

Unofficial channels



People with MS are discovering worlds of ways to connect with each other, from podcasts to blogs.

by Shara Rutberg

In 2014, Jim Fairchild was in a “really deep, dark spot.”

Slammed by major exacerbations of his multiple sclerosis, the 49-year-old Vancouver, Washington, resident stopped working and driving at the same time.

“I’d lost my purpose. I’d lost my connection with people,” recalls Fairchild, who was diagnosed in 1998.

Then he found something that “saved his life.”

It wasn’t pills. It wasn’t a diet.

It was podcasts.

When a friend of Fairchild’s wanted to talk to him about podcasts, he assumed he was going to be interviewed. Instead, Fairchild’s friend suggested that he start a podcast of his own that focuses on MS. Though Fairchild didn’t really even know what a podcast was at that time, he agreed.

He asked himself, “How am I going to do this? How open and vulnerable will I be?”



Jim Fairchild, pictured with his daughters, hosts the “How You REALLY Doin’?” podcast, which features conversations with people living with MS. Photo courtesy of Jim Fairchild

“When I interviewed my first guest, I ended up admitting I wear [adult diapers],” Fairchild says. “I saw the guest’s jaw drop. Listeners say they heard his jaw drop. It has been my most talked-about interview.”

Conversation can be powerful, especially when you’re both vulnerable and willing to speak, Fairchild says. He realized he needed to get his emotions out and talk to people who understood. Podcasts allowed him to do that. Twenty-two episodes later, his “How You REALLY Doin’?” podcast (howyoureallydoin.com) features conversations with a range of people living with MS. It’s connected him with an entire community of listeners.

Podcasts are just one way people with MS can connect beyond the “official channels” of organizations like the National Multiple Sclerosis Society or MS centers. Instagram, Facebook, blogs, Twitter and online chats also can offer worlds of connection online.

Take it with you

“As a person with MS, we get a lot of information thrown at us, and it doesn’t always come in a way we can digest immediately or at a good time,” Fairchild says. Listeners can take their time and listen to podcasts when they want to, at a time when they don’t feel stressed, he says.

“I often hear from people who listen on their ride to work or when they’re getting medicine

infused,” says Kathy Reagan Young, host of the “FUMS: Giving MS the Finger” podcast (fumsnow.com/podcast), which provides information and inspiration with a wicked dose of humor.

“It’s such a user-friendly medium,” says Jon Strum, host of the RealTalk MS podcast (realtalkms.com), which delivers the latest on research, advocacy and caregiving. It’s far easier to listen to something than to navigate a website, he says.

“A computer can be challenging for people with MS—seeing the screen, manipulating the mouse. Podcasts are the easiest, most accessible way of sharing information. You can literally take it with you, and you can listen to it while you’re doing something else.”

Podcasts can offer a more intimate experience. “When I listen to podcasts, it really feels like it’s a friend talking to me,” says Reagan Young. “It’s such a different way of communicating.”

The blogosphere beckons

When Dan Digmann was first diagnosed in 2000, he says, “the first website I found about MS was playing a Muzak version of Celine Dion’s ‘My Heart Will Go On.’ It had me bawling my head off.” Digmann and his wife, Jennifer, who also has MS, decided to create their own blog to put something more positive online, danandjenniferdigmann.com.

“We both have MS, we’re dealing with so many things, and we don’t sugarcoat it,” says Jennifer. “But at the same time, we want there to be positive voices out there. To be honest, I’m in a wheelchair, and when people are diagnosed, that’s one of their biggest fears. I hope I show that life is still worth living and you can have an amazing quality of life if you’re in a wheelchair.”

MS can be very isolating, says Dan. “You’re not able to get out as often as you like. With social media, you’re still able to connect with people.”

Blogs and all forms of social media are a two-way street, the Digmanns say. “It’s the back and forth it creates that’s special,” Dan says. “We get to hear other people’s stories.”



Dan and Jennifer Digmann, who both have MS, started their own blog to create a positive online community in which to connect with other people with MS. Photo courtesy of Dan Digmann

Much of that back and forth is with other MS bloggers. “We’ve never met face to face, but I count them as our friends,” Jennifer says. “It’s a very tight-knit community. We comment on others’ posts. We keep tabs on each other.”

“I know what this disease is like, and I don’t want anyone to feel alone living with MS,” says Jennifer, who says having a community makes it easier to deal with the disease—and an online community can be just as powerful as an in-person community.

Simonne Simpson started her blog “Staying Healthy With MS” (stayinghealthywithms.com) when she found it hard to find anything online that she could relate to when she was diagnosed at age 31 in 2015. After delving into research on diet and lifestyle, she wanted to share what she’d found.

