

# A Life of Dignity and Worth



**SHEILA ANN DOROTHY KEOGH**

**July 24 1937 - June 3 2008**

## **INTRODUCTION**

During the year 2005 I interviewed Sheila Keogh (nee Essex) as part of a Government of Canada Centennial Flame research project that involved exploring the lives of Canadians with disabilities who have significantly contributed to public life. The following is an account of the dignity and worth of Sheila's life, as she shared it with me and allowed me the privilege of sharing her life with others.

Audrey King 2008

## Meeting Sheila

It was always a challenge getting round the corner and into his tiny office. But once there, it was worth it. He was always the same with a welcoming smile and a gesture to usher you in. He was a "REAL" doctor, an R.D. kind of DR. who cared more about "YOU", the person, than the particular body part you'd come to see him about.

*"There's someone I want you to meet", he said one day, hanging up his Dictaphone and walking round the desk to pinch my cheek.*

*"She's in the ICU right now but going home soon. The two of you have much in common. Can I give her your phone number?"*

A few weeks later, she telephones and I am amazed to hear the voice of a woman I've heard about for decades.

Her father, Reverend Roy Essex, first mentioned her during one of his visits to Ottawa. I was a teenager then.

*"You'll never guess what she's up to!" he said during one memorable visit. "Last time I got home from Ottawa there she was, sitting on the sofa, grinning like the cat that swallowed the canary - engagement ring on her finger!"*

A decade later a Toronto nurse mentioned a recently discharged patient with disabilities similar to mine. And then, a few years after that a Children's Aid social worker told me of an adoption she'd just arranged for a woman who'd had polio and her husband. Sheila again?

My attention returns to the voice on the phone.

*"Hi," she says "I'm Sheila. "I had polio in 1949 and have used a ventilator ever since. What kind of ventilator do you use? Dr. Epstein told me there's a new kind out there, something smaller that works on positive pressure and you've been looking into it. I'd love to find out more."*

I invite Sheila over.

We compare notes, experiences, opinions, ideas and chat just about everything else we can think of. And, just as Dr. Stanley Epstein R.D. predicted, we're soon the best of lifelong friends.

Audrey King  
August 2008

## SHEILA ANN DOROTHY KEOGH

July 24, 1936 - June 3, 2008

### In The Beginning

Sheila was born on July 24, 1936, the only child of a British born Toronto Baptist Minister and his wife. Her father, the Reverend Roy Essex, joined the Canadian Army at the start of World War II, leaving Sheila and her mother to manage on their own during his seven year tour of duty in Europe. Sheila was three when he left.

She was a resourceful, creative and independent child, one of the original “latchkey” kids. While her mother worked at Sears, Sheila’s job was to come home at noon, clean up from breakfast and make her own lunch. If her mum was home sick, Sheila was the cook for the two of them from a very early age.



*“I loved cooking, especially on Saturday mornings when I’d get up at seven, but not the cleaning up of course. When I was 11 or 12 I was really into crafts, making shell jewellery which I sold, and designing and sewing clothes for my dolls.. I sewed simple clothes for myself too, like maybe a skirt. I liked reading and learned to play the piano well enough to enjoy it. I loved children and babysitting. After school I looked after the two little kids next door, taking them for walks and playing with them. Not for money but because I wanted to. Their Grandma was taking care of them because their parents were in hospital with TB. I was quite an active kid really, riding a bike and swimming regularly in the public pools.”*

Sheila describes her childhood as wonderful, a period of time filled with happy memories of camp and endless summer swimming suit days with her parents and best friend Marg on the shores of Lake Simcoe.

She was also an excellent student, completing Grade 4 and 5 in one year and entering high school at the age of 13. On September 19 1949, after attending Bloor Collegiate for only two short weeks, Sheila’s life changed forever.

## Encounter with the Virus

Sheila vividly recalls the events of that weekend.

*“I went to school on Friday with a very stiff neck, not feeling very well. I remember coming home and playing the piano for hours before going up to bed. That weekend we were at Margi’s house and I just lay on the couch all morning with a fever. The doctor came and tried to put my head between my knees. I just yelped because it was so painful!*

*He told my parents he was positive I had polio and was really, really sorry but I’d have to go to Riverdale Hospital because no other hospital would take me. The ambulance came and took me into emergency where the nurse on duty happened to be a member of my dad’s first church. She’d known me as a little kid at the summer camps my parents ran for underprivileged kids. That helped a lot and made mum and dad feel a whole lot better. Then they did a spinal tap, the pain of which I remember to this day, and took me up to a room and put me on a bed. That evening I could reach for the glass beside the bed. A couple of hours later it was a struggle to reach the glass and by morning I couldn’t reach it at all. I remember that my fingers could still work the pop-up toy someone had put in my hand, but I had to crawl my fingers all the way up my chest to reach my face.*



Sheila, in 2002, posing beside the iron lung she was in during acute polio onset in September 1949

*They told mum and dad I’d be in an iron lung by the morning. During that night they came and got me and put me in the lung. I remember being so worried about mum as she was claustrophobic since being locked in a closet when she was six.*

*‘Don’t let mum see me,’ I said to dad. ‘She’ll be so upset.’*

*It must have been terrible for dad too because as a Minister, he’d spent the weekend helping families identify bodies from the S.S. Noronic, the cruise ship that caught fire in Toronto harbor. He was never able to go into the Flower Building at the CNE grounds after that.”*

Sheila did not realize she couldn’t breathe until they opened the lung for treatments or to give her a bedpan.

*“That’s when it really hit. I was gasping for air. Struggling to breathe was the most horrible thing every time the iron lung was opened or the cuirass taken off.”*

Sheila was moved to a bed a week or so later and the newest innovation in mechanical artificial respiration was applied to her chest. This rigid airtight turtle-shaped dome, called a “cuirass,” fit snugly between hips and armpits.



#### HOW THE CUIRASS WORKED

A hose connected the cuirass to an intermittent vacuum cleaner motor which intermittently sucked air from the cuirass at a set breathing rate and pressure. The vacuum thus created sucked the chest up, causing air to enter the lungs. Between breaths, gravity caused the chest to descend, and in doing so, air was exhaled

The cuirass did the same job as an iron lung but it freed the patient from total confinement in a coffin-like box and made paralyzed body and limbs more accessible for nursing care and physiotherapy.

Sheila readily accepted the cuirass for the life support it gave her, but at age 13, she was mightily embarrassed by her situation.

*“As soon as I got put in a bed and they put that stupid cuirass on me my parents would try to bring neighbors down to see me. I’d have a freaking fit because I didn’t want them to see me like that.”*

Sheila embraced the idea of physiotherapy, particularly as some movement was returning to her feet and left leg but she wasn’t so sure about the obvious pain involved. Never one to just lie back and take it, she observed the girl in the next bed who screamed in agony when her arms were stretched to the limit and then pushed yet a little further past the endurance point. Bearing the pain that comes from stretching stiff and atrophying muscles was manageable as long as you started yelling before the pain began.

In the spring of 1950 the famous Dr. William T. Mustard from the Hospital for Sick Children consulted with the Riverdale staff.

*“He looked at my legs and said to the physiotherapist, ‘This girl has been lying here for 6 months already? Why haven’t you gotten her out of bed and stood her up?’ All of a sudden I was sitting on the side of the bed and being stood up. I was so weak the world was spinning around me. After Dr. Mustard’s visit they got me up in a wheelchair every day and I gradually became able to walk with someone supporting me. If my arms hadn’t been paralyzed I would have been able to walk by myself with crutches. By that time I didn’t need the cuirass during the day. I could breath on my own when I was awake.”*

## **A Struggle for Life and Breath**

*“But getting through the nights without breathing support was a whole different story.*

*At first they took the cuirass away all night to try to force me to breathe on my own, but I couldn't sleep because I couldn't breathe and by the end of five days I'd be exhausted and delirious, drifting in and out of a toxic state. Each time I'd get a chest infection and they had to put me back in the iron lung for two weeks until I recovered. Then they'd start all over again. I was continually being told I just wasn't persevering, that I had no guts, no intestinal fortitude, that I just wasn't trying. This repeated torture, the struggle to breath, kept up over and over again until they decided on a new tactic. They'd let me have the respirator for a few hours during the night, from 3a.m. to 6 a.m. only.*

*Even then the doctor would come around at night when he thought we were sleeping and turn the pressure way down so I'd start gasping and fighting for every breath. I used to find an orderly to put sandbags on the cuirass in order to get a tighter seal and more pressure. It was pure survival, honey! The whole five years I was there I only ever got two hours sleep a night, maximum!*

*During these endless long nights of struggling to breathe, I'd have to void constantly, defying all rules of 'bedpan three times a day only'. The nurse wouldn't answer my yell for the bedpan so I solved this problem by wetting the bed. When she woke up from her nap to do her 3 a.m. rounds she would have to change my bed, of course, so I soon had her trained to respond to my call.*

