

Part Five

Conclusion

In any field of human activity, if you make progress little by little, then you can eventually achieve things that you never believed possible. When you are small, you think your Dad is very clever. You think, how will I ever grow up and be able to do all the things he does. Once you have grown up and look back, because you have learnt everything over a period of twenty years, it seems quite surprising that once you thought it would be difficult.

The way you teach children arithmetic is the way you can teach them to speak or to do other things, as long as you take it one simple step at a time and make sure they understand the first step before they progress to the next.

The cerebral palsied, if asked to step from handicap to normality would continually fail no matter how motivated they were. If asked to move a fraction at a time, in a very systematic way towards the goal of intelligible speech, they will be able to succeed fraction by fraction, so that eventually they will be able to utilise the basic neurological equipment they do have, to learn the essential movements necessary for intelligible speech.

Professor G Andrews

The Human Communication Laboratory of the University of New South Wales.



The first intake of children at The Spastic Centre Mosman

If you can't beat them, join them

Upwards of three thousand individual CP passed through our hands during the lifetime of The Spastic Centre, and all of them have a unique story to tell. Some of the stories have been lost by death or dispersal, and some others have been locked away in their inner consciousness behind the grey veil of their inability to communicate.

All are stories of a single, self-determined human being, confined behind the physical handicap of speech and hand function. The resultant thoughts, the memory and the motivation have been burning away, behind the faulty nerve barrier of communication, for all the years of their lives.

Now, comes the great moment – when the magic of electronics and language come together – the restrictions of communication are swept away and a torrent of words emerges – dispelling forever the stereotyped label of cerebral palsy.

DENNIS STABBACK

Dennis Stabback is thirty-six years old and uses a head probe or stylus with a conventional keyboard. Dennis is the athetoid who was responsible for sparking Dr Peter Neilson's interest in cerebral palsy in 1966. The General Manager, Bruce Hume, had noticed that Dennis could manipulate a Press when his hands were firmly attached to the operating lever, but was unable to operate it otherwise. This led to the investigation of the first experiment and ultimately the foundation of The Spastic Centre Research Unit.

Dennis says, "Until recently, I used a word processor to prepare the news journal that is distributed throughout Centre Industries. At the moment I am establishing a resource area, using a word processor and a data-based programme. The resource centre is to be an information base for both disabled and non-disabled employees of Centre Industries.

The word processor enables me to independently correct and edit my own work. Without this piece of equipment, it would be necessary for me to constantly require the services of another person to assist with my work.

The value of this physical independence to me cannot be overstated. Independence that allows me to sever some of my ties with other people is an immeasurable gift.

I also use a Cannon communicator to communicate with people. This enables me to type a message and provide the 'listeners' with a written copy of whatever I have typed. Once again I use my head probe to operate the communicator. Not having hands that I can use, and not being able to talk, does not prevent me from communicating and pursuing my interests.

Not being able to speak gives me far more time to listen to what other people are saying – time to understand and reflect on what has been said.”

GREG MOTT

Gregory Mott is a thirty-nine year old severely disabled athetoid working in Centre Industries D.E.P. section. His speech is difficult, dependent upon the listener's translation aptitude. He operates his electric wheelchair with the back of his right hand, and uses a head pointer for typing. Greg is a Past President of the Centre Industries Chess Club, and Chairman of the Cerebral Palsied Work Committee. He lives at home. Greg said, "I started at The Spastic Centre in 1946 at the age of two years. The Centre was operating out of an old white house at Mosman. When I commenced there were only about eight patients being treated, because there was not enough room and nobody knew about spastics.

By that, I mean doctors did not know how to treat them. Then a couple of years later, the parents decided to put up a new building. They had a lot of help from other people such as the Newtown football team and many other sportsmen. By this time, when I was three and a half, the physios had more idea what cerebral palsy was all about, and they were learning how to treat it. I was having physio, speech therapy and school work three days a week. The reason that I only attended the Centre three days a week was because I could not stand the travelling; my home was 20 km away, and the long journey there and back was a bit too much for me. In the early days the Centre had a couple of old Army ambulances and volunteer drivers. They used to pick us up, drive us to the Centre and then home again.

When I was five years old my physio had me sitting up with special supports. One year later she put a pair of skis on my feet. These skis, as they are called, are like a big pair of shoes. They are made out of wood and are pretty heavy. Now I had to learn to balance myself. I learnt how to do that after a lot of bruises, which I received when I fell over. The next thing was walking, and to everyone's surprise I took my first step with a lot of effort.

Then, to my dismay, I became very sick, and entered hospital. The doctors found that I had a hernia and they would have to operate. They said that if they did not, I would die. I had the best doctor in Australia, Professor Lorimer Dodds. He gave me a slim chance of coming through the operation, and it took about eight hours to repair the hernia, during which time two ribs were removed. I finally overcame that hurdle.

Now it was back to schoolwork, and in 1953 at the age of nine, I found that I had missed about two years of education. After my operation, the physio said that I would never walk again. My occupational therapist found that with a hand splint and an electric typewriter I could do my lessons. I finished primary school without much trouble. I graduated to first year and, to my surprise, I topped the class.

Then it was on to second year. My first year teacher asked me if I would be prepared to do correspondence work. Naturally I said yes. I like a challenge. The Correspondence School sent my work out every month. I finished the year with average marks. I went on to third year and at the end of that year, when the results came back, much to my surprise I found that I had come first in English, and over all out of eight normal pupils I finished second. This was in 1962, and I started work at Centre Industries in April that year.

The first day that I was at Centre Industries I was very nervous for some reason. Anyway, my job was to count out two hundred screws into a box. Then Friday came – pay day! I received twenty cents, which I thought was great at that time. I counted screws for about three years, then my boss gave me a go on a power press, stamping out contacts for telephone relay sets. I mastered this job after a couple of months. I stayed on that for years.

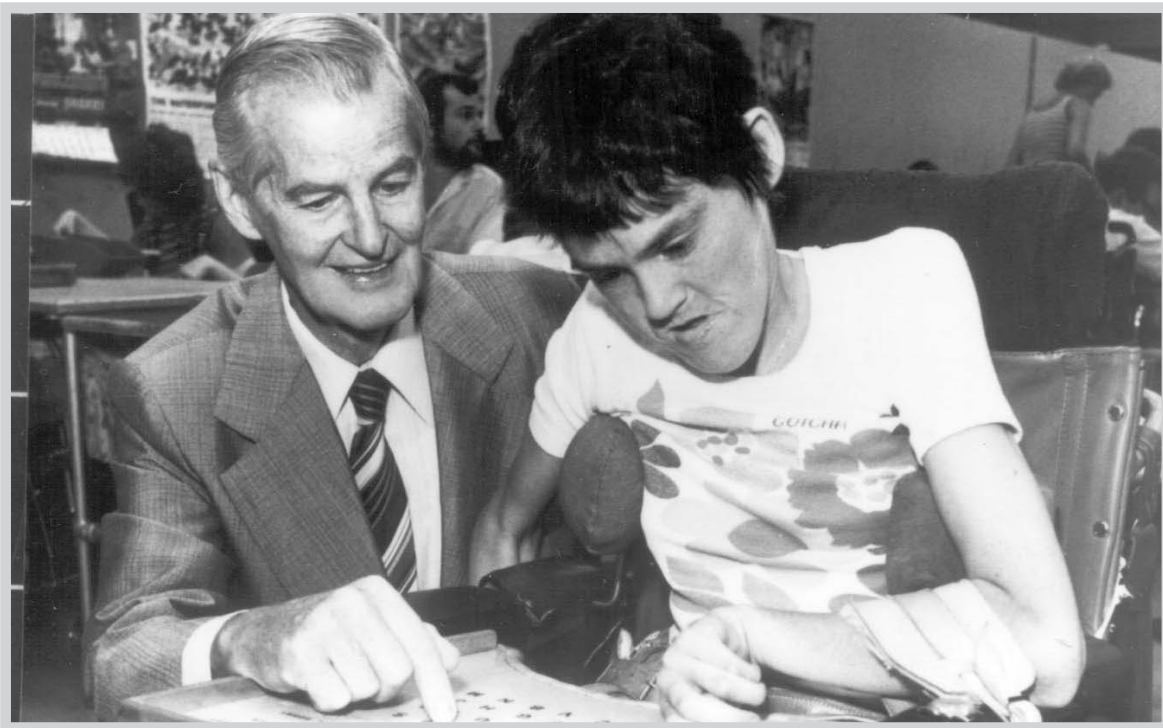
During that time, the engineers had developed a motorised wheelchair. I had my chance to drive one, but my chair had to be specially made. The physios and engineers designed it specially so that I could sit in it. The next thing was to drive it. I don't think the people in charge thought that I would be able to handle the chair, but if you are determined enough you will succeed, and boy, was I determined! After a few crashes and nearly running over the General Manager I proved everyone wrong! I could handle it!

