

# Accepting Multiple Sclerosis

My diminishment, my companion, my song.

BY RUTH JUST

I have had multiple sclerosis (MS) for 35 years. During that time I've lost one ability after the other. I am now completely dependent upon the care of other people.

There is no cure for MS. I will have this disease for the rest of my life, and it will continue to get worse. I'm angry, I'm bitter, and I'm envious. I think I have a right to feel that way. Who wouldn't be?

But over the years, I have slowly learned that there is more. Although I can't choose not to have it, I can choose my attitude about living with the disease.

The book *On Hallowing One's Diminishments*, by a Quaker writer named John Yungblut, has taught me a great deal. Yungblut uses the word "diminishments" to describe any of the ugly and painful experiences we all have: accidents, war, birth defects, job layoffs. The word "hallowing" means to regard something as holy. But for Yungblut, it also means to regard a diminishment as a trusted companion.

MS is my diminishment. But Yungblut is asking me to regard this horrible disease, which has taken so much from me, as a guide through life. This makes no sense at all. But he promises that if I can see my diminishment this way, I will discover a whole new world that I didn't know existed, a beautiful world with new opportunities, satisfactions, and insights.

Yungblut says that the first thing I must do is to accept MS. Acceptance is simply a decision for which I, alone, am responsible. No one can do it for me. And I must accept it not just once but over and over again. Whenever anger, grief, and envy arise in me—when I see what other people can do and what other people have—I must remember that I have decided to accept MS.

When my whole family goes to Germany and I have to stay home, I must remember my decision to accept MS. Every time I look at the cracked linoleum in my one-bedroom apartment and yearn for the beautiful home I have lost, I must remember my decision to accept MS. Every time I see my red and swollen feet encased in ugly support stockings and remember looking sharp strutting

off in a new pair of shoes, I must remember that I have decided to accept MS. Every time I have to spend several months in bed healing a pressure wound and think what fun it would be to go on a bike ride with my sisters, I must remember my decision to accept MS.

I struggle and I groan under the weight of this responsibility. But somehow I have learned that I can do it. Yungblut is right. I am living in a new world. New opportunities abound. And I'm amazed to find that I feel very thankful for this new world.

MS has created a special bond between my husband and me. He has stayed with me and offered me his love and support through all of these years. Would I have seen the fine mettle of this man were it not for MS?

Many of the people who take care of me are new immigrants from African countries. Getting to know these people has been the most enriching experience of my life. Africa faces overwhelming problems: corrupt governments, civil wars, drought, abject poverty, AIDS. But my new friends remain proud of their native countries. They are patient, they work hard, and they are willing to make great personal sacrifices to help their people. They know that one day Africa will experience peace and prosperity. One day all of Africa's children will go to school.

When I ask myself how it is that I've had this opportunity to know these sterling people, I realize it is

only because I have MS. They are part of my new world. We encourage each other, and our friendships are rich.

My diminishment has also made me a member of the MS community. The many fine people I have met inspire me with their courage. We share each others' joys and sorrows. I need these people and they need me.

I love the title of Maya Angelou's book, *I Know Why the Caged Bird Sings*. This is my challenge—to be that bird. I'm proud that I'm up to it. A bird does not sing because it has the answer; it sings because it has a song. NN



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