

1. The origins of a commitment

In order to place Ted Freeman's career path in context, I asked him to describe his background leading up to his first involvement with people with brain injuries. This chapter is his response. He prefaced that description with a quotation:

What we are today comes from our thoughts of yesterday.
And our present thoughts build our life of tomorrow.

— The Buddha

He told the following story.

In 1949 at the age of sixteen I worked pushing a barrow at the Sydney City Markets. I had been a schoolboy at Canterbury Boy's High School in Sydney—a selective high school whose motto is 'Truth and Honour'. In the 1950s, few students went to university. Most school-leavers worked in the public service, the police force or the commercial world of shops, offices, banks and insurance companies—the so-called white-collar jobs. Others went into trades as blue-collar workers or became labourers like me. As a schoolboy, I can recall riding in a tram past the imposing sandstone gates of the University of Sydney, looking at the students and thinking I would never be able to enter a university. I wondered how people without money could ever study there. My family had none.

My father, an Englishman, came to Australia in October 1911. He joined the 18th Battalion, 5th Brigade, 2nd Division of the AIF and was wounded by shrapnel at Gallipoli in 1915 at the notorious 'Hill 60' when, as raw recruits, they were given orders to assault an entrenched Turkish position with bayonets. He later fought at Bullecourt on the Somme in 1916 and at Passchendaele in the Third Battle of Ypres in 1917 where he sustained a gunshot wound to his right leg. An above-knee amputation was later performed. In the days before modern anaesthetics, blood transfusions, antibiotics and resuscitation, the mortality from such a wound and operation was high, often 25 per cent. My parents met in Sydney when my father was in Rose Hall, a Red Cross rehabilitation facility.

My mother was a country girl from the far northern NSW town of Mullumbimby where her father, Charles Alfred Shepherd, was the veterinary surgeon. He had served in the Veterinary Corps in the Boer War and my mother had been named 'Victoria Mafeking'. She was invariably known as 'Maffie' to family and friends. Country girls came to Rose Hall to help with the general care of the returned soldiers. My parents were married in 1929. Some sedentary occupations were specifically reserved for disabled soldiers and my father became a lift attendant

at an insurance company in Sydney. We lived in a War Service Home. My father died in 1937 leaving my mother to raise my brothers Bill, aged seven, and John and I (twins), aged four.

When our father was dying, John and I were placed for six months in Burnside Presbyterian Homes, an orphanage at Parramatta. Neither John nor I can recall a great deal of this time at Burnside but when I look at my grandchildren I wonder how such fragile and tender young children do survive what for us was in effect the loss of both father and mother during that time. My mother had to return to work to support the family. In those days women were paid roughly half the male wage so it was a constant struggle for her. But she was a courageous woman who loved us with a passion and maintained her good humour through all her difficulties.

One day my mother questioned me about my future. 'Have you thought about what you are going to do with your life? Have you thought about going to university?' She suggested that I apply to the Sydney Technical College to study for the Leaving Certificate. I enjoyed the learning process and did well enough to gain a Commonwealth University Scholarship. This provided for my university fees and a small living allowance while studying at the medical school at the University of Sydney. Early in my studies I met a gorgeous girl, Dorothy Thomson. She and I were married in 1956. It has remained a love match as we have journeyed through life together. It was unusual for a student to be married. Some distant members of my family reminded me of cousin 'so and so' who had failed at university when he married. But we were both happy and I passed all the exams.

Money was short. We did have a job cleaning the local church and Dorothy played the organ for weddings and funerals as well as teaching some music students. If things became really difficult I would work as a brickie's labourer or at whatever job I could find during university recess.

After graduation in January 1959, I gained a broad experience of most facets of medicine by working for four years in hospitals in New South Wales, Queensland and Papua and New Guinea. At the end of 1963 I took the position as Medical Superintendent of the Paton Memorial Hospital, a Presbyterian Mission hospital in Port Vila, the capital of the New Hebrides, now Vanuatu. The New Hebrides at that time was an undeveloped group of islands in the South-West Pacific jointly controlled by Britain and France. This form of government was known as the Condominium, although ironically called the 'Pandemonium' by the locals and expatriates.¹

1 Marney Dunn (1997) *Pandemonium or Paradise*. Crawford House, Bathurst, NSW.

My time in Port Vila exposed me to a wide range of medical, surgical, obstetric and paediatric problems and some diseases not seen by medical practitioners in developed countries. Malaria, pneumonia, tuberculosis, dysentery and meningitis were rife. Leprosy also occurred on some of the islands. The hospital had excellent Australian and New Zealand mission nursing sisters but inadequate funds and often depended on donations from voluntary organisations like the Red Cross for equipment and pharmaceutical drugs to continue to provide a service to the people of the New Hebrides, both indigenous and expatriate.²

Microscopic pathology was limited to slides for tuberculosis, malaria parasites, spinal taps and anaemia. X-rays were used to examine fractured limbs and for the detection of pneumonia or tuberculosis in the lungs. Much of the success of my medical work depended on close visual observation of the patient and using my hands to feel, palpate and percuss in order to make a clinical diagnosis. These classical methods of inspection, palpation, percussion and auscultation, which have been taught to medical students throughout centuries, have now been superseded by laboratory investigations, sometimes to the disadvantage of the patient. Young physicians seem confused about physical examination. Together with the (clinical) history, physical examination is the doctor's best-kept secret: powerful, portable, fast, cheap, durable, reproducible and fun.

