

Jenny Continues Her Story 1961 – 1982

I was thirty years of age when the engineers at Centre Industries developed a push-button electric wheelchair.


Since then, I've had an entirely different life. It was surprising and unexpected, but funny in a way, because after I got my licence to drive myself unaccompanied by my OT trainer, I felt so lonely. I had never been alone in my life. I always had someone pushing me in my wheelchair. It affected my speech too, because the pusher, probably unwittingly took over the conversation with a third party. Now I was on my own, sink or swim. I had to make myself understood without the pusher's help.

When my father told me I would be working in a factory, I was horrified, and told him quite definitely that I would not work there. This I kept on saying for months and months. Early in 1960, a shell of a factory building was erected by 350 men one Sunday, near the Country Children's Hostel. In time, I accepted my fate, as I knew there would be nothing else to do. I was not happy. On 5 December 1960, the Adult Group, which had increased to eighteen, moved into Centre Industries; I was a bit sad because I was ill that day, which meant I couldn't say goodbye to my friends at Mosman.

What a first day! We just sat in a front room, which was the canteen, all day. People kept popping their heads in and out of the doors. The factory workers couldn't take their eyes off us during the meal breaks. We had two occupational therapists and two aides, but even they didn't know what to do. By the end of the day we felt like wet rags. The next day was different. We were in the factory all facing the wall, with the able bodied at the back of us. When I complained about being put in front of a blank wall, I was told the 'big boss' had said that everyone was to sit the same way. We didn't talk - that was a rule. I thought this was silly, but I wasn't game enough to say anything. However, if the same thing happened today, I'd be saying what I thought.

I should explain here, that the instructor who was in charge of the CP Training Unit was a quadriplegic from an accident on the football field. He had been in touch with us at Mosman. Mr Blackler was a nice man, but he didn't quite understand about CP problems. So he and I clashed a lot.

My first job was folding boxes, and my first pay was twenty cents a week, of which I was very proud. I found by the time the morning was over, with the thump, thump of the big machines, the smell of oil, the other general noise, the repetitive work and my own physical condition, I was so tired that it took me all my time to get through the rest of the day. I was even going to sleep at the dinner table at night. So after a while, I asked if I could stay in the canteen and type, which I eventually did. Some days I would fold twenty boxes and other days over a hundred, depending on my spasming and the way I felt. This led to a new type of handsplint because the old one was too big.



In those early days of Centre Industries, the CP were in a sort of difficult position because we didn't know where we were going. We were somewhat segregated from the able bodied, and we didn't know about factory life, and we missed the protection of Mosman. I felt I had to spend some time in the Training Unit each day, just to watch what was going on and to see that the CP were treated properly. We had a CP committee, with two young men and myself, to see to the needs and the welfare of the CP and liaise with Management on their behalf. This Committee is still going, with the same basic ideas. However, the members have changed, apart from me.

Those first six months here at Centre Industries were difficult. We were doing little jobs like counting and sorting, folding things. Then fate had a hand in it - Mr Blackler had a car accident and was off work for four months. This meant that the General Manager, Mr Hume had to take over the Training Unit, as well as his other duties. Within a few weeks, some CP were put onto machines, small presses and other jobs, both in the Training Unit and out in the factory. This was a terrific morale boost for us, mainly because we were working amongst the able bodied, who did their best to understand us, but really they did not at the time.

I was given some flat silver things with holes in them which I later found out were called 'springs'. I was to learn a whole new language, like 'dies' that were not dyes you dye a dress with - they were part of the machinery - and 'cheeks' and 'cores'. A 'cheek' was a square bakelite flat thing, which the 'core' would go through, then be pressed together in the machines.

After the first week, I wanted to surprise my father because he didn't know about me working on a hand press, slotting springs, or so I thought. So I fixed it with Mr Hume that he would bring father around on a set route. However, being my father, he came the opposite way, so I didn't make the impact I wanted. My new handsplint made work easier, but by lunch time I'd had it, and it took a full hour at lunch to unwind and relax, and in the afternoon I used to type.

I learnt that you were 'told' not 'asked' to do things, which I hated. I felt that the work was driving me up the wall. It was a whole new life; no longer the protected atmosphere of Mosman School, nor the familiar faces popping in and out of the door. Instead, the grease and oil and the smell of it, and being among able bodied strangers made it seem worse.

Mr Hume didn't know much about CP, and as I didn't know anything about factories, it merited an exchange of thinking; he taught me about factories and I taught him about CP. We worked well together and I settled down. I worked in the Training Unit in the morning, keeping my eyes on the welfare of the CP, then after lunch I typed in the canteen.

Although I talked to them about the problems, I never have and I never will use my parents' name for my own purpose or influence. Due to this, I was sometimes a lone wolf. I will never forget my first pay, which was the grand sum of twenty cents. I spent it all on sweets in the canteen. My pay went down the next week to ten cents. When I asked why, I was told that my production had gone down. It went up and down so much that I never knew what was going to be my pay envelope each week, but I didn't really worry about it. After Christmas we had a further intake of CP, making about thirty altogether.

