

Society aims to stamp out stigma surrounding dementia

By Brock Weir

Despite increased awareness surrounding dementia and all its forms, recent studies have shown there is still a distinct stigma surrounding the disease that affects 564,000 Canadians, over 15,000 of whom live in York Region.

But the Alzheimer Society of York Region is looking to address that stigma head on in January, Alzheimer Awareness Month. To mark Alzheimer Awareness Month, the Society has released the results of a Leger-led survey which polled a sample of 1,500 Canadians. The survey found that 46 per cent of respondents would feel ashamed or embarrassed if they had dementia, while 61 per cent said they believed they would face discrimination of some kind.

Further results showed one in four Canadians believe their friends or family would avoid them if they were diagnosed with dementia while only five per cent said they would make the effort to learn more if a family member, friend or colleague received the diagnosis.

‘The stigma largely manifests itself in a way that people will address dementia only when they are in a state of crisis,’ Loren Freid, CEO of the Alzheimer Society of York Region tells *The Auroran*. ‘The stigma often prevents people from seeking help sooner, and in seeking help sooner there is help that can be provided, things that can be done in order to maybe mitigate the progression of the disease and provide important supports to families earlier in the disease process, which the family might find comfort in receiving. I think the disease then becomes a bit of a roadblock to seeking assistance earlier rather than later.’

Many times families don't know how to interpret the signs of dementia, he adds. Some might believe that the actual symptoms of dementia, when they ultimately present themselves, are simply part of the aging process. Many times, however, this is not the case. ‘We can help people better understand whether or not they are [symptoms] and if you understand that certain behaviours are not part of the normal aging process, this will help the family to understand the situation better,’ says Mr. Freid. ‘The stigma [can lead to] a lack of adequate information on what can be done sooner in the disease process.’

To help combat this stigma, an initiative of the Alzheimer Society is First Link, which encourages that very thing: encouraging families to seek assistance during the first signs of dementia.

First Link works with family doctors who have patients diagnosed with dementia in facilitating dialogue between families and the Society. Families through the program give permission for the doctor to contact the Society and the Society, in turn, to reach out to families.

‘Instead of waiting for the family to contact us at the point of crisis, we are trying to encourage seeking help sooner at the point of diagnosis,’ says Mr. Freid. ‘First Link is one way we are approaching this and this also takes the pressure too off the family having to make the call. We can make the call to the family and the family can choose whether or not to accept the service.’

They are also raising awareness through re-engaging their Change the Dialogue campaign, which aims to not only challenge the stigma but ‘provide an environment where people are comfortable having that important dialogue around dementia.’

‘Family members can still be vibrant, active members of the community, particularly in the early stages of the disease and that person can still benefit from a life-fulfilling existence with the disease,’ he says. ‘That can only happen if contact is made early. We know of a caregiver here who has gone on vacation with his spouse when his spouse was diagnosed early with dementia. It was early enough in the disease process where they were able to travel and enjoy the experience. That is what we are really trying to say: if you can bypass the stigma, you would be creating a much greater opportunity to ensure a fulfilling life experience for the person with the disease. If there is ever a time for somebody to enquire, for somebody to ask questions, this is a great time for them to call us and we'll be happy to direct them accordingly.’

To do so, you can contact the Alzheimer Society of York Region at 905-726-3477.