About ten years later, I was asked if I would like to join the computer section, working out the rate of the keypunch operators. I said yes, but I found for some unknown reason I couldn't use a hand splint to type with like I did at school. I thought that I might be able to use a head piece, which is a band that goes around your head and has a pointer attached. Again, they said it would be too hard, but that determination I spoke of earlier came through and I learned to type with a head piece. So up to the computer section I went.

A year after I started there I was due for my long service leave. I had been saving for years to go to America with my brother. We didn't only go to America, we went to Hawaii, Tokyo (where Dr Noda introduced me to the night life and the bars), and then to Hong Kong. I had a ball. Then it was back to work.

Late in 1980, Centre Industries bought a new computer and six visual display units. Much to my delight I was chosen to operate one of these VDUs, and that is what I am doing now.

I haven't known any other way but being handicapped, therefore I have built my life around it. There is one thing that is very hard to get used to, and that is when I go anywhere people look at me as if I have just come from another planet or something – that really gets me going. My handicap doesn't have any effect on my lifestyle. Naturally I would like to have a better lifestyle, but I can't so that's that. My ambition in life is to succeed in my job and try to better myself in my work. Also I would like to go overseas again; I am in the process of saving for that now."



Kathleen Coppins with her point-board which was her sole means of communication until we discovered the Japanese electrical machine which had a printout on a tape.

KATHLEEN JOYCE COPPINS

Kathleen Joyce Coppins is unable to use an electric typewriter. She has battled against the reflex action of the tongue thrust through the whole of her life because of its effect on speech. Now, with her electronic speechmaster, she is able to communicate freely. She says, "I come from a family of eight. My mother and father are very good to me; they are very understanding. I have three sisters and four brothers and I love them all. I am a great auntie four times and an auntie fifteen times.

Being a disabled person as I am, that's not to say disabled people aren't the same as anybody else. We cry, we love. Yes, I have been hurt, but like anybody else I haven't learnt my lesson yet at thirty years of age.

I was about nine years old when they tried me in a red wheelchair. Dr Reye said if I could use it without letting my tongue spasm come out, I could have a wheelchair, so I had to show Dr Reye I could push myself and keep my tongue in. Well, all the physios and all the teachers were watching and helping me keep my tongue spasm in. Anyhow, Dr Reye said OK, you can have a red wheelchair.

When it arrived, I was home on school holidays. They sent the wheelchair home in bits, so Dad had to put it together, with a lot of bad words! But when I had that operation on my legs, and after six weeks in plaster, I was too long for my little red wheelchair and had to go into a larger one.

When I was about fourteen I used to get mad at my speech disability and I used to go in my bedroom at home and slam the door if I was in a bad mood, and I would cry. Now I think I know why I used to do that – I wanted to be just like my sisters and my brothers, doing the things that they were doing, like sewing and making some dresses and going out.

Now I have accepted my disability, it is a bit easier but even when I hear someone has been married, then I start to wonder what would it be like to be an able bodied person – really.

We used to have a wood fuel stove and Mum would make the most beautiful roast dinner with gravy, and the most beautiful apple pies and gramma pies that you ever tasted. I loved sitting and watching the flames dancing all round the walls. But when we had a new electric stove, the dancing stopped.

When I was young and Mum and Dad took me out, people would just stare at me as they pushed my wheelchair up the street. I often wonder what they thought. Mum used to say don't worry about them, they are little people.

As a disabled person, I find that making friends is a bit hard, though I have made a few very good friends at the hostel and at Centre Industries. When I meet new people, I can almost tell if they are going to be good friends by their reaction to me as a disabled person.

Such as Peter and Greg; they made friends by saying hello – without being afraid of me.”

PETER LOSURDO

Peter Losurdo as born in 1946, in a little village on the northern coast of Sicily. He said, “Before coming to Australia all I knew was that I had some sort of paralysis. In those days, and in the little village of my birth, cerebral palsy was unheard of. It was in Sydney that doctors diagnosed the problem. I am a cerebral palsied quadriplegic, and came to Australia with my parents at the age of three and a half. Six months after arrival, I attended The Spastic Centre, where I was put into the Kindergarten class.

The Centre has been my life. If my Mum and Dad hadn't come to Australia, I guess I would have been institutionalised. Back in the village, my Mother was told by her friends to drown me! I am very glad she did not heed that advice. I have four sisters, all younger than myself. We are a very close-knit family, and I enjoy a number of nieces and nephews.

I attended school until the age of sixteen years. I then went into the Training Unit at Centre Industries, and after two months went into the Drilling Section, where I worked for the next ten years.

Over the years I had surgery to the ankles, knees and groin, and at one time was in plaster for four months. Until about six years ago, I was using a walking frame, but now I accept the fact that I must reluctantly submit myself to a life in a wheelchair.

After working in the Drilling Section, I did timekeeping and undertook intensive work training for the handicapped. Then I was made Supervisor of the male aides, which is what I am doing today.

I was one of the cerebral palsied involved in Dr Neilson's research at The Spastic Centre Research Laboratory, which I found very interesting.

My main hobby is classical music. I have a comprehensive collection of recordings which I greatly enjoy. I live at Venee Burges Hostel during the working week, and spend weekends at home with my Mother, with whom I speak in the Sicilian dialect. I am told that mastering two languages has been a singular achievement for one whose speech is considerably affected by cerebral palsy.

My job gives me a sense of achievement being able to help my fellow cerebral palsied. It is rewarding to know that I am able to supervise the able bodied male aides of my department.

One of my most memorable moments, as Chairman of the Cerebral Palsied Committee, would be when I made a presentation to Mr McLeod upon his being named "Father of the Year". It took me days to get over that excitement!"

GREGG WAYNE GILLETT

Gregg Wayne Gillett is profoundly deaf. He uses an Apple computer for communication but his education is only just beginning. He types and writes, and his reading is minimal. He says, "I am twenty-seven years old. I have three brothers. Glen is twenty-eight, then me, Grant is twenty-four and Garry is twenty. My mother's name is Pat and my Dad's name is Don. I live in a home unit at Kensington. We have a swimming pool and a barbeque.

When I was a little boy, I went to school at Mosman Spastic Centre from 1961 to 1974.

Ten years ago I went to work at Centre Industries.

My interest is Stanmore Deaf Club. My best friend is John Windsor. He is deaf also. We go on outings every weekend, everywhere. John has a Sigma car. He lives at Maroubra. John picks me up at the Stanmore Deaf Centre for Youth every Friday night. We have all my friendly deaf people at Stanmore Deaf Centre.

I like football. My favourite team is South Sydney. For four months I played soccer for Centre Industries against all visitors. We played weekends at Dee Why. My friend George Krams is deaf also. He lives in Randwick.

My Dad and I go shopping at Doncaster Avenue, Kensington, for food every Saturday morning.

