

5. What future after emergence?

This chapter's primary aim is to describe the development and implementation of Freeman's ideas for assisting patients and their families through the period after discharge from an acute-care hospital. What it was possible to achieve in practice evolved through several stages, largely as a result of the changing circumstances within which he practised. The intersection between Freeman's life and his fight on behalf of his patients, referred to above, is most evident in this chapter.

Freeman's absolute horror at the plight of those who had been effectively abandoned within the healthcare system, with no possibility of ongoing rehabilitation, was clearly a strong motivating influence for him. He has provided an account of a visit to Weemala, an institution which held a significant number of younger people with long-term severe brain injuries. This visit occurred in 1989, a decade after his initial commitment to the research, but it is likely to represent an accurate summary of his impressions following earlier visits to similar institutions. It is, incidentally, an indication that not much had changed by this later date.

The visit in question was undertaken to assess a young man with a severe brain injury, at the request of his parents. Freeman found that one in eight of the residents was there on account of brain injury. Perhaps these were part of the group who had no family support. Perhaps they included people like Cecil, in Chapter 2, whose family had acted on the advice to 'walk away and forget'. There are also likely to have been patients without families and others whose families lacked the resources, including financial capacity, required to care for them at home. He reports that:

Weemala smelt of despair and when I visited there I felt that I was back in Ward Four at Peat Island. There was a scarcity of staff and few visitors. There was no noise except for the heart-wrenching cries of the inmates tied in their beds or chairs. The place was filled with bad odours, which could be detected the moment you entered the building. Weemala had been built in 1906 for Sir Henry Moses and had been bequeathed by him as a Home for Incurables. In 1989 it had 176 patients. Twenty of these were admitted with severe brain injury. There were patients with stroke, multiple sclerosis, cerebral palsy, cerebral tumours, mental retardation and rheumatoid arthritis. The wards varied from two to seven beds. There was limited privacy, provided by yellow curtains hanging from rails around each bed. There was no area for the patients' special belongings, and in the

hospital brochure it states, 'Valuable items and large sums of money are best left at home or in a bank safe deposit, no responsibility can be accepted for lost or stolen goods.'

I found Weemala repulsive, and mentally cleansed myself when I had finished my inspection, appalled by what I had witnessed and outraged that any person should be subjected to such suffering, and certainly not those whom the minister responsible for Weemala called 'helpless people'. If this was protection by legislation, the legislation urgently needed to be revised.

Freeman's observations on Weemala describe a situation in which virtually all of the practical initiatives provided to patients in the course of his ideal post-emergence rehabilitation scenario were countermanded. Sensory input was denied by the system. Any 'risk' of stimulation was minimised. Inadequate staffing precluded any attempt to provide some opportunity for interaction between a resident and another person, even if this had been institutional policy, which it clearly was not.

At the same time, staff limitations would minimise chances of any manifestation of 'soft signs' being reported, let alone acted upon, again even if this had been policy. The conditions were certainly dissuasive of visitors and, even if some had ventured in, would have precluded attempts to undertake any program.

As recounted in Chapter 1, Freeman's consuming interest in the plight of people who had remained unconscious beyond the acute stage of brain injury and his resulting interaction with unorthodox therapists led to the termination of his appointment at Peat Island. An opportunity to remain committed to the management of affected people was provided, in the first instance, by the offer of financial support from World Vision and then by an undertaking on the part of the NSW Government Insurance Office (GIO) to provide support. As part of this agreement, Freeman became Medical Director of the newly formed Brain Injury Division of the Australian Brain Foundation.

Under this new arrangement, his first opportunity to apply on a larger scale the practices that he had come to recommend for individual patients came with the provision of funding to trial those practices on a group of inpatients. This trial was to occur in the Westmead Hospital. The story of the failure of the trial to proceed will be considered in the next chapter but it may be noted at this stage that a refusal by his colleagues to accept the continuity of the rehabilitation process beyond awakening and on to subsequent management was a substantial obstacle. Nevertheless, the feasibility study preparatory to the trial was completed and served a useful purpose in extending practical knowledge of both opportunities and difficulties.

With the abandonment of the 'Westmead' project, the GIO withdrew funding from the hospital. In place of it, the GIO provided funding to support the implementation of Freeman's rehabilitation strategies in a freestanding inpatient facility, the Brain Injury Therapy Centre (BITC). The period of operation of the BITC—a little more than three years—permitted the enthusiastic application of the full gamut of his ideas for ongoing rehabilitation. This period provides the source of the approaches to be described below.

The functioning of the BITC was irrevocably curtailed in 1989 as a consequence of a violent assault on the Centre and on Freeman by the NSW Minister for Health. This assault, under the protection of parliamentary privilege, represented the culmination of an ongoing attack that took a variety of forms. The nature of this attack, together with an examination of its basis, is the subject of Chapter 7.

Following the closure of the BITC, the final decade of Freeman's professional career was spent as a solo practitioner travelling to patients throughout New South Wales. Whilst this loss of resources prevented the vigorous team approach to rehabilitation that had been possible at the BITC, it inadvertently demonstrated what was achievable for patients with brain injury by means of a minimally resourced domiciliary rehabilitation program.

Any account of the development in Australia of attitudes to rehabilitation following brain injury will include much of the story of Ted Freeman's career. Accompanying the events identified in the preceding paragraphs were substantial changes in his personal circumstances. Within a short period following the parliamentary attack, he relinquished his source of income, with his professional reputation besmirched. Reference has already been made to the financial complications that commonly beset families of people with brain injury—for example, the reduction of income experienced by carers. The parliamentary attack had a similar effect on the Freemans. The manner in which Ted Freeman contrived to continue his mission of providing advice to families with a brain injured member will be recounted in the last part of this chapter.