One afternoon, about two weeks after we began working at Centre Industries, I was left on the toilet at about 3.30 pm. I waited and I waited for the two aides to come back to me. As you can well imagine, there was a lot for the aides to do with about twelve girls. At 3.45 pm I started to call out. In those days everyone stopped work at 4.30 pm and the aides went off at 4.15 pm so by four o'clock I was panicking a little bit, and trying to attract the attention of the women in the factory. We had a very small toilet block, and the noise of the machines was very loud. I was getting in more of a panic, which made it harder for me to yell for help. I was wondering what I would do overnight, and as I got more frightened, I lost my voice entirely. By 4.25 pm I was in a great old state, and managed a few yells, but still no one heard me. Then as the women went out, one by one, I really thought I was there for the night.

I was thinking what I could do. I couldn't move myself because I was braced from my feet up to my neck in aluminium splints. There was no way I could move myself at all. I had support under my arms but that was all, and by this time they were aching. So what could I do? I kept making noises, but there was dead silence except for a couple of voices, outside in the factory. I knew I was to go to the hostel instead of to my home that night because my parents had a meeting. I thought the people at the hostel might ask questions as to where I was,

but then, I wasn't too sure that they knew I was to be at the hostel. I knew I wasn't expected at home.

I yelled, then I started crying. I heard a woman come in to wash her hands, and I thought this would be my last chance, so I tried to yell and the sound would not come out at first. I continued yelling for quite a while and, as she was on her way out, she heard me. She came in, got me off the toilet and fixed my clothing. By this time I was so glad to have someone with me, and to realise that it was all over.

My rescuer did not know how to tilt my chair up on the back wheels to wheel it; I tried to tell her, over and over again. Finally she understood what I was saying and wheeled me up to the front door. By this time everyone knew what had happened. The Sister from the hostel had come down to find me, but she did not know, then, the drama that had gone on before.

The next morning I came down to work and was laughing about it all, until I saw one of the aides crying. She felt terrible, so I tried to calm her down. The other aide was very upset too, so I tried to make them laugh about it, but all they could do was cry.

From then on, there was a bell put in the toilet wall, but not where a CP on the toilet could reach it. It rang in the General Manager's office. We used to bump it on occasions, and we had a message from him not to ring it. Anyway, later the bell was moved outside, and this experience taught me a big lesson, which I used later.

I was always watching for things to do with the welfare of the CP - I was like a watchdog. If a problem came up I would take it to the Committee, and we would take it up with the management. Gradually, things got better for us. Early the next year, I asked the Board if I could have six weeks in which to make the toileting situation a little bit better for the girls. I told them that if they were not satisfied at the end of six weeks, I would be perfectly happy to drop it. They gave me the okay and every opportunity and facility that they could.

There were a number of CP who couldn't balance themselves on a toilet seat without an attendant to support them, and this affected the bodily relaxation necessary. Among these, was a girl named Joy. I decided to do something about her myself. I developed a chair with hinged padded arms which could swing out while the aides were lifting the girl onto the toilet. A padded back was fitted, and a seatbelt securely fastened at the back, so that the aides could leave her unattended. The hinged sides were locked back in position when she was seated. This was my first success, and the girls were very happy. It made the aides' work much easier. A pull cord switch was later added to ring a bell for attention. I then had bars made for the two other toilets. I should perhaps explain that we had a very small toilet block. It had four very small cubicles, and three larger ones, ranging in size. A row of basins stood outside the toilet block. There was a separate locker too, and off that, a rest room.


As those six weeks went on, I found most of the girls could help themselves quite a bit with their washing and make-up and pulling themselves up on the wall bars to go to the toilet. So I gently eased some into doing what they could to help the aides. I encountered some interference from therapists, who thought they knew more about this problem than I did, but they weren't remotely interested until I started.

By then, it went so far that a couple of members of the Board had to be brought into it, because in those days, I just didn't have the confidence to deal with it myself, although I tried to. By the end of that six weeks I was accepted, but I still had a long way to go. I filed my first report, which was the hardest thing of all to do. I didn't know where to start, so I just told my own story.

As that year went on, I felt myself becoming more and more involved with training and encouraging the girls to do things. The aides could not always be with me, which was a bit of a strain because, with a girl up on the bars I was scared, knowing she might topple over at any stage. The girls were scared too, but nothing serious happened, and this was the start of the biggest thing I have ever attempted. I was still very unsure of myself, so I looked for help in my decision making from everyone. Fortunately, I had many good friends and my mother and father to see me through this period, but it lasted a long long time. In fact it took me up until a few years ago, when I really knew what I wanted out of life and have become more and more confident. I think my increase in speech has helped me too.

At this time also, my sister Robin was engaged to be married, and as my wheelchair was so uncomfortable, we decided to make a whole new one for the engagement party.

Expansion of the factory involved a new toilet block so, knowing what some of the girls needed, I had the



plumbing fittings improved in design more than the previous block, in order to give the girls more of an opportunity to be independent. I insisted on coloured things, every shade I could think of, so that the girls would want to do more because of the feminine appearance.

