

Living with an Acquired Brain Injury

Introduction

It is generally accepted that people working with individuals who have any type of handicap, should have a certain amount of empathy with their clients and should strive to understand how their clients feel and think. People working with those who are brain damaged have a particularly hard time doing so. One can have some understanding of what it means to be blind by simply closing one's eyes; yet how can a normal person understand what it feels like to be brain damaged?

I am in the unusual position of being a trained clinical psychologist who suffered brain damage and who has slowly recovered most of my faculties. In other words, I have been on the outside looking in, and also, on the inside looking out at the world of the brain damaged person. At this point in my recovery, I have a foot in both worlds, for I can remember what it felt like to be completely normal intellectually, and also what it felt like when loss of function was at its worst.

Perhaps this informal and very subjective narrative may be of some help in assisting normal people to empathize a little better with the brain damaged individual. For, unfortunately, most brain damaged people are unable to explain precisely how they feel; those who have been brain damaged since birth, of course, have never had the experience of functioning normally and thus have no standard of comparison of their present state with that of others.

At the age of thirty-nine, I was an exceptionally healthy male with a keen interest in outdoor sports such as skiing, canoeing, and swimming. I had been a clinical psychologist for sixteen years and was married to a social worker; we had three children. I was active intellectually, reading a great deal both in and outside my field, and enjoyed classical music and playing the piano.

The Trauma

I have no memory of the head-on automobile collision that took place one spring evening. I have driven the same stretch of road innumerable times since then, listened to the testimony of witnesses, even examined official photographs of the wrecked vehicles, but nothing triggers any memory of the emotional responses. Hospital records indicate that I was admitted in critical condition, with a broken neck, fractured skull, broken jaw, broken ribs, multiple fractures of the right arm, splintered left leg and ankle, broken hip, internal injuries, numerous abrasions and contusions. The brain damage, which could be only partially assessed at first, was severe enough to render me totally unconscious for almost a week. I was paralyzed on the right side, and showed no response to visual, auditory or other stimuli. Heroic surgical procedures and the use of life support machinery kept me alive the first few days, but I was given little or no chance of surviving and it was thought that if I did survive, I might well do so as a "human vegetable".

I have no memory of the first few weeks in the hospital's Intensive Care Unit. My wife was with me almost around the clock for the first two weeks and for several hours per day thereafter until I was discharged. She tells me that, even when seemingly unconscious, my body was constantly in motion, tugging at the traction, trying to move limbs immobilized by casts, testing out my limits of movement. On some level, it would seem that my body was fighting on its own, even when my brain was unable to function.

Early Communication Attempts

As the profound coma lifted at the end of the first week, my first response was to recognize, by smiling at familiar figures such as my wife, the children, and other relatives. At this time, my wife thinks I had regressed emotionally to almost an infantile state, wanting to touch her and the nurses, wanting to hold onto her hand and becoming agitated when she had to let it go, even for a moment. At the same time, I showed a great deal of agitation and rage. Frequently, I would fight desperately to be free of the traction and would hit out angrily at those around me.

When somehow or other, I managed to roll completely out of bed and land on the floor, cast, traction, broken neck and all, I was placed in a straight jacket and wrist restraints, and these added greatly to my emotional distress.

My family recalls that I seemed quite desperate to communicate and my failure to do so infuriated me as much as the physical immobility. I would try to write, but the script was almost illegible. Many letters were reversed, syllables were repeated over and over, and the meaning was garbled and incomprehensible. I am told that I would become so frustrated at people's inability to understand me that I would stab the pencil through the paper, crumple it up, or hit out at those around me. Speech was, of course, out of the question since I had a tracheotomy and was also on a respirator. I can only guess at the fear and confusion that must have filled me during those long, pain-filled weeks during which I was unable to move, and unable to communicate in any way. Perhaps it is as well that I have no memory of them.

It was with the removal of the tracheotomy tubes and the restoration of my speech, that my confusion and agitation began slowly to subside. I have some hazy memories of this time. My first memory is that of the plastic surgeon removing wires from my jaws that had held them in place while the fractures healed. The intense pain seemed to jolt me into some contact with reality. I remember seeing the doctor as a gigantic, looming figure, although in reality he is a slight person.

Time and Reality Orientation

During this period, I had no awareness of time. I existed in a world of here and now. I was not even aware that such concepts of "time" existed. I knew who "I" was, but did not think of myself as being a child, a boy, or a man. My wife and my mother (who had died some years previously were both present in my thoughts and were indistinguishable to me. The staff of the hospital was also interchangeable shadowy figures. I remember feeling passive, accepting, acquiescent. People came and went, did things to me: I did not question them.