The prognostic pessimism prevailing while patients are comatose frequently extends to the general perception of their future potential in the event of their emergence from coma. Depending on the opportunities that are available to people with a brain injury when they are no longer comatose, such pessimistic prognoses can readily become self-fulfilling. It would require overweening self-confidence in the healthcare system to postulate, as some have done, that the programs undertaken by families and volunteers had not significantly contributed to more worthwhile outcomes for many patients than those foreshadowed in their prognoses.

It will already have been clear that the patients whose stories were touched on in Chapter 3 were members of families who were committed to helping them. Surveying the many patients whose management had been influenced by Freeman's philosophy, all appear to have been members of such families. Reflecting the critical role of families in searching for some chance for their injured member, there were no instances of young patients without close next of kin coming to his attention. Most commonly, Freeman's assistance was sought directly by patients' families, with information about him having been disseminated on a 'word of mouth' basis. Yet severe head injuries are not restricted to people who are part of a strongly supportive family.

One may well ask, what about people who sustained a severe brain injury but lacked a committed family? While the numbers of patients falling into this category cannot be reliably ascertained, they have undoubtedly existed. It seems inevitable that some of the residents in the 'Home for Incurables', mentioned above, fell into this invisible cohort. It is also probable, given the stories of other patients with committed families, that some of those in this invisible cohort could have had better outcomes if they had been afforded similar opportunities.

The development of Freeman's ideas

Emergence from coma and improvement in a patient's condition thereafter represent two parts of a continuum. The separation of emergence and subsequent progress into separate chapters is intended to emphasise, as strongly as possible, patients' dependence, following awakening from coma, on the nature and level of support that are available thereafter. Far from being the end of a saga, emergence usually connotes the beginning of a much longer and more demanding period (both for patient and for family) of moving towards recovery.

The preceding point, while absolutely self-evident to families and friends, was not accepted by some of the prospective researchers in the Westmead trial. It was contended by some of those not familiar with Freeman's earlier outcomes that the participation of any patient in the trial should finish when emergence from coma was observed, or after 10 weeks, whichever came first. The reason for this limitation was that undertaking post-emergence procedures on patients in the trial was regarded as supplanting 'conventional' rehabilitation programs. This attitude failed to appreciate that the approach Freeman wished to test represented an alternative to the established approach to rehabilitation. He soon realised that straying onto another's patch can be hazardous.

This imposition of a cut-off point sought to place the attainment of a neat piece of publishable research ahead of the welfare of the patients whom the research was purported to benefit. It could be considered as a manifestation of an extreme

form of 'medical compartmentalisation'. This entails a management structure in which each problem that the patient encounters is likely to be considered and dealt with in isolation, rather than the medical attendants being prepared to see the patient as a whole and regard management as an ongoing and uninterrupted program. This systemic inadequacy is not confined to patients with brain injury, nor is it a problem that has since been satisfactorily resolved, notwithstanding its widespread recognition.

Freeman has summarised what he regarded, at an early stage of his involvement, as the prevailing professional attitude towards the recovery process after brain injury:

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

Scientific belief that 'nothing could be done' was supported by the dogmatic statement, included in every neuropathology textbook, that it was not possible to produce new neurons once an individual had grown beyond the perinatal period. That this statement is incorrect has been repeatedly demonstrated during the past decade. One unsubstantiated, and invariably unstated, assumption arising from extension of this proposition was that development of new neurons *must necessarily* be an integral component of recovery of the injured brain. *Ergo*, it was believed that 'no capacity to form new neurons' was synonymous with 'no capacity for recovery'. Contradicting this line of argument, Freeman's advocacy of the concept of 'neuroplasticity' based on observations of his patients was dismissed as scientifically untenable.

The location of post-emergence recovery will usually differ from that of the comatose stage (family home rather than acute-care hospital) and in the intensity of nursing and other care available. It has been acknowledged by medical personnel of high standing in the profession that there is an enormous difference between the care and treatment provided to patients in intensive care units and that available once they are moved to another hospital ward. For instance, Bryan Jennett, the Glasgow neurosurgeon jointly responsible for devising the Glasgow Coma Scale, commented on the situation as he saw it in 1997:

While there are advocates for prolonged programs for active rehabilitation, the reality in most countries seems to be that many rehabilitationists are reluctant to accept these patients until they are showing some signs of recovery and are therefore expected to benefit from rehabilitation. As a result, most such patients either remain for long periods in acute care

settings or are transferred after a few weeks to nursing homes. Because of this, some believe that many vegetative patients do not reach their full potential for recovery.¹

Jennett's insight, to which many of his colleagues would have subscribed, is notable for what it omitted. The seeming inevitability of transfer from acute care to a nursing home, or similar institution, reflected unawareness that slow-stream domiciliary rehabilitation was practicable and worthwhile for some patients. Ted Freeman's beliefs about the importance of longer-term maintenance of rehabilitation reflect his concept of the 'three accidents' that a person with a severe brain injury may experience.

The 'first accident' is the initial trauma, an event that cannot be changed. The 'second accident' occurs when there is haemorrhage in the brain and the brain cells swell. I stressed the importance of the optimal environment to the recovering patient, after requiring intervention by the neurosurgeons and the intensivists. The 'third accident', in my opinion, occurs because often the patient is left with minimal therapy once they are out of the life-threatening state.

