



I Crowdsourced My Pain...

...and it worked! This is what you can learn from my adventures in social media self-medication.

By ELLEN SEIDMAN

→ IN RECENT YEARS, I'VE turned to Facebook and Twitter friends for advice on everything from finding the best sushi restaurants to handling relatives gone bonkers. So when I was stricken with one of the most debilitating conditions I have ever experienced, I did the logical, 2015 thing: I crowdsourced my frozen shoulder.

About a year ago, my left shoulder began hurting inexplicably. Arm movement grew increasingly restricted until one day I could no longer reach my hand fully upward or behind my back. Never before had the words *Can you unhook my bra?* been so unsexy.

#OUCH

An orthopedist diagnosed me with frozen shoulder. It's sometimes caused by an injury, she noted. I hadn't had one but, hmm, I *had* overzealously trimmed some hedges. (Suburbia: dangerous to your health.) Frozen shoulder starts with inflamed soft tissue around a joint that ultimately loses range of motion. The condition is more common

in women over 40 and people with diabetes, and it's said to affect up to 5 percent of the population. If you tell your 9-year-old you have it, she will sing "Let It Go" from *Frozen* just to be funny.

Exercises the orthopedist gave me helped improve movement but not the pain, which made me grouchy; it felt like someone was stabbing my arm with an ice pick. Comedian and fellow FS sufferer Ricky Gervais, appearing on David Letterman, described crying on the floor in agony after

playing with his cat. I knew what he meant; certain movements unexpectedly brought tears to my eyes.

I flung open the car door. *Whoa, that hurt.*

I reached into the fridge for a jar of pickles. *OMG.*

I sneezed. *.\$%@!!!*

So I visited a chiropractor, who spied my work tote and lifted it. "That's not a bag—that's a weapon!" he said, noting that it caused extra shoulder strain. D'oh! My Rx: a comfy Vera Bradley backpack, shopping therapy at its best. Next I started physical therapy, consisting of muscle manipulation followed by neuromuscular electrical stimulation—basically, vibrating pads. My

arm felt better when I left the session, but by the next day it was killing me again.

#HELP.ME.

Traditional tactics, including prescription anti-inflammatories, weren't alleviating the chronic pain. Finally, I turned to social media for salvation. I posted on Facebook and Twitter that I wanted to remove my frozen left shoulder, and had anyone ever dealt with that? Instantly, I got 20-plus responses. "Have you tried a cheap little TENS unit?" someone asked, a mini version of the machine at physical therapy. I checked with the PT, who said it might help. (So why hadn't he recommended it?!) I chose a highly rated one on Amazon, just 33 bucks. The buzzing felt good.

Showering was a challenge, sleeping even more so; I couldn't get comfortable. While roaming Facebook, I discovered Frozen Shoulder Friends, a private group. I joined, and as I read posts, relief flooded through me. Members even had a name for those flashes of pain: *zingers*. I asked for

sleep advice. Most popular response: on your side, hugging a pillow. Yes! Oh, yes! Also good: a heated bag of rice. Instead, at bedtime I applied a nuked buckwheat-hull pack. The heat loosened my muscles a bit.

I browsed online patient communities and posted questions. One person suggested rubbing in lavender essential oil, which has analgesic and anti-inflammatory properties. It helped. I learned to put a tennis ball in a sock, stand with my back to a door and rub my shoulder up and down over it to ease stiffness.

I have deep respect for medical experts. Yet in turning to real-people pros, I tapped into the vast wisdom of been there, soothed that. In fact, 72 percent of Web users say they have searched for health info, per the Pew Internet Project. I found it therapeutic, too, to hear from those who had "thawed."

Not all suggestions worked. For one, I refused to sleep sitting up in an armchair. Downing jalapeño poppers to reduce inflammation: just, no. An ex-colleague on Facebook raved about Roling, a soft-tissue manipulation technique. The two sessions didn't do much for me. Worse, the practitioner said I was "discomfort averse." I

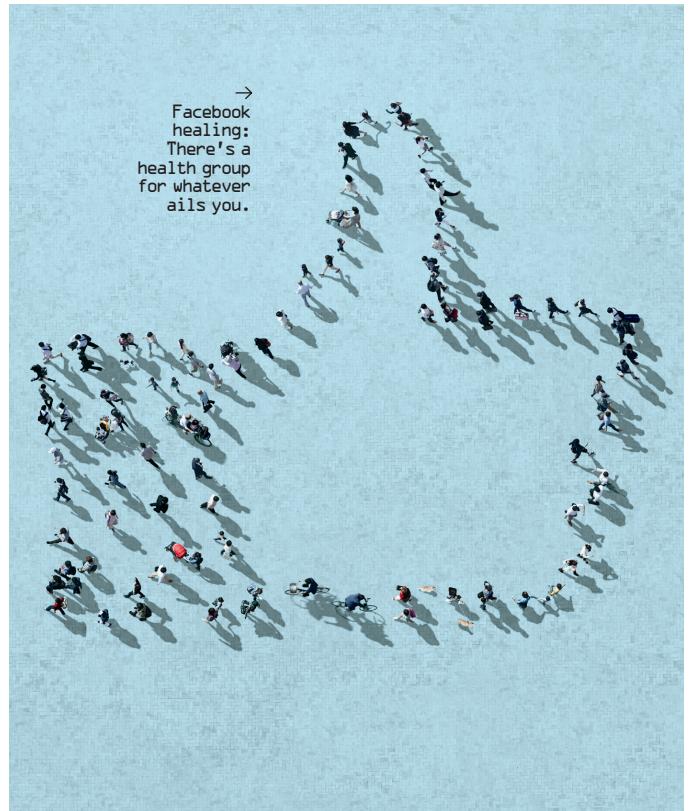
wanted to slug him with my buckwheat-hull pack.

Social media also came in handy when I outsourced complaining. (You can moan to your family only so much.) I vented on Frozen Shoulder Friends about everyday stuff that hurt, like applying deodorant, washing my hair and...living.

One woman posted a video of herself trying to remove a shirt, and we all LOL'd.

Crowdsourcing made the pain manageable, but still, I wanted a cortisone shot to improve my ability to actually move my arm. I checked with my frozen Facebook peeps, and the majority said it worked. So I went for it, and I heard the angels singing. The pain was gone. I could do my exercises without gritting my teeth.

Frozen shoulder can take up to two years to heal. My range of motion is slowly improving. Over on Frozen Shoulder Friends, a woman boasted, "I just undid my bra!" Me, I can't wait. Maybe I'll even take a video. ■



FIND YOUR RELIEF.COM

Online patient communities enable sufferers to share symptoms, questions and treatments. "People in these groups trade the sort of daily living advice doctors may not have

time to give these days," says Lisa Gualtieri, PhD, an assistant professor at Tufts University School of Medicine who specializes in tech and health. "You just need to use your judgment. Getting advice on sleeping is one thing, supplements is another." Popular communities:

- ▶ **MDJunction** has hundreds of support groups, for issues from allergies to breast cancer.
- ▶ **Healing Well** is another virtual community for sharing tips and virtual hugs.
- ▶ **AskAPatient** features patient-submitted reviews of medications.

- ▶ **HealthTreatment** is a collection of patient experiences and ratings for drugs, treatments and procedures. It also lists clinical trials.
- ▶ **PatientsLikeMe** gathers user data and compiles treatment and symptom reports for a variety of health conditions.