

2. Misdiagnosis: Patients' stories

Statistics of brain injuries cannot adequately convey their longer-term impact on affected people and certainly fail to reveal the manner in which decisions and commitments made, on their behalf by others, can influence their longer-term outcomes. This chapter examines the stories of 10 of Ted Freeman's patients, based on his clinical notes and written by him so as to facilitate their accessibility to lay readers. These stories are reproduced without modification and have been selected from two dozen included by Freeman in a chronological account of his work. That selection has been undertaken in order to illustrate a number of recurrent features.

One recurrent feature is that of an inaccurate early diagnosis of vegetative state. Although the international medical literature had repeatedly drawn attention to the frequency of incorrect diagnosis of vegetative states, this caution does not seem to have been understood. Faulty diagnosis led to the formulation of a prognosis that was invariably very negative. That prognosis, in its turn, was liable to lead to a management recommendation that the patient was unsuitable for formal rehabilitation and should receive no more than basic care. In the ensuing months and years, the ultimate condition of some patients and, with it, any potential for later improvement were further compromised as a direct outcome of the recommendation.

The total number of people with severe brain injuries whom Freeman was asked to see in the course of his career amounted to approximately 200. Whereas a majority of these became long-term patients, some were assessed only once. In relation to the latter group, Freeman explained that they

tended to be patients who were unresponsive and it appeared that attempting to impose a program that was demanding and impossible to fulfil on the family would have stressed them beyond reason. I had to be honest with the family and tell them that I did not think I could help.

In some instances, the diagnosis of 'vegetative' was patently wrong at the time that Freeman met the patient; in others, it subsequently ceased to be applicable. The term 'vegetative state' is applied when a patient periodically has open eyes but, nevertheless, is considered to be unconscious. Alternatively, if the patient's eyes remain closed, the condition is described as 'coma'. Since then, the adoption of 'vegetative' as a term in popular parlance has very successfully corrupted its meaning. For example, referees at football matches are commonly denigrated as 'vegetative' and the adjective has spawned its corresponding verb: one may now 'veg out' in front of a television set. Unfortunately, this popular

loose application appears often to have re-entered medical use. One suspects that it has frequently been thrown around without the completion of thorough, repeated clinical examinations.

The first two of Freeman's case reports exemplify either initial misdiagnosis (Peter) or premature and unduly pessimistic diagnosis (Donald). In these, as in all of the following case histories, patients' names have been altered. Of particular concern in Donald's case, as remarked in Freeman's notes, was the reference by the attending registrar to 'brain death'. As the question of organ donation had been broached with the family, the possibility that one or more of the people attending Donald had made a formal (mis)diagnosis seems credible.

As with the term 'vegetative', the expression 'brain death' has acquired a life outside intensive care wards—again, sports referees are often categorised as brain dead. It would be most unfortunate if this term has also crept back into some hospitals in its imprecise use. Accounts given by families of severely brain injured patients refer to 'vegetative' quite often; less frequently to 'brain death' with discussion of organ donation. As the original source of these references when they arise in families' accounts at a later stage cannot be retrospectively verified, it is not usually practicable to differentiate misinforming of relatives from inaccurate recollection. The excuse of impaired family recollection is not applicable in the case of Donald, which follows.

Donald's story

I saw Donald in a major teaching hospital. His sister had asked me to assess him. I went to see the Medical Superintendent first. She did not approve of my involvement, but gave me permission to see Donald. I spoke to the Neurosurgical Registrar. He told me that there was no point in seeing Donald, saying he was 'brain dead'. His family had been asked to donate his organs. I met Donald's wife and sister, who took me to examine Donald. I could not detect any positive reactions. I told them so. I suggested that a trial of 'coma arousal therapy' might be warranted. The family agreed.

That night Donald's sister rang and asked what I intended to do. I explained that I could not return to the hospital—I would be refused entry. She was a courageous lady. She said, 'That's not good enough. Will you come and tell us what to do?' Two days later I went to their house in a Sydney suburb and told them what I thought could be done. I discussed a coma arousal program with them and they wrote it down.

I heard no more for some weeks until Donald's sister, only a very tiny lady but obviously very determined, rang me. She said, 'I know you are not going to believe

this, Dr Freeman. We did everything you told us to do every day. I went in there today and worked on him and said to him, "Donald, we come here and work on you all day long and you never say anything." She continued: 'He slowly turned his head towards me and said "Hello".' I was amazed. Donald was eventually sent to a rehabilitation hospital and later returned home, where I saw him again. He talked clearly and lucidly, walked with a walking stick, fed himself and possessed bowel and bladder control. He has since successfully completed a technical course.

This story has a worrying aspect. It casts doubt on the diagnosis of brain death, but clarification would be needed as to whether a neurosurgeon gave this diagnosis. I have seen two other patients whose families told me the person was considered brain dead. One patient did remarkably well and is walking and talking and driving his four-wheel drive on holidays with his family. The other is still slowly improving.

Peter's story

On another occasion I was asked to assess Peter. He had been placed in a terminal-care hospital for people who had suffered a stroke or had end-stage cancer. Peter was in his early forties. Once again the diagnosis was 'vegetative'. I waited for a family member to come, but as none was available I commenced the assessment. I knew as soon as I met Peter that he was aware. He made eye contact immediately. I said to him, 'Peter, I know you can understand everything I say to you. Would you blink both eyes for me?' He did so. I asked, 'Will you blink your left eye?' He did so. 'Will you raise both thumbs?' He complied. 'Will you raise your right thumb first and then your left thumb?' He did so. I asked him to move his legs. He did. I was very excited. This man was demonstrably capable of understanding and complying with many requests. The diagnosis was absolutely wrong and could easily be shown to be so. I left the room and found the Nurse Unit Manager. I told her what I had found and asked her to come back to the room and observe with me. She hesitated, but agreed to do so. With encouragement, Peter showed his range of abilities again.

I telephoned Peter's referring doctor and gave him a description of what I had found. He showed no interest. I was distraught and unsure what to do. I asked his permission to speak to Peter's relatives. He agreed grudgingly. He clearly resented my interference. My heart sank when the nurse brought in a lady in her late sixties already in grief and of non-Australian background and I went out to the nurse and asked for other relatives. There were none. I told her I would make a detailed report of my finding and send it to the doctor. I went back to the room to say goodbye to Peter. His mother was sitting by his bedside weeping over him. I left, feeling almost as distressed as his mother. The following day I prepared a detailed report and posted it immediately to Peter's doctor. He did not acknowledge it. One week later I rang the doctor to check to make sure he had received my report. I said, 'This is

Ted Freeman. I am just ringing to make sure you have my medical report on Peter. How is he? He replied: 'Thanks for the report, Dr Freeman. Peter died two days ago.' I was stunned. 'What did he die from?' I asked. 'He had a severe attack of diarrhoea and we thought in view of his severe brain injury we would not treat him.' I exclaimed, 'But he had so much that could have been worked on and such potential!' He replied, 'We did not think so.' I said, 'So he died from dehydration and electrolyte imbalance?' He said, 'That is correct.' I put the phone down in dismay.

