Choosing to Flourish: Living a Powerful Post-Polio Life

by Linda Wheeler Donahue

Polio twisted me, shriveled me, and weakened me. It left me in the rejected pile like a heap of damaged goods. However, I amazingly triumphed over this paralyzing crippler! No, my damaged and dead neurons did not suddenly spring into life. No miraculous surgery corrected my polio deficits. No magical elixir cured me. My astonishing victory of personal growth all took place in my mind.

My problems with body image began when I was a little girl. I remember a distinct "look" from churchgoers after the Sunday service. That look was sympathy laden. It conveyed to my parents: "How sad that you have a crippled little girl." I experienced variations of that look all through childhood and into my teen years. We, polio survivors, were stared at, looked upon with pity, ignored as though we were invisible, left out of the popular circle, and in some cases, teased and tormented. It did not take us long to make the connection between our bout with polio and social rejection.

We had to develop our own survival mechanisms. Some of us tried to cope by becoming "passers;" that is, trying to pass as able-bodied. We hid our disability as best we could. One polio survivor, who has paralysis in her arms and shoulders, told me of going to great lengths to manipulate her elementary schoolroom surroundings. She created situations that would assure she would be the last pupil remaining in the classroom. She went to all this trouble because she did not want her peers to see her struggle to put on her coat at the end of the school day. I did something similar. I sat on a bench in front of the public library and tucked my atrophied legs under the bench, pretending to be as whole and adorable as Sandra Dee! Creating a false identity comes at a great emotional expense.

Even as adults, we polio survivors realize that much of the way we view ourselves, and the world around us, is the result of negative messages ingrained in our psyche over the years. The real crippler, for me, is not as much the polio virus, as the toxic signals I assimilated about my flawed body. I developed low self-esteem from the cumulative affect of thousands of recurring messages telling me that I was not acceptable.

Now I want to tell you how I banished those old malignant messages and replaced them with positive, self-affirming thoughts. It involves me telling you something I am not proud of. All of my life growing up and as a young adult, I avoided people with disabilities. I did not want to acknowledge that I was, indeed, part of that branded population. I am ashamed to say I did not want to lower myself by associating with people with even more stigmatized disabilities. Well, the stroke of irony is this: not until I embraced other individuals with disabilities, could I heal myself.

In 1985, I experienced a life-changing event that led me down a new path. I signed up to attend a conference in Hartford, Connecticut geared to women with disabilities. One image that remains with me even today is the shocking sight of all sorts of mobility devices everywhere in the hotel lobby. There were women in manual chairs, powerchairs, on crutches, on ventilators, pushing walkers, and wielding canes. My emotions went in two opposite directions. One feeling was: "I'm home at last," contrasted with the reverse feeling: "Oh no! What am $\underline{\textbf{\textit{I}}}$ doing here?"

The next image that warms my heart to recall is seeing Shelley Teed for the first time. Here was a strikingly attractive, thirty-something woman with bright smiling eyes and a mass of curly hair going this way and that. Born with spina bifida, she skillfully used a neon bright powerchair. Her tiny legs and feet protruded straight in front of her, and most telling of all, she dressed them in fuzzy **RED** socks.

Her commanding voice had a theatrical tenor as she projected instructions to various people on how to arrange the room, where to line up the presenters, etc. Shelley was a take-charge person, and what amazed me most was how comfortable she was in her own skin! She whisked around the conference rooms with utter confidence.

I was enthralled. I met my "roll" model for sure. I wanted to be as enlightened and as freed as Shelley Teed. Over the next years, Shelley and I became fast friends. I often think that if I had only met someone like Shelley in my formative years, my self-image may have been very different. Growing up, I never knew anyone who had polio, in fact I never knew any other disabled kids. All I had to inform my psychological struggle were the false messages of Madison Avenue. A "Shelley" in my life at that time, would have gone a long way toward eclipsing the shallow ideals put forth by the mainstream media.

Inspired by Shelley and the other dynamic disabled women at the conference, I decided to become an activist for disability rights. I did a complete 180-degree turn-about, from evading people with disabilities to seeking them out! I found that when I united with other people with disabilities, enduring bonds of friendship strengthened me. In addition, becoming a disability advocate is making the world a better place. When we join forces with other individuals with disabilities, we affirm each other; we gain strength, comfort, power, and healing. Where do you find others with disabilities? Join a local advocacy group; share your gifts at your nearest independent living center; volunteer at a rehabilitation hospital. By joining the disability culture, you will find you are free as never before to be the real you.

When I bonded with other people with disabilities, I learned to reject a lifetime of negative inner self-talk as false and shallow. I opened myself to new, positive thought patterns and began to redefine who I am and what I stand for. I realized that consumerist-driven, stereotypical images of "attractive" are oppressive lies. I bathed in the healing notion that I am OK just as I am, complete with atrophied legs and polio weakened body. When you accept yourself, you project confidence. Society respects you because self-acceptance is stunningly attractive, and something able-bodied people are unaccustomed to seeing in someone who is disabled. Other peoples' positive responses to you will help you shed a burden you may have carried for decades.

Let me give you an example of this newfound acceptance with my post office story. As a person with an obvious disability, I can never be anonymous, invisible. I am always conspicuous, always the center of attention. Therefore, it was with a certain amount of dread one day that I loaded some packages in my van for a trip to the local post office. Why the dread? Because I get tired of being Exhibit A. Because I do not always feel like being the world's disability educator to little children. Because I sometimes just want to blend in.