John, George, David and I will go on the tour bus to Perth, W.A. for the 8th Australian Deaf Games 1985-86 for one month, and we will stay in a caravan park. I have a new T-shirt with 'New South Wales' on the back.

Maybe I will win? Or lose? Time will tell . . ."

ADRIAN LYNCH

Adrian Lynch is now forty years old. He spent his earliest years on his parents' poultry farm at a suburb, which in those days was regarded as 'rural'. Adrian says, "I started at the Mosman Spastic Centre school when I was three years old. We lived so far distant that The Centre bus could not collect and deliver me at home, so my father drove me to and from a collection point each day.

Through the intensive training at The Centre, and the perseverance of my mother, I learned to walk when I was nine years of age. I have always admired the dedication of the teachers and therapists at Mosman.

I am interested in all sports and follow them keenly. I am a keen chess player and together with other members of the Centre Industries Chess Club, I have played in competition with other clubs throughout Sydney. Last year, overall, we won fifteen games out of thirty. I have recently been made a Life Member of the Chess Club. I listen to music a lot, both on the radio and on cassette. My preference is for 'middle of the road' music.

I am a regular attendant at Church, which is the real key to my outlook on life. My Christian beliefs sustain me, making it possible for me to accept my disability and be thankful for the many blessings that have come my way. I have spoken several times at Church gatherings, relating how I was able to overcome my disability by persevering in doing things that able bodied people did, and what other disabled people did, to compete with able bodied workers. I wanted to demonstrate that we do not want, or need, any pity.

Now I live at McLeod House, but go home when my mother's health permits.

A highlight of my life occurred when Her Majesty the Queen and the Princess Anne visited Centre Industries in 1974. At the time, I was lifting some wire onto a shelf in the coil winding section and Princess Anne spoke to me.

Having joined Centre Industries in 1963, I have been a witness to all the different phases of growth. Considering the level of my education, it amazes me that I have been able to work in various sections of the factory. I regard my job as important, to keep my mind occupied and to make me useful in the community. I am thankful that I can play a small part in helping the economy through the manufacture of our electronic components. I am a clerk in the Component Stores.

My main problem in being a spastic, is that I am unable to co-ordinate my muscles in everything I do. I am dependent on someone to cook and cut up my food and to do my laundry, as well as to assist with travel, as I am unable to use public transport, other than a taxi and taxi-buses. Despite this, I enjoy quite a degree of privacy, something which is not available to a lot of other handicapped people.

I was part of Dr Neilson's A.T.R. research programme for three years, concentrating on action reflex in my right arm. I enjoyed the work, knowing that it will help future cerebral palsied people.

My ambition in life is to be associated with the general public as much as possible, because I have found through experience, that it helps a great deal to forget one's handicap and enjoy life as much as possible, even maybe in a limited way.

It takes a very long time for the community to accept and understand that really one is a normal person, and needs no pity."

COLIN BARTON

Colin Barton is aged forty-three years. When very young he had surgery on the hips. Doctors told his father that he would never walk, but Colin was determined, and is an independent walker. He spent his childhood in the Crippled Children's Home at Campbelltown. At the age of sixteen years, he was obliged to leave there and so went to stay with his sister in the country. After this he was accepted into a mentally retarded unit of the Sunshine Home.

From there he was rescued as an intelligent cerebral palsied by The Spastic Centre and taken into the pilot country children's hostel at Mosman, and later transferred to McLeod House. At Mosman he met his future wife, Beverly,



John Baldwyn, Chris Nixon, Adrian Lynch, Dennis Stabback, Judy Geppert.



C.I. Chess Championship 1981. Dennis Stabback, Adrian Lynch, Robert Kenny, Greg Mott, Lindsay Sinclair.

also cerebral palsied, and after a twelve-year courtship, they finally married and moved in Venee Burges Hostel.

Colin joined Centre Industries in 1962, where he has been engaged in stores work, systems supervision, machine shop operations, and transferred to the E.D.P. Section in 1973.

He says, 'Over the years I saved my money to buy a car, which I did in 1968. I love driving and taking trips. Every weekend I take Bev out for a drive, sometimes quite long distances. Learning to drive was a great achievement, proving to everyone that it was possible for a handicapped person to drive.

My job means everything to me. Like everybody else, I need a job to pay my own way in life. When you are born a spastic, you virtually accept it from the outset, even though you have the same ambition as the non-handicapped. You just try harder to achieve what you can. One has always to live with one's disability. It was once said that everyone has a handicap.

My ambition in life is to keep on living!!'

LINDSAY SINCLAIR

Lindsay Sinclair, now aged sixty-three years, was born the eldest of a family of six children at Temora in New South Wales. His movements are slow, and he has difficult speech and limited hand movement. Describing his life, Lindsay said, "When I was born my parents did not expect to take me home. They had me baptised in the hospital. I was taken to many doctors, and when I was four a doctor operated on me. The operation was to transplant a nerve, but whether the operation did me any good it is hard to say. I started to walk when I was seven years old.

Some of my aunties suggested I would be better off in a home, but Dad would not hear of it. He felt that it was his responsibility to bring me up himself. For this I'm very grateful. I was brought up as a normal child. Of course, having sisters and brothers made a difference.

I learned to count when I was four. I used to take medication, which I liked and had to count up to a certain number before I got the medicine. One Christmas I received a slate with the alphabet on it. I just about knew the alphabet at the end of Christmas Day, and so my mother bought me two reading books. After I had finished these books, my brother brought books home from school, for me to read. Then I read my own books, which had been given to me, and also Dad's books. My brother Ron went to high school and when he came home for the holidays, I read his text books. I did sums on a slate, with a piece of limestone.

I lived on a farm for thirty-two years, and in town for eighteen years before I came to Centre Industries. I did all the odd jobs that I was able to do. I was not paid for anything I did, but to be able to do these jobs was a good enough reward for me.

When I was fifty-two years old my father died. I thought there must be something that I could do, so my sister-in-law wrote to The Spastic Centre. I spent over two years in the Training Unit. I felt I wasn't getting anywhere, so I asked to see the psychologist. I had some tests, and they found that I had a high I.Q. I was one of the group picked to study the computer. We met Monday afternoons with the systems analyst. There were blackboard lessons and books on computer programming. At that time I was working in the Machine Shop and not very happy with the amount of work I was doing, so I asked if I could study these books instead.

I was transferred to the Computer Section in 1973 as a Trainee Programmer. My supervisor says that, with all of my handicaps, I can compete with the able bodied programmer.

While I have no regrets not previously having a job, my present employment means a lot to me. I have been to places where I would not have been had I not had the programming job.

My job gives me an income, which makes me independent. Above all, it gives me a chance to prove to myself, and other people, that I am capable of doing a worthwhile job. Not being able to do all the things that able bodied people can do, I learned to appreciate the things that I can do. My ambition would be to work as well and as long as my health lets me.

It is what you can do, not what you can't do, that matters. Real enjoyment comes from doing things – a sense of achievement. The bigger the handicap, the bigger the achievement."

Summary

In nature there are neither rewards nor punishments - there are only consequences.

– Ingersoll

This is not a survey of the rapid growth of a new charitable establishment, born out of the heartache and bitter impatience of parents, unable to obtain treatment for their children. It does not tell of struggles against financial failure, official indifference and political evasion, nor of the difficulties in wartime and afterward of finding premises, obtaining and training qualified staff, breaking down the initial passive resistance of the medical profession, organising a transport fleet, erecting and equipping a building complex in the midst of severe housing shortage. And getting a large group of people of all classes, types and creeds, to work efficiently together, towards a common end.

Such a story might be told, but, interesting as it may be, the real story of The Spastic Centre is the story of its many thousands of children and adults.

In this volume, space considerations can only afford a representative sample of the dauntless and indomitable spirit that typifies our cerebral palsied.