Misdiagnosis: Implications for treatment

Apart from their common feature of a misleading diagnosis and subsequent prognosis, the stories of Donald and Peter illustrate some other incidents frequently occurring in Freeman's case records. Not uncommonly, treatment was withheld from patients considered to be vegetative at an early stage after injury because, in the opinion of the treating practitioners, future quality of life would be sufficiently poor that its occurrence was best avoided. This does raise the question of the time frame after brain injury for diagnosis of the vegetative state.

There is no ethical imperative to provide treatment irrespective of its intensity or invasiveness and of the patient's potential for achieving an improved quality of life. Any reasonable application of the concept of proportionality would rely upon some balancing between the possible discomfort to be inflicted on the patient by treatment and the quantum of possible benefit. 'Extraordinary' measures (however one defines them) may well not have been appropriate in Peter's case, but what appears to have been forgone (probably intravenous fluids and antibiotics) could hardly be dismissed as 'extraordinary' in assessment of a patient who evinced considerable (unrecognised) potential for improvement.

As a general principle, or perhaps a general lack of principle, Peter's case seems to have been an example of medical opportunism in which 'routine' treatment, unlikely to be uncomfortable for the patient, is withheld *because* that course of action is likely to lead to death. When the alternatives of non-intervention *versus* the 'Freeman' approach intended to offer the best chance of regaining consciousness are discussed in a later chapter, this point will be taken up again. There is also a 'third way'—namely, withdrawing medical support at an early stage, thereby precluding any determination of what potential for improvement could have existed.

Another aspect of these two cases that should be noted here, although its more detailed discussion will also be deferred, was the rejection by his colleagues of

any involvement by Freeman in these cases. As will be described in Chapter 7, he was told not to return to Donald by the Neurosurgical Registrar: his report on Peter was unacknowledged and discounted by the general practitioner.

The outcome in Peter's case contrasts sharply with that of any of the patients to be discussed in the next chapter. That chapter will discuss a few of the stories of the families of young people with very severe brain injuries. Most of these people had fewer early signs of regained awareness than Peter and, for this reason, might have been considered less likely ultimately to achieve favourable outcomes. They differed from Peter, however, in having families who were prepared to do whatever might offer some hope of improving the lot of their brain injured family member. As will be recounted in that chapter, these relatives regularly resisted advice to abandon the person and instead committed the family to a prolonged domiciliary rehabilitation program that made enormous demands on them. It does not require too much reflection on these stories to recognise that the best prognostic feature predisposing to recovery after comparable degrees of injury is to have such a family. Peter, unfortunately, did not.

Whereas the stories of Donald and Peter were chosen to illustrate the tendency for a diagnosis of 'vegetative' to be applied loosely, and frequently inaccurately, the next two stories illustrate some of the early consequences of this common tendency.

Misdiagnosis: Ethical considerations

Roger's story

As Ted Freeman wrote:

The phone rang early one morning at home just as I was about to leave for work at Peat Island. A father asked me to assess his son Roger. Roger, who was eighteen, had been riding his motorbike down a bush track two years before. An unknown person had strung a wire between two trees at shoulder height. It caught Roger around the throat, smashed his windpipe and knocked him off his bike. He stopped breathing for some minutes and his brain became damaged due to lack of oxygen. 'What can he do?' I asked. 'He can't do anything. We have been told that he is a vegetable. They call him persistent vegetative state,'¹ the father replied.

I drove to their farmhouse. Roger's father met me at the front door. We shook hands and I walked in to meet his wife. I followed them into the family room

¹ Bryan Jennett & Fred Plum (1972) Persistent vegetative state after brain damage. A syndrome in search of a name. *The Lancet*, i, 734.

where the patient lay motionless on his back, stretched out full length on a brown leather, padded bench. It was hot in the house. He had one sheet under him and one covering him. His eyes were closed. I walked over with his father, stood at his right side and introduced myself. 'Roger, my name is Ted Freeman. I am a doctor. Your mother and father have asked me to come to see you.' There was no movement, no speech, no facial expression or reaction. He remained motionless. I noted both pupils were widely dilated (enlarged)—a sign of damage to both oculomotor nerves in the mid-brain region of the brainstem. I carried out a neurological examination that confirmed he had severe brain injury.

I asked Roger's father, 'Can Roger do anything?' He pulled out a small object and said, 'Not much. One thing he will do is reach for this cartridge [a shiny brass army bullet casing]. Roger can see, but he cannot hold his eyes open. I have been told the nerves to his eyelids have been damaged.' With his thumb and the index finger of his left hand, the father prised both his son's upper eyelids open. The father took the cartridge in his right hand and held it above Roger's face. Slowly, he raised the cartridge and said to his son, 'Take this shell.' Little by little, Roger's right hand moved up until his fingers closed on the shell and he took it.

The parents had been told that this young man was in the persistent vegetative state (PVS). The diagnosis was obviously wrong. Roger was not vegetative. He was a thinking human being with the ability to hear and understand the spoken word and the motor skill to move his right hand and arm towards an object and grasp it with his fingers. They said that 'the lights are on but no-one is at home'. I asked, 'What else can he do?' The father replied, 'I can get him to cry.' Before I could stop him, he moved to a record player, switched it on and said, 'This record always makes him cry!' The music was the recent recording of a pop group. When the music started, Roger started to sob loudly. Tears flowed over his cheeks wetting the sheet under him. I asked the father to stop the record and said, 'This is more proof that your son is not vegetative. He can feel emotions. He can think and he has memory. This means his higher brain is working. He is in the "locked-in state".'²

What can be more terrifying than to be absolutely at the mercy of your environment and the people in it, and totally unable to control what happens to you? Some patients can be observed by their families or nursing and other healthcare professionals to demonstrate awareness and therefore cannot be considered as PVS. They are in the 'locked-in state'. I call this state the 'ultimate dungeon'. These unfortunate people have a brain that has the ability to process the stimuli from the environment through their eyes, ears, skin, taste and smell, and so on, but their brain stem has been damaged so much that they cannot work their muscles or use speech to communicate to others. There has been recognition of this dilemma for some years.

2 Jean-Dominique Bauby (1997) *The Diving Bell and the Butterfly*. Fourth Estate, London.

How could Roger be diagnosed as in coma or vegetative when he was so obviously aware? Second, why was it that the family had observed more than the physicians, and third, why was there no place where Roger could receive treatment? Roger's mother, who had been standing at the back of the room watching, walked over to her son and put her arms around him. Crying, she turned to her husband and said, 'I knew they were wrong. I knew they were wrong, but you would not listen to me.' I had seen this situation before. I spoke to both parents. 'This wrong diagnosis is not your fault. It happens commonly with patients like Roger. There are some members of the medical profession who declare people as PVS without really examining them properly and at a far too early time frame after the injury.'

