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Living with a Disability

Living with a disability? The term you see more and more on websites and hear in discussions and presentations is “different ability.” Admittedly, it takes awhile to think of yourself as living with different abilities, instead of a disability. And if some well-meaning physical therapist had patted me on the shoulder after my accident and said, “Now you have different abilities,” I would have responded with “Thanks for the fine euphemism!” Although I wouldn’t have said “fine.” It takes awhile.

Besides, I had a better plan. My strategy was to ignore the instruction of the physical therapists, the occupational therapists, and the psychologists. I was sick of people in white coats. And what did they know about it anyway? My scheme was better. Watch every old movie on the Turner Classics Movie Channel for the rest of my life. Then one day, my boss at Cochise College called my daughter at 10:30 in the morning and told her that Martha Stewart was on channel such and such and to go put it on for me. My boss was trying to be funny. He knew I hated Martha Stewart - long before it was popular to hate her. But my daughter took it one step further. She took the remote from me, put Martha on, and then left the remote on top of the television. She told me, “If you want to change the channel, walk over to the TV and get the remote yourself!” Either she had enough of my self-pity or was sick to death of Doris Day, Greta Garbo, and Clark Gable. I have written this child out of my will!

Grace and humor. It does bring you back. Grace and humor are very necessary to our lives. We certainly need a sense of humor when the children move back in with the grandchildren, when the roof leaks and the foundation cracks on a new home, or when

everybody suddenly gets a stomach flu on the first cruise we ever booked. But we need a special kind of grace when a serious illness or disability strikes us or a loved one.

Eight years ago I was shot in the back while out riding my bicycle on a Sunday morning. That event initially left me paralyzed from the waist down. Grace and humor, my family and friends, modern medicine and those physical therapists, occupational therapists, and psychologists – plus, I must add, a tremendous outpouring of support from this community - have enabled me to reach the point where I can walk again - with a walker and braces.

I will tell you that the psychologist at Health South explained openly in a group session that 90% of marriages break-up when a spouse suffers a traumatic injury. It was a startling statistic and I don't know why he shared that information or that he shared it with every therapy group. I have not researched if the percentage he quoted is truly accurate. I do know that a gentleman who was in my group and myself were both older and to this day we are both still married. But the stress and challenges will bend you to you almost break. We were drowning in medical treatments and medical bills. We were also in the middle of a criminal case with detectives and lawyers in our home constantly. We had a 15 year old daughter at home, whose face and needs seemed to be a blur most of the time.

Interestingly, the couple that helped my husband and I understand what we might be in for were the same two people that witnessed my shooting that Sunday morning and had come to my aid – calling 911, applying pressure to my wound, and covering me with a blanket until the paramedics arrived. They visited us after I came home from Health South (a rehab facility) and shared that they had a son who was a tetraplegic as a result of a car accident when he was 18 years old. They related how the stress of that experience – medically, emotionally, and financially nearly ripped their marriage apart. Eventually they found balance, learned to manage

the caregiving differently, and made their own relationship a priority again. When caregiving is available it frees a husband and wife, or a parent and child to nurture their relationship beyond the constancy and urgency of addressing health care needs. It is amazing the advice and direction you will take from a caregiver who is a stranger – the same advice that you would fight about with your spouse, child, or sister. I will talk about the importance of caregivers and caregiving shortly. But finding others who have shared similar traumatic experiences, either individually or in a support group is essential. It is healing. And helps you to realize you are not alone.

I realize we all get a little tired of Dr. Phil, Oprah, and other “feel-good” proponents who tell us to value everyday of our lives, because at any given moment your world can be turned upside down. But I know that statement is not a cliché. You don’t have to think of a disability as limiting your life. Yes, you do have to think of it as changing your life, as taking you on another path, to be sure. You begin to know a “new normal” – an overused expression, but the right one.

I knew my world was returning to normal when my teenage daughter said to me as we were leaving for the mall one day, “Mom, please take your wheelchair, you are so slow with the walker.” There was no malice in her statement, just the typical whining of an impatient teenager with a parent. Believe me, I welcomed that she was no longer afraid of my disability and that she could speak so casually about it.