We started The Spastic Centre in 1945 and Centre Industries in 1961. I feel very humble when I think of the years between; it should not have taken so long. All I can say is that in those years we have established a firm basis for our future work and can use our experience in all areas to plan much more effectively in medicine, education, work training, employment, neurophysiological research and the individual's independent lifestyle.

In 1945, we did not know whether the cerebral palsied child was educable. All the professional help we were offered said they were not. The years have proved how wrong they were. Similarly, in Centre Industries we did not know whether adults, as heavily handicapped as our cerebral palsied, could contribute to their own training from a commercial and manufacturing basis. Now, however, their ability to do so is unquestioned, even for the severely handicapped. The chapters of this book provide us with an invaluable record of the achievements of very many people from our staff and from the people outside our organisation. We are grateful for their participation and for their skilled achievements in our work. On behalf of our children, we offer them all our warmest thanks.

In 1945, in Australia, and indeed in most of the world there was no formulated body of medical, psychological, neurological or educational professionals experienced in the handling of cerebral palsied children. Physical treatment was largely based on successes obtained in poliomyelitis treatment, and had little relationship to the problems of the cerebral palsied.

It was wrongly assumed that mental deficiency was symptomatic, and that a continuing series of orthopaedic operative procedures was necessary in most cases, to combat the distortion of joints brought about by the increasing tension of the affected muscle groups.

Since that time the picture has changed dramatically. One common theme runs through the whole fabric of our medical treatment, education, work training and residential living. We now know what is required physically, medically and educationally. We know that the apparent physical disability is only the manifestation of secondary handicaps, which we should be able to

prevent. We know what we need to do in preventive work on the young baby, and are looking to medical science to further reduce the incidence of cerebral damage prior to the birth process.

Over this period of almost forty years, the life expectancy of the cerebral palsied has been extended from what was probably ten to twenty years, to a normal life expectancy.

Control has been established over the frequent epileptic fits previously experienced, and our orthopaedic surgeons are now able to predict, with some accuracy, the improvement they will obtain from the various surgical procedures, following the intensive physiotherapy and retraining programmes, now available to them.

We know that the physically handicapped baby, child or adult, is a normal person first and foremost. The neurophysiological anomaly is incidental to his basic needs as a complete person. First, they need the love and security of their homes and families, then they need such special services as are necessary to enable them to take their place in the normal world.

Mrs F.N. Kerr, Headmistress of our school at Mosman, set the pattern that has operated over the years, when she stressed the role which the school plays as part of the social education of cerebral palsied children who, along with their brothers and sisters, must be prepared for their future, whatever it is; whether it is towards independence economically or independence of spirit and of thought. School becomes the first major social group which the child contacts after he has left his home. The teachers' responsibility is to lead these children to an awareness of the wealth of knowledge, which is in the world and also an awareness of the beauty which exists. Teach the cerebral palsied child to think, but also teach him to see and feel.

As Dr John Foley of the Cheyne Centre, London, U.K., says: "Athetosis is a disorder of movement, not a disease ... The layman, untroubled by neurophysiological niceties, sees the problem simply – they can't sit, can't move at will, can't talk, and yet take everything in ... There is no other condition in which an intelligent individual may be obliged to spend a lifetime deprived of the ability to communicate or move, or in which there is such a discrepancy between motor intention and accomplishment. There is no other condition in which early prediction of ability is so often belied by ultimate achievement, if modern aids are provided from infancy."

Our search has embodied all the many pathways of education and medicine that have emerged in those years. From the antibiotics of the war years – to the CAT scan of the nineteen seventies. From the RH blood groups, the radical orthopaedic surgery, splinting of the nineteen fifties – to the neurophysiology of the nineteen sixties and seventies. Last of all, from the Mothers and Babies Programmes of early treatment – to engineering and employment of cerebral palsied in Centre Industries in the nineteen sixties to the present day.

We broke new ground by challenging the validity of the sheltered workshop approach to the work training and employment of heavily disabled, young adult cerebral palsied. We established Centre Industries for that purpose. To carry out this objective effectively required the setting up of an efficient manufacturing complex, staffed by competent able bodied workers and equipped at an engineering level that enables it to compete successfully in industry standards of engineering, efficiency, quality, price and delivery.

We emulated the mainstream of industry and, instead of a sheltered workshop, we insisted, for the first time, that the concept of Rehabilitation Engineering Support Services be accepted. This led to the modification of the work stations, machines, and hand tools, and was used to increase the productivity of our CP workforce. We have not yet seen a person whose physical handicaps are so great that he could not be significantly improved by applied treatment and technology.

Engineering principles and techniques are obviously applicable to the function problems of the cerebral palsied handicapped workers, in the same way that they have always applied to other workers in industry. Thus, the cerebral palsied worker is placed in direct competition with the able bodied employee. We employ an equal number of able bodied workers who are vital to the scheme, because they provide the CP worker with a normal working environment.

The incentives for both the able bodied and the cerebral palsied worker are identical – firstly money in the pay packet, and secondly the social advantages of being an 'in' member of a large heterogeneous workforce.

At Centre Industries, we have demonstrated the capacity of the heavily handicapped cerebral palsied to work in sophisticated electronics manufacture, using standard machine tools in direct competition with the able bodied. Our main frame computer is staffed by twenty cerebral palsied workers, in systems analysis, programming, operations and data input, with a similar number of VDU terminals.

The Centre Industries concept of rehabilitation engineering support has spread to Japan, where the Ministry of Labour has sponsored the 'Model Factory' scheme. They are for-profit companies, which the Government provides with low interest loans of 70% of the required capital. In 1984, there were 252 Model Factories employing thousands of severely handicapped persons. The

Model Factories must have a minimum of 50% handicapped workers, and the loans must be for capital and not used for operating costs.

In the United States, Centre Industries was established in Wichita, Kansas ten years ago. Additionally, ten centres are currently in a submission to the United States Senate, in answer to the President's call for improvement in the life of the 35 million severely handicapped Americans. Centre Industries in Wichita has proven a concept that is both morally and economically sound, says the proponent John F. Jonas.

The following gives a passing glimpse of the Speech and Education research work done by the dedicated team, headed by Miss Brereton and her supporting therapists, under the control of our Medical Director:

BASIC ABILITIES PLAN 1967 – Demonstrated the gains in perceptual thresholds, and ultimately in I.Q. levels, by extending the control and experience of the child beyond the limited and artificial environment imposed on him by his handicaps. This was followed by –

INTERACTION GAMES – 1969 – The neurological approach to treatment of severely handicapped children without speech, starting at the earliest possible age.

LEARNING ABILITY AND BEHAVIOUR 1972 – Physiotherapy can alter motor experience. Facilitated movement can replace passive movement. Abnormal motor experience is likely to influence learning ability and behaviour; modification of the motor handicap could produce a child who is more able and has better social adjustment.

SOUNDS AND SYMBOLS 1973 – For speechless cerebral palsied children. Prior to this, the conversation of children without speech, depended on their ability to spell. This frequently left them without an effective means of communication until ten years of age, or older, by which time the natural flow of language may have been inhibited. The three-and-a-half year old cerebral palsied child has little difficulty in working with these global concepts, or handling a vocabulary of over 1000 words.

MOTOR PLANNING – Miss Beatrice Le Gay Brereton in propounding "Motor Planning" showed remarkable insight in her "Study of Motor Disability in Cerebral Palsied Children" in the early seventies, planning the movement appropriate to the situation. And it was ten years later that Dr Neilson arrived at the same point by painstaking neurological experimentation.

Over the last forty years, my wife and I have worked as a team to build The Spastic Centre to its present heights, and it is fitting that all of the effort, strain and sweat should be crowned by the ultimate achievement of finding answers to the riddle of cerebral palsy, but it still remains enigmatic.