There were three toilet blocks built, one after the other at Centre Industries. Being me, I got myself involved, because I wanted certain things for my Personal Independence training, such as the toilets, basins and taps put in the right positions so that the girls had the full benefit, to make us as independent as possible. I drove the builders and architects crazy because I insisted on certain things, which they thought were not necessary, such as space in the cubicles for motorised chairs to be able to move around, as well as more space for the aides, who must operate from either the left or the right hand side, depending on the physical involvement of the individual CP.

In bed one night, I designed a back-to-front toilet, that is a toilet facing the wall, with bars in front of it instead of on the side wall, so that the girls could just go in and pull themselves up on the bar, without having to turn around on the toilet seat. When I explained to the builders what I wanted, they threw up their hands in horror and said it could not be done. But I was so sure it would work I would not give in, so finally they relented, still saying, "It won't work." However, it did, and several CP girls have become totally independent using it.

For someone like me, with slow speech and not being able to move myself around, because I didn't have my motorised chair in those days, it was terribly difficult to deal with all that went into the building of the washrooms. The architects and plumbers involved were the experts, but they did not realise the importance of things like pipes under basins being put as close to the walls as possible, so that wheelchair steps could go under the 'S' bends, the basins and toilets being placed in the right position, away from the walls so that a CP in a wheelchair can reach the taps or plugs, and toilets placed behind doors for reasons of privacy. All those little things that would make the CP girls more independent. It was a difficult time for me and I got most of the things we needed.

In the washrooms we have every type of tap, every type of cistern, shelves that let down and up, as well as bars on the walls. This means that the girls can learn to be more independent, especially when they go out into another job away from Centre Industries. It does help in their own homes as well; also this is important when they go out to a friend's home, or go to the pictures, or go somewhere else where they do not have as much help.

From the time I started helping the girls to do personal things for themselves, as simple as taking something out of their own handbag, or getting onto the toilet, or have a wash and doing their own make-up, I began to become more and more involved with these detailed problems. So many of us, including myself, had never ever turned a tap on or off, used a key to unlock a door. So I drew up a programme for some of the girls who I thought would benefit from this help. I started with four girls, and now I have twenty-five for half an hour a week, with an aide who is there for safety reasons and to give any help if required.

Some of the girls do not like this much, because they've always had things done for them, and they think it is a bit of a waste of time. Usually, once they've successfully accomplished one thing, they want to try something else. The more handicapped ones seem to enjoy it more; they often do better and are more willing to try, whereas the less handicapped demand much more help. When the girls come to Personal Independence for that half-hour period, I find out what they can do. During the rest of the week, the aides try to help them carry it through.

Fortunately, I have McLeod inventiveness. We have a large safety pin on the plug to make it easier to get in and out, a piece of ribbon on the end of a zipper on a purse, a powder puff with elastic on one side so the girls can hold it and not drop it. The soap is in a net holder so that the soap doesn't slip out of the girls' hands, but other girls don't need the net. We also have several types of lipstick holders, and many other things to help the training of the girls.

The girls might have an idea and we try it out first. If it doesn't work we think up something else - it's a two-way thing. We gradually withdraw these things, then the girls find their own way of managing. I do encourage this as I feel the girls have a right as adults to air their own opinions. The female aides are a vital part of Personal Independence because they carry out the girls' training during the week.

For the few girls who are able to go right through their training and go to a normal toilet without help, it means they can go out anywhere socially, or go into employment and be totally independent. This takes many years to achieve, but when it does happen it gives a lot of satisfaction, both to the girls and to me.

After each session of Personal Independence, I dictate what each girl has done and I write a Yearly Report to the management. Personal Independence is not an easy job by any means and, like everything else, it has its ups

and downs, but it is rewarding to see the least little improvement in anything the girls do, no matter whether it is big or small, and the glint in their eyes when they achieve something, makes it worthwhile. As the years went on, more and more CP were coming here and I was in the Training Unit in the morning, because I was interested in all CP, especially the very handicapped ones.

As well as training the girls, I also train more than twenty able bodied staff aides in the way to carry on the Personal Independence training. This means I must be as close to them as I can.

The aides are handpicked by our Senior Aide and myself, and over the years we've had so many come and go. In this job, I've learned to work with people. I'll never forget how hard it was to sack someone. The things that went on inside of me when I had to do it still upset me, but not now to the same degree. Unfortunately, over the past five or six years I've had to withdraw from the factory job in the Training Unit because I've had so much else to do. I still go in there as often as I can. However, there are other Committee members working in the Training Unit, and we work together much more than ever.

Together with my other activities, there was the CP Committee work to do. Unfortunately, I had many arguments with the Committee. I was always, and still am, very stubborn on the things affecting the CP that I feel should be attended to, but others who were less handicapped did not see the things that I saw in the same way. So some of the original members of the first Committee, after about three years, resigned, and management then appointed two boys, two girls and myself. Eventually after some years that, too, broke up, and our present Committee was appointed. They are very good at their job because they care, and also we had a bigger voice with Mr Hume. This made it a lot easier for me, mainly because I've got most of the same drive that is necessary in this kind of work.

