

As for retirement, I am no different than most men when it comes to their identity. I like to think I was a way-above-average trial attorney with many hard fought battles in the win column. My identity was shaped by my profession, and giving up my profession was in many ways giving up my identity. I was simply too young to retire. It took me more than a year and considerable soul searching before I could become comfortable enough with the reality that my disability had effected a life choice over which I had no control, that I was able to give up work as a trial lawyer. After eight years, I have reshaped my life, I rest more, use my wheelchair more, and feel better for it. I have developed a consulting practice that takes as much time as I care to give, and that suits me fine.

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## **LIFE IN THE RETIREMENT LANE: OBSERVATIONS FROM A ROOKIE**

*Sunny Roller*

I just retired five months ago. But really I didn't. Or did I? Actually, I never really understood this thing called retirement until I tried it, nor am I completely sure how to make it work well for me. So, I search and I question as I transition into this new time of life, and I have found that retirement for me must be clarified almost on a daily basis.

How do I define who I am now? The first month after saying farewell to all of my work colleagues and my adapted computer station at the office, life was weird. I was stressed and quietly out of sorts. Edgy. I had never done retirement before and carried around a strange sense of confusion. But then I came to realize that this is a time to drive my own retirement car, so to speak. I can choose an acceptable make and model, the speed and direction, and I can select every day's destination for myself.

The *American Heritage*® Dictionary defines retirement as "withdrawal from one's occupation, business, or office; withdrawal into privacy or seclusion." Contrary to the emphasis on isolation, I have not

withdrawn from my occupation as a post-polio researcher, educator, and writer, nor have I pulled out into seclusion. I continue to work from my home office and happily see more of my friends and family than ever. So it goes once again, as has often happened in life as a polio survivor, I am creating my own life role descriptions, ignoring the norm and any false societal assumptions, and then helping the people around me understand and share my self-determined personal definitions.

As a woman who uses a C-Pap machine and hand splints at night, crutches, leg braces, a corset, a scooter, and a manual wheelchair and who is experiencing the late effects of polio, I am now retired at the age of 58—earlier than my non-disabled friends. But as I continue to work on a captivating research project from my home office, I sure don't feel like the proverbial "cow put out to pasture." Rather, I feel relieved of the accustomed daily drudgery of mentally, physically, and forcefully having to compel my treks to the university office every morning. Before, I was fatigued—especially in the mornings. Because my new role is delightfully more flexible and therefore disability-friendly, I know that I have transitioned from "life in the fast lane" to "life in the retirement lane." Now I am able to set my own pace and have time to do so many of the interesting and nourishing things I had set aside to maintain a full-time job. I am busier and happier than I have been in years and am even feeling healthier than a year ago—both physically and fiscally.

Knowing that I may indeed still be in retirement's "honeymoon" stage after only a few months, I am concerned about what lies ahead, however. How do I make retirement work for me through the duration of the journey? In the years ahead, I want this to be mostly a pleasure trip as it is right now, not a sinister odyssey fraught with suffering and painful restriction. I continue my search for a new self-definition.

Recently, I started my quest for a relevant retirement education by "kitchen table-chatting" with polio survivors who are retired and admired by their post-polio peer group. I asked them to share some of their respective viewpoints. They don't deny that life could be difficult, but exude an appealing *joie de vivre*. One of them emphasized from his electric wheelchair that people should "Always, always, always keep a positive attitude about life." He said to believe that things will work out no matter what, do everything you can to stay hopeful, and pursue a variety of hobbies and keep loved ones very close. Another post-polio leader said that being an advocate for other polio survivors gives her a

sense of fulfillment and satisfaction. She agreed that when she retired, she moved from a position of contending with raising children, working full time, and caring for those who were ill, to a newfound time of real contentment—her present-day retirement years. A part-time walker, part-time scooter-user, she is busy, happy, and making this time in later life work well for her. Another woman with post-polio told me that over the years she had overcome so much adversity that she feared almost nothing today. In fact, when a couple of thugs tried to mug her in a parking lot, she screamed and beat them off with her two Loftstrand crutches until passersby came to her rescue.

As my conversations evolved, I came to realize that there are several key topic areas to consider when contemplating and creating a happy retirement as a polio survivor. These are: attitude, physical health, fiscal health, retirement activities, housing and transportation accommodations, and relationships. What I know so far is that these are interlaced and interactive.