Roger's parents stared at me. 'What can we do? Can you help?' they asked. We sat down with a cup of tea and explored the options. There were not many. Roger had already been discharged from the teaching hospital and had been ruled as 'not suitable for rehabilitation' by the rehabilitation service.

Most doctors they had spoken to about the continuing treatment of brain injury had told them nothing could be done with these people. The common attitude was the one held by the medical superintendent of a large Australian institution for disabled people. He believed, and I quote: 'The hardest single aspect of coping with head injuries is that fundamentally we are all spectators as the recovery process takes place.' Of course, if we can only observe the process of recovery and not take an active part, there is no point in having rehabilitation units.

Roger's parents were grateful when I had him admitted into a terminal-care hospital that had a minor rehabilitation component. There he came under the care of a doctor with the typical negative approach to these patients. Roger was given no rehabilitation. The admission became one of respite care for his parents. In fairness to the hospital, they were chronically short of nursing and paramedical staff. Roger was no trouble for the hospital to look after. A patient who cannot speak or move but lies in bed or sits strapped in a wheelchair all day does not require much nursing care apart from attention to food, bowels and bladder. Oral feeding, which may be carried out at home by family members, is often dispensed with in the hospital and replaced with a tube into the stomach through which semi-fluid nutrients are fed. This is far less time-consuming than feeding a person with a spoon mouthful by mouthful; but it denies the patient the pleasure of taste—one of life's delights. You don't have to be a gourmet to enjoy food.

Since Roger could not open his eyes, he enjoyed listening to his music from audio tapes. So that he would not disturb the other patients, he listened through headphones. These had to be placed in position by the nursing staff. One day Roger's father brought him audio tapes that contained some erotic dialogue. Roger enjoyed these immensely. He smiled and laughed and the erotic stimulation produced a penile erection. A member of the nursing staff became suspicious when she saw Roger's

reactions to his tapes. She put on the headphones and listened. What she heard disturbed her greatly. She reported this matter to the Director of Nursing, who regarded the whole matter as unseemly. The tapes were removed from this young man and the parents were told that if they wanted him to listen to 'that disgusting stuff' they would have to take him home. They were in a quandary. They made the decision to take him home so they could care for him again. I saw him at home again, but four months later he died from asphyxiation after inhaling food. This couple had had two sons. Their eldest had died some years before.

There is something dramatically wrong with a scientific or medical system that condemns people to a life worse than death when knowledge that could help has been available for decades. This is not just a medical issue. It must be one of the major ethical and moral issues of our time.

Rupe's story

Rupe was a patient I examined about four weeks after his injury. He was a man in his early forties who had been diagnosed as vegetative. His wife, Aileen met me at the terminal-care hospital. She was very supportive of her husband. After I had talked for some time to Aileen, she took me to Rupe's bedside. It was immediately clear to me that Rupe was not vegetative. He was able to obey numerous commands and he demonstrated a great deal of awareness. Aileen was delighted to observe his responses as all the information so far that had been given to her had been that Rupe was vegetative and his prognosis poor. She could see for herself that he was recovering. I recommended that Rupe be transferred as rapidly as possible to a rehabilitation hospital. I left the hospital in high spirits, elated by the fact that this man could be saved. I heard no more about this patient until three years later. Aileen phoned me and asked if I would see Rupe, who was now in a nursing home. 'What has happened?' I asked. The whole sorry story of neglect then came out. He had not been given enough time to respond well at the rehabilitation hospital, in fact only a few months, and then the insurance company had transferred him to a nursing home.

I introduced myself. 'I am Ted Freeman. I am a doctor. I have seen you before, some years ago. Is it all right if I examine you?' He ignored me. Instead, his right hand went to the Communicator machine and by the use of his index finger he commenced to punch some letters into the machine. I could not see what he was writing, but when he had finished he punched another key and the message was spoken. 'Have you been to medical school?' I laughed and replied, 'Yes, I have. You need have no worries about that.' He looked at me again and turned to punch out another message on his Communicator. I waited, wondering what it would be.

He finished typing and pressed his voice activator to broadcast, 'I don't want any mug looking after me!'

Rupe and I got on well. The nursing home was receptive and keen to help so we soon had Rupe standing on one leg and pulling himself out of his chair. He was much happier and he knew that he was slowly regaining some function. Aileen was very pleased, but one day all therapy was stopped. The nursing home expressed concern that Rupe might fall or that the nurses could hurt their backs. There was no such thing as the 'dignity of risk' for Rupe. Rupe did have a legal case against the insurance company. He was an innocent party in the accident and his case came up in the Supreme Court in another State in a major provincial city. I had done numerous medico-legal reports for the barristers representing Rupe. They were going to fly Rupe and Aileen to the city where his case was to be heard. They asked me if I would be prepared to give evidence in the Supreme Court. I agreed. I arrived the day after Rupe and Aileen. Aileen told me that the previous night, she had taken Rupe to the casino and he had had a 'wow of a time' on the 'pokies', and so on. The morning of the court case he met the policeman who had pulled him from the burning wreckage of his vehicle. Rupe had cried and constantly typed out on his Communicator, 'Thank you. Thank you. Thank you.'

When I arrived at the court the barristers asked me if I could demonstrate the extent of Rupe's cognitive function to the judge. They said they would move Rupe into the court early so that he could become accustomed to the atmosphere. Rupe's wheelchair was pushed to the front of the courtroom. There he sat twisted and bent and all scrunched up with his Communicator on his knee. The court reporters were watching him closely, wondering what was happening as Rupe sat tapping away with one finger at his Communicator. I became worried. Would he make some inappropriate statement that would be broadcast over the whole of the court and be prejudicial to his case? After some minutes, the court official entered and in a loud voice called, 'Silence, please. All rise. In the name of Her Majesty Queen Elizabeth. This court is now in session.' His honour the judge entered. All rose to their feet and bowed—that is, all except Rupe. At that precise moment, he pressed his audio button and the words rang out loudly and clearly around the Supreme Court, repeating: 'I hope the judge will forgive me for not standing. I hope the judge will forgive me for not standing. I hope the judge will forgive me for not standing.'

At first the judge was taken aback by this unusual occurrence. He looked towards Rupe. The moment he acknowledged Rupe's request, Rupe stopped his message. He was not perseverating at all. He only wished to be acknowledged as a human being. It was easy to present the evidence for medical misdiagnosis. In fact, it was a 'lay-down misère'! The judgment was made in favour of Rupe and against the insurance company. In my opinion, the question must be asked why this man was cast into this horrendous predicament.