I am told by my wife that during this period I was less physically agitated: calm, often dreamy, and seemed happy in a childlike sort of way, smiling frequently and making few demands.

On the day that I regained some consciousness, my wife constructed a large homemade calendar, which she placed beside my bed in clear view. On each visit, she would make a point of drawing my attention to the day of the week, the date of the month and the year, as well as the time displayed on the large wall clock near my bed. This seemed to have no effect at first. I would repeat the information after her but forgot it immediately. It had no meaning for me.

One day, however, my "mental clock" began ticking again and the concept of time began to become significant. Somehow, I assimilated the fact that eight o'clock meant the end of visiting hours and my wife's departure, something I hated to have happen. One morning, I remember becoming quite agitated as the clock drew towards eight. "Why isn't my wife here? It's almost eight and visiting hours are ending."

When she laughed at me and informed me that it was eight in the morning, I remembered feeling foolish and embarrassed, and covering up as best I could: "Oh yes, of course you're right." From that

time onwards I began to orient myself in time, frequently becoming confused, but making steady progress. It was in the area of daily time that I first began to realize that I had a deficit within myself, since those around me were clear headed and confident about facts and I was not.

As the sequence of night and day became cleared, the large chronological picture began to come into focus, though with difficulty. Looking back, I know that while I was in the early stages of recovery, I “lost” about ten years of memories. At first this did not matter to me since past, present and future were all combined into a seamless here, now.

Nor was there a boundary between reality and fantasy. I cannot myself remember, but I am told that during the first weeks I was delusional and hallucinatory at times. A nurse’s gown hanging behind the door became an intruder, ready to attack. Some delusions obviously served as an escape mechanism from the ever-present pain and physical restriction or served to explain to me why I was in the position that I was in. For example, I am told that I thought for some days that I was on an ocean liner with my wife bound on a pleasure cruise. Observation windows in the intensive care unit became portholes, nurses became stewardesses and so on, and my cubicle was a stateroom. Or, I would imagine I was on a desert island, surrounded by lapping waves.

Gradually, as I became more oriented and more aware that “something had happened to me”, the split between reality as seen by those around me and as I interpreted it became more painful. I would argue with those around me in defence of my fantasies. Gradually, most of these died away, but the fantasy persisted that I was in the Kamloops hospital where I had spent some months as a teenager, and that my parents were still alive and living in the family home near Kamloops where I had grown up. I see now that this was my way of coping with the ten-year gap in my memory, a gap that I simply could not admit to myself at that point in my recovery.

The first breakthrough towards acceptance of reality came in a particularly poignant form. I had been asking with increasing vehemence for some days why my mother had not been to visit me and harassed my wife with demands that she do something about it.

Too tender hearted to confront me with the fact that my mother was long dead, my wife tried to fob me off with various excuses. Quite suddenly, one day, I looked up at her and said in surprise and grief; “What are we arguing about? My mother can’t come to see me. She’s dead.” I began to weep. Traumatic though this reliving of the grief of her death was, it was the beginning of a new stage of progress. From that moment on, I knew roughly where I stood in the stream of time. I had some grasp of the continuum of life and death, youth and age, childhood, parenthood and adulthood.

Step-by-Step Recovery

It was at that time also that I began to wish with great intensity to get out of the hospital. Moving to the Rehabilitation Ward was a positive step for me, and my memories shift in sharper focus at this time. Getting out of bed and into a wheelchair, moving around the ward, socializing with other patients, and eating my meals in the communal dining room, all helped me to get back into the world of reality. Staff members became individuals instead of interchangeable, but there was still a degree of fuzziness about my perceptions of people and things at that time. Returning for further surgery months later, when I had regained a much greater degree of functioning, I was astonished at how worn the ward was, housed as it was in the oldest wing of the building. These details had completely escaped my attention before.

It was then, also, that I started to use my adult qualities of judgment for the first time since my accident. Wanting desperately to get out of the hospital, I made a conscious decision that I would “play the hospital game” in whatever way was necessary to get out. I made sure, for example, that before my doctor’s visits I carefully noted the date, day and time so I could answer his questions. I ate all my meals, I spent hours exercising and practicing with my crutches, I worked hard at

physiotherapy and I refused sleeping pills and painkillers at night so that there was no danger of sleeping too soundly and wetting the bed.