In 1966, we prevailed on Dr Peter D Neilson to take a scholarship to investigate the causes of muscular spasm in cerebral palsy. At about the same time we became very interested in a programme for the early treatment of cerebral palsied infants within the first year after birth – the Mothers and Babies Programme.


These two developments were critical to our understanding of the neurophysiological patterns of cerebral palsy. The results that have flowed in the wake of this have a direct bearing on the projects which are summarised here.

Dr P.D. Neilson is a unique blend of electronic engineer and science graduate turned into a neurophysiologist by his interest in cerebral palsy. He worked through the neurology of the cerebral palsied, upsetting previously held beliefs of the nature of the condition and the myths that had grown up behind the accepted medical therapies. Now, after eighteen years work, he is prepared to advance an entirely new therapy based on his neurophysiological findings

We are facing the eternal problem of equating the cost of a research programme with the demands for money to be spent on existing children. Therefore, Dr Neilson's work was done on a shoestring. To the best of our knowledge, it is a unique Research Unit created specifically to investigate the neurophysiological mechanism underlying the movement disabilities of cerebral palsy.

Considerable progress has been made in improving the world's understanding of the physiological mechanisms responsible for spasm, rigidospasticity, and involuntary movement in cerebral palsy. Research has also demonstrated that, by focusing training on specific problems, therapy can be devised to teach cerebral palsied to self-regulate spasm and reduce the amount of involuntary movement. Research, however, has led to the view that the primary cause of the motor defect is not spasm, rigidospasticity and involuntary movement, as is usually suggested, but an inability of the damaged nervous system to translate movements, in terms of desired perceptual goals, into appropriate sequences of motor commands to achieve these goals. Reduction of spasticity is an essential component of any therapy, since spasms can, and do, block voluntary movements and the spasm leads to deformities of muscles and joints.

The consistency of the 'Sensory Motor Theory' with observations of motor development in cerebral palsy, leads us to believe that



we are getting closer to the primary problems in cerebral palsy. This has produced a feeling of great excitement, and expectation, in those of us involved.

While we have climbed the foothills of the mountain range of cerebral palsy, we are still battling our way forward over the pass that will, we hope, provide a clear view of the plain beyond. If it only reveals another mountain, and then another, we will meet those difficulties when we get that far ahead. We know the general direction of our travel, and we have an electronic compass to guide us – that was something missing in 1945, when we only had personal intuition to show the way.

As to the future, we have heights to climb, which will carry our work far beyond existing levels. Starting with the babies, we are looking to increased preventive measures to reduce the total incidence of cerebral palsy, early treatment in the Mothers and Babies Programmes to reduce the severity of the action of impaired muscle groups on growing joints, more specialised teaching staff, with equipment designed to enable our children to obtain an education that really does equate with that of a normal child, more sophisticated electronic communication devices, more knowledge of the mechanism of speech, and some means of obtaining effective control of the muscular spasms of the cerebral palsied, apart from drugs, therapy and surgery.

We must keep abreast of the latest techniques: of paediatric, orthopaedic and neurological medicine, of educational techniques, of medical therapy, and rehabilitative engineering, especially as it applies to electronic and computer science.

Lastly, and perhaps the most important of all, we must obtain full economic and social self-sufficiency for the even more severely physically handicapped cerebral palsied person.

These are our minimum needs for the future.

Epilogue

Nureyev hoisted Dame Jenny high above his head. With all the grace and beauty of the world's prima ballerina, Jenny stretched her body to the limit. The pas de deux was perfect, and the ovation reverberated around the walls of the famous Bolshoi Theatre for a full fifteen minutes.

The Allambie Heights girl was pleased with her performance and, as usual, Rudolph was impeccable.

"Nureyev is my idol – he's beautiful," Dame Jenny told the press, as she and her partner left Moscow for Rome.

That is Jenny McLeod's favourite dream – but one she knows can never become a reality.

Jenny cannot walk.

The world of 'Swan Lake' – of pas de deux and pirouettes – will always be closed to her.

Jenny is a spastic – one of thousands of cerebral palsy victims whose bodies do not work properly, but whose minds do.

Dreams are far from being Jenny McLeod's only outlet in life – in fact, her achievements would make any able bodied person proud.

She looks forward to the day when cerebral palsy is defeated.

"I'm so glad for the babies of today – modern treatment now prevents them from being so severely deformed by cerebral palsy," she said. "There are still many spastics born in the world, and I call them half mine. So I do have a big family of babies of my own after all, don't I?"

After four years of struggle, Jenny has been able to discard the apparatus, which formerly supported her.

But the dreams will never be discarded.

"I am very interested in ballet, and if I'd been able to walk or dance I would have loved to have been a ballerina," she said. "I have seen Rudolph Nureyev on both occasions he's been to Sydney, and he is my idol. I think he's beautiful."

Jenny has danced with both life and death.

She will never dance with Nureyev – but she is a dame in every sense of the word.

"Manly Daily"

This epilogue is difficult for me to write. Let me start with an entr'acte – a telex dated 16 February 1981 to Dr Takeo Noda of Tokyo:

A personal request – my daughter Jenny is in trouble. The drug Lysivane which she has taken for twelve years has gone off the market without warning, and the recommended medical replacement drug affects her speech and throat spasms. May and Baker in England are the manufacturers and I wonder whether you might have surplus stocks available from the wholesalers in Japan. She requires 5000 (five thousand) 50 mg tablets to give her a weaning period of a year's supply so that we can establish a satisfactory substitute. My only excuse for worrying you is that she was getting on so well with Lysivane and establishing an independent lifestyle for herself. I have not got a lot of years ahead.

Then I sent a telex in similar terms to Mr Leslie Park of United Cerebral Palsy in New York, U.S.A., and to the International Cerebral Palsy Society in London.

After some weeks, Dr Noda provided a replacement supply of 1000 of the original Lysivane, which were marketed in Japan under the name Parkin and in the meantime, Mr Leslie Park sent us five bottles of Parisidol, which was the American equivalent.

But Jenny refused to take them because she did not want to go through the same process in the reverse direction and we couldn't blame her, so this was a reserve supply. Jenny improved on the Disipal over the next six months. Her speech seemed to be better than it was before, but this was offset by her extension spasms, which seemed to be worse.

Jenny says, "February 1981 started a disastrous year for me. It began one Monday, when the retail chemist returned an order for the drug Lysivane saying it was now off the market. I had just two tablets left, and then my spasm started. I went home early from work, and I couldn't make it the next day, nor for a month following. It affected my speech so I couldn't get a single word out, and my throat was gagging like fury so I couldn't get my food down. My father and a nurse took two hours for a meal, holding my chin up while I masticated my food.

Dr John Grant prescribed Disipal as a suggested replacement drug. This improved my throat spasm, but at the expense of my extension spasm in my legs and arms. It was a month before I returned to work and six months before I reached a similar standard of performance in speech and in control of muscular spasms as I had attained with my previous drug."

Then the lightning struck again:

'9 September 1981. Dr Takeo Noda, Tokyo, Japan. I regret to inform you that Jenny has developed a growth in her right breast. Following surgery, this involves cobalt treatment daily from the radiotherapy department for six weeks. In her favour, she has maintained her valiant determination to get back to work as early as possible. You may know the effects of the radio therapy are debilitating and make her excessively tired. Will you advise her Japanese friends of this, especially Dr Takahashi, Professor Yokomizo and Toshi Nagasaka. It is now eight months since I last appealed to your help on the Lysivane issue, and it has taken us this long on the new drug to get Jenny back to where she was. She has mastered this, especially in her speech which is better than normal. This is a stroke of fate which we must accept, but I cannot help but feel the unfairness of it all.'

And Dr Noda's reply:

'19 September 1981. I got your personal telex in regard to Jenny. It was the most shocking news that I heard from you during past years. I pray to God that she might keep her courageous independence and I will take any amount of trouble to help her. If you mind, would you tell me details about her? And I also want to know if you have possibility to come to Japan in this time for the November meeting of the McLeod Society of Japan. Please tell my heartfelt comfort to Audrie.'