About 1963, I asked our doctor if I could leave my leg braces off, to which she agreed. This started to make my legs, which were like matches, a lot stronger and it did help the spasms. What joy to be free at last of the ugly aluminium braces, with their leather kneecaps and, most of all, the clumsy boots. Now I could wear pink shoes with a party dress.

This started me thinking casually about this need for physiotherapy in the factory, because the doctor thought that some physiotherapy would loosen up my muscles. Eventually we did get one physiotherapist, but inevitably she left to get married about a year later. We then got a full time doctor at Centre Industries, and she recruited four physiotherapists and a male occupational therapist.

Back in the period from 1954 to 1958, there had been more and more meetings at night for my mother and father and, as there was no one to care for me at home on those nights, I went to the hostel. It was called McLeod House because my father was so involved in building it. It took about five years to build, using voluntary help and fathers at weekends. I often went there during the building with my father, because someone very special to me at that time was helping to build it. It has four wings, one for the boys, one for the girls, and one for the treatment rooms. The fourth wing was designed to be a hospital wing, because we felt that outside hospitals did not understand the nursing needs of a CP child or adult, especially as most of them had little speech. However, later arrangements were made for post-operative nursing at our own hostel, so then we didn't need our own hospital wing. That wing was later converted into an adult residential wing. I used to sleep in the girls' dormitory. I found it most embarrassing to be undressed in the dormitory, and then have to be carried out in the hallway to go for my bath. The building was centred around the children whom I loved, and I would take every opportunity to go and play with them.

The nursing routine got me down a bit, though, because it was geared around the children. We had to get up very early in the morning, and then wait at night until all the children were bathed and toiletted before we could be bathed. Also, we were treated like children by the staff and we were very regimented. When the hospital wing was converted to the adult wing as a trial for another hostel, we had a bit more freedom. Although there were rooms along the corridor, I was still in the dormitory, mainly to be a self-appointed watchdog again for the heavily handicapped girls. One thing I found was that we could not sleep in at the weekends because all the beds had to be made, and all the other things had to come first before us, which was pretty tiring. They used to ask me why I looked tired all the time.

Robin's wedding was lovely, and I got myself a big brother, which I'd always wanted. Ron treats me like a sister; no pity, no giving in, and is marvellous in every way. In fact, the first words he said to me when they came out of the church were 'Hello sister.' From that day on, I always knew that if ever anything happened to my mother and father, Ron would see that I was looked after. I would never ever live with them, because I believe they and I have separate lives to lead.

In 1965, we had a visit from an orthopaedic surgeon from Edinburgh, Mr George Pollock. He examined my neck and said there was nothing structurally wrong with it and expressed the view that the muscles needed building up. He said the collar actually impeded the muscular control of my head. That gave me some hope of getting rid of my hated collar, which I had worn for eighteen years. I started taking the collar off for five minutes every day, gradually increasing it to longer until, after eight years of hard labour with a lot of physiotherapy and a great deal of perseverance, I was able to leave it off altogether. The year I took it off my mother was ill, so I was able to relieve her of the task of taking it off when I got home.

In 1969, an American surgeon was here on a Fulbright scholarship, showing some of our doctors his methods of orthopaedic operating on CP. My mother wanted Dr Silver to see my right hand, which was still in a leather splint. This had stopped me using the hand since I was sixteen. She had to talk me into seeing him. I told her flatly I would not have another operation, ever - 'Only if I was dying. But I did go over to Mosman, and Dr Silver did have a look at my hand. My thumb was contracted into my palm much more than it had ever been. He told me just what they could do and he talked to me quite a long time, telling me what the operation would involve. He said to me, "You're an adult, you can decide yes or no, it's up to you."

So over the next three or four weeks I just put it aside in my mind, thinking of it occasionally. Then Dad suggested that he see Dr Silver with me, and over to Mosman we went. Dr Silver went right through the procedures again and again, and told us just what they would do. On this day there was another doctor with him and also our Medical Director, and they were talking quite a bit, with Dr Silver holding the floor. Someone said, "We haven't asked Jenny yet if she wants to have the operation." So I thought a moment or two. I had nothing to lose, so I said, "I'll give it a go."



Jennifer McLeod meets H.M. Queen Elizabeth and H.R.H. Princess Anne.



Audrie McLeod



Jennifer McLeod



Jennifer McLeod

Two days later, I found myself in Lewisham Hospital, which is a Catholic Hospital, with kindness that I didn't know existed in a hospital. I had a special Sister who I knew very well. She used to come in the daytime and stay with me most of the day.

On my first day I thought they were going to take X-rays, or be dramatic or something like that, but it didn't happen that way at all. Everything was so calm, after my last experience in hospital. Late in the afternoon, a Resident came in to check me over, and asked if I'd had mumps and measles and all that, then he asked me how long I had been like this. My nurse, who had a quick wit, said two weeks, and he did a double take. He didn't know what to say, the poor boy, so we fixed him up with the right information. But there is something missing in a doctor's education when he does not know about cerebral palsy at first hand.

