

Reaching for Wellness: Skill by Skill

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Reji Mathew and
Dr. Angela Ryan

Photo Credit: Susan Marell

Wellness is a growing movement in health care centers around the country, aiming to guide persons seeking medical care to go beyond the demands of managing their illness and work towards achieving as much health as possible.

The post-polio community is a diverse one, as polio has affected each person differently, and the subsequent challenges each person faces are unique. My story is that I contracted bulbar polio at 9 months and spent the majority of my early childhood overcoming my original paralysis. Despite haphazard outpatient care, I recovered and achieved a high level of functioning. Three years ago, at 38, I started exhibiting symptoms of post-polio syndrome (PPS). To adapt to the mobility changes, I transitioned into walking with leg braces and forearm crutches, driving with hand controls and typing with my voice.

The unexpected changes in my functioning were stressful and anxiety provoking. I was catapulted into a new emotional journey, requiring me to re-evaluate my coping skills. As a working university professional and writer in New York City, I took this turning point in my life as an opportunity to refocus my academic interests and writing efforts to the study of hope and resilience. Through my own learning and countless interviews of others, I have come to understand wellness in terms of the themes I describe below.

Attitude of Curiosity and Learning

Anytime there is a change in a person's ability to function, it is a new experience. It is common to feel loss or anxiety. Learning how to re-negotiate my mobility using assistive devices was a challenge, but the real jolt was the shift to living my daily life in slow motion. I move slower, tasks take longer and fatigue can be inhibiting.

Managing fatigue is the first skill I have had to master. An attitude of curiosity and learning has helped me rethink how I reestablish daily activities. Whenever I want to achieve a

goal, I conduct experiments – calculating time frames, setting smaller goals, consulting with experts – until I find the right formula to achieve it. This mindset is helpful to me when I am working on writing assignments, as my projects require a mix of travel, interviews in different time zones and multiple deadlines all at the same time.

Each day I calculate my muscle exertion for the day, just as a diabetic person would do with diet and exercise. The main insight I learned from managing fatigue is that I don't take one day at a time any more, because New York City life can be unpredictable: traffic jams, navigating crowded city streets and commuter delays.

I have a general idea of what I want to accomplish each week. I then plan each day in units, early/late morning, for example. When I am on the road for a writing assignment, I may not be able to rest as I need to, so then I will break down my day further into moments. I will say to myself, "Let me just take a deep breath, relax and focus on getting through the next 15 minutes."

Dr. Mathew is writer and advocate ... See her website at www.rejimatthewwriter.com showcasing her articles on health, wellness, living well with disability and links to various resources.

Positive Cycles versus Vicious Cycles

I have built the majority of my new skills around relapses and setbacks. In the first year of living with PPS, my mobility challenges slowly started to narrow my life. Determined to improve my daily functioning, I learned that I need to start positive cycles of wellness instead of recovering from vicious cycles of relapse. For example, I relapsed two weeks after my first discharge from outpatient rehabilitation. My entire left side shut down, and I was unable to walk.

I used my behavioral analysis skills to understand how I was using my muscle strength. I realized that I was opening and closing doors in my office complex about 15-20 times a day. I started asking for help so that I could reduce this daily strain. Planning for or avoiding unnecessary drains is a central way I maintain a steady pace of life.

Intermittent Rehabilitation

The other side of managing a medical condition well is keeping the body as healthy as possible. My physiatrist advocated for me to receive intermittent rehabilitation treatment, and we problem-solve every step of the way to build skills for every mobility quandary: gait training, driving, transferring safely and managing my activities to keep me as injury free as possible.

My physical and occupational therapists taught me that there are a variety of ways to modify each standard exercise, and this helps me to find the right amount of movement my body can tolerate. Now, in addition to my daily exercise, I stretch throughout my workday to keep my contractures as flexible as possible.