While I was at Paton Memorial Hospital the British Administration sought and obtained a grant from the World Health Organisation (WHO) for me to study surgery in Edinburgh—the oldest surgical school in the world and one with a first-rate reputation. The British intended to build a new hospital in Port Vila and offered me the post of medical superintendent. Dorothy and I packed up the family of six children and went to Scotland in December 1968. I studied hard and completed the Fellowship of the Royal College of Surgeons of Edinburgh (FRCSE) and returned to Vanuatu early in 1970.

Some months after my return I was performing a caesarean on a patient with an obstructed labour. I began to sweat profusely and, with a severe headache and tremors, I thought I had malaria, although I had taken my preventative drug, Chloroquine. I developed a stiff neck and I began to fear meningitis, which was confirmed by lumbar puncture performed by the excellent New Hebridean doctor Dr Makau Kalsakau.

I can vaguely recall early one morning being taken by stretcher on a small boat from the hospital on Iririki to the Vila Airport where the Royal Australian Air Force had a Hercules air transport waiting. Noise protectors were placed on my ears, and I was given an injection. I have no recollection of the trip or arrival at Sydney Airport.

2 Edward Freeman (2001) *Doctor in Vanuatu*. University of the South Pacific, Suva.

I awoke in Sydney Hospital in a back room adjacent to the intensive therapy unit, since the doctors thought I might be infectious. The room was obviously the storage area for the unit and I was alone. Night closed in. I was too weak to eat the food. It was May, the weather was cold and I had come straight from the tropics. I lost body heat and began to shiver and desperately wanted more blankets. A bell had been placed on a bedside table, but it was out of my reach. I yelled as loudly as I could for help, but no-one heard.

Hours later a nurse came into the storeroom, looked at me in surprise and said, 'What are you doing here?' I had been forgotten. She gave me some warm blankets. The weakness I experienced is difficult to describe. It was past fatigue. Just as a person can be mentally desolate, I am sure that the body can be physically desolate. I had no power. The effort of breathing seemed to take all my strength. Any other action was superfluous. To move an arm or a leg or to attempt to sit up or to eat took enormous concentration and effort and resulted in extreme fatigue. The only people I wanted to see were my wife and immediate family.

After some weeks, I had finished my antibiotics, my lumbar puncture results were improving and no further treatment was necessary. Over the days, I urged my wife to 'get me out'. I couldn't wait to get home even though it was only to a small mission flat in an inner western Sydney suburb.

I learnt two things from my illness. First, the experience wrote into my brain what it would be like to be disabled, to be so locked into one's body like Annie, who wrote that being in an institution 'removes all hope'.³ Second, I realised that the best place for the sick person, if at all possible, is home.

A year later I was appointed the Medical Superintendent of the Gosford District Hospital on the Central Coast of New South Wales. Gosford was a burgeoning town close enough to Sydney to be a commuter suburb. The position was mainly medical administration with a small clinical component. Excellent doctors served the patients in the hospital. This was in the time of the honorary medical system when the doctors proudly gave their time unstintingly to both public and private patients. I remained in this position for five years before going into general practice.

One day in 1979 a mother came into my consulting room. Her five-year-old daughter had an ear infection. The little girl had suffered cerebral palsy from birth and could not talk. Medical schools did not teach about the conditions of cerebral palsy or Down syndrome. These two conditions tended to be lumped together as an unfortunate fact of life and the children were regarded as being

3 Anne Macdonald & Rose Crossley (1980) *Annie's Coming Out*. Penguin, Melbourne.

mentally defective and were often placed in mental institutions or hospitals for the developmentally delayed. The medical opinion was that nothing could be done for them.

But this child seemed to communicate with her mother. With increasing curiosity, I questioned myself, 'What is going on here? This is an unusual scene. Is this mother really getting through to her child? Am I missing something and, if so, what? Can I learn something here?' I left the surgery that evening puzzled over what I had seen. I described the consultation to Dorothy when I arrived home. She said to me, 'You are obviously intrigued. What are you going to do about it?' I replied, 'I don't know.' Shortly after this episode I met the grandfather of a child with cerebral palsy. He was raising funds to send his grandchild to the United States for treatment at the Institutes for the Achievement of Human Potential (IAHP) in Philadelphia. I inquired about this institution. My medical and educational colleagues warned me strongly against the institutes, which were not recognised by the medical profession. They told me the institutes had produced no scientific evidence to back up the claim they could help children with brain injury. They said the institutes provided false hope and treatment was expensive. While the word charlatan was not used, this was the message. I was advised not to go. But I was interested. I wrote to the institutes and asked if I might visit. The reply was welcoming.

