

3. Families: No easy way forward

Any reading of the preceding chapter is likely to leave a strong impression that the families of the patients whose stories are summarised were very much part of those stories. The frequently cited adage that a severe brain injury inevitably affects more than one life springs out of the pages. Family responses can range from utter despair and literally walking away from the affected member consigned to a nursing home or similar institution to a total commitment to attempts to rehabilitate him or her, usually at home.

It does not require too much reflection to realise that there are major impacts on a patient's family. First-order consequences are likely to be psychological and economic. Second-order consequences may involve intra-family relations, educational and career aspirations of a patient's siblings and changes in the lifestyle patterns and employment opportunities of all members. The precise nature of the consequences is likely to depend on the relationship of the patient to other family members.

This chapter is based on a collection of letters written by family members. The patient stories in the preceding chapter were reproduced unedited from Ted Freeman's account and incorporate the insights and experience gained from working with a large group of patients with brain injuries. In contrast, the stories that follow provide an account of a young person's progress after brain injury as perceived by the family for whom all of this represented a new experience. These family accounts have been drawn from a collection of letters written in 1995 and addressed to a federal parliamentarian who had expressed interest in learning about Freeman's approach to assisting people with brain injuries.

A total of 53 such letters were examined when selecting those presented below. Applying a selection process to such material may be criticised on the basis that it has been slanted to favour particular points of view. If one were purporting to draw statistically valid conclusions, this criticism would be justified; however, the intent of this selection is to present a qualitative description of the wide variety of impacts, positive and negative, of patient-family interactions.

Of the collection of letters, 35 came from one or both parents; 12 were written by a spouse. Three came from volunteers who had participated in programs, two from siblings and one from the patient himself. He is a remarkable young man with great IT skills. The age profile of the patients was almost completely in the first three decades of life, with the youngest aged three. The circumstances of

the brain injury were overwhelmingly motor vehicle accidents (around 80 per cent), with smaller numbers attributable to strokes, physical assaults, cardiac arrest, asphyxia and epileptic seizures.

Additional information, concerning the impressions of families who had participated in Freeman's programs, details a group of responses from patients' families to a short questionnaire circulated by Ted Freeman. Once again, no claims of statistical validity are made but the tabulated responses record lived experiences. Finally, a letter outlining one family's conclusions, composed by the parents of Joe, whose story was presented in the previous chapter, is a realistic account of experiences many of which were certainly shared by others. Attention is also directed to the published letter from Ian's parents, which was reproduced in the previous chapter.

To anticipate the thrust of the letters and recapitulate the nature of the consequences described in the preceding chapter, it is apparent that the sudden occurrence of a life-threatening brain injury will have a major, frequently devastating, psychological impact on other members of a family. When the affected person remains unconscious for a prolonged period, this impact will be aggravated. The receipt of a prognosis that is, at best, extremely guarded and commonly dismissive of any hope of recovery will augment this reaction. At this time, family responses may split in different directions. Some people commit to trying everything possible to assist the family member; others accept medical advice, often given within weeks of the accident, to commit a patient to a nursing home, institution for the terminally ill or similar and then to 'walk away and forget'. Others waver between positions.

Some of the most trenchant criticism of Freeman, examined below, has been that his approach engenders 'false hope' in the first group of families. Implicit in this argument is the notion that false hope will worsen the major psychological impacts on a family. A more balanced consideration of consequences for a family must acknowledge that psychological impacts on those electing to 'walk away and forget' may be at least as significant and quite possibly more depressing. Walking away may be easy; forgetting may not be.

It does not require a doctorate in psychology to anticipate that repressed and unresolved grieving among those who accept the advice to abandon a relative may well outlast the disappointment in the 'Freeman group' if there is no success after they give it their best shot. I am not aware of any published long-term follow-up interviews with the 'walk away' group. It would certainly require extraordinary sensitivity and considerable resources to undertake such research.

The predictable economic consequences for a family of caring for a member with acquired brain injury will vary with the position of the patient in the family.

When the patient is the breadwinner, the immediate effects of loss of income will be obvious. Comparable impacts may occur if the breadwinner decides to forgo paid employment in order to play a lead role in family members' attempts to rehabilitate the patient. Insurance payouts to cover care of the patient are not always available at an early stage if there are disputes about liability. Some patients have not been eligible for compensation at any time.