All of this paid off, for after having spent only two months in the hospital instead of the eighteen months that had been anticipated, I was allowed to go home. I have to confess that until I saw the inimitable silhouette of the Okanagan Lake Bridge at Kelowna etched on the horizon, I secretly cherished the last of my delusions (that I was still in Kamloops).

The car ride is sharply delineated in my memory. I had great difficulty in visually “tracking” sights as they whirled past the windows. I felt dazed and stunned by the kaleidoscope of sights and sounds. It felt strange to drive along the streets, unable to remember what came around the corner, yet knowing as soon as I saw it that it was familiar. I have never felt so intensely what it was like to be poised on the knife-edge between known and unknown, with the strangeness turning into familiarity as the road unreeled before my eyes.

The most intense moment came when we drove into our yard. I had wanted ardently to “get home” while in the hospital, but “home” was just an emotional feeling. I had no idea what it looked like. Suddenly there it was, in all its loved reality, with a homemade sign my son had made: “Welcome Home Dad” flapping from the porch. As I hobbled in, a huge chunk of memories fell into place intact: But these were not just memories of the physical layout of the house, where the things were, and so forth, but also the feelings and emotions that went with them. When I saw the sign, for example, I knew that my son had made it, that “Dad” was me and I was an adult and a father.

For the next eight months, I recuperated at home before returning back to work. Looking back, I see that I had three problems to deal with. First of all, there was the physical rehabilitation: learning to cope with the casts and crutches and these were eventually discarded, learning to cope with the permanent disabilities that remain. Secondly, there was the task of assessing the brain damage, and learning to live with and work around the deficits. Thirdly, there was the process of emotional or psychological healing; building up sufficient confidence in myself to be able to discard the role of “handicapped person” and resume the full load of responsibility at work and at home. I had to keep working on all three of these areas at the same time, for lack of progress in one area slowed down progress in the others and vice versa. For example, an arrangement of stout knotted ropes enabled me to pull myself out of bed and the purchase of an electric coffee maker permitted me to get up at my preferred early rising hour and make my own morning coffee, rather than lying helplessly in bed waiting for my wife to wake up and haul me to my feet. This gave me a great psychological “lift” and spurred me on to other steps of independence. Learning to manoeuvre safely on crutches led to being able to go shopping, to church, to friend’s homes, all of which provided mental stimulation and promoted a return to normalcy.

Learning to live with the brain damage was, for me, a major area of challenge, and still is. The diagnosis, after extensive testing, was damage to the temporal lobe of the brain, several cranial nerves and lesser damage to the right parietal area.

Implications

The results of this damage were: lack of taste and smell, impaired short-term auditory and visual memory, lessened emotional control and a greater tendency toward depression.

It has been found that damage to the right temporal area of the brain often leaves the sufferer blissfully unaware that there is any deficit, even when it is quite obvious to those around him.

Damage to the left temporal area, however, often allows the individual to be keenly aware of his deficits. It was thought that this is why this type of damage predisposes the sufferer to depressions.

In my case, I initially denied that I had any deficits at all, and it was only after the process of physical and psychological healing was well under way that I could accept that I had damage in some areas and begin to cope with it. For example, for weeks I denied that I had any loss of taste or smell, yet

these senses were, in fact, totally absent for over a year and have only partially returned even two years later.

My short-term visual and auditory memory was severely impaired for a long time. Here again, I initially denied this and it was quite frustrating for my family to tell me things, which I would forget immediately, later on insisting vehemently that I had not been told anything in the first place. Again, I would meet a person for the first time and, seeing them an hour later, fail to recognize them.

Or I would read a simple paragraph in the newspaper and by the time I got to the last sentence, have no recollection what the first one was.

Having been a highly self-controlled person all my life, I found myself with a hair-trigger temper and labile emotions. It is theorized that this state is due to CNS irritation or else that some part of the brain, which is responsible for “braking” the mental motor, is dysfunctional after brain damage has occurred.

A corollary of this deficit is the perseverance frequently displayed in brain damaged people, and which I recognize in myself. I realize that I have much more of a “one track mind” than I used to, and my thinking tends to proceed along linear lines. Possibly, this is due to the deficit in the mental “braking” process, discussed above. When once embarked on a train of thought, I find it very hard to stop, deal with a side issue and then return quickly to the original theme. Distractions, either external or internal, are hard to handle, and I find myself most comfortable in dealing with clear cut issues, where I can reason in a straightforward fashion.