I pulled into the handicap-parking slot, lowered my ramp, and disembarked. I am sure I was quite an interesting sight with my scooter platform loaded with packages. Well, I decided to make this a positive experience! I held my head up, forced a little smile, and drove into the

building. All eyes were on me, or so it always seems. This day, I know I gave an image of self-confidence. The postal employees were very pleasant and welcoming and I left the post office with a happy feeling. Nothing was different about the building, about the workers, about the way I drove my scooter . . . no, the thing that was different was something within me, it was my attitude. I felt approval; I even felt admired. I know I can never really be a nameless, faceless person in a crowd. Therefore, I have decided to make the best of my celebrity!

We polio survivors grew up being told to always be brave, be good soldiers, and "never *ever* feel sorry for yourself." Moreover, being the good soldiers that we were, we obeyed. Now I am here to respectfully disagree with that advice. I think it is perfectly OK to grieve your disability, to mourn your losses; in fact, it will help free your spirit.

Many of us were polio guinea pigs when we were children. We had to display our bodies to groups of male doctors in the interest of "medical education" all without our consent. We may have been asked to strip, walk back and forth in front of complete strangers, and subject our limbs to manual manipulation to determine flexibility. Often we were treated as inanimate objects and talked about as though we were not in the room.

I have begun an initiative with The Polio Outreach of Connecticut in which I invite members to "tell your polio story." This is a kind of truth telling exercise that I feel will liberate and bond. There are two almost opposite benefits from having people share their disability stories. The first is that many people felt they alone had these feelings and struggles. It was a tremendously positive, affirming thing to hear others express similar feelings. When you address hurts that you never fully acknowledged before, you transform inner realities.

When you tell your polio story, you get a chance to grieve your losses. What was that word? Grieve? We are not supposed to feel sorry for ourselves! However, grieving is necessary and healthy. This is a neglected emotional process; often our feelings are "stuffed" because ablebodied folks among our family and friends do not want to hear that we suffer, that we have losses, that our life is often difficult and painful. I encourage you to grieve your loss as healthy and natural and do not feel you must present a false front of "my disability is no big deal" or "it doesn't bother me."

Relive the all-important teenage years and confront the pain. Take time to confide in a close friend or try writing journal entries about your teen experiences. This is a way of allowing the memory to surface in your psyche. Then in the light of day, you can embrace what is good about the memory and eradicate what is hurtful. A profound release from heartache happens when you give way to grief. You face it, process it, discard it, and replace it.

In counseling sessions with people with disabilities, we deal a lot with issues of sorrow over loss of body function. In post-polio syndrome, these losses are gradual over time. Our PPS trail is not a clearly defined path with road signs along the way. It is largely leading us to an unknown destination, and that unknown is anxiety producing.

The great thinkers and philosophers tell us that happiness is a choice; we can choose to be happy. I am here to tell you that I know that to be true! All those old negative messages can be erased and taped over with good, strong, positive transmissions. In psychological terms, this process is called cognitive restructuring. I call it choosing to flourish.

Living a powerful post-polio life means you are thankful for simple things. You take comfort in ordinary events, often taken for granted, that millions of people upon the earth can only dream about: a full refrigerator; clean running water; a soft, warm bed; a long hot shower. When you choose to flourish, you will be released from fear, worry, and self-doubt. Like me that day at the post office, you can decide to start every day with optimism. When you rejoice in each new day, you empty your heart of pain and your mind of worry. You choose to flourish.

Did life with polio weaken your sense of worth along with your muscles? You can improve your level of self-esteem at any stage in life. One way to gain confidence is by simply practicing confidence. Visualize yourself as a proud, confident person. If you act self-assured, you will soon *become* self-assured. Choose to flourish.

An important way to live your own powerful post-polio life is by adopting the habits of a healthy lifestyle: good nutrition, helping others, laughing out loud every day, taking time with your grooming, and surrounding yourself with positive people . . . all are immensely important. Live a life of high aesthetics. Invite music, books, gardening, art, travel, color, and whimsy into your life. Choose to flourish.

A secret of life is not what happens to you, but what you do with what happens to you. All the resources you need to start living life to the fullest are right there within you. You make hundreds of decisions every day . . . choices abound in your life. You can choose to be bitter and angry or happy and filled with a love of life. If you fill your life with goodness and love of others, you chase away the fog of fear and self-doubt. Happiness is a choice; choose to flourish!

When I opened this essay, I said that polio twisted me, shriveled me, and weakened me. These statements were all true, but I was describing what polio did to my self-confidence. I learned that by changing my mind I could embrace my life with joy and acceptance. I could choose to flourish . . . and so can you.



About the Author

Linda Wheeler Donahue, Professor Emeritus of Humanities, is a polio survivor, writer, and speaker.

She is President of *The Polio Outreach of Connecticut* and is a frequent presenter at conferences, focusing on the social/emotional complexities of disability. Choosing to flourish remains her ongoing objective.

Linda's essays on subjects of disability dignity, positive thinking, and living with the aftermath of polio have been published worldwide. She welcomes feedback and can be reached at LinOnnLine@aol.com.