This was the most terrible thing to happen to our lovely daughter Jenny. Our family and friends were devastated at the news. You can be logical in the control of your thinking, but controlling emotions is harder. I know that is the price all parents pay for having children - you must give a hostage to fortune for illness, or accident – but we thought we had paid the price with Jenny's cerebral palsy.

For forty years of her life span, she had battled her way through: an orthopaedic hospital at the age of five years, with the archaic gutter splints in bed every night, the pelvic control braces by day, which stretched already tight muscles even tighter, then a neck collar to support her head, and a corset with steel supports for her back. From the age of sixteen years, muscular spasms forced the abandonment of use of her right hand (which was her better hand) for ten years. With plaster casts used successively over the same period, she had to obtain control of her head, master the control of her electric wheelchair at twenty-four years of age, and improve her speech over the succeeding years. It does seem unjust that she should have to accept this physical burden and then to add the scourge of cancer – but there is no justice in life.

But Jenny was made of sterner stuff. So instead of saying, "Why did it happen to me", she said, "Through my life, I have been cast in the role of a leader of the cerebral palsied. My life has been devoted to a crusade for the rights of the cerebral palsied, especially for those who are heavily handicapped as I am, in The Spastic Centre, then in Centre Industries and finally in Venee Burges Hostel. Now I have been selected for the additional task of pioneering the path to success in the cancer treatment area."

She says, "I haven't got time to be ill", and refuses to worry about the future, saying, "If it happens, it happens, and we'll deal with that when it comes." She is more concerned with the twenty-two female able-bodied aides, who are her managerial responsibility. They had been getting inefficient in the feeding and toileting of the severely handicapped cerebral palsied in Centre Industries during her six months absence while she was undergoing treatment.

There were no tears – just a calm acceptance of the fate in store for her. The surgeon did not expect his patient, on the first day after the operation, to produce a questionnaire on her future cancer treatment with twenty-three questions which she had the nurse copy for her. Later he recalled that incident, saying, "Jenny is the first person who has ever asked me those questions."

My wife and I had a long-standing appointment in Japan, and on Jenny's insistence we made the trip when she had only a week of daily radiotherapy treatment left

The telexes tell their own story:

'Finished treatment not allowed to have bath for two weeks. All is well. Back to work maybe next week for half day. Have fun, love Jenny.'

'Your telex received. Sorry about your bath. Glad to know that you are planning to go back to work, but take it easy. We are now in Kobe. Doctor Takahashi and all the Sendai people send you their love.'

'Burrandong was wonderful had fun, bus trip OK. Johnsons were lovely asked me up next January. Feel good. Work tomorrow half day. Miss you. Hope things are going all right and Japanese are not working you too hard. See you soon, love Jen. PS. See Holecek on Friday, let you know any news.'

'Saw Holecek. Everything clear. Bath tonight. See you soon, love Jen.'

She is a beautiful creature. Her wheelchair holds her slight frame – she weighs only thirty-five kilograms and, in spite of her years, she is ageless. She looks like a faery child, aeolian and ethereal. Then she talks to you, and you become aware of the cutting edge in which she exhibits her mother's practicality, which manifests a fierce independence on behalf, not of herself, but of the other cerebral palsied for whom she has made herself responsible.

During the next twenty months, we were alert for the appearance of a lump that would presage more surgery. As the months wore on, we were able to comfort ourselves with the knowledge that the statistical survival rate for breast cancer was 86 per cent, and it was presumably working out for Jenny. But alas, in February 1983, the surgeon discovered a suspected cancer had spread to the other breast. Jenny was watching his face during her examination. His expression changed and hardened, so she was prepared for his verdict when it came. Another and larger operation followed, and daily doses of radiotherapy, extending over two months. We were bitterly disappointed.

Jenny was no stranger to hospitals, but the daily treatment with cobalt radiotherapy was a new experience. Her doctor was a young man, and they established a rapport on the first visit. I think he tried to treat her with professional detachment, as he said he could not get too close to his patients for obvious reasons. As the weeks wore on, his detachment melted, when Jenny wrought her own magic on him.

The treatment was given in a huge machine something like an X-ray machine. That was a problem, because the table of the machine was very narrow, to permit a 360° travel about the vertical axis of the table. Jenny suffered from a 'startle reflex', brought on by the high physio tables in her early years that had as a consequence established a fear of falling, when all of her muscles in spasm could roll her off the narrow table onto the floor. (Commencing in the nineteen seventies, all physio treatments were done on floor mats).

The time of each treatment was about thirty seconds, and it needed to be exactly set on the axis of the previous treatment. This was accomplished by marking the skin of the body with indelible colours – green, purple and red. So bathing was banned for the six weeks of treatment. During treatment movement is forbidden, and this posed a major problem for Jenny because she could not hold her arms in the required position for thirty seconds, without spasm of her muscles

The team had never had a cerebral palsied patient before and it was strange to them, but fortunately Jenny had gone prepared with straps and sandbags, so that she would keep perfectly still. No one could be in the room when the cobalt ray was activated. Jenny was locked in with the huge looming machine with its red position lights and with the large steel doors clanging tightly behind her. She said, "It is very lonely here, and thirty seconds seems thirty minutes, especially when your nose is itchy and your hands are tied down." The operator had a small window and a computer scan screen, but that was hardly enough to get rid of

the feeling of solitary isolation. Jenny tried to get her doctor to put music into the operation room, and pictures on the ceiling so that there was somewhere to look. But without success. The team of operators was extremely nice to Jenny, with their smiles and laughter that offset the depersonalisation of their equipment.

Jenny had saved her money since early girlhood for a holiday in Europe. Financially she never had a chance of doing that, but lack of money does not prevent you dreaming, and the intensity of dreaming would make some of it come true. She used to say that when she was eighty years old she would leave Centre Industries to look after itself. She would have saved enough to take off for Europe, and at eighty-four years she would return to Sydney and then she would simply 'pop-off'.

With the recurrence of Jenny's cancer, we feared that if she left it too long she may not be able to fulfil her life's ambition. So Jenny put in hand her selection of the people who were potentially her retinue of aides for her European trip. The Bank's travel agent and Jenny worked together refining her itinerary. Jenny insisted that she was the leader and paid all the bills for fares and accommodation.

Jenny made a deep impression on the handicapped groups during the Japanese Exchange Student visit in 1978, and wherever we went during this tour of Japan we were besieged with enquiries about her health, and loaded down with presents for her. One that won our hearts completely was presented to us by the handicapped workers in Mr Iwata's workshop north of Sendai. This present symbolised one thousand prayers for Jenny's recovery. It was in the form of strings of multicoloured origami folded cranes, which is a lucky symbol in Japan.

Jenny finished with the cobalt radiotherapy in May, and she planned the trip to commence on 15 July 1983, so in that eight weeks she had to prepare. The surgical operation was severe and the cobalt treatment was additionally debilitating, but she was adamant in her refusal to put off the July date. She did not say so, but reading between the lines, we realised she felt that if she postponed the trip she might not make it later on. Then, to make matters even worse, she had an excruciating attack of shingles, which the doctor said often attack patients whose resistance is below par. It lasted about eight weeks, and even when the blisters had broken it was getting perilously close to mid-July. We did not think that she would be able to make it physically. Her weight was down to 31 kg, but her dauntlessness was unimpaired

You can imagine what our feelings were like to see Jenny off in the Qantas flight Q05 for Rome. My wife and I were experienced travellers and aware of all the things that can go wrong on such a flight – loss of luggage, ill health of Jenny or her companions, theft of money or possessions, passport loss, and infighting of her companions on such a long intensive itinerary over six weeks. Fortunately our fears were unjustified.

