.

I had to work hard at the lies. To my superiors and peers I had a "chemical imbalance" that the doctors were trying to iron out. That euphemism was Dr. Gladstone's suggestion. He knew where I was coming from. He'd been through it so many times. Besides, it made a good excuse if I had to be away from work.

In those supposedly enlightened days, truth could kill. I had to learn from bitter experience that truth is easier to handle than lies.

For a full 14 years, I persisted in popping increasingly more pills to keep afloat. Then in 1993, I couldn't hide the involuntary tremors or freezing any longer. I had reached the point where I never knew whether I could get from the house to the car, or from the parking lot to the school and back again, without pitching or freezing.

Of course, everyone in the school tried to make it easy for me. They would come to my rescue if I had an attack, or needed a respite to get myself together.

That wasn't all. In my weakened state, I was constantly subject to a host of new medical crisis, physiological and neurological. As a result, I had to take more and more sick leave and ever-increasing doses of medication that came with some pretty scary side effects.

There were times when I just couldn't get to a washroom in time when I needed one. Other times, I had to resort to taking a wheelchair wherever I went in case I seized up.

I was out of strategies to hide the truth. I knew I had to quit teaching, but what could I do? That was my life. To make matters worse, every alternative I thought of had its own special drawbacks.

What incredible luck... just when I needed it most. The Teachers' Federation had recently negotiated a full disability package. That, I thought, was the best route for me to go. Start over completely without having to worry about an income. Seven years before I was eligible for a full pension, I retired. I was 49 years old.

13. Rebuilding my life

How do you start rebuilding a life?

First, I had to come to grips with the real me inside, not the 'show no emotion' macho me. I had to admit, to myself first, that I am vulnerable. I had to learn that bursts of emotion, like a good cry or a string of curses, are perfectly normal responses to the feelings of impotence and frustration that would now overwhelm me daily.

Of course, I had been programmed otherwise. As were all the guys I ever knew. I hated to be by myself and try to contend with the thoughts swirling through my head. I lived to socialize with my peers. But admit to warts, to faults? To say straight out, 'I love you. I need you. Admit I'm nothing without you?' Never!

Parkinson's changed all that. I had to come out because I might die if I didn't.

When I told my buddies one by one, I was shocked by the answer I got. "I knew something was wrong. I knew you didn't want to talk about it. I was just waiting till you were ready to level with me so I could help in some way," or, "I thought you were shutting me out. I wanted to help, but you never told me, so I never had a chance."

What a I fool I'd been! Once I opened up, not only did my buddies rally round but we've become even closer. We don't feel embarrassed any more about letting our insides hang out.

I owe that to Parkinson's. It's made me a more complete person by helping me break down barriers to allow meaningful relationships to flourish.

How did I learn to open up, to admit to myself and my world, that I was one sick guy, that there will be times when I'm going to need help to take a step, to straighten up, to move on? I owe that to the Parkinson's Association, and its magical mentor and at that time sole administrator, Maggie Wheelock.

Teaching coping skills is one of the Association's goals and Maggie was the one who made it happen. I first met her over the phone, all bubbly and upbeat. I met her in person when she came to pick up a cheque for Parkinson's tulips my students sold at a Parents' Night at my school. She organized the therapy support groups for victims and for their families. It was the skills I learned there. It was the work she recruited me to do for the Association, and it was the advice she would ask of me on the chapter's work, that really turned me around. It gave me new confidence and helped me to move on. I ended up counselling newly-diagnosed Parkinson's patients, and was active in the chapter for two full years. She helped to make me feel useful again, and gave me an entirely new career lead in counselling and group leader training.

As the chapter's focus turned more and more to fundraising, I decided to turn to another source of confidence building that has ended up being my consuming passion: Golf.

14. A Parkinson's credo

We appreciate you who take the time
To listen to us when our speech is difficult,
You who help us to know that if we
Persevere we can communicate effectively.

We bless you, who walk with us in public places,
Ignoring the stares of strangers, for in your
Companionship we find havens of relaxation.

Thank you for not ordering us to hurry, and
Even more thanks to you who do not snatch
Our tasks from our hands to do them for us,
Because often we need time rather than help.

Our gratitude to you when you stand beside us
When we enter new and untried ventures, for
Our failures will be outnumbered by the
Times we surprise you and ourselves.

Blessed are you, when by your actions
You assure us that value as individuals
Is not measured by our disabilities, but rests
In the God-given self which no infinity can confine.

Donald Brill

15. Playing the game... of golf and life

I'd been an avid golfer since I was 11 years old and even got a summer job as a caddy at the York Downs Golf Club at Sheppard and Bathurst in Toronto. I'd hike the mile and a half to get there from where I lived... there was no regular bus service along Sheppard then. I'd slip and slide down into the valley (there was no bridge there yet, either), and climb back up to get to the clubhouse. I gradually worked my way up from a 'C' caddy at $1.50 a round to an 'A' caddy at $3.00 a round.

I was only a runt of a kid when I started, but I was keen. When I wasn't caddying I was allowed to help in the pro shop.

I liked the playing members and they liked me. Something about the game got to me. I stuck with the club through my teens. I practiced my swings when I wasn't caddying. Eventually, the pros started to coach me and I really improved my playing skills. More than anything else, they taught me that golf is more than a game of skills. It's a test of concentration. Focus, stay calm, and you'll make it, the game taught me.

Caddying and shagging balls (and watching out not to get hit by shots), I had a chance to observe the players carefully. The ones who focused and kept calm, no matter what, did play well. I saw others get increasingly angry and wipe out altogether.

There are many other variables, besides the human factor, that a golfer has to take into account. There are wind, weather and ground conditions. There's a specific club to meet each variable head on. . When all the variables, especially my state of mind and my level of concentration, clicked together, what a sweet thrill it was.

I had tried many sports, but for me this was it. There's no game like it. Every stroke is a test. It's you alone against all the elements, all the variables. If I mess up, I alone have to kick my butt. If I get it together, it is bliss.

Every summer, my parents took us to our cottage, but when I was 14, I talked them into letting me stay home by myself so I could keep my job at the golf course. They arranged for me to have a room above the pro shop. From then on golf would become my passion. Eventually it saved my life.

Of course, there was method in their madness. They were giving me a chance to prove how I could handle myself on my own. It was how their parents had dealt with them at my age. My folks always said that's how you learn to grow up.

In those days, the golf course was country, serene. I felt so in tune with nature I wished I could live like this the whole year through. I lived for the time I could spend on the links.

When Parkinson's struck, I thought I was finished with golf because a new set of obstacles surfaced. My body was now a weather vane. Storms raging outside ripped through me inside as well. I would seize up with pain and stiffness. When my body went out of whack, my mind would rage. My moods would parallel the weather with storms that swept through my body. Most of the time I couldn't control my movement, so my game was erratic. If I wanted to connect, I had to learn slowly with a grim determination to focus and stay calm.

Every time I got onto the golf course, I realized I was vicariously playing the game of life, my life, too. The important thing was to give it one more try, because it just might prove to be the perfect shot that pushed me to the next level. Even today, when I can no longer control my movement, I have on occasion hit a good shot, started walking toward the ball, and suddenly pitched forward, involuntarily somersaulted back onto my feet, and continued. When a seizure can be triggered at any moment, it's on the golf links that I have the most control, where I feel most triumphant.

