

Jenny Takes up the Story

My father and mother decided to come to Sydney from Perth when I was five years old, on the way to America to get treatment for me, but the war prevented this so we settled in Sydney, for which I'm very glad. My parents felt Sydney had more to offer me in possible treatment. My father had come on ahead. It was wartime and my mother travelled alone all the way across Australia with all our belongings, my younger sister who was about eighteen months old on one arm and me on the other arm, clutching my doll 'Sarah' and all her wardrobe. We came by train, and both my sister and I were travel-sick. I remember very vividly when we stopped in the middle of the desert, and aborigines were all round the train and my sister Robin and I were terrified because we'd never ever seen a black person before.

I had a normal little girl's childhood with dolls and fairies and Santa, with the help of my little sister. Then one day my mother put the radio on to 'The Kindergarten of the Air', which was for very young children, and she sent me out of the room for a minute and came back to find me trying to move my limbs in time to the music; that and other things, like every nursery rhyme which I knew off by heart, confirmed her belief that I could learn.

Then we moved to a house in Gladesville which was on a steep hill overlooking the air raid searchlights at night. My father used to take me outside at night to watch the lights. He also fixed up an electric car for me with a battery instead of pedals, with a gear and a steering wheel. At that time I couldn't hold up my head at all. I was floppy and couldn't sit erect, so I used to drive the car with my head down, looking up with my eyes, and I used to take great delight in running into people. I learned to drive it, and could park on the spot. I had a lot of fun out of it, as it enabled me to move freely around the house, for up to this time I had to crawl on my stomach and one leg. Robin regularly got things for me, such as my toys, and she used to pull me out of my chair by my feet if I wanted to crawl. By the time I turned six, my parents were trying to get in touch with other parents with children similar to me.

While they were doing this, I was having the most cruel six months of my life in an orthopaedic hospital, mainly because they didn't know what a spastic child was. The treatment I and others had, was so heartless and difficult that I just could not cope with it. My fear of falling increased because they let me fall over many times, saying I was lazy. I had chicken pox at Christmas time and they burnt all my presents, including Sarah, the day after Christmas, to prevent the infection spreading. My father used to park the car behind the bushes outside the fence, and take me out to wave to Robin who was not allowed into the hospital to see me. While I was still in hospital, a man lent us a big house in Mosman for a school and medical treatment centre. This was the beginning of The Spastic Centre. It started with about forty pounds, approximately thirty children, and a lot of hard work and hope. So one Saturday my father came and dressed me in a pink winter dress and took me out of the hospital, to where Robin was waiting outside the gate, and home at long last. Mother had gone away for the weekend to raise money for The Centre. I can still see Robin dancing up and down on the path.

As I was only six years old, I wasn't aware of the organising of The Centre, only that my parents were so busy, but never too busy to see us. However, this meant that Robin and I had to rely on our own resources more than other children, which in a way was a good thing.

My family had moved into the house in my absence in hospital. Home was a kitchen downstairs, two bedrooms and a lounge room upstairs. Monday came and my father took me down to the school teacher, but I wouldn't let go of him. I was so terrified after my experiences in hospital that it took me quite a long time to get over the fear of other people handling me.

We had two Education Department teachers, one for the older children and one for the infants, in which I was, but I would not let anyone call me an infant. We had one occupational therapist, two physiotherapists and a speech therapist, plus another elderly lady for supervising a rest period after lunch. We all had to lie down and go to sleep for an hour or more, because it was thought that this was beneficial for relaxation. We also had a doctor who was learning and researching. The unpaid mothers did all the housework, cooking for lunch, and did the toileting. We had voluntary drivers in cars who drove the children to and from The Centre. Many of these were parents too.

My mother had a very small office to organise the school and medical unit, transport and to raise money for The Centre. Our day was split up – school either in the morning, with a rest after lunch, or the afternoon, and the other part of the day was split again with physiotherapy, speech, and occupational therapy under the strict supervision of the doctor. This meant that our schooling was slow, especially as some of us couldn't write. So that we had to have either the schoolteacher or the voluntary helpers, or one of the less handicapped ones, do this for us.

This was where I found Julie. She could not write but she could talk, and I couldn't talk but I could write, so we were able to help each other right through school. The short time at school and the spasming of my eyes, which interfered with my reading, slowed down my education, but I wanted to learn, so it didn't matter how I did it!

I used to hate my rest period, but that was the start of my musical interest, because we had records played to us on a gramophone on the old verandah, to make us go to sleep, but I never did. I couldn't see the sense in lying down wasting an hour when there was so much to do. So, many times the elderly lady came over and read softly to me so I wouldn't wake up everyone else, but this soon stopped, and I had to conform.

It was an exciting day when I moved into the older schoolroom. I was nine years old. I had my first desk all to myself. I opened and shut it quite a few times before I could really realise the significance of it. I can remember very vividly that day, because I was so proud of myself, until my teacher gave us multiplication sums on the blackboard, which I couldn't do.

