

Support changes everything for people living with dementia: Society

January is Alzheimer's Awareness Month and the Alzheimer Society of York Region is aiming to connect people living with dementia ? and their families ? with the supports they need so they don't have to face the journey alone.

Finding supports early is key in this journey, they say, and the Society's First Link program is a great initial step forward.

First Link is a program offering services and information to people living with Alzheimer's and other dementias on risk reduction, living well with dementia, up-to-date research, referrals in more. It's all about helping individuals and their families manage the many challenges dementia can present.

'It's a horrible, difficult disease for anyone, but people fare a little bit better if they're connected earlier,' says Andrea Ubell, Director of Programs & Client Services, for the Alzheimer Society of York Region, which is based on Edward Street in Aurora.

Since the program's inception, Ubell says the number of people who have reached out to become involved has been 'steadily increasing,' something she attributes both to more people being diagnosed as well as more doctors being aware of what the program offers.

'What usually happens when you go to a doctor is they say, 'You have this disease, here's a number, give it a call.' The beauty of First Link is when the diagnosis is first made at the doctor's office, the families and the person are asked, 'Would you like us to connect you with the Alzheimer Society?' At that point, referral is sent to us, and we call them in a week or two, depending on how urgent the situation is, and stay in touch with the family, too.

'In the old days, and it still happens, you got to a geriatric specialist or you get a diagnosis, they may or may not see you again unless there's a problem. Knowledge is power and helps us to cope better.'

The program also connects patients and their families with other organizations that provide supports, such as CHATS (Community & Home Assistance to Seniors), for people with different needs, including those in the early stages of dementia.

'Part of what the Alzheimer Society of Canada is doing is trying to combat some of that stigma,' says Ubell of some of the preconceived ideas people have about Alzheimer's and other forms of dementia. 'Unfortunately, here in York Region we don't have a memory clinic, per se. People are not often diagnosed until they are well into the disease. Family doctors are a little bit reluctant to give people that diagnosis. Families and the person with the disease, because of the nature of the disease to some people and how it presents, are reluctant or unable to accept it. They don't reach out for help and we see them in our emergency rooms at a crisis point.'

To underscore the importance of making contact early, Ubell recalls one family who became involved with the Society back in 1992. A son reached out regarding his mother's life with dementia and their family support groups and education classes proved invaluable ? and proved invaluable again when the man's wife reached out to them again several years later.

'She was aware enough to see there were changes in her husband. She was seeing them, able to get to a doctor early, get him diagnosed, get him on some medication, and I would say for the first few years they lived very well with the disease and that's the whole point of us trying to reach families early,' she says. 'It's telling people they're able to live well in the early stages of the disease and, as the disease progresses, with the right support, families will be able to get through this with support. It's a very difficult hill. 'Call us.' That's the main thing. Reach out and call us. There's never a question that is something you shouldn't ask. If we don't know the answer, we will find it out. It's support, it's educational resources, and it's linking to services whether they be our service or community services. The health care system is a really challenging one to navigate, even if you work in it, it is very confusing. If we can help in any way, please don't delay calling.'

To get connected to support, contact First Link Coordinator, Sara MacLean at 905-726-3477 or smaclean@alzheimer-york.com. For more information, visit alzheimer.ca/york/en/help-support/programs-services/first-link

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