If the parents of a patient who has sustained a severe brain injury devote a large part of their time to implementing a rehabilitation program, the patient's siblings may feel deprived of parental attention. Straitened family financial circumstances may threaten siblings' educational aspirations. In some instances, a severe brain injury may strengthen family cohesion but in others it may become a disruptive influence. All of these consequences for a family undertaking a domiciliary rehabilitation program crop up in the family letters but attention in selecting the extracts has been concentrated on the tenacity exhibited in their concern and care for the injured member.

Brian's story

Whilst some families opted to take their patient home because of dissatisfaction with institutional rehabilitation, Brian's parents were forced to do so when funding of his care was ceased abruptly. In the event, the experience he had at home subsequently could not have been provided within an institutional environment.

Brian was seventeen when he was critically injured in a motor vehicle accident, two years before this letter was written. Describing his course in an intensive care unit, his parents recalled:

He had numerous operations and we were told by medical staff that he was 'brain dead' and had a 3% chance of survival. After six weeks, our son remained in a deep coma with a prognosis of severe brain damage. The doctors told us that they were to hold an executive meeting to decide whether to turn off Brian's life support. We were horrified. Three days after this meeting the neurologist said his chances of survival had increased to 10%.

In desperation we contacted Dr Ted Freeman ... [he] assessed Brian and we commenced a coma arousal programme with some 35 volunteers.

Brian was transferred to the rehabilitation section of another hospital where he remained for 12 months.

We continued to carry out Dr Freeman's coma arousal therapy program with Dr Freeman visiting Brian fortnightly and changing the program on a regular basis as Brian improved.

At this time the insurance company funding Brian's hospital costs indicated that it would no longer do so. Faced with a choice of bringing him home or placing him in a nursing home, his parents opted for the former.

We were told by the rehabilitation doctor that Brian would never have any quality of life, particularly that he would never have his traciostomy [sic] tube removed. He would never eat orally and would always have to be fed through a gastrostomy tube. The trachostomy [sic] tube was removed under instruction of the Ear, Nose and Throat Specialist approximately three weeks before Brian left hospital. Since Brian has been at home we have been able to slowly introduce solid foods orally and he now eats normal family meals. Although Brian cannot speak he is very alert and aware of what is going on. He expresses happiness, anger, frustration, sadness, anxiety and is just learning to communicate yes and no with basic head nods. He enjoys watching his surfing videos, Mr Bean and several TV shows.

Our volunteers now number approximately 50 and they carry out two therapy sessions daily devised by Dr Freeman. The first session is usually carried out by ladies and involves fine motor skills, identifying colours, words and photos, doing puzzles etc. The second session is very physical and usually carried out by Brian's school friends and other men. It involves Brian standing unaided, rolling him over a barrel, peddling an exercise bike and helping Brian to regain his balance. Brian also has daily physiotherapy, weekly martial arts, weekly massage and fortnightly speech pathology.

Although no one can accurately predict Brian's future capabilities he has certainly come a long way and exceeded all expectations.

A first comment on the program in which Brian has been entered could relate to its intensity. It would be among the best in this respect, but this assessment should be immediately qualified by noting that there are many among the best in the letters. A second observation could address the vigorous nature of the sessions carried out by Brian's school friends. While feasible for a nineteen-year-old patient with a previous history of considerable physical activity, it would probably be impractical for a 'typical' forty-year-old. Against this, attention could be drawn to the preponderance of younger people (that is, under thirty) among patients affected by severe brain injury after motor vehicle accidents

and then entered into programs recommended by Freeman. Coincidentally, it follows that this cohort of young patients will have the most to endure, in terms of duration, if committed to a nursing home.

Reading his parents' account of Brian's emotions and daily activities some two years after his accident, questions may be raised about his quality of life. If so, it would be appropriate to recall the remark of Dr Keith Andrews of the Royal Hospital for Neurodisability in London to the effect that if one of his patients had a view of his own quality of life that differed from his (that is, Andrews') then he (Andrews) must be wrong. A closing observation on the account given by Brian's parents would relate to the utter improbability that such a labour-intensive rehabilitation would ever be practicable within the formal healthcare system.

Inevitably, this raises a question of resource allocation—namely, whether some diversion of support from a medical goal of 'curing' into slow-stream non-institutional 'caring' rehabilitation targeted towards achieving the best possible quality of life should occur when an individual's prognosis is pessimistic.