Arguing from the well-documented association between duration of coma and the quality of longer-term outcome, which deteriorated with prolongation of unconsciousness, Freeman suggested:

Coma victims were placed in sensory deprivation by three factors: their injuries, the poor sensory input from their environment and the heavy use of sedative drugs.

His inference was that, if the period of impaired consciousness was shortened by measures such as less sedation and gradual introduction of opportunities for increased sensory input, subsequent outcomes might be improved. It remains impossible to determine with certainty whether the coincidence of duration of coma and extent of subsequent recovery reflects mere association or real causation. Does ultimate recovery depend only on the initial severity of the injury, or does prolonged coma aggravate the acutely inflicted injury? It seems probable that whichever interpretation is appropriate could vary from patient to patient. It might also suggest that testing the possibility of improvement in outcome as a result of shortening the period of coma is a very reasonable proposition.

As mentioned above, prognostic pessimism, when it leads, as it commonly does, to a retreat from intensive attention to the patient, often to something little

¹ Bryan Jennett (1997) A quarter century of the vegetative state: an international perspective. *Journal of Head Trauma Rehabilitation*, 12, 1.

better than abandonment, will usually prove to be accurate. Whilst most of the patients' stories included in earlier chapters describe a family's rejection of the nursing home option in favour of caring for the patient at home, Cecil's story is a sad illustration of how the die can be cast when a gloomy forecast is acted upon.

An important factor in the inculcation of prognostic pessimism is undoubtedly the 'disconnect', referred to above by Jennett, between the medical attention available at the acute stage and in the long term. Neurosurgeons, for instance, may work unremittingly in the interests of an individual to save a life after head injury but, by the time this has been achieved, another injured individual has arrived at the hospital and is making a full-time demand on their skills.

While no numerical information is available on this point, one could wager with considerable confidence that none of Freeman's patients described in Chapters 2 or 3 had met up, several years later, with those medical professionals responsible for their acute care. With hindsight, had they done so, the pace of acceptance of Freeman's ideas may have been accelerated.

This possibility might have to be constrained by acknowledgment that awakening of a comatose patient, even when followed by a prolonged improvement to attain a life regarded as worthwhile by patient and family, is effectively a repudiation of the early prognosis. Medical professionals are certainly not unique in being uncomfortable if confronted with evidence that they got it wrong.

Another factor that has certainly been influential in prognostic pessimism, but as a 'back-up' to support the others, has been the translation into the case of the individual patient of the conventional wisdom (hardly the right noun, but the phrase can carry questioning connotations) about the pathological processes associated with brain injury that it is necessary to reverse or circumvent if any degree of recovery is to be achieved.

Finally, a factor of general applicability when individuals living with any major disability enter the healthcare system is the risk that professionals associated with their care may project their own opinions onto the patient. Thus, if I would not want to continue living if I were to be in a condition similar to that of the patient then I can 'reasonably' infer that he or she would reach a similar conclusion. To respond to this, there could be nothing more appropriate than Joe's response from Chapter 2: 'life goes on and I wouldn't be dead for quids.'

Freeman's approach to rehabilitation was essentially dependent on the families. Expressed succinctly in two of the family letters in an earlier chapter was the description of domiciliary rehabilitation as a combination of 'social contact' with 'physical activity'. The relative emphasis on these two components might

vary with the age and gender of the patient. Given that many of Ted Freeman's patients were young males who had been physically active before their accidents, the strategy for older, less active persons might need to be tailored differently.

Significantly, but not unexpectedly, as already remarked, there are no histories, among Freeman's files, of patients who had a brain injury, but not a family. If one had sustained a brain injury and, in due course, had been assessed as not suitable for rehabilitation, early dispatch to a nursing home may have been inevitable. This 'invisible cohort' of patients could not be accorded input to any trial of coma arousal.

The evolution of Freeman's approach to assisting people severely disabled by brain injury appears to have taken place very much in parallel with his practical experience rather than being something that had been completely foreseen. It is likely to have been continuously amended in the light of that practical experience. As already stressed, Freeman's zeal to assist patients and their families was fuelled by his personal observation of the plight of those whom the system had sidelined. Added to this was his conviction, based on reading and supported by observations in some US clinics, that the phenomenon of brain plasticity was real. Whilst the term 'plasticity' was not in general use in relation to brain repair at the time, Freeman had been frequently making use of it in advocacy for change by 1983.

During the 1980s and 1990s the 'extraneous influences' on Freeman's practice were, I suggest, the complex financial ramifications of insurance compensation after severe brain injury, the ongoing proposition that a randomised control trial of his methods was *de rigueur* before they could be generally sanctioned and the equally ongoing opposition to the man and his methods on the part of some of his colleagues. It is not practicable at this distance in time to dissect the interplay between the last two influences, and to attempt to do so would serve little purpose now.

As a starting point for considering the strategies that evolved, one might identify Freeman's involvement with his patient Roger, described in Chapter 2. This occurred in the late 1970s when he was still employed at Peat Island. As he had no support available that could be directed to assisting patients outside that institution, the only help he could provide to patients and their families was to advise about rehabilitation measures that a family could undertake. He could also attempt to facilitate admission of the injured family member, when appropriate, to facilities that offered some chance of rehabilitation.

After leaving Peat Island, a departure largely determined by incompatibility between his views on rehabilitation after brain injury and those of his supervisors, Freeman lacked the resources to help patients until, at the beginning of 1983,

the NSW GIO committed to support him. At this time, Freeman undertook a study tour of the United States, returning with increased enthusiasm for implementing programs of sensory stimulation after emergence from coma. Perhaps the observation that most impressed him about possible approaches to stimulation occurred when he visited the Greenery, a facility near Boston that specialised in rehabilitation following brain injury. He recalled:

The Greenery 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.

