



Notes from a Survivor: A New Life, Part IV

By Stacy Rosevear

September 2005 I celebrated my fifth year of life post-stroke. It's a new life of sorts. Not one I planned nor prepared for, but it's mine. Every day, whether disappointing or uplifting, remains what I choose to make of it.

I'm proud of realizing my dream to become an artist despite stroke-induced challenges. It's exhilarating. However, I'm also very proud of how I got to this point and it's that story I'd like to share in this final installment to my four-part series of life post-stroke.

When I look back at my stroke, it is as if I had as a baptism of sorts - an awakening or a rebirth. It's a second starting point. As I face new challenges there's a constant balancing act to keep remembering how far I've come and how hard I've worked. I am proud of where I am but facing new challenges and finding purpose in this new life can be very draining.

For example, I find it extremely hard to ask for help. I find it difficult to accept even when it's offered without my asking.

It is my nature to act resourcefully. Like I respond to a hot stovetop by retracting

the offended body part, my first reaction to difficult change and ominous hard work ahead is to pull away from the pain.

To overcome these challenges I've learned to control and manage my natural reactions. Taking full advantage of Vocational and Psychiatric Counseling tasted bitter at first, but in the end, acted as saving grace. Working in the capacity I did prior to the stroke wasn't an option. My brain and body did not allow for this.

Just now I am embarking on a path that works well with my gifts, limitations, and emotional capacity. I've had to turn 180 degrees to redefine success, failure, worth and purpose for myself. Even now I still doubt what I'm doing. Sure life is filled with reevaluating and refining, learning
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Who's Who



Doris Anderchak

Doris is the Research Care Manager (RCM) for the TBI Model System Telephone Study. The RCM provides supportive counseling, educational information about TBI, problem-solving assistance and referrals to community resources. The goal is to help individuals increase their success at dealing with multiple, complex challenges experienced after a TBI.

Doris has been working in the field of disability research and rehabilitation counseling for almost twenty years. This includes over tens years of experience as an Independent Living Consultant for the Division of Vocational Rehabilitation and as a project coordinator for previous TBI grants at the University of Washington. She has an extensive working knowledge of the independent living and community integration needs of individuals with brain injuries, spinal cord injuries and other neurological disabilities. Doris received her Masters degree in Counseling from Seattle University and is a Certified Rehabilitation Counselor.

Beyond the Injury continued...

to be present in this time I'm given, in this place and with this body. The unique challenge for those with brain injuries is that even after 5 years, this process can still feel new due to changes within us.

People who do not know me more than skin deep cannot tell I've had a stroke. They don't know the work it has taken to get here. That's ok because I know inside what I can do and what I can contribute. It is that knowledge that I act upon. I choose not to avoid the pain of dealing with my injury. While many times it is almost unconscious now to forge ahead, just like it's almost unconscious to grab the handrail and slow my pace considerably when descending stairs, it's a daily choice. I just do it.

I wish you well on your journey. Sharing this with you is an important part of mine.

Look for more articles and artwork by Stacy Rosevear in issues to come!



Story I: The Babysitter
from Childhood Story Series
16 x 20
Acrylic on Board
Stacy Rosevear, 2005
stacy@yo-yodyne.com

Importance of Exercise After TBI , Part I

By Denise Hansen

Nearly 8 years ago, on a round trip bike ride from Seattle to Edmonds, I crashed. In 15 years of bike racing I never had a close call. But that day, 5 miles from home, anxious to beat a red light, my luck expired. In the seconds it took for my tire to jam in a groove, my life changed forever, and my motivation for exercise lay on the road alongside layers of skin from my face, legs and shoulders. The momentum of 25 mph catapulted me and the bike over 40 yards and across 4 lanes of traffic. Finally stopping underneath a minivan, I suffered numerous fractures and complications from severe muscle trauma and nerve injuries. The impact crushed my helmet and my brain suffered injury as well. Despite surgeries to repair bone, years of rehab, and the best treatment options available, I continue to endure relentless, debilitating chronic pain that refuses to back off.