Golf and life are such a perfect match up. Just when I think I'm prepped to shoot a perfect game, when I have all the right strokes figured out, I'm hammered by something totally unforeseen, and I have to start all over again. But I have learned too, that if I gather myself, and give it just one more try, I might just ace a hole (I've yet to score a hole in one.). That's true even in my advanced Parkinson's state, when I can no longer hope to control my movement. Golf is still my life-affirming test. I spend every winter in Florida just so I can keep playing.

When coaching young players, the first thing I try to teach them is to visualize the path they think the ball will take. It's the best preparation and evaluation method I know. I also tell them to plan in their minds all the traps they may encounter. It saves the frustration of the unexpected.

Golf has seen me through many a crisis. I remember during my first CAT scan having a strange fantasy that I was teeing off on a small hill about 200 yards from the green, and if I could fade the ball, it would land near the 100-yard marker. I took my eight iron and aimed left of the flag because that was the wind direction, hoping to take out of play the bunker on my right.

To my horror and dismay, the ball went straight into the sand trap. I zoomed over by cart and found the ball just a foot from the trap. I chipped it to within eighteen inches of the hole, and sank the ball for par. I was just on my way to teeing off for the next hole when I heard Whrrr, Wheee, Whrrr, and a voice broke through. "Mr. Dingman you can open your eyes. We're finished." I had survived comfortably my first CAT scan.

I recently learned there's the possibility that golf may have contributed to the onset of Parkinson's. Back when I was a young caddy, I used to lick the balls clean and wipe them dry on my shirt. That's how it was done back then. It's possible the toxins from those balls can build up in the system and emerge as Parkinson's. Well, so what? Smoking can come back to haunt us as lung cancer decades after we've stopped smoking. Anyway, it's the game that counts. I've learned so much and had so much satisfaction from golf that I wouldn't give it up for anything.

Golf has made my life livable. It has rescued me from acute stress and severe distress, and provided vital exercise. It gives my life purpose and meaning when I'm at the end of my rope.

To explain, let me walk you through a typical game.

16. Playing the course

The moment I walk onto the course, I start thinking about and planning for the game I'm going to play.

First, I choose just the right clothing for the weather conditions, the kind of game I hope to play, and even for whatever mood I happen to be in. There are days when I'll change several times before I head for the course just to get it right. (I always carry rain gear just in case.)

Then I start planning my strategy. With whom will I be playing? What physical state am I in today? What special challenges does the course have? What clubs will I need to meet all the challenges?

Next step: warming up. Stretching and limbering ease Parkinson's-challenged muscles.

Finally, I play mind games. How am I going to get my best shot at par? I go over every inch of ground I'll be covering, every wrinkle in the course. How do I compensate for whatever state my body is in today to make the score I have set for myself?

Despite all this, I am never anxious about the game ahead. I focus only on the challenges, the goal, and the camaraderie. I know from experience that I'm just as good as the next guy in spite of my condition. The bottom line is that I'm excited about playing.

I get to the golf course maybe an hour before tee off. I do what I call my 'three ball routine'. I start with a pitch shot, and then I try a seven iron, and then a putting stroke. This routine helps me focus on my strengths. I visualize each shot: the path the ball will take, the distance, pace and speed. I try to imagine the obstacles different holes can throw at me, and how I can best them.

As I head up to the first tee, I chat it up with my partners, none of them handicapped in any way. It's all golf chitchat, a bit of bragging, a bit of planning and projecting. We might even wager a few dollars just to add to the competitive edge. Of course, I play with a handicap. I may freeze, go stiff, or stumble because of the Parkinson's. (I have to make sure I've medicated myself adequately beforehand to avoid this as much as possible. I don't want to have to take time out to re-medicate myself during the game.)

For the first two or three holes, I'm talking to myself trying to get my head into the right space. It's mind over matter for me, especially if the weather is unsettled. If it's very hot, I have to keep drinking so I won't dehydrate.

I use the clubs that suit my condition best. Graphite, I find, is more forgiving than steel but the length and accuracy of the drive, even though it depends on the weight and shaft of the club, is still up to me.

I'll start off on a real high, but I know that if I don't cool it and relax, I'm going to shut down fast. The game I'll play will be erratic. If I try to quicken my pace, like taking too hasty a shot, or if I linger too long over one shot, I know I'll lose my balance and pitch right over.

Every moment I have to battle myself for control. I keep telling myself, "Relax. Enjoy the game. It's not a PGA tournament." Most of the time this dialogue works, and I get to the 19th watering hole feeling good.

One day my daughter Marni shot a video of a game in which I partnered with my son-in-law. Seeing myself on screen cued me in and clued me in. Watching myself in action for the first time, I could tell what works for me and what needs improving. Most importantly, I saw that on the golf course I'm not as dyskinetic as I am during a routine day. Oh, sure, I could see that I'm off balance here and there. (I heard myself saying under my breath, "Don't freeze up... Keep moving... Don't be so jumpy on the swing... Step over the club [to get back in balance])."

I saw myself rushing to beat the rain that had started to fall. If I kept that up, I'd be in trouble. By the ninth hole, the sun was out again, and I could see that I was off pace, but this time it was because my medication was wearing off.

In spite of the flaws (that only I could detect), I looked to myself just like any other guy on the course. I was amazed. What an eye opener! Besides, I had a great time playing with my son-in-law and learned so much from my daughter's video.

There's always a price to pay after a vigorous game. I'm often stiff as a board when I get home. Every joint in my body aches. I have to lie down for a while, and then force myself to get moving again so that I don't freeze up altogether. One step over Dingman Device or a golf club or hockey stick or Linda's foot, whichever is handy, is usually all it takes for me to regain mobility.

Regardless, every day I look forward to the next round. Every round means I'll get it together to play a better game. My score is still usually somewhere between 80 and 100, most games closer to 80. The most important thing is that I am out there doing it.

17. The support team... golf

Now you could well ask, is it wise for a Parkinson's patient to be out playing golf in all kinds of weather, shivering or sweating, and pushing myself to the limit? Wouldn't some gentler form of exercise keep the body fresh and agile? What happens if I fall or freeze? Who's going to get me through the crisis?

First off, as I've pointed out there's a close link between golf and life. Golf sharpens the senses and reflexes, and the elements shape us. Golf teaches strategies for success. The rewards, both personal and social, are unique.

Golf widens my world as my life becomes ever more restricted because of the Parkinson's. Because of golf, I can still feel that at least in some areas I'm still master of my fate, not just a victim of nature's whimsical changes. On the course, I feel equal to any challenge, something I don't feel anymore off the course. Every game is a new set of challenges to be mastered.

My golf friends know the power of golf just as much as I do. The rewards of a good game, the satisfaction, the enhanced self-esteem; and let's not forget the lessons of a bad game: honing strategies for success. As partners on the course, we help one another to keep focused on the goal, not on the trials and failings along the way. They deserve recognition.

