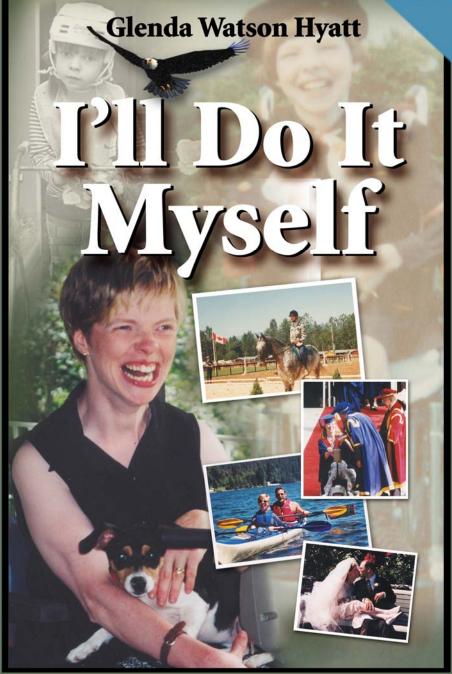
EXCERPT EDITION



I'll Do It Myself



Surrey

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INTRODUCTION

I have dreamt of writing this book, my autobiography, since I was around the age of ten. Egotistical? Perhaps. I see it more as part of my legacy, as my way of passing on the lessons I've learned in hopes of making someone else's life easier, as my way of showing that having cerebral palsy is not a *death* sentence, but rather a *life* sentence.

First, and foremost, I am writing this book for youth and young adults with cerebral palsy and other disabilities to motivate, to inspire and to share how I have navigated life. Sometimes simply reading how someone else handled a particular situation gives the reader the encouragement and ideas for handling a similar situation. Other times knowing others have had similar experiences – to know one is not alone – can be so comforting, and can offer strength and hope.

Secondly, I am also writing this for parents, who, after having their bundle of joy gently placed in their awaiting arms, are given the devastating news their baby has cerebral palsy. In an instant, their hopes and dreams for their child, as well as for their family, are smashed. I hope this book offers a glimmer of hope for these parents, as well as for the siblings, grandparents, aunts and uncles. I want to show that life can still be meaningful, despite cerebral palsy. I hope the book offers parents insights and ideas when raising a child with cp; however, realizing that no two children with cp are the same, there is no guarantee these ideas will be appropriate for every child.

I am also hoping that Human Resources managers, who want to do the right thing by hiring employees with disabilities but still have fears and uncertainties because they don't know anyone with a disability, will experience an increased comfort level being around people with physical disabilities and will venture into the pool of underutilized skills, talents and knowledge.

This book is also for individuals who enjoy reading about the lives of others in order to gain a new understanding of other people or to gain a new perspective or insight into their own life.

Lastly, I hope the book will enable doctors and medical professionals to see beyond the diagnosis, the prognosis and the *can'ts*, and see the patient as a person filled with capabilities, potential and desires. However, that may be expecting far too much from only one book!

Thank you for reading and for sharing in my dream.

IN THE BEGINNING

I entered this world one Friday morning in early November, 1966, in Vancouver, British Columbia. A light dusting of snow covered the ground. Mom said the North Shore Mountains looked like upside down pink ice cream cones as the sun rose outside her hospital room window.

My parents were living in Nanaimo on Vancouver Island, but Mom's doctor wanted her to give birth at Grace Hospital in Vancouver. Nanaimo did have a hospital, but according to Mom's doctor, it was merely a first aid post in a hospital building. Any serious cases were airlifted to Victoria or Vancouver. Perhaps it was doctor's intuition that wanted her at the best maternity hospital in the province at that time.

Mom travelled over to Vancouver in mid-October to stay with her parents, my Nana and Papa, while Dad stayed in Nanaimo to work. Mom and Nana enjoyed those couple of weeks before my birth, shopping for baby things at Woodward's \$1.49 Day. If Mom's relationship with Nana was anything like my relationship with Mom, I have no doubt that they had silly fun and good laughs during those two weeks.

Mom had a normal pregnancy, and everything was fine up until my actual arrival. Then the situation became somewhat scary and uncertain. Mom had a reaction to the Xylocaine epidural and went into convulsions. The doctor had to pull me out with forceps, which meant I didn't have

time to read the instructions on my way down the chute. I missed the fine print on needing to breathe immediately.

