

## **WHEN YOUR LIFE INCLUDES A WHEELCHAIR**

### **Chapter 1 ILLNESS AND YOUR RELATIONSHIPS**

At the time I became ill, I was health & fitness editor at the Los Angeles Times Syndicate. Oddly enough, I spent my days immersed in reading material about fitness, exercise, nutrition and general body care, and going to lunch or attending meetings with fitness leaders like Bruce Jenner, Nathan Pritikin, and Norman Cousins. Yet I was completely unprepared when faced with the onset of a problem that left me unable to walk properly, much less participate in horseback riding and competitive show jumping (which I did two to three times each week), jogging, dancing, or any other physically rewarding activity.

Not surprisingly, my pre-illness lifestyle was a hectic, high-stress one. I went through a heartbreaking divorce. I had a short-tempered boss who made sure I went home in tears more often than not. And for several months before my walking problems began, my appetite and sleeping patterns were reduced to the bare minimum. In the midst of all the chaos, I juggled two active sons and a wide circle of friends. In retrospect, it's obvious that I spent far too much time burning my candle at both ends. No wonder my health suffered. Stress can and does exacerbate symptoms in a disease like multiple sclerosis.

And thus began a saga that has taught me enough, my friends joke, to earn my own medical degree. The first neurologist I saw spent 15 minutes testing my reflexes and watching me try to walk steadily before abruptly telling me I had multiple sclerosis and curtly suggesting that I go home and get my affairs in order. After that, I saw an internist who ran a day's worth of tests on me and came to the conclusion that I was an extraordinarily healthy young woman. He said he thought I might have a viral infection, but couldn't confirm that without a spinal tap. I decided that if I were as healthy as he said I was, then my body would surely regain its equilibrium without the added trauma of a spinal puncture and a hospital stay. I was finally learning that, despite a lifetime of robust health, even a self-styled, super-efficient, hyper-productive, adrenalin-propelled Ms. Type A had limits on how much stress a body could bear.

Not too long ago, after years of fighting my physical condition, and hoping, praying and struggling for a "normal life," I realized that regardless of my slow and wobbly penmanship, I had bottled up words that needed to be released. I was no longer able to live with hidden fears and swallowed tears so dangerously close to the surface. Writing three earlier books had taught me that struggling to share my thoughts and feelings with others is the most effective way of clarifying and accepting them for myself. Torturing myself with life's pre- and post-disability differences, I should have been reminded of Ecclesiastes 7:10: Do not ask why the old days were better than the present; for that is a foolish question.

As a result, the challenges of my severely restricted life are still present, but they no longer make my life a senseless struggle or an unrewarding existence. As I look back on the process of acknowledging my disability, I see that I have been taught lessons I would otherwise have avoided.

I have gained a vantage point from which I can hear and see my life more clearly. The process of becoming disabled has, blessedly, had its share of positive aspects. I've been forced to slow down and enjoy life, rather than continue on what now, in retrospect, seems like an annoying pursuit of perfection. Lack of mobility has forced me to accept that it is okay to just be me, without accolades or accomplishments. Illness has forced me to enjoy the things I can do and postpone the things I cannot. It has acted like a diluting agent on my perpetual impatience. No longer do I fume if kept waiting or put on hold. Just being part of our remarkable, wonderful world

is a gift, so I don't have to insist that life always be orchestrated the way I think it should be played. In some ways, illness has made me calmer, slightly more accepting, hopefully more tolerant and decidedly more appreciative than before.

Illness has also taught me that few things are as psychologically devastating as not having your own mobility. When I hear people complain about trivialities, for example a cold sore or an incorrectly cooked restaurant entrée, I wonder what they would think if they lost their ability to walk. But then I remember that there are many forms of discomfort, and not all of them are as obvious as mine.

My struggle has forced me to see that a strong body is a God-given gift, not merely an unquestioned birthright. This challenging experience has also taught me that ill health can open the door to surprising gifts as well as increased awareness and understanding. Yet I still include in my secret wishes Isaiah's message: Brace the arms that are limp, steady the knees that give way.

## **Chapter 2: YOUR RELATIONSHIP WITH YOURSELF**

Although a wheelchair user soon learns that established relationships with friends, family, and colleagues irrevocably change, the most important transformation is the relationship you have with yourself when you become disabled. From the vantage point of being in a wheelchair for almost 15 years, it seems there are two choices: acceptance with protest, or acceptance with resignation. Without knowing precisely why, I chose the former.

