

How Long Might Recoveries Continue After Very Severe Brain Injury?

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Introduction

While most people who sustain a severe brain injury will not return to their premorbid state, a majority will show improvement over time. To what extent can we call such improvements ‘recovery’? Jennet and Bond interpreted recovery as a return to normal life, perhaps with minor neurological or psychological deficits [1]. This may happen for some survivors of brain injury but is unlikely to occur for those with very severe damage. The majority of patients will fit Marshall’s definition that recovery means the ‘diminution of impairments in behavioural or physiological functions over time’ [2]. Kolb provides a more apposite definition when he suggested recovery typically involves partial recuperation of function together with substitution of function [3]. This is probably the definition of recovery that most closely reflects the situation for most survivors of severe brain damage. More recently, Hammel suggests that recovery should be more about focussing on what people can do rather than what they cannot do and that it is not so much a cure as a process of changing one’s attitudes and values [4]. Recovery in this context is concerned with helping people to live “a hopeful, satisfying, meaningful, purposeful, and contributing life within the limitations caused by one’s disease or impairment” (p57). Such aims could also be seen as applying to the rehabilitation that is being achieved in the cases described below. Before looking at these cases it is perhaps worth noting that there is a mistaken belief among some patients and families that all recovery will occur within a certain time period. This is sometimes six months, sometimes one year and sometimes two years. While this may be true for people with mild injuries, those with very severe injuries may continue recovering for many years. This paper describes four patients with very severe impairments who continued to show improvements for many years.

Kate: Continuing Recovery for 21 years

Kate was a teacher when she became ill with acute disseminated encephalomyelitis (ADEM) in 1997 [5]. She had damage to her brainstem and both thalami. She had a disorder of consciousness for several months. She was one of the very first patients in a vegetative state to have an MRI scan [6]. Her responses to photographs of familiar faces differed from responses to scrambled images with the same colours and brightness and the results were no different to those of an age matched control. When Kate left hospital 22 months after becoming ill, her family was told that any further recovery was unlikely. At that time, Kate could make hardly any noise and had very little movement. She received 8 years of neuropsychological

rehabilitation and since then she has been seen each year to monitor her recovery. The first paper about her demonstrated that Kate had normal cognitive function and the second described treatment for her emotional difficulties [5,6]. Wilson and Bainbridge describe her story in detail [8]. She was last seen in December 2018. She remains physically impaired; she is in a wheelchair, is tube fed and has a tracheostomy in place. However, she is cognitively normal and has used a computer for many years. She received speech therapy for 6 years. This was stopped as it was thought she would show no more change. Kate used to rely on a letter board to communicate but, determined to talk, threw this away after 14 years. She now communicates with perfectly intelligible speech. Recovery has slowed but has not completely stopped. Although severely physically handicapped, Kate continues to improve 21 years later.

Tracey: Some Delayed Recovery after Locked-In Syndrome (LIS)

Tracey sustained a mid brain stroke in January 2008 probably due to a dissection of the basilar artery through hyperflexion of her neck while performing gymnastics. This resulted in a LIS. She was assessed in detail in and her cognitive functioning was, for the most part, good [9,10]. Tracey is co-author of a chapter telling her story [11]. She was seen recently ten years after her stroke and four years after finishing rehabilitation, when she was seen in her current placement. Her mobility, facial expressions and vocalisations were observed. With regard to mobility there were noticeable changes. She can now manoeuvre her electric wheelchair with head movements and has an environmental control system for switching on the television, opening the door and so forth. From an expressionless and motionless face caused by the accident, Tracey now has a very mobile visage with plenty of expressions: she can smile, laugh and express surprise. Despite the fact that most of her communications are with her eyes, she has some vocalisations. She can say “hello” and “thank you” but with difficulty.

We know from other studies that recovery does occur for some patients with LIS [12]. For the majority, however, LIS is complete and permanent despite some minor improvements. Tracey would fit into this category; she has made improvements but remains with a LIS. The chief evidence for this is that her main communication is with her eyes. What is not clear is how much more recovery could be achieved with more intensive rehabilitation.

Gary: good recovery after a prolonged period with a disorder of consciousness

In 2011, when he was 28 years old, Gary was assaulted by a gang of youths while trying to protect his father. He sustained several skull fractures and severe brain damage. He was expected to die. He survived but went on to develop hydrocephalus and needed a shunt to drain the fluid from his brain. He also had seizures; and later had a piece of bone removed from his skull because his brain was swelling. Eleven months later, surgery was required to replace that bone. Gary had little awareness of his surroundings for many months. He was in a vegetative state (VS) for fourteen months and then in a minimally conscious state (MCS) for a further five months, so he had a disorder of consciousness for a total of nineteen months [13]. Prognosis for such patients is poor.

There are conflicting answers as to how many patients regain consciousness after being in a state of low awareness for many months. One study suggests 9 per cent of patients regain consciousness after six months while none do after 12 months [14]. The Multi-Society Task Force Report on persistent vegetative state says recovery of consciousness is less than 14 per cent [15]. Giacino & Whyte suggest 20 per cent while Luauté et al 2010 put this as high as 33 per cent. It is also unclear how many of these make a good recovery. Most studies seem to agree that the outcome for patients in the Vegetative State (VS) is worse than for those in the Minimally Conscious State (MCS), and that those who are in a state of low awareness following traumatic brain injury do better than those with anoxic or cerebrovascular damage [16]. These authors go on to say that “those who recover after one year are typically severely limited in function” (P 37). Although there are reports of patients recovering consciousness and some functional ability after a long period in a state of disordered consciousness, such patients are relatively few and they tend to have a shorter period of low awareness.

Gary was exceptional. He regained full consciousness after 19 months and then continued to improve for a further three years. He learned to walk, he talks well, he makes jokes, he scored above average on the block design test from the Wechsler Adult Intelligence Scale -4 including extra points for speed. When last seen in 2018, he was independent and to all extents and purposes a normal young man.

Final Case: A man with a severe traumatic brain injury following a fall at home

The last case is perhaps less dramatic than the others described but it shows that improvement, albeit at a slow pace, can continue for years. This 31 year old man fell backwards while at home, hit his head and lost consciousness. There was respiratory distress and vomiting and he was transferred to hospital. His first neuropsychological assessment was two years later when he was just emerging from the MCS. The evidence for this was that he occasionally responded to a request such as “lift your finger” and “open your mouth” and he closed his eyes firmly when he did not want to engage. This behaviour appeared to be volitional. He was seen every few months over the next five years. When last assessed in 2019, that is 7 years post injury, he was still improving even though he was still severely impaired. He now talks very quietly, he can look at the correct object or picture when two stimuli are held up. He is engaged in the making of a memory book about his everyday life and can make choices about what he wants to do. It is expected that he will continue to improve over the next few years.

Conclusions

This paper has shown that recovery from acquired brain injury can continue for many years. For this to happen, we need to continue to provide the optimal environment and support the patient and his or her family. We certainly should not give up too soon. All four cases described here had on going rehabilitation for many years. If normal practice had been followed, most of these people would have been sent to residential care after six months or so. They would have probably ended up with contractures and a poor outcome [17]. The main message here is not to stop treating patients too soon. Some, like Gary, will make a remarkable recovery, some, like the final patient, will need on going care but all have shown that improvement does not stop after two years or whatever time period is suggested. They all fulfil Hammel’s view that recovery and rehabilitation is about helping people to live a purposeful and meaningful life.

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