One doctor worked on reviving Mom, while another one worked on saving me. Luckily, a pediatrician specialist was just leaving the hospital and was called back to try to get me breathing. Perhaps it wasn't a coincidence that the specialist was there at that particular moment. He was probably one of the angels sent to save me that day. It was touch and go for a while. Dad nearly lost both of us.

I definitely would not have held my breath for six minutes had I known what hassles it would cause for the rest of my life. Talk about learning from experience. You would think the first lesson for a newborn would be somewhat easier!

FAMILY LIFE

The early years were happy times for us as we did much together as a family. In the late spring and summer months, we went camping in our tent trailer. On one weekend camping trip, we had barely finished eating, and I was still sitting in my wheelchair at one end of the picnic table with my tray attached to my wheelchair. A cheeky squirrel scampered on to the table in search of scraps. He neared my end of the table. I sat still, which is not an easy task with athetoid cp. He ventured onto the corner of my tray long enough to leave his footprints on my white tray. I was so excited that I wanted to take the tray to school on Monday morning for Show n Tell. Mom witnessed the whole encounter, and I wouldn't let her wipe off the tray for the rest of the weekend.

Monday morning Mom dropped me off in my classroom, putting the tray in the corner with the other ones, and then walked down the hall to her room as she was a Special Education teacher in the same school. The aide came in and, noticing the "dirt" on my tray, dutifully took it to the sink to wash it off. Very disappointed, I watched as my Show n Tell was washed down the sink. I was too afraid to say anything because she probably wouldn't understand me; after all, I'm *non-verbal*.

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OCCASIONAL AND PART-TIME THINKERS

Speech therapy seemed rather bizarre to me. The therapist sat on a floor mat with me lying on my back between her outstretched legs. My legs wrapped around her waist, and her stinky toes were in close proximity to my nose. She then proceeded to stick her fingers in my mouth to wiggle my lips, supposedly to loosen them. She alternated between using her fingers and ice cubes. When the speaking segment of the therapy began, she pushed on my chest in attempts to improve my breathing capacity. After years of this hefty woman pushing down on my chest, I am convinced that was why I was such a late bloomer.

As I laid on my back staring at the ceiling tiles, I was puzzled. *What was I supposed to do when I met people in the real world? Lay down on my back, on the floor, before speaking to them?* I envisioned myself sprawled out on the ground when meeting a friend at the shopping mall or grocery store. This was not a dignified thought. Not surprisingly, pillow talk is some of my clearest speech!

After the speech therapist with stinky toes, I had one for a brief time who had me sit upright for the entire session. What a concept! One of the most sensible things we did

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was make an alphabet card, small enough to carry with me, which I could use when people didn't understand what I was saying. I simply spelled out the word on the card. Sometimes the low-tech solution works the best, and I've had many variations of that card through the years.

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SCHOOL DAZE

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School was an older building; actually, it consisted of two buildings and a portable. The main building had four or five classrooms for the primary grades, the staff room, changing room and the principal's office. The older kids were upstairs in the other building, accessible by a long, steep ramp.

As this was before *integration* and *mainstreaming* had been invented, all the Special Ed students went to this school, which was actually an annex of a larger school, several blocks away. This was definitely segregation. But, at that age, I didn't know any differently. I was excited to be starting school with my new notebooks, crayons and lefty scissors. And, I do remember hating missing school when I was sick. It was so boring to stay home.

Being *non-verbal*, my teacher Mrs. Rutherford was concerned that she wouldn't hear me when I needed help, so she gave me two small brass bells – I think they were her mom's dinner bells – to ring to get her attention. It was soon discovered that the bells weren't necessary as I was verbal enough to catch her attention when needed.

Because getting to the chalkboard was difficult for most of us once we were placed in our seats, we each had an 18inch square piece of chalkboard at our desks for practicing our printing. It was also easier to work on a horizontal surface rather than a vertical one. Initially, my printing was wobbly scribbles. With practice and extreme concentration, I controlled my jerky movements enough to make my letters almost legible more of the time. I also kept a chalk eraser handy, though inadvertently an uncontrollable movement erased a *good* letter. In frustration, I did the letter again.