*Those of us with paralyzed breathing were told we would only get well if we persevered and the reason we weren't getting better was that we didn't, and we wouldn't be acceptable in society or have a future "in our condition." Every ounce of self-confidence was continually undermined. There were so many ways they told us what they thought of us and how useless we were.*

*For example, when I got pneumonia my left lower lobe was blocked. A specialist from TGH was supposed to come and do a bronchoscopy but he never came and that lobe is blocked to this day. The doctor told my father he could give me antibiotics but they would cost \$12, so did he really want to bother? My father said 'Yes, of course I want to bother!' With each new polio outbreak all therapy stopped for us "respos" because, they said, they were wasting their time on us.*

*Another time two physiotherapists were walking me outside and I fell and hurt my knee. My knee swelled up but there was no x-ray or ice. Years later the fracture was confirmed on an X-ray. Once I nearly drowned in the physiotherapy tub when the physiotherapist left me and my head slipped off the head rest. She came back just in time to pull me out of the water and threatened me with severe stretching if I ever told anyone.*

*Many times I was put in a bathtub and left alone for half an hour or more. On one occasion a "sicko" orderly kept coming in and leering at me. When I told the nurse about it I was accused of lying. Once I complained about the bathwater being too hot.*

*The nurse responded by throwing jugs of ice cold water on my chest and laughing. The shock of the ice cold water made me extremely breathless. I will never forget that feeling. She wouldn't stop even when I was screaming.*

*When I look back on those years I realize just how cruel the everyday treatment was. Liquids were forbidden between meals and only four ounces of juice were allowed at breakfast, lunch and dinner. No water was ever offered so bladder and kidney infections were common. I'd often have a terrible pain in my back.*

*If you missed having a bowel movement one day the next day it was a soap suds enema which made you nauseated for the rest of the day. My mother smuggled in Feenamint and handed it out to others when they needed it too. I was always getting impacted and once was given four soap suds enemas in one day.*



Sheila's dog & her Uncle pay a visit

*The food was so awful mum brought food for everyone when she came to visit me every day. We hid a secret supply of cheese, peanut butter, crackers and jam outside the window. The nurse found it once and there was hell to pay.*

*After a while I could use my legs well enough to push the chair with my legs and I used to go wandering out in the park beside the hospital.*

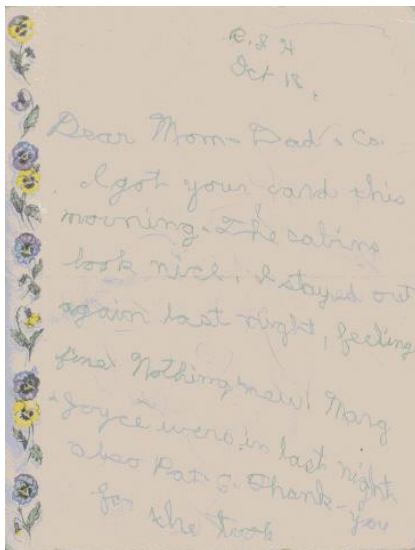
*The neighbours complained about us lepers, about the 'polio's' being allowed out, so we were banned after that.*

*I remember that some ladies started a Polio Patient's Comfort Club. They raised funds to buy us a TV and furnish two sitting rooms, one for the men and one for the women. I was always being punished by not being allowed to go out of my room because I liked to play Cribbage and only the men played it. Eventually no one used these rooms at all because the rules were so strict. Nobody could get out of their wheelchairs so I can't imagine what hanky panky they were afraid of!"*

"What did you do to keep up your education during those Riverdale years?" I ask Sheila.

*"At first I had a teacher who came from the Toronto school board. He was good but when my parents moved to Etobicoke, that was cut off. Then a retired principal volunteered to come and tutor me. He was like Mr. Chips, riding his bike to Riverdale with his scarf flying in the wind. After a while I was getting ticked off and bored with him so I would pretend I was sleeping and he stopped coming.*





Sheila learns to write again

*The problem was, he taught me Algebra and conversational French and I wasn't at all interested in those subjects.*

*Finally my mother signed me up with Ministry of Education correspondence courses and that's how I worked my way through the rest of high school.*

*I took English, medieval history and geography but I hated algebra & geometry so I didn't take them. I got some credits at the Grade 11 and Grade 12 levels but my education is all over the map and I don't really know what Grade I got in the end. Let's just say, I'm not your regular high school graduate!"*

Sheila's parents were able to visit often. They played an essential role in advocating for Sheila as well as relieving the boredom and suffering of institutional life. They took Sheila to movies, to picnics and shopping with her friends. But, as she struggled to breathe night after night, year after year, Sheila became increasingly convinced that she would die unless her father got her out of Riverdale before her eighteenth birthday.

*"My faith in the medical profession deteriorated. I saw my friends dying all around me as a result of not being allowed to use their ventilators - even though they probably still had weakness in breathing. My friend Shirley was 14 when she got polio, a month before I did. By October she was being "punished" because, they said, she was bad because she was just not trying to stay out of the iron lung all night. They said she was a "baby" and moved her to a room all by herself at the end of the hall, the farthest room away from the nurse's station. Her parents were not allowed to see her and neither was anyone else. She wasn't given any ventilation support at all - it was the "cold turkey" method. One week later she "mysteriously" died.*

*With all this going on around me I became very cynical and frightened and angry. I knew they didn't care if I lived or died and would actually probably prefer that I die because my life was only going to be a burden to society. Around that time I read a magazine article by Helen Hayes about her daughter Mary who got polio. She said no one with polio lived more than 3 or 4 years so I became even more convinced I would die too unless I got out of Riverdale before my five years were up. If the doctors and nurses figured I would soon die anyway and believed I would never amount to anything, what was the point of staying there any longer?"*

## **Breaking Free**

Sheila left the hospital in July 1954 just before her 18<sup>th</sup> birthday. Her father signed her out against medical advice, waiving the Hospital of all responsibility and accepting the fact that Sheila and her parents could never expect any help from them in the future.

Today, February 2005, I'm interviewing Sheila in her warm, accessible and welcoming Etobicoke home, the home she returned to in 1954. Now, over fifty years later, there is an elevator at the side door and a sloping bricked ramp amidst attractive front yard landscaping. She meets me at the front door and asks my opinion of the newly painted deep salmon walls and renovated fireplace. She escorts me through to the family room that overlooks the snow-covered back deck and garden. On a cold day like this it's especially "warm" in the family room that doubles as Sheila's well-equipped, computerized office. A ceramic heater with knobs that Sheila can operate with her foot sits under the desk, blasting out extremes of heat that only those with limited mobility can appreciate!

We finish yet another Scrabble game before Brian heads to the kitchen to get lunch. Sheila and I continue socializing, both of us in our power wheelchairs, catching up on the news and comparing notes. Sheila suddenly drops her ventilator mouthpiece and purposely scoots out to the kitchen, her ventilator alarming at the sudden drop in pressure. She's forgotten the dessert in the freezer. Message delivered, she quickly returns, leaning over to scoop up the ventilator circuit as I ask yet another question.

"What was it like coming home after five years of hospitalization?" I ask.

*"It was the most horrible experience," she recalls with emotion.*

*"Talk about hospitalitis!" I was totally unprepared for the emotional adjustment that followed. I thought it would be wonderful but when I got home I cried for three days non-stop. My poor parents thought I'd be very, very happy but instead I was just devastated. All along I had said I wasn't coming home until I could do everything for myself, but now it hit me that I was home and I was a freak and I had no friends. During those five years at Riverdale, little by little my girlfriends had stopped coming because their parents didn't want them visiting an isolation hospital, and now that I was home my friends that I'd made at the hospital were gone too.*

*And then, practically as soon as I got home, a photographer and newspaper reporter were there from the March of Dimes. They printed the most embarrassing article.*

*As a pretty fragile 18 year old you can just imagine how publicly humiliated I felt. They put in all kinds of dramatic stuff like, 'she can never be left alone'. I felt like a frigging idiot and I just got so mad.*

*You're trying your best to get used to making a life with 'normal' people again and they do this and it puts you right back down in the ground again.*

*That was so horrible. It takes away what little self-esteem you have and blows it right out the door. I don't know why they didn't realize that.*

*I'm afraid I really took it out on my parents for a while, especially my mother. Nothing pleased me. I was bratty, stubborn, and rebellious about any little thing at all. I was angry at the whole world. I was a real witch. I was very grateful to get out of Riverdale and still be alive, though.*

*One of the first things I did when I got home was start using the Huxley ventilator the West Kiwanis club bought for me, all night long. For the first time in five years I got a full night's sleep. It was amazing how quickly I became a different person. I stopped getting colds all the time and my health and energy improved dramatically. That was wonderful.*

*Riverdale Hospital stuck to their guns about not helping. I'd been home for a few months when the ventilator wouldn't work one night. Dad had to phone the Huxley company in the States for help. It was a broken belt and luckily he was able to fix it. He realized he needed to learn more if he was going to keep it going so he went to their production plant in Colorado for a week. When he came back he started fixing other people's ventilators – Janet Halliday's, Jean Ballantyne's, Eric Hook's in Richmond Hill and so on. Soon he was volunteering with the March of Dimes and was sent all over Ontario to fix people's respirators – that's they were called then. The Dimes paid his way and the cost of parts. They eventually created the Roy Essex Award for volunteerism which dad presented every year at the March of Dimes Annual meeting up until his death."*



Toronto Telegram and Toronto Star articles about the work of Rev. Roy Essex, circa 1970's



“That’s how I met your father,” I remind Sheila. “He came to Ottawa to do maintenance on my ventilator. I clearly remember him telling me about you sitting on the couch looking like the cat that swallowed the canary!”

