

Finding answers to tough questions

Some days it is hardly worth the effort of getting out of bed. Even if we don't feel like that, we have all had a relative or friend who does. Aching body, poor appetite, shortness of breath, always tired. Living is a trial. Is there hope? Can anything be done? Tom has an answer, because Tom has been there.

When Tom was diagnosed with congestive heart failure (CHF) he already knew he had some big problems. His plans for retirement had fallen apart. Instead of traveling, taking long walks and ballroom dancing he found himself housebound. He missed the social contacts built up over his 30-year involvement in the arts community. He was tired all the time, isolated and hopeless. Most of all, he feared an early death.

He had to find some answers. "I realized I had to learn new ways of taking care of myself", commented Tom. And fortunately, he did.

Tom's first set of answers came when he enrolled in St. Paul's Hospital *Healthy Heart* Program. He learned how to be an active partner with his physician in managing his CHF using tested self-care strategies.

"I no longer consider myself just a patient," he stressed. "I am at the hub of my care, working in partnership with my doctor and other health care providers. My role on this team is to be my own health manager. After all, I am the one who knows best how I am feeling."

He learned about the importance of taking his medications and monitoring his symptoms, as well as making changes in his daily life that improved his overall health and quality of life. Most importantly he discovered the value of using a weekly action plan for setting health goals. Included in these goals was a regular exercise program.

"I started an exercise plan that was right for me", said Tom "and I learned how to manage my fatigue by including regular rest periods as part of my day."

Tom's biggest breakthrough came when he discovered a six-week Chronic Disease Self-Management Program, through the University of Victoria. This program has helped thousands of British Columbians through peer-led training sessions, to care for their own health and cope with the emotional, social and physical effects of chronic disease.

Tom learned relaxation techniques to deal with stress and the feelings of depression, fear and anger that kept surfacing as he adjusted to his illness. "Some of the coping techniques we learned were pretty corny, but when you're upset, they work!" smiled Tom. Almost everyone with a chronic illness has these feelings and needs these skills.

The program also provided Tom with useful tips for communicating effectively with family and friends and with the various health care professionals whom he now had to see regularly.

"I realized it was up to me to keep health professionals informed of my condition and my efforts to deal with it."

Tom participated in the Chronic Disease Self-Management program for six weeks and enjoyed the 2 ½ hour sessions. The presenters were people who themselves had chronic disorders, and who knew first hand what worked and what didn't. The other participants had similar problems and concerns, and it felt good to have lively discussions with them. When the sessions ended, he took part in a telephone buddy system with some of the other participants so they could provide support to each other.

Using the time management skills he learned and having a weekly action plan have kept him on track to this day. He monitors his symptoms, maintains his exercise routine and does all the other things he discovered that would help him be healthier. His new abilities reinforced the knowledge he had developed through the Health Heart Program.

“All these new skills helped me change my perception of how I should live with congestive heart failure. I decided not to think of myself as a victim of the disease, but to make choices about the quality of life that I could have”.

Tom is quick to add, “There is no such thing as ‘instant health’. Now I manage my life more carefully, so that I enjoy the best possible health I can. Active problem-solving makes me focus on what I can do better to feel better about my life.”

People with chronic diseases have to live with their illness 24 hours a day for the rest of their lives. Like Tom, they need to become experts about their own health. Health Planning Minister Sindi Hawkins agrees, noting that close to \$1 million has been allocated towards assisting Health Authorities make the Chronic Disease Self-Management Program available in more communities across the province over the next three years. The program's peer leader training will be delivered through the University of Victoria's Centre on Aging, a pioneer in teaching patient self-management in BC.

“Individual patients have more incentive than anyone else to improve their own health and with the right tools, they can do just that”, says Minister Hawkins.

“There is more to life than just my disease. In fact, I recently picked up my new passport”, smiles Tom. He has found his answer, and perhaps your relative or friend can too.

For more information, contact: hlth.cdm@gems1.gov.bc.ca