

## POLIO STORY

I contracted polio in September 1951 in Melbourne. I have many vivid memories; they are branded into my soul. I was four years old.

I remember that I went to a local school fete with some people who lived next door to my grandparents. I used to play with their little girl. Her name was Dawnie Atherton. When I came home after the fete I felt very sick and began vomiting. I also had a very bad headache. I remember my parents and grandmother asked me what I had eaten. "A drink of lemonade and a black jelly bean", I said. In my mind's eye I could still see the jellybean in my hand before I had eaten it.

I was very sick all that night. In those days if you wanted to go to the toilet in the night and you were four years old you would use a potty under the bed. I remember trying to do this. My right leg had gone stiff and it "wouldn't work." Somehow I managed to climb back up onto the bed. I did not call out to my parents. By morning I was completely paralysed.

I was taken to Fairfield Infectious Diseases Hospital. Later, my mother told me that somewhere in the pit of her stomach she knew I had polio. My grandmother told me years later that she had never seen my father cry except on that day. As a young adult I too saw him cry when we were watching a film on television about Sister Kenny, and a small child's paralysed legs were being examined.

I was diagnosed at that time with "gross paralysis". The doctors told my parents that it was the worst type of polio, and that either I would never walk again, and the leg would not grow or if it did, it would be badly deformed.

In the hospital I remember being put naked onto a table which was covered in a cold white sheet. I was lain on my side. Many doctors and nurses were there with face masks on and white coats. I was given an injection in each of my vertebrae, and one in my left arm.<sup>1</sup> I remember being very cold and frightened. I was put into a cot in an isolation ward where I was expected to lie all day with sand bags around my legs. Food, I seem to recall, was taken through a bent glass straw. I didn't like this soggy baby food because I knew I was not a baby. Behind and above the cot was a small window. I remember trying to stand up on the good leg to look through it. A very grumpy nurse was on the other side, and she gestured angrily for me to lie down again. I longed for my Mother and Father and my merry little baby sister. Sometimes my parents would appear, though masked of course, and in white coats. I remember I asked for my little woollen cream and red dog to be brought in. Somehow he was a friend and a comfort. Many years later I asked Dr Colville how long children were kept in isolation. He said it was three weeks, and then usually another three weeks in hospital after that in general wards for cases like mine.

Several years ago my mother told me tearfully of her anguish at that time because when I came out of isolation I wouldn't look at or speak to either of my parents for quite a while, but just turned away from them and stared at the wall. I have no memory of that, but I remember being in another ward with one other little boy of four years old. I think his name was Donny. At least here there were more people coming and going, and occasionally you could hear a radio in the distance.

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<sup>1</sup> This is how I remember it, but it has been explained to me that this would have been a lumbar puncture and a blood test.

That was the sound of home to me. I remember being frightened and calling out in the night. A very kind nurse came and sat next to my bed and helped me to relax by getting me to watch the shadows of the leaves on the wall. She told me to watch those and see if I could see the fairies there. The next night I called out again, hoping that she would come. This time a very grumpy nurse came who told me sharply to be quiet and go off to sleep.

The next ward I was in was full of children of many ages. Opposite me was a bigger boy called John Pick of about eleven, who made everyone laugh. And next to me was a little one year old girl called Margaret. Eventually Margaret went home. A tiny baby was brought in a cardboard box, but I didn't see her again. Again the food was a problem. Grated apple was mixed in with almost liquid mashed vegetables. This mixture was doled onto plates with an ice-cream scoop. I remember being shame d by a nurse for not wanting to eat my food. I remember the burning of my cheeks and the tightness in my throat.

My parents visited often, and always they brought with them a little present. My favourite was a little weighted man who could somersault down a slanted book. This ward was much more fun than the other two. Sometimes we were put out onto a balcony, but I remember that being quite cold. I had been asking my parents if I could see my baby sister as I missed her so much. One day, to my delight, my father held her up outside the doorway. There was this darling smiling baby with her olive skin and merry face.

We were taken to bathe in what seemed to me huge silver tanks. It was a mixed group of four children. I remember a girl called Muriel of about ten or eleven trying to hide her private parts from the boys. After one such bathing time I remember being wheeled back towards the ward. In the distance I saw the familiar wavy hair and body shape of my dear father. I was to go home that day.