Dallas's story

Dallas's story provides a striking example of the feasibility of achieving a worthwhile improvement in a person's life experience notwithstanding long delay in instituting a domiciliary rehabilitation program. It also emphasises that a family may consider that the stresses associated with long-term, intensive support in the home may be more acceptable than the ongoing stress following permanent placement in a nursing home.

Dallas sustained severe brain injuries in a motor vehicle accident at the age of sixteen. This was seven years before his parents contacted Freeman. Their comment on the first meeting was 'no promise of rainbows but good strong advice'. Before this meeting, they 'became desperate to find help for Dallas who had been written off by medical staff from the very beginning'. Following the first meeting:

We began the program in 1992 with good solid hard work with 60 volunteers. Now [1995] we are at the stage where Dallas has dropped the program because he can attend a fitness gym and work with a trainer. Recently Dallas had his legs lengthened by having his knees straightened because the tendons had shortened due to sitting so long [seven years] in a wheelchair.

Dallas's mother provided her analysis of the program: 'You may wonder what this program is. Well I, Dallas and our helpers liken it to good hard physical training and social contact that these isolated people get after sitting around for years doing nothing.'

This analysis is close to that quoted above from Brian's parents. Dallas's mother reflected that:

Some people say this type of program is very hard on the family but what we say is not being able to get help is terrible and seeing the patient lying around and knowing that they could do more if only the help was available.

The stress that such programs place on families like those of Dallas and Brian must be considered in the light of the psychological stress, alluded to above, which could well be the lot of families who have taken the advice to 'walk away and forget'. A concluding observation from Dallas's mother on his behalf has much wider applicability:

From the time that Dallas had his accident he was treated as a cereble [sic] palsy child, instead of as a recovering accident victim. Someone even said recently to our daughter 'Oh he should be with a psychiatrist as all head injured people are'. I ask you how will we ever be able to educate people that not all head injured people are the same.

This is a profound insight from a patient's mother.

John's story

John was removed from the 'conventional' rehabilitation system because of his parents' dissatisfaction with it. While he remained severely limited, he was able to resume life as a member of a family, something that was of great value to his parents and to John.

John was involved in a motor vehicle accident at the age of twelve. His father recalled:

The advice—he would be at best vegetative and it would be best to place him in a nursing home [at the age of twelve]. He stayed in hospital for six months. It was a difficult period for my wife and myself, both emotionally and physically. We had the trauma of trying to accept his condition and the final outcome, the financial concerns for ongoing care [the circumstances of John's accident were such that third-party insurance was not prepared to accept liability, and medical insurance,

believing it to be an insurance case, would not meet costs] and the long hours of hospital visits and still maintaining a semblance of normal family life for two other children at home.

After John spent six months in an acute-care hospital, his parents succeeded in having him accepted into what was described to them as the ‘most switched on rehab. centre for head injuries’ (in Sydney in the early 1980s). John’s father wrote:

Oh how depressing it was for him to spend the next four months propped up with pillows! My wife could not tolerate the inactivity and used to spend six hours a day with him giving him passive exercise. She was reminded by the authorities that ‘she wasn’t covered by worker’s compensation’. Furthermore she was counselled that she was an over anxious and over expectant mother. At ten months John began to respond to command[s] and made meaningful movements and commenced to communicate.

Two points require comment. John’s mother was undertaking passive exercises with him for prolonged periods each day. This could be read as an activity similar to those undertaken by many other parents in the course of a program suggested by Ted Freeman, except for one detail. This occurred some two years before the family established contact with Freeman. To explain this independently evolved similarity some decades later, my suggestion is that both practices—Freeman’s programs and John’s mother’s interventions—were initiated in response to an intuitive belief that they could possibly help the patient. This belief may have been initiated by incidental observations of improvement that were reinforced subsequently by their persistence and gradual augmentation as a program continued.

Some two years after their experience in the ‘switched on’ rehabilitation centre, John’s parents made contact with Freeman:

With Ted we felt for the first time that someone understood our situation and was prepared to offer a programme of rehabilitation for our son. John attended the Brain Injury Therapy Centre in Eastwood for over three years and steadily made progress which improved his quality of life and allowed us to successfully care for him in the home environment. It was with disappointment that we saw the Centre close for lack of funding. In our case we carried on with a home program with community volunteers and following the rehabilitation therapy learned at the Centre. Ted Freeman continued to visit at home and advise.