Dorothy and I left Sydney in June 1979, landed in Vancouver and bussed overland to Philadelphia. Since I was experienced in clinical and administrative work in both developed and undeveloped countries, I thought I only needed a short time there, perhaps a day or two. Dr Glenn Doman, the founder of the institutes and the author of a well-known book on brain injury in children, was originally a physical therapist and had worked previously in partnership with an educationist, Dr Delacato, but the two had separated.⁴ Dr Doman greeted me warmly. When I asked him about the question of outcomes, he answered, 'You can have access to all our files and do as much research as you like to see our results.' I did not think this would be any help since I knew very little about brain injury—a subject never taught at medical school.

I was shown around the centre and finally introduced to a very senior physician, Dr Edward Le Winn, MD, FACP, formerly the senior attending physician emeritus (chief) of the Albert Einstein Medical Centre in Philadelphia. Dr Le Winn's honest and positive but careful attitude to the children with brain injury intrigued me. I left the institutes late in the afternoon and when I arrived back at the hotel I said to Dorothy, 'I would like to revise our plans and stay in Philadelphia longer.' I went for the next four days to the institutes. The repeated

4 Glenn Doman (1974) *What to Do about Your Brain Injured Child*. Doubleday, New York.

message was that much could be done to help the person with a brain injury but it required time and effort and resources. Without these inputs there could be no improvement.

Each day I met with Le Winn and examined children, discussing with him their initial problems, their potential and possibilities for improvement. I watched as therapy was tailored specifically for each child. The dedication of the families impressed me and also their grasp on the realities of their problems. I did not see any evidence that these parents were given false hope. Rather, they were encouraged to look at what may be possible. At this interval, I am reminded of the conclusion to a 1995 article: 'It is not too many years ago that students were taught that the human nerve cell is so highly specialised that it cannot repair itself.'⁵ Our teachers were wrong.

The central philosophy of the institutes was that the dynamic potential—that is, spare capacity—of the injured brain to improve is enormous and it is important to redevelop certain areas of the brain in order to obtain improvement. The brain has to be worked in the same way that a muscle needs to be worked. If the brain is not worked it will atrophy (shrink).

This change in the brain cells has now been termed 'plasticity'. In those days the term was either not invented or rarely used. Its significance for those with a brain injury is immense because the injured brain does not suddenly become rock-hard and solid. There is no reason to suppose that the injured brain loses the ability to change and regain some function if it is given the correct environment. In other words, the injured brain can be reorganised by providing the optimum environment. Neurological reorganisation was the basis of the institutes' work.

The other concept that the institutes promoted is that the correct way to regain function is by redeveloping the most primitive areas of the brain and building a pattern of development on this basis. Just as the developing infant learns to push back in the bassinet, then roll over onto his/her front, then push along the floor on his/her abdomen, then lift his/her head from the floor and rise up onto hands and knees, then crawl, then stand holding onto a support structure, then cruise from one piece of furniture to the next and then walk with the arms held out to balance before walking freely without support, so, the person with a brain injury may need to go through the same stages as they recover. This developmental approach has many other supporters. It fits in with the work of Piaget, Gesell and other well-known developmentalists. It is rather like building a house by laying the foundations first before the superstructure is placed in position.

5 Donald G. Stein, Simon Brailowsky & Bruno Will (1995) *Brain Repair*. Oxford University Press, Oxford.

I found much to be genuine at the institutes both in the people and in their methods. I could not discount the work I had witnessed there. It whetted my appetite to explore further. Much of what I discovered later as an independent researcher supported the work of the institutes.

Dorothy and I returned to Australia from Philadelphia. The medical group practice where I worked was large and demanding and the questions raised in my mind in Philadelphia about brain injury were soon swamped by more pressing demands on my time.

But on Thursday, 10 April 1980 our lives changed totally and forever. While I was playing tennis with some friends a police car arrived and told us that our eldest son, Matthew, had been killed in a road accident. We both started crying in disbelief. Ross, our youngest son, was also present. We gathered him up and drove home totally overwhelmed with grief and loss. You never think that such a thing is going to happen to a member of your family. Our children as well as Dorothy and I were heartbroken.

We made arrangements for Matthew's funeral. We intended to see his body but the undertaker rang to say that it would be better not to. He had sustained a severe head injury and was killed instantly. The editor of the local newspaper, whom I knew well, rang up for information about the accident. He asked, 'How is Dorothy?' I said, 'All right.' What else can you say? Talk seemed pointless. He then said to me, 'You will be all right, Ted, since you are used to this sort of thing!' He meant death of course. I was amazed, for he was a kindly man.

I did not go to work for a week. Dorothy and I went to the beach each day and sat. There was not much conversation between us. What could we talk about that was of any significance beside the catastrophe that had struck our family? On about the fifth day after Matt's death I said to Dorothy, 'I feel that there is something special for me to do.' Almost instantly, I knew that I had to research brain injury.