My father had devised a set up in the car where a plank of wood went from the back of the back seat to the back of the front seat. This meant that I could be still bandaged into my Thomas<sup>2</sup> and placed upon the plank, and thus taken in the car.

At home my mother had a surprise for me. I had always wanted in my four year old words "a doll with flapping out hair", as dolls in those days had woolly hair stuck straight onto their heads. My mother had bought a doll, removed its hair and had arranged for a hairdresser to make a wig for her out of real human hair. As she held the present behind her back, I could see the wonderful brown hair flapping out to the side. Later my grandmother made a sequined ballet dress for my doll Susan. I could stare at her sweet face, comb her long hair, watch the sparkles, and dream of being a ballerina.

But these times were also pretty torrid I think. Every day there were the same rituals. I was totally confined to the Thomas. Both legs were bandaged in. I was bound around the torso and my arms were bandaged up to the elbow. My mother also had to do a lot of carrying, attending to the potty, the needs of a young baby, and later, with my father, the daily exercises. My grandmother came over most days and would read me stories. I remember her too being tired, and nodding off to sleep on hot days. I remember one such hot day my mother was very stressed. My baby sister was crying a lot, and my mother was shouting and upset in another room. I remember closing my eyes and screaming and screaming, squirming and raging against the bandages that were so hot and were

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<sup>2</sup> A Thomas was a metal frame in the shape of a human figure. The limbs and torso were bandaged into it.

holding me in. The next thing I knew my mother was standing at the foot of my pram. She stood there quietly, staring at me. She was now calm, and eventually I too became calm again.

In response to those times my imaginative life began to grow. Because I was bandaged in and could not move except for my hands, I would love to draw and tell myself made up stories. I would also imagine my inner self leaving my body and dancing above myself. I can still picture it. I have on a beautiful coloured shirt, fringed with lace, and my limbs are lithe and free like those of a fairy being.

Sometimes, my grandmother would take me for walks. I was on a long flat pram bandaged into the Thomas. Actually, I was on it all day and every day and then returned to the Thomas in bed at night after a bath. She wheeled me along streets where houses were being built, and we used to pause by an old hedge which was full of singing birds. Nan had the thoughtfulness to buy me a pair of sunglasses because she said I was looking at the sky all the time. I remember them well, they had white plastic frames. Another time she took me across the road to a huge paddock. It was full of bright yellow daisies and she made daisy chains for my head and neck. The perfume was potent and life giving. I remember these as happy times.

Other happy memories are those times of being read to by my parents. My mother loved to share the fairy books of Ida Rentoul Outhwaite, and I adored the illustrations. Visits from the neighbouring children were special too. One girl delighted in “playing hospitals” and used all the spare bandages for the splint to bind up her very willing younger sister. These friends were Carole and Laraine Gates.

My father, when he came home from work, would help with bathing and chores and later he devised a set of weights for me to use to exercise the leg and he and my mother would then supervise the exercise time after dinner. One day he surprised me with a small imitation Thomas made from welded together spoons. It was made for one of my dolls. This may seem strange, but actually it was a very therapeutic toy. I don't think I bandaged my doll into it, but it was in the background of many games, and further “normalised” things somehow.

I remember feeling very cramped up and achy and crying on one Christmas day and my father saying “Dr Swann says you can have a little time out of the splint today”. This was really a very special occasion as it happened on no other day during this whole time, such was my parents' diligence in their care of me.

I remember being taken to the annual Christmas parties for the “Society for Crippled Children” and the clinics at Caulfield where I and hundreds of other “crippled children” were seen by doctors and physios. Discussions took place, exercises were given and aides of all types were reviewed. My mother always hoped for Dr Colville as he always listened to her, and valued what she said about my progress. I remember physiotherapists coming to our home, giving exercises, making plaster casts, and talking with my mother. I remember when I had to learn to walk again, after about a year. I was by this time five, but the ground looked a long way down to me. My physio, Miss Thompson, held me upright and was very firm, but encouraging. “Are we going to do some walks today?” she asked. I felt afraid, but I also trusted her. It was as though I had to tell my body that it could do what I really knew it could not do. However, with encouragement, I made myself do it, and eventually I learned to walk again. Later, we had another physio who came to the house. Her name was Miss Cosh. Fortunately for my mother this lady could also help with breathing exercises for my sister, who by this time had developed asthma. This lady had turned up at the door. She was completely out of her allocated area and said to my mother that she didn't

know why she was there. Many of these seemingly serendipitous occurrences (and there were others) my mother attributed to answers to prayer.