“Yes, Sheila says, “that was one of his favorite expressions,”

“When you got used to being home again, what did you do? You’re just not the kind of person to sit around and do nothing.”

*“I started taking courses - secretarial, correspondence, that sort of thing. Anything mum and dad suggested or wanted me to do I refused, of course. I’d have no part of that!”*

*Gradually, I started getting involved with people my age at the church. Dad was the Indian Rd Baptist church Minister and some of the young people there would ask me to go to things and come and take me with them. My friend's mother was the Sunday school superintendent and she got me involved with a fellow, the chap who later on built our cupboards here. The two of us worked in the church office. He did the money while I did the attendance and organized the teachers, the curriculum and the programs. You know me, I have to organize somebody!*

*I was going for therapy too. When I first left Riverdale, I was allowed to return three times a week for outpatient physiotherapy. Gradually that dwindled down to once a week. I wasn't really making any progress though. I'd always wanted to go to a rehabilitation hospital like Lyndhurst. Other people who got polio were transferred there when they got over the acute illness stage but they wouldn't take me because of the ventilator. My thoughts about going there never went away so after two years or so at home I got up my courage and made an appointment to see Dr. Jousse."*

### **A New Lease on Life**

*"I'll never ever forget my first visit with Dr. Jousse. I'll never forget what he said when I started to tell him all the things I couldn't do. He stopped me cold and quietly said 'We won't worry about what you can't do but what you can and might be able to do.' I will never forget those words. He opened a whole new door and gave me a whole new way of looking at myself. My whole attitude about myself changed completely. His belief in me, as well as the fact I now could breathe and sleep without gasping for air was really the beginning of the rest of my life.*

*I suppose I didn't have to, but I did go back to tell the head doctor at Riverdale why I wouldn't be returning. He said to me; 'You are very ungrateful after all we've done for you. We did much more than we had to. Lyndhurst will not be able to do anything more and you are just wasting everyone's time.' I thanked him and quietly said I had to try. I never saw him again.*

*My life opened up at Lyndhurst. The attitude of everybody, the doctors, the staff and the patients was so different, so positive, that it turned my life completely around. I saw people worse off than me making lives for themselves, going places, doing things. When you've been continually told for five straight years that you're no good, you're nothing and then all of a sudden you are treated like a person who matters, it made the world of difference.*

*I got much stronger, tremendously stronger. Just everything about me got stronger. Soon I was walking the length of the hall on my own with the physiotherapist just supporting me with one finger on my hip. I wasn't out of breath at all. It was quite amazing how well I did. I met people and I made friends. The March of Dimes paid for several of us to go back and forth by taxi. As I got more confident I started branching out and doing things on my own. I went to other patient's houses to visit. I'd get the taxi to drop me off down town and I'd come home with a new hair cut. Mum would have a fit of course, but I did it anyway."*

“You were making a life of your own!”

“*Exactly!!!*”

### **Romancing Brian**

Pictures from Sheila’s Lyndhurst days reveal an attractive, vivacious, dark haired beauty. It’s completely impossible to believe Sheila would not have been noticed by the opposite sex. Sheila was choosy, mind you; fiercely independent and quite clear about exactly the kind of young man she was looking for.

*“There were a couple guys I sort of liked at Lyndhurst”, she says, “but I wasn’t going to have anything to do with them because they couldn’t walk. They always laughed because I said if I’m going to get involved with a guy he’d have to have good arms & good legs.*



*I met Brian through the church. He would pick me up at Lyndhurst once a week or a couple times a week after he got off work and we’d go out together for supper or a movie before I went home.*

*We had to do it that way because if I went to a movie from home my father would feel he had to come with us.*

*I still had problems with coddling parents at home. They thought I shouldn’t go out on my own or even be left alone at home by myself! We had a lot of fights about that!*

*I’ve always had this thing about wanting to be left on my own. I can’t stand people around me, even now. The only way I could get my parents to leave and go out to their meeting or whatever, would be if I said Brian was coming soon. I just wanted them to go.*

*I didn’t need a babysitter. One time they came back before Brian arrived and there was all heck to pay. I was still getting royally told off when Brian arrived. My father said to him; ‘you are not allowed to see Sheila, she’s being punished.’ Brian said; ‘I’m going to see her’ and he just walked right through. After that, dad used to say, ‘Brian went down in my estimation from that moment on. He disobeyed me.’*

*When Brian and I decided to get married Dad wasn’t too pleased of course. I’m convinced he and mum thought I was in for a rude awakening and a very unhappy life.*

*They probably thought Brian would walk out on me and I'd end up with a broken heart.*

*Finally, my friend Marg told them to leave me alone. 'So, she'll get 20 years of happiness,' she said. 'What more can you ask?' Some of Brian's relatives didn't approve either. They tried to talk him out of marrying a cripple.*

*Some wouldn't come to the wedding but here we are, still happily married some 47 years later! That's some kind of a record even for able-bodied people!*



Sheila and Brian married in 1959

Brian and Sheila considered buying a duplex with Sheila's parents and even side-by-side houses in the neighborhood. Ultimately, limited finances and Sheila's need for nearby assistance during Brian's working hours led to both families remaining together in the home of Sheila's parents with an accessible addition and elevator eventually being added.

Two couples sharing the same household wasn't always easy.

*"Mum tried hard to let us live our separate lives," Sheila explains, "but dad still wanted to have his little girl. It wasn't easy, really it wasn't. Quite honestly, any other guy would have left but Brian had the patience of Job, especially in the later years of dad's life when he was elderly and needed looking after. But, by 1961 we were able to put a down payment on a cottage up north and were able to have the weekends apart. As mum always said, 'it's good for you and it's good for us.'"*

### **Working Woman**

Sheila shows me how she has set up her accessible office at the end of the family room. She uses a big red track ball instead of the traditional computer mouse and a thin electronic pencil balanced between her fingers to enter data on a tiny 4"x 6" Magic Wand keyboard.

Sheila babysat and sold her own crafts long before she became disabled. Even as a patient at Riverdale Hospital she sold Regal cards and gifts. As soon as she settled in back home she scanned the newspapers for jobs she could do from home. Her drive for independence has always been fierce.

*“I worked for a bridal photographer for \$1.00 an hour,” she tells me, “and then for a real estate agent who was a crook, for about a year. I’d write envelopes, make phone calls, anything at all I could do from home. I organized volunteer drivers for the Cancer Society for 15 years and I also got some part time jobs through the rehabilitation counselor at Lyndhurst. Mum had been a secretary before she got married so she helped me with filing, paper shuffling, typing and that sort of thing. She was my arms, so to speak. By earning my own money I was soon able to buy my own clothes and my own furniture. That was really important to me. I was a real “bugger” you might say, because I wouldn’t let anyone pay for anything. Looking back on it now, I guess it was my one way I could be independent.”*

Sheila laughs at one particular memory.

*“I’ll never forget one job I got through Lyndhurst. I spent a whole day counting rubber bands and it literally drove me round the bend. Can you believe it! I was so depressed and so upset I was in tears! I remember thinking there’s no way I’m going to spend the rest of my life counting rubber bands!”*

### **A Bundle of Joy**

*“It was around that time that the Lyndhurst counselor asked Brian and I if we’d ever thought about adopting a child. We’d been married eight years by then. I did love children and I always read Today’s Child in the Toronto Star. I had sort of thought I could probably manage an older child but didn’t think we’d ever have a chance of qualifying so didn’t investigate. He suggested we talk to Marilyn Noell, a quadriplegic Children’s Aid Society social worker. Marilyn said a baby would be better because he’d grow up getting used to us and would have less emotional baggage. She got me thinking more seriously about it and got us started.*

*I contacted the local CAS and they hooked us up with a social worker who came and delved into everything. They had to get references and interview mum and dad as well. When the social worker started off negatively because I had a disability I got my back up and said ‘If Roosevelt can be the President of the United States of America, I think I can be a mother!’*

*Brian and I really didn’t think it was going anywhere but we did get approved. In fact, everything happened so fast it was quite a shock. We got the approval on a Friday, and then on the Monday we got a phone call to come and look at a 4 month old baby. When we went to see him they told us we could take him home the very next day!*

*We were all tickled pink, especially my parents who’d been positive and excited right from the beginning. None of us were at all ready and we only had 24 hours to get everything together! Brian and dad went to get a crib and mum rushed off to get some baby clothes from the Bay. It was quite a commotion, especially as we were in the middle of renovating our kitchen at the same time! All of us could hardly believe it.”*

“How did you manage?” I ask Sheila. “Being a mother on wheels is one thing but not holding and handling a baby is another.”