You might think it sad that we’ve reached the point where my disability is accepted with such ease or as our new normal. But isn’t life about change? How we adjust or adapt to those changes marks who we are in life. We have to watch our children grow up, and hopefully not move back in with those grandchildren. We watch our parents age, some divorce, some remarry - some to spouses younger than we are. We see changes in the workplace, in technology, in

science, and medicine. Life changes are accompanied by joy and pain. We attend weddings and funerals. We experience good health and poor health. We realize financial success and loss.

When you are in the lows, people will allow you to wallow only so long. I was especially fortunate to have my sister come out on family leave for a month to help us with day to day adjustments and also be present during difficult days at the criminal court. As you can probably guess she was a gentle, but firm taskmaster – insisting I dress, shower, and exercise every day. Can you imagine? But she was a Godsend for my husband. I still feel that my injury and recovery were tougher on my family than on me. When you see people you love running themselves ragged in 10 different directions, functioning on no sleep and fast food, you are consumed with guilt and wonder if you should swallow all your morphine pills. Would that make their life easier? Of course not.

Respite for the care giver is critical to successful recovery for the entire family. What possible good will it do to have another family member laid up, exhausted, susceptible themselves to illness or injury? If other family members cannot help, then beg, borrow or steal to get assistance. No one person should be giving care 24/7. It is inhuman. And so, I truly understand the need for nursing homes. However, what should be changed at these facilities is a whole other conversation. We were fortunate to have funds available through the Cochise County Victim Witness Program for both rehab and home health care – when the funds ran out for these through my health insurance.

I will share that when my sister returned home, she must have prayed for my next caregiver to be part angel and part medieval torturer. And this home health aide was not about to let me wallow either. I was rolling down the hall in my wheel chair one morning with an open container of yogurt in my lap. The aide was walking behind me. The yogurt fell out of my lap

and splattered onto the floor. I started to cry about the mess and how sorry I was that she had to clean it up. The aide calmly grabbed a bunch of paper towels, knelt down and wiped up the mess. I sat there sobbing, pitifully. She finally looked up at me and let me have it. “Oh, cut it out! You never dropped anything when you had two good legs!” I was stunned. How dare she talk to someone in a wheel chair like this! Then we both burst out laughing. It was a turning point for me and the best medicine anyone had delivered. You must find a way to adjust, adapt and make sense of your world – with whatever falls in your lap or out of it.

I am very fortunate that my disability is manageable and I can resume many of the activities I enjoyed before my accident. Unfortunately, many people are dealing with a disability or disease that consumes their entire life with pain and struggle. For these individuals, a special kind of grace is needed. Joy and peace seem far from your reach when you cannot move beyond pain, especially if the only solution for you is medication that keeps you sedated or lethargic. Hopefully, the efforts of celebrities like Michael J. Fox, Muhammad Ali, Neil Cavuto, Teri Garr, Doug and Laurie Flutie – and always the work of the Christopher Reeves Foundation - will bring more awareness and funding to devastating diseases and disabilities. Bravo to President Obama for lifting the ban on federal funding for stem cell research and for ending DEA raids on state clinics that provide prescribed marijuana for glaucoma and cancer patients.

I was on the Commission on Disability Issues for the City of Sierra Vista for seven years and we often stressed in our meetings and in public presentations that the disabled population lives with challenges that the larger aging population – translate “baby boomers” - will soon face themselves. Thus, when we encouraged businesses to be disability friendly, it was a reminder that in the years ahead we will have more shoppers struggling to open the heavy doors at stores, more patrons carefully treading the gravel parking lot at restaurants and more leaking bladders

that will know where every bathroom is in town. Certainly, the voice of the aging, like that of the disabled population, will continue to seek through the political process, reasonable accommodation in public places, opportunity to work, and medical assistance that does not exhaust savings and retirement resources. Is it not better that accommodation, opportunity, and affordable health care be forged in a proactive legislative process, rather than hammered out in negative lawsuits? More kudos to President Obama for initiating a forum to discuss comprehensive health care reform.