By the beginning of the next year I was six, and I was to start school, one year later than I was originally supposed to. For the first year, I went for only half a day and then came home to go back into the Thomas for the rest of the day. I was walking now. My first calliper was a small knee-high one, but soon I had a full length calliper on my right leg. My father had built a special chair for me to have at school. It was a wooden high-chair and the calliper would hang on a hook under the tray in front. My foot was to be slipped into wooden wedges and turned inwards. Callipers, splints, plasters (these were worn at night) and the like were all used to avoid deformity of growing but unstable limbs.

School of course was torture. I was left by myself in the class-room at recess. My mother put some toys for me to play with into a little case. Sometimes the teacher would ask some of the children to play with me at recess. Often they would say yes but would then run off as soon as she was gone.

Later when I stayed at school all day and was in the schoolyard, I suffered terrible ostracism and persecution. If I tried to join in the children would make fun of me. They would imitate my “funny walk,” and would smack me and laugh if I tried to run after them and if I fell over. I could never use the toilets as some of the older children would gang around the entrance and say, “You’re too ugly to come in here”.

Eventually my parents decided to move me to another school. This was after an aunt of mine had been past the school one lunchtime and had witnessed several children beating me. This is an incident I don’t remember, probably because it was commonplace. What I do remember was walking home from school, being taunted by children from behind me, and breaking into tears as soon as I reached home.

I remember being taken to meet the headmistress of my new school.<sup>3</sup> I was nine, and I was to go into grade four. My father took me into her office. When you have a visible disability you are used to people looking at you with a mixture of sympathy and disgust. This woman was different. She looked at me straight in the eye- she looked at **me** the human being, and past the disability. Her gaze was one of acceptance, love and compassion. This was a healing moment for me. I began at that school, a private girls’ school in Melbourne, and the calliper and the polio were never mentioned. Someone had prepared the way. Someone had explained things – I was never discriminated against at this school. There were many things I could not do, but this was accepted and understood. I had a happy and successful time there for the rest of my school days.

At around ten years of age I was taken to a specialist doctor, Mr Price, who had done some work with tendon transfers. As I understand it, a healthy tendon was to be taken from the good side of the leg to help strengthen the weak side. Another option was to go to America for an operation. I always remember my father saying, “If it will help, we will pay anything”. At that time, he didn’t have a lot of money, but he was prepared to get it somehow. He also said to the doctor “Can you take one of my tendons?” And my father was an active sportsman. It was decided at that time not have the operation, but to wait a while longer to see how I would grow.

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<sup>3</sup> Mrs. G.D. McKie, Principal of Kilvington Baptist Girls’ Grammar School.

In the meantime and at all times before this, my parents had done everything for me that the doctors and physios had suggested. Dr Colville had told them that the leg would grow better if it was kept warm. My mother made for me a fur-lined gaiter that was worn over the full length calliper, which in turn was worn over full-length woollen socks knitted by my mother. My father had seen in an American magazine an electric blanket. This of course was in the 1950's before you could get them here. He arranged for one to be specially made for me with tapes on it. The blanket was tied around the leg at night on top of the plaster. Apparently my father had found a Mr Herbert who lived in Malvern who was prepared to make one. He made several prototypes before they struck upon one which would not get too hot and "cook the leg". Exercises were diligently supervised every single day. I know I owe my parents so much, but I also know it took its toll on them. Eventually my polio leg began to look more like the other one. I had had many years of one being shorter, thinner and weaker than the other, but now even the feet sizes became the same. Doctor Colville was surprised, but very happy. Later it was decided that I did not need to have any operations.

By the time I reached secondary schooling, although I still had a limp and many permanent weaknesses in the leg, I was told I would be able to do without the calliper. On that day, after the visit to the doctor I ran to the front of our house. A fresh cool wind rushed onto my cheeks and into my hair, as I ran freely up my street, past my school, towards the train station and back again. My heart was laughing and bursting with joy at the same time. I was eleven years old, and my polio childhood had come to an end.