Our bedrooms and lounge room were being used as treatment rooms, and lack of space became a big problem. There were more and more cerebral palsied children who needed treatment and education as parents, and some doctors, heard of The Spastic Centre. This made it necessary to build onto the existing house and grounds. As there was no money, this was done by fathers and voluntary weekend helpers. The Centre was growing as more and more spastics joined us. Our buses were now old Army ambulances with paid drivers. We now had more medical staff, two more teachers, but much more money was needed.

At weekends my father, Robin and I went to the beach a lot, because it was felt that the water might make my movements better and stronger. Robin held my feet and my father my top or my arms, and swung me in the water and I had great fun. One day Robin and my father left me for about a quarter of an hour in a hole in the sand, and some boys came by and threw sand in my eyes and face. My father never left me there again.

I got the blame from my teacher for messing up the schoolrooms on weekends, when it was really Robin, so I used to growl at Robin constantly. We went to the pictures a lot on Saturday afternoons. During weeknights I listened to my radio, mainly for the 'Argonauts', a creative children's programme run by 'Jason' and his 'Argonauts'.

The ages of the children varied a great deal, and we were not in classes of the same age group as in a normal school environment. This did not worry most of us, so long as we were learning and doing real school work.

Owing to my physical handicap, I still could not hold my head up, nor could I sit in an ordinary chair because I

was so floppy, so they made me a plaster front collar and a heavy leather back brace, and sat me in an upright chair fastened at the back, with straps to hold me up. The back brace had straps which did up over my shoulders and made me so sore under the arms as I was so thin. The physios used to rub them with soap and water to help relieve the soreness. As well as all this, I had short calipers. I hated them, but there wasn't much I could do. I think my hand movement was better then than it is today.

In those days physiotherapy was rather different from today. All movement was controlled and every part of your limbs was stretched, and it hurt. Speech therapy was just a bore. However, occupational therapy I liked, because I was making things.

Like most other children I wanted to walk, and the physiotherapist who I had at that time almost had me walking on crutches which we named 'Ginger and Minnie'. She stuck a picture on each crutch. Then, much to my disappointment, she left, and so did my walking.

Physiotherapy was sometimes a very painful effort then, but usually I became very friendly with some of the physios and was able to try a bit harder for some of them. Looking back, I don't think I tried enough in those early days to improve myself. Occupational therapy was making things like baskets, weaving – that sort of thing to exercise your hands.

Speech therapy was still not expressed in a systematic way, and consisted of breathing and making sounds of letters. I must admit that perhaps I didn't try very much, mainly because of lack of improvement. I couldn't see any sense in doing it, although my speech was a word at a time; or some signs made by my face, hands or legs. Like wrinkling my nose when I didn't like something, moving my jaw up and down when hungry, and sticking my tongue out when thirsty, or when I didn't like someone (when they turned their back).

At this stage, I had practically no speech except for a few words which would pop out, however, in the middle of the night I used to wake my father and ask him all sorts of questions, because I was totally relaxed and could speak quite easily. I did this so that I could catch up on the things that puzzled me at school. I did it for ages and ages, until I realised what it was doing to my father, with an hour's conversation at two o'clock in the morning. Yet, during the day I had to use signs, the odd word, and later a communication board. My friend Julie was a very bad athetoid and she couldn't keep her limbs still, but she had good speech and she used to interpret for me, so our friendship grew.


My interest in the Argonauts continued. By writing, drawing and generally communicating, the listeners, from seven to seventeen years old, could become Argonauts too. I was 'Ismeny 3'. It was a programme of participation in which you learnt things. One day when I was only eight years old, the radio people from the Argonauts came especially to see me, which was very exciting. We only had one radio at that time. Robin had her shared time, and I had mine. Actually, the radio taught me a lot of things, and still does.

About a year after I moved into the senior class Julie came up too, and from then on we were constant companions. I had an incurable sense of humour, and Julie made me worse, so I was always getting into trouble with the school teacher, and Julie was to blame. It was said my laugh could be heard right up to Queen Street hill, because I could only laugh on my indrawn breath, and it came out as a funny kind of crow that made everybody else laugh too.

Another big thing happened to me at that time. I went to my first ballet in the Mosman Town Hall with my parents. During the interval my father asked me how I liked it and I said, "He's got no trousers on!" – not having seen a man in tights before. From that night I developed a great love of ballet and it has grown so much that I've always wished I could have been a ballet dancer. The older children went to the Symphony Concerts at the Sydney Town Hall and my teacher, when I asked if I could go when I was eight, said, "When you are nine, Jenny Wren, we'll take you". So I attended these right through school days, and grew to love music more and more.

I was always a child who liked to do things with my hands. In my spare time I made things. I painted and drew, and if I thought I could not do something, I would keep on trying.