Laurie Buckland was the longtime head pro at Aurora Highlands

Golf Club. Laurie is presently golf director at Wooden Sticks G.C. He hired me to Marshall and sometimes on the first tee as a Starter, knowing my condition, because he understood how much golf was helping me. He knows because he's been there, done that. He suffered a severe stroke at 45 and because of it, he is still speech challenged. Golf helped him to find a way back to living normally. He has not only taught me how to master my condition; he counseled me. He taught me how important it is to be open and up front about my condition and with my feelings. He's helped me regain confidence and self-worth. All it takes, I've learned from him, is a strong will, a clear goal, and focused effort. He's helped me move up and move on.

Neil Smith, presently CPGA professional at Maple Downs G.C. has used golf to come back from the brink of an addiction to alcohol and tobacco. He has shown me how golf can turn my life around too. From him I've learned how to treat golf as a holiday from grim reality, how to use it to strengthen skill and will. He has shown me that golf is more than therapy, though... that it's a breakthrough sport, constantly taking one to new levels.

Craig Moyer, his wife Shirley and son Drew have helped me more than they will ever know. Craig followed a dream. After the sale of a successful gravel business he bought a golf course, Bear Creek. Despite a bad back, he's at the club every single day, enjoying a round, or doing any job that needs to be done. He wouldn't ask someone to do a job he wouldn't do himself. He's passing his work ethic and his compassion on to his son Drew, who's well aware of how much Bear Creek Golf Club means to me in mastering the Parkinson's Challenge.

Bob Wall played in the World Hockey Association and the National Hockey League for 13 years, and saw action with several teams. It taught him, and he passed it on to me, that no matter how much you're kicked around, you have to hang on to your dreams. In the end, he learned and he teaches that it's up to each of us alone. Just get on with it, is his motto. He's helped make it mine too, and I know it works, because he now owns three Tim Horton's franchises and still has time to be my golfing buddy and friend. Not bad for a guy who never graduated high school.

Peter Calvert is another longtime friend who also has a story to tell. He made it big time as an insurance adjuster and had all the bells and whistles to prove it. A powerboat, a Corvette, and a monster house. Then, his longtime business partner died suddenly, his marriage fell apart, and he lost a bundle before the dust settled. Yet he invites me to play golf with him even though I think he secretly hates the game. He knows how important golf is to me. He always has time for a game of pool, a coffee, and a shmooze. Playing with guys like these, I come off the course refreshed, resolute, reassured and confident, even if I haven't played my best. All they ask is that I let them help me open up so they can help get me through. Without their support, I'd be an empty shell.

18. Betty, Lil, Val, Patti, Linda

The cast: Linda, my wife, Betty, my mother-in-law, Patti, Linda's sister, Valerie: Linda and Patti's cousin, Lillian: Betty's sister, Linda and Patti's aunt.

The Setting: a summer retreat at Valerie's cottage on Muldrew Lake outside of Gravenhurst..

Linda: I remember the day of your wedding, Patti. Three days before heading to England, this was before the diagnosis. George couldn't stop shaking. I didn't know how I'd get him to the church, never mind to England.

Patti: I remember looking over at George and seeing him literally vibrating.

Linda: Les had phoned from Freeman's Formal Rentals to tell me that George was shaking so much he couldn't sign his VISA receipt. What should he do? I thought, 'Maybe he's having a nervous breakdown'. And then I thought, 'What'll I do? I'll have to look after the kids and him in England all by myself.' I called Dr. Williams and he assured George and me that once he got to the church for the wedding and on to England, he'd be O.K. It was just a stressful time.

Betty: I remember thinking. 'George is walking so strangely, so erratically. Maybe he's been drinking or something awful like that.'

Linda: You know, that incident reminded me that every time we went on drive, George would sometimes shake so much I would have to drive. It seemed that just thinking about going through customs and immigration would set him off. A trip across the border, George would be shaking so much I'd have to drive. When we were in England for that year, and right after, he was an absolute wreck. We thought it was because of the kids he had to teach. They were so handicapped. So every day I'd have a Canadian Club and ginger ale waiting to calm him down when he walked in the door. And there were whole weeks he'd be so stiff or so shaky when he got up that I'd have to get a doctor's note for him to stay home. There were times when he couldn't get out of bed to go to the bathroom without someone to support him.

After England he went to a physchiatrist for months until he said to George, there's nothing wrong with your head. It must be something physical that's making you shake so.

Valerie: (Valerie has been a volunteer at the Parkinson's Society for 10 years) you know, I've worked with lots of Parkinson's patients but I don't think that any of them function as well as George does.

Linda: Well, he doesn't try to cover it up any more. But you know, after 30 odd years on medication, it doesn't work as well or as long, so he can't hide it even if he wants to.

Valerie: I always tried to get George to talk about how the disease was affecting him.

Linda: One of the things I learned was that there are times when he just needs to be left alone to work things through. At first I used to be at him all the time to tell me what's wrong. What can I do? Now I can tell by his body language, even his voice, just how he's feeling and I know that bugging him just doesn't help. He knows what to do. So I just ask, 'Is there anything you need?' and then leave him to it.

Betty: He never lets on though just how much he's hurting all the time.

Linda: Well, you know he gets stiff if he's in one position for too long. (So we don't go to shows much.) We'd be shopping and if he got boxed in along a narrow aisle, he'd panic and freeze right up. People would think he was crazy or something. Well, you can't live like a hermit, so when we went shopping he'd insist on staying near an exit so he can make a quick escape if he seizes up. I've learned to look for signs of panic and if I see he's struggling, I'll put my foot in front of his to get him moving again (this is a little strategy we have worked out).

Betty: Sometime I ask myself why God would put that on a person.

Valerie: I've met many people volunteering at the Parkinson's Society and I've often come away wondering why it's the nicest people who get hit like that. One fellow had all the surgery available to help him and I still can't make out a word he's saying. It makes me feel so embarrassed. Imagine how it makes him feel to see me struggling to make him out.

Linda: I've had to look inside myself a lot over this. At first I didn't know how to get out what I felt, I just felt so overwhelmed. It took me a long time to work through it.

Betty: I feel so much easier about it now that George will talk about it. I had to keep my feelings to myself too.

Linda: George didn't want people to feel sorry for him or focus on him alone. Now that he's more open, people are so much more comfortable with him. In the beginning he thought he had cancer or something awful like that, and that he was going to die and leave me with three kids to rise all by myself.. It was hard for me to talk about anything, in case I made him feel worse.

Patti: You know, there are days when the kids in my class are too much for me. They have so many problems and I know I can't save every kid. I just want to stay in bed and then I remember George telling me once that if I help even one kid then I have been successful. That's always stuck with me. You're not a failure, he was telling me, if you can't do it all. It's a lesson I've never forgotten. I know that George lives that motto every day. It's the trying and not giving up that counts the most.

Betty talking about the Team

I was introduced to George by my daughter Linda, two teenage kids in high school. He made a good impression was polite, neatly dressed and a ready smile. He would look you in the eye while they both got a lecture about being out beyond the curfew. They were great young people, working part time, going to school and having fun.

They finished high school, Teachers' college married and started on their careers. Along came Chris, then Craig they took it all in stride. This soon became a very busy family. Next came Marni to complete their perfect family.

