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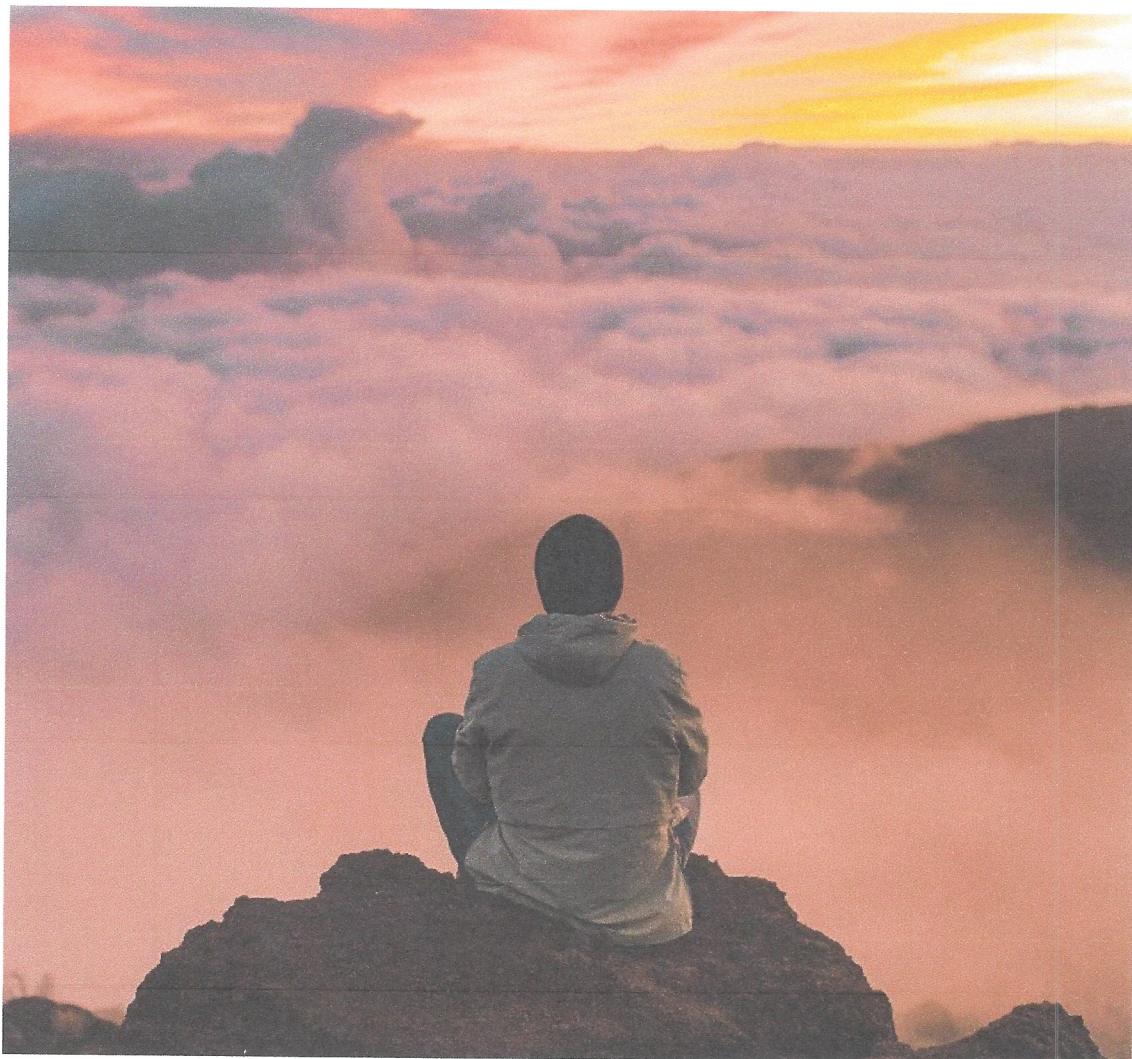
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STROKE AND TRAUMATIC BRAIN INJURY (TBI) LIFE MAGAZINE

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What Would You Do?

By Walt Kilcullen

I have been a volunteer mentor for stroke and traumatic brain injury survivors for almost twenty years. I don't give medical advice or financial advice. I just help each of my survivors to set goals, help them to get services such as Medicare, Medicaid, housing and food, and I listen to their problems. Basically, I try to help them get their lives back. I help them move on from what they can no longer do, and emphasize what they can do.