*“It all fell into place amazingly quickly and quite naturally. Brian was working down town so he’d get me up at six before he went to work. Dad went in to change the baby and bring him out. I did the feeding. In those days I was able to bend my left arm up a little, just enough to lean over a dish and feed him. I couldn’t do that now. I couldn’t actually hold a bottle but I could get my thumb in the plastic part of a Playtex bottle and secure it that way. Brian’s job was to make the formula and mum dressed Danny. Even the kids next door got in on the act right from the beginning.*

*The day we brought him home Sue and her sister Karen came over with a big poster for his bedroom door which said ‘DANNY’S SECOND MUMMIES’. Without me even suggesting it they came in every day after school to play with him or take him out for walks in his carriage. It was just wonderful. They were a tremendous help. They’d put him in his stroller and off we’d go round the neighborhood, one pushing him and the other pushing me.*



*I’d secure him on my lap with one of those baby harnesses everybody rejects as ‘terrible’ these days. It was fastened to my chair so there was no danger of him falling. I had no power chair then but I could push the chair with my feet for short distances.*

*We were quite a sight with Danny on my lap, the dog on one side and Brian and the girls on the other.*

*We had wonderful neighbors at the Canal Lake cottage too. Their three daughters played with him all day long, especially Dale, the middle one, who was his constant shadow.*

*We’d dress him in his life jacket from the time he got up in the morning to bedtime so that gave us an added measure of security.”*

## **Raising Danny**

“It takes a village to raise a child,” I comment. “It sounds like that’s what happened. The people around you just naturally helped raise Danny during those early years.



You said you used a particular nursing bottle, a Playtex, because you were able to hold it and also a safety harness. Did you have any other adapted equipment?"

*"I didn't have a crib where the side lifts up like some mothers in wheelchairs do so they can slide under and change and lift the baby from the crib. There was no point because I couldn't lift or change Danny. When he was tiny I used to carry him around in a baby seat that sat on my lap. When he got old enough to pick things up he shouldn't have my great aunt made me a huge double apron with a big deep pocket. I would say 'Danny, let me see it' and he'd put whatever it was on my lap. If it was something he shouldn't have, I'd slide it into the pocket. It was a brilliant idea because the pockets were so deep you could never find what you'd slip into them. It was the best thing I ever had."*

"Did people have doubts about your ability to raise a child?"

*"Oh yes! Nobody ever actually said these things directly to my face but I heard that people thought I couldn't raise a child because I couldn't spank him. Come to think of it, when Danny was in Grade 6 and didn't want to go to school one day because he'd been threatened with a knife, his principal did say what he thought directly to my face. He said, 'Well you can't really expect much from Danny because he's adopted and you are in a wheelchair. He is obviously spoiled and doesn't have to do a thing.'"*

"What did you say?"

Sheila pauses, clenching the mouth pipe between her teeth as she takes another breath.

*"I absolutely blew my stack. I went berserk! I said, 'This child does more than most children. Your opinion is pure prejudice and absolutely disgusting!' I was so mad and so upset. Brian and I stormed out of his office. As soon as I got home I called friends who had sons going to St. George's, a private Anglican boys school. Danny started Grade 7 at St. George's and it was the best thing we ever did."*

"What about disciplining Danny? How did you manage that?"

*"Well to begin with, Danny was a contented baby and a good eater. He was a very active kid, mind you, who never napped after age fifteen months. He'd fall asleep on the floor, we'd pick him up and put him in his crib and he'd sleep right through till morning. He was strong willed though, but I was an even stronger willed mother!"*

*As Danny got into the early childhood stage, if he did something wrong I would chase him down the hall to his bedroom, pushing my chair with my feet. Before long, I'd just have to say 'go down the hall to your bedroom' and he went without any protest. Then it got to the point where I'd just give him the 'look' and he'd say to me, 'I'm going, I'm going' and off he'd run to his bedroom until I told him he could come out!*

*When Danny was four he was being a little bugger one day. I can't remember what he was doing but he wouldn't listen to me, so I caught him up with the back of my chair and trapped him between my wheelchair handles and the door. He couldn't get out because I was holding the chair against the wall with my foot as hard as I could. He wasn't hurt at all but he was yelling his head off 'I'm going to tell daddy! I'm going to tell daddy!'"*

“Were there any conflicts between you and Brian and your parents in how to raise or discipline Danny?”

*“Oh sure,” Sheila says. “There are in every home. Brian and I didn’t always agree about child rearing but we worked it out. Danny was always more obedient to us because mum and dad would let him away with things. My father, especially, would let him do anything. I used to get so mad!*

*My mother used to say, ‘I had you trained when you were one year old! He’s going to be going to kindergarten in diapers!’ and I would answer, ‘Mum you didn’t have me trained, you had yourself trained. No kid has ever gone to kindergarten in diapers!’*

*Danny kind of trained himself with only a little help from me. When he was about two, my parents went away and I had a girl in to help. Danny didn’t like her at all and didn’t want her to help him with anything. Disposable diapers were just on the market so I showed Danny how to get the diaper off by himself and sent him in the bathroom to get some toilet paper. I got him to lean over in front of me close enough so I could wipe his bum. Then he would take the toilet paper back to the toilet and flush it away. He was trained overnight!*

*When Danny was old enough the three of us would sit around the table and talk about any problem Danny had got himself into. We’d say to him, ‘What do you think we can do about this?’ We threw it back in Danny’s lap. He remembers that to this day.*

*Danny understood and followed directions well from an early age. He learned how to climb up on my lap before he could talk. He brought me things I couldn’t reach myself and started getting things from the fridge as soon as he could open the door himself. That’s why that school principal made me so mad! Danny was an independent self reliant kid who wanted to do things by himself and wanted to help others too.*

*Because he was so active we got him involved in lots of activities - ORF music, sports, taking him and his friends to MacDonalD’s and so on. Brian taught him how to golf and they loved doing that together. When he was 8 or so he was naturally becoming more independent and spent a lot of time with his two buddies. I strongly believed in letting the ropes go as much as you possible, so I always said to him ‘I don’t care what’s going on but you must phone and let me know where you are, regardless.’ Mind you, when Danny was a teenager I could have killed him many times over!”*

Sheila laughs as she recalls another "mothering Danny" episodes.

*“I remember one day I was pushing myself with my feet as usual, out onto the deck. I got stuck on the doorsill and I asked Danny to put his foot on the back and ‘do what daddy does.’ He was about three and didn’t quite have the idea of how to do it. He put his foot in the right spot, yanked the chair a little too vigorously and we all went flipping over backwards. Danny was caught underneath. I was so scared he was hurt, yet I knew the handles at the back of the chair made enough space to keep the chair off the floor and off of him. But Danny was trapped in that space and screaming his head off. Nobody was*

*around, of course, but I was expecting the plumber soon. He came to the front door and called in "Mrs. Keogh, Mrs. Keogh, I'm here. Where are you?"*

*Danny started yelling at the top of his lungs, 'Get daddy, get daddy' and I'm trying to out yell him with 'I'm at the back of the house. Come to the back of the house!'" When the plumber did come around I just said to him, 'don't look, don't ask, just pick me up!'*

One of my favorite "Raising Danny" tales is the tale of the "Toilet Show & Tell."

Sheila was sitting on the toilet one day when she noticed a tissue on the floor beside her feet. She leaned forward to dangle her "good" hand over the paper, intending to pick it up. She lost her balance and fell ass over tea kettle face down into the bathtub. Danny, who was 6 or 7 at the time, heard her cries for help and was first on the scene. One look at his mum's devoutly positioned nether end was enough to send him scurrying for cover under the nearest bed. Next on the scene were Brian and her dad, who pulled her up and positioned her back on her throne of equanimity, none the worse for wear. All was well the incident was forgotten until a week later when Sheila attended a teacher-parent night at Danny's school. "Are you alright Mrs. Keogh?" Danny's Grade One teacher asked with an anxious look on her face. "Are you sure you are okay? Danny told us what happened at last week's Show and Tell!"

Sheila glances proudly at Danny's photos, at the many awards on the wall and the golf trophies on the mantelpiece.

*"I think my son's done rather well," she says. "When I see what other kids do these days and the trouble they get into, I think we got off very easy."*

Sheila and Brian have every reason to be proud. Danny, after graduating on a golf scholarship from Florida University, was a Canadian Pro-golfer for several years with his contemporary and friend, Mike Weir, and then moved on to propose, initiate and become CEO of Mike Weir Accessories.

### **Taking Care of Business**

Danny began nursery school when he was three at Sheila and Brian's church, Islington United. It was a parent volunteer cooperative. Before long Sheila was appointed registrar and then the Chairperson of the nursery school's board of Directors. Eight years previous experience in running children's programs and being the Sunday school superintendent just could not be ignored.