The next morning I woke up about five o'clock and was given a cup of tea. Everything was so quiet, it made me feel calm, and everyone was so pleasant too. They wrapped my arm up and wheeled me to the theatre, and I waited outside for about five minutes, when Dr Silver came out and the other doctors too. He said to me, "Do you still want to go through with this?" So I said, "I'll give it a go. If you're game, I am."

The anaesthetist knocked me out, but it seemed ages, and just as I was going out, a nun in a white habit came behind me and put her hands on either side of my head. When I woke up the nurse was there, and they took me down to my room. My hand was in plaster, and Dr Silver had told me I'd feel uncomfortable. That night, every time I pushed the bell someone was there with an injection. Then both doctors came to see me, on the Saturday, which I thought was rather nice, and Dr Silver loosened the plaster a bit. For the rest of the day I was all right, and the following day I went home. I would have liked to stay longer, which I told the Sisters, and they just laughed.

Five weeks later, Dr Silver took the stitches out, and the plaster off. I think that was the worst part of it. Then he gave me a lecture and said, "What we have done for you is to restore the hinge of your thumb to its original position. That is all that a surgeon can do. We cannot give function to your right hand - that is a job for you and your physiotherapist to do. You can't expect to overcome ten years of disuse of the muscles of your hand overnight. You must be patient, but not too patient. You must exercise your hand every hour of the day for six months or a year, until you get back the function you lost at sixteen years of age!" I took his advice, and after a lot of intensive work on my hand I was able to get some function from it. Today I can do things with it just as I did when I was younger. Which is great!

I was wholly set on having an electric wheelchair, but first we had to design and make one that I could handle with my limited finger control, and that was two years hence. As Centre Industries grew, I and other CP were pushing to get motorised chairs, because our hands are not good enough to wheel a manual chair. We got a couple of different chairs on loan from another company, but they were not suitable. In fact, I took one home and wrecked the house by climbing up the wall, because my hand couldn't let go of the joystick. Then Mr Boyce, our occupational therapist, tried to get me a couple of comfortable seats and backs, because I have a persistent backache, but when we tried them out they were uncomfortable. His theory was that if you were comfortable in your chair, it would make it a lot easier to manage the controls, and I agree with that fully. In the meantime, they had developed six motorised chairs, which disappointed me a little bit because I was jealous - they were the joystick type, which I couldn't control.

I was still sitting in a very heavy wooden chair that I'd had for ages, and which had to be tilted to move me. It was awfully hard for everyone, including me. I didn't like to be stuck in the one spot for too long, although I was used to it, nor did I like having someone pushing this great big chair, although it was comfortable for me. Eventually, after about three years of trying to get the right control and the right seating, Mr Blackler came up with the idea of using an aircraft seat, which was just right. It had everything I needed, including an ashtray! Then I finally got a press-button control from an engineer, who thought about it a lot before actually designing it, because he was scared that I'd be hurt, if it went phut!

Once I got the controls and the chair itself with a few adaptations, we started training. We began in the gym, with chairs in the middle so I could get the feel of it. After a while, we ventured halfway into the factory. Each day we would go a little bit further, until we got to know where the awkward spots were. Mr Boyce used to close his eyes quickly sometimes, especially when I went under a ladder, with a man on it, fixing a light. People used to ask me why I never smiled when I was driving, but my whole concentration was on the chair. Half an hour was all I could take. We both ended up back at the gym with taut faces. It took me half an hour before I could

do anything else. I can still see and hear Mr Boyce saying, "Go to your right, go to your left, charge them Jenny, charge them!" I was so scared of bumping the able bodied, especially when they jump over you, but Mr Boyce said not to take any notice. It took me about six hard months to get over this fear.

One day I was feeling good, so I led Mr Boyce up into the lift, pressed the lift button and got out on the next floor. Mr Boyce was having kittens. I went in and out of the desks without touching many, then I led him back down to the gym, again with not a word spoken and his face as white as a ghost. He said to me, "Would you mind telling me next time where you're going? I nearly had a heart attack!" I said, "I did it on purpose; I wanted to try it out." Anyway, two months later I got my L plate licence, which gave me permission to go unaccompanied anywhere in the factory.

In 1966, the first Adult CP Conference was held in Perth. It was the first adult conference held on various aspects of our lives. Four CP, including myself and CP from other States, attended this week-long conference. On the way, we had a look at the Spastic Centres in other States, so we would know about them before we arrived. We reached Perth a week before the actual conference, which was to be held at the Perth Spastic Centre Hostel. As I was getting into the Spastic Centre bus on the tarmac of Perth's airport, I thought to myself - that's funny, no family - then all of a sudden people were streaming across the tarmac, waving and shouting. Hundreds of them were all over the place and all over me, saying, "I'm your cousin; I'm your aunt; or I'm your uncle so-and-so." They all followed us to the motel, and we had quite a gathering in the two rooms adjoining each other.

