



**Perspectives by a Person with MS
Living with Assistive Devices
By Cindy Miller**

“When the Heart weeps for what it has lost, the Soul rejoices for what it has found.”

Sufi expression

Living with MS is not only living with the unknown, but also learning to accept the help necessary to move forward in life, in spite of MS. I have experienced most of the “wonders” of MS in the 16 years since my diagnosis: from “invisible” MS, to a move into a secondary progressive form in the last 5 years, causing me to move from “wall-walking”, to cane, to crutches, to scooter for distances and super-walker at home, to part-time power chair use at home this past year. I also worked my previous job primarily from home beginning about 6 years ago, due to my increasing walking problems, then had to retire on disability a little over a year ago, due to MS fatigue.

Because of these experiences, I feel I am really qualified to spend a few moments talking with you about the whole issue of dealing with and using assistive devices, frequently referred to as **Durable Medical Equipment**, or **DME**.

First of all, let me say, as amazing as it was to me, I found I went through the exact same thoughts and feelings every time I even *considered* using a different device, and then again when I made the decision to even *try using* the device!!!!!!

And so, as is typical with so *many* things with MS, just when I felt I had dealt with the perceptions, issues, thoughts, and emotions about using a device, had accepted it, and had learned to cope with my feelings – **BANG!** MS changed again and required me to think about *different* equipment!

I found that I had to go through the identical processes *each* of these times – dealing with the same perceptions, issues, thoughts, emotions, coping, and acceptance of both the *consideration* of and actual *use* of the new equipment!!! What would people think of me? How would they react to me? How would I deal with my own feelings if they stared at me, asked questions of me, or worse yet, felt they pitied or condescended to me? Would using it make me feel embarrassed? Would I know how to use it without looking like a fool? Did I really need it, or wasn't I just “giving in” to the MS, showing to the entire world what a “weak person” I was? Could I find a way to use it and not make it really visible? (Maybe I'd just leave it in the car and use it only when I “really needed it”.)

After considering these thoughts and feelings over and over each time I was dealing with a different device, I realized the **real** issues were within me and related to my own self-image and sense of self-acceptance. After a lot of thought, each time I found I had to make a conscious **choice** to at least *try* the new equipment. I felt I needed to deal with my inner

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fears and at least give it a try. I had nothing to lose, unless **I chose** to let it make a negative difference in my life. I would swallow my fears, give it a whirl, hope that it might end up giving me something positive, and at if I did choose to permanently go with the new equipment, deal with my feelings and fears at *that* time.

In other words.....TAKE THE PLUNGE!

Each time I found the hardest thing to deal with was my own fears and pre-conceived notions. Usually after only a few minutes, hours or days of using it, I found it was a tremendous *positive* change! I'd realize how much energy, both mental and physical, I had been using just to maintain my activity *without* the equipment: how much easier the use of the device made it for me, how much more energy it allowed me to have, how much more independent it allowed me to be, how much better it helped me feel about myself! The other thing I found was that it helped me to see how many things I had *stopped* doing without even realizing it, but that I could now do again! Of course, then I had to go through this entire process *again* when I'd make the commitment to actually *use* the device, and then *again* when the need came to try *another* new piece of equipment each time my MS progressed. And each time, it was like going over all of it for the very first time. But each time it was more than worth it!

I found a willingness to "accept" the new device was the *hardest* part, each time requiring me to do the same soul-searching as the time before. Always the same questions yielded the same answers, even though they were related to a *different* piece of equipment. What would people think? Probably nothing much, if anything. And if they know me well, they would probably think I was being smart to make it easier on myself. Would they react to me, with pity or condescension? I found that generally people did not really treat me much different, if they knew me and were my friends. On the contrary, I found them generally *more* relaxed and at ease around me since they could see both my struggling less, and my own sense of comfort and independence returning. If they didn't choose to see it this way, or chose to pity me, I could take control of the situation and choose to view these behaviors as their problems, **not** a reflection on me or my personal worth. If they persisted in such negative behavior, I could also choose to just withdraw from the situation entirely, feeling it totally unnecessary for me to continue to absorb their negative feelings. What if they asked questions? I found people generally to be quite interested, and I have come to view myself as a person who can educate others on the equipment itself, and also to the person "behind" the equipment, a person who is the same as before, just doing things a bit differently.

Most of all, I found I had to resolve some self-image issues within myself. If people stare, they are either uncomfortable with things that they do not understand, or they are just plain rude. So, I choose to be a role model for them as far as "handicapped" people go, letting them see that *life goes on and we are just the same, just adapting a bit differently to our own personal situation*. For those that are just rude, nothing will change them, so I

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choose to ignore it and spend my energy on people who are truly interested, caring, and willing to see things differently.

I learned that there are many people out there to support me and teach me how to use the new devices most easily and effectively. I had to accept that I would need to practice, know that I would make mistakes, and learn to laugh at both them and myself. I learned that, in using such equipment, I was neither “giving in” to MS, nor “weak”. I learned to be **proud**, rather than embarrassed about doing something positive to allow me to continue living and enjoying my life.

I had to come to accept, within myself, that I haven’t changed who I **am**: I just need to adapt and live my life a bit differently. More importantly, I **remain** the same person I always was, although in many ways, I am better. I have learned lessons and a perspective on life that I would not have otherwise. The slowing and “quieting” of my life as a result of MS, and the use of these different “assistive devices” has allowed me to see and savor the important things, as I never have before. As a direct result of both these changes in perspective and time, I have a renewed sense of creativity, and the ability to focus my life energy on the things and people that are truly important to me.

“The game of life is not so much in holding a good hand, as playing a poor hand well”

H.T. Leslie

Cindy Miller, RN

Cindy Miller is a Registered Nurse.

Her vast experience, not only with nursing, but as a person with MS herself provides her with much authority in both areas. Her nursing career has taken her into the realms of Hospice, Home Care and major medical insurance company. She specialized in DME and in her State’s Safety-net Insurance Plan for those who are rejected by traditional health insurance. She has much to contribute and joins forces on a regular basis with other professionals in the field of MS rehabilitation. This current article is part of a program that was presented regarding the use of Assistive Devices for those with Multiple Sclerosis.

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