At age thirty-nine, Sheila started taking a night school course in Day Care Administration at Humber College. Brian drove her back and forth to the campus; Sheila memorized the lectures and scribbled notes as best she could. Her mother provided typing assistance on the assignments required.

*"In the end I passed with an A+" Sheila brags. "Not bad for an old doll in a class of young kids eh? I learned a lot in that one year."*

Eventually, problems with the nursery school/day care supervisor arose, causing frequent staff turnover and loss of children. The staff decided to start up their own nursery school in the empty basement of Indian Road Baptist church, where Sheila's dad was Minister. Everyone got involved in the renovations, even seven year old Danny helped to paint the walls. In October 1977 the nursery school opened with five children and one teacher. Lucy, who lived beside the church, was the cook, Sheila was the administrator, and Sheila's mum the seamstress and food preparer who also sewed the sheets and cooked freezer meals for the children.

*“Brian would take me there, dump me, go to his downtown job and do all the grocery shopping, maintenance and cleaning in between. He was a trust officer in the bank by then. How I lasted all day without peeing, I don't know, but in those days we could do that, right? It was a real Ma and Pa operation that we had going, that's what it was.*

*After a while we decided to see if we could make a go of it without Brian's salary. We banked all his earnings for 6 months. It was touch and go for a while, I'm not kidding, but we got approved by the Ministry of Community and Social Services for a subsidy contract and by February we had 10 kids coming. We hired more staff and as money started coming in we gradually bought more toys, another cot and so on. It was all very gradual.*

*In 1984 or 1985, the Etobicoke School board asked us to set up programs in their empty classrooms at Park Lawn and Etienne Brule Public schools. So we closed the program in the church basement - that space only permitted 30 children anyway. It was a good thing we did because the next year dad was killed in an auto accident and the church was sold. We invested some of my inheritance in a Stouffville nursery school, but that ended up being too far to drive back and forth or keep a proper eye on, so we sold it after 11 years. It just got to be too much for us to manage.”*

## **Supporting Sheila**

Brian has obviously been the main physical “arms and legs” behind the day care operations and Sheila the key administrative element. Many others supported Sheila's daily physical support needs along the way, thus enabling her to accomplish and achieve so much.

*“It was my parents and family friends when I first came home,” Sheila explains, “then Brian came into the picture. When Danny was old enough he was a wonderful helper too but I drew the line at ever letting him help with any intimate personal care.*

*We went through a real crisis in 1977 because Brian had a hernia operation and a gall bladder operation which got infected. They sent him home with an open wound right down to the rib cage. He was off work for three months. I tried to get home care but they wouldn't give it to me because I had no ‘medical’ needs. My neighbors, friends and parents, who were very elderly with major medical problems of their own by then, had to help out.*

*Another time Brian got a bad attack of arthritis and was in bed for three months. Mum had died by then. We contacted the Red Cross, trying to get some Home Care again but they said 'NO" once again. They said I didn't need nursing care and 'you have a fifteen year old son who can easily dress and undress you and take you to the toilet!'*

*It was just awful trying to manage. Dan was 15 years old, I had Brian in bed sick and I was also trying to cope with dad and all his problems. Maria, our cleaning lady at the time, was an absolute Godsend as well as our friends and neighbors who would come in to get me in and out of bed.*

*After mum and dad died Brian became my only caregiver. Then Brian had to go in for a second hernia operation. I definitely would have been up the creek without a paddle again except some Attendant Outreach programs had started in Toronto and I had a friend who was on the board of one of them. Because their program wasn't yet full to capacity and this was a crisis, Bathurst St. Charles gave me one hour of help a day to get me up in the morning. My other friends and neighbors filled in the rest until Brian got well enough to help me again.*

*Bathurst St. Charles kept me on as a client and eventually was able to give me more hours of help. Then they cut me back to three days a week and then up again to five days a week with two hours of help coming per day. Their help was indispensable! Some spouses have a fit if you have help coming in or taking over what they see as their job but Brian never batted an eye!"*

*"Are you still receiving Outreach Attendant services?"*

*"Oh No!," Sheila says. "I heard about Direct Funding, a program where the Province of Ontario gives money directly to you to find, hire, train and direct your own attendants, and I applied for it.*



*Direct Funding is the greatest, the best support program yet. You can decide when you get up and go to bed and all that jazz. It's absolutely the best thing since sliced bread!*

*Before I was always worrying about what would happen if something happened to Brian because, after mum and dad died, I'd been totally dependent on him.*

*Direct Funding has made it easier to gradually relieve Brian of my day to day support needs. It means he can get up and go and do his OWN thing. I think that's fair after all these years, don't you?*

*He can go off and do his volunteer works, golf, go out with his friends or whatever he wants. It means he can have a life and not be totally tied to my care.*

*Brian absolutely loves the program too. He was never threatened at all. If you thought for one minute he'd have his nose out of joint, I've got news for you! No way!*

*But, Direct Funding is not for everyone. It wouldn't work for people who are totally unable to stand up for themselves or people unable to do a payroll or deal with people. It wouldn't suit the helpless, dependent sort of person. That's what I'm trying to say."*

## **Sheila Here and Now**

Today, Sheila and I relax on the deck of their log style cottage just north of Burlington on the Niagara escarpment. It's a gorgeous summer day, with a fresh scented breeze from the tall pines surrounding us and the babble of Sixteen Mile Creek as it flows past their lawn on its way to Lowville and Lake Ontario. It is so peaceful here, so restorative - a perfect place to pass the days and find your soul again.



The white chinked log cottage is welcoming, folksy and charming. Brian's love of gardening is evident and Sheila's interests in décor and design are everywhere. Martha Stewart Living, Better Homes & Gardens, Ontario Motorist and CARP magazines lie scattered around the cottage, as do photo albums of the many motor trips they have taken over the years.

Sheila tells me a tale from their previous cottage at Canal Lake that involved a frantic rush to shore and her dramatic rescue from their sinking boat when a leak was discovered in the middle of Canal Lake. That cottage was sold soon after, in favour of this one which is only 30 minutes from home.

## Bit by the Travel Bug

*“When I was a child,” Sheila tells me, “my family always went on road trip vacations to the Maritimes and Eastern USA, so when Brian and I got engaged we returned to that area. Our honeymoon was a motor trip and after that we always took a motor trip every year. I could still stand at that time so Brian would put me in the passenger seat, fold up the manual wheelchair and toss it in the back along with my cuirass, the Huxley (ventilator) and the luggage.*

*We bought time share vacations when we sold the Canal Lake cottage. There were so many places we could go together as a family - Michigan, Florida, New Hampshire, Myrtle Beach, South Carolina.*

*We’ve also taken three cruises with friends over the years. Cruises are great for wheelchair users because you don’t have to pack up and move to a new motel every day.*

*We flew the Concorde to England in 1991 to see Brian’s sister and other relatives. We rented an accessible car and borrowed the same kind of ventilator from Dr. Spencer at St. Thomas’s Hospital in London.”*



“It can’t be easy to travel with all the equipment you need to take,” I comment.

*“Well, over the years it’s been a breeze really, when traveling by car. But now I can’t stand so I have to take a travel Hoyer lift, which isn’t a problem except for the fact that all the motels and hotels today have boxed up their beds so the legs of the lift can’t go underneath – which means you can’t use the lift at all.”*

“What about airlines and cruises?”

*“Over the years I’ve had my battles with taking the vent but I’ve always won with verbal argument and a letter from my doctor. I’m not so sure I’d win today though. If they hear the word “ventilator” they freak out, BIG time! They think people with ventilators live in ICUs and shouldn’t be traveling, especially not on their ship or airplane! On my last cruise I finally learned what to do. I just didn’t mention it. I just dragged it on board with me and there was no problem at all. What they don’t know won’t hurt them, right?”*

I remind Sheila of the marvelous vacation we took together several years ago at Bay Point Resort near Panama City Beach, Florida. Sheila and Brian took us to their favorite places, filled us with good food and local lore, not to mention tales of their hair-raising hurricane experience on their way home from that trip - which kept them trapped on the

Highway for six hours in Kentucky. Thank goodness for the cigarette lighter ventilator outlet in Sheila's van which kept her ventilator running!



Sheila and friend Audrey on the accessible ramp to the beach at Seaside, near Panama City Beach, Florida, USA

*“Bay Point Resort at Panama City, Florida, has been a favorite vacation spot for many winters, but during the last few years, the inclination to pack up and go has pulled less strongly”.*



Sheila explains:

*“During the last few years I’ve sent Brian off on trips without me to places he’s always wanted to see, such as Western Canada and Banff or Cape Breton Island. Traveling on organized coach trips makes it really easy for him. This year he went back to England to spend time with his sister and go to Scotland with them, a place he’s always wanted to see. I do all the organizing and he can just pick up and go and not worry about a thing.*

*That’s the beauty of Direct Funding, you know. It gives me the flexibility that you get with a normal life which allows Brian to go off for a well deserved break. Neither one of us worries about a thing because I can organize my attendants to stay back here and I can do my own thing without Brian. That’s when I get things done, you know, like going through the basement and garage and throwing things out. It’s my big chance to purge the house of stuff we haven’t used in years. Don’t you ever tell him that, though!”*

“What’s that dear?” Brian absent mindedly mumbles as he comes around the corner and enters the cottage, a case full of coke in his arms.



