

Health

THE GLOBE AND MAIL



AGING

Role-playing helps caregivers cope

Innovative program teaches those looking after a person with dementia to problem-solve in an organized way

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As the population ages, more Canadians are being thrust into a role they never expected to assume and rarely have training for – as primary caregiver for a loved one with dementia.

“There’s no road map for this disease and how to cope with it,” says Sandra Atlin, who found herself desperate for help after her husband, Gordon, developed Alzheimer’s disease three years ago, a condition that began with mild cognitive impairment five years earlier.

“I felt overwhelmed by what was happening,” says Atlin, 78. “His short-term memory has completely gone, utterly. ... He can’t make decisions any more, not even about what he eats.”

Atlin had attended support groups, but it wasn’t until she discovered an innovative program at Mount Sinai Hospital in Toronto that she learned how to better cope both with her 86-year-old husband’s illness and the roiling emotions engendered by her new role.

The program, begun about four years ago at the hospital’s Reitman Centre, is designed to address the needs of a husband or wife providing home-based care for a spouse with dementia, or for an adult child looking after a parent. The 10-week course typically includes about five caregivers, who come together for an intensive 2½-hour session once a week, led by trained professionals, such as a psychiatrist, social worker or psychologist.

Besides becoming versed in the complexities of Alzheimer’s and other dementias, caregivers are taught how to problem-solve in an “organized and effective fashion,” says program leader Dr. Joel Sadavoy.

The approach is aimed at helping individuals cope with the burden of round-the-clock caregiving, from the endless day-to-day decision-making to feeling physically and emotionally drained. During the sessions, caregivers are trained to crystallize the nature of a problem, strip away the related emotion, then come up with potential solutions, says Sadavoy, head of community and geriatric psychiatry services.

“Someone might say: ‘I’m overwhelmed by my husband’s dementia. I feel like I have no life and I have no time for anything,’” he says.

With the help of program lead-



Sandra Atlin learned in the Mount Sinai program how to react more effectively to her husband, Gordon’s, apathy. NATHAN DENETTE/THE CANADIAN PRESS

ers and other group members, the caregiver is asked to keep whittling down the problem to get to its core.

“What comes out is: ‘I would really like to be able to go out two afternoons a week from 2 until 5 to be with my friend Jane and my friend Harriet,’” Sadavoy says.

“Once you get to that level of detail, then it becomes possible to actually find solutions. What you can’t find solutions to is the overall feeling of ‘I don’t know who I am anymore and I have no life.’ That’s how problems usually come out, highly charged emotionally, with a sense of overwhelmingness and complexity.

“The goal is to teach the method of thinking and at the same time to create in the caregiver a sense of mastery and control.”

What’s novel about this program is the use of actors – called patient simulators – who role-play scenarios with caregivers as a means of working out specific issues raised by individuals in the group.

For Atlin, dealing with her husband’s family doctor was frustrating and demeaning because he tended to dismiss her concerns and was loath to answer ques-

tions about her spouse’s medical care. With the actor stepping into the role of the doctor, Atlin was able to practise how she would handle future interactions.

“I got some advice and some practice on how to approach him, and I got the courage, because when I did approach him, in reality, he didn’t like it a bit,” she says. “I got the courage to leave him. And I don’t know how I would have handled that without it.”

“I had the opportunity to practise how to be straightforward and strong with this as my husband’s advocate. And we now are with a much better person for him – and for me.”

Atlin also learned how to react more effectively to her husband’s altered behaviours. Like many people with dementia, he often exhibits apathy, though thankfully, she says, he is not physically or verbally aggressive. Role-playing helped her find a way to get her husband out of bed on those mornings when he was determined to stay put.

“I know he likes to help me, even now. So I would say, ‘Well, can you help me make breakfast?’ And he would reply more positively to that approach, instead of

‘Come on, get out of bed. Your breakfast is ready.’”

Sadavoy says the group lets caregivers feel connected and understood in a “safe place.”

“Caregivers are very lonely, actually,” he says. “Nobody really knows what it’s like unless you’re right there on the spot in the midst of it.”

A few similar programs are in place elsewhere, including one through the Chinese Geriatric Community Services of Calgary and the Yee Hong Centre for Geriatric Care in Toronto, and Sadavoy would like to see the course expanded across the country.

That notion may get a boost with the recent launch of a program for working caregivers, funded by a \$2.84-million grant to Mount Sinai from the federal Social Development Partnerships Program.

Sadavoy’s team has specially designed the course for Canadians who are juggling a job and the care of a loved one at home, a double-barrelled role that can lead to poor work performance as well as an elevated risk of depression and anxiety. The Working Carers Program is being delivered by Ceridian Canada, which pro-

vides health and work-life support services to employees at client companies.

A 2012 Statistics Canada study found that 28 per cent of – or eight million – Canadians aged 15 or older were caregivers to family or friends with various long-term health conditions, including dementia. Sixty per cent of those were employed. About four in 10 employed caregivers said they arrived late to work, had to leave early or take time off to care for their ill family member or friend, the report found.

Although retired from her career as an adult educator, Atlin has needed to seek periodic help from personal-care workers so she can get some respite from 24-hour caregiving. Asking for help was difficult, in part because it brought on a sense that she wasn’t doing enough, Atlin says.

Atlin says the caregivers course helped her deal with that guilt. “I think the problem-solving especially made me understand that if my problem is guilt, there are ways I have to get over that because that doesn’t help me or Gord.”

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