

Get social



For people with MS, social media can be a source of deep and meaningful connections.

by Matt Alderton

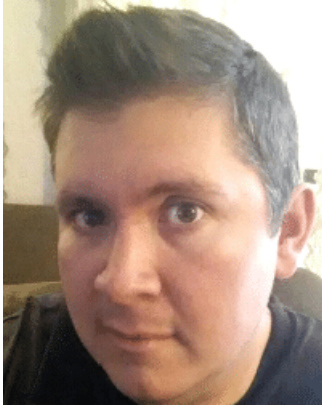


Mary Pettigrew is the creator of MSpals, an online community of people with MS. Photo courtesy of Mary Pettigrew

When he joined Twitter in 2008, Damon Davila didn't know what to expect. Social media, he

assumed, was all selfies and status updates.

“As far as I knew, it was just for typing that I was eating a cheese sandwich,” quips Davila, 33, of Pomona, California. Soon, however, Twitter became much more important to him. After years of experiencing tingling and numbness, Davila learned that he might have multiple sclerosis. “My mind was blown,” Davila recalls.



**Damon Davila
manages the Twitter
feed for MSpals.**

Photo courtesy of
Damon Davila

“I went online and tweeted, ‘I think I might have MS. This sucks, and my hands don’t work,’ and someone actually responded. She said, ‘Hey, I have MS. I write a blog about it. Check it out.’ I read it, and I really connected with it. I thought, ‘This girl knows exactly what I’m going through.’ So I contacted her, and eventually we became really close friends.”

Davila has since forged dozens more relationships on Twitter. In fact, he now has more than 600 followers and manages the Twitter feed for [MSpals](#), an online community of people with MS who connect using the hashtag #MSpals. “You meet a lot of different kinds of people on Twitter, and in the process you meet people you can actually relate to,” Davila says. “Because they have MS, too, you can tell them all the weird stuff that’s going on with you, and they won’t judge you. They get you.”

It’s not for everyone, Davila admits, but for him and many others, social media is an indispensable source of connection.

24/7 support

Online friendships go beyond the usual social and emotional benefits. In addition, they are:



**Society blogger
Trevis Gleason
writes about life
with MS at
[MSconnection.org/b
log](https://www.msconnection.org/blog).** Photo courtesy of
Trevis Gleason

- **Global.** There's always someone somewhere to talk to—day or night. “Insomnia is a big deal for many of us with MS,” says **MSpals** creator Mary Pettigrew, 48, of Dallas, who has more than 5,000 followers on Twitter. “It’s nice to know that if I wake up at 3 a.m., my buddies in the United Kingdom are awake.” Being part of a global network also gives you access to diverse opinions and information about programs in other countries, says Trevis Gleason, 48, a Society blogger at [MSconnection.org/blog](https://www.msconnection.org/blog) and author of Everyday Health’s [Life With MS blog](#).
- **Convenient.** Carolyn Palmer, who has MS-related mobility issues, says the best thing about Twitter friends is that they’re accessible even when other sources of support aren’t. “If I’m having a really bad day, my legs aren’t working and I can’t drive to a support group, I can get support right then and there while I’m lying in bed,” explains Palmer, 57, of Rancho Cucamonga, California.
- **Relevant.** “It’s a lot easier to find your niche online,” explains Davila. “If you go to a local support group, there may only be five, 10 or 20 people there to choose from; online, there are thousands.”



**Carolyn Palmer
looks to Twitter
friends for support
about her MS.** Photo
courtesy of Carolyn
Palmer

Joining the party

Davila likens social media to a party. “Whether you know people or not, if you show up you’re going to meet people,” he says. Among the most popular venues are:

Twitter. Twitter offers real-time interaction; it’s a giant conversation, and everyone is invited to participate. “On Twitter, it’s much easier to meet and interact with people,” Pettigrew says. “For instance, if you stumble across an interesting conversation or a hashtag-prompted live chat, you can jump right in.” (Hashtags are a way of identifying a key word of discussion on Twitter.) “Once you get used to using the search tab to find tweets of a certain topic, you also find lists of people associated with those topics,” Pettigrew adds.

To get started on Twitter, try searching for [@MSpals](#) or [@mssociety](#); then browse the search results for users you can follow, conversations you can join and other hashtags you can search.

Proceed with caution



Whichever online community you join, be aware of etiquette and safety practices, such as the following:

Be as open as you're comfortable being. Privacy is a legitimate concern, but the more open you can be about your life, the more meaningful connections you'll make, according to Damon Davila. Otherwise, he says, "It's like being at a party and ignoring any new person who walks up to you."

Think before you post. Unless you're in a closed community, consider everything you post to be public. "Be careful about what information you're sharing and the implications of that," advises Maura Dunn, senior manager of Social Media and Community for the National MS Society. "If you haven't yet disclosed your MS to your employer, for example, you may want to tread lightly."

Remain skeptical. "Beware if you're reading words like 'cure,' or that people have 'stopped' or 'reversed' their MS," Trevis Gleason says. "It's the old adage: If it sounds too good to be true, it probably is."

Beware of trolls. Although most people in online communities are warm and welcoming, there may be occasional detractors—"trolls," in Internet parlance. "They say things from behind a keyboard that they would never say to someone's face," Mary Pettigrew says. If you encounter such people, it's best not to engage them, as they're typically looking for a reaction. If they persist, block them or report them to the community manager.

Facebook. Pettigrew notes that Facebook is more about sharing—such as photos, videos, articles and stories—while Twitter is more about chitchat. Facebook also offers more privacy controls including closed (by invitation only) groups. Twitter-based MSpals, for instance, has a corresponding closed Facebook group; only its members can post and view articles, photos or status updates on the group page.

MSconnection.org. Sponsored by the National MS Society, [MSconnection.org](https://www.msconnection.org) features thematic discussion threads and chat groups where users can connect privately with people who share similar MS experiences. For example, there are threads about MS research and health insurance. Groups include those people who are newly diagnosed with MS or who have progressive MS; those for people who are single and living with MS; for animal lovers with MS; and for friends and family affected by MS.

"You can ask questions, get tips, discuss what your life with MS is like and find feedback and support," explains Maura Dunn, the Society's senior manager of Social Media and Community. The site allows anonymity because it doesn't use full names, and it doesn't share email addresses or locations.

MSconnection.org users also can join Society-hosted online support groups, which are led by peer facilitators who are trained to share online and offline resources to assist with specific questions.



Tim Sabutis turned to social media to connect with people more like him. Photo courtesy of Tim Sabutis

Tim Sabutis, 25, of Omaha, Nebraska, started using **MSconnection.org** in 2013. “I stopped going to live group meetings because many times the people were a little bit older than me, had a bit more of a progressive disease than me and were talking about things that would raise my anxiety about having MS. That pushed me to the online community,” says Sabutis, who now serves as one of the site’s peer facilitators, heading up the Young Adult Group. “It’s more specific to me, so it’s more motivating to me.”

As long as you’re cordial and cautious—outgoing but not outrageous—you can easily turn people with whom you have lively chats into lifelong chums. “Being online with people from all over the world made me see that I’m going to be OK,” Palmer says. “MS is what it is, but having friends who understand what I’m going through has changed my life.”

Matt Alderton is a Chicago-based freelance writer.

Every connection counts! Connect with others with MS at [MSConnection.org](https://www.MSConnection.org).