George and I used to have some interesting talks in our kitchen on Church Ave. I always enjoyed these conversations; however I noticed something happening that I did not understand. George would or could not talk about it. I had such a feeling of helplessness. Finally he was diagnosed! Our whole family then tried to get as much information about the disease as we could. Someone heard of a talk show, read an article, saw a TV show or listened to a lecture about Parkinson's disease. The word was passed around. We all listened or watched and usually gained some knowledge of this condition.

George has struggled for many years with this disease, but has kept his sense of humor, and is very busy doing things to help himself and others. What really keeps him going is his passion for the game of Golf and this wonderful team of two. They certainly deserve a lot of credit for their battle is not part time, it is 24/7.

Love you both Mom.

19. Don’t quit

When things go wrong as they sometimes will
When the road you're trudging seems all up hill
When the funds are low and the debts are high,
And you want to smile, but you have to sigh,
When care is pressing you down a bit
Rest if you must, but don't you quit.
Life is queer with its twists and turns,
As every one of us sometimes learns,
And many a failure turns about
When he might have won had he stuck it out;
Don't give up though the pace seems slow
And you may succeed with another blow.

Success is failure turned inside out
The silver tint of the clouds of doubt;
And you can never tell just how close you are,
It may be near when it seems so far;
So stick to the fight when you're hardest hit
It's when things seem worst that you must not quit.

Unknown

20. Marni

My first real confrontation with my dad's illness was at my wedding. I saw him struggling up the aisle like an old man; every step he took was a battle.

Mom had warned me that Dad may not make it, but I refused to believe it. 'On the most important day of my life, Dad wouldn't be there to give me away?' I thought. 'Never!' But seeing him struggle with each step he took up the aisle, I suddenly realized what he must be going through, what he had been going through for so long now. The pain. The shame.

In that moment, Dad touched Superman status in my eyes. Here he was, so broken by the Parkinson's, yet so determined to do me proud no matter what the cost. To keep going no matter how awful the hand he's been dealt, he was more than my rock. He was the rock that propelled the whole family. He gave us strength. He gave us character.

I remember at a very young age being afraid of Dad. I was a timid little thing and he was so big. He had such a powerful teacherly' voice. Rather than talk to him directly if I could help it, I used Mom as a go-between, even though she kept telling me, 'Talk to him. He's nice. Really,' but I couldn't, not then anyway. (If I knew then what I know now, however, I would have changed that one thing.)

Still, he was a great family man. I can't drive by a campground without remembering the countless weekends we spent trying to squeeze into some cramped campsite, and Dad struggling to get the Coleman stove lit. I remember him once bringing a fresh caught lobster (a monster size it seemed to me) to the site, and watching it change colour as it boiled. Afterwards my brothers tried to terrorize me in mock attacks with its severed claws. It all ended in a big feast and a big laugh. Those childhood camping trips are still a vivid memory.

We were a sports crazy family too. Every week we'd go to some sporting event where either my brothers were playing or my Dad was coaching. When my Dad wasn't home for dinner we had "anything" night, that meant you could have whatever you wanted for supper. Dad had a special coaching jacket he wore. I recall he chewed gum the whole time. The smells of those arenas are still with me.

Looking back, I realize now just how deter mined Dad was to keep his disease from intruding on and disrupting our family life. He was also teaching us a lesson in how to live. 'Don't give up. Don't let disease, or whatever, dictate how you should live your lives.'

I guess I was maybe 12 or 13 when I really started noticing Dad's disease... his freezing, shaking, or wobbling. I remember his getting so angry when he couldn't do something he was trying so hard to do. I had no idea what it all meant then. He didn't talk about it much. He just got on with it as best he could. That was his style. Besides, guys don't show how they really feel. That was my Dad: loving, caring, doing.

When I was a kid, I took ballet for a few years. I went from recitals to competitions, and even won a few. Dad and Mom would always come to see me. In one competition, I had a routine that involved lifting one leg while I balanced on the other. As I was lifting, I lost my balance and fell.

I was devastated. I had let my team down. All because of me, we weren't going to win. Well, the first person I saw backstage afterwards was Dad. I was crying. He gave me such a hug. He told me I had done a terrific job. "But we're not going to win," I bawled. "You're crazy," he said. "You did your best. That's all that matters. And I say you did a terrific job."

Well, the rest of the program went off perfectly, and I learned one big lesson. One faux pas isn't such a big deal. Dad's confidence calmed me down, but more important, I realized fully for the first time that no matter what, my dad loved me for me. It's something I never forgot.

My brothers and I used to play on soccer teams and we always went to watch one another play. I don't ever remember my dad begging off going because he felt sick. He tried to keep everything as normal as possible.

Now that I'm married and have kids of my own, those lessons have helped me a lot. No matter how frazzled I feel, I know I have to keep things going for everyone's sake.

I know why Dad loves to golf so much. It keeps him going. It makes him feel like a whole person. I know without his 'get on with it' attitude he'd be a shut-in bound to a wheelchair. Instead, he's learned how to get moving again when he shuts down, and how to get out of a funk when he needs to.

In addition, he's learned how to open up. He always has a hug for our kids and us. He always tells us how much we mean to him, how the time he spends with us is so precious to him. He's more of a dad now than ever. To Dad, nothing about people is silly or stupid. So we're all more open now, thanks to him.

When I was around 16, I started to smoke, but not at home, of course. I thought I was so clever hiding it from my parents. One day on a family outing, Dad, casually as you please, asked me for a smoke. I was shocked. How could he know? It was his way of reaching out: so cool, so casual, so nonjudgmental. Well, I stopped smoking cold turkey that very night, and was determined to find out his secret for dealing with people in such an affirming and supportive way.

Today I see how every day is a battle for Dad. I also see his strength of will. I see clarity in his eyes. No blame, no anger. He just knows so well who and what he is. Everything about him cries out 'Go for it. I'm going to lick this.'

To me, Dad is the backbone of the family. I think I had him in mind when I chose my mate. He's so like him: compassionate, genuine, straight, determined, always there for us.

Not long ago Dad bought a new computer printer and he couldn't get it to work. Parkinson's and all, he stuck at it for hours until he figured it out. Not many in his condition would do that.

There are days when he just can't walk because the Parkinson's is so bad, but he'll use the Dingman Device as many times as necessary to get himself going. (He now has a fancy cane with a laser beam). It's his way of saying, 'I have a life and I'm going to make the most of it.' Just watching him cope has taught us to be positive no matter what. There's nothing like seeing him come off the golf course having beaten his own best score.

Once when I was battling a physical ailment, I could always rely on Dad for good straight advice. I'd call him up all in a panic and he'd say, "Relax, Marni. Try this, and it'll all ease up." He might be having the worst day himself but I'd never know. For me he offered encouragement, respect and love. From him, I've learned to stare the monster down until it shrinks to nothing and I can move on.

That's strength. That's character. That's love. That's my Dad.

21. Repair surgery and beyond

Any injury a Parkinson's patient sustains adds stress to a body already stressed to the max. It makes a body's shutdown times even more exhausting. It's harder to balance and move. There is 10 times the discomfort.

For me it was a rotator cuff injury in my right shoulder, received during a bad fall down the stairs at home. The doctor put off surgery until he couldn't any longer. I had to psych myself up for it.

