

Postpolio Syndrome:



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For many, the fear was over. We had beaten the odds. Some of us entered the world of “normal”—or so we thought.

The Second Time Around

(Part 2)

The nightmare of the polio

epidemic of the 1940s and 1950s in America robbed young people of lives and limbs. Now in midlife or senior years, some polio survivors are experiencing new physical symptoms of pain, dramatic energy loss, or debilitating fatigue. Today there is no vaccine rescue, no miracle drug, and no high-priority research to give hope to those with postpolio syndrome (PPS).

Dirty Tricks

Panic subsided in America as science came to the rescue with life-saving vaccines. But there are no preventative measures against the ravages of an old affliction. As in the Ironman Triathlon, you must first qualify in a similar competition. Many of us qualified for round two (PPS) by surviving round one (polio).

Of the 750,000 polio survivors in the U.S., 30% are now facing round two of their childhood curse. The unspoken mantra of most walking survivors is, “Anything but the wheelchair.” To postpone this fate, we dragged our reluctant bodies up flights of stairs or walked blocks or miles to prove we could compete. All the while, we overdrew our account of banked energy. We moved from polio to PPS.

People with PPS live in an exclusive society, a private club that has strict entry requirements:

You must first have had paralytic polio. Thirty to fifty years later, polio is striking again in the form of recurring muscle weakness, intense fatigue, and new joint pain. Although PPS was well documented in *The Polio Paradox* in 2002 by Richard Bruno, healthcare professionals often avoid the label. Some doubt the category as a legitimate entity, while others dismiss PPS as the normal aches and pains of aging. PPS medical “specialists” are rare.

PPS is technically not a disease with a viral or bacterial cause but is the result of the toll taken on an already compromised neurological system. There is no definitive diagnosis but rather a diagnosis by exclusion. In the *Handbook on the Late Effects of Poliomyelitis* (1999), Maynard and Headley cite the common denominators:

- (1) A prior paralytic polio episode
- (2) A mid-life period of relative neurologic stability
- (3) A gradual or sudden onset of new distressing symptoms in mid-life

Deterioration of motor neurons creates overall weakness and crushing fatigue, while a lifetime of compensation results in muscle and joint pain—for many, a daily companion.

We are x-rayed, CAT-scanned, and MRI-ed to find the culprit, but it is the same destroyer we met years before. Our new inconveniences are badly timed as mid-life often brings other nuisances such as divorce, retirement, mortgages, loss of a spouse, and age-related illnesses. The

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[Polio survivor Charlotte now uses a chair lift in order to navigate steps.](#)



The world outside is often an obstacle course for people with postpolio syndrome. Charlotte is thankful for ramped access in many places.

harsh news is, no clinical tests are conclusive, the situation is not reversible, and there are no life-changing medications or Sister Kenny reincarnations. There is no cure!

It's Also About the Heart

Emotional factors can be as significant as physical issues for some survivors. In *A Nearly Normal Life*, Charles Mee reminds us, "No one recovers from a serious onslaught of polio...the damage that has been done is incorporated into their life...." It's almost impossible not to bring emotional trauma into this new phase of life. Multiple operations, hospitalizations, and extensive physical therapy yielded emotional scars from confinement, isolation, separation, and often lack of support from others.

Adult survivors struggle with the frustration of finding answers to energy/fatigue/pain issues. We often get caught in a dead-end medical referral cycle because "who knows about PPS?" Few have had the advantages of professional counseling or support groups. In our family, my polio was never talked about; it was the crippled white elephant in the middle of the room.

My childhood held dark thoughts of fear, anger, and abandonment brought about by hospitalization, social isolation, and family separation. From 1942 to 1945, my comforting father was away fighting Germans across North Africa and Europe. My surgeries required long trips to a medical center in New Orleans during gas-rationed wartime. Families were not allowed to stay overnight in hospital rooms at that time, so I was a 9-year-old alone in a frightening world. I have held anger at well-intended medical professionals who made unrealistic promises: "You'll be running around again before you know it." A harsh memory of mine is being kept alone in a classroom rather than being carried downstairs to the playground to be with other children at recess.

Having a disability represents loss of control and independence that unleashes a flood of emotions I rarely understand. I try to act nice and be cooperative but often hear "bad attitudes" escape my lips. Bitterness is not pretty and occupies a dark corner of a wounded heart. Buried feelings lie in wait to be triggered like land mines of post-traumatic stress disorder (PTSD). I consider myself tough, enduring difficult circumstances and disappointments. However, my emotions are like tissue paper when an incident evokes a submerged memory of isolation or abandonment.

The unpredictability of our old emotions is the real enemy. Stress and anxiety exaggerate the environmental hazards of broken pavement, slippery floor tiles, or stairs without railings. There is no way to foresee the sudden collapse to the ground, no way to predict the inability to get out of bed until noon, no way to see coming the *déjà vu* of panic or rage that embarrasses us.