For most of us, self-image boils down to how we view ourselves under emotional, financial or physical duress. Some people wholeheartedly embrace a challenging lifestyle. And in many ways this makes sense. In today's enlightened world there are endless mechanical, structural, and personal aides to streamline an otherwise compromised lifestyle. This makes it particularly easy to focus and think of yourself as disabled, in the same way a diploma or a certificate changes someone's identity into that of a college graduate, a CPA, or an attorney.

When the arrival of a disability is sudden and severe, the overnight transition to an identity associated with that disability is inescapable. People with spinal cord injuries work long and hard to gain small and slow (very slow) improvements. In situations like mine, the process is an elongated one of very slow and possibly inevitable, decline. The good news is that there is plenty of time to become accustomed to physical losses. The bad news is that it requires strength to accept and adapt without giving up. People struggling with a chronic progressive illness like multiple sclerosis (MS), amyotrophic lateral sclerosis (ALS), or Parkinson's disease learn to adapt gradually and to restructure their self-image incrementally. Those with cerebral palsy or other lifelong conditions that begin in childhood have relatively stable physical challenges.

Re-establishing a healthy relationship with yourself after life has taken a dramatic downturn is no easy task. There are a few things to keep in mind when restructuring your inner life. Perhaps the most helpful realignment is to acknowledge and accept that, after becoming disabled, your identity can no longer rest solely upon what you do. By definition, a disability limits or curtails one's scope of activity, and the resulting loss of "accomplishment" means the ego-driven self-image automatically undergoes a major downshift. But just because you can no longer swim, skydive, play the piano or run a marathon does not mean that you are a less worthy person. It simply means that you are a less physically active person. And that's a huge distinction.

It is important to remember that doing whatever it takes to maintain your self-esteem and positive self-image after a period of illness or diminished health is not only worthwhile, it's essential. A wise friend has reminded me on countless occasions that instead of conducting a continual self-evaluation regarding what I can or cannot do physically, my time would be better spent compiling a mental inventory of character assets. This exercise is a guaranteed mood lifter. Instead of lamenting over the fact that you can't go dancing on a Friday night, why not spend the same block of time doing something that doesn't challenge you physically, like getting together with friends? And if you find yourself edging closer to sorrow and self-pity, do something nice for someone else. A little introspection (as in "What can I do to be of service?") will not only improve your spirits, it will have a positive effect on other people in your life. After all, it's far more important for you to be a thoughtful, non-judgmental, cheerful and pro-actively compassionate person, to exercise your spiritual muscles, than to be buff, blessed with a great backhand, or merely be physically active and athletically fit.

Regardless of your level of disability, try to think of yourself as an emotional or spiritual athlete rather than a physical one. If you keep track of the positive things that you do each day on an inner level, rather than concentrating on your body's achievements, you'll soon discover a growing sense of accomplishment and peace.

Back when this country was much younger, Thoreau reminded Americans that it was important to deal with our inner calm instead of with the hustle and bustle of an externally focused, achievement-oriented lifestyle. In his words, "It's what a man thinks of himself that really determines his fate." One of the best ways to improve your relationship with yourself once your body has limited your physical abilities, is to pay less attention to the achievements and opinions of others.

After a disability, new friendships are often made and old ones fall away simply because sometimes it can be hard to see a "different self" reflected in others' eyes. But if your own vision of yourself is strong and clear, it won't matter quite so much what other people may or may not think about you or how they view your changed circumstances. By the time we are adults, we should be able to make choices based on what we believe is best for us, which takes into account our own physical, spiritual and emotional priorities, rather than living in a state of perpetual anxiety over the opinions of family, friends, colleagues or strangers.

It is without a doubt essential to maintain as good a relationship as possible with yourself after your life circumstances have been drastically altered. As long as you remain confident in your own skin and continue to be your own biggest fan, negative external circumstances will have far less power to upset your emotional equilibrium. And a healthy self-esteem, even if it's trapped in an unhealthy body, is sometimes only a prayer away: 2 Corinthians 4:16 That is why we never give up. Though our outward humanity is in decay, our inner strength in the Lord is growing every day.