Leaves from Jenny's diary:

'It was extremely hot in Rome. Fortunately I had fourteen hours of sleep on the plane. Saw the Pope among 5000 others. Luigi's breakfasts are something to write home about. The Trevi Fountain and The Spanish Steps are all in the same places.

We went on a five-day trip with mostly American tourists. The bus driver was fat, and lifted me onto his stomach and into the bus without any trouble. Florence, Assisi, Venice, Verona and Milan – they were all pleasant, and bring back happy memories. I have decided that when I am rich I am going to have a villa in Venice.

Then the flight over the Alps into Switzerland. Bright sunshine over the mountain and snowy peaks, and then the lakes. We explored them all, by cablecar, train, bus and steamer. We got ourselves stranded in mid-lake when a hailstorm hit us for half an hour.

A flight to 'Gay Paree' for my birthday the next day. When we got to my hotel room a bouquet of red, red roses was waiting there from Dr Noda of Tokyo, and some friends of my father sent an armful of flowers with an apology because they had left Paris for the coast. We had a birthday dinner on a floating restaurant in the Seine, and I happily left my year behind me. Now to prepare for the next.

I bought a frock in Paris, in fact two, and did not check the price until they were wrapped up. Then I had a heart attack when I converted francs into dollars. I have not been brave enough to tell my parents or friends how much they cost, but that is my secret, and after all, who has two gorgeous Parisian frocks in her wardrobe!

London was the next stop. The roses in Kensington Gardens and Trooping the Colour. The policeman on duty at the Palace who permitted me to enter the high fence so that I had a grandstand view, and more

shoes to add to those previously bought in Rome and Paris – fifteen pairs in all.

Then to Bonny Scotland. Edinburgh first and lunch with Mr George Pollock, who was the surgeon, who in 1963 visited Centre Industries, examined me and told me that I did not need the collar that I had worn for the past fifteen years.

The Military Tattoo in Edinburgh Castle – I had seen it on TV but this was the real thing; the skirl of the bagpipes and the Scottish uniforms and the massed bands of men marching.

We then hired a van and took to the Highlands, finishing our trip at Dunvegan Castle, the home of the MacLeods for six centuries. Big Kenneth MacLeod and his wife made light of the problems getting me and my wheelchair up to the Great Hall. It is approached by a winding narrow staircase as a protection against surprise attacks. I saw the Faerie Flag, which tradition says was reserved for use in a critical passage of history. Kenneth said it was last waved in 1745, when the clan was dispersed. We ended our last night of the tour of Scotland on the banks of Loch Lomond, with the moon and the mist reflected in the water.

There was always some unexpected person. For instance, at dinner in Edinburgh a man introduced himself as Derek MacLeod and said, "Let me welcome you to Scotland on behalf of the Clan MacLeod," and then stayed for an hour.

I was sad to learn of the death from a stroke of big Kenneth MacLeod shortly after I returned home. We only stayed two days in Dunvegan, but he was so kind and gentle as often a big man can be, and I felt that I had known him all my life.

Back to London for a week, shopping and sightseeing, and then back to Sydney.

I was surprised on our tour that everybody was kindness itself. Five airlines, starting with the Qantas attendant who stretched me out on three seats and made sure that I could sleep for fourteen hours. The bus drivers in Italy made certain that I was comfortable, and the wheelchair was waiting for me at comfort stops on the way. An elderly American tourist from the bus tour was always unobtrusively on hand with steps and stairs, and when on a water taxi in Venice he was on hand again to lift me into the bobbing craft one metre below ground level. The hotel staff could not do enough for us in Italy, Switzerland, Paris and London.'

'At Centre Industries I picked up the thread of my work again, I had been away during most of the year, and when I was in the middle of treatment I could not do justice to the management position. Following the year's end with the Christmas and New Year holiday break, I came back in 1984 jumping out of my skin, physically fit and in fine fettle. I had put on more weight, and as a result of my tour my speech was better than it had ever been.

Now I have three years of solid work ahead of me, bringing the cerebral palsied in Centre Industries up to their own physical capability, and maybe beyond it!'

I have stolen one of Jennifer's sayings for the title of this book –

'Nothing is Impossible'

Audrie McLeod's Diary to Jennifer

In 1938, co-founder of The Spastic Centre, Audrie McLeod began a diary for her baby daughter, Jennifer Gay McLeod. This remarkable manuscript tracks Audrie's emotional journey from the wonderment of the first few weeks to her growing concerns for her baby Jennifer. It is a journey with which many parents will identify, even today.

Jennifer was diagnosed with cerebral palsy sometime after Audrie concluded this diary. She and Neil (Mac) McLeod went onto establish The Spastic Centre in January 1945.

Our thanks to Dr Robin Way, Audrie and Neil's second daughter, for allowing us to publish Audrie's personal diary.

My dear little Jennifer Gay,

This is your book, for you when you want to know what your life has been from the time you are born. You are such a very sweet little baby that it is only right that there should be some other record of your sweetness than in my own heart and mind.

To begin with, you were born at 7.30pm on August the Ninth, 1938. Just eight days earlier than we expected you. You were such a funny little red-faced bundle. Such long black hair. A little cheeky turned up nose, three adorable dimples and such a tiny rosebud of a mouth. Your eyes were big and wide open from the time you were born. Your ears were very tiny and set so flatly to your head. What you had of eyelashes (and that was very little) were so fair as to appear non-existent. This with your very fair eyebrows gave you a very surprised look, which was comical to see. Your skin was so fine and dry that you were not bathed for ten days, merely rubbed with oil.

You were a very sleepy little soul. Much more interested in sleep than in your food. So much more interested in sleep that your weight began to go down and a great many heartburnings you gave me as a consequence.

When I brought you home from the hospital, I think I was the most frightened woman in the world. I shall never forget those dreadful first weeks. There I was so very ignorant of babies with the most precious little bundle in the world and to look after and bring up. I was afraid to leave your side. I spent hours just creeping around looking at you, afraid that you might die if I once took my eyes off you. The first night at home I lay awake waiting for you to wake and cry and you slept all night with never a murmur. I took you to the Health Centre to be weighed three days after I came home and you will never know my relief when I found you had actually gained several ounces.

No account of you could be complete without mention of your behaviour. There never was a better-tempered baby. You slept and ate and just lay awake and looked wise. You cried very little, which is probably just as well or I would have been certain you were dying and been rushing to the doctor every day. You began smiling at four weeks and have been smiling every since. At three months you began lifting your head and making endeavours to sit up. You also began to realise that you had hands and began to play with your rattle.

Now, at four months, you can lift your head and shoulders up off the pillow and if by any chance we sit you up and hold you, you crow and laugh with delight. Today they told me at the health centre that you could have Bowens Food as a supplement, so I feel that now you are beginning to grow up and that this is the first step towards an independent life of your own.

Now my dear little baby I would like you if possible to be able to see your father as he is now but I'm afraid I am not gifted enough to describe him with perfect justice. However, I will try to tell you something of him. His is tall, 6 foot 3 inches. Very thin with the kindest face I have ever seen. Remember this my little girl and never forget it. Your father is a perfect gentleman. There was never a better way of describing him and never a man to surpass this quality. He is kind and patient. Always interested in other people. Generous almost to a fault. Loyal. Honest. A fine brain and that endearing quality which makes everyone his friend. You should be very, very proud of him, for there could be no finer man than he is. I would like you to know him as he is now and see him through my eyes.

Whatever the future may bring, little Jennifer, you will always have the knowledge that you can only be proud of him. He would never do anything to hurt you or bring you shame. I am so afraid that something may happen to

him and you will never know him. We have been married now for six years and in that time I have never seen him cross or discourteous. I only hope that I can prove myself to be worthy of him in the future. Now my little darling I must leave this to take you for a walk.