Although learning to print, and then to write, were important steps in learning to read, it was evident that printing would not be efficient. It took too much energy and was too time-consuming to keep up with my work, and that would only worsen through the grades. Learning to use a typewriter was a necessity.

An electric Smith Corona typewriter was placed at the back of the room, which a few of us shared. When it was time to do typewriter work, Mrs. Rutherford dragged me in my desk chair over to the typewriter table and then dragged me back to my desk when I was done. Then it was the next student's turn. A while later, perhaps once funding became available, we each had a typewriter at a second desk beside us. We simply dragged the typewriter back and forth as we needed it. It was much easier, especially on Mrs. Rutherford's back.

As I have only one somewhat functioning hand, I only typed with one hand, my left hand. While typing, I steadied my hand on the typewriter *hood* to give myself some control over the spastic movements and used my thumb to hit the keys, causing my wrist to be in a dropped-wrist position. This concerned the adults, particularly the physio and OT. Although this was decades before repetitive strain injury and carpal tunnel syndrome had been invented, they were concerned that the dropped-wrist position would cause damage over the long-term.

They decided a splint with a stick to hit the keys was needed to keep my wrist in a good position. With this contraption snuggly Velcro strapped to my arm, I was expected to have enough arm control to steady my hand mid-air, without resting it on anything, and to accurately hit the keys. And this was less frustrating than printing with a pencil? After a few days, the splint ended up in the back of my desk drawer, and I resumed typing with my left thumb, my hand in its compromising position. I type the same way today, as nothing else feels as natural. For a non-verbal individual who relies on written communication, my left thumb is my most valued body part.

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In Grade 4, I had a new teacher, Mrs. Peart, at a *new* school because several of the Special Ed classes were moved over to the main school. Eventually, the annex was torn down, and the lot became a car dealership that stands only blocks from where I'm writing this now.

Being at the main school, our class now had access to the school library. We trekked down the hall to the library once each week to learn about the Dewey Decimal System and to check out a book. After a few weeks, the librarian strongly encouraged me to check out the very limited section of books on tape, assuming that using the newest technology at the time might be easier for me than holding books and turning pages. Honestly, I felt as though she was more concerned that I might crumple the corners as my cp hands turned the pages.

Being a teacher, Mom knew that listening to stories was not the same as reading books. Limiting her bright child to tapes to avoid crumpled corners was not acceptable. Mom, who firmly believes that one catches more flies with honey than with vinegar, politely mentioned to the librarian that I had owned books since I was young and was very careful with them. As a young child, Mom gave me old Sears catalogs to look at so that I learned how to turn the pages without worrying if a page got accidentally torn.

After that one incident, I *read* the entire *Little House on the Prairies* series. I so wanted to be Laura Ingalls, living in a little log house and experiencing her adventures. From there I read books like *Ice Castles* about a talented figure skater who became blind but continued competing by hiding her disability, *The Other Side of the Mountain* about an Olympic-bound skier who broke her neck during a qualifying competition, and *Joni* (pronounced Johnny), who also became a quadriplegic resulting from a diving accident.

Back in Grade 2 or 3, Mrs. Rutherford gave me *Wren*, a children's book about a young girl with cerebral palsy, loosely based on an actual person. It also had illustrations of Wren standing in her long legged braces and crutches. Unlike other children's books, which I enjoyed but didn't identify with because I couldn't see myself in the illustrations, I could relate to the pictures in that small book.

Back then, I didn't know any successful people with disabilities who were much older than me, and I don't recall any people with disabilities in the public eye. These books, particularly the autobiographies, provided me with much needed role models. They showed me what was possible, despite having a disability. It was one thing to have my parents, teachers and therapists tell me to work hard so that I could accomplish anything I wanted. It was another thing to read about adults in wheelchairs who

became teachers or got married. I began to realize what was truly possible. Those books planted the seed, when I was about ten, that I would one day write my own story to help others to see what was possible when living with cerebral palsy.