I am a firm believer in the concept of the 'wounded healer'. I believe it is possible that the person who is wounded can turn that hurt from a negative to a positive. The strength that arises from experience of this pain can be used to minister to other people passing through a similar episode. I am not a pastor, priest or minister and my strength does not lie in that direction but I had been and could be a healer. That much I knew. On the back cover of Father Henri Nouwen's book are the words:

It is his [Nouwen's] contention that the minister is called to recognise the sufferings of his time in his own heart and make that recognition

the starting point of his service. In other words, the minister must be willing to go beyond his professional role and leave himself open as a fellow human being with the same wounds and sufferings.⁶

I knew I must learn more about brain injury and find my professional role in helping both the patients and their families. I approached a friend in the Department of Health, Dr Ted Cullen. I told him I wanted to work with patients who had been brain injured. He was supportive but explained there was not much work or research being done with patients diagnosed as brain injured. He did say, 'This is probably not what you want but there is a position at Peat Island Hospital.'

Peat Island was a hospital on the Hawkesbury River for people with mental retardation and developmental delay. I regarded it as being at the lowest point in medicine, but a friend said, 'Ted, you haven't tried it yet. How do you know if you don't try?'

In January 1981, I met with the Medical Superintendent of Peat Island and walked around the wards with him. There were approximately 160 patients, or residents as they were called. Some had been inmates for almost 50 years. The staff were caring but it was a custodial institution. Many of the wards had an open-door policy. One ward did not. It was Ward Four. Its doors were heavily padlocked and the windows had heavy wire mesh over them. It was a prison. The smell of human urine, faeces and vomit hit you the moment you entered. The patients were shouting, screaming, yelling, banging their heads, jostling each other, walking or dragging themselves from one place to another apparently without purpose. Many had adopted the typical institutional constant rocking movement—backwards and forwards—whether standing, sitting or lying on the seats or on the floor. Some were openly aggressive. It was *One Flew over the Cuckoo's Nest* in reality.

Most of the nurses, male and female, genuinely cared for the people. At no stage did I see any staff member physically abuse any resident. It was the healthcare system that was at fault. The staff were caught in the system to the same extent as the residents except they had those two irreplaceable advantages—power and freedom—both denied to the inmates. I took a deep breath of fresh air each day as I walked away from Ward Four to rid the smell from my nostrils and the noise and sights from my brain. I realised that if I was put in Ward Four as a resident I would go mad. The environment would destroy me as I am sure it did those unfortunate people.

I researched the medical records of each patient in Ward Four. One-third of admissions were post encephalitis, often from measles; one-third were admitted

6 Henri Nouwen (1979) *The Wounded Healer*. Image Books, New York.

because of cerebral palsy. No information was recorded about the other inmates. I noted many records on incidental things such as skin rash or ingrowing toenails or haemorrhoids but only minor entries detailing the brain injury or the mental state or behaviour of the inmates. The data were very unbalanced. The clinical notes indicated no therapy had been given even on a trial basis in Ward Four. The residents in this ward were there forever. For them, death was the only release. There were diversionary programs for residents in other wards of the hospital. The actual objectives of the programs were difficult to determine. Mostly, it seemed they were ‘revolving-door’ programs, which meant the residents did the program and finished in precisely the same position as they were in when they started.

In its fully functioning period a decade or so before, Peat Island and an adjoining island, Milson Island, had a total of 650 residents. Three doctors would certainly have been needed but the establishment for medical officers had not been reduced with the decreased patient load. The island was heavily over-doctored. The Medical Superintendent was a very kind man near retirement age. He attended the hospital every weekday and ran a general practice clinic for minor ailments. There was another doctor, who had an inquiring mind and who gave me considerable help. And then there was me—three doctors for 160 patients, most of whom were not physically sick.

I soon realised that there was little work for me to do. A small office in the front room of the former mortuary became available for me. I started a program of learning and research. Every morning I arrived at 8.30 and after checking on some of the wards I moved into my room and studied my books and journals for hours each day. Where to begin was the difficulty. My only information was from the institutes in Philadelphia. Just to mention their name produced a highly emotional, antagonistic and at times aggressive reaction in both medical and educational circles. Also, the National Health and Medical Research Council (NHMRC) in Australia had issued a report that stated that there was no scientific basis for the work of the institutes (this, of course, was true in 1976).⁷

I decided to research normal brain function and after that consider the effects of a brain injury. I read every piece of literature I could find relating to brain function and brain injury. By the end of 1981 three concepts appeared to provide a theoretical and possibly practical approach to helping people with brain injury. They were canalisation—that is, the inherent pathway of development and redevelopment of the brain—the enormous spare capacity of the brain, and the neuroplasticity of the brain.

⁷ National Health and Medical Research Council (1976) *Report of the Therapeutic Goods Subcommittee to Investigate the Methods used by the Institutes for the Achievement of Human potential*. 82nd Session of Council.

While I was working at Peat Island I met Ian Hunter, the Clinical Director of the Australian Centre for Brain Injured Children (ACBIC). Ian came from Melbourne, where his centre was located, but he travelled around the capital cities of Australia and consulted with families whose children had suffered a brain injury. Ian had trained in Philadelphia at the Institutes for the Achievement of Human Potential. Whenever Ian came to Sydney we discussed programs and therapies. I found him to be responsible, conscientious and honest in all his dealings with the patients and their relatives and I learnt much from him as I sat in on his clinics and watched his approach.

