

Patient-Centred Care in Barrie, Ontario: *“Your Health In Your Hands”*

SUCCESS STORY



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Your Health *in your* Hands:

Patient-Centred Care in Barrie, Ontario:

"My action plan was to try to meditate twenty minutes every day. It worked so well the first time I tried, I fell asleep for two hours!" Yvonne Lee's confession elicits laughter and lots of nodding from the fifteen men and women in the Chronic Disease Self-Management Program at Barrie Community Health Centre.

It's a six-week workshop for people struggling with one or more chronic conditions. Yvonne Lee is one of three volunteer lay leaders for the group. She is also a breast cancer survivor who suffers from arthritic knees and spinal stenosis, a very painful degenerative disease. Today, in week three of the program, she's encouraging each of the participants to share their progress on an action plan they made the previous week. Bill B. is the first to speak up.

"My plan was to ride my stationary bicycle twice a day, five times a week, but the weather interrupted and I ended up shoveling snow instead."

Bill is 78 years old. A smoker for fifty years, he was diagnosed with COPD seven years ago, arthritis

thirty years ago, and now he is battling prostate cancer.

"This course is giving me the courage to approach my problems one by one and not let them get me down. I have a new lease on life."

These words are music to the ears of Christine Colcy, Director of Primary Health Care and Chronic Disease Management at the Barrie Community Health Centre and the champion of this self-management program. Two years ago, Christine sent two physiotherapists and one lay person down to



Bill B., Self-Management Group participant

California to get training to lead a course called the Chronic Disease Self-Management Program. It was developed by Dr. Kate Lorig at Stanford University. It's a structured, evidence-based, patient-centered program taught by trained volunteer lay leaders. The program runs 2.5 hours per week for six weeks and is designed to teach participants, and their caregivers or partners, the skills they need to manage the day-to-day challenges of living with a chronic health condition. The main goal is to improve the quality of their lives.

"The biggest problem I experience despite all my illnesses is depression," Bill admits. "It's very hard when you lose the ability to do all the things you love in life."

Bill was attending the Breathe Easy Program at the Barrie Community Health Centre when he learned about the Chronic Disease Self-Management Program. He enrolled immediately and is very glad he did.

"Before we adopted this model, we had disease-specific groups for everything from diabetes to arthritis to Parkinson's disease," says Christine, "but most of our participants were suffering from multiple chronic conditions. They needed concrete coping skills and we were looking for a more patient-centred approach."

Christine launched the self-management program with funds from the core budget of the Barrie Community Health Centre and a strong commitment from the Board of Directors to support

this change in resources and approach for the community. Since then, six groups have taken place and eleven lay leaders have been trained to lead them. This is group number seven running out of the Barrie Community Health Centre.

Each week, the fifteen participants are assigned reading on a subject from Kate Lorig's book entitled, *Living a Healthy Life with Chronic Conditions*. Topics include goal-setting, appropriate medication for symptom management, effective communication techniques to develop healthier relationships with spouses, partners and health care providers and managing fear, frustration and difficult emotions. Today, the topic is coping with pain and fatigue.

"Close your eyes... sit up tall and place your hand on your belly. Now breathe deeply in through your nose as if you are smelling roses..."

Lay leader Yvonne Lee is demonstrating a deep belly-breathing technique. It's just one of several relaxation techniques the participants will share today to learn how to cope

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with their pain and the symptoms of their chronic conditions.

“Now breathe out through your mouth as if you are blowing out a candle...”

They have spent the last five minutes brainstorming and sharing other ideas such as aromatherapy, meditation, listening to music and visualization.

Yvonne is teaching and learning too. Before her training to become a lay leader, she was a participant in one of the first groups in Barrie.

“This program teaches you how to think out of the box, to be inventive in dealing with your disabilities. You learn skills to help manage both your physical and mental challenges. You learn to be self-aware, to work with your doctors and not against them. The action plans I make every week help me get through a day, a week, a month – now I can help others too as a lay leader.”