HIGH SCHOOL

[In Grade Eight], Because I only took five courses out of a possible eight, I had three spare blocks that I used for doing homework since it took me so much longer to type my assignments. I still did hours of homework every night and every weekend in order to keep up with the pace of the courses. While I never turned in a late assignment or asked for an extension, I did make sacrifices, particularly in later grades, as the workload got even heavier. I missed out on doing things with friends that may have been as important to personal development as spending hours on homework. Looking back, I'm not sure if I would do things quite the same way again. Although, with a computer and word prediction software rather than an electric typewriter, I could have done my work more efficiently; thus, saving me from typing a rough draft of a paper and then a good copy. Perhaps I could have done my best on my homework and still have had time to be with friends rather than being in my bedroom most of my high school years.

Occasionally, I escaped my cell. At the end of October came the Halloween Dance – my first high school dance! I was excited! However, because I was still in my manual wheelchair, this posed a minor problem. I needed a pusher, and, in case I needed to go to the bathroom, it had to be a female pusher. Barb was unavailable that night, so, naturally, Mom filled in. I dressed as Santa with a

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cardboard sleigh, created as a family effort, attached to my chair. Mom was dressed as a toy sack behind me, and she wore a red, yarn wig to look like a Ragedy Ann doll within the sack. I took my Mom, dressed as an old bag, to my first high school dance! Not the *norm*, but everyone was cool with it.

During the fall, I discovered high school basketball, particularly the senior boys' team. I went to several evening and weekend games at the school, sometimes coercing my brother Kevin to go with me. One day before the lunch bell rang, the principal announced that the senior boys had an afternoon game in Abbotsford in the Fraser Valley, about an hour and a half away. Any fans wanting to go to cheer on the team simply had to get permission from their last period's teacher. What Grade 8 girl wouldn't jump at the opportunity to miss last class to watch senior boys run around in shorts? Barb phoned Mom to ask for her approval, and then she called her husband to tell him she would be late coming home. I was carried onto the awaiting school bus, my wheelchair was stowed underneath. I was part of the group.

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In February, I got my first electric scooter, my little Amigo. It was mainly black with a bright yellow cover over the motor, and it reminded me of a bumblebee. Mom and I had seen a woman in an Amigo at a shopping mall while we were on vacation the previous summer. The seat actually swiveled so that the woman could easily stand up at the cashier to pay for her purchases. We had never seen such a neat thing. We caught up with the woman and asked her about it. It seemed ideal for me. When we mentioned it to my physio, she hadn't heard about it. She tried putting me in a small, low electric wheelchair. She set up an obstacle course in the therapy room and let me try it very briefly. When she saw that I wasn't steering the chair very well, she yanked me out, and that was the end of it. She even suggested to Mom that I should not have an electric wheelchair. It didn't seem to matter to her that the hand control was on the right side, and I'm left-handed! I felt like a sixteen-year-old who is given the much-anticipated, first opportunity to drive a car in a deserted parking lot and then is not allowed to drive anymore because she can't handle the car. She hasn't had any driving lessons yet!

Anyway, Mom and Dad located an Amigo scooter at a medical equipment store and arranged for me to try it for a day at school. It was wonderful! And, I think Barb enjoyed the break from pushing my wheelchair up the long ramp for the day.

Despite my physio's opinion, Mom and Dad decided to purchase the Amigo. I no longer had to rely on others to push my wheelchair. I was so excited about the freedom to go where I wanted, whenever I wanted! Driving it took some practice, and I did run over a number of toes in the process. I even had a recurring nightmare of losing control and driving down the stairs at school, particularly the open staircase in the library. Thankfully, that never happened.

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Shortly afterwards came another momentous day. My friend Beth lived around the corner from us, five or six houses up the street. She invited me to her house one Saturday afternoon. Mom walked with me to the corner of

our short block and then watched me wheel up to my friend's house, which, luckily, had a ground-floor entrance with a family room on that level. This was the first time I was able to go to a friend's house alone, without needing a parent to drive me. I was spreading my wings! One giant leap for Glenda's independence!

My Amigo scooter not only gave me a form of independent mobility; it also gave me an independent selfidentity. I no longer needed someone always around me to push my wheelchair. I no longer needed to be attached to someone or someone attached to me. I was no longer under someone's control when moving. With my Amigo, I could move around without someone behind me, towering over me. I could move independently, a whole new experience.