Roger and Rupe represent two more instances of misdiagnosis of vegetative state. In Rupe's case, this error should have been immediately evident any time that he was examined, and the question posed by Ted Freeman of why he was

cast into such a horrendous predicament is entirely appropriate. Recognition that Roger was not vegetative was not so immediately apparent and it is easy to understand how a conventional neurological examination could get it wrong, especially if the clinician was not endowed with good interpersonal skills.

In the absence of the regular Freeman approach of recruiting a family member or close friend when setting out to examine a patient, the information that Roger regularly responded to certain specific stimuli, and hence the occurrence of these responses, could not have been elicited. Whilst operating through a family member was Freeman's regular practice, intended to place a patient at ease, in Roger's case it delivered a bonus of information. I am inclined to add a postscript to the quotation from a medical superintendent referring to patients with severe brain injuries and cited by Freeman—perhaps it should be: 'we are all spectators *and often not very careful ones.*'

Apart from sharing the misfortune of misdiagnosis, Roger and Rupe illustrate the manner in which this primary event can lead to system-mediated deprivation. In Roger's case, the opportunity to receive auditory input through his headphones was taken away. His tears on the occasion of Ted Freeman's initial examination and his arousal in response to a tape recording when in the nursing home indicated not only a level of consciousness, but also a capacity for emotional response—an even more damning refutation of a 'vegetative' diagnosis. Further sensory deprivation is likely to have been imposed by the replacement of oral feeding, with its attendant sensations of taste, texture and scent, with tube feeding. In Rupe's case, the sentence imposed by the system was three years in a nursing home after a short attempt at rehabilitation. Even some well-intentioned small attempts at rehabilitation were aborted because of possible 'risk' (one wonders whether only to the patient or also to the system to which he had been committed).

Roger was a person who was 'locked in' as a direct result of his brain injury. While his ability to see things and to hear and understand conversations remained intact, he had extremely limited ability to undertake actions in response, which would have confirmed that he was aware and could see, hear and comprehend. In very severe cases of being 'locked in', a person may be completely aware but restricted to using nothing more than eye movements to respond.

Cecil's story: Locked in by the system

In contrast with being locked in because of damage to those parts of the brain required to respond, some of Freeman's patients could be appropriately regarded as locked in by the system in which they were placed. Cecil, whose story follows, provides an example of such a predicament.

Cecil had been a fit young man, married with a family, when he had a motor vehicle accident and was severely brain injured. The care he received in the emergency department and operating theatres, I assume, was excellent for he had been admitted to a major Sydney teaching hospital, which had a superb reputation. As well as his brain injury he had broken bones: fractures of his left humerus (upper arm) and right femur (upper leg). Because of the extent of his brain injury, it was decided not to operate but to treat his fractures 'conservatively'. That means to put his arm in a sling and possibly to splint his right leg. (The usual treatment of such injuries would be to operate and fix the broken bones in place by means of plates or pins, and so on.) Three months after his accident, Cecil was transferred to a terminal-care hospital with the diagnosis of 'vegetative state', and six months after the injury he was assessed by a rehabilitation specialist, who wrote: 'In view of his cerebral cortical damage, his semi rigid limbs with contractures and the length of time since the injury, I would not advocate rehabilitative procedures and would urge consideration not to treat infections with antibiotics.'

Eight months after Cecil's accident, his father asked me to assess his son. I asked if members of the family could be present, but was told that this was not possible. His wife did not want the assessment. On the prearranged day, I presented myself to the Director of Nursing, who gave me the clinical notes. She escorted me to the ward. There were six beds in the ward. The room was dark and smelt of human decay. I thanked the director, who retired. I approached Cecil and drew up a chair next to his bed so I was at his eye level. I did not want to stand over him. He immediately made eye contact and looked at me directly as I explained who I was and why I was there. I told him that I would not hurt him and that every time I intended to touch him I would tell him. He continued to make excellent eye contact. In fact, his eyes were glued to my face. I spoke openly to him. I placed my hand in his right hand and asked him to squeeze it. He grasped it strongly. There is a 'grasp reflex' in many people with a severe brain injury, which occurs instantly you put something into their hand. This is similar to the reflex action of an infant when an object is placed into his or her hand. I asked Cecil to release his grip. He did so immediately. The release of the grasp indicated this was not a reflex happening but an active movement with the muscles controlled by the brain.

I held a torch in front of Cecil's face and moved it from side to side and asked him to follow it with his eyes. He did so. I shifted it further to the right and asked him to turn his head so he could see it. He did so. He did the same when I placed it on his left side. I asked Cecil for permission to examine his arms and legs. He nodded his head in agreement. His left arm and right leg had united in an abnormal position. I asked him if I could feel the fracture sites. He nodded. I did so and it was obvious he had no pain. I asked him to move his left leg and straighten it out. He did so. I said to him, 'Cecil, I know that you can understand everything I say to you. If you believe this to be true, can you nod your head.' He nodded his head several times.

I realised I was the first person to show Cecil that I knew he was out of coma and it was important I tell him of this fact and that I would do all I could to help him. As I did so, tears came into his eyes. I said goodbye, and put out my hand to shake hands. He slowly reached out with his right hand and attempted to take mine and shake it.

I left the ward and went to the nurses' station and spoke to some of the nursing staff. They agreed that Cecil showed emotion. 'When is the most emotion you have seen?' I asked. They replied as one: 'When his wife brings in his children, he always cries!' This confirmed my findings. This man was not in PVS. He wasn't even severely locked in. He had loads of comprehension and a great deal of movement, which I believed could be increased with therapy—enough to free him from his dungeon. I rang Cecil's doctor and told him my conclusions and the evidence upon which they were based. He appeared disinterested. I asked if I could make contact with Cecil's wife. He said she had been told her husband was vegetative and to go away and forget all about him. I persevered. 'Okay,' he said. 'I will see if she will agree to meet with you. Give me your phone number.'

Some days later, Cecil's wife rang me. 'What is the point of a meeting?' she asked. I explained my findings to her. 'I don't think that changes anything. I have been told nothing can be done,' she replied. I pushed for a meeting. Eventually, she came to the terminal-care hospital to meet me. It was a great disappointment. I asked her to walk with me into Cecil's room so I could demonstrate Cecil's awareness and my findings. She refused. I suggested that we arrange a 'trial of rehabilitation therapy' for Cecil. She refused. She said, 'I just want my husband to be kept comfortable.' How she believed keeping Cecil in his present state would provide mental and emotional comfort for him I could not understand. I could do nothing more. I was powerless to help Cecil. I wrote out a detailed clinical report and sent it to Cecil's doctor and to his wife and father. I heard no more for some months until Cecil's father asked me to review his son again.

