

Where to Find Online Support Programs for Diabetes

Controlling the frustration of diabetes can help you control your blood sugar.

By [Amir Khan](#) Nov. 12, 2014 | 12:58 p.m.



There are 29 million people [who have diabetes](#) in America, which equates to nearly 10 percent of the population. Manny Hernandez says he might as well have been the only one. In 2002, when he was diagnosed with [Type 1 diabetes](#) at age 30, Hernandez found himself thrust into a world he didn't fully understand, with very little guidance offered to him.

“Four years after my diagnosis, I joined a support group for insulin pump users,” he says. “For the first time in four years, I was surrounded by people like me. It changed my life.”

Being able to open up and talk freely about his disease with people who understood what he was going through was a turning point in his life. “I learned more in 30 minutes with them than I did in the four years of managing the disease on my own,” Manny says.

Not only did that meeting help him better understand and better manage the disease, it lit a fire under him to do the same for other diabetics. In 2007, he created [TuDiabetes.org](#), an online support network for people with diabetes, and [EsTuDiabetes.org](#), its Spanish counterpart. Those sites led to the nonprofit Diabetes Hands Foundation a year later. “These projects started as a side job for my wife and I,” Hernandez says. “We would come home from our day jobs and spend hours working to get the site up.”

Today, there are more than 65,000 active users on the sites. “Our aim is to make sure that no one who's touched by diabetes ever feels alone,” Hernandez says.

People typically come to the site for the first time after a tough day managing their disease, says Hernandez, who wants them to find an open, welcoming support network. “There's a very frequent message we keep hearing when people join,” he says. “They all say they hadn't met anyone with diabetes before, and that they've been feeling so alone.”

Breaking Down the Barriers

TuDiabetes.org is just one online resource available for people with diabetes. Over the last few years, numerous sites and support networks, such as MyGlu.org and TypeOneNation.org, have launched and offered Type 1 diabetics a place to air their frustrations, share tips and talk to others with similar experiences, says Hope Warshaw, a dietitian and president-elect of American Association of Diabetes Educators. “The diabetes online community is a really burgeoning and blossoming entity of tools and activities,” she says. “The community really began coming into its own about four or five years ago, and has started to remove some of the barriers between health care providers, the diabetes industry and patients.”

Another program is the [PEP Squad](#) (Parents Empowering Parents), a Facebook group where parents of Type 1 diabetics can offer support to each other. The group was started by Wendy Rapaport, a clinical psychologist and adjunct professor at the Diabetes Research Institute Foundation, who says the group offers much-needed support to its members. “As medical professionals, we can’t ignore the emotional and social aspects of diabetes,” she says. “Diabetes affects patients and their families, and the diabetes online community recognizes just that.”

Diabetes can be emotionally exhausting, Hernandez says, and these groups offer a way to [vent some of the stress away](#). “Sometimes, even if you do everything by the book, you can obtain radically different results,” he says. “It can be frustrating, and it takes a toll. Sometimes you just need to talk to someone who understands. The diabetes online community understands how much work goes into managing your disease.”

These groups also have an advantage over in-person groups, Rapaport says. “You can get support any time of day,” she points out. “There’s no set meeting time.”

The Dangers of Online Medical Advice

One of the major drawbacks to the communities is that you can’t be sure the [medical advice you get online is accurate](#). When a forum is public, it’s up to the moderators to keep inaccurate and potentially dangerous information out, which Hernandez says he and his team takes very seriously. “The first line of action becomes the community itself,” he says. “People want to see their community continue to thrive, so they report potentially false information.”

TuDiabetes.org also doesn’t allow prescriptive advice. “We’re OK with people telling each other what worked for them or how they manage their diabetes and [what they eat](#), but we don’t want people telling others how to change their therapy,” Hernandez says.

Nevertheless, the risk still remains, Warshaw says, which is why online communities can’t take the place of a relationship with your doctor. “It certainly can play a role in care and management, and it can help people get practical information, but it’s no substitute for professional medical advice,” she says. “Don’t make any changes to your care based on what you read without talking to your doctor.”

Making the Most of the Communities

If you have diabetes, Hernandez recommends joining one of the communities. Even if your disease is under control, you can [share your tips and tricks](#) to help others who might not be so

lucky. “By joining, you can connect with other patients,” he says. “This has the immediate result of you impacting their health and their emotional well-being.”

Whatever community you join, start by sharing your story, Hernandez says. It might just seem cathartic to you, but it can have a major effect on someone else. “I was originally misdiagnosed as having [Type 2 diabetes](#),” he says. “It took a while to figure out that I actually had Type 1. Sharing my story might help someone else go back to their doctor and get re-evaluated, so they don’t have to go through what I did.”

Joining the communities also lets you take part in raising awareness, he adds. “One dimension that has become a very strong element is advocacy,” Hernandez says. “It’s not just enough to affect change in ourselves, but to work for a change in the community.”

One way to do that is to take part in social media. The diabetes community has flocked to Twitter, hosting frequent chats using the hashtag [#DSMA](#), which stands for diabetes social media advocacy, and urging people to exercise using [#WalkWithD](#).

Ultimately, the diabetes online community gives people access to what they’ve been missing – mental support. “The community recognizes one of the most important components of the disease, the emotional and social problems, which has been sorely lacking,” Rapaport says. “If it was up to me, every person with diabetes would see a psychologist. This is a good start.”