It was Socrates who first said that questions are more important than answers. Only questions, he said, could keep people intellectually honest.

Transferring answers from one brain to another has fairly predictable consequences: answers are safe. Infecting minds with questions is hazardous: it is impossible to predict the outcome.

I was preparing a paper on coma when *The Lancet* published a letter by Dr Le Winn and Dr Mihai Dimancescu, a New York neurosurgeon who had established a coma recovery unit in the United States.⁸ They gave quite startling and positive results from a small group of comatose patients they had treated using increased environmental stimulation. Le Winn sent me a copy of his paper, which detailed his method of sensory stimulation in the patient in coma.

At this time the attitude of the administration at Peat Island changed. The Area General Medical Superintendent called me into his office one afternoon. He appeared to be very annoyed. He asked, 'Did you know that your name had been linked with Ian Hunter and his organisation [ACBIC]?' I said, 'Yes, that is possible.' He told me it was against Health Commission policy to be associated with this organisation. He demanded to know what scientific proof they possessed. I listened to him quietly and then said, 'Come with me and I will show you what your so-called scientific principles have produced. I will open the door of Ward Four and you can look inside. That is what your scientific principles have done.' He finally said, 'I forbid you to have anything more to do with Ian Hunter. You are not to see him again.' I said, 'I'm sorry. I cannot agree with your request', and I left his office.

I was not the only one asking questions. There were other people seeking to expose the failure of the health system to fulfil its duty of care to similar patients. Peter McLean, the previous secretary of the NSW Subnormal Children's Welfare Association, produced a report on Stockton Hospital, an institution with 830 residents. He wrote: 'I am still finding it difficult to cope with what I can only

8 Edward Le Winn & Mihai Dimanescu (1978) Sensory enrichment in coma. *The Lancet*, ii, 156.

call an appalling state of affairs at Stockton Hospital.⁹ He writes of the lack of staff, that the children sense their 'aloneness and rejection', that some children were 'self mutilating', and that 'some children never left their wards'. McLean finished:

I have not written about the abuse and deprivation of just one child in an isolated case. I am writing about 300 children in just one place alone. How many other institutions in this state are doing more or less the same thing to handicapped children. It may be better to replace the word 'state' with the all-embracing word 'country'.

I asked a variety of people to come to Peat Island to observe the condition of the patients. They were psychologists, physicians, ministers of religion and politicians. All were appalled, but there seemed to be no authority that could actually expose the conditions and resolve some of the problems.

I desperately needed a group of reputable people to whom I could report. At the suggestion of a friend, a support group was formed to keep me 'in balance' and, as much as possible, out of trouble. One friend who agreed to join the group warned me that 'you are in a difficult work area. The road ahead will be hard.' Dr Malcolm Mackay, a former minister in the Menzies Government, became the chairman. Malcolm had a deep and personal commitment to the research as his own daughter Elsbeth had died following a traumatic brain injury. Two Sydney businessmen, a former moderator-general of the Presbyterian Church of Australia and a physician colleague completed the group.

There was general agreement among the members that the letter published in *The Lancet* on the subject of coma by Le Winn and Dimancescu might be the way forward. The committee reasoned that traumatic brain injury was different from brain injury in childbirth. Traumatic brain injury involved a situation where a once healthy and vibrant person with full faculties was suddenly altered by one accident. Unlike the situation with brain injury present since birth, lifestyle and abilities had already been established.

Following my confrontation with the Area General Medical Superintendent, I realised that I was in serious difficulty at Peat Island. I still had research to do. I did not want to leave, but I knew the axe must fall. I had challenged the healthcare system. I had questioned the authorities who controlled my employment. I was regarded as a troublesome heretic. The pay scales for doctors on my grade at Peat Island were very low and the financial upkeep of our five children was considerable. We were not lavish spenders, rather the reverse. Our lifestyle was simple. I spoke to Dorothy about the importance of the work on brain injury. She knew a great deal about it since I constantly discussed

9 Peter McLean (1981) *Report on Stockton Hospital*. NSW Subnormal Children's Association, Sydney.

with her the events of each day. She expressed concern, however, that I was so immersed in the study of severe brain injury that it was dominating our lives. But I continued to do the research. I finished a paper on coma incorporating the new knowledge I had acquired and sent it to a selection of medical people. Some thought my document could be worthwhile, but more research needed to be done.

An arrangement was made for me to meet with a neurologist and a rehabilitation specialist. The neurologist had an open mind and positive approach, but he also quite reasonably suggested that further investigation and research were needed. The rehabilitation specialist was not receptive. When I met him in his office he had not bothered to read the paper. I soon found that he had a very narrow concept of what could be done with people who have been brain injured. He told me: 'No matter what you do for them, they just keep coming back. They are part of the "revolving door" syndrome.' He said, 'You should be working out how to retire rather than delve into areas about which you are totally ignorant.' I was kept on at Peat Island as long as possible, but finally that position was terminated.