That whole week was spent in getting to know all members of both families, most of whom I hadn't met since I was a baby. They took us everywhere. I really enjoyed it so much, as up until then I'd just known my family by name only. I was able to leave my collar off some of this time, during the family gathering, which made me feel like anyone else

They had 'McLeod Night', when the McLeods gathered all together. I can remember when I was about two, that one of my cousins who was then a fairish little boy, used to bring me sweets from his tuck shop at kindergarden, and when he too came in there was a hushed silence and I said to Alan, "My God, you've changed!" He had a dark beard and moustache and dark hair. Nevertheless, I still thought of him as a little boy who used to bring me sweets.


Then they had a 'Mell Night' - my mother's family - and the place was packed full of people. I've never been so crowded in my life. All of them were a bit shy, and scared of me, but they managed to get over that. By the end of the two weeks there I could put a name to most of them.

When I got back home I again threw away my communication board. We can blame the four weeks' concentration on my speech, unassisted by my parents, or staff at home in Sydney, who were ready to assist me.

Just before Christmas of that year, we had a tiny little bundle of pink skin arrive in my sister Robin and Ron's household. They took my mother and me down for her first inspection. Every time she moved, someone would say, "Look at that - look at that!" Melissa was all ours, and no one was more proud than her father. Two years later a sparkling, fat little baby boy called Christopher came, but I had learned my lesson with Melissa about not nursing her. Not that anyone could, as she would scream blue murder if anyone apart from Robin or Ron touched her.

When she was just walking, my mother put a chocolate on the shelf in the kitchen, and Melissa would take mother's finger and lead her to the chocolate. This worked wonders in establishing a contact between them. Christopher proved to be a totally different baby, and I made a point of nursing him, so he used to come to me much more readily. Even now, he still sits on my lap and we have a great old talk and he nearly covers the whole of me. Then Jeremy came, and he was different too.

The years have been most eventful for me. What with meeting Her Majesty the Queen of England, Her Imperial Majesty the Shahbanou of Iran, going on a cruise with two friends and loving every minute of it, especially Suva, where we had an Indian taxi driver who was determined to show us everything. He stayed with us most of the day and evening, and he lifted me in and out of the car about eight or nine times during this period. I even found myself being carried into a Fijian Village and placed on a mat on the floor of a hut. It was a lovely day. I found the sea was just as I'd imagined, and completely relaxing.



Two years later, I was off again. This time it was to a seminar in Holland on leisure time activities for handicapped people; we wanted this for our nursing homes. The seminar turned into the motivation of life, which we didn't get much out of because we were the only country who thought work was the motivation of life, so we were a little alone. Still, it was a good experience.

We stopped off at Rome and London and Singapore, and went to see Spastic Centres in these places, which was good experience because it showed us how lucky we are. I learnt a lot from that trip about travelling, people, and fun, and it also gave me a lot more confidence. I know now what I will need when I make my own trip around Europe in the future.

Over the years there have been many changes. Mr Hume left, which was a blow to me, because I knew I could go to him at any time about little things. Since this happened we have had three other General Managers. The place has expanded, not in building size, but in moving departments to give maximum work space. A new complex has been built on the factory for all rehabilitation departments, like physiotherapy, occupational therapy, doctors' rooms, assessment and MODAPTS, and so many other professionals, including our CP Committee room, which will be manned in time when we get more members. The idea was to pull the rehabilitation, therapy, medical, teaching and training staff out of a detached 'clinic' environment and to involve them more directly in the work of the CP in their working environment on the factory floor, and to get some more handicapped CP in our training area. This I have waited for for twenty years. I have always said these people should not be left to vegetate but should be able to go into the factory and feel just like anyone else.

Now, we have an intensive training programme going for those fifty very handicapped CP, and all the rehabilitation staff are involved.

In 1974, we built our adult hostel, the Venee Burges Hostel. It was geared to be a residence for working adults, and we made full use of our new freedom, instead of being treated as older children in the Country Children's Hostel. We were invited to select all our own furnishings and wallpaper. Now we are in an adult atmosphere, we stick together more. We have four dormitories and twenty-eight single rooms, and when I come down from work I know I'm home as soon as I reach the front door, with my own personal bits and pieces, in my own room.

I was called upon to design the toilet areas in our Venee Burges Adult Hostel. I've thought of taking a course in plumbing, but decided it would be too dirty. However, with all the building of the washrooms, I have gained a lot of experience, which I would never have had. At the same time, it has given the CP and other handicapped people more independence.

I have been responsible for the female aides since 1962, with access to and directions from the General Managers of Centre Industries. Over those years, I have been responsible for selecting and interviewing new staff members and dispensing with those who proved to be unacceptable.

I have set up a programme of staff training so that anybody knows their responsibilities and duties. My objective is to instill upon my staff that they are responsible for caring above anything else. They must encourage the CP as much as they are able, to provide personal independence and not to do things that impede it, even though it might take a while longer. We look for people to be interested in the day-to-day work of the department and to be interested in the people. The two major aspects of their work are feeding and toileting.

Feeding - In every way, to keep food off mouths, faces, clothing, table and wheelchairs. This applies to morning and afternoon teas, and lunches. They must maintain the dignity of the person being fed. They must understand why we are doing that in a certain way; it leads us to encouragement for personal independence. The head must be on the mid-line as much as possible. We feed them slowly and carefully. We make sure that they eat enough food.