It fascinated me to see that their intense Coma Treatment Program used sensory stimulation in an effort to increase sensory awareness. They employed each of the five senses: smell, touch, taste, sight and sound. The staff/patient ratio at the Greenery was 1–1 and an average of four hours of therapy was given to each patient per day. This certainly seemed the way to go. The staff were extremely helpful and cooperative.

Utilisation of all five senses in attempts to gain access to a patient seems quite logical if one takes account of human evolution as reflected in the differing degrees of specialisation of the discrete neurological systems underpinning these senses in different non-human species. For example, whilst olfaction, the capacity to smell, has become relatively less important in the course of human evolution, it is a common observation that it may become more used, and useful, in people who have had long-term loss of one or more of the other four senses.

Putting ideas into practice

The scope of stimulation programs was considerably broadened by the GIO's approval of the study of coma arousal at Westmead Hospital. For the first time, it became possible for Freeman to have the support provided by a number of nurses with full-time commitment to overseeing programs to be undertaken, in collaboration with families, in the hospital. Observations made by these nurses identified very practical ways of providing less orthodox avenues for stimulation. Perhaps predictably, these related to nursing rather than medical care and so their value was not readily acknowledged by other hospital staff. As Freeman has written:

The nurses had found that the patients relaxed in a bath of warm water and that passive movement of the arms and legs was much more gentle for the patients than 'dry' work; however, our nurses were instructed (by the hospital administration) not to continue to bathe the patients. Furthermore, they were directed not to take the patients outside the airconditioned hospital into the fresh air and sunshine. We had observed that it was often in the gardens that patient awareness could be seen for the first time as the patient turned his head to look towards the sun or the surroundings.

Whilst this major expansion of resources enabled Freeman to translate his evolving ideas into practice on a scale not previously possible, it was constrained, as alluded to above, by a divergence between the goals of Freeman and those of hospital personnel. Whereas he envisaged rehabilitation as entailing an ongoing commitment to management that was not to cease *after* awakening, others considered that this event should terminate the provision of stimulation. Apart from the disagreement over when stimulation should cease, there had been some resistance within the hospital in relation to which measures could be adopted to provide stimulation. In talking with families of young patients with brain injury, Freeman usually suggested that, given appropriate conditions, improvement may be expected to continue, albeit at a decreasing rate, throughout the remainder of their lives.

This divergence in interpretation of what the project was actually to be about did not bite until some time after initiation of the preliminary feasibility study for the trial. At this stage, the numbers of 'emerged' patients began to accumulate. Whilst some of these people were admitted into existing hospital rehabilitation programs, Freeman's concerns lay especially with others who, whilst awake and aware, remained locked in. This disagreement came to a head in 1985. Freeman and his collaborators wrote to the hospital administrators spelling out their belief concerning the nature of therapy required by those patients who had emerged from coma. This letter, which warned of the disadvantage to them if this was not undertaken, contains a most succinct statement in response to the question regarding the future *after* emergence, which was posed in the title of the present chapter. Freeman wrote:

Since the initial application to the Research and Ethics Committee the feasibility project has clearly identified that environmental stimulation to the point where a patient can no longer be considered in coma does not take the patient to the point of being ready for the current rehabilitation service. Without this treatment, the gains made in bringing the person out of coma more quickly may well be lost in a treatment vacuum. The current rehabilitation service cannot cope with the intensity of therapy needed in

this phase. Typically such a patient will wait in a high dependency ward until their own slow progression towards recovery gets them to the stage that the current rehabilitation service assesses that it can help them.

This divergence in aims led to the abandonment of the project at Westmead and the establishment, with GIO funding, of a freestanding facility in the Sydney suburb of Eastwood. This facility, the Brain Injury Therapy Centre (BITC), was able to admit patients who, having emerged from coma but being ineligible for rehabilitation within a hospital (because they failed to attain the prerequisites for entry into existing rehabilitation services), were likely to be abandoned. The BITC also assumed responsibility for day-care patients who, until that time, had been assisted in a facility at Baulkham Hills, supported by the GIO. The subsequent period during which the BITC operated was notable for the complete implementation of Freeman's strategies for longer-term rehabilitation.

Funding for provision of rehabilitation to patients entering the BITC was provided irrespective of their insurance status. This was not so for other institutions. The timely availability of financial compensation influenced the possible support for rehabilitation available to patient and family once the acute stage had passed. Apart from insurance status, the issue of whether, and to what extent, the patient was conscious could have a substantial impact on the size of the continuing financial support to be provided as compensation. If a patient was accepted as being in a persistent vegetative state, the extent of ongoing support that would be provided was considerably less than that which would be considered reasonable for a similar patient who, it was acknowledged, had regained some level of awareness. Essentially, the level of support in the first situation might amount to little more than very basic nursing measures. Consequently, there was a strong incentive for lawyers retained by any insurer to obtain an expert medical opinion to certify that a patient remained in a persistent vegetative state.

Recognition by the GIO that comprehensive resourcing of rehabilitation offered an opportunity to improve the outcome for brain injured people by reducing their level of dependency, and ultimately to reduce costs on the industry, led to the funding of the BITC. This incentive was reinforced by a strong humanitarian commitment on the part of the GIO staff with whom Ted Freeman interacted, and entry to the BITC was determined by the likelihood that a patient could benefit from it. As mentioned above, a patient's insurance status was irrelevant. As a result, Freeman was able for a period to provide inpatient rehabilitation in a manner that he considered optimal. Support provided by the BITC prepared residents for transition to domiciliary programs with ongoing support from the centre's staff.