My goal of returning to competitive cycling has faded as I come to terms with the body which betrayed me with its stubborn refusal to heal. The cognitive dysfunctions of a brain injury plague me and I am followed by a nameless cloud of fear. Biking rattles me and cognitive confusion renders me unable to make the quick decisions one needs to ride safely. Never to physically recover enough to allow me to compete or enjoy the rush of speed and endurance challenges, my fragile identity remains at question. You see, although exercise provides numerous health benefits (more on that later), disease prevention was never my motivation to endure lunatic training levels. I was motivated by personal challenge, vanity, and closeted bragging rights. I trained 200 miles per week to spare my fragile ego the self imposed humiliation of failing to be first to

reach a summit or worse, to be dropped from the pack when racing. I felt subtle physical superiority when remarks were made on the size of my quads and muscle definition in my calves. Sadly, exercise preserved a longstanding misconception that nothing else about me was remarkable. Exercise shored up a wobbly self image and lack of confidence.

Unfortunately, following my accident, as the size of my thighs began to shrink, and my strength diminished, so did the motivation I had for exercise. I struggle to find the point of an hour of rowing or a slow paced bike ride on the Burke Gilman. The all or nothing attitude which served my past identity, allowed me to just do it. The challenge to create form around the amoeba like identity of today, leads me into daily negotiations with the excuses of pain, fatigue and disorganization and often turns into I just can't do it. Fortunately, although I have lost something once essential, I have not lost myself. I reach deep into my competitive spirit, and realize I must find within me the desire to do my best. So, with new motivations and improving attitudes, I keep score under the new uninvited rules. Since an hour of exercise is more difficult now than an 80 mile training ride ever was, I get more points. It all comes down to the degree of difficulty.

In the next issue, I will discuss why exercise is important for someone with a TBI. The barriers may seem insurmountable, but within yourself, you can find the motivation to succeed.

Research Volunteers Needed

The Effect of Community-Based Exercise on Symptoms of Depression in Persons with TBI study is examining the effects of aerobic exercise on depression and anxiety in persons who have had a mild to moderate TBI in the previous 6 months - 5 years. The study offers a supervised 10-week exercise program to participants along with education and motivational components. If you are interested in participating in the study, or for more information, contact Nadya at 206-685-8354.

Beat Fatigue - Slowly but Surely

Ken Jelinek, OTR/L, ATP, Outpatient Therapist at UWMC

Physical and mental fatigue are serious issues that can be addressed with planning and assistance from professionals and caregivers alike. This article will provide background information and practical tips to help gradually increase your endurance.

Fatigue can undermine concentration, attention, memory, communication, and physical activity. Abnormal fatigue is often described as an excessive tiredness and lack of energy unrelated to exertion and not helped by rest. Problems with abnormal fatigue can occur independent of depression and younger people and those with milder injuries tend to report greater fatigue.

Does it get better? Physical and mental fatigue usually diminishes over time; it should be greatly improved within 6 months after a serious brain injury. Does it go away completely? For many, it appears that it does not; two years after brain injury at least 50% identify fatigue as one of their biggest problems. For a variety of reasons, fatigue is often not systematically addressed. Fortunately, there is much you can do to reduce fatigue if you or your caregivers can prepare for and follow a program. Did you know that adding a well designed exercise program can help your physical and mental endurance? It may seem counterintuitive, but exercise can boost your overall reserves.

Adding activity slowly and incrementally is often the answer for newer and older injuries. For instance, an hour of morning activity may be all you can handle. From there, you slowly and incrementally add activity followed by rest breaks; closely monitor your fatigue

levels until you reach an acceptable level that you can tolerate. Avoid extreme fatigue!

What can you do for fatigue?

Preparations:

- Consult your physician
- Start a diary to understand patterns and triggers
- Plan proper nutrition
- Follow a sleep schedule and reduce disruptions
- Use stress management and relaxation techniques
- Educate caregivers and include them in the goals
- Get help to become and stay organized
- Consult an OT for energy conservation techniques and devices
- Consult a PT for an exercise program

Practical steps:

- Do strenuous activities when energy is normally highest and rest when energy is normally lowest
- Take scheduled naps and rest breaks, but be increasingly active in-between
- Simplify tasks whenever possible - conserve your energy
- Add tasks only as you can tolerate them; slowly and incrementally
- Set a cut-off time for ending daily activities
- Be positive about your ability to manage the symptoms!

Resources:

- www.tbiguide.com/fatigue.html
- www.bcftbi.org/resources.html
- www.biausa.org/
- Perform an internet search using the words: brain injury fatigue

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uwtbi@u.washington.edu

Or visit our website at:

www.depts.washington.edu/rehab/tbi/