Coping Needs

In learning to live with my brain damage, I have found through trial and error, that certain things help greatly and others hinder coping. In order to learn and retain information best, I try to eliminate as many distractions as possible and concentrate all my mental energy to the task at hand. A structured routine, well organized and a serene atmosphere at home and as far as possible at work, is vital to me. In the past, I enjoyed a rather chaotic lifestyle, but now I find I want “a place for everything and everything in its place”. When remembering is difficult, order and habit make a minutia of daily living much easier.

Coping is also easier in the milieu that is free of emotional tension, competitiveness, anxiety and pressure. I see all of these as “distractions” that lessen my ability to learn, just as surely as noise, chaos and change in the physical setting. I find it hard to absorb and retain new information in a meeting with people who are new to me and where there is a constant interchange of ideas and personalities. Yet in a one-to-one situation with a familiar client, or working in my office with colleagues whom I know and trust, in an orderly and systematic fashion, I can retain far more and function far more effectively. In other words, simplification of the external situation, both physical and emotional, assists me to master new information. The more complexity around me, the less I am able to cope.

I also find that physical fatigue cuts down my concentration and so I now try to tackle new tasks in the morning, when I am physically fresh. I resort to extensive note taking on professional matters as well as carefully recording all my appointments, financial details and so forth at home. In mastering new information, I go over the subject matter many times, using all possible sensory input channels; reading it, writing it down, repeating it aloud and having someone re-read it to me.

These ways of modifying the external environment will, I am convinced, assist and brain damaged person to learn better. From a purely internal point of view, however, I feel that other psychological factors are extremely important.

Understanding the Brain Damaged Person

First of all, any brain damaged person is going to feel some degree of anger, denial and depression as his deficits become apparent. These have to be dealt with if the individual is to succeed in using his fullest potential and in coping with the real world.

For example, as I have mentioned, for many weeks I denied that I had lost my sense of taste and smell. I never mentioned the loss to anyone while I was in the hospital and it was only on the "safe ground" of home that I took the first steps towards admission of this deficit. This was to complain to my wife that food "tasted funny". I accused her of adding something strange to it, and then theorized that she had bought food that wasn't fresh or that had gone bad.

Finally, when I was able to accompany her to the store, buy the food myself and be assured of its quality, and do the actual cooking myself, I had to admit that the fault was not in the food itself but in my own senses. The same process had to be gone through in other areas of deficiency, mental and physical, as I denied the deficits, came up against the hard edge of reality and finally accepted them.

Anger and depression inevitably accompany the final admission of such deficits, sometimes separately, sometimes together. I remember periods of intense depression during which I would retreat to the bedroom for hours on end, covering up my true feelings by saying that "the noise of the children was too much for me." I was also subject to fits of rage and had a hair-trigger temper that could be ignited by the smallest incident. This all became so difficult for my family (themselves under great stress) that my wife insisted that we see the psychiatrist who had worked with me while I was in the hospital.

Almost immediately after the interview began, he recognized and pointed out my extreme depression. I broke down and began to weep and it was then that I was able to recognize my feelings for what they actually were. Talking with this understanding doctor, who was familiar with the medical and neurological background of my situation, was of great help in "working through" my depression.

Medication was of help as well, but the important part was seeking help, being able to understand my feelings, and being able to talk about them and express them, in tears if appropriate.

My intense anger was dealt with in the same way. I talked about it with my doctor and my family, and we discussed what situations were most likely to trigger off an explosion and how to avoid these situations or diffuse them. Medications eased the process, and gradually the anger dissipated.

I have had to recognize, however, that a problem still remains in this area. I cannot cope with anger as well as I was able to before my accident. Rage, related to my losses, does not just lie under the surface waiting to explode as it did earlier in my recovery. Yet, like any other person living in the real world, situations arise which make me justifiably angry, and I am still, today slow to anger. The difference is that now, once I become angry, I find it impossible to "put the brakes on" and I attribute this directly to my brain damage.

It is extremely frightening to me to find myself in this state, and I still have not worked out a truly satisfactory solution, except insofar as I try to avoid anger provoking situations or try to deal with them before they become too provoking.

Regaining Independence

In the final analysis, though, the problem was greatly alleviated by my taking on gradually increasing responsibilities, first at home, then at work. Each step gave me a sense of accomplishment and self-confidence. It is salutary to accept one's losses, but there comes a time when one must reaffirm what remains and even begin to explore previously untapped potentials.