In my life I went on to University, became a Secondary School Teacher of English and History, married and had five children. At nineteen I had become a very bad migraine sufferer and these migraines continue to plague me. I had actually had quite bad headaches throughout my childhood since the day I got polio, but at nineteen they developed into full migraines. When my children were older, I began to study Theology and eventually I returned to teaching as a teacher of Religious Education and English.

I always loved teaching; the classroom dynamic, the class discussions, the magic moments when a student understands a new idea for the first time, the students individually, the relationships with other staff members and the daily anecdotal exchanges between students and staff. Unfortunately after eight years I had to retire due to ill health. The migraines had become a daily occurrence with a consequent complex juggling of medications, and my body had no energy in it. Also, the polio foot had begun to "flop" and was causing me to stumble and fall. There were many stairs at my school, and I began to get worried. At lunchtime I would mostly have to go and lie down. The bell would ring, and once again, as in the old days, it was a case of the will telling an exhausted and weakened body that it had to get up and move. At night when I came home from school I was so exhausted that I would have to go straight to bed, but I would have to get up later to eat, prepare lessons and do marking. One night my husband and I looked at each other and we agreed "This just can't go on". So at the end of that term I retired. Not long after that I moved house and "over-did it" by being too long on my feet, and over-exhausting my body. I had two days when I could not walk at all. It was then that I got very serious about finding out about post-polio services and other help.

My situation now is not straightforward. I can walk for ten to fifteen minutes at any one time. I have discovered great benefit in doing exercises, but sometimes my body can be too weak and floppy to do them for several days, though Carnitine has helped this. Even if I am resting in bed, before I get up in the morning I can be aware of a great exhaustion and weakness in all the body, especially in my arms which is not where I originally had polio. Sometimes it will be like this

for several days and then I will feel better again. My situation is aggravated and complicated by the extreme migraine problem. I usually wake with a migraine. Depending on its intensity, I take an Imigran tablet or an injection, which is stronger and works more quickly. Unmedicated, the migraine would take its natural course and I would be in intense pain and would be vomiting before too long. I have between one and four migraines per day, but fortunately I can usually control them with medication. I am still trying to manage, if possible with some dignity, the juggling of new post polio symptoms, the pain and medications, life's somewhat diminishing activities, and how, when, if and to whom to explain it all.

Upon reflection I think that my early polio experiences had a deep effect on my later life. Many experiences, of course, are common to many childhoods but for me it is all mixed in together. Firstly, never, and not for one moment, could I have taken for granted the freedom of being upright and able to walk out into the day. Also, my imaginative escapes from my body when I was paralysed, suggested to me that I was more than my body, and this idea with all its implied questions, continues to intrigue me. My ostracism and persecution at my first school developed in me a sense of outrage at the injustice of discrimination of all sorts, be it for physical, mental, racial, or creedal differences, and I developed a consequent empathy for the "under dog". Having to walk when I didn't think that my body could to it developed within me a strong and determined will, though I have noticed in other polio stories that this desire to use the will over the body ceases at some point (probably now in my case [and it doesn't work anymore anyway!]) to be the best idea. I have also used this will to endure some very negative situations in my life for far too long, because I could endure them.

The love and acceptance I felt from the meeting and subsequent student/teacher relationship with my second school Principal showed me that hope and inner healing were possible. This woman turned out to be a deep and fine Christian person. She taught Christian Education in the school, or "Scripture" as it was called then. As I first heard them, the Bible stories enmeshed with my inner being, and I had found a way to follow. I had seen and experienced in my teacher something that I also saw in the figure of Jesus Christ as I perceived Him in the Gospel stories.

The storybook and oral stories told to me by my mother and grandmother, opened my eyes to wonder, imagination and humour. I witnessed in Mum and Nan an inspired, determined and practical love, and my father modelled a silent, sacrificial and thoughtful modality.

My sister became a classical ballet dancer, and as I watched the beauty and fluidity of her body in dance, my heart was deeply moved. I felt a kindred joy when years later I gave birth in turn to five healthy little babies who grew freely and energetically towards adulthood. I found something miraculous and healing in bringing forth these five perfect little bodies from my own imperfect one. Grandchildren are now being born, all radiating out their own unique beingness, and eagerness for life. And so, life continues, multifaceted as it always will be. As I write, an autumn sun warms my cheek, and my heart overflows with a rich harvest, gleaned from the sorrows and joys of fifty-five years.

J. Marguerite Swann, April 2002.