I was always anxious to go out and find out for myself what the world was all about. Fortunately, I had parents and a sister who understood this. However, as The Centre grew, my parents had more to do overall to keep it running and to find the money, and so I was fortunate enough to have friends who took me out. One of these



was a voluntary helper who had a mildly retarded boy and two other boys. I went to their home on weekends. They all treated me like a sister and we had much fun together. We went swimming, and the boys would take me in and make me float. Their father every morning put shaving cream all over my face while I was in bed, and I had a hairbrush, and I hit him with it, in fun. The boys did everything for me and made me do things too. They were just like big brothers and always have been since then.

I went and stayed with Julie too. We would commandeer her parents' bed. We would wake up in the middle of the night, talk, giggle and laugh. Her mother used to complain, but we'd still do it. Then Julie came to stay with me; we formed a very firm friendship. Julie used her feet to do practically everything. She could not use her hands at all, and had sticking plaster on her fingers to stop them rubbing together. We had a lot of fun.

Our schooling improved as the years went by. We got hold of three old IBM electric typewriters, which used to 'blow up' regularly, and a few adding machines which were specially made with letters not numbers. These were used as typewriters with rolls of paper instead of the ordinary sheets. We also had magnetic boards with letters on magnetic blocks on them. This made it easier, but having so many children who needed special attention, we had to share these communication boards.

Our teacher was very strict about behaviour, and did not have any favourites at all. I was not the boss's daughter to her, so when she gave us a lecture on anything that we had done, we sat and took it, our faces down low. I was in later life very pleased that she had been so strict, but underneath she was very soft, like the time I had some sweets in my desk and she caught me eating one. She just said, "Don't you think this is not the time to be eating sweets?" From then on I didn't have any more in my desk.

We had occasional Bible reading, and one boy was a complete heathen. David was very handicapped and without any speech. He laughed and giggled and the teacher would put him outside the door. If anyone else giggled at David, they were put out too. When I first knew her she frightened me to death, but much later on I became less scared of her.

We went out a lot from school. To the symphony concerts at the Sydney Town Hall to which all the other schools went, and if any of us made a noise woe betide us the next day. We went to other places like the Art Gallery, the opera, ballet, the Zoo and other very different places. I think that this was her way of widening our horizons. We were of all ages - from nine to sixteen and very handicapped. I cannot think how she managed to cope with all the problems.

The next day, we would either have to write out a description of the outing or make some verbal comments. We were all at different levels, which didn't matter a great deal to me at the time. She knew us all, and she catered for us one by one. She never expected the impossible, but she expected the possible always, so that made us respect her and take what responsibility we could. We had the same subjects as other school pupils - English, maths, history and geography, as well as other things. She gave us the widest education she could, for which I am very grateful and always have been.

The new school and medical treatment building was opened in 1949. Then more children came, and many more outpatients were coming too, so we took on more staff, with better facilities. In 1952, even this building was not enough, so we took off the roof and built on to that again. Because there was not a road from the top school building to the new medical building further down the hill, we had to be transported right round the block in buses. These had Morris motors, and the seats had been specially fitted inside for us. Many times I used to fear falling off the seats because, living at The Centre, the only time I went in the buses was going to and from school, and I hadn't learnt to balance myself.

Things were changing, and ideas were changing. Physiotherapy and posture, particularly. More emphasis was put on stretching muscles, holding them with metal braces, as well as our schooling. Instead of having treatment each day for half a day, we now had a day in the week when we stayed in school all day. This was good, because I got more out of it. Even so, I still needed to rest in the middle of the day after lunch, for an hour on a bed outside the schoolroom.

Julie and another girl needed the rest too, but to rest and relax was harder then because Julie would start me off laughing about something. Our teacher would come out and blow me sky high for making a noise, because there was a lot of work going on in the other schoolrooms around us. So we stuffed handkerchiefs in my mouth to

make less noise, but even so I still got into trouble each day.

There was a panel of dentists who each gave half a day weekly; they still do, which is rather wonderful. Teeth care for us is of the utmost importance, because of their effect on speech, so we had a room set out like any other dental surgery. Each week there was an anaesthetist, and while he was getting ready the dentist did some of the other CP, then they did the other patients together.

My first anaesthetic was given on the dining room table at Bondi when I was six years old, with a terrified anaesthetist, a terrified dentist and a terrified patient! From then on I knew, if I didn't have any breakfast and my parents were making a special fuss about organising other things, I was going to have an anaesthetic. This built up such a fear of the smell of ether that, even now, I cannot control my reaction to the smell. At the slightest whiff of ether I have just got to get away from it. By the time I was fourteen, I decided to try without a general anaesthetic for my teeth. The first time, I met a very nice dentist, calm, cool and collected; I cried a little, but still, that didn't matter. I had my first front teeth filled without the injection, and from then on I never had another anaesthetic for my teeth.

