

CARERS Program teaches people there is life after caregiving – but only if you take care of yourself

There is life after caregiving, says caregiver Nancy Kraft, but only if caregivers learn the skills needed to not only care for others, but themselves.

“Loneliness, confusion, anger and denial,” these are the feelings associated with the caregiver’s journey, said Nancy, who looked after her husband Bernie, who had Alzheimer’s disease, for three years. Bernie died two years ago of a brain bleed. He was 85. The couple were married for 55 years.



Nancy Kraft with her husband Bernie, who died two years ago from a brain bleed.

Three years ago, Nancy participated in The Reitman Centre CARERS Program, a free program for people caring for someone with dementia. The program focusses on caregivers, offering them the practical skills and emotional supports needed to not only care for others, but to help themselves.

“(CARERS program) showed us if we didn’t put ourselves first, there would be nothing left once the show was over. If we put ourselves on hold, the damage is much greater,” said Nancy, who was in denial her husband had the disease or she needed help.

Once she began to attend the eight-week program, Nancy said realized the CARERS program was exactly what she needed.

The CARERS Program “validates you. You are impatient and angry. You are able to be impatient and angry, but you (are reminded) you’re angry at the disease, not the person.”

While there were caregivers in her program who were at a variety of stages of their journey, she said the fact she was surrounded by people who truly understood what she was going through was helpful.

“(The) caregivers were all really suffering,” said Nancy, who says caregiving is a “lonely journey.”

Caregivers, through, “are not aware of their suffering and the program helps with that. I found it took me to a very safe place where I could be open and honest.”

Giving caregivers what they need in order to remain healthy is the goal of The Cyril and Dorothy Joel and Jill Reitman Centre CARERS Program, said Dr. Joel Sadavoy, a geriatric psychiatrist and medical director for the Reitman Centre at Sinai Health System and the person who created the program about 10 years ago.

Dr. Sadavoy said caregivers, who are not giving any training, are “drowning in their roles” with the stress of supporting a family member, particularly a spouse “creeps up on you slowly.” While eventually most people learn the skills they need to care for people, “it’s at a great cost. And this program addresses complicated set of needs.”

Dr. Sadavoy said prior to beginning the CARERS program, he noticed caregivers of those living with dementia were suffering.

While people who choose to become parents have the necessary skills or have taken courses to gain them, those who are thrown into the role of caregiver, particularly of a spouse, find it very difficult and do not have the necessary skills to deal with behaviour issues associated to someone living with dementia or the changes in their relationship.

“In addition they need a systematic approach to dealing with often very intense emotional” situations they find themselves in. Caregivers “frequently feel isolated and unsupported. The heart of the philosophy of the program is that caregivers receive a comprehensive 360 degree approach that caters to their needs.”

The CARERS Program is a small-group setting of four to six caregivers. It runs for two hours a week for eight weeks. The program focusses on practical skills and emotional supports needed to care for people living with dementia; teaches problem-solving techniques and a structured approach; provides strategies for keeping a meaningful relationship with the person living with dementia; and coaches care partners in communication skills through the use of simulation.

“In the beginning we teach caregivers a new way of thinking, problem solving,” Dr. Sadavoy said. A couple weeks into the program, the clinician, or the person running the program, introduces simulation, where an actor plays the role of a person living with dementia and acts out a situation a caregiver may find herself in.

“Caregivers are coached by group on how to think differently, how to behave differently,” Dr. Sadavoy said. “At the same time, the group engages in discussion about (their) emotional state.”

Dr. Sadavoy gives the example of when a caregiver is fighting with her spouse and the spouses pinches her. The caregiver pinches him back.

“It’s a bizarre interaction. The caregiver needs to find a way to address it.” Dr. Sadavoy said the caregiver is coached on the ways she could react differently the next time and then, as a “group, they talk about what it is like to have these new relationships.”

Nancy said the simulation was exceptionally helpful. “When you are with someone every day you don’t see the big changes, you fill in the blanks and don’t even realize that you are doing it. The role playing helped,” she said as it gave you a new perspective and new ways of handling situations.

“It validated the journey. It was like watching a movie of your life. When you are in the midst of a caregiving role you can’t see the crisis you are in, you are reacting. The role playing allows people to see their situation, but like watching a movie so you can see what you need to do differently.”

AS York is one of nine Alzheimer societies that is currently hosting the CARERS Programs thanks to provincial funding, Dr. Sadavoy said. Dr. Sadavoy said it was decided, after much research, that not only was the program still relevant, it was much needed if the province is to help the number of people currently caring for those living with Alzheimer’s and other dementias.

In York Region alone, more than 15,000 people are currently living with the disease, with a diagnosis directly impacting 10 to 12 direct people.

Dr. Sadavoy said it was determined the program would still be effective if it was taught outside The Reitman Centre. Representatives from the centre train group of clinicians at its downtown Toronto facility so the clinicians can bring the program to places throughout the province.

The goal is to have the CARERS program running at 14 Ontario health regions and hosted by the various Alzheimer society chapters.

“We train health professionals at each site to deliver the program...Each society has its own environment and the program is tailored somewhat, but it is consistent in the way it’s delivered,” said Dr. Sadavoy. “The bottom line, the goal is to reach 15,000 care partners (family caregivers) over three years.”

In addition to the CARERS program, The Reitman Centre is in the midst of rolling out an online support program, which will be video-conference based. It also offers the TEACH program, a slimmed down version of the CARERS program, which runs for four sessions and includes up to 10 caregivers.

Thinking about caregivers now, said Nancy, “my heart breaks for them. God, it’s a lonely journey. Until you walk in our shoes, you don’t get the picture. (In the program) we were taught to focus on us, it gave us power. It educates. It provides information. It made (caregivers) aware of the position they were in and it gave them the skill so they can help themselves...it’s not their disease and they have to be healthy caregivers.”

AS York is hosting CARERS programs until March 2022. Contact Isabella Velikovsky at ivelikovsky@alzheimer-york.com or call 905-726-3477, ext. 236.

Books to help caregivers navigate a dementia journey

Nancy Kraft was the caregiver to her husband Bernie. She said she felt very alone on her caregiver journey and didn't share her worries, fears or doubts with anyone, trying to protect her husband from the stigma of an Alzheimer's disease diagnosis.

Instead, she read a number of books that helped validate her feelings. "I took my girlfriends to bed...it validated my journey hugely."

Her book suggestions include:

No Saints Around Here by Susan Toth

Through the wilderness by Robert and Anne Simpson

Under the Bridge Backwards by Barb Roy

Ten Thousand Days Ten Thousand Sorrows by Olivia Hobbidale

The 36-hour Conversation with Nora

The Alzheimer's Diary Experience by Joan Sutton