

WHERE THERE'S HOPE, THERE'S LIFE

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Introduction

Twenty-two years ago I was leading an enviable life as a veterinary surgeon. I enjoyed every minute of my life. In fact, I was in love with it.

Then in a single moment I lost that life, surviving massive brain injuries with open skull fractures, in an automobile accident. Once recovered from the coma, I was given the devastating prognosis: My greatly diminished vision would never improve and I would be in desperate pain for the rest of my life.

Brain injuries devastate both the victims and their families. The circumstances surrounding them can be horrific - to put it mildly. Sooner or later you realize that you have lost your whole life and career - and not only the specific job you'd had but your ability to work at anything. That alone is a huge burden for any human being to endure.

But that comes later. First comes the confusion and pain. Try to imagine waking up tomorrow morning in someone else's body, with somebody else's mind, and with the worst headache you have ever experienced.

What would it take for you to come to terms with *that*?

Then imagine being told that you would have that headache for the rest of your life? I come from an exceptionally long-lived family. In 1984, I was young enough to expect to live another sixty years. Sixty years of torment.

Yet that is what we face as brain injury patients leaving the hospital. A continuous headache which robs us of vision, memory and all hope for the

future. And what greets us at “home” - if we are lucky enough to be sent there, rather than to some warehouse for the living dead? The strong likelihood of rejection by lovers, family, and friends - that’s what.

We are no longer people. We are a potential suicide statistics.

To survive all that, even just to undertake rehabilitation, is an enormous task for any human being. Yet this is the population that you must deal with in your practice. Difficult and despairing survivors who have had all the hope beaten out of us, not only by pain and trauma, but by the very words of our doctors and surgeons.

Thanks to my medical background and my lifelong habit of never giving up, I gradually improvised my own rehabilitation, in which behavioral optometry played a major part. I am a veterinarian, not a physician. Everyone in this room almost certainly knows more about the human CNS than I do. But please bear with me as I list what I regard as the 3 most important words to keep in mind when working with ABI clients. These words are crucial to the rehabilitation of any kind of trauma survivor, but are especially crucial when it comes to the brain injured. I did not find them in any book, mind you. I discovered them from my own experience. If you take away from this meeting nothing but these three simple words, I’ll have done my job. So, here they are:

Uniqueness

Hope

Teamwork

1. Uniqueness

Physicians and surgeons rely on their patients to have identical systems to diagnose & treat: respiratory, circulatory, digestive, reproductive & so forth. But the human mind is somewhat different. Not only our genes but also our experience and education help to shape the structure of our brains. The result is that each individual has a

unique and individual mind and therefore a unique and individual set of possibilities. To the degree that medical professionals attempt to fit all brains into a single mold and prognosticate and treat us according to the nature of the injury alone, they make a huge and often disastrous mistake. If I had accepted the prognosis I was given, I would not be standing here before you today.

For those of us with behavioral or depression issues – and that is certainly the vast majority of traumatic brain injury survivors - I urge you to *please, please do not confuse the person with their bad behavior.* You may imagine that such behaviors are the main barriers to a successful outcome, but believe me, they are symptoms, not causes. As one who went through it all myself, I can tell you that such behavior is a result of the pain and confusion caused by the injuries, combined with the anger stage of mourning, plus unbearable frustration and fear. Such behaviors do not necessarily reflect who we are or how we want to be or remain. Give us reason to hope, and at least some of those behaviors will begin to change.

2. Hope

Each survivor comes out of that operating theatre in a somewhat different shape. But the medical professionals must have hope for the patient in order to recognize that. And they must also foster hope in the patient if the patient is to make the best recovery of which they are capable.

Unfortunately, many do the opposite. They see their patients as hopeless and indoctrinate them and their families with the same view. Such doctors honestly seem to believe that no hope is better than false hope. Well, I have been there. So, let me tell you THE most important thing I will say all morning: Where there is hope there is life. Where there is no hope, there is no life. Most brain injury survivors I have spoken with, both in the US and OZ, had left the hospital suffering and hopeless – and were still suffering and hopeless years and decades later. What could be worse than that?

As human beings, we need hope. Even false hope is better than none. Pass it on.

And please don't ever dismiss false hope as mere denial. In fact, don't underestimate denial either. The hope that carried me through years of rehabilitation was the hope of practicing veterinary medicine again. That was a false hope in that it turned out to be beyond me. So, you might say I was in denial all those years. Yet that denial gave me a life preserver to cling to when I had no other.

Those years of false hope and denial served me well. They kept me alive and inspired me to work on my sight and get my pain under control. They kept me going through my darkest days. With their help, I discovered not only what I couldn't do but also what I could. And here I am today, writing books, giving presentations and being an advocate for other brain-injury survivors.

