PROFILE

Community Advocates Mike and Karen Kessler Share Their Story

Mike and Karen Kessler

In 2014, Mike Kessler, a member of Alzheimer Society of Windsor-Essex County, was in a car accident that caused him to suffer a non-traumatic brain injury and a concussion. But even after receiving two years of speech therapy and physical rehab, he had still not fully recovered — particularly when it came to his cognitive health.

"Things were actually getting worse," Kessler said. "It was my wife, Karen, that noticed all the symptoms that I was displaying. I would have trouble completing sentences and completing thoughts. It took a lot of personal advocacy on Karen's part to actually get me in front of a neurologist."

Almost 18 months after Kessler's first symptoms, he came home with a diagnosis of vascular dementia and mild Alzheimer's.

"For me, the diagnosis was actually a relief," he recalled. "Some people look at it as a death sentence. What I didn't want to do was give up. I'm a fairly hopeful guy. Now that I had the name of the monster that I'm facing, I knew there had to be a path forward."

Two months after his diagnosis, his wife contacted the Alzheimer Society. The Kesslers were assigned an education support coordinator (typically either a trained social worker or a nurse, who advises new Alzheimer Society members about different programs and support initiatives). And, the couple joined *Minds in Motion*, a four-week program that incorporates physical and mental stimulation for people with early to mid-stage dementia and their care partners.

"After the first day, when Mike spoke about himself, the person running the program had tears in her eyes, and said, 'Can you stay after? Could you be on my podcast?' That's where it started, and since then there have been opportunities dropping out of the sky to advocate," Karen said.

Since those early days, the Kesslers have become champions for building dementia-inclusive communities, through participating in programs, advocating for policy at the local and federal levels, joining boards, being repeat guests on podcasts, posting videos to his own channel, and speaking at major fundraising events, with crowds of 1,500 people.

If Kessler had one message for those grappling with an early cognitive diagnosis, he said, he would be to be honest about your situation - with yourself, at the very least. "One of the big things that gets in the way of someone's treatment is denial and pride," Kessler said. "What do I need to deny it for? It's kind of obvious at times. If I'm able to tell my story, maybe I'll help someone else at least face the idea of getting diagnosed, because early diagnosis is vitally important."

Kessler's own experience of waiting 18 months for an accurate diagnosis solidified his belief that primary care physicians need to receive better educational training about dementia and its signs. And as members of the Patient, Family and Caregivers Partnership Council for the Windsor Essex Ontario health team, the Kesslers are working to make local hospitals more dementia-friendly by advocating for increased training of hospital staff when it comes to caring for patients with dementia.

Further, they are seeking approval of a proposal at a local hospital to have a wristband of a different color, either light blue or yellow, that can identify patients with dementia. As soon as patients are admitted to the hospital, they would be given this wristband by the staff. Kessler believes it would change the experience of patients with dementia in hospitals and make them more accommodating environments.

"So they [hospital staff] know that I have dementia, they have to be patient with me, speak slowly, maybe repeat requests one instruction at a time - and my caregiver gets to go with me," Kessler explained.

Mike and Karen have been such present advocates, they say, they are becoming accustomed to being stopped by strangers occasionally and engaging in conversations about dementia. "The advocacy doesn't stop with professional media," he said. "I'll advocate no matter what, it doesn't matter- [at a] coffee shop and somebody stops us and talks to us."

Outside of their advocacy work, the

Kesslers maintain an active lifestyle and find joy in still doing many of the things they loved prior to Kessler's diagnosis, like hiking and canoeing.

"One of the newspaper people said, 'Why do you have so much hope?'" Kessler added. "Why not? Where there's breath, there's hope. I don't want to give up. I don't want anyone else to give up. Let's just try to make the time that we have the most productive and the happiest we can."

Contributed by the Alzheimer Society of Ontario. For more information visit https://alzheimer.ca/on/en