Linda Mercieca is the Program Practice Administrator. She is in charge of intake, marketing and promotion for the self-management group and is delighted by the successes she is seeing. Participants are referred by their family doctor, health care professionals at the Barrie Community Health Centre or by friends and family. While today’s group is only the seventh they’ve run, Linda already has a wait-list for group number eight.

As a nurse, for years Linda assisted with many of the disease-specific groups at the Barrie Community Health Centre. Most of those groups are still running, but out in the community under the auspices of disease specific organizations or through recreation centres.

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LINDA MERCIECA

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So is Anne L. She’s sixty years old and looks a lot younger. In 2006, she single-handedly re-roofed her daughter’s home. Today, she can barely drive or dress herself. A serious fall at work a year ago resulted in compound fractures to her arm and a chronic condition called RSD – reflex sympathetic dystrophy. She is in constant pain. She signed up for the self-management group as soon as she read an article about it in a local newspaper in Orillia. Each week her daughter drives the 38 kilometers from Orillia to Barrie so her mom can attend the group.

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"I look absolutely normal, but I suffer from severe chronic pain in my arm and hand. I was becoming seriously depressed. No one understood how devastating it was. I no longer had control of my life. And then I came to this group. Now I have support and I am taking baby steps. People understand me and I am learning how to fix my whole body, not just this arm and this hand."

Back at the group, after two and a half hours, the leaders are wrapping up. They reiterate the vicious cycle of chronic disease – pain leads to stress, then anxiety, and depression, resulting in more pain, fatigue and illness. They review some of the tools they discussed earlier in this session to break the cycle and then encourage the participants to make action plans for the coming week.

"There are nine storeys in my apartment building," says Bill, "I'll walk all the hallways and climb the stairs each and every day."

Anne commits to practising deep belly-breathing. "When I'm in pain, I hyperventilate and panic. I need to learn how to control my breathing."

If necessary, some of the participants will be referred to appropriate community resources. After the six-week course is complete, they will also receive assistance in navigating the health care system to access services they may still require. A few weeks later, they will be invited back to a two-hour refresher program to see what progress they are making.

Soon their progress will also be evaluated to determine how effective the model is in encouraging and sustaining change. Christine Colcy expects the Barrie results to mimic those of similar programs across the country. A three-year study at the University of Victoria has shown that patients with chronic conditions who attend the Chronic Disease Self-Management Program use more coping skills to deal with their pain, exercise more, communicate better with their health care providers and experience less depression and fatigue than those who don't take the course.

Christine Colcy is already seeing these kinds of results informally. She's working on spreading the concept around the LHIN to ensure the program is targeted to groups that reflect the cultural and geographic diversity of the area. As the chairperson of a regional action group dealing with chronic disease prevention and management, she is striving to get more funding to train lay leaders and roll the program out north and south of Barrie. While highly cost-effective, this chronic disease self-management program



Anne L., Self-Management Group participant



Lay leaders running the Barrie Self-Management Group

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YVONNE LEE

still requires clerical and administrative support to expand beyond the walls of the Community Health Centre.

"This is a very popular program," Christine asserts, "and I am confident we will get the support to see it expand."

Christine is also engaging other community resources to support it. For example, she would like to see transportation and recreation services better coordinated with the program to improve access for the participants.

"We're working at an inter-ministerial level to embed the Chronic Disease Self-Management Program into our communities. We have learned from the program here in Barrie that it builds community capacity. It trains volunteer lay leaders to run the programs and they bring those skills into all aspects of community life. We are building an effective and sustainable model of chronic disease self-management and training patients as partners in their own care."

Anne L. is a prime example.

"This group has been a godsend to me. I am taking charge of my body again. When I recover enough of my own strength, I want to take the course to become a lay leader and help others too."

For more information about the Chronic Disease Self-Management Program at Barrie Community Health Centre, contact Linda Mercieca at (705) 734-9690 x222, linda.mercieca@bchc.ca or Christine Colcy, Director of Primary Health Care and Chronic Disease Management, at (705) 734-9690 x250, christine.colcy@bchc.ca.