Recently, one of my stroke survivors asked me, Walt, "what would you do if your wife had a stroke?" I could have given him a brief answer, but instead I told him that I would explain what I would do the next time I came for a visit. Then I went home and wrote this article.

First, I would be sure I knew what type of stroke my wife had: was it ischemic (clot based) or hemorrhagic (brain bleed)? Was it located on the left side of her brain, the right side, or on the brain stem? Let's assume it was a left-brain ischemic stroke (the survivor who asked the question had such a stroke). If it left my wife with serious paralysis on her right side, she would not be able to use her hand and arm at all and could only walk with a brace on her affected leg. She most likely would also suffer from expressive aphasia which means she could not speak in sentences and could not verbally express herself.

After her stroke, my wife would have been stabilized in the hospital, gone through months of rehabilitation at a rehab hospital, followed by months as an out-patient three times per week. Once the insurance company decided she could no longer benefit from further treatment, mostly as a result of doctor reports, the insurance company would end coverage. So, she'd come home. What would we do now?

I would begin by tackling the physical disability. That means applying neuroplasticity as aggressively as possible. Neuroplasticity is the process by which the functioning parts of the brain transfer neurons to the nonfunctioning side taking over its functions. After a brain injury, everyone experiences some degree of neuroplasticity. As a result, some survivors recover and are close to their original condition. Others,

however, continue to have serious disabilities. It all depends on the degree of damage to the brain from the stroke or TBI.

If my wife had total paralysis of the right hand and arm, I would start with passive exercises, which means that the strong hand/arm must help the weak hand/arm to perform a particular task. An example is to put a group of children's blocks in a pile. Next to that you put an empty bowl. The left (strong) hand holds the right (weak) hand, helps the weak hand to grasp, pick up the blocks one by one, and release each block into the bowl. Understand, this is not a quick fix. It is a marathon. These exercises must be done two to three hours a day for at least six months before any improvement might be achieved.

If the arm and hand show some movement, that is, she has the ability to pick up an object with the weak hand, we can apply active exercises. I have read countless books on brain injury recovery, but the best that I have read is Stronger After Stroke by Peter Levine. Levine outlines all of the exercises you need to apply both passive exercises and active exercises. Levine also recommends E-Stim machines and Botox injections to enhance the results of neuroplasticity exercises. Both Botox and E-Stim machines should be used to enhance active exercises while Botox should be used to enhance passive exercises.

The method that has proven most effective using neuroplasticity is called Constraint Induced Movement Therapy. This can only be used in patients that have some movement in their weak arm/hand, i.e. can pick up an object. CIMT was developed by Dr. Edward Taub, from the University of Alabama Birmingham. He refers to this treatment as "rewiring the brain." Therapists who use CIMT describe it as recovering movement due to non-use of the affected limb.

CIMT immobilizes the strong hand and arm by either placing it in an oven mitt or in a sling. This forces the survivor to use only the impaired limb. Over time the strong hand/arm rewires the brain to force the patient to use the weak hand/arm making it more useful over time. Although there are clinics that offer programs using CIMT, it is easy to do on your own at home. Therapists recommend a treatment of three weeks, five days a week, three hours a day, where the patient does exercises focusing on the weak hand/arm. Then you must keep the strong hand/arm in the mitt or sling for the rest of the day. To read about case studies, use a search engine such as google to find about this therapy.

I would also explore getting my wife into a clinical trial. Almost all trials can be found at clinicaltrials.gov. You can also inquire at the closest rehab hospital to see if they are conducting an appropriate trial or if they know of any facilities that are.

Since I also said my wife was suffering from expressive aphasia, I would also eventually try constraint induced aphasia therapy. This can also be done at home and can be explained through a search engine. There are also clinical trials using CIAT.

With all this planned therapy, you can see it is hard work. I would steer my wife away from what she can no longer do to toward what she can do. Over the years, I have found success with the people that I mentor in this partial list of ideas: join a stroke or brain injury support group, try handicapped horseback riding, join a yoga group for people with disabilities, enroll in a facility that offers aquatic therapy, explore finding a driving center for people with disabilities. They will evaluate her potential to drive again.

And finally, I would take every precaution to be sure she doesn't have a second stroke. This includes monitoring blood pressure, cholesterol, weight gain etc.

