

9. Some conclusions

The history of Ted Freeman's commitment to improving the subsequent lives of young people who had sustained brain injuries, and their families, includes many events that neither he nor they are likely to have foreseen. Those events raised issues with particular relevance to acquired brain injury but also suggested broader questions related to more general aspects of systemic healthcare delivery and to medical practice, and the relevance to it of ethics and research. Whilst all of these topics have been considered in preceding chapters, it may be helpful to assemble some of them here in order to consider briefly their wider implications.

Systemic inadequacy in response to catastrophic disablement

Although this story relates to a single medical practitioner and a few hundred patients, it is extremely relevant not only for a much larger group of practitioners and their patients but also for all Australians as citizens and healthcare consumers. Some important general lessons for the existing Australian healthcare system's approach to severe disability could be learned from the story of Freeman, his patients and their families.

Consider the healthcare system as it currently impacts upon people like Freeman's patients. The Australian Government Productivity Commission has done just that. An inquiry into disability care and support was released in July 2011. The Commission's report summarised the situation in the following terms: 'The current disability support system is underfunded, unfair, fragmented and inefficient.'¹ Not bad for openers from a government commission reviewing a medley of government programs.

The section of the Commission's report dealing with 'catastrophic injury' could easily be read as an account of many of the patients whose stories were told in Chapter 2. The report observes that '[s]evere brain injury and spinal cord injury are the most common types of serious or catastrophic injury'.² Expanding on the patient profile, the report concludes that '[t]hese injuries are mostly experienced by young men aged less than 30 years old and usually entail a

¹ Australian Government Productivity Commission (2011) *Productivity Commission Inquiry Report. Disability Care and Support*. p. 2.

² *Ibid.*, p. 794.

period of initial acute care and intensive medical and social rehabilitation to return to some level of independence'. It added: 'Around half of all catastrophic injuries are the result of motor vehicle accidents.'³

Freeman's concept of the three accidents affecting people with severe brain injury has been described above. He envisaged the 'third accident' as being an exacerbation of pre-existing disability by inappropriate treatment procedures. This issue is picked up in the Report when it argues:

People with disability and their families often experience severe social, financial and personal disadvantages over their whole life. While some of this is due to the disability in the first place, much is also due to the dysfunctional nature of the 'system' providing them with support.⁴

In a comment that accords all too accurately with Freeman's description of the conditions in which patients were kept in Weemala as 'repulsive', the report discusses 'leaving people in increasingly abhorrent conditions'.

Some general inadequacies of a healthcare system which regularly fails patients undergoing a slow recovery after severe brain injury were identified in the Report. The experiences of Freeman's patients raise concerns about the attitudes and practices of some health professionals towards people with potentially catastrophic levels of disability, including those with other serious physical injuries such as quadriplegia.

Prognostic nihilism becomes self-fulfilling

Freeman's story should direct attention to the entrenched negative attitudes of many of the medical practitioners who were responsible for the early care of those people who later came to Freeman's attention. The family accounts provided in Chapter 3 are representative of the much larger group from which they were drawn. There was no collaboration involved in their writing, yet there are some very consistent features. Apart from the liberal use of the term 'vegetative', the overwhelming impression with which one is left is that of a consistent negativity, often verging on nihilism, on the part of clinicians.

It is both prudent and reasonable for a clinician to be guarded in issuing a prognosis to a family. One might hope that the practitioner keeps two things in mind. The first of these is to provide information that, to the best of his or her ability, is likely to be accurate. The second, surely, is to consider the likely impact of that information on the patient's family and to attempt to present this

³ Ibid., p. 793.

⁴ Ibid., p. 155.

in a manner that will avoid, as much as possible, the aggravation of that grief which has already stricken them. The first can be based on knowledge gleaned from a textbook; the second requires rather more.

Prognostic caution can never provide an excuse for the crass advice to commit a family member to an institution and then forget him or her. Yet this advice recurs too frequently in family accounts of medical interviews to be a quirk of memory on the part of family members. It is not possible after this interval to account adequately for this attitude, but a number of explanations seem possible.

The first is that no practitioner wishes to be proved wrong in issuing a prognosis. An encounter between the acute-care clinician and any of Freeman's patients five years later would have been rare. Given the way in which the system works, it is unlikely that there would have been any awareness (on the part of the acute-care clinician) of whether a patient had confounded a prognosis by attaining some unpredicted level of recovery. A generally applicable message here is surely that any doctor practising in a specialised area who lacks access to long-term information concerning patients encountered only during the acute stage of care makes prognoses at her/his peril.

Nihilistic prognoses have great potential to become self-fulfilling, as exemplified in some of the patient stories in Chapter 2. Freeman was frequently accused of engendering unrealistic hopes, which were most unlikely to be realised, when he suggested to a family that some chance of improvement remained, but surveys of his patients' families, such as those from Macquarie University, and the observations of the social workers participating in the 'Westmead trial' suggest otherwise.