By this time Cecil had been assessed again by the rehabilitation specialist, 11 months after the accident. He wrote:

The patient has changed a little. He can now lift a cup with his left thumb and forefinger and drink. He sometimes indicates 'yes' and 'no' with minuscule neck movements appropriately but not often. I do not consider any form of rehabilitation or stimulation therapy is indicated.

It was obvious that this doctor had a very negative approach, but even he must have known that the obeying of a command was a prime indication of the patient being out of coma or PVS. He advocated transfer to a nursing home. When Cecil's father contacted me again he was distraught. Not only had he and his wife lost

their son, but now friction had developed with his daughter-in-law over Cecil's treatment. The intensity of the emotion meant they were denied contact with their grandchildren.

Fifteen months after the accident, Cecil was moved to a nursing home. I heard no more of this man during this time. Two years and four months after the accident, Cecil was assessed by a psychiatrist, who noted the opinion of a nursing sister. She was emphatic that the patient was largely aware of what was going on. If he did not like a TV program, he shook his head. If he did not like a particular activity, he would stiffen and close his eyes. He appeared to enjoy the visits of his children and on one occasion wept when told they were away on holidays and would not be there. In summary, the psychiatrist stated:

The fact that he does communicate indicates a greater degree of awareness of his surroundings than was originally thought possible ... It is probable that he also has some awareness of the major changes in his mental and physical state and that he does, in fact, suffer as a result.

At much the same time, a report was prepared by an orthopaedic surgeon, who noted: 'All his fractures united though not in a position which would have been considered acceptable for an otherwise well patient.'

Cecil's left arm was now 3 cm shorter than the other and his right leg was 6 cm shorter than his left. Both fractures had united with overlapping, separation and angulation. I had no further contact with the patient until four years after his accident when I examined him in the nursing home. He obeyed many commands. Once again, I urged in my report that '[e]very effort should be made for him to regain, by urgent and intensive rehabilitation, more adequate means of communication'. Nothing was done. Two years after this (six years post accident), he was admitted to a rehabilitation hospital for two weeks. They reported:

He was able to assist with transfers. He was generally uncooperative with therapy tasks and this would appear to mitigate against future gains. It is recommended that a much longer trial of speech therapy assessment would be needed ... in order to more accurately assess his potential.

As you can imagine, two weeks of therapy after a delay of six years can only be described as absurd. He could assist with transferring from a chair to a bed or vice versa so he was able to partially take weight on his left leg, but because he was generally uncooperative they thought that this would be a block on further gains. There was no sensitivity or recognition of the fact that for six years this man, with adequate awareness to comply with requests, had been so hurt mentally, emotionally and physically that he must have had a deep well of anger and frustration eating away inside him—enough to make him uncooperative. But having lost all control

over his environment, this in the end was the only way he could exert his willpower. Perhaps if someone had asked him what he wanted to do rather than telling him what to do, he might have been more cooperative.

I have always been a strong believer that the anger and aggression in a person with a brain injury are their body language indicating that they do not like their present situation or what has happened to them. I am a firm believer that if this anger is worked with and is channelled correctly, it has the potential to be extremely productive. If, instead, the patient is damped down with drugs or is physically restrained with belts and straps to the bed or chair, the frustration and anger will only increase.

Cecil's parents were distraught with the system that had done this to their son. They could see Cecil was aware and in a terrible plight. They asked to meet with me to discuss what could be done to help him. Seven years after Cecil's accident, I was asked to review Cecil again in the nursing home. I went through the usual protocol and, having been given permission, went to his room. He immediately turned his eyes and head towards me.

I said 'hello' and put out my hand to him. He did not shake hands. He was about to have some morning tea, which consisted of a glass of flavoured milk and some fruitcake. I asked him which he would like first. He nodded towards the milk. I asked him if I could sit and talk to him, and also did he remember me. He nodded 'yes' to both. After his morning tea I asked him to move his head, arms, hands, fingers and legs, and he happily complied with my requests. When I asked him if he could stand, he nodded 'yes' and, with me supporting him, he stood on his left leg. His right leg was shortened and could not touch the floor. After an hour or so, I thanked him for his attention and went and spoke to the nursing staff. They said that he was receiving one hour of therapy per week and had not been taken home for some years. They said he often wrestled with them and had on occasions tried to kick them. I explained to them that this aggressive behaviour was his body language stating emphatically that he was most unhappy about his situation. It was a perfectly normal reaction to his unresolved predicament. They said he often sat crying.

I wrote to his doctor:

Because of his [Cecil's] great awareness of the environment and his very significant emotional response, I consider he is in a state of great sensory and emotional deprivation which constitutes a grave disadvantage to him. To maintain this patient in the present circumstances, without him being given the opportunity to prove his ability to regain function is medically and morally unacceptable.

I proposed a plan of management. The doctor failed to acknowledge my report.

I did see Cecil at one more nursing home. I was delighted when the Director of Nursing asked me if I would be prepared to give a lecture to the staff and readily agreed. The nursing staff divided rapidly into two groups. There were those who were amused by Cecil's behaviour and regarded him as a bit of a joke. These people were not interested in seeing the humanity in Cecil. There was another group led by a senior nurse who said that she often gave Cecil a cuddle and he would respond by clinging onto her and reacted to her caressing and patting. This nurse provided the only sensitive touch that Cecil received, as his wife and children never visited him. His parents, because of their age, had now become incapable of travelling to the nursing home to support him.

Soon after this I was notified by the Director of Nursing that Cecil's wife said she would prefer I did not see him again as my visits upset Cecil too much. I had to comply with this request, but I believe Cecil realised he had potential to progress and became angry when this was not recognised by the nursing staff.

Cecil concurrently sustained fractures of his arm and leg in the accident responsible for his brain injury. His clinical history when Ted Freeman first met him eight months after that accident described his early orthopaedic management as 'conservative'. Given the detail of what had been done, or more accurately what had not been done, the euphemism 'conservative' should have read 'limited to first aid'. Whereas some of the patients whose stories have been included above developed contractures and stiffening of limbs as a consequence of subsequent neglect in management (euphemistically reported in case notes as 'unsuitable for rehabilitation'), Cecil's subsequent deformities were completely predictable, given the withholding of routine orthopaedic treatment, and completely attributable to that withholding. The withholding reflected an assessment that was based on premature and incorrect prediction of his capacity for neurological recovery, on an erroneous assessment of his conscious state in the weeks after his accident, or both.

As a result of the early decision not to provide any treatment worthy of the name for his fractures and of unwillingness on the part of his medical attendants to reverse that decision later, Cecil was effectively locked in by his mobility limitations. As Freeman remarked in his notes at his first meeting with Cecil, he was the first person to tell Cecil that he knew he was out of coma. In response to the ongoing belief of others that he was unaware of events around him, Cecil was subjected to ongoing sensory and emotional deprivation, presumably for the remainder of his life.