*“I find that I don’t want to be bothered anymore with all the hassles and effort of a big trip. “You can’t eat like you want and we miss our comforts, like our own self adjustable beds! Brian is seventy now and has arthritis and some back problems. I can no longer stand to transfer and traveling with a power and manual wheelchair, mechanical lift and ventilator is a lot more work than it used to be, although we do have an accessible van and in the last couple of years we hired someone to help with driving and luggage.”*

*Honestly, I’m much more content now to spend weekends and holidays right here. Brian can putter around, do his own thing and golf everyday right here with his buddies. We rent movies, go for walks, have friends up and entertain them here on the deck. We enjoy doing that. Also, the cottage is close to St. Jacobs, Niagara, the Stratford Festival and lots of other interesting day trip places. When we want to go somewhere I just get in the van, plug my ventilator into the cigarette lighter outlet and breathe away to my heart’s content as we drive throughout rural Ontario.*

*To make it perfect though, what I’d absolutely love to have is a tiny quiet ventilator that hides under my chair and runs off my wheelchair battery. That way, I’d have it with me all the time and when we go to the theatre I wouldn’t have to keep coming out during intermissions for a shot of air.”*

*“You know what?” Sheila suddenly says. “I’ve been very, very lucky. Really and truly, compared to many people with severe disabilities. I’ve had far more opportunities in life than many able-bodied people. I admit that and I feel very privileged and grateful.”*

### **Contributing Factors**

“Luck’ is one thing” I say to Sheila, “but obviously there are many other factors that have contributed to who and what you are today.”

“That’s for sure.” Sheila responds without hesitation.

### **Marriage and Friendship**



*“I’ve been lucky enough to have a wonderful husband and a good marriage. That’s been very, very important.*

*I had parents who wanted me to have a normal life regardless, and did everything they could to make it happen.*

*My friend Margaret, who is really more like a sister to me, always stayed by me and when I first came home from Riverdale the Young People’s group at church got me involved. That was very important because they always accepted me as one of them.”*

## Hope and Belief

*“It’s so very critical what health care people with power and authority think of you, especially in the beginning when you are so scared and helpless and look to them for hope and advice. I wouldn’t be where I am today without the philosophy of Dr. Jousse and his therapists. They definitely turned me around. Riverdale had continually put me down so by the time I got home I felt totally hopeless and worthless. Dr. Jousse’s words, ‘We’re not going to worry about what you can’t do, we’re going to worry about what you can and might be able to do’ got me thinking in a whole different way. Once I became a daily outpatient at Lyndhurst I met lots of positive people and made good friends and then I met Brian and began to think maybe I wasn’t such blight on society after all.”*

## Peer Support

*“I didn’t learn a thing about life with a disability from medical people. I learned from other disabled people, especially patients at Lyndhurst like George, and later on from friends like you. I always kept in touch with friends from Riverdale and we learned from each other over the years. Unfortunately my Riverdale friends have gradually all gone.”*

## Technology -Ventilators

*“Technology has been important over the years as well. To begin with, I wouldn’t even be here if the iron lung hadn’t been invented when I got polio. The cuirass made it possible for me to be in a bed where I could have physiotherapy. Come to think of it, without the cuirass I wouldn’t have been able to come home in 1954.*

*My switch to positive pressure started when I used it in the hospital when I had pneumonia. Dr. Epstein was my doctor there and that was when he introduced me to you. Our best man gave me the money to buy a positive pressure unit to use during the day and the RT at Toronto Western ordered it for us. It really, really helped a lot.*

*Then I switched from the cuirass to positive pressure at night like you did, and got an LP3 unit paid for by Vocational Rehabilitation, a government program that helped people maintain employment. Eventually my insurance company paid for the much more reliable PLV100 and I’ve used it ever since. My health has improved 1000% since I started using positive pressure, especially during the day, rather than struggling to breathe all day long like I was. The cuirass was no longer giving me proper ventilation so the PLV100 came along just in time.*

*The smaller size of positive pressure has made it so much easier to travel. These days I find myself hoping that a simple small quiet ventilator will come along, one that I can tuck away inconspicuously under my wheelchair and use all the time wherever I might be, by running it off the wheelchair batteries or plugging it into the van outlet.”*

“What about your wheelchair? Has that made a difference?”

## Technology - Wheelchairs and a Van

*“Getting a power chair was wonderful,” It was like getting back my legs after all those years. I didn’t have to wait for somebody to push me anymore. Yes, I could always push myself a little with my legs but I couldn’t go any distance. With the power chair I could just take off, go round the block by myself, go to Cloverdale Mall and disappear so no one could find me. I was like a little kid with new found freedom! A couple of times Brian had to send Danny to find me. It was fantastic!”*

Sheila chuckles as she remembers the early days.

*“One night soon after I got the chair I decided to go out and around the block on my own, even though it was pitch black outside. I hadn’t said I was going because this freedom and independence was my new thing. Brian had the sprinkler on, the kind that alternates one way and then the other every few seconds and, of course, my timing was off. My chair got caught in the spray and stalled. By the time Brian noticed I was gone and began to look for me I was absolutely soaked. I was stuck - getting sprayed again, and again and again. There were a few more adventures like that before I settled down!!*



*The power chair just gave me such a feeling of freedom – it really did! I became a totally different person. My personality changed completely! I kept wishing that I’d had the power chair years ago. Just think! I could have taken off with Danny on my own rather than rely on the kids next door.*

*I didn’t get a power chair until 1990 because I always thought my hand wasn’t strong enough to operate it.*

*It was a homecare physiotherapist who finally said ‘I’m sure we can work something out’. She took me to Invacare where I tried a head control chair and nearly killed everybody when the chair just shot across the room. I said ‘No, this is far too dangerous’ so we started looking at other possibilities. Eventually I got a chair with a flat area built around the joy stick to rest my hand on.*

*We had to synchronize getting the power chair with buying a van of course, because you obviously can’t lift a power chair into a car. We hadn’t been able to afford a van until Dad died so I was dependent for many years on the manual folding wheelchair and Brian helping me transfer in and out of the car. By the time we bought the van I was really getting scared about being stood up, especially in the winter when my legs didn’t work as well. I fell a few times and Brian had to go in the house and get Dan to help lift me up and into the wheelchair. I’d make every excuse in the book not to go out in the winter because I was so scared of slipping on the ice.*

*The van meant I could go out without worrying. Both the power chair and the van gave me a lot of independence and freedom from worry.”*

### **Elevator, Track Lifts, Computer, Magic Wand Keyboard**

*“Our home and cottage are full of all kinds of devices that make life easier. We have a microwave, toaster oven, washer, dryer, vacuum cleaner, and refrigerator. Brian has his electric golf cart, power lawn mower and PT Cruiser. I have an elevator at the side of my house, ceiling lifts to get me in and out of bed and the bathtub, floor heaters, my computer which I can easily operate with my Magic Wand keyboard and track ball.*

*My computer is my window to the world– with a little finger motion I can instantly access maps, yellow pages, restaurants, travel agents, daily newspapers. You name it, I’ll find it.*

*I actually had my track ceiling lift in place a long time before I really used it. It was always much quicker for Brian to just pull me up to standing and transfer me, but after a few falls that caused a weakened, wobbly knee and ripping the ligaments in my foot at Danny’s wedding, that was the end of my standing transfers. What with Brian’s bad back and everything else, I thought ‘why am I doing this? It’s too dangerous. The lift was already in place because it had been installed quite a while ago so outside agency workers could help me when Brian had his surgery. I thought ‘what the heck!’ and I’m very glad I made that decision. It’s just given me so much more freedom and, honest to goodness, I am very sure I would have fallen and broken a leg by now.*

*When it comes to technology, if I see something that gives me more independence and makes life easier for Brian and I, I go for it. Some people get incredibly hung up about these things because they think it makes them look more ‘disabled.’ I think it’s the opposite. You are much more disabled without them. Humans were born to use tools, you know!”*

### **Direct Funding**

*“Direct Funding has also made a huge difference. It has been a Godsend, a really important opportunity. It really has! It means I’m not petrified of the future like I used to be. I’m still terrified of being neglected in a nursing home, of being left alone, but as long as I have a house and the money to pay for someone to look after me I’ve got the security I need. The thought of a nursing home just curdles my insides and I don’t want to end up being dependent on my kid either.”*

### **Negative Influences**

*“What, if any, factors may have held you back, limited your achievements or negatively contributed to your development and achievements over the years?”*

*“I don’t think I’ve ever really gotten over those terrible years at Riverdale because I will always hate asking anyone for anything. At Riverdale we learned to beg; ‘please, when you get a minute’ or ‘when you’re not busy, may I....?’*

*I learned to ask for nothing, unless absolutely necessary. This habit took many years to break. Even today, if I sense any reluctance at all I just shut up and do without and I will never ask that person for anything again.*

*My self esteem eventually came back, especially after Lyndhurst, but not to what it was. I still won't go to big social events because I don't like meeting people who stick out their hand and expect to shake mine. I was petrified that Dan & Laura would have a receiving line at their wedding but thankfully they didn't want that. I know you have to hide how you feel and I do. I cover very well but underneath I still feel like a frigging freak. I was shy to a degree before I got polio but not as much. I don't like cocktail parties either, where you make small talk but - you know what? I would have been like that anyway."*

### **Sheila's Secrets of Success**

I have my own ideas about Sheila and what makes her tick. I think I know the personal strengths and attributes behind her achievements but I want to hear what she says for herself.