I recently was also referred back to a brace clinic to update my ankle foot orthosis for a new design to aid in my walking. Being able to go back to rehabilitative care every few months to learn new techniques and ask questions has enabled me to preserve and maintain a high quality of life.

I also commit to staying updated on the latest technology. Once a month, I scope the latest websites or rehabilitation magazines to learn of any tool that could help me function better. I recently discovered iGoogle, an interactive web page where I can download tracking tools to help chart medical appointments. I also use a wide range of hand tools, such as grip gloves for walking with crutches, as both of my hands have atrophied and I don't have grip strength.

Vital Absorbing Interest¹

Managing a chronic medical condition can easily feel like a fulltime job. Finding a vital absorbing interest, activity or hobby that can help in taking a mental break is critical.

I have always considered the expressive arts a path to hope. A central theme in my writing is how the arts can aid in coping with the stressors of illness. To expand my life, I took a painting class. After the first few weeks, I was unable to sustain the muscle energy to paint and then drive home independently. I stayed in the class regardless and observed. It awakened me to the world of visual arts, now a constant source of uplift. I also studied with a music teacher who guided me to connect to music without playing an instrument.

I started a guided imagery project two years ago, which has been most

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The Fifth Brazilian Symposium on Post-Polio Syndrome (PPS) was held in September 2009 in São Paulo, Brazil.



Tatiana Mesquita E Silva, PT

The Brazilians involved with organizing this seminar are very determined to add to the world's knowledge of PPS and improve the health status of Brazilian polio survivors. Groups and health professionals from Portuguese speaking countries who would like materials from the conference presentations should contact Tatiana Mesquita E Silva, PT (TATIMSILVA@GMAIL.COM).

Dr. Acary Oliveira, Chief of the Neurology Department at Federal University of Sao Paulo's Medical School and head of its PPS Clinic, was the conference manager who also gave informative and entertaining talks on the "Neurologic Aspects of PPS," and its history and management in Brazil.

Frederick Maynard, MD, Marquette, Michigan, presented "PPS – Where Are We Now?," Daria Trojan, MD, Montreal, Canada spoke on "PPS Fatigue" and Olavo Vasconcelos, MD, Bethesda, Maryland, reviewed "Clinical Trials on PPS Treatment."

Local faculty member Tatiana Mesquita E Silva, PT, reported research results on "Sleep Dysfunction and Its Treatment in PPS Patients" and "Hydrotherapy for PPS." Micra Ocanhas, PT, talked about "Bowel and Bladder Incontinence in PPS Patients."

Fernanda Maggi, PT, gave an excellent summary of PHI's 10th Conference in Warm Springs, Georgia, April 2009, which was attended by five representatives from Brazil.

Polio survivor Luiz Baggio, Secretary for the Rights of Disabled People's Office and founder of the Brazilian Post-Polio Association (www.abraspp.org.br), also a conference organizer, convened and ended the seminar with thoughtful remarks on the role of polio survivors in society and the current needs of those with PPS. ▲

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gratifying. Friends donate cinematic photos of natural landscapes from around the world, which I then share in guided imagery stress management sessions with patients.

Repeatedly, I've learned the importance of staying open to new ideas to manage stress and lift my spirits. Ongoing learning has led me to adaptive yoga, Reiki, laughter therapy and relaxation techniques to refuel both emotionally and physically.

Restoring Flow

Good days and bad days occur equally, but with my skills, I manage my condition as well as I can, and I have

restored a state of flow to my life.

Wellness is an integration of a holistic set of strategies. It can be accessible to everyone, but it is an acquired skill set that takes time, practice, experimentation and effort.

The main focus of my writing is seeking out the details of coping, which is how I understand hope. I am always in search of stories to share with my readers, so they will be encouraged to keep reaching for wellness, skill by skill. ▲

1. Ellis, Albert. (2007). *Overcoming Resistance: A Rational-Emotive Behavior Therapy Integrated Approach*. Springer Publishing.