His misery was further compounded by the intra-family disruption between his parents and his wife, an event to which his medical management had in no small way contributed. His wife accepted and acted upon the medical advice that Cecil was vegetative and she should go away and forget about him. His parents

resembled most of the families of other people who sought Freeman's advice in not accepting this 'solution'. It appears to me to be self-evident that any other people with severe brain injury whose relatives accepted the negative prognosis that they were given, as did Cecil's wife, would not show up in any review of long-term outcomes. In effect, they would become an unquantifiable cohort similar to the family of Peter, referred to above, when life-sustaining measures had been withdrawn, on the basis of a misdiagnosed 'vegetative state'.

Domiciliary programs

One of the criticisms of the implementation of domiciliary programs to assist people with long-term brain injury is that this option may place great strains on family interactions. As will be seen when families' stories are presented in the next chapter, this is certainly possible. To introduce some context, however, I believe that this is at least as likely to eventuate under a policy of 'go away and forget', but published studies on the families of this more compliant group do not appear to exist. Freeman's closing reflection that Cecil's parents were 'distracted with the system that had done this to their son' provides a fitting epilogue to his story. Whilst the term 'locked in' when applied in relation to the medical condition of a patient with brain injury is taken to refer exclusively to disablement attributable to that injury, the preceding stories illustrate the manner in which a patient's disability can be greatly augmented by inappropriate management. In effect, a patient may be locked in by the system.

Recovery: Patients' stories

Contrasting with the rather dismal stories of Peter, Roger, Rupe and Cecil in which each of these patients' potential for improvement was curtailed for a variety of reasons, in many other instances, this potential was realised. An essential factor in achieving this difference was the nature of family responses to the diagnoses and accompanying prognoses. These responses shared a common feature—namely, not to accept the proposition that nothing could be done to assist their family member.

This chapter will conclude with five of Freeman's case histories recounting instances in which families resolved to do everything in their power. All five people were the subject of dismal prognoses. All five were taken home. All achieved vastly more than had been foreshadowed while they were residents of institutions, albeit the ultimate levels of recovery within the group varied considerably. All expressed pleasure in being alive notwithstanding their various limitations. Yet, as will become apparent from their case histories, all

differed in many aspects of that recovery. It is not valid to assume that the damage produced in the brain of any two patients is identical and, consequently, one can never assert with certainty that differences in outcome are unequivocally a reflection of differences in management. That said, it is very likely that the much better outcomes in the remaining patients owe much to the commitment of their families.

Mark's story: Family therapy

Mark was in a country hospital. His parents, Roy and June, were desperately anxious to help their son. They had been told that Mark's case was 'hopeless'. They were told he had been so severely brain injured that nothing could be done and he should be placed in a nursing home. Mark was covered by third-party accident insurance, but the company disputed responsibility. This doubt about the medical responsibility for Mark's care placed June and Roy in the invidious position of receiving minimal assistance from the normal government healthcare scheme and an unwillingness on the part of the insurance company to provide care. Many carers found themselves in this position, often for many years until the legal matter was resolved.

June and Roy were worried about the time factor and my costs for travelling hundreds of kilometres each way to their town. I settled their anxiety by informing them I would visit Mark without charge to them and would only make a charge against the insurance company if they eventually won their case.

Using Roy and June as my bridge, I went through my assessment protocol, detecting 'soft signs' of awareness. It was obvious that no gain could be made by leaving Mark in hospital, so Roy and June decided to take him home and to work with him with the help of family and friends. Slowly, the benefits of their efforts brought rewards. Mark became very aware, and so a more intense program of movement was started. Mark had a tremor that totally affected his whole body and was very noticeable in his eyes, which flicked constantly to the side.

Slowly, Mark learnt to roll over from his back onto each side, and then to hold his body up on his hands and knees, but he could not move forward. Next he learnt to hold his head and body upright while kneeling with his arms draped over the back of a sturdy armchair. Over the months, he regained more control and, falteringly, he moved one arm forward in an attempt to crawl and with continuing work eventually was able to stand and hold himself upright on his knees. It was a great day when he stood with support. Over the months and years that followed, he relearned to walk with a walking frame. Roy bought a large three-wheel bike for his son and taught him to ride along the streets of his town. No-one could assume that Mark would ever return to his pre-accident state, but his gain is vastly better than being left in a nursing home. Roy and June sent me a letter. They wrote:

I would like to say Ted, we are so proud of Mark. He is doing well. He does not use a manual wheelchair anymore. He walks in a frame. We gave Mark a 40th birthday party and invited 60 of his friends. June and I were so proud of Mark when he stood up and made a speech. It brought tears to our eyes.

Mark's recovery, entailing a slow process of relearning how to raise his body, then to sit up and ultimately to stand, recalls the progress of the growing infant. I doubt that any small child standing for the first time could have received more enthusiastic parental acclamation than Mark received on returning to this milestone. Implicit in his parents' description of his birthday party is the pleasure that he and they experienced in his achievements.

Joe's story: Parental determination

Joe, a jockey, suffered severe brain injury when his horse broke a leg and fell on him. Profound brain injury was diagnosed on his admission to a major city hospital. His father, Kevin, and mother, Audrey, were aghast when told their son was unlikely to survive and, even if he did, he would be vegetative. The hospital proposed disconnecting Joe from his life supports and terminating his life. Kevin met with the hospital administration and challenged the withdrawal of treatment from his son. The hospital said Kevin had little influence in the matter and the power to decide rested with them. Kevin refused to accept their authority and contacted his solicitor to stop the termination of Joe's life. Kevin blocked the hospital's action. Kevin rang me about four months after Joe's accident and asked me to assess Joe in hospital. He was diagnosed as being vegetative. With Kevin present, I assessed Joe. The conditions in which Joe was kept were substandard and the hospital was antagonistic to my presence. They made their feelings known in their general demeanour, and in a very offhand way they provided me with the clinical notes.

Joe's parents were relieved when I told them there was some minor evidence of awareness and they asked anxiously whether I would be prepared to admit him to the Brain Injury Therapy Centre (BITC). I told them I could not give a guarantee that I could help, but if they wished I would admit Joe. Kevin was on tenterhooks as I listened to what he, Audrey and also Joe's sister, Debbie, had observed. Joe arrived at the BITC more aware than when I had assessed him in the hospital. It was obvious that the change of the environment, possibly even the journey, had been beneficial. Dr Ross Fulton assessed him and found him fit to receive the therapy that Kevin gave to his son. Each day Joe improved and this could be measured by the size of the smiles on the faces of Kevin and Audrey. Joe started to communicate 'yes' and 'no' by means of thumb movement—up for 'yes', down for 'no'. Slowly, over the weeks, he held his head up and moved it around to look towards his parents,

the staff and the volunteers. With support, he started to sit upright in a chair and reached out with his hands to take objects held in front of him. He was able to move his legs slightly.

