

ADAPTING TO ADAPTIVE EQUIPMENT ON OUR OWN TERMS

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When I was a 5 year old little girl who just got polio, my Mom tells me that I was anxious to get on my feet again. I didn't like being in bed or in a chair all day long. I wanted to go places and get on the move again. My therapists explained to me that I had "lazy legs" and that I could walk again if I wore braces on them. So, being an active little kid who was used to running more than walking, I was thrilled to learn to stand up and walk again with a pair of braces, a corset and 2 little crutches.

When I was a 35 year old woman who had used braces and crutches for 3 decades, Frederick Maynard, my doctor, told me I should start using an Amigo part time. That was August of 1984. I was not so thrilled. I was overwhelmed with humiliation. That felt like a defeat. I told my doctor that I wasn't sure about using a wheelchair. I had grown up being proud to walk. I often heard, "well, at least you don't have to be in a wheelchair." I had real reservations about using an electric cart. Would my friends still like me? Wheelchairs are the classic symbol of disability. Would they want to be seen with me? I literally called them on the phone and asked them. I wondered if using an electric cart could totally annihilate a person's sex appeal. That's an important issue. I ruminated daily with the idea over the next 4 months. Finally at Christmas time I hesitantly told my doctor that I was ready to order a cart. He was very pleased and happily wrote out a prescription

for whatever I wanted. My vocational rehabilitation counselor was also very pleased and within a month had efficiently made all the arrangements. With delight the Amigo company delivered a brand new scooter right to the door of my home. They went into the garage and installed the trunk lift into my car. Man, I had it all. Scooter, electric lift--ready to go anywhere packed neatly into my oldsmobile. New mobility? New freedom? New independence? Wrong! That scooter sat in my car trunk for the next year. I'd peek at it occasionally to check for corrosion. I thought the battery might freeze out. When asked if I'd been using it, I explained that I just didn't find any occasion when I needed it yet. Vocational Rehabilitation had paid \$4,000 to give my car weight in the deep winter snows!

I just needed time to get used to the idea. I spent too many years valuing and prizing my ability to walk. How could using a wheelchair be okay? How could I incorporate it into my positive self-image? The real challenge would be to convince myself that it was a gain rather than a loss. How could using it make me feel like I was better off rather than worse off? Everybody but me thought it was okay. And I knew it was the intelligent thing to do. I figured if I was supposed to conserve it to preserve it, I'd better use it. If I was going to start a new job in a sprawling building, I'd better use it. I knew I had to outsmart myself, so I began thinking in a new way. I began to think existentially--deciding that things in my life only carry the meaning that I choose to give them. I had to cognitively restructure the meaning of wheelchair in my life. That wheelchair had to transform from a negative to a positive image in my mind or I'd never use it. So I decided to only use it at first for positive things. So the first thing I did was go to shopping malls with my best friends' children. They squealed with delight as they hopped on my lap for rides. They loved it. I could have

sold rides to the other little kids who watched us with awe as we gracefully tooled around. I went with my adult friends on pleasant walks through our tree-lined neighborhoods, which was something I could never do before. One is closer to seeing and smelling the flowers in a wheelchair, you know. We decided to go only to fun places with it at first like to art museums, and the zoo. It worked! I turned that wheelchair into a love and funmobile! Now I use it much of the time at work. I can go farther and faster than ever and really enjoy having it.

Adapting to adaptive equipment is not an easy process for most of us. Doctors advise, "get a cane, wear an new brace, breathe with this respirator, use a wheelchair. Carry it, strap it on, put it in your mouth, learn to get from place to place in a completely different way." It seems like a simple and very logical solution to a serious rehabilitation problem, but it is not an easy transition for us who have to live with the changes.

I have found that there are some keys to successful adaptation that start the moment your doctor prescribes a piece of assistive technology:

1. Know that you don't have to do what the doctor says. You can rightfully reject his or her advice. It's your lifestyle, not theirs.

2. Know that if you don't want to completely reject the advice, you CAN take your time in assimilating it. You have the right to think about it for a long time, if you choose. You may need to seriously re-think the meaning of the device you have been asked to use. Is it going to make you feel more trapped, stigmatized, dependent and unattractive? Why? Is it your own biases holding you back? Or are your assumptions an accurate basis for rejecting the prescribed device? New equipment should liberate you more, not confine you.

It's up to you to check your own reality on this issue. It's important to evaluate what your top priorities are in life. Will this new equipment enable you to continue reaching your life goals and participating in activities and relationships that are really important to you? Can you take charge and make this equipment work for you?

3. You should also double check to be sure that the best apparatus for you has been prescribed. You may want to get a second opinion. If it is more strenuous and potentially dangerous for you to hoist a scooter into your car even with a built-in lift than it is to walk long distances, then you must question the prescription. Your new device, whatever it is, must be user-friendly.

4. You must be able to learn to trust the new equipment. It takes time, practice, and commitment to learn how to use the device with confidence. From the start we need to expect and build in an uncomfortable adjustment period time. It shouldn't be more than 4 weeks probably. That's the time that braces need adjusting and we learn to pick things up from the floor in a wheelchair. We need to learn the mechanics of the brace or wheelchair. We need to have an emergency backup system. We need to know what extra pieces to have on hand if something breaks down and how to fix it temporarily. We need to know in advance who to call when there's a breakdown. We must learn about the services and processes of the equipment supplier and develop a good working rapport with them. It helps to figure out what stores in town might sell items you can use to fix a breakdown. Doing this kind of homework can encourage us to incorporate the equipment into our lives faster.

5. Once you've learned about the device, you may need to teach your friends about

its workings. For example, if you get a manual wheelchair that requires a friend to push it, they may need some driving tips before you take on an all-day shopping excursion.

6. To sum up this entire list of key points, I'd say that the main thing to remember is that you control your adaptive equipment, it doesn't control you. I like having the extra hardware when I can see the payoffs. I can go more places. I can go faster and further. I can use the airports and fly now that I figured out that a sky cap and a wheelchair can expand my horizons more than I ever dreamed possible before I knew about them. I learned that sex appeal has very little to do with hardware. It has to do with our choice of thoughts and behaviors regarding ourselves and the people in our lives.

Adapting to adaptive equipment isn't something any of us want to do if we had our druthers. But staying in control of our lives and as liberated as humanly possible is something all of us can choose to do in our own way, in our own time, and on our own terms.