John’s father has succinctly indicated the gains he associated with his son’s time at the Brain Injury Therapy Centre. This was considerably less than enabling

John to establish an independent lifestyle, but was nevertheless considered to be valuable—it became feasible to care for him in the home environment. Whilst some commentators might dismiss this as an inadequate return for the parents' effort, John's parents did not. The closing assessment from John's father was emphatic: 'Today at the age of twenty five, John while still severely incapacitated, still follows a daily home programme, still improves a little, keeps healthy, enjoys life and is a happy soul.'

John's story draws attention to the value a family can attach to a limited recovery sufficient to permit a young person to resume life as a member following a severe brain injury. Many brain injured people who participate in intensive rehabilitation programs may be in this category.

Matthew's story

Matthew's story provides an example of the value of what, in some medical assessments, might be considered a very limited recovery. The value of that recovery for his family was enhanced by its occurrence after a very discouraging beginning.

After sustaining a brain injury in a motor vehicle accident at the age of ten, Matthew remained in coma for three months. His parents recalled their early experience: 'After speaking to the hospital doctors, we were advised to forget our son and walk away because he wouldn't improve. We were also advised that rehabilitation hospitals would not accept him because he was too bad.'

Matthew's family contacted Freeman and brought their son home, where they undertook a rehabilitation program. Seven years after his accident, Matthew's mother wrote:

Our son is still in a wheelchair but gives us love and laughter and is still improving. He goes out on social outings. He also goes to craft lessons. It's been a very hard seven years for our family, also for our son, but the hard work has shown success. If we had listened to the hospital doctors, our son would still have been in a nursing home, locked away from the outside world at the age of 17 years.

It would require a fairly two-dimensional mind-set to attempt to quantify Matthew's quality of life, which is essentially a judgment to be made by the subject and the family. Such an assessment will be likely to consider the individual within the family. 'Conventional' medical assessment will never be able to assess the value of the lives of people such as John and Matthew because this would necessarily entail insight into mutual interactions between

the individual and other family members. The impact of the presence of the injured person on relationships between other family members would also be very relevant.

Leah's story

This story exemplifies the way in which a family's distress following accidental injury to a daughter can be compounded by a premature negative prognosis; however, it also illustrates the way in which refusal by a family to accept that prognosis, accompanied by retention of hope, led to dogged persistence, with attempts to help her.

Leah was involved in a motor vehicle accident at the age of nineteen. She suffered multiple injuries and the extent of her brain injury was not apparent for a week. In retrospect, her father considered that this delayed recognition had averted pressure to make decisions about the continuation of life support. The extent of her brain injury became apparent when her sedation was withdrawn and she did not wake up. Leah's father recalled:

The doctors felt then that she had suffered lack of oxygen at the scene of the accident and there was no way to assess the extent of this damage. So started our grief, anxiety and uncertainty with little encouragement about any way to help Leah. Her mother refused to listen to the doctors that nothing would be done until Leah woke up. She felt in her heart that there must be a way to wake her daughter.

Then out of the blue a friend told us about Dr Freeman and lent his copy of Dr Freeman's book to us. We were able to understand Leah's problem and found great relief in realising there may be a way to help Leah. When approaching Leah's doctors I was surprised to find them cold to the idea of another doctor assessing Leah. I finally got permission for Dr Freeman to see her. This turned sour on the day he arrived as the head of the hospital department refused to let him assess Leah, despite her doctor's reluctant permission. Luckily Dr Freeman was able to assess Leah if he promised not to touch her.

After his assessment we were given a program to help stimulate Leah's senses. To us this was the first positive action in helping Leah. I must say that despite disapproval we were allowed to implement these exercises. Family and friends worked together in trying to get a response from Leah. After many weeks of loving care Leah started to respond. Dr Freeman kept the exercises up to date and Leah finally awoke, but still there was very little recognition from Leah.

We kept the exercises up day and night. We never left Leah without trying to get a response. More heartbreak came when we were told Leah would only have two choices after leaving the hospital, a nursing home or constant care at our home. We kept up the program knowing that many of the hospital staff felt it was hopeless.

