

#ilivewithdementia

By Sarah Sobanski

It's January and that means it's time to talk about Alzheimer's awareness.

According to a press release by the [Alzheimer Society of Hastings-Prince Edward](#), "Almost 50 per cent of Canadians would not want others to know if they had dementia."

I have to say, that makes sense to me. Alzheimer's is such an intimate disease.

The society wrote, "While awareness about dementia has increased, stigma and negative attitudes around it continue to persist."

This year, as a part of its awareness campaign, the society released a new survey of 1,500 Canadians between 18 and 65. The purpose of the online survey was "to spark conversations and encourage Canadians to see dementia differently."

Shortly after my opa died - after several years of struggling with Alzheimer's - many of the surviving members of my family discussed what it would be like if they or their loved ones developed Alzheimer's.

"Fifty-six per cent of Canadians are concerned about being affected by Alzheimer's disease. Of greatest concern is their fear of being a burden to others, losing their independence and the inability to recognize family and friends."

We asked questions: Is it better to be unawares when moving on from this world? Could you ever imagine slowly forgetting your friends and family? Is it easier to let go if you're forced to? Could this happen to you?

Of course, it could. Rationally speaking any of us could develop Alzheimer's.

But Alzheimer's, in its nature, is almost unbelievable in many ways.

We asked, "How could someone forget you - their child, their grandchild?"

It isn't a good place to sit and wonder. But it makes sense that the disease that causes you to lose your memories is also so shrouded in mystery.

This unknown, these questions that the disease leaves might very well be a vast contribution to the negative connotations we surround it with. Alzheimer's is scary - why discover when you can forget?

Finding of the survey revealed "46 per cent of respondents would feel ashamed or embarrassed if they had dementia, while 61 per cent of those surveyed said they would face discrimination of some kind."

I wonder what discrimination we might face if any of us were to develop Alzheimer's. Would someone take advantage of our growing inabilities? Would they treat us differently even in the early stages - make us feel small because things aren't coming to us as easily as they used to? Would they have the patience?

"Canadians believe that people with Alzheimer's disease or another form of dementia are likely to be ignored or dismissed (58 per cent); be taken advantage of (57 per cent); have difficulty accessing appropriate services or supports (56 per cent); be feared or met with distrust or suspicion (37 per cent)."

"One in four Canadians believe that their friends and family would avoid them if they were diagnosed with dementia, and only five per cent of Canadians would learn more about dementia if a family member, friend or co-worker were diagnosed," according to the society.

In the press release, CEO at the Alzheimer Society of Canada Pauline Tardif said, "These results validate our thinking, that stigma is one of the biggest barriers for people with dementia to live fully with dignity and respect."

"The findings underscore the work we must still do to end stigma once and for all. There is no shame in having dementia. We can't let negative perceptions stand in the way of people with dementia seeking help and support. Life without discrimination is a right for anyone affected by this disease," she said.

I couldn't have said it better myself. Be better than the statistics. If you or someone you know has Alzheimer's learn how you can better understand what he or she and those close to him and her are going through at [ilivewithdementia.ca](#) and possibly look for things like [assisted living fullerton](#) and other places to help you and them get through this difficult time.

Bancroft's Alzheimer's Society awareness walk takes place at Hastings Centennial Manor Jan. 27 at 9:30 a.m. to 11 a.m.