

## My Story

In his own words, the 13 year old writer of this article describes with frankness the bravery of his early years in his struggle with spina bifida, his determination through his primary school years and his hopes for his future. He wrote his story while in 6th class in Ringsend National School, Dublin.

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### The First Four Years Of My Life

I was born on 31st. October 1974 at 6.20 p.m. I was brought in an incubator to the Children's Hospital, Crumlin where the doctors discovered I was suffering from "Spina Bifida" and it was inoperable. They told my Dad that I would not survive the night, but I was destined to prove them wrong.

I was to spend the next four years of my life in hospital. My Mum was quite ill after my birth and did not see me until I was three weeks old.

I was to be allowed out of hospital on the 23rd December 1974, but when my parents came to take me home, they were told that I had two hernias and my head had enlarged, due to "Hydrocephalus" or as it is more commonly known, "water on the brain".

So that was Christmas spent in hospital. In January 1975 I had two operations on my stomach and two weeks later, I had a valve inserted in my head to make life a little more comfortable. The doctors still told my parents that I would not live.

The next seven months were spent in and out of hospital with one set back after another. At eleven months my spine was still open ("Spina Bifida" means split spine). I got very ill and I was loosing my spinal fluid through my spine. The doctors told my parents that I would die within two weeks unless they operated. My parents gave the go ahead and on the 15th October 1975, I was taken to the theatre. The surgery lasted six and a half hours and it was touch and go for a few days after.

When I was twenty months old, my Mum took me to Lourdes. While in Lourdes my kidney ceased to function and I became very ill. I had to remain in the hotel for the rest of the trip. When I arrived home my Mum called the doctor straight away. He said I was dying and asked would my Mum prefer to have me at home or in hospital for the time I had left. The family said they would keep me at home. My Gran and two aunts came to stay to help my Mum but on the third day the doctor said that I should go into hospital. At this stage I was in a coma. I remained in this state for eight days until I gradually came out of the coma. My Mum said that prayer alone had brought me through. Then, my feet began to grow crooked. Following this I had four operations on my legs. The next two years were again spent in and out of hospital with minor problems.

At the age of four I went to playschool for the disabled in Ballymun. At this time I was wearing calipers to help me stand, but after a while my back got sore from these. I had to get a further operation on my back. During this time I was living in Finglas.

### **The Beginning Of A New Life For Me**

On the 1st November 1978, my family and I moved house to Ringsend where I attended a school for the disabled in Sandymount for a few months. My parents however, decided I should go to a National School with other children of my age.

The first school my Mum took me to would not even consider taking me in because of my wheelchair. My parents then approached the National School for boys in Ringsend where the Principal, Mr. Cathal Fleming, gave me the chance to prove that I was capable of working with able-bodied children. My Mum often tells me how I was a bit of a novelty at first, and then how I was treated as an equal - "like one of the lads"

I liked most subjects at school, but wasn't too keen on Maths. I joined a recorder group, but didn't like it very much. I then joined the school band on the percussion stand. Although I could never take a physically active part in P.E. classes, I did try and involve myself by keeping score at matches and supporting teams at home and away. I always went on school outings, so I was never left out. When the doctors heard that I was attending a National School they were extremely pleased. This was mentioned at the next meeting of the Spina Bifida Association and more and more parents of physically disabled children were encouraged to follow suit.

During the next few years I settled down happily at home and at school. I made my First Holy Communion at the age of seven. During the years following this I had two more new valves inserted. I developed "Scolioses" (a curved spine) and I was taken into hospital to have it seen to. I stayed in hospital for tests where it was decided that my birth defects were too bad and nothing more could be done for me.

I attended an Independence Course in the summer of 1987 in which I did very well.

### **What I hope For The Future**

I am now thirteen years of age and this is my last year at Ringsend National School. I will be sad to leave after so many happy years and as everybody there was so good to me.

I have lots of friends, but my very best is Stephen Sheridan who I have been with since the age of seven. Although, I am confined to a wheelchair, I enjoy life very much. I am always out and about and enjoy playing pool. I have a small job on Saturday nights which involves minding cars while owners attend the races in the Greyhound Stadium at the top of my street. I earn quite an amount this way which means I can play pool without always asking my Mum for money. I still play percussion in the school band and we hope to take part in some competitions soon. I am looking forward to that.

I would have liked to become a fireman or an ambulanceman, but I know that will never come about. I hope that when I enter my new school, I will be as happy as I was in my previous one. I will try to study hard as I will need good results to get a good job.

Some day I hope to be an accountant or be involved in office work. Maybe, I will get a job manning the phones in the Emergency Services. That, I would like very much - it would make up for not being a fireman or an ambulanceman. Who knows what the future will hold. I'll just have to wait and see. Finally, I would like to thank my Mum and Dad, my sister Avril, and my brothers John and Pat for always being there for me. Despite my condition, they never patronised me. I was punished for doing wrong just like anybody else. I love them all very much.