At thirteen, I was growing up and I went into town with my parents to see an orthopaedic surgeon. I was a most modest girl. He wanted me to strip, but I kept on my singlet, and when he had examined me I was dressed out of the room where I waited for my parents to come out. That night I knew something was going on and at first my mother refused to tell me, saying it was all right, don't worry. Anyway, after a lot of pushing I learned that I was going into hospital the next week. After I got over the initial shock, my father explained to me that my left hip had come out of joint, because it had not been required to bear my weight in walking. To get it back the doctor was to 'prick the muscle'. That meant cut, but I didn't know; to loosen my legs so that I could part them. We had an old friend who was a trained sister and who had nursed Robin through rheumatic fever, and it was arranged that she was to look after me.

A few days, later we all went up to the mountains for a bit of a break with friends; Julie and her mother came too. This was to build me up for what I had to go through later. Then I entered a private hospital. I had a big room to myself overlooking the harbour. My mother made sure that I heard her say to Sadie, the sister, 'Jen likes to know things, so will you please tell her whatever you're going to do?' The night before the operation Sadie prepared me, wrapped me in cloths, but she had to use ether for the sterilising. I slept well that night, but was woken by another night-time special sister whom I didn't know. She did the same as Sadie when preparing me and used ether, so I poured some of my precious 'April Violets' perfume onto a hankie and held it to my nose. I never used that perfume again.

About 8.00 a.m., they carried me up the stairs with four nurses each holding one corner of a sheet, to the theatre on the floor above. My parents were there, but they were not allowed to come up. I was laid on the operating table and given pentothal, which was the best part of all.

I didn't know what hit me when I woke up. I was lying on a frame which had rubber padding. It came down from my neck to my feet, but my legs were stretched so wide apart that they weren't part of me. They were bandaged onto the frame, with my feet straight up against a piece of calico attached to the frame, which made me lie straight, but it was so painful. I was in so much pain I didn't know what I was doing. There were no relaxing medications like we have today, so it was positively excruciating. I don't remember much more about the day. I think I was so dopey that I woke and went back to sleep. However, I do remember as I came out of the anaesthetic, there were flowers where I could see them. That night I just screamed and screamed with pain. The special sister I had with me didn't know me very well, and tried to do what she could to ease the pain with an injection of morphine every four hours or so. I remember well that, one time when I was awake, an elderly sister from the hospital came into my room and said to the sister, "Can't you keep her quiet? She's waking up the whole hospital." I remember thinking to myself, if you were here where I am, what would you do?

The next day and night were just as bad, because I just could not stop the spasming at all, with the pull on the muscles of my legs, my feet and back. We tried everything, and Sadie was marvellous – hot water bags, ice, pushing my head right forward with pillows, and just moving me a little bit where she could, but every movement hurt like mad. Then on the third day, the doctor came and moved my legs further apart still, which made it even more traumatic.

By the fifth and sixth day, I was getting used to the position and didn't have quite as much pain, and was settling down when the doctor came again and moved my legs even further apart.

During the week I was in hospital one of the nurses told me that there was a boy in a frame, just like me who had a similar operation, so we sent each other messages via nurses and sisters. I never saw John, but he must have been going through the same thing as I was.

When I was told I was going home in an ambulance, I was quite thrilled at the thought, but I was still spreadeagled onto the frame, and that didn't allow any modesty at all. Sadie wrapped me up tightly in a blanket and then two ambulance men had to carry me on a stretcher, but they had trouble getting me through the doorways without tilting me painfully and I began to wonder if I would fit into the ambulance. When we were nearly home Sadie asked the ambulance men if they would just blow their siren for me at the top of the hill. I got a great kick out of this! When I was being carted upstairs some of the kids from school were lined up all the way to my room. My bedroom was so filled with flowers that there was hardly room for my legs and me. I was still in a lot of pain, and being moved didn't help either, but by the next week it wasn't so bad because my muscles were getting used to the position.

Another problem with all this pain was that I couldn't get any words out at all. Not even yes or no, so I used a wink for yes and either a screwed up nose or head shake for no, with all my other signs. About the end of the second week I was put into a smaller frame which only came up to my hips. My legs were still fighting against the position of being tied so wide apart, and at even the smallest movement I would yell. I wasn't used to sleeping on my back, so my father used to tip me on my front, which gave me some relief. I got a bit more sleep, and he slept in the room with me.

The third and fourth weeks were better, and almost every day Sadie moved me onto the balcony to get some sun, as well as get me out of the room. She read to me, played games with me, or just was there. Julie came up every lunch hour and brightened me up for the day. Everyone was in and out and one day I expressed a wish to my teacher that I would like to go back to school, so they arranged for me to get down the stairs to the schoolroom for a couple of hours a day.

After five weeks or so, I had to be taken off the frame. This meant that for ten minutes a day the physio came to move both my legs. Oh boy, did it hurt! My right leg, once it was undone from the bandage, used to jump up at the knee, and this made me frightened to give it at all. I would scream blue murder at the sight of the physio, but gradually she got me off the frame. I don't know really which was worse, going on the frame or coming off it.