Then, on the eve of the operation, just as I was making final preparation, I had a call that the operation had to be postponed. The operating room had flooded because of a freak stogy in.

I had to go back to worrying and waiting... a full two weeks. Finally, the phone call came. This time it was for real. I was wheeled into the operating room and put to sleep. The surgery took more than an hour and a half because when they opened up the shoulder, they found more damage to the tissue than the X-rays showed. They did what they could, but in recovery, the doctor warned me that even without a chronic illness like mine the healing would be slow and uncomfortable.

Because of my Parkinson's and the inevitable disruption to my medication routine during surgery, they gave me morphine along with the regular anesthetic to calm me down. Sure enough, as the effects of the morphine wore off the day after the operation, I developed a violent reaction. I couldn't stop vomiting. It was awful. I don't know how many times I had to be cleaned up before I could regain control.

It took even longer for the Parkinson's drugs to kick in properly because my "on and off' times had become completely unpredictable. I couldn't straighten up, much less walk properly. I was a mess.

Linda stayed with me 24/7 those first few days, sleeping in an armchair when she could. She had to help me out of bed and hold me up when I had to go to the washroom. When she dozed off, I'd try to help myself but couldn't. We had agreed that I'd whistle to get her attention if she were sleeping. By that time, my voice was so weak that sometimes she just didn't hear me. I was in agony.

Thank God for Linda. The hospital staff was competent and friendly but they were just too busy to attend to my every need. I had to guide them every step of the way about my special needs, like my Parkinson's medication schedule. I laid out cards on the bed to remind them of my medication schedule. As an added precaution, I kept a stash of pills beside me in case they forgot or were too busy. I knew that if I shut down I could easily damage or destroy what the doctors had worked so hard to repair.

The situation continued for three full weeks, first at the hospital, then at home. Linda must have been exhausted from it all. She hardly had any sleep the whole time. Yet through the whole ordeal, she was always upbeat and never faltered.

The rehabilitation took even longer. For my shoulder to heal properly, I had to keep the ai m stretched out fully all the time. It was held in place by an abduction pillow. It was like having a sports bag filled with towels under my armpit. We had to take the front passenger seat out of our vehicle to make room for me to get in and out of the back.

Any movement, upright or flat out, was awkward and uncomfortable. To make matters worse, it was January and I couldn't take a chance on slipping. Mobility outside the house had to be by wheelchair, with the sidearm off to accommodate my extended arm. What a bummer. The discomfort from the pillow was worse than the surgery itself.

Somehow, we got through it without any major crises. Oh sure, I did fall once in the kitchen, but I managed to catch myself going down so there was no damage. Linda, ever patient with me, never let my distress give way to despair. She kept her own anxiety under control as well, even though she was running back and forth to Richmond Hill trying to help her mom cope with her dad who needed full time care, now that his mind was failing.

She was always there when I had to go for physio and especially when I needed help to get going in the morning. I'd wake up all achy and stiff, or I'd freeze suddenly and need help to get moving. She'd be there right away with her foot out for me to step over it. This was the strategy we had developed for me to initiate movement.

There were times when I couldn't, or wouldn't, be able to get myself moving if I didn't make a supreme effort. However, I knew that if I didn't, I'd end up being a shut-in or worse, for the rest of my life. If that happened, I'd be unfit company for man or beast. I was already stir crazy from the icy conditions outside that seemed to go on forever, but if I were to venture out on my own, the elements would devour me. I wasn't ready for that.

We managed to get away to Florida for a short holiday, where we stayed with our friends Sid and Mabel Jones and Betty Sickle. Our wonderful friends were more like soul mates. We developed a special trick for me when I had to go to the toilet during the night. Linda was at the back of the house and I slept at the front, so we ran a string from the back to the front that I could yank if I needed assistance. My shoulder made it impossible for me to get out of bed unassisted. I suggested we tie the string to Linda's big toe but she didn't think that was such a great idea. Instead of her big toe, we used something that rattled.

Of course, the big lesson was that I couldn't manage without Linda's support. Even such a basic function as swallowing can be fouled up by Parkinson's and become life threatening. I had to have someone close by to see me through each far too frequent crisis. I'd be a disaster without help. No longer could I depend on my body to respond as it was designed to do.

In the end, I know it's all up to me to carry on, with a smile if possible. I keep going and my world keeps turning. Yes, there's a crisis brewing every minute for which I'm always having to psych myself up. It makes for one tense life, but getting on with it is my single aim and goal! It's who and what I am.

22. Not just another joust

As I write these last lines, I'm just past my 63rd birthday. My Dyskinesia has been getting worse lately. When I shut down now, my speech starts to slur and I can get somewhat incoherent. I have to use a cane and a walker to get around. I'm just not that steady anymore. I need a walker especially at night for toileting. I just can't function nearly as well as I used to, despite all the pills I devour.

As I age, my Parkinson's becomes increasingly harder to control. I fall down more. It's even happened in the middle of a road. That's why I need the cane and walker, sometimes even a wheelchair. I'm not as confident as I used to be swimming or bicycling. Yet I need to exercise to keep things under control. It's lucky that I was always a fitness nut. I'm used to a regimen of exercise. I don't have to learn it at this stage of my life.

There's a lot more on my plate now, too. My father-in-law has died. My mother-in-law is aging (thankfully very gracefully). That's been hard on Linda as well as me. We sold our house in the country so we could be closer to the family and so we could afford to go to Florida for the winter. Winters in Canada make me stir-crazy with my condition. Going to Florida allows me to do what I love most, play golf all year round. We moved into a granny flat in my son Craig and his wife Shawna's house, and that's been a huge adjustment.

Right now, I'm battling with the insurance company to get back the

$1200 cost for the cane and walker. These are not recognized medical expenses in Ontario, unlike in the States. I'm appealing their decision, hoping they'll reconsider on a personal basis because of my condition.

The rotator cuff surgery didn't work out successfully, which was a real blow, considering the long and painful recovery I endured.

Shortly, I have to retake a driver's examination to renew my handicapped driver's permit.

It seems like just when I'm turning a corner, there's always something new to kick me in the teeth. Recently, I developed symptoms of diabetes. My blood sugar level has elevated, so I'm going through a battery of tests, not to mention another battery of pills, to try to control it. Kidney stones are a possible side effect that has the doctors concerned.

Currently, I'm undergoing an assessment process to determine if a new experimental procedure will help me. My current neurologist, Dr. Janet Myasaki at Toronto Western Hospital thinks I might be a good candidate for the pedunculopontine (PPN) nucleus operation. I'd be one of only half a dozen human candidates so far. The PPN nucleus, it is believed, controls initiation and modulation of gait. Research so far has shown that the application of neuro-active stimulants to the nucleus have proved highly successful in relieving monkeys of Parkinson's symptoms.

If I am chosen, I'll have to decide if I want to proceed. The positive effects have been proven but the results are reversible over time. Actor Michael J. Fox was diagnosed with Parkinson's when he was 37 He has had a similar surgery and it has helped him.

It reminds me of the woman I was counselling once on the Parkinson's hot line. Her family just didn't understand what was happening to her. She said she didn't even want to get out of bed. Well, I talked to her for numerous hours over a period of time. Other phone counsellors had given up on her when she was handed over to me.