In March 1982 I went to Melbourne to observe Ian Hunter at work and to learn more from him. Once again I had a demonstration of how difficult it is for the medical profession to deal with alternative thinking. I invited a medical friend to come to the ACBIC clinic. He arrived late and was obviously distressed. He told me that his colleagues in his medical practice objected strongly to his coming to an organisation that was not accepted by orthodox medicine. He had argued with them and finally walked away from them in disgust at their attitude.

On returning to Sydney, I approached various organisations for support. I prepared a copy of my paper on the new approach to coma and submitted it to the NSW Government Insurance Office (GIO). The Chief Medical Officer expressed interest in the document. GIO paid large sums of insurance money to those people who had survived severe brain injury. It made sense to reduce the extent of injury if possible and therefore lessen the payout amounts.

I spoke to many Rotary clubs about the problems of the children who were in places like Peat Island. Each time I finished my address, concerned Rotarians came to talk with me in order to find out what they could do. Sometimes awkward situations occurred. My speech was still very much based on the findings of my work at Peat Island and the disregard that the government and medical profession showed towards these unfortunate children. I always quoted part of the report from December 1981 by McLean of the Subnormal Children's Welfare Association and also the comments from the report of the Anti-Discrimination Board of New South Wales:

The failure of public policy has been to render people with intellectual handicaps virtually second-class citizens and arguably the most impoverished and underprivileged group in our society. If the test of a society is how it treats its poorest, most marginal people, then the findings in the report indicate that our society is seriously wanting.¹⁰

After I had given the speech a few dozen times, I knew it by heart and rarely referred to my notes. Before one of the biggest and most powerful Rotary clubs in the country, when my eye roamed around the audience, I caught sight of a collection of medical administrators responsible for the hospital and health service that I was attacking. One administrator had been delegated to give the vote of thanks. He was very sparse in his comments and our meeting afterwards was frosty; however, there was a great deal of goodwill from the Rotary clubs in general. They all expressed interest and wanted to help, but no-one seemed to know what to do.

Malcolm Mackay, the chair of my support group, had been appointed as a consultant to World Vision, the large and very effective international charity that supports people in underdeveloped countries. Malcolm arranged a meeting in Melbourne with the Executive Director of World Vision. He sought the opinion of a medical consultant, which was very positive. Some days later, early in June 1982, Malcolm Mackay invited me to another meeting with World Vision. The organisation had decided that my work could benefit those with brain injury in underdeveloped countries as well as in Australia and therefore would support me. The support, which would begin immediately, would not be a professional wage but more of a stipend, paid six monthly, as well as a small expense account to provide for travel and accommodation costs; but it was enough to keep my family afloat.

I usually get to sleep easily and sleep very well. That night in Melbourne, I was so excited I lay in bed with myriad thoughts churning through my mind. I suppose the uppermost thoughts were thankfulness and gratitude and I couldn't wait to get home to tell Dorothy. Now I could continue with the work. The Executive Director of World Vision gave me a letter of introduction:

World Vision has taken up the challenge to enlist support for Dr Freeman so that he can continue his investigation into the most recent developments in the field of brain injury to children.

In the course of our worldwide care for children suffering from the effects of poverty, malnutrition, war and violence, we are continually confronted with multitudes of children suffering from what many feel to

¹⁰ NSW Anti-Discrimination Board (1981) *Discrimination of the Intellectually Handicapped*. NSW Anti-Discrimination Board, Sydney.

be irreparable brain damage. This moves us to seek for any possibility of treatment which might enable these children to be released from a living prison and take up useful and meaningful lives.

A Health Commission official offered some office accommodation and also research facilities in his building. He did make some reasonable requests: that traditional scientific procedures should be followed and that the name of the commission could only be used with their specific authority and no publications should be issued without their approval. It looked like I was on the way at last. Funding and some semblance of credibility, even though small, had arrived.

I now began working in earnest on the research into coma. Two generations ago a coma that lasted for more than a couple of days would have been virtually unknown because the patient would have died. It is my belief that nowadays, because modern medicine keeps people alive by artificial means, patients can survive in coma for weeks and months. Medical technology has provided the ventilator, which can breathe for them, fluid is provided through intravenous lines and urine is drained away by catheter. Tubes inserted through the abdominal wall directly into the stomach (gastrostomy tubes) provide food.

I soon found that there was a considerable body of medical opinion that regarded coma as a sleep-like protective state and that nothing should be done to the person in coma, apart from general nursing care. The patient should be placed in a darkened room and allowed to sleep, during which time the brain would heal itself. Many orthodox doctors supported this theory and would not listen to opinions to the contrary.

At one medical meeting I spoke to the keynote speaker, a professor, about the possibility that this passive approach should be challenged, as it was well documented that the longer a patient remained in coma the worse was their outcome.¹¹ I suggested to him that coma victims were being placed in extreme sensory deprivation by three factors: their injuries, the poor sensory input from their environment and the heavy use of sedative drugs. His face went very red. He said, 'You are totally wrong', and turned away. He refused further discussion. I found this attitude to be quite common.

