

Transitioning to a Wheelchair: An Exploration of Our Fundamental Fears

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When actor Christopher Reeve sustained his spinal cord injury in a horse riding accident, he went immediately from Superman to Man in Wheelchair. In contrast, some polio survivors, myself included, go through a lengthy, angst-ridden decision-making process before we plunk ourselves down in a wheelchair.

We listen to the recommendations of our physicians, and we sheepishly explore the idea with our loved ones. We recognize that using a wheelchair would keep us from tripping and falling. It would help us conserve our limited energy and surely would make daily life a lot easier. Why, then, is this decision so emotionally intricate and agonizing?

Let's go back to our beginning. Does this sound like you? You contracted polio as a baby, child, or young adult and endured a long hospitalization. You were separated from your family at a tender age and may still have some psychological wounds from that trauma. You emerged using braces and crutches for mobility. However, in many cases, your medical professionals gradually eliminated those aids.

You made an impressive recovery, walking unaided for many decades. Then years after onset, you began to experience weakness, fatigue, and pain. You were diagnosed with post-polio syndrome.

You now use a cane for support in walking; possibly, you were fitted for a brace and/or forearm crutches, and you find that

motorized shopping carts at the grocery store are of colossal help to you. But, life is still much more difficult with the late effects of polio.

Did you once adore concerts in the park? Now you decline to go because walking on that uneven grass is far too difficult for you. You stay home.

Did you once savor the fun of cruising the mall with your daughter-in-law? Now you decline to go because that much weight-bearing and walking is far too painful. You stay home.

Did you once thrill to walking the boardwalk at the beach, absorbing the sights and sounds of the ocean atmosphere? Now you decline because the length of that long, winding boardwalk is too much to manage. You stay home.

You and your polio medical professionals recognize that the time has come for you to use a wheelchair for most of your mobility needs. However, the thought of appearing in public in a wheelchair fills you with dread. The key phrase is "appearing in public." Alone in your home, you love the way you can move smoothly, gracefully, and without pain and fatigue. But the image of using your wheelchair out in public terrifies you. Why? You realize on a rational level that using a wheelchair would be very liberating. But that rational base is overpowered, indeed almost buried, by the negative emotions that shout: "No! No wheelchair for me!"

Let's examine some of the contributing factors for this resistance.

As a child, you received considerable praise for your attempts to walk unaided.

Much of your self-esteem is wrapped up in the fact that you are still able to walk.

Society places an inordinately high value on walking.

The wheelchair makes it virtually impossible to be a "passer," that is, to pretend you are non-disabled.

It is the image of a wheelchair that is, indeed, the universal symbol of disability.

These are only surface reasons. The deeper, overriding reason for your reluctance stems from a negative association of ideas. Think of an algebraic equation: YOU are on one side of the equation and DISABLED is on the other. That association of ideas is laden with shameful emotional overtones. Why? Because, historically, people with disabilities are stigmatized. They occupied a low rung on society's "A List."

I remember the various social cliques in high school. Teenagers were ranked in hierarchical order as "preppies, jocks, greasers, and nerds." Very few kids with disabilities landed in the most popular crowd, and we absorbed that message like water into a sponge. Although those classifications have undergone various transformations over the years,

CONTINUED ON PAGE 6

I have a sense that we still long to belong to the "popular crowd."

Our resistance to using a wheelchair is intimately connected to our unwanted view of ourselves as disabled. We are influenced by a deep-rooted prejudice in society that it must be better to be ambulatory than to be in a chair. For example, there may be no greater medical triumph than getting someone "up out of a chair."

How my heart pounded with dread and self-consciousness the first semester I wheeled into the faculty meeting. That wheelchair gets the credit for "outing" me. I now had to admit to the world that I was, indeed, a Person with a Disability. Ever since that day, the liberation has been mine!

It is an important healing step to act on the belief that it is okay to be YOU and to know that the consumerist driven, stereotypical images of "attractive" and "popular" are oppressive falsehoods rather than the truth. It is stunningly appealing for a person with a disability to exhibit confidence and self-acceptance. People are not used to seeing this. When you perceive others' positive responses and you realize these responses are to YOU, as you are, you will be freed. When you receive positive reactions to the real you, not despite your disability, nor because they are unaware of your disability, but to YOU, you will shed a burden you may have carried around since adolescence.

If you love the comfort and ease of using your chair in private but dread the thought of using it in public, you can use the power of your human consciousness to

restructure your perceptions and free yourself. You were paralyzed by polio; don't be paralyzed by society!



Linda, being fitted for her first power wheelchair, at Gaylord Rehabilitation Hospital in Wallingford, Connecticut.

Are you still suffering from antiquated tapes playing incessantly on your internal tape recorder? If so, it is time to erase those old tapes. You can trade in your negative thought patterns for powerful new positive beliefs. You can liberate yourself and claim your rightful place in society.

Think about sitting proudly, head held high, in your sleek manual chair or perhaps zipping around in your sporty, power-chair. Visualize yourself maneuvering gracefully over the grass at the concert in the park. How lovely the grounds look when you are no longer fearful of tripping. How sweet the evening air as the melodic musical sounds touch your heart.

Picture yourself on a swift mobility scooter at the shopping mall with your favorite friend, scooping up bargains. You can "shop

'til you drop" and still have energy to go out to dinner.

Envisage yourself traveling the length of the boardwalk at the ocean. Your senses overflow with the ambiance of the seashore. Since you have no pain or fatigue, you are much more free to hear the seagulls scream, to smell the salty sea breeze, and to celebrate the sheer joy of this outdoor experience.

I know that this is still a difficult decision. Generally speaking, I think we are in a climate in which the mobility-limited person has to swim upstream against self-imposed inner conflict, as well as from family and friends who are caught up in the "use it or lose it" mantra. If we are to make optimal advantage of wheelchair mobility, we need a lot more people willing to swim upstream, proudly and confidently, to change that climate. Won't you join me in the swim?

Dread of using a wheelchair is based on old emotional baggage. Toss that baggage out. Wheel with pride and flaunt your self-acceptance. You will be a role model to all who encounter you. ■

CORRECTION A reader informed us that the **National Odd Shoe Exchange** IS in business. To find out more about their services or to register with the exchange, call 480-892-3484 or write to National Odd Shoe Exchange, PO Box 1120, Chandler, AZ (Arizona) 85244.

CLARIFICATION The **Post-Polio Support Society NZ, Inc.** contacted us to say that the Polio Course at Queen Elizabeth Hospital in Rotorua is currently available only to North Island survivors. The Society is working hard to make the hospital a center of excellence with services available to all of New Zealand's survivors.