Freeman has given an account of the transfer from the hospital to the BITC:

We breathed a sigh of relief when we cleared our desks, collected our documentation and equipment and parted company with Westmead Hospital. The conflict over the preceding 20 months had been emotionally demanding. The clinical nurses in the team had been extraordinarily tolerant and long-suffering for the sake of the patients and their families. The whole team transferred to St Edmund's Hospital in Eastwood. St Edmund's had been an old-fashioned cottage hospital. Facilities were limited at first and conditions difficult. The hospital consisted of a large house with rooms that had served as the wards and we accommodated our patients in these rooms. Six patients insured by the GIO were transferred with us from Westmead Hospital. We closed the Day Therapy Centre at Baulkam Hills and those patients also came to the facility at Eastwood.

Two general practitioners with an excellent reputation provided clinical care for our patients and had total control of the patients' medical treatment. If these doctors said a patient was too sick to receive therapy, it was withheld.

Another house in the grounds, once renovated, became the Therapy Centre. Until the renovation was completed we hired a large tent in which we gave the patients their therapy. This was far from ideal. It was very hot in the summer and in wet weather the grounds became waterlogged and mushy, but the staff worked with total dedication. One night, after a particularly long spell of rain, the tent finally collapsed.

A splendid team of experienced nurses now worked at the Therapy Centre. In order to cope with the different aspects of the work, the three nurses in authority were given different streams of vocation.

One nurse, with wide experience in the wards at Westmead, Bev Burrell, was the obvious choice as the acute-care nurse.

She assessed patients in acute-care hospitals when requested by the families and only when permission had been granted by the attending doctor. These patients were generally still in coma, but out of the life-threatening state. She examined them and documented their condition before writing a program, which she taught to the families. This meant that she travelled widely throughout both the city and the country areas in New South Wales and also the other States. She became very adept at diagnosing the condition of the patients and was a great help to families lost in the medical system. She frequently encountered the displeasure of the authorities at hospitals she visited [perhaps as a surrogate for Freeman].

A second sister, Robyn Sedger, took charge of the Brain Injury Therapy Centre at Eastwood. She supervised the other registered nurses (RNs) and coordinated the families and volunteers as they provided therapy.

This became a massive job as the number of patients gradually increased to twenty-three. Her very diplomatic and careful manner ensured that all patients were properly cared for and their families supported through the most difficult times. Volunteers from the Eastwood area and other parts of Sydney came in abundance. Many were mature-age people who could use their life experience to relate to the patients. Often this involved small actions like encouraging a person to move a thumb or a finger so that communication could be established with the use of a computer keyboard. Slowly, people who had minimal movement increased their muscle range, coordination and strength. These small achievements brought a sense of liberation to the patient and were applauded by the volunteers and the staff. The younger and fitter volunteers worked with patients who were 'pumping iron': pulling weights with their hands or standing on tilt tables or riding on exercise bicycles. Often there were three or four patients in a room being helped by volunteers and supervised by a member of the nursing staff.

GIO provided a heated swimming pool and each patient was given the opportunity of floating and working in the water under the care and supervision of the instructor. Those who were incontinent had body wetsuits provided and were not denied this special type of therapy. There was such camaraderie in the centre that the atmosphere of hopelessness that permeated some rehabilitation centres had no possibility of surfacing here amongst the noise, the bustle and the excitement. One of the volunteers, a sister from St Joseph's Convent, wrote about the work being done at St Edmund's:

I feel very strongly about the work done there and the quality of life we can give these patients who otherwise would be put in nursing homes. What is life about but Love, Sharing, Caring and even the smallest improvement is rejoiced in by all patients, staff, relatives, friends and us volunteers. There is life and joy here. Come see for yourselves.

A third senior sister, Yvonne Ayrey, took charge of the development and control of domiciliary rehabilitation—our third stream of intervention.

She travelled throughout the State at the request of families who had decided to take their patient home rather than put them in an institution. This move from hospital or nursing home to a patient's home demanded a great deal from the family, but our nursing sister quickly became an expert at assessing the patient and the family situation, working out possible therapy for the patient and meeting with the volunteers from the community to teach them how to provide the therapy.

These three nurses were all first rate and each gathered assistants with the same dedication, commonsense and compassion. An additional four experienced personnel—all excellent—were added to the nursing staff. With the grapevine of communication actively working, many families contacted us to see if we could help when they had been told that ‘nothing further could be done’ for their brain injured relative, or that ‘the end of the road had been reached’, or ‘what you see is what you’ve got’.

Freeman’s account of the BITC identifies the features that sharply differentiated his approach from that prevailing in the mainstream healthcare system. Care of residents was undertaken by a team of highly experienced nurses. Recruited to assist under their direction were volunteers from the community bringing a range of backgrounds, interests and skills. Apart from the quantitative difference of the BITC from conventional hospital care in the ratio of carers to residents, there was opportunity for an even more significant qualitative distinction. An example of this described above was the availability of volunteers to assist residents to use finger movements as a means of communication. The time-consuming nature of activities of this type would preclude hospital staff from committing to them. An allocation of several sessions of ‘rehab’ each week could not accommodate such intensive involvement.