Leah's response was sufficiently promising that it was decided she could be sent to a rehabilitation centre in another city rather than to a nursing home. After two months, it was felt that Leah was missing her parents' daily presence and that, consequently, it would be better for her to return home. At the time of writing his letter, her father summarised her status as follows:

Leah is now able to dress herself, toilet herself and three weeks ago she took her first steps on her own. It is still hard to understand her when she talks, but when she says: 'Dad, Mum, I love you more than you ever will know'. I break down and weep inside.

As with any individual patient, it is impossible to declare with certainty that this attention *caused* her gradual awakening. What *can* be said with considerable confidence is that *recognition* of the first signs, and hence the resultant intensive efforts of family and friends to encourage the progress of her returning awareness and responsiveness to others, would have been much less likely, if not improbable, in the absence of those efforts.

Leah's father's account of her emotional response to her parents, given its dependence on higher brain function, testifies to the quality of her mental recovery. The sense of achievement of both patient and parents with what some might consider to be relatively modest results emphasises again the issue of *who* is entitled to judge progress.

Paul's story

Paul's family, like all of those whose story is recounted in this chapter, was confronted with a choice of 'nursing home or take him home'. The latter course, which they adopted, imposed great day-to-day difficulties on them, but their persistence was reinforced by their reflections on the likely nature of his existence as a young man in a nursing home.

Paul sustained brain injuries in a motor vehicle accident when aged twenty-one. Four years later, his parents recalled the assessment of his doctors at the time:

While we can never really tell, Paul has suffered a very severe brain injury and the chances of his recovery to any significant degree would appear remote. Paul could neither move nor communicate at this time and his breathing pattern was still erratic and of concern.

His early course was problematic: 'His progress was limited and twice he was returned to the intensive care unit following breathing difficulties.'

After four weeks, Paul's suitability for rehabilitation was assessed as 'borderline' but he was transferred to a rehabilitation centre. His response was erratic. Some 10 months after Paul's admission, his parents were told that Paul's improvement to that time suggested that he was unlikely to benefit from further rehabilitation and, consequently, he was to be discharged. The advice at that time was: 'Place Paul in a nursing home or take him home and care for him, but we wouldn't recommend that as his improvement will be negligible and it will be emotionally intolerable for you as parents.'

At this time Paul's parents heard of Ted Freeman and contacted him:

With much apprehension but with Ted's guidance and support we elected to care for Paul at our home. Ted had suggested that the home environment would automatically provide a positive catalyst toward Paul's wellbeing and this was evident at a very early stage.

Caring for Paul at home necessitated his mother giving up paid employment and his father taking on part-time employment, and this, together with the lack of compensation, severely constrained family finances. His parents wrote:

Ted's long experience in the area of brain injury enabled him to introduce practical, effective strategies, not always based on traditional medical assumptions, which converted to what we now call 'a voluntary home based rehabilitation program'. This involved sourcing volunteers, dedicating part of our home to Paul's activities and rostering helpers around Paul's variable and unpredictable attitudes. With enormous assistance from our volunteers, who numbered over 100 at one stage, we initiated a re-training program for Paul as well as providing the 24 hour care he required for his personal inadequacies (bed and clothing changes 3 times each night were not uncommon in the early stages). The results some two and a half years after the program was initiated have been worth it as Paul can now walk with assistance, feed himself, play a variety of computer games, go out (accompanied) to restaurants and movies and he is no longer required to take medication. While he still can not speak he can utter phrases and is totally aware of what goes on around him.

They reflected: 'What would have been his lot in a nursing home at 21 years of age?'

Paul's progress during an extended period in a rehabilitation centre did not produce sufficient improvement to justify its continuation. The account of his program at home should dispel any notions that domiciliary rehabilitation will be a simple matter. The dedication shown by Paul's family was extraordinary, although not exceptional. The closing reflection from their letter concerning his fate if in a nursing home is sobering.

Christine's story

In common with the preceding stories, Christine's involved initial discouragement followed by family assumption of the rehabilitation role. What her story does document especially well is the enhancement of lifestyle that she achieved. One senses that her parents' comparisons of her swimming and riding prowess were not with what she could undertake before her accident but with her enormous limitations when discharged from hospital.

Christine was involved in a motor vehicle accident at the age of sixteen and remained unconscious for six weeks. Her father's letter contained many of the features already noted from the preceding five family letters, for example: 'Doctors told us that she would be a "vegetable" for the rest of her life and would never get out of bed so book her into a nursing home and get on with your lives.'

