What to Say to Someone With MS

by ABIGAIL BUDD

How to Be Supportive Without Being Patronizing

I've often pondered this question when grumbling about people saying the wrong thing to me. People often can't win — they mean well, but their remarks make me scream inside sometimes, and this got me thinking about the things I respond to without cringing.

When do I feel supported by well-meaning comments, what do people do that I find helpful?

Make Me Feel Like an Equal

Strangely, the place I feel most supported and the least patronized is at work. My colleagues make me feel like an equal and as long as I have help here and there, I can be professional and do my job as well as anyone else.

This is so important to me and my sense of identity, and I'm so grateful to my team for helping me feel like an equal. One particularly helpful colleague sets up the interview room for me, for example, so when I see clients I can get in easily, park my scooter and get on with my job.

I thanked him the other day and he said, "Don't thank me, it's my job," and looked slightly annoyed I'd singled him out for praise. His attitude that nothing is too much trouble is so supportive and I know I can ask him for help whenever I need it. Mine is an "equal opportunities" employer and I'm lucky that all employees take this seriously, as I've worked for organizations that made me feel like a nuisance and a burden before and it did nothing for my self-esteem as a disabled person.

So, for me, it's not necessarily what people say that makes me feel supported; it's the practical help that's offered and the attitude in which this help is delivered that I find helpful.

Offer Practical Help

I asked the MS community on Twitter what they found helpful and many of them agreed with me. One man said he'd like people to offer him practical help such as mowing the lawn, as he can't do this himself.

The cost of being disabled can add up as we have to pay people to do all the things we can no longer manage. I pay a cleaner, for example, and my Twitter friend no doubt has to pay a gardener to mow his lawn — so any offer of free help is always appreciated!

My mum helped me cook fish pie for my family yesterday while my husband took the kids to the park. This simple act of feeding my family made me feel fantastic! My mum got all the ingredients together so I could weigh them out and make the sauce. She peeled and mashed the potatoes while I did the rest. Without her help I'd have been exhausted just getting the ingredients together, so it's these little things that help so much.

Treat Me Like a Normal Person

Many people on Twitter didn't want their MS referred to all the time and just wanted to be treated normally. They want to know their friends and family are there for the bad days, but not to assume they know when they're having one. This is so hard for people trying to help and support us, as they are not mind readers!

I just want people to listen when I need to talk and not to judge me when I'm having a bad day and can't get anything together. I often have to cancel plans as I can't always manage a full day at work followed by a night out.

My friends recently changed their plans at the last minute and came to my house as I was exhausted. It was so nice to see them all and we had a lovely time. They didn't make me feel like they'd missed out and we had just as nice a time at my house as we would have anywhere else.

Ask Me What I Need

I also love it when people ask me how they can help, rather than assuming they know what I need. There's a lady at work who jumps up and runs to help me open the door to the office every day. I don't need the help but am too polite to say so, thanking her elaborately every time she does something I can do perfectly well myself!

What I do need help with is getting my scooter back in my car at the end of the day and will ask reception staff for a hand. When I first started the job they asked what I needed help with and I showed them how they can help with my scooter. Now they do it without being asked as they know what I need and they want to help.

Listen

I think that's the secret to it. Friends and family need to ask questions and genuinely listen to the answer, don't presume you know what we need. MSers have a responsibility for speaking up too. Tell people how they can help and don't be afraid to ask when you need a hand.

The most important thing for me is when people ask how I am and actually listen when I tell them about my symptoms. Sometimes I want to explain how it feels to have MS and people who listen properly tend to be the ones who understand.