In this vein, I have mentioned that being able to get out of bed unassisted and make the morning coffee was a great step for me in the direction of full recovery. Next, I took over the planning and organization of the family's meals, shopping lists, and some limited cooking. As time went on and I

grew stronger, I took over all of the housework, cooking, cleaning, laundry and so forth. I enjoyed doing these things but at first they were quite an ordeal for the family. A shopping trip that would have taken my wife and hour would occupy an entire morning, with me making laborious lists, checking and rechecking. Let alone the problem of getting me in and out of the car, maneuvering up and down the aisles with crutches, casts and shopping cart to be taken into account.

Yet, looking back, I realize how vital it was for me to feel that I was no longer totally dependent, that I had certain responsibilities and tasks within the home that were mine alone, and that I was to some degree at least justifying my existence.

My family was most supportive but I remember having to push hard at times against their tendency to overprotect me and treat me as a fragile invalid. In fact, at times I lost confidence in myself because they didn't think I could do something. This is a sensitive area and one that probably presents the greatest difficulty for the families of brain damaged people. Most families have reserves of compassion and protectiveness that they can draw on in dealing with a hurt member. Supporting the injured one is not hard; it is the letting go that is difficult. It takes a great deal of sensitivity and courage for family members to change roles at the appropriate time and let the handicapped person "go it alone". At times, it may take the intervention of an outsider (doctor, friend, colleague) who is not so emotionally involved to nudge the family into their new role and allow the handicapped person to take the next steps on the road to recovery.

In my case, this happened when I had to make a decision to resign from my job. I had no confidence in my abilities to handle the work again and my wife accepted this. I felt that it was only fair to any clients and colleagues that I resign and allow my job to be filled, so with much sadness I sent in my letter of resignation.

My director, backed by the rest of the staff, did something that took courage and perception. She refused to accept my resignation and after a long emotional session, somehow gave me the confidence and courage to return to work on a part-time basis. Her confidence was not misplaced; I found that I could handle the work, and thanks to her, retained my job.

I would say that it is imperative that brain damaged people (especially youngsters who have no previous achievements to fall back upon) be provided with challenges and responsibilities. What is the point of struggling to learn, to absorb, and to achieve on an intellectual level when one is not allowed to exercise one's new powers in the real world? Such a person is literally, "all dressed up with no place to go".

No matter how "hard" it is for family members, teachers and others to let the brain damaged person "do it on his own" and no matter how much "easier" it would be to take pity on him and do it yourself, and no matter how long it takes or how messy the job when done, the brain damaged person must keep moving towards the fullest development of his potential. In my own case, without that gradual build up of confidence in small matters, starting with making the first cup of coffee on my own, I would never have been able to take the final step of going back into full time employment.

Conclusion

In brief then, I have found that internal and external factors must mesh smoothly in order for the brain damaged person to reach his fullest potential and cope with his disabilities. An accurate diagnosis of the deficits must be made and must be understood and accepted by the individual and by those closely involved with his rehabilitation. The individual and his family must be motivated to pursue the fullest development of his potential. Challenges and responsibilities must be provided as he progresses, permitting a growing sense of self-worth and involvement in the real world. Environment at home and at school or work must be structured to maximize learning.

One last word. No one really knows just how great an individual's potential is. In my case, I was given a slim chance of survival and it was thought that I would be a human vegetable if I did live. Instead, I am living a full and productive life and in fact, can honestly say that I enjoy it more than I ever did before. People close to me tell me that I am easier to live with and work with, now that I am not the highly self-controlled person that I used to be. My emotions are more openly displayed and more accessible. Partially due to the brain damage that precludes any storing up of emotion, and partially due to the maturational aspects of this whole life threatening experience. I have come through the crises in my life with more respect for myself and more trust in others. My new openness of feeling makes it easier for me to communicate with others and for others to understand me. People know "where they stand" with me at all times and trust me more.

Furthermore, my blood pressure is amazingly low! My one-track mind seems to help me take each day as it comes without excessive worry and enjoy the simple things of life in a way I never did before. As well, I seem to be a more effective therapist since I stick to the basic issues at hand and have more empathy with others than I did previously.

I do not bewail what I have lost because I am at peace with myself. I have fought a hard battle, given it my best, and won far more than I or anyone else ever thought I would. I ask only that other brain damaged people be given the chance to fight their battles too, and to find out for themselves what their potential is.

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