Unlimited access of family members to patients could enhance the work of other volunteers by ensuring a sense of security from day to day. Inclusion of family members in programs also served as a preliminary to domiciliary rehabilitation, which remained the ultimate goal of the BITC. Integration of BITC activities into patient care in the home, either after a period as a resident in the BITC or as an alternative when distance precluded regular family attendance at Eastwood, was another integral feature of the Freeman approach (the example of Joe’s father in undertaking a 400 km round trip each day in order to participate in activities at the BITC, while inspiring, could not realistically be copied by most families).

All of these human activities occurred within a physical location unlike that practicable in a modern hospital, where throughput of people requiring inpatient treatment for acute conditions is essential in order to achieve maximum outcomes from bed occupancy. Not only would an acute-care hospital setting for BITC programs have been an unacceptable diversion of resources from the duties of the institution but it also would be clearly less satisfactory for the participants. Accommodation in a domestic setting with daily opportunity for outside experience accorded with the aim of maximising variation in stimulation opportunity.

Taken together, the human contribution with its mix of professional and volunteer participation located in a domestic-scale physical environment, more closely resembling that with which residents would have been familiar during

their life before brain injury, promoted the creation of a unique ambience. As encapsulated in the quotation from the sister from St Joseph's Convent who was one of the volunteers, the BITC 'epitomised life and joy'.

The BITC challenged

As referred to above, the work of the BITC was very adversely affected by an attack on it by the NSW Health Minister. In the immediate aftermath of the parliamentary attack on the centre there was consternation among the residents' families and the staff. Nevertheless, the activities within the centre and the two operations undertaken in the community under its auspices continued. At this time, Ted Freeman felt that he should step back from a close supervisory role in the centre, and sought an alternative administrative arrangement for it. He suspected that much of the antagonism being publicly expressed towards the centre was directed at him personally and might abate with his withdrawal from day-to-day involvement. In seeking to set up an alternative arrangement, he made a decision that he was soon to regret. His selection of a person with financial experience together with marketing skills to administer the centre was intended to reverse the decline in funding, and the ensuing curtailment of services, which followed the adverse publicity generated by the parliamentary attack.

On her appointment, the new administrator engaged major legal and accountancy firms to work for the centre. Freeman recalls watching with increasing concern over the following months, as 'there was an extraordinary securing of funds including a large loan from a financial institution'. At this time he withdrew from all clinical involvement with the BITC and resolved to retire. The situation worsened dramatically when the administrator returned from a visit to the United States with ideas for major development of the BITC. Freeman remembers by then having 'a distinct feeling of unease about her management although [he was] unsure what action to take'. His impression that the centre was losing its soul as relations between its staff and the administrator progressively deteriorated was confirmed when the entire senior nursing staff resigned.

In response to this crisis, the Australian Brain Foundation terminated its connection with its Brain Injury Division, which was then disbanded. It was replaced with a new group, designated as the Australian Brain Injury Institute, with the BITC administrator as its executive director. A finance director and a public relations manager were appointed, the former having the brief of raising \$20 million. With failure to achieve this, the board became concerned. The executive director was dismissed and the overseeing body went into liquidation. The largest circulation Sydney daily tabloid devoted its front page

to an investigation by police into suspicions of financial mismanagement at the BITC. Freeman remembers this period as being worse than the separation from the Westmead Hospital four years earlier.

Freeman has described the events that followed the BITC debacle:

I was convinced that I must now retire if my work was to be assessed correctly. In January 1990, a retirement dinner was arranged for me in Sydney at which Dr Malcolm Mackay spoke eloquently of the plight of people who had sustained a brain injury and the long-term effects on their families. The Board of the Brain Injury Division was then disbanded and connections with the Australian Brain Foundation were terminated. Chris Snow recorded that a new organisation had been formed to care for patients with brain injury; however, this organisation foundered after some months.

Dorothy and I discussed in detail what action we should take. It was obvious that we would have to sell our house in Sydney—a fact that was most distressing to Dorothy as she loved the cottage and its location and we had many friends in the area. We had also just completed an extension that had given me an office and shifted me from the dining room, which previously I had cluttered with my computer and books.

We put the house on the market. Fortunately, it sold quickly but as the mortgage rates at that time were 17 per cent, we only had a couple of thousand dollars after the sale. I needed an income quickly as we had several children at university and some still at school and my previous occupations on the mission in Vanuatu and as the medical superintendent at Gosford had all been relatively lowly paid compared with a private medical practice. We could have returned to the Central Coast but with our family in Sydney this was not a good option.

I was fortunate to find work at a medical centre run by an excellent practitioner, on the Northern Beaches of Sydney; but my heart still hankered to be with people with a brain injury and their families. One day the phone rang and a person greeted me with 'Hello, Ted, this is Annette on the phone. I have had a hard job finding you. Bruce and I wondered whether you would be prepared to come and see John again? We were very distressed about what happened at the Centre but no-one else seems to want to help.'

I thought about my answer quickly and said, 'Lovely to hear from you, Annette, and I would be very happy to come and see John again. Could you give me your address.' So I started again.

Word spread rapidly amongst the families who had been treated as outpatients at the BITC. Each day brought more phone calls from families of previous patients. Many families, new to me but seeking help when the established healthcare system failed them, also made contact.

Within two months I had resigned from the medical centre and found I had more than enough patients to keep me busy every day. The calls came from all around Australia, often with, 'Are you the Dr Ted Freeman who treats people with brain injury? If so, I would like you to come and see my son/daughter, husband/wife.'