A second possible factor contributing to the generation of predictions of a hopeless outcome in many cases may have reflected the projections onto the patient of a clinician's personal convictions about a patient's feelings. Thus, if *I* would not want to be in *your* situation, then neither should *you*. The fallacy of this attitude has already been discussed. Some may consider a person living with severe disability following a catastrophic brain injury as 'confined to a wheelchair'. Others, including many of the patients, may consider themselves to be 'confined without a wheelchair'. Perhaps more listening to affected families might have served to persuade some clinicians to amend their attitudes and seriously reflect on Freeman's approach. Perhaps not, given frequent medical prejudice against layperson involvement in the rehabilitation process.

Evidence-based medicine in relation to brain injury

Another question exemplified by Freeman's story concerns how one is to test new evidence. The development of evidence-based medicine is ensuring that only therapeutic approaches that are both effective and safe should be promoted. That is a laudable aim; however, it is necessary that the design that is to guide the assessment process in any instance be appropriate to what is under test in that specific situation. The selection by rote of a double-blind randomised control trial to assess the efficacy of coma arousal provides a superb rebuttal of the adage that 'one size fits all'.

A common perception of randomised control trials is that any risk involved in the trial can be expected to impact upon that group of subjects who are allocated to receive the new therapy. This would be envisaged as a positive adverse effect of the new therapy. This concept becomes inoperative when the best available treatment administered to the control group is effectively 'no treatment'. In this situation, the potential risk may be a negative adverse effect on the control group reflecting deprivation of a potentially beneficial therapy. An illuminating slant on the 'orthodox' approach to people remaining in coma (namely, wait and see) was the designation by Chinese researchers of the 'no treatment' approach as 'Western medicine' (Chapter 8).

As designed, the Westmead trial should have been recognised as both unscientific and, even for the 1980s, quite unethical. Some aspects of it raise the question of compatibility between the roles of a medical practitioner *qua* researcher and his or her duty of care as the patient's doctor. This is certainly an issue with much wider and ongoing implications, raising serious questions of real or perceived conflicts of interest. The story of the failed Westmead trial should be recalled in planning any future trial to test new therapeutic approaches that do not lend themselves to the 'standard' methodology.

Another serious concern that emerges from the story of the aborted trial is the absence of any reliable data on the outcomes of the conventional, conservative management of brain injury. The most practical methodology for evaluating Freeman's approach in comparison with the 'best available' alternative would have been to consider his outcomes against those of 'conventional' management. That those practitioners undertaking a conservative management approach were ready to dismiss Freeman's clinical results although they had not been prepared to undertake a formal assessment of the success of their own practices is most revealing. Equally so was the frequent dismissal of his propositions, while ignoring positive clinical outcomes, by decrying the absence of basic scientific evidence to support them.

The closing of the medical mind

One of the most disturbing aspects of Freeman's story is the attitude adopted towards him by some of his professional colleagues. It would be difficult to conceive of a more clear-cut example of closed minds than their repeated refusals to appear on the program of scientific seminars at which he was to speak or to attend meetings of small groups if he was to be present, given that he was an esteemed participant at such events overseas. The general lesson to be learned from this conduct could be that, if one purports to make decisions on the basis of evidence, it is essential that one be open to considering new evidence, even if it is at odds with one's established position.

A few very competent practitioners publicly stated that, whatever the explanation of Freeman's observations, they merited serious consideration. Other colleagues expressed support for Freeman privately but felt unable to acknowledge this to others. The attitude of the second group should raise some questions about the way in which the medical profession conducts itself. It seems probable that at least some of his critics conflated a lack of evidence for any existing mechanism for brain repair with evidence for the lack of such mechanisms. In the same period, there was a complete paucity of scientific evidence underpinning the generally accepted theory—namely, that neuronal repair was impossible, irrespective of circumstances. In recent years, evidence against the conservative practice of management of brain injury has steadily increased. Whereas Freeman's reference to 'plasticity' (a term he was using in the early 1980s) was invoked in the Cuff Report to disparage his approach, the phenomenon of neuroplasticity—that is, the capacity for brain repair—has now been accepted unequivocally

Science catches up with clinical observation

Freeman encountered disbelief when he postulated, on the basis of his observations of recovery by patients with brain injury, that the brain had an inherent plasticity that could provide a basis for recovery. Two decades on, the adult human brain is known to possess stem cells able to give rise to new neurons. The concept of plasticity is accepted by all! Nevertheless, one should now be cautious in automatically attributing recovery from brain injury exclusively to the generation of new neurons.

