

# Saying no



## **It's a part of life when you have MS, but there are ways to make it easier.**

**by Shara Rutberg**

It was Wednesday evening when Michael O'Grady's 14-year-old daughter hit him with a teenage emergency. The shoes she was planning to wear to Friday's semi-formal dance no longer fit.

"Dad," she asked, "can you just take me to the mall for new ones after school tomorrow?"

O'Grady, 52, was diagnosed with multiple sclerosis in 2012. Since then, he's learned how to manage his daily energy. He's learned how his cognitive and physical abilities shift during the day. "I know my own body and how my day goes," he says. "And I know I can't go anywhere at night. I'm pretty much shut down by that time."

Another critical thing the Lincroft, New Jersey, father of three has learned since his diagnosis? How to say "no."

"There are times when I can do things and there are times when physically, it's not going to be safe," he says. He had to turn his daughter down.

"That hurt," he says. "I'm her father, I should be able to do simple things like that."



**Michael O'Grady (bottom right) was diagnosed with multiple sclerosis in 2012. He's learned how to manage his daily energy to balance life as a father.** Photo courtesy of Michael O'Grady

Predictable — and unpredictable — symptoms make saying “no” part of life with MS. Experts and people living with the disease share strategies for turning down requests and dealing with the guilt and other feelings when you have to decline invitations or cancel plans.

### **Have a standard line ready**

“Having a standard line, like an elevator pitch, that you know in advance can make it easier to respond,” says Paige Bentley, a North Carolina mental health professional who was diagnosed with MS in 2007. Amy Clark, diagnosed with MS in 2002, agrees. Her line, “Please understand I live with a chronic disease and there’s going to be times and days when I just can’t do what I want to do. People were generally pretty understanding,” says the California resident.

She also suggests adding a caveat to responses if you think you might be able to take part but aren’t sure. She would say: “My intent right now is to be there, but you need to know that I might wake up on that day and not be able to.” Bentley suggests using a “soft RSVP,” like, “I’d love to come, but would it be OK to let you know the day of?”

Suggest people make contingency plans, says Deborah Mandelbaum, who practices in Maplewood, New Jersey, and New York City, and works with many clients who have MS or have a family member with MS. For example, “if it’s being the class mom in school, have a backup to call if you’re not up to it. If it’s leading a big meeting at work, have a second-in-command ready.” Practically speaking, it lets things get done. But beyond that, she says, “it gives people the message that you take this seriously but may not be able to do it. It also takes the pressure off you.”

### **It’s OK to say no**

When a hard no is required, give yourself permission to give it, says Tracy Clafin, 63, who has relapsing-remitting MS, and has led MS self-help groups in Chico, California. “It’s really hard at first, but be honest and give yourself permission to say ‘no.’”

When you do turn down an invite, or cancel plans, how much do you need to explain? “Educate,” says Mandelbaum. “Explain that MS can change from day to day. Fatigue is an issue. It’s nothing personal against the person doing the inviting, but there’s a lack of predictability and a lack of control with this disease.”

How much to explain depends on each person, she says. “Some people are openly curious, others aren’t going to want to know at all.”

Having invisible symptoms can make things harder. “I don’t wear my MS,” says Ann Marie Johnson, who was diagnosed in 2002 and has been an MS peer counselor, self-help group leader and has served on the National MS Multicultural Advisory Committee. “But I tell people all the time, ‘there are many faces to MS.’ Just because a person is walking, it doesn’t mean there’s not invisible stuff going on.”

You might lose some friends. Some people will understand. Some won’t. “That’s the reality of life with any illness — cancer, or MS or diabetes,” Mandelbaum says. “There are some losses of friendship and relationships. But you can’t change or control others, you can only try to be positive and offer information.”

“Your real friends are understanding,” says Johnson, who lives in Brooklyn, New York. “Other friendships have to be redefined.” Other relationships, she says, need to end.



**Ann Marie Johnson, diagnosed with MS in 2002, is an MS peer counselor.** Photo courtesy of Ann Marie Johnson

She had one friend who not only failed to understand why she couldn’t do things the way she used to, that friend actually “made me feel bad about being sick,” Johnson said. That woman

is no longer in her life.

“MS teaches you what real friendship truly is — and that’s about being honest about who I am and what the ‘new Ann Marie’ (post-diagnosis) can and can’t do,” she says. “This woman just kept longing for the old Ann Marie. It’s enough that I’m longing for the old Ann Marie. I don’t need friends longing for her, too.” Choosing who you keep in your life is “about who’s going to be in that journey with you,” she says.

That longing for the pre-diagnosis self is normal, experts say. “It’s a larger part of acceptance,” Mandelbaum says. Guilty feelings that may arise after declining invitations or canceling plans become more about sadness and loss, she says. “Acceptance is something we deal with a lot in therapy, going through the Kubler Ross stages of grief (denial, anger, bargaining, depression and acceptance).” What makes it even more challenging with MS, is that the loss is constantly changing. “What you might have done six months ago, you might not be able to do now,” says Mandelbaum. This makes it harder for people living with MS to deal with and it can make it harder for other people to understand. “Friends may wonder, ‘Why six months ago were you able to go on that hike and you can’t now, even though you don’t look any different?’” she says.

### **Suggest alternatives**

Another approach to making plans is to give a response that’s not a “yes” or a “no,” but rather is a “yes, in a different way.” Accept the invitation to spend time with someone but present a way to do so that you can handle. Offer an alternative, says Mandelbaum. “For example, I can’t come over Saturday night, but I’d love to catch up — can we Skype? I can’t make a New Year’s Eve party, can we do lunch New Year’s Day? That way the message is ‘it isn’t that I’m not interested in you, it’s that I can’t do the requirements of getting there.’”

“Shift your mindset so you don’t think you can’t do something. Instead think now you have to do it in a different way,” says Johnson. Consider whether “the moment, or the memory” is more important. Is it more important that you go on a long walk with friends or that you get to spend quality time with them? “For me, it’s more important to be with my friends,” she says. “And I had to let them know that.”

Bentley encourages the people she counsels to shift from FOMO — the fear of missing out — to SHOMO — show up more. “Show up more for the things that are important,” she says. “It gives us the opportunity to say ‘no’ when we have to and a really strong ‘yes’ to things we can do.” In that way, she says, MS can help us see things more clearly, and “bring some clarity and purpose into the day-to-day.”

### **Step by step**

Bentley suggests following these steps when making or canceling plans:

Step one: self-acceptance. You might say, “Yes, I do have this limitation in my life that means I’m going to have to pay more attention to my needs and ask for help.”

Step two: self-compassion. Acknowledge your feelings. “Name the feeling that you’re feeling, like sad or guilty. And remember you’re not alone — there are other people who need to cancel plans, too. Everybody has something. It just might be more frequent for people with MS.”

Step three: self-trust. “Remind ourselves that we can trust ourselves to still do the things that are important to us, to stay connected with the people who are important to us and really show up for those opportunities.”

It’s not easy, she says. “Remember, you don’t have to struggle with this alone,” Mandelbaum says. Explore support groups and therapy. O’Grady finds strength and empathy in his support groups and “two years of therapy have helped me manage my acceptance — and my daily energy. I’ve accepted what I can and can’t do. And I’m not afraid to say no to things.”

In the end, O’Grady’s family was able to work around his Wednesday night “no.” His wife rearranged her schedule to take their daughter to the mall. And the entire family was able to — together — enjoy how beautiful she looked in her new shoes and her semi-formal dress before she headed off to the dance.

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