Both the aging and disabled individual seek to be recognized by the abilities he or she does have, rather than the challenges they must cope with on a daily basis. No one today thinks of a person who wears eyeglasses or a hearing aid, who has a hip or knee replaced, or who requires heart stents as “handicapped.” I will leave it to you determine how the need for Viagra should be defined. Nonetheless, well being concerns even the most healthy as we age.

I think it’s no secret that most of us want it all – long life and quality life. And that may mean living with eyeglasses, hearing aids, oxygen, wheelchairs, canes or walkers. Plus, amazing medications, that may not all be good, but are not all evil either. Of course, we have to take responsibility for our health. If you’re in good shape, do what you can to maintain. If you have an illness or disability – again, you can wallow sometimes, but then you have to adjust, adapt, and act. Take part in your own recovery and healing, by whatever path makes sense for you.

I was dragged kicking and screaming by a good friend to take part in the Commission on Disabilities Issues. But from the very first meeting I realized that disability plays no favorites – socially, economically or politically. Individuals with PhDs and Masters degrees, people that have worked devotedly for 30 years in the same job since high school, Democrats and Republicans, men and women are challenged with MS, MD, spinal cord injuries, loss of sight or

hearing, and mental health challenges. We had parents with disabled children fighting for their place in this world. The most common thread we heard at CODI meetings is that the disabled population wants to contribute and participate in the lives of their families and communities. It has been said that a nation is judged on how well it cares for its poor, its sick, its children and elderly. But it's more than just caring for them; it's keeping them involved in life - with those different abilities. The ADA and disability commissions at local levels across the country go a long way in raising awareness and achieving accessibility and reasonable accommodation. I realize that mainstreaming – and that may not be exactly the right term, and it is sometimes a controversial term - is a huge task in an economically stressed time where it is hard enough for fit persons to keep home and health together.

Perhaps it is fear. Very few of us get out of life without meeting some medical challenges. And we don't like to be reminded that an accident, injury, or illness can strike us or a loved one down. No one wants to be dumped or forgotten in a back bedroom or nursing home. (I am not criticizing nursing homes and the intense challenges they must meet with little staff and low budgets.) Incorporating individuals who can successfully live with their disabilities by attending school, going to work, driving, shopping, attending civic and social events – this kind of public presence can go a long way in helping to overcome that dread. God forbid, if the worst happens and we can manage it, we want to know there is still a place and purpose for me, my spouse, my child, my parent, in the world. How critical this dynamic is for wounded soldiers returning home.

My day to day life. I rush for no one. That could mean a broken leg or hip. I plan to stay away from people in white coats as long as I can. I'm no longer angry at people who talk loud or very slowly at me just because I'm in a wheelchair or use the walker. Not all disabilities are the

same. It's a matter of education. Again, I realize that for many people, especially aging people, walkers, wheelchairs, and oxygen tanks are a frightening prospect that may be in their own future. You get the two extremes – people avoid you like the plague or they over-help to the point of detriment. Again, it's a matter of education.

It has been hard to reenter the workforce. Yes, I could take a job that pays minimum wage and we would lose our house. I have sent out over 500 resumes. I am sure that my age and disability have worked against me – regardless of laws that presume to prevent discrimination. So you have to work the system. You don't have to lie, but as a friend in Human Resources suggested to me, no longer state or take the points for your disability, at least get to the interview, and let them talk to you, let them see how little accommodation you need and what you can bring to the company. (This is my personal experience and I am not advocating this tact for every disabled individual. Each must explore his or her own avenue back to employment and certainly use whatever tools are available.) So I am now reworking my resume and leaving out that I am disabled. We'll see what kind of responses I receive – especially during a downturn in the economy. I also write and am working at getting published, a challenge all its own for which no one pays you – even a compliment. And the worst case scenario – TCM never runs out of old movies. But I won't watch them for the rest of my life!