For the next six months any small movement, particularly in my left hip, used to hurt and crack painfully, but at least it helped my hip not to go out as far as other people's did. My right leg still used to jump, so, until I had enough confidence and control over it, we tied it onto the other one for my bath and dressing.

At that time there was a theory that the more braced one was, the more one was in the correct position and the better the treatment. So I wore a full collar to keep my head up, a lighter corset in place of the old leather back splint, and what they called a pelvic control brace. It was a heavy aluminium structure which came around my hips down to my feet, fitting into boots on either side, and because I had been on the frame they put a bar in between my knees to keep them as far apart as ever. The brace was jointed at the hips, knees and ankles so I could move my knees and hips, but this meant a modification of my chair. The chair had a great block of wood in the front of the seat between my knees, to stop me from slipping forward. It was uncomfortable, straight up at the back. However, it didn't give a modest girl a hope of being modest, and I was forever pulling my skirt down in the front. The brace had to be taken off while I had physiotherapy and some of the other girls had to have wardsmen to take their braces off, but I refused.

Physiotherapy was still aimed at straightening one's back, arms and legs, and was most uncomfortable. I became very attached to a physio who looked like my sister Robin, and I found that I did this with some other staff, too. I dreaded new people – mainly, I think, because of my speech difficulty. If I couldn't get out what I wanted to say, I sometimes asked in school if I could write a note, so that I could get my thoughts across, and generally, Mrs Kerr would agree.

One day in school, I was asked to read something from the blackboard, but my eyes would not follow the line from left to right. We didn't know why, or what had caused it, but it did affect the speed of my schooling so

much. Someone had to read everything out to me, and that made it slower. Then we noticed that in very strong light my eyes became stuck to my right side. This was through spasming of the scanning muscles of the eye, and it affected everything I did. The only way I got any relief was to put something over my eyes for a time. This happened at the Town Hall orchestral concerts, because of the bright footlights, so Mrs Kerr would sit behind me and put her hand over my eye, for hours and hours. Sometimes it took time to relax them. The spasming of my eyes meant I couldn't follow a line of print from left to right unless I turned the book sideways. I avoided reading whenever possible; we tried everything to stop that happening, but the eye doctor really didn't understand what the spasming was all about. In fact, several times I felt like hitting him, because he talked to me like a baby. If there was one thing I couldn't stand, and still can't stand, it is being spoken to like a baby or a nong-nong.

I was developing independence, or trying to. As my parents became busier and busier with the development of The Centre, and my father had his own job to do as well, I just had to make my own decisions, although I asked advice when it was something really big. It was hard, but I am glad it happened like that. I was stubborn too, and had a strong mind of my own.

One day when I was about twelve, the midday meal, with pumpkin, was set down in front of me. The schoolrooms were our dining rooms at that time, and an occupational therapist was in charge of feeding. I decided not to eat the pumpkin because I didn't like it at all, so I ate all the other vegetables and left the pumpkin. I sat looking at that pumpkin for an hour and a half, in tears. No matter what the therapist said, or did, I would not eat that pumpkin. So finally they took it away. We had a tuck shop where the voluntary helpers sold sweets and, as I love sweets, I wasn't allowed to buy anything at all that week. After that incident Mrs Kerr came into the room, and I can still hear her saying to me, "That was a silly thing you did." That was all she had to say. The next time I ate a little bit of it, but hated every mouthful.


I was always industrious with my hands, so I used to wake up at 5.00 a.m. and make things – basketry, draw, paint things like coathangers and flowerpots, play with my ten or eleven dolls, have a tea party in bed, or make things for my friends. I found other things to do, and these were done in bed because I was completely relaxed at that time of day. My father would sit me up and then go back to bed for an hour, and then have breakfast, after which either my father or mother would come and give me breakfast in bed, bathe and dress me for school. However, my father was always late, and I would get a glare from Mrs Kerr every morning when I wasn't there at nine o'clock.

As my mother became more and more involved with the administration of The Centre and my father had a position in a big firm in Sydney, we had a series of housekeepers. Most of them were very nice and good to me and Robin, so the first thing I had done for me after school was to have my brace and collar taken off, have a drink, and lie on my lounge. The family dinner hour and after was very precious, because it was one time that we were all together. We had a lot of fun.

The Centre acquired a small house at Cremorne which was used for country children to stay for their treatment and education. We had a Matron who had a spastic son who was a holy terror, to say the least, but his saving grace was that he was intensely musical. Gradually, when our parents had to go out at night, Robin and I would spend part or all of the nights there, until one night when I was about fourteen, I said to my parents that I was not going there in my night clothes any more as I felt I was getting too old. After that, I often stayed there overnight. Sometimes I stayed up with the mothers of the children, playing poker or something else, and occasionally slept on the floor in the hallway, because there were sixteen children there, plus the Matron, in a very small house.

