

I must apologize for putting off this letter until now. Especially since it's about something that has had such an impact on my life. I can't believe it has been 4 years since I had my first MS attack and have had quite a roller coaster ride since then. It was quite a scary time when I was having so many relapses and new symptoms and trying to figure out how to live with this unpredictable disease. I have had to learn so many new skills in dealing with MS and there is one person responsible for many of them and that is Karen [REDACTED]. I was so fortunate to work with such a kind, caring and skilled professional and loved being part of the team at work with her. When all of a sudden I became the client, I was so grateful to have her on my team again. I remember how difficult it was when my energy was so low that doing anything like cooking a meal would exhaust me and put me back in bed. My legs were not very predicable and sometimes I would not go on family outings or plan anything. The days my legs were really bad, I would sometimes be in bed for days or during relapses, for weeks. I also remember how difficult it was having a disease that often looks invisible and I could be out shopping and look normal and come home and be in bed for 2 days. I often worried about what people thought when they saw me doing normal things when I was able. I didn't realize what people with invisible diseases go through.

Then came Karen and showed me how to live well with MS. I never imagined I would ever need a wheelchair, but Karen made it so much easier for me to accept using one. When she first suggested it, I was very opposed - thinking that I didn't need one. But little by little, she gently guided me to be open to it. Because she taught me so much about energy conservation with small things like using the shower chair, sitting down when drying my hair, using my electric wheelchair when cooking, etc. it has enabled me to live my life more fully. I needed her to be as insistent and encouraging as she was with me because I didn't think I was bad enough to need a wheelchair. I would have continued to struggle. You would think I would know better working in healthcare for 20 years! But I also learned that when it happens to you, it is a whole different ball game. It has been hard being on the other side of health care, being the receiver instead of the giver, but it has also taught me a lot.

Karen helped me to get a wonderful little electric wheelchair that zips around the house and looks good too (it's red)! It makes a huge difference when I have leg weakness and now I can get around the house so easily. It used to be so difficult for my husband and kids to see me trying to get around and there were times my kids would cry when they saw me struggling to get to the bathroom or just trying to get up. It has improved their lives as well.

Karen also helped me to get a transport chair which comes with us anytime we are going somewhere that there is a lot of walking. I now go on outings with my family and we always take the wheelchair just in case and it has proved to be invaluable. I would never be able to go on a shopping trip or go to places like Disney without it. My family and friends have all gotten used to just taking the chair and even if I feel well, I know I have to use it to conserve energy and prevent the flare ups that follow from not using it. I can even have my catnaps in it. Karen is the voice in my head reasoning with me when I sometimes feel embarrassed to be using the wheelchair or when I worry about what people think when they see me walking one day and in the wheelchair the next. She is much more than an OT! Karen always added some humor too which made things easier. There may not be a cure for this disease and I have finally stopped trying to figure out what brought it on or what brings on relapses and worrying about the future. My MS has taught me to be in the moment and be grateful for every day, hour, minute that I am well and for the abilities I still have. When I am not well, I always remember the saying "this too shall pass" and I feel grateful for all the people in my life that help me get through those times. I haven't given up on a cure, but right now my goal is to live well with MS, and Karen has been a huge part of that. Karen, thank you for all your help. I now have more freedom and independence which is something that I can't thank you enough for. I feel so lucky to have worked with such an amazing group of people as those at Closing the Gap. When I was first sick, I will never forget the kindness shown to me by all the staff. The flowers, cards, food, etc. were so wonderful. I just hope you all know how much it meant to me and my family and how wonderful you all are. Keep doing all the amazing work you are doing and please know what a difference you make in people's lives. You certainly did in mine!

Forever grateful,

love 