3) Teamwork

During the course of my rehabilitation, false hope was gradually replaced by the real thing. The first step came when I found a chiropractor, who achieved what the doctors had said was impossible – fully relieving my pain simply by putting my head back on straight. The pain was not banished forever, of course. It returned, again and again, and in fact it still does. But I am pain-free much of the time, and when my head does begin to ache, I know where I can go for relief.

Also enormously helpful was my speech pathologist – not so much for anything specific she did, but for treating me like an educated and intelligent individual capable of living a full life.

But perhaps most crucial of all was my first behavioral optometrist. Dr. Fuerst. The first time we met, Dr. Fuerst said two critically important things to me. The first was, “We can work on the visual loss due to brain

damage.” The second was, “You have to do your vision exercises at home every single day. The only excuse for not doing your exercises is if you have already died.” I followed his advice to the letter and today, when I’m wearing my glasses, I have 20/20 vision across most of my visual field.

Dr. Fuerst knew that I would respond favorably to such stringent demands, because he knew me before I ever walked in the door. I had been referred to him by a learning disabilities specialist at the University of California at Davis, one who had taken the time to get to know me and become my case manager. You have to know a survivor’s individual personality in order to treat them most effectively, and this is especially true of the brain injured. That is why a case manager is essential, to advise and coordinate.

That is also why my third watchword is *teamwork*. Rehabilitation is a team effort. Recovery from brain injury is beyond the province of any one specialist. Neurosurgeons can get us through the initial crisis, but no more, and even they don’t do it alone. You should have seen the list of doctors my solicitors had to pay. BO & VT are just as specialized as the neurosurgeon who takes all the credit.

So don’t fool yourselves into imagining that you and your specialty can handle all the needs of your brain injury survivors. Even the greatest medical genius on earth couldn’t do it alone. It takes a team.

Who do we need on the team? Most survivors will require many or all of the following:

A chiropractor or osteopath for the vertebral injuries almost inevitable with TBI

An occupational therapist

A speech pathologist

A psychotherapist

LDS for cognitive rehab

An educational kinesiologist

Feldenkreis practitioners

BO & VT

A case manager to coordinate this multifactorial team.

And, ideally, at least one devoted family member, who will follow through on a day-to-day basis.

Recovery and rehabilitation are a long, hard road. Over the years, I have used all manner of professionals and family members as my case manager. Currently, my GP and occupational therapist have been acting together with really spectacular results, helping me build my new life.

I had advantages many brain-injured patients do not. I was blessed to have enough functional brain tissue to work out what I needed and to find it. I was also lucky in that virtually all of my deficiencies were caused by damage to the brain, not the peripheral. My personality was essentially intact, including my will to work hard for my goals and fight for what I want. My birth family was wonderfully supportive and loving, once I got away from my husband, who was not. Many brain injury survivors are not so fortunate. For them, the team effort is all that more important. But even I could never have recovered without it.

So, if you are to help your brain injury patients, you must learn to network with a variety of professionals in your area and build teams. As a shortcut, you may want to use your local state information and advocacy service for people living with acquired brain injuries. I have 2 lists available at the OEP booth. One is for all the states in Australia and one for the USA & the rest of the world.

Conclusion.

Success does not require a total cure. Progress and improvement are often good enough. Let me assure you, 20/20 vision in both eyes even with a permanent bilateral field defect makes for a much better life than practically no useful vision at all.

It is now widely understood by the medical profession that improvements can still occur 10 years or more post-trauma. In my case, it's been over twenty years, and I'm still improving. *So never, ever give up on us!* Just remember that progressive improvement is difficult to achieve for someone who is in constant pain and has had the hope beaten out of them. So, the first priority is to diminish the pain and restore the hope.

Uniqueness, hope and teamwork. Uniqueness, hope and teamwork.
Remember those three words, and they will change many outcomes for the better. And if you have room in your memory for only one word, make it *hope*.

The woman who wrote this book [hold up 1st edition] was no longer a potential suicide statistic. I had progressed to victim with restored vision and manageable, occasional pain. My old life was still destroyed, but I was no longer in denial. I had become ready to move on from my losses and to replace false hopes with real ones.

Yes, there really is the possibility of life after brain injury, and I stand before you this morning as living evidence. A survivor once diagnosed as hopeless, I am now building a new life and career. Yes, I still have to work at it. But I am also still making progress. Yes, I still have a long way to go, and sometimes the journey truly does seem endless. But I am often free of pain and what I'm doing at this moment is fun and rewarding. I have far less need to grieve over my losses, now that I have these gains to enjoy.

So, go back to your practices and your ABI clients & start building rehabilitation teams. Help your clients to renew their hope. If you need a little help or encouragement or a hint as to where to begin, stop by the OEP booth before you leave and look at the second edition of my first book. Boy, has Bob Williams got a deal for you! And don't forget to pick up your lists of ABI support organizations. Thank you.