Drinking - Arrange straws, glasses, paper cups appropriate to the person so that they have the drinks they require, no matter how long it takes. The male CP are fed by the seven male aides. I do not supervise the male aides, but we have a close contact with the head male aide. In addition, there are thirty male CP fed by female aides at lunch, morning and afternoon tea. In warm weather, I send around jugs of water and plastic cups to the benches throughout the factory, so as to keep the dignity of the person under control and prevent an untrained person slobbering a drink over face and clothing.

We have over one hundred lunch orders to be prepared each morning after the chef has advised the menu. The aides collect the food and drink and bring it to the table already cut at a separate serving table, or at the table as required. If there is any doubt about the way to feed, then I go to Mrs Northern, speech therapist, and she helps with the problem.

Toileting - I have been responsible for the design of the female toilets, including the back-to-front toilets, adjustable bars, adjustable seating in the toilets, which are designed with the heavily handicapped in mind. The waste drains of the washbasins have been changed so as to avoid hindering the passage of wheelchair foot supports. Approximately sixty of the female CP have to be serviced entirely. Thirty female CP need to be assisted with dresses and personal needs; the aides help them with hands and face washing, makeup and clothing tidiness. There are approximately thirty who are totally independent. Due to the peaks of traffic, some delays may be experienced corresponding with arrivals and departures, pre-lunchtime and after lunchtime.

Caring - We insist on personal care. That demands time, and we wait for the person. Some people are slower in toileting and some people are slower in feeding, and all of them are entitled to talk. This makes the aides' job harder, but they must be trained to wait. If you have a person whose speech is impaired, it is more important for him to get the message across, irrespective of time taken to wait.

The care taken by our aides could be qualified by the things they do outside working hours. These include telephone messages, shopping, accompanying CP on social outings, visits to their homes for a meal, and the warmth that they exhibit in their personal relationships.

Personal Independence (P.I.) - I have not included my Personal Independence Programme, because I regard that



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as being a plus to my real responsibilities. It might be said that my P.I. Programme is a lot of work for such a little result, but for the persons themselves they don't regard it that way at all. It is just the first step to being able to do things for themselves, instead of relying on other people.

My interest has always been geared to the severely handicapped CP because this is my role in life. This has been very close to my heart for some years. I feel very strongly that the severely handicapped should have the same opportunities to get into the workforce as any other handicapped person, even if it takes years to get there. No one should be sitting around without help to reach a goal just because there is no one working with them to achieve something. Some people think that because a person is heavily handicapped and cannot move or speak that they are retarded, and treat them like children, whereas most CP are intelligent and it is frustrating and degrading to be treated as a child. I desperately hope that these very handicapped CP will be able to be transferred from the training area to the factory, even if it takes ten or more years. Most people want to learn, especially after their ordinary schooling so they can go to University or Technical College, but this is not possible for us because those places are not built for the handicapped, nor are they staffed for us.

Recently, the speech therapist started a communication programme for both deaf CP and others who cannot speak. We believe communication is the most important facet for us in both our work and leisure. Everything is being done to help in this sphere of communication.

We have a very good physiotherapy department, with ten physiotherapists and six aides to help them. As I have had a lot of physiotherapy over the years, I have become very interested in the different techniques, especially the Bobath method, which is mainly relaxation and positioning in the correct way, aiming at keeping that position. This is for adults, but for a CP baby the Bobath treatment aims to get the baby into a pattern of movement which any other baby would use, such as head control, crawling, sitting, and standing. This means a lot to me, mainly because, had I not been born like I was, these babies would not have the opportunity of this treatment and all that the Centre offers.

In 1978, I was invited by the McLeod Society of Japan to take my place in a welfare student exchange programme. It was designed to show to the Japanese rehabilitation world that spastics were capable of working, even though they were heavily handicapped. We were a team of three males and two females. Two of us were in wheelchairs full time, and one half-time, depending on the length of walking to be done. All were employed at Centre Industries – in computer operations, computer programming, a telephone switchboard operator and an engineer's typist. I was, of course, the Supervisor of a team of twenty-two able bodied aides for the feeding and toileting of our 150 CP girls at Centre Industries.

Japan is a mixture of big bustling cities, quiet countryside with rice paddy fields wherever you look, and a background of extremely beautiful mountains. When we visited Mount Fuji, she unveiled herself of her mist and cloud, and on her summit she wore a halo of fresh snow. She had a dress of autumn leaves coloured orange, yellow, red and green wrapped around her. The mountains around her too were covered with mist and cloud, but Fuji held me spellbound, especially as it was my first sight of snow. Sharp contrast to busy, noisy, fast moving Tokyo, which is beautiful in its own way, with 12,000,000 people in it.

All the places we visited were so different, both in scenery and customs; for instance, people bowed more in some places than others. The roadways are narrow and just fitted our bus and another car; the pine trees as well as other types of trees covered the hills. Little houses covered every bit of land available both in city and country.