A marker event now took place. The Regional Director from the Northern Region of the Health Commission referred me to the Royal North Shore Hospital in Sydney with a request to allow me to have access to the medical records of those patients who had suffered brain injury during the preceding three years for a new approach to the patient in coma. I was introduced to two specialists there. One was an epidemiologist—that is, a person who is skilled in plotting the

¹¹ Carl Carlsson, Claes von Essen & Jan Lofgren (1968) Factors affecting the clinical outcome of patients with severe head injury. *Neurosurgery*, 129, 242.

results of changing factors in a statistical group of people or a community and who can structure research projects correctly. The epidemiologist, being non-medical, had an open mind on the subject. The other was a psychiatrist who had done pioneering work observing changes in the immune system caused by the body's reaction to grief.

Both were interested in the research. They considered it a legitimate field of study. It made sense to these two doctors that the patient should be given a structured input of stimulation to achieve arousal rather than leaving the patient to lie in bed in a state of sensory deprivation with no or minimal therapy. The question was how could this reawakening of the brain be undertaken? There were several alternatives but the most natural process was to provide an input to the brain through the senses of vision, hearing, touch, smell and movement.

In late 1982, I was asked to contact Kevin Beckton, the Assistant General Manager (Legal) at GIO, for an appointment. I saw Kevin soon after. When the niceties of introduction were finished, Kevin asked, 'What do you want?' Kevin is one of those no-nonsense people, disarming and very shrewd. He had spent many years involved in investigating claims made to the GIO by people who had suffered accidents and he had helped to establish a spinal unit in Sydney. We discussed the research. I explained that my funding was from World Vision. I said that World Vision would be delighted if GIO relieved them of the funding requirement.

The General Manager of GIO indicated that they were interested in offering a contract. I accepted an offer. Dorothy and I later repaid World Vision all of the money we had received from them. The research gained support at the board meeting of the GIO and things were really on a roll. The NSW GIO had size, status, authority and money. A letter on GIO letterhead gave immediate and substantial credence to the research:

GOVERNMENT INSURANCE OFFICE OF N.S.W.
153-163 PHILLIP STREET, Sydney

Dear Sir,

Dr. E. Freeman MB, BS FRCS(E) wishes to research and document the use of Coma Arousal techniques in the severely brain injured and to offer these techniques to those who may wish to use them.

These techniques are still in the process of development and at this stage there is no firm evidence from Australian Sources on their efficiency.

However some reports from the United States indicate that they may be advantageous in reducing the length of Coma and possibly reducing the extent of neurological deficit.

I am satisfied that Dr. Freeman's approach will be ethical and constant.

The Medical Superintendent of the hospital and the Neurosurgeon or Attending medical officer will be first contacted and the matter discussed with them.

Only if they are in agreement and give their permission will the program be explained to the relatives for their involvement.

Dr. Freeman will not intrude in any way, with the control of the patient and the responsibility for the patient will be solely with the patient's medical officer.

Dr. Freeman will work under the authority of that medical officer. Dr. Freeman is not in private practice and no question arises of his treating any patient beyond what is outlined herein.

(The program is non-interventionist from the surgical point of view and consists of intense sensory stimulation.)

It is important that the relatives of the patient should be involved heavily in the program both from the patient's point of view and also to minimise the load on the hospital.

Neither the G.I.O. nor Dr. Freeman makes any specific claims for the technique and it is important that this is understood by all.

However your help and co-operation with Dr. Freeman would be appreciated.

Yours truly,

J. A. Gill
Acting Assistant Managing Director
Government Insurance Office

Two of Sydney's leading neurologists agreed their names could be attached to the research proposal. This automatically meant other professors and doctors in all medical specialties would feel safe in becoming involved, and many also supported the proposed research. The epidemiologist, the psychiatrist and I prepared a research protocol, which was approved by the GIO.

It was important to learn about the management of severe brain injury in other world centres. March 1983 came and Dorothy and I left for overseas. The United States appeared to be the most advanced, although first-rate work had been

done in Glasgow. Los Angeles seemed to be a good place to commence but it was disappointing to learn that the International Coma Data Bank, into which I had hoped to incorporate Sydney data, had been discontinued.

My next US contact was in Boston with the US National Head Injury Foundation (NHIF). The NHIF had been started by Marilyn Spivack. Marilyn's daughter had suffered a severe brain injury and Marilyn had become angry with the dismal and negative attitude of the physicians. She directed her energies to joining together families and medical professionals in a productive way. The NHIF produced a newsletter on a regular basis identifying the needs of the patient and the family. Just before my visit to the United States, their *Newsletter* of Spring 1982 contained the words '[i]t is impossible to remain aloof when faced with a family, torn by fright and anger, handicapped by guilt and denial and seemingly abandoned by a system which does not care enough'.