When I eventually met her face to face, she kept thanking me for helping her. I told her that she was the solution, not I.

In the end, I know that what will make the difference is what's inside my head and how open I can be about it. One of the criteria to be chosen for the PPN surgery is a positive attitude, I'm told. And patience.

The surgery is in two stages. First, over 5-6 hours, the surgeon drills through the skull and pinpoints the target nucleus. I would be awake throughout so I can respond to the surgeon's questions. I'm also told there is minimal pain involved because the skull has no nerve endings.

Once the nucleus is located, the second stage begins. This takes another four hours and is more painful, requiring a general anesthetic. A thin wire with electrode endings is inserted into the nucleus at one end and to a pacemaker-sized computer at the other end. It is programmed to release the necessary impulses for gait stimulation.

Like all surgery, there's a risk of bleeding or stroke, but if it works, I would feel almost normal again. Although the procedure is yet unproven in humans, it's almost my last hope. There's nothing else left for me.

The greatest danger is that the results are not permanent. This means that as the benefits reverse, it's possible my brain function will diminish too. So how do I feel about it? I'm terrified. But I'm so tired of the constant pain and discomfort after 30 years battling the disease, it would be worth the risk. It would be a tremendous relief to feel even near normal again, if only temporarily. Besides, I'd be helping others who come after me.

I think of it as hitting a golf ball into a blind pin. If I get the shot right, the reward is sweet. If not, the game just takes a little longer. Either way I can't see the target, but I know it's there.

Overall, I'm inclined to go for it if I'm chosen, in spite of the risks. Through all these years of battling Parkinson's I've learned to live in the moment, and leave the unknown and the uncertain to take care of themselves.

I have a wonderful wife, three children, six grandchildren, a loving family, and a great support network. I get to spend my days on the golf course, summer and winter. Life doesn't get much better.

No one is free of crisis, and no life is perfect. I'll keep doing what I think gives me the best chance for happiness, and hope it'll work out. Just keep on truckin' along. That's me!

23. Christopher

When I think of my father, I think about things like courage, integrity, optimism and wisdom. He is someone who, for the formative years of my life was larger than life. Indeed, he was the person that I always looked up to, respected, learned from, and who was the filter through which I experienced the world. What a huge responsibility this must have been for him; to lead his children, provide for the basic things in life like food, shelter, warmth, and love and to provide a role model for us to strive for. He bore all of this with those things that I admired most in him. Things like courage and wisdom.

I remember when we lived in England in 1975-76, while going across a busy street in downtown London. The typical tourists, Mom and Dad with three kids in tow, enthusiastically trying to corral us across the intersection, and coming face to face with what I can only describe as a man in a full length fur coat, top hat, striped pants, and a large, hairy handle bar moustache. Later in my life I would think of this man as bizarre. He didn't stray from his pace or his direction, and he was coming right towards me, my brother and my sister. The next few moments are a bit fuzzy for me, but I remember being pulled out of the big man's way and whisked across the intersection without another glance back. The tension was palpable. We had just missed a close encounter with a shady character. My father commented, when I asked him what would have happened if I had not been pulled out of harm's way. He would have defended us, by doing whatever was necessary to protect his family. Dad was pretty impressive.

Fast forward to the present and I think about that same man, full of all the admirable things that still make him special in my heart, with a debilitating disease that saps his strength, his reflexes, and his energy. My father would have a hard time now doing the things that he did not even think twice about back then on that busy, congested intersection in London. He must parcel out his energy in little spurts so as to pace his activities during the day.

When Dad first told me that he had Parkinson's disease, one of the first things I asked him was whether or not it was genetic. Was I going to get the disease ? No he told me, it doesn't necessarily follow from generation to generation. In fact, that was one of the few sure things that doctors knew about the disease at that time. My father has since told me that this may no longer be true. It is with some degree of trepidation that I enter my 4th decade. There is no substantial evidence one way or the other. Dad has to think twice about how he manages stress, fatigue and things that I take for granted all the time. He has made me appreciate my life even more. Things like waking up and jumping out of bed full of energy to start the new day; a full night's sleep; and patience in the face of undue stress during a normal busy day. Whenever, I get run down, I think about my Dad and the things that he has to deal with every day with Parkinson's. My things don't seem all that bad, considering what he has to deal with. He still tries to face the day with those same qualities that I continue to admire in him; courage, integrity, optimism and wisdom. And, he still is, and always will be a person whom I admire, respect, and love, because he is the strong man in my life.

24. Linda

In looking back, I first noticed that something wasn't right at our daughter's Christening. George was trembling so hard that he couldn't hold Marni at the front of the church. Did he have the flu? A pinched nerve? Over the next four years, more and more of these episodes occurred. I guess the worst time was when we decided to go to England on the teacher exchange program. Before we left for England in August 1975, we rented our house for the year (which meant packing and storing a lot of our things). We moved to a children's camp for four months because our house was rented and because George was going to be the program director for the camp. My sister was to have been married in the fall but moved the wedding to August so we could be in the bridal party. We moved out of the camp and into my aunt and Uncles house for a week; we moved out of that house into my parents home for a week. All of this, as well as wedding preparations and England preparations! When George couldn't sign the VISA receipt for his rental tux and when he had difficulty walking down the aisle in my sister's wedding procession, an emergency call to our doctor assured me that all this stress was leading to a nervous breakdown for him. Once I got him over to England and settled, things would calm down. Well, they didn't! They just got worse! What was happening to this once strong, confident man that I married? I took on more and more responsibilities for all five of us, and we struggled through the year in England.

Once back home, he started going to many doctors and three years later was finally diagnosed with Parkinson's disease. I had just picked him up at the hospital to come home for the weekend. He was elated that he had a diagnosis! He told me it was Parkinson's disease, This news caused me to drive over the curb. My whole future flashed before me. He was going to die and he was happy! My three young children would grow up without a father. How would I cope on my own? I thought Parkinson's disease was a form of cancer (a friend of ours had Hodgkin's disease) and in my panic I thought that was what George had. I have since learned that of all the neurological diseases to get, Parkinson's is the good one.

During those four years waiting to get a diagnosis and even during the years that followed, life was and still is at times a roller coaster ride. Sometimes, things were so bad that we didn't know what to do next. There were times when I would come home notice that the bedroom blind was down and George's car was in the driveway. Not a good sign. He would be huddled in bed or in the family room rocking in a chair with a comforter bundled around him. At one very low point, I remember our oldest boy Chris coining home from university for his high school graduation. George couldn't leave the basement. He decided he couldn't go attend his son's graduation. The rest of the family went without him.

Luckily, at times like that, we had the wonderful support of our neurologist Dr. Gladstone. No matter how busy he was or how full his waiting room, he counseled and encouraged us until we both, yes both, had stopped crying and felt we could go out into the world and try again.

Once George was on a regular medication schedule, things slowly went back to normal. I had to learn to hand back some of the responsibilities that I had assumed, out of necessity, over the years. We had opted not to tell people what was wrong (outside of immediate family). Looking back, that probably was a mistake, because many people knew something was wrong and started drawing their own conclusions. Once (a friend) mimicked the way he walked and laughed at his jerky movements and stutter-stepping. I wanted to yell, STOP; he can't help it.