### *Attitude*

Some say “attitude drives behavior.” Others say “attitude is more important than fact.” All I know for myself is that my attitude is a choice—I am driving my attitude auto. I seem to do better when I focus on the half-full glass, even if everyone around me says it “sure looks half empty,” so I take this personal truth into my retirement years too. A certain amount of faith in myself and in the goodness of the universe around me is absolutely required as I enter this unknown territory. It is a positive expectation about my late life years in the midst of doubt, fear, and annoying cowardice. It is not delusional faith. It is grounded in reality and hope at the same time. It is the confidence that I can look squarely at whatever comes along or might come along and either make proactive plans or make reactive adjustments.

I know how to face the facts, ask questions, seek information, and find help and spiritual strength by tapping into the many resources around me. It is also the knowledge that this focus on adaptation will be a never-ending process until the end of my life. A recent article in *U.S. News and World Report* states that if people are forced into retirement due to medical reasons or a business layoff, and unable to choose their retirement dates, they could be much less happy for the next 10 years unless they quickly take control and do something to re-establish their sense of autonomy. One might get a new part-time job, begin volunteer

work, rather than sit home and mope. I agree that happiness comes from staying productive in whatever way one is able and then ultimately choosing when to retire from that work and move on.

### *Physical Health*

Attitude can affect physical health, which is probably the most fundamental factor for happiness in retirement. In my youth, retirement used to call up thoughts of monotony in a rocking chair that creaked in the center of my grandmother’s silent 1920s house, darkened and lined with knick-knacks. But so far for me, not so! I am joyfully decorating a new condo—sewing, cooking new dishes, staining shelves, working in the garden—and I have more time now to attend to my health than ever before. I have time to create my own personal and holistic post-polio wellness program. Since physical and mental exercise is more important than ever, accompanied by heart healthy nutrition, in some desperation, I joined Weight Watchers with a friend (thank God for friends!) and regularly go to the county recreation center to work out on the accessible NuStep machine with another friend.

When I first retired, I was so discouraged. Having gained weight I didn’t know how to take it off. I was also experiencing increasing muscle and joint pain especially in my back and hips after standing and walking. Losing 15 pounds so far has helped. And I want to lose more in the months ahead. As a polio survivor, I know from heart-wrenching past experience what loss of function is and I am now fiercely committed to being vigilant about the prevention of potential new losses when it comes to use of my lungs, arms, hands, legs, and shoulders. Denial in any form does not work at this stage in my post-polio life.

I want to identify and do whatever I can to ward off new decline and disease. It’s important to find a sound post-polio physician, even if one has to travel miles for an evaluation. Regular primary care physician visits and routine tests such as colonoscopies and mammograms are important. I also want to prevent injury. Proactive visits to brace makers and wheelchair seating technicians to ward off any shocking and perhaps injurious breakdowns are also important to schedule. It feels good to have the new freedom to go to the dentist and eye doctor mid-week instead of on Saturdays. Restorative sessions with a massage therapist have helped me with flexibility. For an extra \$15.00 he will come to my home.

### *Fiscal Health*

The same holds true for my fiscal health in retirement, which affects and is affected by my attitude and physical health. Right now, I am fiscally challenged because I have not been assertive when it comes to financially planning for this time in my life. If I had been wiser and more conscientious, I would have started planning decades ago. I would have set a fiscal goal for retirement, like a million dollars, and worked toward that goal. But I didn't. When I was younger, I didn't learn about setting a retirement lifestyle goal. I should have thought about the extra personal services I as a person with a disability would need to purchase as I grew older living in my home, such as a housekeeper, personal care attendant, and handyman, for example. Nor did I study 403(b)s, 401(k)s, 457s, IRAs, Roths, CDs, mutual funds, money markets, bonds, or charitable trusts. This is scary and it is not recommended.

Right now I need to step out of my denial moat—fast—and make new plans for the upcoming years. To supplement my small employee retirement pension, what are other possible sources of income during my retirement years? They might include salary from ongoing employment—part-time or full-time—(perhaps Vocational Rehabilitation could help with planning and new job training), any fiscal vehicle to save on taxes, renting a room in my house to a student, perhaps an inheritance, a reverse mortgage, Social Security Disability Income, or private disability insurance compensation. Websites such as those offered by Vanguard, Fidelity, or Morningstar can offer additional information, and individuals in the international polio network are well versed in these issues.

### *Retirement Activities*

Being a “retirement rookie,” I am still not quite sure what I will want to do in the months and years ahead, but I will want to stay active and choose to participate in only the activities I enjoy and judge to be valuable. I still want to maintain a strong sense of purpose and I want my late life years to be years of continued personal growth and meaning. I want to matter to other people more than ever and enjoy deepened relationships with those I love. I believe that my physical and fiscal health will slow or accelerate these activities.