Blogging empowers Simpson to turn her MS challenges into something positive: help for others. “I share the experience in a blog post, and through that, I’ve connected with many who say they’ve been through the same thing or that my blog is helping them,” she says. “I’ve had some beautiful emails from people saying my blog has really helped them, which literally makes my day.” Like many blogs, her posts have links to audio translations for those who have vision issues.

Insta community

Simpson uses Instagram ([instagram.com/stayinghealthywithms](https://www.instagram.com/stayinghealthywithms)) to share gorgeous images from her life on the northern beaches of Sydney, Australia, along with luscious, healthy meals

she prepares. She also shares photos of her arm during infusions.

“I’d feel lost without my Insta community,” she says. “We chat about medications, symptoms and misconceptions. But mainly we all encourage and support each other. There’s a lot of love. Everyone I’ve followed and connected with has taught me so much about MS; people I would never have met otherwise.”



Naomi Ridge is one of six administrators of the Women with MS Facebook Group, which has 16,000 members.

Photo courtesy of Naomi Ridge

The image posts on Instagram let people connect with your message almost immediately, says Alex Safford, a 26-year-old self-described “gym addict” whose Instagram account ([instagram.com/the_ms_press](https://www.instagram.com/the_ms_press)) shares not only muscle and meal photos but also heartfelt insight about living with the disease that readers say bring them to tears.

“When I was first diagnosed, I had a very difficult time talking about it with anyone,” Safford says. “Face-to-face [talk] felt too personal, so starting with social media felt like the best way to connect with others going through the same thing. It gave me the opportunity to connect with new people as ‘The MS Press’ and not as Alex. I felt I could be more open and honest about my experiences.”

Facebook groups

When Naomi Ridge, 44, of Watertown, Massachusetts, joined the Women with MS Facebook Group in 2015, it had about 2,500 members. Today, 16,000 members share on the site, where Ridge is one of six administrators. Why such growth? It’s really filling a need—a place

where women can talk openly about MS topics related specifically to them, she says. “Since the group is closed, people can be very open and talk about some of the more taboo topics,” she says. “It’s an amazing community of women,” and one that spans a range of ages. According to Facebook statistics, Ridge says 20% of members are 25–34, about 30% are 35–54 and 18% are 55–65.

Twitter

Dan Digmann likes the 280-character limit required by Twitter. “It really makes you more efficient and effective with the words you use,” he says. RealTalkMS’ Strum also finds the platform an effective way to communicate. He compares it to television. “There’s a lot of junk, but there’s also a lot of really great things,” Strum says. “It’s your job as a critical viewer to separate the wheat from the chaff.”

Chats and forums

Online chat rooms like MSWorld.org have been bringing people with MS together for decades. Founded in 1996 with six members, it now serves more than 220,000 members living with MS. Members can participate in several forums and join a continuous live chat. The MS Buddy Chat app for iOS and Android devices also connects people. Reagan Young (FUMS podcast) facilitates hour-long live chats five nights a week on the app, covering topics such as “MS and career.” “It’s a very inspiring and supportive community,” she says.



Kathy Reagan Young is the host of the “FUMS: Giving MS the Finger” podcast, which combines information and inspiration with a wicked dose of humor. Photo courtesy of Kathy Reagan Young

Jennifer and Dan Digmann are also fans of live chats, having hosted conversations on several different platforms about how MS impacts them. “There’s an added level of anonymity on the computer, where with face-to-face conversations, it can get a little more embarrassing,” Jennifer says. They also value the opportunity to talk live with people across the country. “The internet makes the country and the world seem so much smaller,” she says.

Users worried about typos and embarrassing auto-corrects shouldn’t, Jennifer says. “The MS community understands dexterity issues.”

Buyer beware

Keep in mind that not everything you encounter on social media is true. Some platforms and moderators do rein in inaccurate information. “If we spot things, we’ll try to chime in and warn users of pseudoscience,” Ridge says of the moderators of the Women With MS Facebook group. She says the site users themselves do a good job of calling out suspect posts.

Getting started

There are so many options for connecting online that it can seem overwhelming. Do a Google search and sample one or two accounts to get a feel for the format, topic and personality of the users that resonate with you. Then branch out to see what other users on that account are following. Hashtags make finding your niche on Instagram easy. “You can go to any of the multiple sclerosis hashtags and connect with people from all over the world and follow their journey, all within minutes,” Simpson says. Instagram and Facebook groups both suggest other similar accounts to try as you go.

“Social media is really easy,” she says. “I love meeting and seeing people all over the world going through the same thing as me. It helps me feel like I’m not alone. I can literally pick my phone up, open Instagram and I’m surrounded by a supportive community straight away, wherever I am. My main support network for MS is online.”

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Check out the Society’s online community at [MSConnection.org](https://www.msconnection.org). Find virtual support, read the blog or start a discussion.