

Sick? Read all about it

'We don't just read the books, we live the books'

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THE GLOBE AND MAIL – May 9, 2009

In 2008, a medical student at the University of Toronto went looking for ways to improve the health of people suffering from three poorly understood but severely debilitating conditions called fibromyalgia, chronic fatigue syndrome (CFS) and multiple chemical sensitivity (MCS).

The student knew that the conditions, which are saddled with the typically misguided stigma of "being all in your head," were associated with social isolation. Yet she also knew that traditional support groups aimed at breaking that isolation didn't do much to improve patients' symptoms, largely because they revolved around "negative talk and complaining" that "magnify the illness and perpetuate the sick role."

So she sought out something different and in the end focused her research on a group in Kingston, Ont., whose members - all sufferers of fibromyalgia, CFS, CMS and other conditions and illnesses - overwhelmingly said their health was improved by their participation.

That's right: a book club, founded in 1996 by five women who couldn't get the answers they needed from their doctors.

Back in the 1990s, one of the founders, Diane Dawber, says she couldn't walk or even sit up straight for more than five minutes, and was in constant pain. She was diagnosed with fibromyalgia and, later, MCS. She tried all the usual remedies, including prescription painkillers, but they didn't work.

Then in 1995, her doctor recommended a book called *Wellness Against All Odds*, and Dawber's life started to turn around. "Someone else I knew who was lying on her living-room floor not able to do anything; she decided to join me and so she started reading with me," Dawber says. "We realized that we understood a lot more and took in a lot more when we read together."

Other women suffering from similar conditions joined their informal group, and in 1996, five of them launched the Health Pursuits Reading/Study Group.

Today, says Dawber, who is 63, "I'm not on any painkillers, I can walk for an hour every day, I can play with my grandchildren, and I'm a poet. I've had a book published this past fall and another one coming out soon which were many years in the making."

She even runs an open-mic poetry series in Kingston.

Other members of the club have had similar turnarounds, from a 75-year-old woman who reversed problems she had for decades, according to Dawber, to a 25-year-old woman who suffered from chronic pain after an accident and was also unable to get pregnant.

"I just about fell off my chair," Dawber said of the phone call she got from the young woman saying she was expecting.

The club currently has about 60 members, 10 to 20 of whom come to the monthly meetings held at a public library in Kingston. They're typical book club meetings in some ways; the members read and discuss a new book each time.

But in other ways, they're entirely unusual. They read only books about wellness that are recommended by their doctors or other members (they're currently reading three books on hormones: *It's My Ovaries, Stupid!* by Elizabeth Vliet; *The Natural Superwoman*, by Uzzi Reiss; and *Sexy Hormones*, by Lorna Vanderhaeghe) and they test the authors' recommended therapies on themselves to see which work and which don't.

"We don't just read the books - we live the books," Dawber says. "We try all the strategies and then we discuss it and we put together our results.

"The fur's almost worn off our guinea pig outfits," she adds with a laugh.

After each meeting, the members detail their findings in a newsletter that's distributed to hundreds of people in Canada and the United States, Dawber says.

In January they launched a website (<http://www.healthpursuitsgroup.com>) on which the members share all the best information and tips they've gleaned over the years. They also recommend books and sell an annotated bibliography of the ones they've found the most helpful over the years. And they sell \$5 DVDs of the annual lectures given by invited experts who talk to them in scientific detail about the issues they face.

They have also developed and sell a \$150 test kit that helps users determine what vitamins and nutrients they might be missing.

All the work maintaining is done on a voluntary basis and at the members' expense - research included. Dawber estimates they spent \$250,000 on nutrients and other products during the first six years of the group.

"We're mostly people that don't have satisfactory explanations for what their problems are," Dawber says of Health Pursuits members. "So we go right back to the basics of good health, from drinking water to cleaning up your environment to changing your diet to nutritional support and exercise.

"And we're very scientific, you know. We compare notes and we've been very cautious. We experimented on ourselves and we're not ready to give up on being healthy."

That proactive approach, fuelled by books, seems to be the difference between Health Pursuits and traditional support groups that produce little benefit. The U of T student reported, "Most individuals in this study felt their overall condition had improved since joining Health Pursuits. Since positive social support and development of self-management skills are both associated with improved health outcomes, this result correlates with the other findings in this study.

"It also suggests that Health Pursuits has successfully achieved its goal of improving the health of its members," the study concluded.

Says Dawber, "The essential thing is to have a way to go forward. If you are reading, you're constantly coming up with ways to go forward. And if you're reading together, it helps in the decision-making process of how to go forward and whether to go in this direction or that direction.

Getting better

Although only a member of the club for four years, at 75, Bea didn't want to waste any time and she hasn't. After more than 60 years of fruitless chiropractic and other manual work to relieve a neck injury she suffered as a teenager, she discovered osteopathic work with Robert Black and has made major strides in correcting the problem with both treatment, prescribed exercises and his remedial exercise class. She did the allergy testing and discovered that the foods she thought were good were her allergic foods, including eggs and cane sugar. She got a nutrient test kit and discovered her deficiencies and took steps to correct them. She is so enthusiastic and so much better that she is a major contributor of time and effort to Health Pursuits, keeping the test-kit team on track. And she said she didn't have much of a story!



The Health Pursuits Reading/Study Group in Kingston, Ontario: "Reading together multiplies your pool of wisdom, your pool of experience, your pool of information."