One of the best things we did was to eventually join the Parkinson's Foundation. We didn't join immediately after diagnosis because neither of us wanted to see what life could possibly be like, down the road. But, the benefits far outweighed the negative. We also started a support group for young onset Parkinsonians and their spouses. This resulted in us interacting with many couples who had the same concerns as we did; still working, with young families. Unlike later life onset, young onset (under 50) Parkinsonians face a very unique set of problems. Regardless, of when the onset occurs the situation initially is devastating. Shared stories and experiences for Parkinsonians and Caregivers certainly benefited all of us, and we were in the comfort of our own homes.

They say that any major crisis in a family can either drive the family apart or bring it even closer together. In our case it was the latter. I think Parkinson's has made us appreciate each other and our time together even more. Sometimes when I look at George today and see his daily and nightly struggle to do all the things that the rest of us take for granted, I wonder how he keeps going. It would seem easier to just give up. I have so much love, admiration and respect for him that he can stare this Parkinson’s "in the face" and keep such a positive attitude.

We are currently enjoying the best of both worlds, living with our son Craig and daughter-in-law Shawna for the summer months (no lawns to cut) and enjoying family and friends, then packing up and heading South to Florida to escape the cold Canadian winters. In Florida we enjoy a whole new set of friends.

People have emphasized to me that it is important for me as a Caregiver to try to have some outside interests and activities, for my own health and sanity. Sometimes I struggle to keep a balance in my life: husband, children, grandchildren, mother and… ME!

Glossary of Terms

1. *ON/OFF* – describes time periods when medication is effective and when it is not
2. *Shut Down* – period of time when medication is not working
3. *Dyskinesia* – involuntary movement of arms, legs, or head by themselves or altogether.
4. *Festination* – freezing and pitching forward when trying to walk
5. *ESN-S* – educational sub-normal severe - IQ below 60 usually physically and mentally challenged
6. *Peripatetic Teacher* – works in school as well as makes home visits
7. *Shagging Balls* – retrieving golf balls on practice range
8. Pedunculopontine (PPN) – deep brain surgery
9. *Caregiver* – assists person with day to day functions
10. *DT's* – uncontrolled shaking, psychological horrors of war
11. *Cuppa* – English expression for a cup of tea

25. Craig

The first time I ever heard of Parkinson's disease I was twelve years old. Maybe it was eleven I'm not sure but I remember having a pretty good understanding of it, from a child's perspective. Something was wrong with Dad. He wasn't sick (like with the flu or cancer), and he wasn't dying either. I understood that much. But something was wrong with Dad. I remember realizing that from that point on things would be different.

Twenty five years or so later I can still vividly remember my thought processes. I worked it through in my mind as best I could as a kid. Dad wasn't leaving us like my friend Brett's dad when his parents got divorced. He wasn't going to live in a hospital or have to be in a wheelchair. In fact, he was going to be pretty much the same for a while. He just had Parkinson's disease and it was okay for everyone to know about it now. I'll never forget the family meeting in the basement of our house on Devin's Drive. Mom asked us to come downstairs because they had something important to tell us. We didn't have many family meetings so I knew it must be big. We sat in the family room in front of the fireplace as my parents explained all about Parkinson's Disease. It was serious. Very serious. They talked about how it affected the way Dad walked, and how sometimes he had difficulty moving. They told us that there would be things he couldn't do anymore because of it.

They talked about the Parkinson "tremor". That is what really stuck out in my mind. There was a commercial on TV. It was in black and white, and there was an old man sitting in a rocking chair with his grandson. He was trying to do a puzzle and his hands were shaking uncontrollably. Too shaky even to put a large piece into the child's puzzle. The little boy reached out and gently guided his grandfather's hand forward to accomplish the task. This was all I knew of Parkinson's Disease. This wasn't my Dad. I never saw his hands shake like that. He never had to be in a wheelchair. He could certainly do a simple puzzle. Heck, he even coached my hockey team and played father/ son hockey with me. All of these thoughts scrambled through my mind. I tried to make sense of the idea that my Dad was, in fact, not invincible. It didn't make sense! It wasn't fair! They must be wrong!

However, it all started to add up. I thought back to a point a few years earlier when Mom and Dad told us that Saturday night wrestling with Dad vs. the kids had to stop. Apparently it was his bad back. He used to kick the soccer ball around or throw a baseball back and forth with me and that had not happened for a while. It wasn't anything obvious. To be honest, I never would have considered any of these things to be out of the ordinary. I have only since pieced them together. On their own they are inconspicuous events but taken all together, after the fact, it makes sense.

All of the kids worked it out in their own way. My older brother Chris was angry and upset. He was old enough to have a good grasp of the situation. I think he wanted the doctors to be able to do something about it, like it was their fault. My sister Marni was upset but too young to fully comprehend what the whole thing meant to her, to Dad, or to our family.

Now that I have my own family I have some appreciation for the difficult time my parents must have had when we were growing up. It is difficult enough raising kids when you have health but dealing with teenagers and Parkinson's at the same time must have been a nightmare. I take my hat off to both mom and dad. They really kept it together for us. In fact, I often think of my childhood as the "Apple Pie" experience.

We had a loving family. No divorce, deaths, major sickness (or so I thought), no family rifts, everyone seemed to be happy and healthy and there was always a lot of love. We went to hockey games together, went on camping trips, had family dinners almost every night, and spent weekends as a family. What a charmed life!

I guess that the universe balances things out with challenges like Parkinson's disease. Maybe everyone has to have their share of problems. We had very few within the family so the universe threw Parkinson's at us. Or maybe the PD was the glue that brought the family together. A sort of rallying point that caused mom and dad to create a more nurturing and loving family environment for us. I know that dad sees it this way. Mom I am not so sure.

Dad seems to have come to terms with PD. I think that as a determined, athletic young man he looked at PD and said "Alright, you want a fight? Let's fight. I have had a childhood from hell and I climbed out of that hole to make a good life for my family. So screw you. You will not get the better of me!"

I think that is a fairly typical response from someone in their early thirties faced with an "old man's disease". However, I think what was entirely atypical is my dad's staying power. I believe most people forced to live with PD or a similar problem for so long and from such a young age give up at some point. The thing that makes me so proud of my dad is that he has never rolled over and given up. He just keeps looking at this thing and dealing with it.

Though he has changed in how he has coped with it over the years. As I mentioned above, I think he fought with it at first. It was combat. He developed lots of strategies to try to deny it from affecting his life.

Or at least from letting others see it affect his life. He didn't even tell people he had it. After that I think there was a long phase of coping. There were lots of adjustments in this time period. I think most of dad's life, at this point, was an "adjustment" to try and live a good life and work around the PD. This was the time after he came out and let people know that he had PD. He was still trying to work and carry on as normally as possible, but I believe that he was reacting to life with PD.

I think that after this dad changed tactics to deal with PD. I sensed that at this time he began to try to manage and control it. I was a teenager During a lot of this time and until recently I don't think I had any appreciation for the added stress and grey hair that I (and my brother and sister) contributed. There were all of the typical teenage problems liking drinking and staying out all night, issues with girlfriends and hassles at school. All the challenges that families deal with on a regular basis. Those things are hard enough for a family without trying to cope with chronic disease at the same time. The thing that stands out for me now is not any night I stayed out drinking, or didn't phone if I was going to be late. It is not a major event but a small daily routine.