I got very attached to one of the sisters and I felt that she let me down, which hurt a lot at the time, and surprised me too. As I have been hurt by other people over the years, I built up a little wall, without knowing it. When one is handicapped one tends to have a sixth sense about some people. I have had it most of my life, but one has to cope with it the best one can. The sisters were generally happy-go-lucky women. This made it a home atmosphere. I'm very glad that I had those years, because it was getting me ready for life outside my home. It was hard for me to communicate, so I got my father to write out a few hints on the way to dress me, to position me for sleep, and others like my 'yes' sign.

By the time I was fifteen years of age, my right hand started to spasm, and the only way I could get relief was when my father's strong hand held my thumb out and forced my hand to open wide. My spasming had increased to such an extent that I couldn't use my hands for some things, which was very frustrating, because I had been



using them very well for some time. Although the medication helped a lot to relax me, my right hand, which was my best hand, was cramping in the palm. It was so strong that sometimes my father could not force my thumb out to give me some relief. At first I thought that it would pass, but as time went on it got worse, so I had a number of plasters and splints over the years. The plaster seemed to help more than the splints, mainly because the splints used to press painfully on a little bone inside my thumb. This meant I had to change everything over from my right hand to my left hand, to do all kinds of things. I was determined that I would not lose the use of my left hand, so I still did as much as I could with it.

My right hand went its own way, usually in a plaster cast. It was at times embarrassing, for it would swing out and hit people when I didn't want it to. We had a babysitter at one time whom Robin and I didn't like much, but we put up with her. One night as she was rolling me over to go to sleep, my right hand which was in plaster and quite heavy, swung out and cracked her on the lip. Naturally enough, she didn't come back.

During this time, too, I had to have bands put onto my teeth to straighten them, and glasses to help my reading. So it was a standard joke that I was braced from head to toe and only my ears were good.

One day when I was seventeen I had had a plaster off in the morning, and after lunch my hand started to hurt. Mrs Kerr came over to ask if I would like to go down to physiotherapy for some help. I couldn't get 'yes' out, so the automatic wink came. I didn't know she understood my wink, but when I realised that she did, all of a sudden she was not only my teacher but a friend.

I began to realise what a difficult time lay ahead of me, both physically and mentally. I was doing a lot of growing up. Added to my own physical problems, I experienced the same heartaches and the same problems as any able bodied teenage girl. I wanted to do the things I felt they were doing – things like wearing makeup and pretty clothes, going to the pictures, and wanting to go out all the time, but I just had to accept things as they were, which was frustrating and terrible. I went out quite a lot from school, but on other outings like parties I just had to sit, because of my lack of speech, and hope someone would come to talk to me. Consequently, I became a bit shy; however, I fought this and conquered it after many years. My speech was still a barrier in communicating with people. When I couldn't get words out I started to spell them out by pointing to letters on an old typewriter which I used to record my schoolwork. It was very temperamental at times and used to blow up occasionally, but it was a good friend.

In time, instead of the typewriter, I got a card with the letters of the alphabet on it, to communicate with people. We called this a communication card. I found I could make myself understood better with this method, especially in school.

When I wanted to say something, I found if I said it spontaneously the words would come out, more quickly and more clearly, than if I stopped and thought about it. Nobody, including myself, knows why this happened. Unfortunately, my spontaneous speech didn't happen very often. In the end, I just used signs frantically and hoped people would understand me.

We were experimenting with relaxing medications about this time. At that stage, I would do anything to stop my spasms, so I tried some of them and found that they helped me, but only very slightly and slowly. They had to experiment with me. Many times I felt dopey, but it was worth it. I couldn't swallow pills until I learned, much later, to relax my tongue and drink normally. This took years. Also at that time I had throat spasms where I gagged, especially when I was eating. I could not eat ice cream for about eight or nine years, but that, too, I learnt to eat. I always wanted to be a clean eater, but I dribbled. This embarrassed me so much; I wouldn't go to a restaurant for a meal because of the gagging and dribbling. I wore a hankie under my collar, tucked down outside the collar, to make the collar seem less obvious, as I was embarrassed about this also. When I was about nineteen, I started to wear lipstick every day, and gradually I controlled my dribbling. Then I controlled the gagging when I was about twenty years old.

Due to lack of space, even with the big new building, our bedroom and sitting room were being used in the daytime by speech therapy and occupational therapy, or anything else that fitted in. That was the reason for my parents' decision to build our own home. Every weekend for about two and a half years we used to go to the block of land we had chosen in Seaforth. While my parents and Robin cleared it, and built the main shell of the building, I either sat in the car or in my wheelchair feeling so useless. Father built the whole house except for

the plumbing and electricity. Mother did all the bits and pieces, like painting the whole house, inside and out. During this time no one connected with The Centre came and helped, which made me mad because my parents had helped them to build The Centre at Mosman and were still engaged on building the Country Children's Hostel on each Sunday. However, this didn't seem to matter at all to them, and on they went. We moved in on Boxing Day 1954, without the house being finished, so every spare moment my father would do the woodwork as well as other things.