Much of the disability associated with traumatic brain injury may reflect interruption of pathways between neurons. Plasticity may depend on partial reconstitution of these, or the recruitment of alternative, undamaged pathways, as much as on new cell formation. The acceptance of plasticity by those who

previously denied it, explicitly on the basis of the subsequent discovery of new cell generation in the brain, rather than on longstanding clinical observations of recovery, is logically tenuous reasoning. To maintain that brain repair can be accepted now *because* new neurons can be formed may be as wide of the mark as was the previous dogma, which held that repair was precluded *because* they would not.

Australian isolation

Other very serious questions that are raised by the Freeman experience concern the manner in which changes in clinical practice become accepted or are rejected and the value of empirical evidence in influencing practice. Is it reasonable that medical practitioners are able to ostracise, on the basis of inaccurate claims, colleagues perceived as deviating from accepted practice? Perhaps the most disturbing aspect of Freeman's story is the way in which many Australian practitioners were able to ignore the accumulating overseas evidence pointing to the scientific credibility of his ideas. Given the international acclaim accorded his achievements during the 1990s, the general failure of those Australian specialists responsible for the management of brain injury to acknowledge that reality becomes especially concerning. Inevitably, the question arises as to whether the issue of management of acquired brain injury is an isolated example of this insularity.

What about the family?

One final, and very complex, issue arising from Freeman's story is that of the role of family. In the case of brain injury, this role was determined by the family's intimate knowledge of the patient (literally, 'familiarity'), by the patient's ease when with family members in the home environment and by the family's commitment to help. In a more general context, the family role extends far beyond brain injury. Historically, individuals, whether disabled or not, grew up in a family and grew old and died within that family.

As stated in the Introduction, Freeman's aim in recording his experience, which is shared by this author, is primarily to serve as a 'vehicle of disclosure' in order to bring the events that have been described, and their more general implications, to attention. Whilst the preceding paragraphs may have seemed unduly negative insofar as they deal with practices of the medical profession, one would be remiss if this account did not conclude without re-emphasising the significance of families in all that has gone before.

The battle that confronts the family of a person whose rate of recovery excludes them from accessing regular rehabilitation services accords well with the common truism that 'a serious brain injury affects more than one life'. This battle can be aggravated by healthcare systems that are inherently designed to pick winners by selecting for treatment those people who appear to have the best chance of benefiting from what is on offer. Disagreement over responsibility for funding (for example, between jurisdictions or eligibility for insurance compensation) and territorial disputes within a healthcare system can compound the difficulties.

Modern families and their life patterns have become much more complex. Accompanying the changes, the likelihood that one parent, usually the mother, will not be in paid employment prior to the injury to the family member has diminished considerably, with consequent limitation on the ready availability of care for the injured person in the home. This limitation becomes extreme in the case of a single-parent family or on the occasion when the injured member is the principal income earner.

This volume has recounted the stories of some remarkable families who contrived to assemble extraordinary resources to care for their injured member. The volume has not explicitly recounted the extraordinary social and economic stresses that such families are likely to experience. There is a considerable risk that Freeman's demonstration of the overwhelming advantages for the patient with brain injury of domiciliary rehabilitation in comparison with long-term institutionalisation will constitute a de facto release of government funding agencies from their obligations to this group of patients as well as to many others with disability. Recognition of entitlement to a just level of support for people living with disability, of any variety, within the home environment should be accompanied by recognition of the rights of family members providing care, which are likely to be severely constrained by the accompanying commitments. The commonest constraint occurs when a woman's career is suspended to become a full-time carer. Another unfair constraint is that incurred by a younger person whose educational progress may be severely compromised by a commitment to the disabled family member.

The recruitment, by some of the families, of large groups of volunteers to assist with rehabilitation was an outstanding initiative and, at the same time, a great way of enriching the social capital of their communities. As already considered, the cost, in terms of person hours, of implementing slow-stream rehabilitation is outside the budgetary scope of implementation with paid professional staff. That said, the goodwill of volunteers, like the extraordinary sacrifices of families, must not be used as a means to enable governments to avoid provision of the equitable level of support to which severely disabled members of the Australian community are entitled.

Finally, in considering the situation of the families of people undergoing prolonged rehabilitation following brain injury, the predicament of those who have the injury, but not the family, requires consideration. These are categorised in an earlier chapter as an invisible cohort. Almost invariably, they will have been institutionalised and are unlikely to receive any stimulation from visiting relatives. The numerical extent of the cohort remains to be measured but is likely to be considerable. Their rights are similar to those of other members of the community who are more fortunately placed. Solutions are not currently in prospect. If they are to be sought, at least three responses come to mind. Institutions that have not been planned or structured to provide for younger people who may, to varying degrees, be 'locked in' should release these residents to smaller-scale, purpose-built facilities. Funding to support appropriate staffing of these facilities will be required. Initiatives to foster and support voluntary community involvement to provide plentiful social contact for the residents should be implemented. As in many other areas, when the patient cannot come to the community, the community should come to the patient.