A Neurological Perspective on COVID-19: Stroke and Other Considerations By Dr. John Nogueira

In late 2019, SARS-CoV-2, the novel coronavirus that causes COVID-19, was found to be responsible for an outbreak of pneumonia in Wuhan, China. The virus quickly spread to other countries and by March 11, 2020 a pandemic was officially declared by the World Health Organization. In the early days of the pandemic, when less was known about the virus, COVID-19 was primarily recognized as a respiratory illness that was associated with fever, chills, cough, shortness of breath, and difficulty breathing. In the most severe cases, COVID-19 was known to cause respiratory failure, requiring hospitalization and treatment with oxygen or mechanical ventilation. Indeed, during March and April of 2020, a great deal of media attention was focused on the looming shortage of ventilator machines in the United States and other countries, which would mean the difference between life and death for individuals severely affected by the disease. But, as hospitals around the world mobilized to handle the onslaught of coronavirus patients, doctors and nurses on the front lines of the battle soon began realizing that COVID-19 also had the ability to disrupt other organs within the body, including the nervous system.

Impairment of taste and smell are neurological symptoms that are commonly experienced by patients with COVID-19.¹ As reported in the European Archives of Otorhinolaryngology (the study of ears, nose, and throat disorders), about 86% of patients with laboratory-confirmed COVID-19 infection reported difficulties with their sense of smell.² The number of infected individuals reporting difficulties with their sense of taste was slightly higher at 88%.² While solid data is not yet available on the long-term prognosis, the authors of this particular study reported that 44% of patients regained their sense of smell over the short-term.²

Headache is another neurological symptom that is commonly experienced by patients who have COVID-19.³ The symptom is non-specific, meaning that many

other conditions can cause headache, and the existence of headache, without other typical COVID-19 symptoms, may more likely be due to another cause. The mechanism for headache in COVID-19 is probably related to inflammation triggered by the immune system, similar to the kind of headache that someone might experience with a bad case of the flu.

In patients who are critically affected by COVID-19, such as those admitted to the ICU, or attached to a ventilator, encephalopathy (a broad term for any brain disease that alters brain function) has been commonly reported.¹ Encephalopathy is a confusional state, not unique to COVID-19, which may affect sick elderly or other very ill patients. It is quite commonly seen in such patients who have been admitted to the hospital for a variety of reasons. In the case of COVID-19, encephalopathy may be triggered by a number of factors, including lack of oxygen to the brain from respiratory failure, metabolic imbalances in the blood, and other causes.¹ Seizures have been reported in patients with COVID-19 related encephalopathy,⁴ though they are also commonly encountered in patients with encephalopathy from other causes. While the confusional state experienced by some patients may resolve within days or weeks, the long-term prognosis for encephalopathy in individuals afflicted with COVID-19 is unknown.¹

Stroke is an important, but less frequent complication of COVID-19. The incidence of ischemic stroke (the kind caused by a blockage of blood flow to the brain) has been reported to be between 0.4% to 2.7% .¹ This rate may be higher than in patients hospitalized with influenza,⁵ which suggests that COVID-19 may increase the risk of stroke. The incidence of intracranial hemorrhage – or bleeding in or around the brain – has been reported to be less, at 0.3% to 0.9%.¹ Stroke typically occurs within three weeks of the onset of COVID-19 symptoms, but in a small proportion of cases stroke was the initial problem that led to the hospitalization.¹ The mechanism of stroke in this setting is unclear, but rather than being a direct cause of the virus, it has been suggested that stroke is due to indirect effects such as inflammation, disruption of normal functioning of blood vessels, and blood-clotting issues.¹ Stroke in patients with COVID-19 appears to be more severe than in patients without COVID.¹

Other neurological conditions have infrequently been found to be associated with COVID-19. Guillain-Barre Syndrome, an acute form of polyneuropathy (disease of many nerves within different parts of the body) which classically causes rapid progressive numbness and weakness ascending up the legs and arms, was diagnosed in 5 patients out of 1,200 who had been admitted to three hospitals in Northern Italy over a one month period.⁶ Guillain-Barre Syndrome is typically caused by inflammation that leads to the peeling away of the myelin sheath that surrounds peripheral nerves. While the precise mechanism of Guillain-Barre Syndrome in patients with COVID-19 is unclear, it may be related to non-specific inflammation caused by the virus.