This third period of commitment to assisting people with brain injury following the closure of the BITC had not been anticipated by Freeman at the time of that closure. During it, his activities took the form of driving to family homes throughout New South Wales in order to design and supervise individual programs. In undertaking this, he combined both his original role at the BITC and that of the nursing sister responsible for the supervision of BITC domiciliary programs described above. After a period, he was awarded a Commonwealth grant, which provided a modest level of support for him to do this. Provision of any specialised nursing or paramedical care was not included in his grant.

Whilst this period superficially resembled that following his departure from Peat Island two decades earlier, it differed in the level of awareness of his methods among members of the healthcare industry. He had demonstrated what could be done and had aroused concerns in many about the inadequacies in the long-term management of brain injury. In doing this, he had also refined considerably his ideas on how a domiciliary response to rehabilitation could be implemented.

It was not long before the Freeman practice extended throughout New South Wales and into Queensland. He has provided a graphic description of his practice:

I drove an old, green 1960s Triumph 2000 car inherited from Dorothy's mother's estate and this was soon travelling widely through Sydney and beyond. Only once did it hold me up on the road out near Windsor but I treated it gently and never drove it too fast. As soon as I could, I replaced it with a second-hand 1986 Toyota Cressida with 90 000 km on the clock.

The spread of patients meant a considerable amount of travel, and I soon had the week organised in the Sydney area. Every three months I would arrange to see patients in the NSW country towns like Tamworth, Armidale, Tweed Heads and Taree, and also travelled to Queensland to see patients in Toowoomba, Maryborough, the Sunshine Coast and the Gold Coast.

In relating his financial arrangements, it is not difficult to envisage that he shared much in common with many of the families that he visited:

We had a small Franklin caravan, which Dorothy and I would load with our gear, attach to the Cressida and set out. We were on a low budget and needed to keep travel and accommodation costs to a minimum. In this way, we did not have motel costs, we could do our own cooking and did not need to eat in restaurants, although we did enjoy one meal before a log fire in Toowoomba. It was the middle of a bitter winter.

The majority of the patients were covered by Medicare, and many had exhausted their finances as they sought help to improve the person they loved. Very few could contribute any money for travel costs and I rarely asked them for it unless they appeared to be affluent. Even if they had insurance cover often there was a dispute and the insurance company would refuse to provide any finance for therapy until the legal position was resolved. In some patients it seemed the insurance company withheld resources on the basis that the patient was likely to die without any funds being expended.

When the patient survived, their medical problems often became subservient to the massive legal machinery that had to develop to bring a legal action to the court. A legal case could continue for years until a time could be fixed when the solicitors for both the plaintiff and the defendant felt the matter could go to court. Even then, a date for a court hearing could take months to obtain.

Sharing of circumstances between doctor and patient's family probably augmented the natural rapport that Ted Freeman possessed, already remarked on in the families' letters of appreciation. From his description of this period, it is likely that the Freeman family typified many of those whom they visited in terms of financial resources.

We rented a house in Sydney for one year but renting irritated me because I could never really change anything in the house or garden and I like to potter and fiddle with the gardens and houses. We decided to obtain a mortgage and buy a small two-bedroom, fibro-roofed weatherboard house on a small block of land at Mona Vale, built about 1920. It was a ramshackle place. It had old-fashioned sliding wooden windows in the front that were falling to bits and would not close properly. There was a small lounge room, with an open fireplace, which led into the kitchen, which linked with the back verandah. The bathroom was large with a black-painted concrete floor, an

old toilet and a shower similar to the ones that could be found in old seaside tourist areas. The laundry was a small separate building at the rear. The larger bedroom became my office.

Various people who came were concerned about our 'fall' but we could function in it. One family member was heard to remark to another: 'Dot and Ted have come down in the world, haven't they?' We had made home in many countries and always felt that if we had each other and the family we would make do.

When I travelled to see patients I spent a considerable amount of time assessing them. I always explained the diagnosis, the future possibilities and demonstrated the program of therapy to the family. As one mother told my brother John, 'Ted was the only doctor we have ever met who seemed to know how to examine my son'.

The 'Freeman approach' to domiciliary rehabilitation was ideal for the patients but it did not conform with Medicare's computerised profiles for practice. A consultation of several hours with the family rather than with a patient eventually came to departmental notice and led to provision of a modest level of funding sufficient to enable Freeman's State-wide practice to continue.

Fortunately, even though I had a higher surgical degree, I had never registered on the specialists' lists and I could function as a general practitioner. This meant that patients did not need to be referred by another medical practitioner. Families could seek a consultation directly with me.

The downside was that while I could claim for a prolonged house call, the Medicare payment for this was relatively small. I had to cover travel and the costs of medical indemnity as well as computer, telephone and postage costs. Since I had no allowance for sickness or injury, I had to insure against these costs myself.

In June 1993, Senator Graham Richardson was the Federal Minister for Health. Some people familiar with my work, through personal involvement as volunteers with friends whose family member had suffered a severe brain injury, made contact with Senator Richardson on an informal basis.

At the same time, Professor Roger Rees wrote from Adelaide to Senator Richardson in support:

Indeed it is generally estimated that approximately 5000 persons per year, mostly male and mostly young, experience severe traumatic brain injury largely as the result of road accidents. For large numbers of this

group there is little hope of recovery given the more traditional methods of care in nursing homes and long stay rehabilitation hospitals. This costs Australia billions of dollars per year.

Dr Freeman has attempted to provide alternatives largely through home based and community based care. He travels the country seeing families in need and promoting the idea that the acquisition of skills and improvement in lifestyle is possible for even the most profoundly damaged. There is much evidence that, as a result of Freeman's courageous and painstaking interventions, improvement for persons with brain injury has taken place.