So far, so good. Besides my current job with its related committee and board work, my wellness activities, and household tasks, I have vol-

unteered to be a spiritual counselor in my church. I am also enjoying handicrafts and socializing with friends and family. Movies, meals, and musical concerts keep us busy together. And that is enough! As polio survivors well know, we need to pace ourselves and set daily limits in order to enjoy what we can do. This is an ongoing challenge into retirement, because I have found that this stage of life can be even more jam-packed than before—if we are not judicious.

### *Housing and Transportation Accommodations*

Shelter and transportation are critical issues for those of us who are in retirement. We need accessible homes and means of transport in order to live comfortably with the freedom to move about the community. Selection of a geographical area of the country in which to live may become an important issue for some of us. We need the convenient support of medical and community resources in order to flourish. A temperate climate that is free of dangerous ice and snow weighs in for many as an important consideration. The location of our family and friend support network is a huge factor. Once we have chosen a community, are there accessible or adaptable homes available in which to live? It may be that our homes will need to attract our family and friends more than ever in future years if we acquire greater disability and cannot get into their houses as easily. Therefore I ask myself, “Is my home in retirement welcoming and attractive as well as accessible?”

As we age, moving from place to place may become more stressful. How will we get around if we lose some vision and can no longer drive, for example? What does the community offer in terms of affordable and accessible transportation? As a manual wheelchair user when I take a trip, I have been advised to buy a travel scooter to relieve my aging friends and family members of the necessity to push me up hills and over prolonged distances when we go out together. It just came in the mail today. This little scooter should run well in the retirement lane.

### *Relationships*

Because I worked strenuously to survive in the professional world for the past decades and often with insular social blinders on, I am at a stage in my life where I want my relationships to become the highest priority. Our loved ones will die. Our friends will move away or pass away as our ages advance. We will become experts on grieving. I never

want to regret not having spent enough time with them or saying all that I wanted to them. Never. I want to hold people close to my heart and have them close to me physically now more than ever. I want my compassion level to rise and my ability to reach out and nurture those who come through my front door grow and become a new force.

Life in the retirement lane, now that I think about it, really does hold many opportunities for growth, contribution, and fulfillment. But I must be willing to drive my own retirement car for the entire distance—until the end of the road. It is wonderful knowing that I can choose an acceptable make and model, the speed and direction, and I can select every day's destination for myself. I cannot be afraid of getting lost because the lost can always be found again. It will be a never-ending series of adjustments.

I'm ready.

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## Appendix B: Glossary

### —A—

**activities of daily living (ADL):** routine activities a person does every day, such as standing, sitting, walking, eating, bathing, and grooming

**acute phase (of an illness):** the early or initial stage of an illness

**adaptive equipment:** equipment that helps a person become as independent and functional as possible

**amyotrophic lateral sclerosis (Lou Gehrig=s Disease):** a degenerative disease of unknown cause which results in spasticity and fairly rapid loss of strength and bowel and bladder function.

**ambulation:** walking

**Americans with Disabilities Act (ADA) of 1990:** a civil rights act protecting persons with disabilities against discrimination in the workplace, housing, transportation, and other aspects of life

**ankle-foot-orthosis (AFO):** a short leg brace that supports the foot and ankle in proper alignment, allowing the heel to strike the ground first

**anterior horn:** a cluster of nerve cell bodies located in the front or anterior portion of the spinal cord that form the shape of a horn (when the spinal cord is cut and one is looking down on it from above)

**anterior horn cell:** a motor nerve cell whose body is located in the front or anterior part of the spinal cord; these cells typically provide stimulation to muscle cells in the limbs that contract

**anterior horn cell disease:** a disease or disorder that affects the anterior horn cells; the virus that causes poliomyelitis attacks the anterior horn cells, thus, paralytic polio is an example of an anterior horn cell disease (AHCD)

**assistive equipment (assistive technology):** any equipment or device, such as a wheelchair, braces, walker, or speech aids that help a person to become more independent, function better, or perform activities of daily living or mobility

**atelectasis:** a collapse of the lung

**atrophy, muscle:** shrinkage of the muscle.

**attenuated virus:** weakened virus. This is used in the Sabin Vaccine.

**autonomic nervous system:** The autonomic nervous system has two divisions: (1) the sympathetic nervous system that accelerates the heart