It was quite sad leaving The Centre because my mother insisted on me getting rid of all my dolls. However, I was able to save one. For Robin it was worse, because she had to give away her mother cat who had produced what seemed like one hundred kittens, throughout the five years we had had her.

The first thing we all noticed on entering our new house was the lack of phones, which used to be going day and night at The Centre. There was also so much space. Everything was ours. Robin and I had separate rooms. Mine was eventually pink and mauve. For me, it was an entirely new life. I had bus trips like the other kids to The Centre, picking up people on the way and going home too, instead of just going upstairs. I was pretty tired at first, but I soon got used to it.

My grandparents visited us when our home was being built. My grandpa was a carpenter and joiner in his youth; despite having only one leg, he was helping my father with the handling of the roof timbers, and knocking in nails to the floor. I hadn't seen him since I left Perth, and all I could remember of him was his mop of silvery white hair, and his wartime sign for victory with his two fingers, and he was like that still. My grandma never missed sending Robin and me two dollars for our birthdays.

The night before they left we gave them a party and I was dressed in a very pale pink organza dress, so grandpa sent us six rose bushes for our garden. One of them was a very pale pink, called 'Madame Butterfly', and he said in a letter that that would remind me of him. So I developed an interest and love of roses.

My education was not going well, mainly because of my eye spasms, and I couldn't get things down on paper, only with my electric typewriter which used to break down occasionally, but there was nothing I could do about it, so I just went at my own pace as with everyone else in our group.

We started a senior class Social Club, and this is where I started to learn about people being different from me, because I was the President for a few years. Mrs Kerr guided us without controlling the Club. We had parties, and I tried to get different members to do what I considered the right things: welcoming our guests at the door, taking them inside and handing around food, but I found myself being the only one who would do it. So when the next election came I resigned, but unfortunately when the next party came round everything was just the same. So I decided to try to get back into it and stand for the next election. Again I was back as President. I learnt a lot about organising, planning, and patience from the Club.


Julie was away from school quite a bit for about two years. She had various things wrong with her health, but at that time I did not know how ill she was; she came to school when she was all right, and she would tell me what the handsome doctor did to her. Being a CP or a handicapped person does not mean that one cannot experience the same feelings as any other young girl or boy, or the same frustration, and the same desires. In fact, I think one has more of these.

One morning, when I had just turned nineteen, Mrs Kerr called me into the office and told me there was a new group starting the next year and she asked me if I would like to go there. She asked me to think it over, which I did, and I realised I was not getting as far in my schooling as I would like, so this could be a good move. However, Mrs Kerr told me that Julie was not going to join the group immediately, which was a blow, but I knew she would get there as soon as she could.

I started to cram the schoolwork in as much as I could. I got up to first year English and sixth class maths, and other subjects.

One Monday morning in that November the phone rang at home just as I was waking up. I couldn't hear what was being said, but I sensed that something was wrong. My parents came into the room and told me Julie had passed away – her heart had given out. My world seemed to crumble. I went to school that day, and Julie's lounge was carefully moved out of the schoolroom after we got there. It was a horrible day altogether.

The next few months were awful too, so I was rather pleased to get upstairs into another environment with the



new adult group, although I was quite lost for a long time. I then met my new physio and thought she was quite strange at first. She used to ask me if she was hurting me, which very few physios had asked me before. Anyway, we became friends, and gradually understood each other very well. The adult group, as we were called, comprised nearly all the senior class, with an occupational therapist and an aide. Apart from physiotherapy and speech therapy, we mainly did what we liked, such as writing letters, sewing, reading, carrying on our schoolwork, making baskets, etc. We earned our first small amount of money by doing contract work, although none of us was very keen. Mimi, my physio, spent her lunch hour with me, and through my conversation board talked about anything and everything. Gradually, as we got to know each other, we went out regularly, and this was good for me as it got me out of myself.

We had discussions on ways and means of getting people to come to us. Miss Ellis, our speech therapist, told us "Because you are in a chair and can't go to people, you have to draw them to you by radiating your personality". How right she was! We talked about showing appreciation for things done for us. We all agreed that a smile could say 'thank you' if we couldn't get the words out. This adult group taught us a lot about getting on with other people, and it was good for all of us.

I know other people experience the same feeling, but when you can't talk to people easily, it makes it doubly hard, as they stay away from you. Some people assume that a person who walks unsteadily or sits in a wheelchair is also affected mentally. Others, in speaking to adult spastics, assume a patronising manner and treat them like children. Still others are sorry for us and show it. There are people who can talk easily to us and treat us as they do everyone else. We like to talk to people, even though it takes a long time to get our words out. We realise there are people who are frightened of embarrassing us, and we understand why. We are normal thinking people, inside our handicapped bodies.