Not every family will want to avail themselves of Freeman's ideas or of a move from hospital based care to community and home based care. Nevertheless there are substantial numbers of families who wish to undertake this home based rehabilitation program.²

Freeman's account of this period continued:

In response to this intervention, I was invited to meet with the Medical Services Adviser, Health Care Access Division, Department of Health, Housing and Community Services. He questioned me. 'What do you actually do?' I had taken six case studies to demonstrate the facts and, after a short interval, he said that he could help. He said that there was a Commonwealth Health Program Grant (HPG) that allows for the provision of unusual medical services. This replaces Medicare billing. Payment would be dependent on the number of people treated. The amount of the grant was not large, but it meant I could continue my work.

With hindsight, it is not difficult to see that Freeman's extensive practice of visiting patients around the State, although it had evolved in response to the loss of the BITC, had pioneered domiciliary rehabilitation and established that it was both practicable and effective. Reflecting on this period, Ted Freeman summarised his experience:

By the early 1990s I had seen a considerable number of patients in their own homes and had established programs of therapy for their families and friends and volunteers to follow. Sensory and emotional deprivation and personal space invasion had decreased and increased therapy was provided for the patients.

Families strengthened when they determined to control the care of the person they loved and not be at the whims of the health system. It has been

2 Roger Rees, Letter to Graham Richardson, 13 June 1993.

said that 'what oxygen is to the body, such is hope to the meaning of life', and they developed hope. The patients and families also benefited because travelling to hospitals for therapy was reduced and there was no more hanging around impersonal institutions waiting for assessment or therapy. I always went with an expectation that there would be some positives in both the patient and the family. I was rarely disappointed.

The usual 'medical model' had failed dismally and had little relevance to the problems of these patients and families. Most patients were not acutely sick. They did not require medical attention every day or every week or every month. They only needed medical intervention on an irregular basis if they became ill.

The way forward for them was not by more medical involvement but by education. It was the educational model that could act positively. But medicine was like a dog with a bone: it hung on when it had no justification to do so.

Not every patient improved, but even those patients who changed little had a much better social life interacting with the people who loved them and cared about them, rather than being left in limbo in a nursing home. But, of course, I understand that not every family is in a position to take their loved one home; circumstances dictate what can be undertaken.

In summary, in this third period, following the closure of the BITC, Freeman's activities took the form of driving to family homes throughout New South Wales in order to design and supervise individual programs. Whereas the preceding period during which the BITC was operational demonstrated what could be undertaken with a full-time team working in association with families and volunteers, this final period established what could be achieved by families and volunteers unsupported by such a team. The next chapter will examine in some detail the manner in which attempts to trial Freeman's methods ultimately disadvantaged those people whom they were intended to benefit.

Conclusion

Although the discussion of awakening of unconscious patients in the preceding chapter emphasised the general inadequacy of the hospital system to provide appropriate support at this stage of recovery, I suggest that the story in this chapter of what happens *after* awakening discloses even larger gaps in available care. Awakening is not often, as described in media accounts, a single, abrupt, all-or-nothing incident in which someone who has been unconscious for six

months suddenly wakes up, jumps out of bed and asks for directions to the dining room. Frequently, the first signs of awakening may be quite transient, indeed sufficiently so that their very occurrence is questioned.

Once the person is consistently awake, she or he is likely to have considerable, often gross, limitations to what can actually be done. Frequently, these limitations will disqualify the person from graduation into the institutional rehabilitation program or, if entry is achieved, will so retard progress that the person is dropped from that program. In either case, a patient may transit from acute care to limbo.

Freeman's aim was to develop an alternative placement option, which provided a form of slow-stream rehabilitation applicable to patients who had regained consciousness, but not much more. Rather than the regular rehabilitation schedule, which would be beyond the endurance capacity of these people, or the hour per week token therapy available in an aged-care situation, the aim was to have intensive person-to-person programs, specific to the individual patient and reinforced by their conduct within familiar, small-scale surroundings.

To accomplish such an alternative care option, the GIO funded a day care centre initially and then a residential facility, the BITC. The BITC was envisaged as a placement from which patients could transfer into domiciliary rehabilitation when their progress and the availability of adequate physical facilities and carers in the home had been assured. There was to be continuity between the BITC and home with as much family input as possible into a BITC-based program followed by ongoing home visits by familiar BITC staff. In both locations, BITC and home, participation by teams of volunteers in each patient's rehabilitation program was envisaged.

As events transpired, the BITC operated for a limited period of little more than three years, which was a crushing disappointment to all involved—residents, families, staff and volunteers. On a more positive note, the centre showed what could be achieved, although, with its closure, it became necessary to undertake domiciliary rehabilitation at a much earlier stage of recovery and without the nursing support provided by the centre. This earlier transition is likely to have made the domiciliary option unavailable to families who did not have the resources required.

The success of the BITC, apart from demonstrating what *could* be done, simultaneously showed why it *could not* be done in a hospital setting. The feasibility of maintaining long-term placements and of providing a staff to carer ratio of one-to-one would be ruled out, both on logistic and economic grounds. The long-term daily entry of large numbers of volunteers into wards would present considerable problems.

The solution to these impediments to rehabilitation in a conventional institutional setting arose from necessity as much as from advanced planning. That solution amounted to de-medicalisation of the rehabilitation process. Unfortunately, recognition that any decent concept of 'distributive equity' would entail a transfer of some portion of the funding saved in the institutional setting to support the domiciliary alternative, so making this more widely available throughout the community, has yet to occur.