He started to swallow and eat. He smiled and laughed at jokes and began to obey commands. He came back into the land of the living. Kevin travelled a 400 km round trip every day to give much of the physical therapy and provide emotional support for Joe. After five months at the centre, Joe was taken home and the program continued to be provided there by family and volunteers. Sister Yvonne Ayrey visited the home on a regular basis and assessed Joe, altering the therapy as needed. Joe continued to improve and eventually began to speak, and demonstrated increasing ability in movement, better cognitive function and a great sense of humour.

Fourteen years later, Joe is not back to his pre-accident state, but he can do a great deal, has a wide circle of friends and enjoys life. Was it worth it? Was it worth the time and effort? Did it cost too much? The answers are self-evident.

Joe's parents endured much in addition to the distress directly occasioned by his injuries. Their first challenge came with their fight to avert disconnection of Joe's ventilator. Many other families are overwhelmed by the acute shock of the episode of injury, followed within the week by receipt of a devastating prognosis appended to which is the advice (often given forcefully, as in Joe's case) that the preferred course of 'management' will be to cease life support.

The interval between injury and cessation of support after a preliminary diagnosis that a patient is, and will remain, vegetative varies between intensive care units. Suffice it to observe here that many of the patients in Freeman's files would have fulfilled the criteria for cessation. Using his experience as a guide, there certainly will have been patients similar to Joe among that substantial cohort of people with brain injury from whom support was withdrawn at an early stage on the basis of a very poor prognosis.

The observation that Joe's status seemed to have improved noticeably after the journey to Eastwood serves to direct attention to the environmental deprivation inherent in lying immobilised in a hospital bed. His father's long daily return trip to ensure that Joe received his exercise program from a close family member while at Eastwood was a monumental effort. Freeman has referred on a number of occasions in his writings to the necessity for a family member or friend to adopt the role of a driver who persists as a patient advocate often in the face of contrary medical opinion. Joe's father was an outstanding example of such a driver.

While the procedures in Joe's program were concentrated on regaining physical capacity, the retention of his sense of humour and his comment conveyed to Ted Freeman in a letter from his father that '[l]ife goes on and I wouldn't be dead for quids' indicate that he felt that the prolonged saga had been worthwhile.

Prue's story: Stand up and walk!

Sister Yvonne Ayrey's responsibility at the Brain Injury Therapy Centre at Eastwood was to develop rehabilitation in the patient's home (domiciliary rehabilitation). Yvonne was having outstanding success with her direct, practical and commonsense approach. Yvonne arranged for Prue, who had been in a coma for two months, to come to the Brain Injury Therapy Centre to be assessed. Prue had been in rehabilitation centres and hospitals for two years and 'doctors said nothing more could be done: she would be confined to a wheelchair and need constant institutional care for the rest of her life'. I can recall seeing Prue for the first time. She was sitting in a wheelchair, with her parents, Pat and Ray, standing anxiously beside her. They had been told to place her into a nursing home. Prue was in her early twenties. She was obviously fully aware and understood everything I said to her and, within the limitations of her disability, obeyed all requests. As the assessment was drawing to a close, I looked into Prue's eyes and asked, 'Do you want to go into a nursing home?' She reacted strongly with a look of dismay and slowly she rolled out the words, 'No. I do not want to go into a nursing home!'

I asked Pat and Ray would they be prepared to take their daughter home if we set up a home-based program. They willingly agreed. Tamworth is one of those country towns with a vibrant community and the family was well known in the district, especially since Pat, in her professional capacity, had nursed many of the local people. Within a short time there were 200 volunteers willing to help. They came from all walks of life. Some were professionals, such as nurses, physiotherapists and occupational therapists. Some were farmers and their wives. Some were clerical workers. Some were retired men and women who wanted to help a person in need. They brought with them their delight in watching Prue as she expanded her cognitive and motor abilities. Each one in their turn heartily congratulated this plucky girl as they recognised what she had achieved since their previous visit. After some time, Prue stood up and out of her wheelchair. She slowly learnt to walk with a walking frame and then took a few steps unaided. She helped around the house and took control of her personal care. She resumed work on the computer—which had been her previous occupation. After some time, Prue, who had been a keen horsewoman before her accident, was back in the saddle. Yvonne Ayrey is recorded as saying after Prue had been on a program for one year:

She has changed in every aspect. Her balance, her dexterity and her coordination—everything has improved. Her speech is much better and she

will initiate conversation. She is fit and well and so positive. Prue has a phenomenal driving force that just makes her determined to keep going. She may never be completely like she was before the accident, but she still has years of improvement left and her volunteers seem keen to continue.

While Prue still needs some support, she is now living independently.

Prue's history illustrates the seemingly obvious point that there is nothing to be lost by talking to the patient. On far too many occasions, conversations about a patient deemed to be unaware take place over the patient. As with all the people whose stories are in this group, Prue's rehabilitation occurred at home in familiar surroundings. The description of her volunteer group could most aptly be described as bringing the community to the patient when the patient is unable to go to the community. Another feature of Prue—namely, her 'phenomenal driving force' referred to above—was an essential component of all of these patient stories. In its absence—for instance, in patients whose brain injury is accompanied by clinical depression—the efforts of family and others are unlikely to be as successful as they were in the present group of patients.

Jessie's story: Recovery at home

Jessie was a patient in a major Sydney hospital. A colleague invited me to assess her. She had an unusual type of coma—not from trauma or hypoxia. When I examined her I could find very little evidence of awareness and conveyed this information to my colleague. Jessie came from the country and when it was decided that no more could be done for her she was sent back to the base hospital in the country area, where she remained in the so-called vegetative state. Her husband, Geoff, decided to take her home and set her up on a program there. Yvonne went to show Geoff and the volunteers how to do the program. Slowly, Jessie responded and became more aware. She started to communicate and each time Yvonne went to see her she came back to our weekly meeting highly excited about the changes that were now so positive and so obvious. One day Yvonne was bubbling over and could not contain herself. She said, 'I went to see Jessie. I drove up to her front gate and hopped out of the car. To my amazement, Jessie greeted me at the gate and while clutching my right arm slowly walked with me into her house and sat me down with Geoff. She then made us a cup of tea and produced a cake she had baked to celebrate my coming.'

Jessie continued to improve and I had a letter from Geoff: 'Jessie was the bridesmaid at her sister's wedding. As she walked down the aisle there was not a dry eye in the church. That evening at the reception, Jessie and I waltzed around the floor to a standing ovation.'

Jessie had very little evidence of awareness when examined by Ted Freeman but subsequently regained consciousness after being taken home and then underwent a dramatic recovery. It is not possible to determine whether she may have undergone similar rapid progress in hospital in the absence of a vigorous program of physical and social challenges. From the accounts of other patients, two queries would be legitimate. Would her early signs of awakening have been recognised in a prolonged-care institution? If these had been recognised, to what extent would they have been acted on?