However, it is the people who make Japan; their hospitality was like no other I have experienced. From when we arrived in Tokyo until we left, everywhere we went there was a multitude of people to help us in any way they could, which was overwhelming at times. I was particularly impressed with the young people who took us everywhere, smilingly and willingly. One day in particular stays in my mind, when we were travelling in our bus and I was sitting in my wheelchair. My head was wobbling, and a young man who was holding my chair although it was strapped down, said to me, "Are you all right, or would you like me to hold your head?" I said, "No thank you, it is all right." Then about two minutes after this I happened to look out the window of the bus, and he unobtrusively had his arm on the bar of the bus just so I wouldn't bump my head. Another day I went into a big shop and as the young man who was wheeling me didn't speak English at all, I pointed to wherever I wanted to go and he took me straight to the place. After the first hour, we had communication.

The older people were just the same, only in a different way, they were very charming and would do anything to make us feel at home.

When we went to each Prefecture or city we had to meet Mayors, Governors, and other important people, and present them with various papers and gifts - and present them in the right manner. They were so friendly and put us at our ease. Even so, I shook a bit!

At our first reception in Tokyo we were late because the bus was late in picking us up from the hairdresser. My mother and father were already there, and as we went into the reception and found our places everyone clapped, and by the time I got to my place it took me all my time to control my tears. That night each one of us had to make a speech. This was the same at each reception. Everywhere we went, we were showered with gifts, which was quite overwhelming.

We had a Japanese night in Sendai where we got ourselves into kimonos. We had a Japanese meal and entertainment, then all except myself had a spa bath, a massage, then toppled into bed on the floor. This was quite an experience.

Another funny experience was when we went on the Bullet Train, because the train stopped for only one minute to let everyone on with our large amount of baggage, three wheelchairs and about a dozen or more people. We just made it, but getting off we did it in twenty-five seconds, thanks to Mr Noda's faultless organisation. The Bullet Train is controlled by computers in Tokyo, so passengers are trained to get on and off very quickly. Mr Noda had our bus driven 400 kilometres to our destination the night before so it would be there on our arrival. Then he arranged for a team of three people to get on the train one stop before our destination. They had assembled all the suitcases in the following carriage, and had organised exit for our wheelchairs and our passengers and the thirty assorted hand luggage and parcels.

Another thing that impressed me, was that at each place we visited our hosts would come with us half way to the next place, and then they were replaced by our new hosts.

Right throughout the trip we visited a number of work places, nursing homes and schools for the handicapped. The work places were quiet rooms where people were making various components for many companies. However, there weren't many CP in these places, only hemiplegics, mainly paraplegics, amputees and a few other handicapped. I was a little disappointed in this. We didn't have time to make contact with these people at all. When we were asked why they were so quiet they said it was the Japanese way of working, which was interesting after being at Centre Industries.


In the main, the rehabilitation centres were big new buildings with everything in them, such as hydrotherapy with hoist equipment, occupational therapy department, operating room, other hoist equipment for the bath, ADL equipment including a wall with a stove and sink which moved up and down by a push of a button, and a toilet with the same thing. There was a Japanese bedroom with the same devices to lower the floor, because a Japanese bedroom always has a step up to it. They even have a dentist's room in one of these nursing homes, and a hairdressing room and so many other facilities. However, we didn't see any CP using these facilities at all.

Then we went into a big room half filled with CP, and we sat in front of them and exchanged names in Japanese. They asked us questions. In one such place, which had eight CP residents who were very very handicapped (some stretched out on beds or trolleys in extension spasm, with their heads turned to one side), my first impulse was to go and sit them up, but I didn't. We were asked how it felt to work. We looked at each other and we couldn't answer. These CP really touched me; I felt I had a bond with them, more so than others who were less handicapped.

The schools were just like ours in a way; the same children, happy little faces, and willing to show you what they could do.

We went to a place they used as an operation after-care hospital for CP and I happened to see a little boy in bed through a window, so I broke away from the party and went into the ward. I just felt I had to say 'Konnichi Wa' and he responded and pointed to his leg. As we were passing the ward again, he waved to me and broke into a gleaming smile when I responded. I carried that smiling face in my mind's eye for the whole of our tour. He just typified the children of Japan.

At the Sayonara Party we each made a speech. Murray stole the show because he gave the whole speech in Japanese! They gave everyone a candle in a silver foil base, then as Mr Noda, who was one of the chief organisers, finished his very moving speech, the lights were put out and the candles we held were lit. The whole room sparkled with the light of the candles. They formed a line on each side of the door, then they hummed or



sang a traditional Japanese song of Sayonara, which was quite beautiful, as we passed through the line of people to the door, and as each one of us got to the door we blew our candle out. This was quite unforgettable.

Although we had a very busy schedule we enjoyed every moment of it. We will never forget the kindness and hospitality we received from the Japanese people.

I've changed too. Not basically, but I am more positive. I am still in charge of the female aides, which is a very responsible position, and on several Committees, but my basic aim is to see that all CP get equal rights, and jobs, and recognition, like anyone else!

A spastic's life is what you make it. It has a beginning and an end, but it is up to us entirely to accept the facts of our lives.