*"Well" she says. "I was definitely the kind of person who hated to be dependent. I was determined to earn my own money, to pay my own way from a very early age. That started very young, long before I got disabled. I've always been strong willed too. I know what I like and what I need to be able to function and be independent. I'm persistent in getting what I need. It makes me angry when other people think they know better and won't listen. It drives me crazy! Just because doctors and therapist have gone to university they think they know what I need, but hey, hello out there, it's "ME" that has the experience. Over 50 year's worth! I'm pretty strong when it comes to holding my own. You have to be strong willed to survive!*

*I always plan ahead. That's very important, especially when you are disabled. Instead of waiting for a crisis to happen, I think about things and try to plan ahead as best I can. If you put enough thought into a problem you can usually figure out a way around it, especially if you're creative. For example, I've adapted my clothing by shortening the sleeves so they don't twist around my arms. I wear loose poncho style tops that focus more on texture and pattern than style or fit. This avoids having someone shove my arms through sleeves any more than is necessary. I wear skirts which are much easier to get on than pants and I sit on a towel so people can grab it and pull me back when I need to be shifted. This makes dressing and changing my position a whole lot easier. I hate being mauled and man-handled, don't you? I hate it especially in the morning when I like to get up as quickly as possible."*

Sheila hasn't mentioned that she's also an optimist who tends to focus on the positive. She is a genuinely appreciative person who acknowledges and goes out of her way to help others. She is generous towards those she values and takes neither people nor opportunities for granted.

## Today's World

Sheila has been severely disabled for fifty-seven years, enough of a life span to have seen and personally experienced many, many changes. I tease Sheila about her advanced “elder” status and ask for her opinions regarding today’s world for persons with disabilities.

*“It’s a lot better in society than it was,” she says. “People with disabilities are respected more than they were 50 years ago. Maybe things are not as good as they could be out there but there’s a forward movement happening everywhere. For example, people don’t look at you like you have two heads now. Don’t you find that too?”*

*“When I hear people with disabilities moan and groan and carry on about what’s not accessible and all that nonsense, I think. ‘Honey, you should have been around back in the 50’s and 60’s when nothing was accessible at all. Life was a lot different then.*

*You were not accepted in movie theatres and there was no such thing as accessible bathrooms. There were no curb cuts to cross the street, no electric wheelchairs, no adapted vans, and no computers. All these things have made life so much easier. Just look at the buildings you can get into now! We can go to a whole lot more places and there’s more choices and opportunity than ever there was before.”*

“Do you think kids growing up today have the same degree of self consciousness about being disabled?”

*“Well, I’m really not sure. We live in a media hyped body-beautiful world these days. Image seems much more important than it was years ago. When I was a kid no one had bulimia or anorexia and now kids are terrified of it, let alone being seen in a wheelchair.*

*Yet, today’s generation seem much less curious about us. Kids don’t come up and ask questions like they used to. I can’t remember when that stopped really. I think it’s because people in wheelchairs are out and about these days compared to thirty years ago, so we’ve become more of an accepted sight. We’re not closeted away anymore. In the day care the only reaction I get now is the little boys who want to see what makes the wheelchair work. They say ‘make it go back, make it go forward, turn in a circle.’ Then they get down underneath and try to figure it out. The girls couldn’t care less. Kids used to stare at you and their parents would pull them away but now that doesn’t seem to happen anymore, so that’s good progress.”*

“What about technology and assistive devices? What changes have you seen?”

*“In the early days when I first came home there wasn’t much choice. You bought a basic wheelchair directly from the dealer. You didn’t have a lot to choose from and the decision tended to be yours. Your local store, Eatons or Simpsons, respected and listened to you as the customer. They responded to what YOU wanted.*

*Today there is so much choice that it is not simple to see everything, to be aware of all the options or to make a decision. Nowadays, we have more choice than ever before but there are so many people in on the act, it is very confusing as to who does what and why. With the government being involved as payer through ADP (the Assistive Devices Program), we are forced to have these so called “experts” decide for us, people who haven’t lived our lives or sat in our wheelchairs all day – because they are the only people the government will listen to! The minute government gets involved in any program the vendors jack the prices way up. We might have more choice and more products today compared to fifty years ago, which is good in a way, but I’m not sure we’re any better off at all.*

*Products, like cars, keep on changing and getting more complicated. I hate that. I just want the simpler stuff, the tried and true products that work for me, but they keep becoming obsolete and I have to start all over again each time, at greater expense too.*

*Even fixing wheelchairs and other devices is a problem now because of the advanced electronics. When I first came home with a ventilator in the 1950s my dad could fix it because it worked like a simple vacuum cleaner motor with belts and brushes. Today, ventilators are smaller, which is great, but the guy next door can’t fix it. I mustn’t complain though, because I wouldn’t be working and having the good life I do without my chair, speaker phone, computer, lift, van and so on. The opportunities we have in this country today are fantastic and shouldn’t be taken for granted.*

*In spite of all this ‘so-called’ progress, people with disabilities are definitely at the bottom of the food chain now. We no longer have that control of just going in a store and choosing and buying what we need directly. It’s really too bad because the system has made us more helpless and dependent and they have more power and control over us than they ever used to.”*

## **Health Care Today**

“What about today’s health care? I ask. “So many advances have been made during the last half-century that it’s natural to assume health care is better than at any other time in history. But what do you think? Is it better or worse than it used to be for people with disabilities?”

Sheila is thoughtful.

*“I’m not sure. I think it depends on the individual doctor. I think it’s always been this way and I think it always will be. Fifty years ago Dr. Jakes nearly destroyed me whereas Dr. Jousse turned my life completely around. Today, my own family doctor is marvelous, always has been, just like her father before her who was my parents’ doctor. A gynecologist that I saw many ago was a hateful dictator, whereas another one I saw ten years ago was very impressive. His nurse borrowed a Hoyer lift from the Rehab Dept to get me up on the table and nothing was too much trouble.*

*Then, there was Dr. Epstein who was an absolute honey. I just loved him.*

*Things have changed a lot now though, so I guess I've been lucky. Getting health care these days has become much more difficult.*

*For example, when I got home from Danny's wedding in Connecticut with an ankle injury, I called the X-Ray department at Trillium Hospital. I was in so much pain. They said they couldn't see me unless I got on the table by myself or brought my own attendant to transfer me. Brian hasn't been able to do that for years so I called a MedVisit doctor who drove up in his fancy sports car and looked at my ankle. He said 'I'll give you Tylenol Three.' I said 'I can't take that because pain medication knocks me out and I have breathing issues.' He said 'Well, you're a stubborn old son of a gun and I replied, 'No I'm not a stubborn old son of a gun, I had polio over 50 years ago and I know what I can and can't do and what I can and can't tolerate. He said once again, 'you're a very stubborn old woman' and just walked out.*

*Being in hospital is a lot more difficult these days than it used to be. About 15 years ago I had what seemed to be a gall bladder attack and went to the ER at Toronto Western. The doctor said it was a bowel obstruction. I said 'No, it isn't, I went to the bathroom this morning. He wanted to do a colonoscopy and I said, 'No, you're not going to do a colonoscopy, I can tell you that right now! So they took an X-ray instead. They couldn't see a bowel obstruction so they admitted me and gave me Tylenol 3, which knocked me for a loop.*

*Next morning they told Brian to get me up in the wheelchair. I was so out to lunch my arm got caught in the bed railing and snapped. I said 'Oh shit, you broke my bloody arm.' The nurse said 'That wasn't a very nice thing to say!' and I said, "well, it wasn't your arm, was it?' Then a little Chinese doctor came down to look at my arm. He told me to move it, wiggle my fingers and show him what I could do. I said "What you see is what you get. It's been paralyzed for years, right? He said 'awh soo!' and disappeared.*

*From then on it was a joke. They gave me intravenous, did an ultrasound and sent me to nuclear medicine for another imaging test. A bone scan showed I'd broken my arm years before, which probably happened when Danny was little and jumping on the bed.*

*Transferring was hell because my arm just flops when I'm moved. Every time they moved me it was excruciating but they didn't put anything on to stabilize or support it, no sling or cast or anything like that. So Brian went to Kingsway Drug and bought something to bind up my elbow and stabilize it so it wouldn't be quite as agonizing when they moved me. That helped a lot. The intern came back and said 'Did orthopedics do that for you?' I said, 'Oh ya, hmm hmm.' I can lie like a trooper to save my soul if I have to!*