Even less frequently, there have been scattered case reports of patients with

COVID-19 whose cases were complicated by a variety of rare neurological conditions that cause inflammation in the brain and/or spinal cord, such as meningoencephalitis (a medical condition that simultaneously resembles meningitis and encephalitis, which is an infection or inflammation of the brain), ADEM (acute demyelinating encephalomyelitis) {a rare kind of inflammation that affects the brain and spinal cord, most common in children}, and others.¹ Depending on the anatomical location of the inflammation within the nervous system, these conditions have the potential to cause a wide range of neurological symptoms, including, but not limited to, numbness, weakness, confusion, speech impairment, eye movement abnormalities, and an impaired ability to walk.

Much still needs to be learned about the neurological effects of COVID-19, including the frequency of the various neurological complications, their clinical characteristics, disease mechanisms, and long-term prognoses. The neurological manifestations described in this article originate from case reports and small studies, and much research needs to be done going forward for doctors to have a better understanding of these important considerations.

As a final thought, it should be mentioned that aside from COVID-19 being linked to a range of neurological issues, individuals with certain pre-existing conditions may be at increased risk of severe illness from the disease. Stroke survivors in particular should take extra precautions to minimize their exposure to the virus, especially those who have other risk factors, such as advanced age, diabetes, or hypertension.³

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John Nogueira MD, is a private practice Neurologist in Hackensack, New Jersey

Five Treatments for Frozen Shoulder After a Stroke (that Reduce Pain and Improve Mobility) A reprint article from FlintRehab.org, Published June 9, 2020.

(Editor's Note: Frozen Shoulder can happen after any brain injury including a TBI)

Frozen shoulder after a stroke can be a painful condition that hinders your quality of life. If you want to treat frozen shoulder and relieve the pain, you're in the right place. You're about to learn various causes of frozen shoulder after stroke and how to treat the condition. We hope you can find some relief by the end of this article.

What Causes Frozen Shoulder After Stroke?

The Shoulder is a ball-and-socket joint encased in connective tissue. Frozen shoulder occurs when the connective tissue thickens and tightens around the shoulder joint, resulting in restricted and painful movement.

Frozen shoulder is caused when the arm is immobilized for a long period of time. Stroke patients with arm paralysis are particularly at risk for this condition.

Unfortunately, mobility issues after a stroke are a slippery slope. If paralyzed patients do not participate in physical therapy, mobility issues begin to worsen. Partial shoulder dislocation (a condition known as "shoulder subluxation") can worsen into frozen shoulder.

This condition can be prevented by keeping the arm moving. If frozen shoulder occurs, it can be treated the same way it's prevented: with movement. Not just any movement will suffice, however. Frozen shoulder patients need to participate in physical therapy and other supplementary treatments to overcome this condition.

Treatment for Frozen Shoulder After a Stroke

Below you will find some great treatment methods for frozen shoulder after a stroke. If you want to try any of them, have a conversation with your therapist before you begin to ensure your safety. Here are some of the best treatments for frozen shoulder after a stroke.

1 Physical Therapy: Physical therapy exercises for the shoulder and arm are the best treatment for frozen shoulder after a stroke. They gently introduce movement into the shoulder and stimulate the brain. By stimulating the brain with exercise, patients can help spark neuroplasticity, which is the brain's ability to rewire itself and regain lost functions, such as arm movement.

Stroke patients with frozen shoulder often struggle with paralysis, which makes exercise difficult. Fortunately, patients can start with *passive range-of-motion*

exercises to get movement into the arm during the initial stages of recovery. Be cautious when attempting to exercise with frozen shoulder. If the upper arm bone is disconnected from the shoulder socket, exercise on your own can be dangerous. It's important to work under the guidance of a qualified therapist.

2 Electrical Stimulation: Electrical stimulation is another promising treatment for stroke patients with frozen shoulder. It works by applying electrical impulses through the skin to the affected muscles. Electrical stimulation often brings movement into paralyzed muscles. It's one of the top treatments for post-stroke paralysis. With immobility being the root cause of frozen shoulder, electrical stimulation can help. If the shoulder has become dislocated, electrical stimulation may help encourage the arm bone to go back into the socket. **Your physical therapist will likely suggest pairing electrical stimulation with exercises. Studies have shown that combining these two treatments leads to even better results.**

3 Botox for Spasticity: Botox is a great way to reduce spasticity after a stroke, which can help reduce pain from frozen shoulder and improve range-of-motion. However, it only produces short-term results. Although results are temporary, Botox may offer enough relief for patients to participate in physical therapy. Therefore, this treatment option – although temporary – can help you address the root issue by doing the exercises necessary for recovery.