On Christine's discharge from hospital, a Freeman-planned home rehabilitation program with a team of volunteers was organised and, nine years after the accident, Christine was described as 'leading a happy lifestyle', which included walking, talking, swimming and riding (bicycle and horse). Two comments in her father's letter are quite thought provoking:

The argument has been put forward that Dr Freeman's methods have not been scientifically proven. One of the main reasons would seem to be a 'control' element in his experiments. Well all I can say is that there are vast numbers of patients which have been given very little if any treatment by the brain injury specialists which are admirably suited to be considered as 'control'.

This is surely a small dose of commonsense from a non-medical commentator with personal experience of brain injury.

The father's letter concluded with a recollection from a Brain Injury Council of Australia conference held in Canberra several years previously:

The chair of the session asked 'Is there anyone present who has sustained brain injury who would like to address this conference?' A man stood with difficulty from his wheelchair and said 'I would like to say to the medical profession—you have done a wonderful job in saving my life—but for God's sake help me do something with my life!'

Common features in parents' letters

The letters that provided these extracts are typical of those of the 53 respondents. Several features are common. A diagnosis as 'vegetative' seems to have been freely given. As mentioned in Chapter 2, the adoption of this description in non-medical conversation may be feeding back into medical practice and resulting often in its loose use. Of overwhelming importance from the family's perspective is the highly emotive connotation attached to the term vegetative. This was inadequately considered, I believe, by those who pioneered the term but, given that it has become entrenched in medical jargon, anyone using it when talking with a family should be aware of its emotional impact and handle the consultation process very carefully. In practice, this appears not to have occurred in many instances.

The outlook for many of the patients represented in this and the preceding chapter was certainly not good when families were briefed by medical personnel. It would be unreasonable to expect those personnel to dissemble on this point. Few, if any, of the doctors responsible for early management, be they intensivists or neurosurgeons, would ever have had the opportunity of meeting a single one of the patients described in these two chapters, or the considerably larger group whom they represent, some years after they sustained an injury. Consequently, it is not to be expected that they could indicate that, notwithstanding the gloomy prognosis that they were then providing, they had had personal experience of one patient who had actually regained a standard of life which that patient and family considered to be worth having, despite having been accorded a similarly gloomy prognosis. This recollection would probably be accompanied by the caveat that such an outcome represented a very long shot. Whilst imprecise use of the 'v' word is regrettable, the advice to the parents of a twelve-year-old child to find a nursing home placement can only be categorised as closed minded, since alternative evidence was available. It would also imply considerable insensitivity on the part of the medical practitioner at the time of discussing prognosis with a patient's family. Ted Freeman has drawn attention to a compelling description of this predicament in the following terms:

The US National Head Injury Foundation Newsletter provides a picture of the quandary of the family when thrown precipitately into brain injury:

It is impossible to remain aloof when faced with a family, torn by fright and anger, handicapped by guilt and denial and seemingly abandoned by a system which does not care enough.

All seven of the patients whose family letters were discussed above were alive at the time when those letters were written. A person who has sustained a brain injury of the severity that occasioned a family approach to Freeman may die suddenly and unexpectedly, for example, with respiratory failure as a delayed consequence of brain-stem injury, after years of gradual recovery.

The vicissitudes encountered during attempts to set up a clinical trial of the efficacy of Ted Freeman's approach to helping people with severe brain injuries are outlined in Chapter 6. When a number of families were undertaking domiciliary rehabilitation programs under his supervision, Freeman developed a questionnaire to seek information from them about their impressions of their program. He summarised the results of a simple questionnaire:

Medicine, like most professions, is greatly influenced by statistics. It is only when numbers are available that professionals appear to be able to meet and discuss matters in common. I decided to prepare a questionnaire for 38 families currently receiving therapy at home and I based it on the questionnaire devised by Macquarie University for its Coma Care Family survey. It would have been preferable for my survey to come from an independent source, but I could not get any authorities interested.

