

Keeping America Sick

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At 38, the life I knew and expected for myself ended. In the span of two weeks, I suffered five falls, resulting in bloodied knees, a bruised hip, a bruised wrist and a fractured ankle, leaving me homebound and crawling, unable to bear weight on either leg. Up until this point in time, I managed on my own, living a physically limited but functional life, but now I could no longer ward off the progressive muscle weakening effects of post-polio syndrome. I arrived at a frightening turning point in my life – I was unable to control my gait without assistance.

With dread, I sought help. What generated a greater sense of powerlessness than coming to grips with dead and weakening muscles was the helpless position of being a patient in our health care system.

In my initial consultation, the doctor hesitantly took my history, telling me of a friend she knew who had little luck with this condition. “Well, um ... but ... umm ... we don’t really treat post-polio patients at this office, but we’ll see how far we get.” I did not understand what this meant.

My next call was to a doctor to inquire about a leg brace consultation to stabilize my mobility difficulties. “In this day and age we don’t brace post-polio patients,” he stated. I was confused.

The real shocker came during an initial physical therapy visit, “You’re the typical type A polio patient; you want to do everything!” She misread my anxiety. Crawling was a low point I did not want to go back to. I was starting to imagine my forties as a markedly disabled person. I was simply scared.

Without warning, I was forced to revisit my illness after years of managing on my own. I kept thinking to myself, “I am motivated, insured and informed; someone should be able to

take an interest in working with me.” I was wrong. I cycled through several doctors who were under-ambitious, and I learned quickly that my illness had a reputation, bringing with it a transparent bumper sticker plastered to my forehead:

**CHRONIC – NO IMPROVEMENT
EXPECTED – LOW REIMBURSEMENT**

Looking back, I don’t think these health care professionals were incompetent, but rather influenced by a phenomenon I call *insurance conditioning*. Current health care reimbursement structures in this country have created a paradoxical situation, dictating its own guidelines, often inconsistent with the principles of health management. As a result, most health care settings operate like factories. Acute care gets reimbursement, while chronic care is often ignored or minimized.

As I started doing my own research on reimbursement for chronic conditions, I learned that fellow patients within paralytic spectrum disorders such as stroke, spinal cord injury, multiple sclerosis and cerebral palsy struggle to get reimbursement for illness management treatment options – physical therapy, speech therapy, occupational therapy and updated mobility equipment.

In my case, after persistent searching, I eventually found a caring team of doctors. I took a partial medical leave from my job and started the difficult process of adapting to my new mobility limitations. I entered outpatient rehabilitation and got fitted for leg braces and assistive devices. I underwent gait training and learned muscle preservation exercises. I also learned lifestyle strategies to ration out my muscle strength throughout the day to minimize the risk of further disability. Most importantly, I gained access to current technology, aiding me in remaining an independent person. I am learning how to drive with my hands and type with my voice. Learning how to get up and sit down is the most invaluable intervention; it keeps me independent for daily activities like using the bathroom.

The interventions I received are specific to my mobility impairments, but interestingly, my treatment parallels what I know about counseling chronically ill individuals in my role as a cognitive behavioral therapist. Disease management training, which most chronic conditions require, is an ongoing learning curve over the life span. In reimbursement language, this is known as *preventive* or *maintenance* care. The acute care reimbursement model does not allow for intermittent intervention for the long term treatment needs of the chronically ill – neither do the ambiguous promises of universal health care.

Having access to active rehabilitative care has offered me more than the polarizing choices of health care economics – show up when you have an acute need, or stay home and collect disability. The point is, from a cost/benefit perspective, intermittent inter-

vention keeps me out of the hospital and allows me to continue to be a contributing member of society.

As a health care professional, I know the challenges of managing difficult patient loads, providing emotional comfort session after session. What the economic discourse in this country does not account for are the intangible ingredients of health maintenance and recovery: human regard and imparting the capacity for self care. Self care is a skill most often learned when modeled by another. Patients cannot do it alone.

I have medically stabilized, but I am left with a mix of hope and fear. The questions I grapple with feel like the beginning of an end. How long will I be independent? How long will my muscles last? What kind of care will I need as an aging person with a disability? Will I find a disability policy that will not penalize me for my pre-existing condition? In addition, I am also faced with the enormous challenge of allotting most of my adult income towards planning for health care costs.

The late John Belluso, a playwright who himself suffered from a chronic illness, once commented on disability status: “It is the one minority class in which anyone can become a member of at any time.” Every American inevitably faces the chasm between an active mind and a failing body. For chronic conditions, narrow media portrayals of individual heroics are such a disservice. A more accurate picture is success due to individual will, community support and access to lifetime care. It is estimated that close to 48 million Americans live

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She contracted polio in India at 9 months.

with some form of disability. With growing populations of need around the USA – aging baby boomers, returning veterans and the elderly – these issues will not subside.

This coming election year will be full of health care rhetoric. As long as the health care system continues to be hijacked by a treatment-restrictive economic structure, chronically ill individuals will continue through the vicious cycle from acute need, to band-aid care, to the next acute need. For many chronically ill Americans,

managing an illness is a full time job with no endpoint. And if money is the bottom line, does the acute care treatment framework actually cut costs?

I may have to transition to a wheelchair someday, but for the moment, having had access to skillful rehabilitation, illness-specific education, assistive devices and community resources has led me to a restorative realization.

My illness may be my fate, but it need not be my story. ▲

Letter to the Editor from Jeanne M. Carlock

After reading the recent article about assistance dogs by Dr. Mary Lee Nitschke, I'd like to relate some of my own experiences. In 2006, I investigated getting a dog through an agency that trains service dogs. Some agencies offered to train and place a dog and to train the recipient at no cost. Others required the recipient to help in fundraising. However, with all of them, there was quite a waiting list, from two to four years or more.

Fortunately, I have a wonderful friend, experienced in the training of guide dogs for blind people, who offered to train a dog for me. With her expert guidance, I purchased a golden retriever puppy. Choosing a puppy that was neither too passive nor too aggressive was a challenge, even among those of this breed who are known for being excellent assistance dogs. My dog, Lucy, is now one year old. She has lived most of her time at my friend's home, gradually spending several days at a time at my house. We have training sessions once or twice a week. This will go on for most of the next year.

The article by Dr. Nitschke implies that training an assistance dog is easy for the person with a disability. After watching my friend work with Lucy, I know I could never train a dog. It is very physically demanding. Also, for me there were several questions to be answered: Can I commit time daily to reinforce dog training? Will my husband take on extra duties like "poop scooping" and playing with a large dog? Can I afford all the expenses of owning a dog? And, can we adapt to the lifestyle changes in our home?

I do not think that every breed of dog can become a service dog as was stated in the article. Dogs must like to work, want to please people, be fairly strong, and enjoy retrieving things. For these reasons, Labrador and golden retrievers are often used. ▲