Ian's story: An alternative approach from the start

One night at home we had a phone call from a close friend to say that her son Ian had been riding his bicycle when he was hit by a car and had been admitted to hospital with severe brain injury. Ian's mother, Laurena, came to our home to see us the next day. His father, Bob, was in the United Kingdom on business. The patient was 3 on the Glasgow Coma Scale (the very lowest point). I went into the intensive care ward as a family friend and did manage to carry out a preliminary examination by watching his responses to his mother. Bob returned to Australia as rapidly as possible and, with the help of many friends, the family undertook a modified coma arousal program in the hospital.

The lad remained comatose for six weeks but there were signs that he was arousing. Fifteen weeks after the initial injury he was taken to a rehabilitation hospital where he remained for another six weeks until his parents felt that it would be better for him to be on a home-based program.

When taken home, he was confused and agitated, even aggressive at times. He had markedly decreased awareness and slept for a large part of the day. His facial and emotional expressions were limited and he had difficulty focusing his eyes. He could hold his head upright for only short periods and needed to be strapped into his wheelchair. He was fed through a tube into his stomach and was partially incontinent of bladder and bowels. Sister Yvonne Ayrey set up a program that drew 200 volunteers from friends and neighbours, Knox Grammar School and St John's Presbyterian Church in the Sydney suburb of Wahroonga. My daughter, Susan, helped to nurse him soon after he came home and my wife, Dorothy, became a volunteer.

Slowly, Ian regained his awareness and concentration. He had an enormous drive to get better. The exercises were made user-friendly so that he could accomplish small movements and enjoy that precious sense of achievement. Different exercises were gradually introduced to build on these gains. He commenced to hold his head up for longer periods and sit upright with support in a chair. It was a miraculous day when he stood for the first time. A relearning program was started at his school

and he continued to improve in every way. Today, years later, he is married and has full-time employment. It is wonderful to see this brave young man happily making his way in the world.

*Ian's parents wrote to the Medical Journal of Australia:*³

With this type of injury it must be recognised that the patient's family is also emotionally highly traumatised. In effect there is more than one patient. While traditional patient management systems address the primary patient, the family may be largely left to the dislocation of their life on their own. Being actively involved from the start in the patient's rehabilitation meets the family's need to help their loved one. Incidentally it also makes it easier for them to accept the altered condition of the patient.

Finally bringing the patient home allows the family to regain a more normal lifestyle. Certainly things are different from the way they were before the accident but the family is making its own changes and is not meeting a routine established by an outside agency—nor is an inordinate amount of time lost in travelling.

Ian's story is one of the most remarkable of the Freeman case histories. His initial neurological status—namely, a score of 3 on the Glasgow Coma Scale—denotes a failure to evince any sign of a response to any of the tests. His prolonged period of unconsciousness compounded this gloomy outlook. Fast forward: years later, he was married and in full-time employment. As emphasised previously, no two patients are identical and, presumably, notwithstanding the ominous features at the outset, the nature of the damage he had sustained, and its extent, left open the possibility of recovery, given adequate opportunities. That these were certainly forthcoming is evident from the description of the program that his parents initiated. Complementing this was the 'enormous drive' referred to in his history.

Conclusion

These patient stories tell of a sequence of events, set in train by the initial episode and which, in the absence of direct intervention, tend to progress, inexorably, to an enduring, dismal outcome. Family intervention, under guidance from Ted Freeman, often interrupted the sequence and enabled a more humane outcome to be achieved.

3 Robert Potter & Laurena Potter (1991) Severe brain injury. *Medical Journal of Australia*, 153, 732.

The initial step, following the brain injury that set the sequence in train, was the making of a flawed diagnosis. The nature of that flaw varied between patients. In some instances, the diagnosis of unconsciousness was patently incorrect at the time that it was made. In others, detection of retained, or regained, consciousness required more care, more time and more attention to observations already made by the patient's family members.

The terminology employed in the diagnosis commonly involved the use of the term 'vegetative', a frequent feature in most of the people whom Freeman met throughout his career. Two comments are required in relation to this. The medical literature was not lacking in reports of frequent misdiagnosis of the vegetative state by clinicians with neurological training. To throw around the word 'vegetative' as had been done in referring to many of these patients should have implied that the defined diagnostic guidelines had been observed. Clearly, they were not. The second comment is to stress the ongoing impact that the term could, predictably, be anticipated to have on families.

If categorisation of a person as vegetative failed to depress his or her family, the associated prognosis, generally discounting hopes of recovery, could be relied on to do so. One immediate outcome of this prognosis was likely to be curtailment of acute treatment and sometimes, as in Joe's case, withdrawal of life-support measures.

The gravity of misdiagnosis of any condition will be dependent on factors associated with the inherent difficulty of diagnosing it. Diagnosis of a vegetative state is certainly not simple and the risks of getting it wrong should have inculcated more caution. The ethical opprobrium properly attaching to misdiagnosis, however, derives especially from the completely foreseeable consequences *for patient and family* of the clinician's mistake. The separation, in both time and place, of the acute-care medical setting and the lifetime institutional placement that becomes the fate of poorly assessed patients has ensured that the consequences of misdiagnoses are unlikely to come to the attention of those responsible for making that diagnosis.

A number of patients with brain injury can remain fully conscious, albeit unable to communicate, and are considered to be 'locked in' as a direct effect of the original injury. Another group of patients can be locked in by the healthcare system. Aggravation of the patient's original disability by commitments to minimal care during the acute-care phase can effectively result in 'locking in' of people who have the capacity for a much fuller life. The example of Cecil's case, given above, illustrates how initial failure to treat fractures, because of diagnostic inadequacy, curtailed his chances of a considerably improved lifestyle in later years.

The possible outcomes of long-term treatment designed to provide stimulation and to encourage a person to regain skills that will facilitate increased independence were well shown in a number of the patients discussed above. Others in this group probably had similar potential, but circumstances curtailed its realisation. As noted above by Ted Freeman, not all of the people whom he was asked to meet appeared to have any detectable consciousness and, accordingly, were not entered into programs.

Finally, as an indication of what might be possible, the remarkable story of the patient Ian deserves attention. Given the variety of brain injuries which, while clinically similar, can entail differing degrees of damage, it is not legitimate to use a case history of one conventionally managed patient as a control for assessing the value of a Freeman program for another patient. Nevertheless, Ian's abysmal score on the Glasgow Coma Scale contrasts strikingly with his excellent outcome, and points to the possibilities that may be opened up by very early initiation of a program. This is not often permissible when a patient is in an intensive care unit. If some degree of stimulation is feasible at this early stage without interfering with a patient's treatment, there could be a good case for undertaking it. The letter from Ian's parents in the *Medical Journal of Australia* makes the case well.