I asked the families:

Question 1. Before you started the program were you told by the doctors that the patient was, or would be, vegetative? The replies, all of which were provided by families, were:

Almost always or usually: 33 (87 per cent)

Seldom: 0 (0 per cent)

Never: 5 (13 per cent)

Of the 33 who had replied almost always or usually:

- 29 of the 33 patients now obeyed commands*
- 26 of the 33 patients now could speak*
- 23 of the 33 patients now could weight transfer (take some weight on their legs)*
- 13 of the 33 patients now were walking*
- 22 of the 33 patients now could feed themselves.*

Question 2. Before you started the program were you told by the doctors that the patient would be in a nursing home for the rest of their life? The replies were:

Almost always or usually: 35 (92 per cent)

Seldom: 1 (3 per cent)

Never: 2 (5 per cent)

In fact, 29 of these 35 (77 per cent) patients were now at home.

There was a marked demarcation between those who answered almost always or usually in contrast with those who answered seldom or never. The result was very clear-cut.

I knew that this survey did not prove anything scientifically, but it seemed to justify a more aggressive and positive approach to those people with severe brain injury. I showed the results to several medical colleagues. They remained unimpressed. They pointed out that because I had done the research, it was suspect. They also said I had selected the patients to be assessed. I thought this to be a non-argument. They repeated to me that they considered a double-blind controlled prospective study was the only acceptable research. I felt enormously frustrated at such limited thinking. It appeared totally unethical and immoral for the medical profession to allow a continuing stream of severely brain injured patients to be consigned to nursing homes while they waited for years to produce a foolproof research document. I fumed, but had to bite my tongue. There was nothing else I could do.

Freeman's colleagues had a point but, paradoxically, when their criticism is followed through the only interpretation that can be placed on it runs directly counter to that which they intended. Of course, this is a selected group of patients. They were, effectively, twice selected. In the first instance, they were *selected out* by the medical gatekeepers of the Australian healthcare system. As already explained, the seven family letters, extracts from which were cited above, were selected from a file of 53. These seven were not selected because they were a minority presenting Freeman and his practices in the most favourable light. Rather, they are representative of the whole group of letters. Moreover, the chosen seven best lent themselves to a relatively succinct citation appropriate for a book. The message conveyed starkly in every letter in the file is that the family was told to make arrangements for long-term care without hope of recovery.

The respondents in Freeman's group of 38 families were selected a second time. This second selection process entailed *their selection* of Freeman as a medical

practitioner who, perhaps, had something to offer. This selection process was categorically not influenced by Freeman. Whilst it is now more acceptable for medical professionals to display their wares with the assistance of the advertising industry, Freeman's philosophy and practices were not disseminated in the media. He certainly lacked the resources to do so; I suspect that this practice was, in any case, contrary to principles that he and his contemporaries absorbed in medical school. The families who sought his help had not been referred by medical practitioners. On the contrary, some had been actively discouraged from doing so by their doctors.

Questions of selection bias aside, the responses provided by families to Freeman's questionnaire bear strong resemblance to those much fuller descriptions that have been extracted above from family letters.

The case history notes of the patient Joe from Ted Freeman's records (Chapter 2) are supplemented with a record of the saga for his parents in the form of a series of notes compiled by his father and sent to Freeman.

The notes show as follows.

1. Our fight with the doctors to keep Joe on life support for a little longer.
2. Our fight with the doctors and staff at ... hospital to keep treating Joe. They were just going to let him die.
3. Our first meeting with you gave us some hope but we had to overcome problems to get you in to see Joe.
4. We had problems getting a shunt fitted. It was fitted only after we demanded that you see Joe.
5. After spending a day at Eastwood we decided it was what Joe needed as he had made no progress in the public system.
6. When we first saw Joe at Eastwood, I recall you put a comb in Joe's hand and after some prompting you asked Joe what he did with the comb. He started to comb his hair. This was the first positive move Joe had made. This brought tears to my eyes as I realised Joe did have some hope.
7. From that point on Joe made good progress under your guidance and after five months came home to a home program.

8. Joe continued to improve and we made a move to Queensland where Joe soon became a very respected member of the town being an employer, a substantial rate payer and a taxpayer [Joe's parents had used some of his compensation money to buy him a small farm].

9. At this point in time Joe's fund was controlled by the NSW Public Trustee who we found unsatisfactory. After six and a half years the fund was transferred to [the] Queensland Public Trustee where we are now looking at rebuilding the fund to what it was before.

10. Joe's life is a happy one even though he is confined to a wheelchair and he often says, 'Life goes on and I wouldn't be dead for quids.'