Work with your therapist to apply Botox to temporarily reduce spasticity in your arm and shoulder. Then, use the temporary boost in mobility to accomplish gentle physical therapy exercises to improve frozen shoulder long-term.

4 Shoulder Taping: Now that you know some of the best treatments for frozen shoulder, let's discuss an effective compensation strategy: shoulder taping. Shoulder taping does not treat the root cause of frozen shoulder, because it does not encourage movement. However, it can help relieve pain. A qualified physical therapist can show you how to tape your shoulder, or show your caregiver how.

Arm Slings: If your shoulder has become partially dislocated, then taping may not suffice. If you need a better compensation strategy, your therapist may recommend a sling. Slings can help support the arm and reduce the gravitational pull on the shoulder socket, which aggravates conditions like frozen shoulder. A good physical therapist will also prescribe gentle exercises along with a sling, as a sling does not address the root cause.

Which Frozen Shoulder Treatment is Best for You? If you suffer from frozen shoulder after a stroke, it is important to talk with your therapist about treatment. Therapists can show you how to exercise your shoulder and arm safely. Furthermore, if you need extra help with pain management, a therapist can teach you how to tape your arm properly and apply electrical stimulation correctly. It's extremely important to work under the guidance of a professional for painful conditions like frozen shoulder. Good luck on the road to recovery.

FlintRehab.org offers a weekly newsletter with wonderful informative articles. They also offer two products that treat movement disability as a result of a brain injury. Check it out.

My Story: Eileen Harrison

The following story was written by Sue Harrison, Eileen Harrison's mother, and is a reprint from the "Survivor Stories" section of the braininjurypeervisor.org website.

Eileen came home from college, where she was completing her third year, to study for final exams, renew her driver's license, and get a dress for her brother's college graduation.

None of these events took place. Two days before her 21st birthday she was turning left into the DMV to renew her driver's license when her car was hit broadside by a car going straight ahead. The impact threw her car a great length before it stopped, crashing into a pole. Fortunately, there was a policeman in the DMV and a fire station across the street and thanks to them, they were able to extract her from her car and perform a tracheotomy. The closest hospital was around the corner where she was taken and put on life support.

All this happened while my husband and I were at work. I was not far from the hospital but did not know anything until 3:00 in the afternoon. The accident occurred at 9:30 AM. When the police finally found a neighbor of ours who was home, they told them where I worked and they called me and said to get right to the hospital, that there had been an accident and my daughter was involved. They would not give me any other information, so I called my husband and told him to meet me at the hospital. When we got there, they told us that Eileen was in a car accident and suffered a severe traumatic brain injury, she was on life support and was not expected to live. Being the fighter that she is, she survived being in a coma, being paralyzed on her (dominant) right side, and being in critical condition for a month in ICU.

While Eileen was in ICU, I remembered seeing a movie two weeks earlier about a young woman on Long Island, New York (where we lived) who had a TBI and was in a coma. At the end of the movie there was a link to the L.I. chapter of the Brain Injury Association. When I told my sons, who were with us at the hospital, they tracked it down and found the phone number of the president of this chapter. That night, that gentleman came to the ICU and offered us more support, hope, and information than anyone had as yet provided. This was in 1991. We had no cell phones and no computers. We will always be grateful to this kind person whose son had also

suffered a TBI.

Once Eileen was stabilized, which is more than the doctors expected, we had Eileen transferred to the closest TBI rehabilitation center, which was in Edison, New Jersey. There Eileen blossomed. She worked so hard and had incredible doctors, therapists, and nurses. She was there four months and achieved more than anyone had hoped for, including saying her first word, and ultimately, as anyone who knows her, went on to say much more! She was then transferred to their acute care unit for two months. She started coming home on weekends after about a month and was then discharged a month later and came home to continue rehab at an outpatient facility on Long Island. She was there for 1 ½ years and then moved on to another center as that one closed.

Before moving down to Georgia with us, where both our sons and their families were living, Eileen had some surgeries in Philadelphia; lengthening her arm and foot on the right side, and the following year, a tendon transfer on her right knee. She also had Strabismus surgery for the double vision that was due to her injury. One of Eileen's motivators to walk again was to walk down the aisle at her brother and his fiancée's wedding. Our son's friend, who was to be a groomsman, went to physical therapy with Eileen to learn how to assist her walking down the aisle. She did it.

