Mingle all the way?



Holiday parties can be tough for people with multiple sclerosis; Julie Stachowiak, an author and epidemiologist who lives with MS, explains why—and how you can survive them.

by Julie Stachowiak

The holiday season is supposed to be festive and fun. However, for many of us living with multiple sclerosis, the seemingly endless circuit of parties and social events fills us with dread.

We face numerous challenges, beginning with the social complexities that come with having a chronic disease. For example, people who know that you have MS may ask lots of questions about how you are doing. Conversely, if you reveal your MS to people you haven't seen for some time, they may ask some (potentially annoying) questions about MS itself.

Even if you successfully navigate those social snarls, myriad other MS-related challenges can make a situation like a party difficult. Some of these include:

We are tired. I might feel much differently about a holiday party if it

started at 10:30 a.m., rather than at 8 p.m. Getting through a day with MS fatigue is enough of a miracle in itself. A party means having to get dressed up, dig out our sparkling personalities and converse with others (potentially even strangers) at the very time that we want to slip into comfy clothes and succumb to fatigue. For many people, attending a party that runs late into the night may mean sacrificing feeling good for any part of the next day.

people with MS describe the background noise at parties as being similar to "ball bearings in a blender." Certain music can make us feel anxious or more fuzzy-headed than usual. In addition, the sheer noise level of parties can make it pretty impossible to hear what people are saying or to maintain the train of thought we need for a conversation—especially if we already have problems with attention and information processing (see next item).

Holding a conversation can be difficult. MS-related cognitive dysfunction takes many forms, many of which impede our ability to participate in conversations. Attention and information-processing problems can make it difficult to participate in a large group discussion, especially if topics are moving quickly. Word-finding difficulties result in our vocabulary deserting us just as we were trying to make a point, bringing our side of the conversation to a halt while we search for the one elusive word that we need to complete our thought.

Speech problems may add to our communication difficulties. Dysarthria, a symptom of MS, is a speech disorder in which pronunciation is unclear. It can cause us to speak in slow or unusual rhythms, speak very softly or slur our words. This makes it hard for people to understand us, especially if there is loud music or lots of background noise.

We may not be as coordinated as other people. Even in my youth, long before my MS diagnosis, I had a hard time holding a drink and balancing a small plate at the same time—now, it's just about impossible. Tremors make it difficult to stab small appetizers with toothpicks. Navigating across a crowded room often requires a well-thought-out strategic plan; for those of us in wheelchairs or using walkers, it can be extremely challenging and frustrating.

It may be hazardous to talk and eat (or drink) at the same time. Swallowing problems, also known as dysphagia, are a pretty common problem for people with MS. I have experienced many uncomfortable moments of coughing when food "went down the wrong way," which ended up being very embarrassing for me, and alarming for those around me.

Make it merry

This does not mean that we are destined to stay home while everyone else is having fun.

I often find that when I "do parties" right, I end up having a good time and being glad that I went. Here are some of my tips for dealing with (and maybe even enjoying) holiday parties:

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Choose your parties carefully. Just because you are invited to a party doesn't mean you have to go. A daytime party (think New Year's Day open house) or one involving a small number of close friends and family is likely to be easier. If it makes you feel more comfortable, explain the situation to the host or hostess.

Make the party work for you. Even if you cannot be the life of the party, you can make it pleasant by finding one or two people whose company you enjoy, rather than feeling that you need to mingle with everyone. This way, you can have nice, meaningful one-on-one chats.

Rest up. Take it easy on the day of the party. If you can get a nap in before leaving for the party, even better.

Stake your turf. Scope out an area where there is a place to sit. Don't hesitate to ask your host or hostess if there is a chair that you can use, even if others are not sitting.

Strategize your socializing. Have a two-sentence answer prepared for the "How are you?" question, so that you don't find yourself frantically trying to formulate an appropriate response. Likewise, have a short "elevator speech" about MS ready for those just learning about it.

Limit the booze. Alcohol can make fatigue, balance and cognition worse. A drink or two is fine, but don't try to keep up with "Party Marty" from next door.

Eat mindfully. Not only will eating slowly help you savor each delicious morsel; it's also safer. Those of us with dysphagia are less likely to inhale food into our airway if we pay attention to our chewing and swallowing. Likewise, I only talk when my mouth is completely empty. It's safer and more polite. I also try to avoid eating or drinking when I am talking to people whom I know to be humorous, as laughing and trying to swallow are a dangerous combination.

Leave early. Listen to your body (and do what it tells you) in terms of getting out of there

and into bed.

The bottom line

Whether you stop by holiday parties briefly and leave early, or find other ways altogether to socialize during the holidays, don't be critical of yourself. Remember, these are your holidays, too, and you should enjoy them your way.

Julie Stachowiak, PhD, is an epidemiologist who was diagnosed with MS in 2003. She is the author of the book, <u>Multiple Sclerosis Manifesto: Actions to Take, Principles to Live By</u> (Demos Health, 2009).

To connect with other people with MS about their holiday experiences, join a discussion on MSconnection.org.