When I was 17 I had the opportunity to go to a small private school in our town. It was a fair walk from our house and dad would drive me in the mornings. We butted heads every morning. I wanted to sleep in every day and leave at the last possible minute. My dad wanted to get to work early to mentally prepare for his day and have some precautionary time in case of bad traffic. Being a teenager I had very little consideration for my dad's situation. At that time he was struggling just to get through each day.

Imagine the stress of each day not knowing whether you were going to be able to walk down the halls of your work place without stumbling, or worrying that you may not be able to get from the car to your classroom if your medication decided not to kick in at the proper time. Top this off with a teenage son who didn't seem to care less how late he made you on a daily basis. Funny enough, I don't remember dad ever leaving without me. I can't recall him raising his voice or giving me any ultimatums. What patience. I'm sure he wanted to wring my neck a few times but he never made me aware of it.

Patience is one of his great qualities. I guess it comes from teaching kids. You would go crazy without having patience. I think dad has learned great patience from PD. He spends a great deal of his time waiting for his body to come "on". With a body that gives you decreasing amounts of "on" time as each year passes you need to learn how to be patient and control your frustration. I have watched dad as he sits in a chair or stretches out on his bed after taking some medication. He grabs a catnap or watches a little bit of TV as he waits for the familiar feeling of being "on" to come back. It is absolutely amazing and mind-boggling to watch. One minute he is having difficulty walking and even moving his limbs and the next moment he is up like a shot walking briskly around the house or the yard hammering something or tidying something else. This is the most important lesson to learn from dad. It is a simple but absolutely amazing teaching: Carpe Diem. Seize the day. Make the most out of every minute you have. Dad does this because I believe that he sometimes wonders if he may not come out of his next "off' time.

What if the next time he shuts down he doesn't come "on" again? We take life for granted all of the time. We take our health and our loved ones for granted. We don't appreciate the small things like going for walks in the woods or picking up our children and carrying them in our arms. Dad has got this right for sure. When he is "on", he is on. He is not waiting around for anything. When the legs are working he is going to squeeze every precious second of mobility out of them.

Not only is he patient but he is the eternal optimist. He is always hopeful. Talk to my dad about the future and he always talks about a cure. Talk to him about the research in PD and he is usually on top of the new developments. Ask him how he feels or how he is dealing with it and you will get an emotional, sincere, and honest answer. No glossing over the subject. No "I'm just fine. No problems." You'll also never get self pity or complaining from dad. He doesn't want people feeling sorry for him. He just wants to try to help people understand, for their sake as much as his.

I can't imagine the mental strength it must take to wake up every day knowing that the entire day could be one long, exhausting struggle. Or it might be a good day with some "on" time and some fun. I don't believe that dad ever knows which it will be. And I think it can change by the minute.

After his management and control phase, I think the next step dad went through in his journey with PD was a state of acceptance on some level. I have no idea if this is accurate only he would know but in my mind I can recall the exact time I think it changed. I have noticed a very slight change in my dad since this one particular event. Not a huge obvious change but perhaps the most significant and profound one. It is the greatest thing I have ever learned from anyone.

Mom and Dad were living in Innisfil. Something happened with dad (I still don't know what) and he had taken the car and gone for a drive. He Had told mom he didn't want to be a burden anymore and was going to take off for a while. We knew he would be back. Family is too important to dad and he has too much pride, love, and responsibility to leave. Mom called me in a panic. She was upset and didn't know what to do.

Shawna and I got into the car and off we went. We waited shortly at the house with mom. Dad wasn't gone long. He came in the house more upset than I had ever seen him. We were all upset but I remember thinking that I had never seen dad exactly like this before. Something was wrong in a way that I had never been aware of before. I looked at my dad and I thought to myself "This is finally it. It has beaten him. He has given up and there is no fight left in him." In just a few seconds I went from shock to sadness to disappointment to fear to anger and who knows where else from there.

It was at this point that something absolutely incredible happened. I went to my dad and just gave him a big hug. We both sobbed uncontrollably as I tried to comfort and support him while at the same time deal with all of the emotions I was experiencing. Dad just unleashed his pent up emotions and frustrations. We cried together as he let his guard down and bared his feelings and his soul. I remember the moment distinctly as it was one of the most profound moments of my life. In his emotional, weakened, frustrated state dad showed me more of what life is really about than I had learned from my entire life experience to that point. I had mistaken his emotional outburst for surrender. In reality he was just being himself. He wasn't weak. He wasn't giving up. He was just feeling and expressing, like letting the steam out of a pressure pot. He didn't need me to pick him up or coddle him or do anything for him. He was just letting himself be vulnerable, and honest. We all put on faces and acts all of the time. Dad wasn't doing any of that. He was letting everyone look right down in to the depths of his heart and see his pain. He is such a great man and has led such a great life that he was okay with this. To let people see all of your flaws and emotions and be okay with it is truly an amazing feat. Only a truly good, humble and confident person could so freely let people see this side of them.

I was in awe of my dad. I wasn't sorry for him or afraid for him. I was in absolute awe of him. He was experiencing his life as it came. He wasn't filtering it through anyone else's opinions or ideals. He didn't sort through what would be considered manly and acceptable. He wasn't sifting through what he was feeling and only showing what he was comfortable with. NO. He was just being himself more completely and fully than I had ever seen before. In his pain my dad showed me how a life should really be lived. Live every experience in whatever way is right for you. Be yourself in every circumstance. It is always the right thing to do. Just be yourself. Let the people close to you see your despair and joy, your failures and your triumphs.

I know dad has struggled physically and emotionally with PD for most of his adult life but he sees at least parts of it as a gift. My dad understands himself and accepts himself more than most people ever do and I am sure that it is his lifetime struggle with PD that has allowed him to get so far on this journey.

26. Personal

My journey is ongoing; it doesn't end with the last page of this book. As Michael J. Fox expressed in the title of his book “Lucky Man”, how he feels about his life as a result of his battle with Parkinson's, I too have benefited from the ravages of this condition. The crumbling walls have released my inner demons, I have inner peace, I do like myself, I am worthwhile. Finally I want to thank my life partner for always being there for me. We have just celebrated our 41st wedding anniversary and want to conclude this book by quoting some lyrics from the Kenny Rogers song "Through the Years":

"I CANT REMEMBER WHEN YOU WEREN'T THERE
THROUGH THE YEARS I NEVER BEEN AFRAID
I'VE LOVED THE LIFE WE'VE MADE
I SWEAR YOU'VE TAUGHT ME EVERYTHING I KNOW
YOU'VE KISSED MY TEARS AWAY
THROUGH THE YEARS I'VE NEVER HAD A DOUBT
AS LONG AS IT'S OKAY,
I'LL STAY WITH YOU THROUGH THE YEARS"

I Love You Linda!

27. Muhammad Ali

If you keep a positive mind and an
optimistic outlook on life,
negativity loses its power to make you unhappy

Muhammad Ali