The journey has been long and arduous for Eileen and her family. To this day, Eileen still works to maintain and improve functioning. She still makes improvements and has come to terms with her disability and her deficits. There are still frustrations but they are overcome so much more quickly. We are so proud of her.

Eileen and I became involved with the Brain Injury Peer Visitor Association in an effort to give back and give support to others who have had a TBI and their families who are going through what our family has gone through. My best advice I give to people we visit is, try to stay positive and supportive of your loved one, be sure to take time for yourself every day, even if for only an hour or more if possible, when someone can cover for you. It will help you to remain strong and focused. Do not listen to others who may say, "Well, I know someone with the same injury who can or never will do (such and such)..." NO two brain injuries are alike. Always encourage your loved one to keep trying to do the best of their ability. You never know when the next improvement will happen! Always ask people to address your loved ones and give them the opportunity to respond themselves, if they can.

Editor's Note: I am always on the lookout for resources that may help our brain injury survivors. (braininjurypeervisitor.org is certainly worth a look.)

Thoughts on Recovery and Sleep
By

David Wasielewski

An acquaintance recently shared that she experienced a severe head trauma and concussion. After six months she still could not spend significant time using her computer and had taken several leaves from work in order to allow for recovery. Knowing that stroke and traumatic brain injury were similar, she asked me if I had any words of wisdom on the subject of recovery. We both noted that brain injuries are very different from other injuries. The path to recovery is not nearly as well defined for head trauma and stroke as other injuries and the prognosis is not always as clear.

When you break your arm, you visit the doctor. The doctor takes an x-ray, assesses the injury, and a cast is applied. When you return Six to eight weeks later, the cast is removed and your arm function returns to normal. Brain injuries are a very different situation. The diagnosis is usually less clear. Symptoms of a brain injury are not directly observable. X-rays and scans yield much less certain diagnoses. The diagnosis is made primarily by observing and examining the patient.

Treatments for recovery are much more uncertain and dependent on the individual. Recovery can take a few days, weeks, months, or even years. And full function may never return. The frustration of an uncertain recovery plays an important role with each survivor. The amount of work to be successfully applied involves a delicate balance between effort and rest. Each survivor needs to carefully balance effort and rest as the brain guides the survivor through the healing process.

Recovery from brain injury requires a heightened sense of self-awareness and insight. The survivor is much more intimately involved in gaining brain function than in purely a physical function. Broken arms usually heal at the same rate for everyone. Brain injury recovery is much less certain. As each survivor leaves the hospital and therapy, they are tasked with determining their own optimum balance between work and rest. The discussion inevitably led to sleep issues.

What balance of rest and work leads to recovery and how does the survivor maintain the best quality of life with his/her limitations? The survivor is often released from the hospital with a regiment of new medications, many of which have a side effect of fatigue. My acquaintance and I both found that giving in to sleep was a frustrating but a necessary step in the process. As a survivor I found myself completely frustrated by not being able to maintain a full day awake.

After eventually giving in to fatigue and napping during the day, I then found it difficult to sleep through the night, leading to a cycle of tired days and restless nights, a factor in my struggle with post-stroke depression. The journey toward a balance that enabled a good quality of life including experimenting with various nap times and lengths, eventually led me to finding a combination which allowed both daytime rest and nighttime sleep. Further experimentation with my meds led me to modify the

doses to help decrease the side effects with my doctor's guidance of course.

Muscle relaxants play a huge role in the fatigue cycle. The timing and the dose can often be adjusted to accommodate the patient's need. For me, the process took the better part of a year until I settled into a regular routine. A daytime nap has been an important part of my daytime schedule and my other activities are generally scheduled around it. It is far from ideal but has proven to be effective in managing the after effects of a brain injury while maintaining a good quality of life. I don't recall the issue being addressed by any of the hospital staff while I was there. It seems to be an issue that each survivor must solve on his or her own.

David had a stroke in 2005 ending his career as a logistics consultant. Since his stroke he returned to college for a degree in Sociology. He is a "peer counselor," facilitates a support group, volunteers at the United Way, and is a frequent writer for the Stroke and Traumatic Brain Injury Life Magazine.

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