We have the same ambitions, the same capacity for being hurt and for being happy and sad, as able bodied people. We just want people to speak to us and treat us like anyone else they meet for the first time. Too much notice should not be taken of our disabilities. If people don't understand what we are saying, we generally have our communication cards within reach. We can use them to spell our words, but it takes time.

I was always a bit shy and frightened of people because of my speech difficulties. Then there was my laugh, which was loud and funny. Instead of breathing out when I laughed, I breathed in. In my early teens, I wouldn't accept the fact that my handicap could prevent me from doing things that other girls did. I didn't want to be different from any other girl. I wanted to go dancing, surfing, ice skating and play tennis. Then quite suddenly when I was seventeen, I started to understand my limitations. I accepted the things I never would be able to do, such as walking.

I began to direct my thoughts and energies toward the things I could do. I accepted the fact that I would never walk, but I still kept on trying. It wasn't easy to face up to these cold hard facts. It took years. Out of all this turmoil sprang a new realisation that there were things with which I could fill my life and compensate for my losses. This gave my life a new meaning. As time went by, my interest in people grew and grew. With my speech difficulty I found it very hard to mix with people, but I wouldn't give up. My one ambition was, and still is, to see the integration and acceptance of spastics into modern society, as people.

My twenty-first birthday party was one of the happiest I had had. I always had a party for my birthdays – always – but this birthday meant far more to me than any other. Friends travelled from all over the State for it. Although I was spasming badly all through the evening, this didn't spoil my enjoyment of it. I had written a speech by myself and Mrs Kerr read it for me. Like other twenty-firsts, there were about eight speeches from various guests. Being twenty-one was so important to me, especially as I could vote, which I had been looking forward to for years. I felt really grown up.

About nine months before, I had talked to Mimi and another therapist about going for a holiday to Melbourne. They were both sworn to secrecy until my twenty-first, but mother, being my mother, guessed something was cooking, and I was rather pleased that she did find out. Boxing Day 1959, I found myself up in the clouds drinking brandy and on my way to Melbourne for a week. This was an experiment to see how I would stand up to travelling as I wanted to go overseas some day. The girls were wonderful companions. Our trip was fun and did me a lot of good because the girls treated me just the same as they treated each other. They expected me to do my share of waiting for them, as much as they waited for me. We all decided where we would go and when.

They teased me about my poor taste in food and wine when we went out to dinner. We were companions the whole time. This helped me to overcome some of my shyness. I found myself saying things like 'thank you' without effort to anyone who helped me.

We spent the first day around the city of Melbourne, and had arranged to have dinner in the dining room of the hotel. It was Saturday night, but fortunately everything was pretty quiet. I felt as though everyone was looking at me, and to make it worse a violinist who was entertaining the guests came over and played mournfully in my ear. I didn't know what to do, so I smiled, which was a mistake, and he went on and on. It was my first experience of this kind of living, so I was a bit overawed at first. I'd not eaten in public for years, because I spilt some food and I felt very shy and embarrassed, but at the end of the week, I felt I could eat anywhere. I had promised myself I would have oysters every night, which I did. We went out every day and night, except one. On the Friday night, Mimi had a telephone call to say her mother had died suddenly, so Mimi went home early on the Saturday and we followed later that day.

When we got home, a miracle happened – my speech was freer and so much more fluent. I was able to talk like mad for some reason. No one knew why – even me. Of course I still needed my conversation board at times, but not all the time. It was like a miracle, and as the years passed it got better and I could more or less hold a conversation with people. I also had a lot more confidence; I don't know if that had something to do with my improved speech.

My father was determined to build a workshop for the new adult group, which included me, and he picked the site down the hill from the Country Children's Hostel. During the next few months there were a lot of rumours going around about what the adult CP would do – salvage, laundry, piecework, process work, making things, typing.

While on business at a large factory, manufacturing relay sets for the Postmaster General's Department, my father noticed the machinery they were using, and he began to think there might be a way of setting it up for us. This business was about to close down, so he persuaded the Board of The Spastic Centre that this sort of machinery could be used by both handicapped and able bodied people, working together.

My father had organised a gang of 300 volunteers to build the workshop and to complete it in one day. It took several weeks to get the materials together, and then he chose one Sunday to erect the building.

I was staying in the Country Children's Hostel, and I tried to put on a demonstration of what the adult group was doing. However, all my special friends didn't show up, and to make it worse not many people came to see our display. By the end of the day, I was feeling a bit jaded. My father came and took me down to the newly finished building about 5.00 p.m. There were a lot of speeches, and then another CP and I were lifted up onto the centre of the floor and my father said to me 'This is the place that you will be working in at Centre Industries'.

This brought tears to my eyes, but I managed to wipe them away. It looked SO BIG – and I was SO SMALL



Neil and Jennifer McLeod