

INVITED COMMENTARY

# There is a Human Being Inside Every Patient

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## ABSTRACT

*In this paper, the author recounts her experience in dealing with recovery from a traumatic brain injury. She shares her insights on the dubious practice of patient labeling. The author also affirms her belief in the role a positive outlook plays in recovery.*

*Keywords: Compassion, Hope, Label, Patient, Positive Outlook, Recovery, Traumatic Brain Injury (TBI)*

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## INTRODUCTION

My laptop just crashed. Not a software crash where I can just reboot. Crashed. On the floor. Shattered. Why? Because my head doesn't know what my left hand is doing. And my left hand, well, the whole arm actually, just blithely brushed the laptop off the desk and onto the floor, as I was reaching with my right hand to fetch something.

How ironic that this mishap occurred as I was writing about my TBI (traumatic brain injury). I found my concerns about what I could salvage from my laptop analogous to recovering from a head injury. What data could be retrieved? What would still work? It reminded me of my own self-assessment after suffering brain damage. Could I continue to be a functioning human being?

Almost fifteen years ago I suffered a massive brain hemorrhage resulting in a paralyzing stroke. In a flash, the life I knew was irretrievably

gone. But I vowed not to give in to feelings of despair and resolved to throw myself into my recovery. I had to acknowledge the detour in my life plan and set about reinventing who I was. What began as a pounding headache eventually led to my becoming an involuntary member of the fraternity of TBI patients.

The TBI patient club is a nondiscriminating association that "welcomes" 1.4 million new members and bids good bye to 50 thousand annually in the US alone, according to the National Institute of Disorders and Stroke (NINDS, n.d.).

As a TBI patient, you feel vulnerable; you are fearful over lost function and become impatient for your recovery. You long to resume your daily routine, even the mundane tasks you once resented. You wander down any path that offers a ray of hope. You are a patient, but you are not patient—tolerant, uncomplaining, serene. You are an impatient—irritated, anxious, impulsive, impetuous. I was pigeonholed with these hurtful labels: impulsive, impetuous, in denial. Labeling a person is dehumanizing, and

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when labels are applied to a patient, it stunts the healing process.

I was the stroke in 417, the impetuous one. Surely, this new role as patient is a temporary layer over the real me: corporate achiever, mother, wife, daughter, sister. I will not let labels besmirch who I am as a human being. I am not my current predicament.

The cornerstone of health care is compassion. Integrate the humanity and preserve the patient's dignity while providing top-notch care. To realize this outcome, the medical professional and the patient must forge a partnership where the exchange of information is open and honest. The mutual trust this implies helps to achieve a state of "wellness." In this partnership, there is a shared common goal--getting well.

As a patient, I have high expectations of my health care providers. Topping the list is that they chose their profession out of a sense of duty and not just for the paycheck. I have cultivated a knack for distinguishing between the two, having suffered at the hands of apathetic caregivers early in my recovery. I have always felt that I would rather have no service than lip service. Body language speaks volumes of how one feels about his/her patient. It doesn't take a medical degree to show you care. All it takes are simple acts of kindness—it's not complicated.

In the wake of my brain injury, I thought about what I wanted more—compassion or analysis? In a discussion with my husband, I told him that I felt that compassion was most important in the treatment. He disagreed, saying he'd prefer analysis and a solid diagnosis. I suggested that his perspective was such because he had never been a patient in long-term care. But why one or the other; why not both?

My neurologist once told me that he "had to treat the mind as well as the body." I have come to understand how true this is: the mind can make a healthy body sick or it can improve a sick body. One's state of mind is as important as the treatment plan. Thoughts are things: you are what you think. If you handicap your mind, your body will respond accordingly.

As a patient, it's important to maintain focus on the positive. Positive thoughts are vitamins

for the mind. I recommend adopting a daily mantra; mine is "Positive Outlook=Positive Outcome." It doesn't mean negatives don't exist, but if you illuminate the positives the negatives will remain in the dark. Doctors often talk in percentages, but you can't sum up the human spirit in a number. It is necessary to synchronize the medicine with the power of the human spirit.

There's a direct correlation between a patient's decision to survive and the onset of improvement. And it is a decision, a choice, to continue to work at improvement. For me, it was setting a course for my recovery to overcome my circumstances that in turn energized family and friends, for they too have to cope with the condition 24/7. They in fact have their own diagnosis, *helplessness*. When the patient decides to empower rather than to sabotage the recovery effort, everyone can move forward.

When you lose basic personal functions such as use of the toilet, feeding and grooming yourself, it's easy to fall in to despair. What enables you to keep going is the glimmer of hope that these setbacks are temporary. Everyone deserves a prescription of hope. Hope is the motivator; it offers renewed possibilities. While presenting at a hospital Grand Rounds, a doctor challenged me on how he could hold out hope in the absence of any real chance of survival. I responded, "Ah but doctor, you are equating *hope* with *cure*. My definition of hope is to achieve the best possible outcome."

Often when talking to brain injury groups, I hold up a brick and offer the following metaphor:

Many of you who have suffered some form of trauma probably feel like you've been hit by a brick, be it a car accident, a fall, a sports injury, an illness, an addiction, a stroke. Others of you have absorbed the same crushing blow of the brick because of your association with the stricken, as a caregiver or a loved one.

In the aftermath of that traumatic event, as you try to reclaim your life, you often feel like you have run into a brick wall. Such are the roadblocks and pitfalls to recovery.

But if you persevere, you can start to rebuild, brick by brick. The foundation is already in place. Your trauma does not define your

essence. You might emerge a little different from what you once were, but you are no less elegant or dignified. And in many ways you will be stronger and wiser.

## REFERENCE

NINDS. (n.d.). *Traumatic brain injury: Hope through research*. Retrieved from [http://www.ninds.nih.gov/disorders/tbi/detail\\_tbi.htm](http://www.ninds.nih.gov/disorders/tbi/detail_tbi.htm)

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*Julia Fox Garrison's memoir, Don't Leave Me This Way: Or When I Get Back on my Feet You'll be Sorry (HarperCollinsPublishers), chronicles her recovery from a massive brain hemorrhage and paralyzing stroke. The book's irreverent tone and biting humor garnered national attention and awards, including: an appearance on Good Morning America, an article in People Magazine, selection by Barnes & Noble for their Discover Great New Writers program, selection by The Reader's Digest for its Today's Best Non-fiction edition. Julia lives north of Boston with her husband and son where she is working on her next book about growing up in a loving, if chaotic, household with eight brothers. In addition to her writing pursuits, Julia does motivational speaking, evangelizing for humaneness in medicine. She also speaks to support and patient advocacy groups, businesses, and communities, where she shares her story of personal triumph against overwhelming odds.*