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THE EAGLE TAKES FLIGHT

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My business idea stemmed from an interest sparked a few years earlier. While taking the pre-employment program at the Neil Squire Foundation, the instructors were soon scrambling to keep me busy and suitably challenged. One day the computer instructor introduced me to basic HTML for designing websites. I gobbled it up! I soon realized that, although I grew up in silence, I now had a way to communicate with the world. That realization was so exciting, so liberating!

I continued learning HTML on my own and came across the term web accessibility. Like the real world, the internet also presented barriers to people with disabilities if particular guidelines weren't followed. As I did more reading and learning, I understood that, although using the internet didn't pose insurmountable barriers for me, people with other kinds of disabilities would have problems using it.

These problems existed because web developers and decision-makers were not aware of the need for making websites accessible. To make sure other people with disabilities had the same freedom and opportunities provided to me by the internet, I wanted to assist organizations with making their websites accessible to everyone, regardless of an individual's abilities or the technology used. By making their websites accessible,

businesses would increase the number of people capable of accessing their sites and, in turn, increase their customer base, which translates into increased profits. Their corporate image would improve because no group, including their own employees with disabilities, would be excluded from using the website.

My business plan also included adding disability awareness training and potentially Braille printing (embossing) services in the future. My mission was to increase awareness and accessibility of communication so that people with disabilities may fully participate in all facets of society. My guiding principle was something I dubbed the AAA Principle: *accessibility* also involves *awareness* and *acceptance* of people with disabilities – all disabilities.

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Having a new business with relatively few contacts, being non-verbal, and working in a field about which most people had no knowledge didn't make a great combination for instant business success. As with any business, particularly with a fledgling business like mine, networking is crucial. I did attend a few networking events sponsored by the Self-Employment Program, but I found they weren't highly effective without verbal communication. I even tried printing my business information on postcard-sized cards and handing them to people who stopped to talk, but the cards had very limited success.

I was intimidated to wheel into a room of people standing and milling about because my eye level was their fly level, so making eye contact was difficult. Most people walk into a room and notice how many people are wearing glasses; I wheel in and notice how many flies are undone – a surprising number! With my current scooter I am at breast height. It's not exactly a thrilling perspective for me, but I am moving on up in the world!

The other problem was my actual business. What is web accessibility? People understand the need for making buildings accessible, but websites? Isn't using the internet as simple as point and click? What do you mean blind people can use computers? How do they see the screen or type? Text-to-speech screen readers? Refreshable Braille displays? People would get a glazed look on their faces, say "Oh, that's interesting," and then move on to the next entrepreneur to practice their own thirty-second business spiel. Forget the idea of meeting someone for coffee or lunch to discuss potential opportunities for forming strategic alliances or joint ventures! And, until we got a cable internet connection at home, my business phone line was only used for internet connection. I was terrified to answer that phone. A heavy-breathing, inaudible voice answering the phone would likely kill any potential business opportunity!

HEALING HANDS

As I began sensing the time was right to start writing this book, my left hand, my typing hand, started protesting. *I have been working since I was five, with no real appreciation. I think I'll force Glenda to stop for a while.* My fingers were tingling and going numb, and my wrist and knuckles were fairly painful. Simple things, such as picking up cans while grocery shopping, were becoming difficult. And using the computer, particularly the mouse, was causing pain.

I was scared; in fact, I was terrified. Writing, in whatever format, was my predominant means of income. If I could no longer type, how would I earn a living? I was only thirty-six and still had a career or two ahead of me. Flipping burgers, pumping gas or performing brain surgery were definitely not options for me. What was I going to do? I felt like God was playing a cruel joke on me, and I didn't know what to do.

I had been typing since age five; it was part of me. The typed word is my connection with and contribution to society. Without it I would have nothing of value to offer to society or, perhaps, nothing society would see as valuable. Without the typed word, I would be isolated from society, except for those few who understand or who take the time to learn *Glenda-ish*. Without the typed word, I have no means of expressing myself; I merely survive, with no tangible way of recording or marking my existence.

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Read more about Glenda by visiting her blog at <u>www.doitmyselfblog.com</u>

Join her on her blog for Readers' Café – a place to gather and to share – on the first and third Wednesday of each month, 4-7pm Pacific Time.

To purchase a copy of her autobiography *I'll Do It Myself*, please visit <u>http://www.doitmyselfblog.com/ill-do-it-myself-the-book/</u> Electronic (ebook), paperback and large-print versions are available.

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