In his assessment of life, Joe was at one with Keith Andrews, Director of the Royal Hospital for Neurodisability at Putney, UK. In the course of an interview with a reporter, Andrews remarked: 'Quality of life is something I have, not something you tell me I have.'¹

Conclusion

The accounts given above by families who have lived with a member who has survived a severe brain injury with substantial disabilities offer insights into this experience that statistics cannot capture. The almost invariably banal negativity of the prognostication in the early stages was often followed, at a later stage, by exclusion from rehabilitation systems that lacked adaptability to the needs and potential of the individual. The requirement for patients to conform to a system that prioritised 'cure' over 'care' often reflected a closing of the bureaucratic mind.

Criticism of Freeman's approach to rehabilitation of people, such as those whose stories have been recalled in this and the preceding chapter, has often directed considerable attention to the welfare of patients' families. Interviewing of families by competent professionals, which will be discussed in a later chapter, has found that the initial event of the accident responsible for brain injury has commonly been the most traumatic event in a family's experience.

One criticism of Freeman's approach has been that it may engender 'false hope' in participating families. At least three responses to this proposition appear to be appropriate. First, as exemplified above, many of the people for whom domiciliary programs were undertaken achieved outcomes which they, and their families, regarded as worthwhile.

¹ Jeremy Laurance (1996) Vegetative state diagnosis wrong in many patients. *The Times* [London], 5 July.

A second response, applicable to families who committed to programs that did not produce significant improvement, concerns the nature of hope. I believe that a strong case exists for the value of hope, even when this is not ultimately realised. It is too simplistic to assert that the only value of hope is determined by its ultimate outcome. Hope is a possession that can afford support throughout the period of its currency, irrespective of whether the aspirations underlying it are ultimately achieved. The benefits accruing during that period are unlikely to be retrospectively ablated if the hoped-for outcome does not eventuate. One benefit may be a gradual adjustment to its non-achievement. It is appropriate to recall an earlier evaluation:

Hope is itself a species of happiness, perhaps the chief happiness which this world affords: but, like all other pleasures immoderately enjoyed, the excesses of hope must be expiated by pain; and expectations improperly indulged, must end in disappointment.²

A third response to the 'false hope' contention, which has featured in the literature on the subject, is to direct attention to the psychological impact of a decision to abandon the affected family member to an inappropriate placement for the duration of his or her life. I find it difficult to dismiss the probability that, if there has previously been close intra-family bonding, other family members are likely to remain subject to recurrent episodes of remorse. In contrast, families who have hoped and tried unsuccessfully to bring those hopes to fruition can resume life with the reassurance that they have done their best. From some personal observation, I suspect that families who have lost a member after a concerted mutual effort are ultimately at peace in a way that others who followed the 'walk away' advice never can be.

An issue that will inevitably be raised by stories similar to those touched on in this chapter is that of the value to be attached to the lives of patients who remain considerably disabled after a domiciliary program. In evaluating the value of the life of such a person, I believe that one should take account of the quality of his or her life, of the experience of that family and, most importantly, of the quality of the *interaction* between patient and family during the time which they shared. Any aggregation of the life expectancy in years of people with severe brain injuries cannot capture the value of those years in which the family walked the path together, often experiencing a variety of hardships.

A general question raised by family stories is that of resource allocation. Domiciliary rehabilitation, as undertaken by families following a 'Freeman program', requires a commitment in carer hours, which, if undertaken on a paid basis, would be far beyond the scope of any health budget. It is, nevertheless,

² Samuel Johnson (1953) Letter to a lady soliciting patronage, 8/6/1762, in *Boswell's Life of Johnson* Oxford University Press, Oxford, 261.

quite likely that the value of the work entailed by domiciliary care and rehabilitation will elude economic measurement in much the same way as occurs with housework. Furthermore, the environment of a healthcare institution could not provide the reassurance and security to a severely incapacitated person that is provided by a familiar home environment.

If the role of the healthcare system is envisaged primarily as that of achieving cures within a certain time, perhaps it is reasonable to redirect some budgetary support to assisting slow-stream rehabilitation located outside hospitals and institutions designed to provide aged care. The potential, described in the family stories above, to recruit volunteers to implement this could result in significant lessening of the financial burden on the healthcare system. Ideally, one might envisage a carefully planned transition from hospital to a more appropriate setting as an accredited pathway for people whose possible rehabilitation was expected to be prolonged.