*I was allowed an afternoon pass so Brian and I went to a medical store and bought a heavier splint to strap on my arm. When we came back to the hospital the nurse said 'Oh that's a good thing orthopedics did for you!' I just said 'Oh yes, yes, it certainly was!'*

*Meanwhile the IV in my left arm was going into the tissue and swelling it up like you wouldn't believe. I couldn't move my fingers or anything, but they wouldn't take it out because the doctor had forgotten to sign an order.*



*When the nurse came in and told me she had no order, I said 'Look honey, I got news for you. Either you take it out or my husband will. One way or the other, it IS coming out!' She went out of the room with a look on her face that could kill but she soon came back and took it out.*

*They never told me a thing about the tests, except for the bone scan which showed the old fracture. Quite honestly, I think I had a virus because I had awful diarrhea for a week. I never once saw the doctor in charge, only his intern and other gophers. Even when I was discharged the doctor stood outside my door and gave instructions to his resident. He never came in to introduce himself – not even once – so I wasn't impressed. When I checked out at the desk they said 'Dr. So and So would like to see you in his office in two weeks time.' I said, 'If Dr. So and So can't come in and see me in my room even once after all this time, hell will freeze over before I go and see him in his office! They looked at me in shock but the head nurse sort of winked because she and I had had quite a chat.'*

It 's not uncommon for people with lifelong disabilities to experience fear and avoidance of physicians and hospitals, so I ask Sheila if she thinks her early years at Riverdale have left any lasting impact, any legacy of a post-traumatic stress disorder.

*"To a certain degree" she says. "Even visiting someone in a hospital is uncomfortable and I'd definitely rather not be there. I know it sounds like I have an attitude towards doctors but I really don't. They're not all bad. I have no objections to doctors. In fact, I always wanted to be a doctor. I'm like my dad. I just don't like going to doctors. I've come to believe that anything related to polio is a dead issue and they're not interested in us anymore. We are second class citizens. Maybe it is a phobia, I don't know. I usually think, what's the point? I'll just work it out myself."*

### **Staying Healthy**

*"Brian and I do whatever we can to stay healthy and away from needing healthcare. We are great believers in vitamins. I used to go for massage to reduce the swelling in my legs, which definitely helped. I get good quality sleep, wake up early and eat small with no fat and no sweets, except for once in a while.*

*Part of staying well is recognizing that you are getting older and planning ahead for it. Brian and I have been gradually reducing our day-to-day involvement in the day care business. We only have two daycares now and we just do the books and act as consultants. I stopped chairing the board meetings quite a while ago. That's the way we want it. The day cares are a non-profit corporation and Brian and Dan and I are just members of the corporation and not on the board. This way, if something happens to Brian and me, Dan still has a say.*

*We need that reassurance of security for him in the years ahead. Having our basement finished as a separate living area helps with that because some day we might be looking at live-in help. I have to keep on working at whatever I am able to do and enjoy doing for as long as I can because financial independence will give me more power and control over my life in the future. You can understand that."*

## Sharing the Wisdom

“What advice would you give parents today who have a child with a disability?”

*“I’d say treat them like normal kids. Don’t baby them. Don’t pamper them. Don’t coddle them. Make your child grow up to face the world like everybody else has to. Both you and I were raised to be very independent, even before we became disabled. That’s been our saving grace.”*

“What advice would you give today’s health care professionals who are taking care of children or adults with disabilities? “

*“I’d tell them to get away from believing the medical model to be the one and only solution. I’d tell them not to over focus on the physical, to let us learn to live our lives with the abilities that we still have left. Dr. Jousse’s words to all new paraplegics was ‘okay, if that’s what you want on, we’ll get you up in the bars and get you walking and show you that you can indeed walk again with braces and crutches, but it’s not ever going to be functional. He said ‘We’ll prove that to you and then you can decide whether you’d rather put all your energy and struggle into walking or whether you would rather get a wheelchair and be quick and mobile and able to go to work, run a home, drive a car, and so on. He was years ahead of his time.*

*If people have lived with their disability for many years I’d tell the medical professionals, ‘Listen to the person first of all.’ We know our bodies better than they do because our bodies are unique. Doctors usually have very little or no knowledge about us rare people. When it comes to polio, they don’t teach anything about our disability in medical school anymore. So, please, listen to us. We can teach them a lot if they are willing to listen.*

*I think I’m one of the lucky ones because my doctor has always listened to me. But, when you go into a general hospital, they don’t listen. That’s not only scary; it’s very, very dangerous.”*

## Re-Winding the Clock

“How would you feel and what would you do if you suddenly woke up tomorrow morning with absolutely no disability at all?”

Sheila eyes widen in surprise.

*“It would be wonderful, marvellous. I wouldn’t have to ask anybody for anything. That’s what I’d love the most! I’d be free and able to do what I want by myself. I’d love it! I’d learn to drive the car and just take off. It would give me my wings! I wouldn’t miss one thing. Nothing! I wouldn’t miss the equipment problems, depending on others for help all the time, asking for things, the battles to get a new wheelchair, all that sort of garbage.”*

Sheila pauses and thinks about the question more seriously.

*"It would be like winning a lottery, though, because it doesn't change you or who you are. After the initial joy there would be a tremendous adjustment because you've lived 90% of your life a certain way and now there's a sudden dramatic change. That would be the biggest challenge. I don't know how I'd adjust, but I know I could with time."*

"If you could change just one thing about your disability what would that be?"

*"I'd like to get rid of the ventilator. If I had no ventilator and one good arm that would make me happy. But, if I could only choose one thing it would be the ventilator. The ventilator limits so many things that I want to do. It really does. There are so many things I can't do and places I can't go because of the stupid thing. If I don't take it, I get exhausted quickly so Brian has to drag this stupid thing along everywhere we go. It's embarrassing too."*

"Would it help to have the ventilator mounted on your wheelchair?"

*"The vents I've seen on people's wheelchairs are pretty big and visible and attract so much attention. I know it would help if I could get over the stigma of being seen with a ventilator but it was brainwashed into me years ago at Riverdale that only weak people are dependent on a ventilator. I was only a teenager then and to hear that message over and over has had a lasting effect, I think."*

I ask Sheila whether it would have been easier to have been born with a severe disability or to acquire one later on in life. There is no hesitation in her answer.

*"Oh, it's better to get disabled later on in life, but not too late. You have to be young enough to still be able to adapt. I believe it is better to have experienced some life with an able body than to have had no 'normal life' at all. I say this because I'll never forget those young married women with little children in the beds beside me and how awful it was for them. They had more to lose than I did."*

## **God and the Value of Life**

Sheila grew up in a religiously oriented home, the daughter of a Baptist Minister. As a child and young adult she was actively involved in CGIT (Canadian Girls in Training) church camps and in running a variety of children's church programs over the years. It is natural for me to be curious about her concept of God.

*"God is the name of something that we can think of as being out there or in ourselves"* Sheila tells me, *"some force or overall being that is the source of how we got on earth, how we are made and how life is procreated. We didn't just happen. I believe all of us are put here for some specific reason but we don't know what it is."*

*I'm not so sure God is a person, though. Whether it's God or Allah or whatever name you use, I believe that "Source" has given us certain brains and it's up to us use them.*

*I'd like to think that some overall being is supposedly protecting us but I don't believe God will always be there to look after us. Many people blame God for bad things that happen but you can't blame God for everything. You've got to blame yourself for what happens too, you know.*

*I believe that somehow or other I got polio for a reason but I have no idea what that was or is. If becoming disabled has channelled my life in a certain way, then so be it. Perhaps I might otherwise have turned into a much more selfish human person, who knows? What kept me going, especially in the early years, is the belief there was a reason for me getting polio. It happened for a purpose, even though I've never been at all sure what it is. Maybe in some small way, over my lifetime, my purpose has been to provide a decent grounding for many children who otherwise wouldn't have got that."*

"Has your life been worthwhile?"

*"Oh definitely!*

*Others might judge my life as one of misery because I'm in a wheelchair but to me, my life has always been worth it and still is. I have absolutely no regrets. You won't catch me going to my grave saying 'why me?' I refuse! I cannot imagine any person wending their way through life saying, 'what if?' That kind of thing is futile and a miserable way for anyone to live. I've had a good life. I've accomplished a lot. I've been extremely fortunate to have experienced just about everything that any able-bodied person has. I am very, very lucky, and . . .*

She looks me in the eye, grinning unabashedly,

*"... soon, very soon, I'll be sitting right here with another little baby on my lap. my very own precious little granddaughter. Whoever would have thought it!"*



Sheila with her granddaughter,  
Scarlett . April 2008.

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## **POSTSCRIPT**

Sheila died unexpectedly on June 3, 2008, leaving behind the legacy of a life well lived.

She will always be remembered by her husband Brian, son Dan, daughter-in-law Laura and granddaughter Scarlett.

Neither will she be forgotten by the many people in her life whose friendship and acquaintance she honored.

Audrey King  
2008