Marilyn started to form chapters of the NHIF in the United States and soon realised that she was not alone in wanting to gather knowledge of the families' predicaments and bring it into mainstream medicine. Within a period of two years, 14 States had formed chapters. It was interesting that even in 1982, Professor Ben Yishay, Associate Professor of Clinical Rehabilitation Medicine at New York University, wrote in the NHIF *Newsletter*:

I would like to cite the appearance in recent years of several publications which provide us with newer and more hopeful insights into the potential inherent in the human brain for the restoration and reorganisation of functions following brain injury ... the traditional model of rehabilitation is not suited for an estimated 80% of persons surviving a traumatic head injury.

While in Boston, I visited a well-known rehabilitation hospital: the Greenery. This was a revelation. It had been opened 10 years previously. There was no morbid feel about the hospital. It was full of US initiative. They had active units that specifically dealt with patients in coma. Vigorous attempts at arousal of the patients took place in an effort to give them every chance to regain function. The Greenery had links with institutions that had high reputations such as Tufts New England Medical Centre and St Elisabeth's Hospital, a teaching affiliate of Tufts University.

My next visit was to the Head Injury Centre at Lewis Bay, Hyannis. This was smaller than the Greenery but had a similar approach. Its Progressive Coma Management Program measured 'the individual's capacity to respond to a variety of sensory inputs', and it admitted patients who had a decreased level of awareness for more than six months—that is, in the persistent vegetative state.

From Boston, I went to the Bronx Municipal Hospital in New York to speak to one of the neurosurgeons. He thought stimulation of the patient in coma was a waste of time. He said that using a torch to give a light input to the eyes would be likely to cause the patient to have an epileptic fit and that the only way the problem could be solved was by developing the chemical transmitters that are used by the brain to send a message from one nerve to another. He was dismissive of any alternatives.

One of my main reasons for going to New York was to make contact with a neurosurgeon, Dr Mihai Dimancescu. Dr Dimancescu had pioneered 'coma stimulation'. He directed the International Coma Recovery Institute in that city. Unfortunately, I could not meet with this great groundbreaking doctor as he had been called away urgently to assess a patient in Europe. Some years later we did meet and shared our experiences.

On the Sunday when we were in New York we went to church in the lovely, historical Fifth Avenue Presbyterian Church. It was special for us because the choir sang Gabriel Faure's *Requiem*, which starts with: 'Grant them rest eternal, O Lord, and let light perpetual shine on them.' The minister who conducted the funeral service for our son Matthew had told us that on the night after the funeral he had sung this *Requiem* with a major Sydney choral group.

I had seen enough in the United States to support a new approach to coma. It seemed that much was already being done in the United States. I could not foresee that there would be any difficulty in introducing such an approach into the hospitals and the medical profession in Australia. I had not, however, taken into consideration the massive power base that would be required to achieve any shift in the present treatment of coma; I should have known better.

The epidemiologist, the psychiatrist and I realised that the protocol for the coma arousal research must be undertaken in a major Australian hospital. Soon after my return to Australia, we approached the neurosurgeons at Royal North Shore Hospital and Westmead Hospital and presented the protocol to them, accompanied by the letter from GIO. They showed some reserve, but were not opposed to the further development of the document. One of them said that 'anything which can be done to help these victims of brain injury would be welcomed'.

By June 1983, the protocol had gained wide support from the universities and hospitals in Sydney. Kevin Beckton expressed GIO's pleasure at its progress. While both Royal North Shore and Westmead hospitals had been approached initially, Westmead, a large hospital in western Sydney with an excellent reputation, seemed to be the more receptive. What's more, Westmead needed a piece of equipment for research. They were \$20 000 short of the money needed.

Kevin Beckton agreed that GIO would donate this amount. Westmead was also better for me personally since I knew some of the doctors from student days at medical school. I studied intensely everything in the medical journals that related to coma and brain injury. There was a lot of activity in overseas centres: in the United States at Richmond, Virginia, and also in Britain at London and Glasgow. The developed countries were now recognising that brain injury had reached epidemic proportions and was a massive problem.¹²

By the end of 1983 the protocol had been scrutinised and passed by the Ethics and Research committees of the Westmead Hospital, and the GIO decided to fund a feasibility study on coma arousal at Westmead Hospital. Kevin Beckton notified me that he had received permission from the GIO Board to provide research finance that would allow clinical research to commence at Westmead. The research protocol required the cooperation of many different departments in Westmead. These included neurology, neurosurgery, intensive care, rehabilitation, nursing, social work, physiotherapy, occupational therapy and speech pathology. Each department was autonomous, but interlocked, and each needed to be encouraged to take part. The Director of Research Resources at the hospital told me that the hospital had never had such a large research proposal before.

Conclusion

Ted Freeman's account of his life preceding a commitment to people with brain injury identifies events that afforded him insights into the experiences of those people and their families. Coupled with this was the horror evoked in him, and others, by the conditions in which many people with severe, long-term disabilities were maintained within the healthcare system. A possible solution to some of his concerns was offered by the availability, from a large insurance company, of financial support to research the possibilities for improvements to the existing situation.

12 Bryan Jennett & Graham Teasdale (1977) Aspects of coma after severe head injury. *The Lancet*, 1, 78.