Feb 10th 1939

I'm snatching a few minutes to write in your book while you sleep. What a picnic I've had these last few weeks. Firstly you refused to eat, and of course that worried me until I wasn't eating either. You poor little kid - I didn't realise that you wouldn't eat because half the time there was nothing there for you to eat.

Anyhow I eventually saw the Doctor because I felt so ill and he said I must wean you. That started our little picnic. I put you on modified cow's milk and you completely ignored it. I would put it in your mouth and you just spat it out again. I tried for an hour and a half to feed you one morning but as you only had two teaspoons in that time I was panic-stricken. I rang up the Health Centre and Sister Hayes told me to bring you over immediately. I threw some pillows in your pram and just fled crying all the way. The Sister fed you by force and you screamed all the time. It took another hour for you to get four ounces of milk and by the time you had that much you were soaking wet with perspiration.

That was five days ago and I will have to feed you forcibly. However you now have Bowens Food with modified milk for breakfast, soup and vegetables for dinner and Waiyena and modified milk for tea. For morning and afternoon tea you have tomato juice and prune juice and you have me for early morning tea and supper. In your soup you have a piece of carrot, parsnip, a small potato, a tablespoon of barley and two leaves of spinach.

Talking of spinach – the first day I gave it to you, you sat up alone for the first time and you haven't yet repeated the performance. That was on the 18th January. You sit up in the bath and you do really try to sit up at other times but you don't get very far as yet. Since you have been having the modified milk you have been a little angel. As good as gold just laughing and kicking when you wake up. Such a change from the bedlam of the past three weeks. You can now suck your toes and you certainly do. You vary a bite of toe with a teaspoon of soup. It is really comical to see your toes covered with carrot. You seem to enjoy it anyhow.

You are growing into a very pretty little girl. Your eyes are so very blue and your lashes are growing so long. Mac loves to watch you wake up you always look so sweet at that time. I often find him standing by your cot just watching you sleeping and he will put his arm around me and say, "Isn't she lovely?" and you really are. We are so thrilled with you little darling. I do hope I can pay you back for all your sweetness.

March 9th 1939

Seven months old today and you still can't sit up! You are still a little monkey with your food darling. You eat it if you feel in the mood, which is not very often. You have been completely weaned and now have modified milk at 6am. Barley jelly and modified milk at 10am. Into this milk you have the yolk of an egg, but so far you are only up to five drops. This is increased drop by drop until you have the whole yolk. You have soup with two tablespoons of sieved vegetables in it and one tablespoon of sieved baked apple and four tablespoons of custard or junket for your 2pm feed. For your tea, you have Waiyena, or Bowens Food or groato or Farex or ground rice and modified milk. Through the day you have rusks, which you love, a piece of apple tied in muslin to chew. You have grape juice, orange juice, prune juice and tomato juice. I seem to be cooking food all day long.

You can roll over very nicely now. Wish you would sit up. You are a funny little frightened baby. I can't leave you crying or you work yourself up into a nerve storm. I was frightened to death when this happened first. You sounded so terrified. Indeed I'm still frightened now. It is heart rendering to hear you. I cry myself.

Jennifer Gay, you are without a doubt the sweetest baby I have ever known. We took some very good snaps of you a few weeks ago. Are you always going to be so sweet I wonder? I hope so. This is such an unsettled world at present. War scares and alarms all the time. Will there be another war in your time? I do hope not. The world has not yet recovered from the one twenty years ago. However I'm very much afraid there will be another upheaval before long and then what will happen to us I do not know my baby darling. You are really too sweet to know the horrors of a war.



May 3rd 1939

I haven't had much time to write in your book my baby. You seem to take every spare minute I have. You will be nine months old next week and still you can't sit up. You are certainly getting quite close to doing so but you can't do it yet.

I have just finished making you a blue smocked frock and bonnet. You look so adorable in these clothes. I feel so proud of you when I take you out. I have also made you three pairs of Vyella pyjamas with feet in them. These look very sweet on you also.

You are having three meals a day now. You are really a little monkey with food. I have such a job to make you eat. Other babies seem to have trouble to get enough to satisfy them but not so you. Why are you like this I wonder? Tomorrow I'm going to start you on meat and fish. Wonder if you will like that.

Mac takes you to tennis with him now. Every Saturday afternoon, I dress you up and off you both go. He's very proud of you, as indeed I am too. You are really a very pretty baby and so how could we help being proud of you.

We bought a swing to try to help you to sit up. So far it hasn't helped much but you do like sitting in it.

You have a very affected little cough, which you discovered you could produce at will and now you cough every time you hear anyone else do it. Some poor man in the tram had a very bad cold today and he coughed all the way home and so did you.

Jennifer darling we do love you so much. If anything happens and we can't be with you when you are growing up I want you to remember this. My one fear is that something may happen to us and you will need us and have no one. Once, I didn't want to die because I loved living. Now I don't want to die because I love you.

I bought you your first pair of socks last week. They are size 0. They are so sweet but too big for you. I do wish you would learn to sit up. It's the one thing I have really longed for you to do.

July 29th 1939

Little darling I'm going away for a holiday tomorrow and leaving you behind. I don't know how I'm going to leave you, my baby. Yet I must go. I am so nery and cross lately and I'm afraid of becoming a burden to you. I have found myself losing patience lately and that won't do. When I speak crossly to you, your little lip drops and you cry as if your heart was breaking. You are such a sensitive little girl. I do hope you grow out of it. This world is a hard place for sensitive feelings. I want to shield you from everything but know some day you will live your own life and I don't know how I'm going to stand by and watch you try to dodge the pitfalls.

You are so much in love with Mac. When he is around you insist on going to him. I'm so glad about this darling. He is such a kind man and I hope you will always want to go to him with your worries. He loves you so much. Somehow I can't imagine that we were ever alone. You have just taken possession of our hearts and lives and can make or mar a day by your willingness to smile.

You have gained weight remarkably in the last few months. Your cheeks are so pink and your eyes are so bright. What a change from my languid little girl of four months ago. You can almost sit up. You are still a little frightened, but gaining confidence rapidly. Oh Jennifer darling I love you so terribly. How I want your life to be carefree and happy.

Well little girl, I have had my holiday and how I missed you. I think it has done me good though and it is so lovely to be back with you again. You looked so incredibly small and pathetic when I came home and it was so lively to see you. I'm glad I went because I realised how much you mean to me.

October 1939

You still can't sit up darling and, what is more, won't try. I worry so much about you. The Doctor assures me that it is purely nerves that are making you so backward. However I feel so helpless and inefficient. You are steadily cutting teeth.

Once a month I console myself with the thought that at least you are so very pretty that it doesn't matter when you walk or sit up.

December 1939

This year of worry is gradually drawing to a close. It has been such a hard year for us both. I do hope the next year is better for you my baby. You are making big efforts to crawl now. But you can't quite manage it. You manage to get around quite well though and are certainly getting stronger.

January 26th 1940

After all this time of inactivity you have suddenly got beyond yourself and started to cut teeth at the rate of knots. Somehow I don't quite know why you have cut seven in three weeks, which is amazing. Particularly as two were double ones. You now have ten. Very creditable.

You will refuse to sit up and of course don't walk, and you are nearly 18 months old. However you are trying to talk and always exclaim, "Oh petty fows", when you go into the garden. You can say "Naddy" and "Wenny" for Daddy and Jenny.

There is another violent upheaval again and nations are at war with one another. It seems to me that there will always be bloodshed and strife in this world but now thankful I am that you are a little girl while this present trouble is on. You will at least be spared the agony that all grownup people are suffering.

I am taking you to Rockingham next week for a fortnight to see if you benefit from the sea air. I hope you do. You had a grilled chop for the first time yesterday and how you loved it! You at least eat your food without any trouble so I think you must be getting better. The Doctor informed me that he never expected you to live twelve months ago so at least we have something to our credit. I'm glad I didn't know that then.

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