Mee states, "The mind...lives in a realm where it can take flight." A destructive survival technique is to keep strong feelings at a distance by memory loss, fantasy, or denial. I have strug-

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gled most of my adult life with not wanting to be seen as a disabled person. I avoided association with “one of them,” even eye contact, in public. This burden was lifted in 2008 after crossing the North Sea on an 18-sail Tall Ship. I was part of a crew with disabilities on a 3-masted ship out of London. Regardless of our limitation, we set the sails, pulled galley duty, and did four-hour night watches. I finally embraced being part of this noble community. I was “disabled.”

I am not alone in avoiding reality. Ralph writes, “My greatest regret is that I did not accept my limitations early on.... It has taken almost 20 years for me to begin to feel okay about my disability.”

Finally PPS brings back the ultimate injustice, the biggest dirty trick, anger at the very thing we thought we had beaten and left behind: our polio self.

Polio is no longer a threatening health issue in the United States. Public-awareness posters and fund-raising telethons have been replaced with more current urgent causes. Money for research has become more scarce as the PPS population diminishes due to advancing age. Advocacy groups move forward for continued research and possible new therapies. Although the incidence of polio in America has been zero since 1980, the Centers for Disease Control reported significant increases in documented cases in Tajikistan, India, Nigeria, and Sudan in the last year. The Bill and Melinda Gates Foundation is generously leading the way in global polio eradication. Yet the work is far from over.

Live With It

It’s the old tale of the seeker struggling to the mountain peak for a word of profound wisdom from the guru whose simple utterance is, “Live with it.”

It’s how we live with it that matters. Bruno and Maynard’s works describe what PPS is. Mee’s book and various blogs share how it is to

live with PPS. As polio survivors move into their mature years, age-related conditions create additional problems. Scoliosis, or lateral curvature of the spine, plays havoc with posture and back alignment. The degenerative joint disease of osteoarthritis demands new medication and less mobility. Progressive bone loss of osteoporosis is more frequent in polio survivors over 65.

At some point a diagnosis is almost irrelevant, but the strategy for living well with grace is critical. Once we have grieved the loss of our former mobility, we can move on to constructive life adjustments.



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Polio survivor Joan has experienced the transition from cane to crutches to wheelchair to scooter but still travels and volunteers extensively: “Attitude is everything; do everything you can with whatever abilities you have.”

Joan misses dancing, Hope yearns for pretty shoes, and I fantasize about stiletto high heels!

Personal Survival Plan Checklist

- ___ 1. Architectural adjustments to living space, safety precautions
- ___ 2. Vitamins, supplements, weight control
- ___ 3. Pain management, supervised medications
- ___ 4. Support group, counseling, new interests/hobbies
- ___ 5. Caregivers for personal, cleaning, shopping needs
- ___ 6. Healthcare benefits, city/state services
- ___ 7. Assistive devices from grab bars to voice-activated computers
- ___ 8. ADA guidelines, local transportation
- ___ 9. Low-impact exercise, especially stretching and hydrotherapy
- ___ 10. Adaptive sports

One strategy is taking responsibility for what you can change. Use the checklist above to discover what you may have missed in your personal survival plan. Celebrate if there is one new idea that can make a difference in your quality of life.

Adaptive sports programs offer a wide range of options. SPORTS 'N SPOKES magazine (January 2009) lists 22 adaptive sports, and this number grows annually.

“Ralph” reports that in 2007 he conquered the up and down staircases of China’s Great Wall and recently won second place in a four-mile

seated paddleboard race. My website, disabledadventureshawaii.com, describes water and land activities on the Big Island of Hawaii, as well as resources to cope with sand and ocean access.

In fact, “access” is the operative word for people with mobility issues. Despite assistive devices, the world outside our front door can be an obstacle course. The challenges include parking, transportation, walkways (curbs, ramps, crosswalks), doors, elevators, stairs, and even sand and gravel. The Americans with Disabilities Act (ADA) is leading this battle for a barrier-free environment.

Because neurons do not quickly regenerate, rebuilding strength in damaged muscles has a poor prognosis. However, failing energy levels can be successfully boosted. Professional literature emphasizes adequate night rest, short daytime naps, and frequent breaks from routine—difficult for driven, Type A types like me.

I may use an electric scooter, but I erroneously believe I can carry on at the same high-speed pace as always. I can’t. I get fuzzyheaded and cranky. A 20-minute lie-down turns me into a reasonable human being.

Repeatedly the ten responders to my survey gave this practical advice: “Listen to your body.” Calm down, slow down, lie down! Naturopathic physician Michael Traub, ND, recommends easily available supplements such as CoQ10, creatine, and acetyl-L-carnitine to enhance energy.

But will my mobility be restored? This today is primarily my bright-red, battery-operated scooter that can be stored in the trunk of my equally bright-red VW Beetle. Polio took away my legs—but not my spirit.

In the film *Dead Poet’s Society*, Henry Thoreau’s carpe diem was translated into “live deliberately...live deep, and suck out all the marrow of life.” Said another way, you learn to live in the difficult times, in the spaces free of physical or psychic pain. You learn to live richly in the gift of time given to you.

You run with endurance the race set before you.

Contact: www.disabledadventureshawaii.com. ■