

Opportunities to Meet, Talk and Learn about Dementia

Standing outside the meeting room, you will hear hoots of laughter and friendly discussion. These are the sounds of the CHANGES support group for persons with early stage dementia.

Today the group is discussing whether to talk about their diagnosis with others. Trudy hasn't told anybody other than her spouse and has asked the others to share their experience.

Several group members say they feel it is important to speak openly about their diagnosis with family members, friends, and even people they meet in their daily activities. Rachel says that telling people makes her more comfortable as she doesn't worry about trying to hide her memory problems. Thomas says he values being able to talk with his family about the changes he is experiencing and what they can do to help. Laura says she wants people in her town to understand that she is still capable of doing many things and living an active life.

When a person receives a diagnosis of dementia, the question quickly arises... "who should I tell?" For many people, this question is full of uncertainty. They may worry about upsetting their family members or fear that friends will stop calling. These things can happen, but talking about the diagnosis can also have many positive outcomes.

For the individual with dementia: Often individuals who have shared their diagnosis with family and friends say it helped reduce their stress. They feel their family and friends are better able to understand and accept any changes in their abilities. They also value the opportunity to talk about what kinds of help they would appreciate, so that family and friends can provide support in appropriate ways.

For family or friends: It is common for family or close friends to notice the warning signs of dementia. They may worry about how to bring up the subject or worry that the person is missing out on treatment opportunities by delaying testing. Talking about the diagnosis with family and friends reassures them that the person is getting appropriate medical attention. It also allows them to assist the person and to access support for themselves to understand the illness and plan for the future.

For the community: Some people with dementia talk openly about their illness with people they meet in their daily activities. Some become advocates by speaking with the media and government representatives. These people play a key role in making our communities more dementia-friendly. Many people have never had first-hand experience of dementia. When people with dementia talk openly about their diagnosis, they help educate others and reduce fear and stigma.

Ultimately, it is up to each individual to decide when and how to talk about their diagnosis. What may feel right for one person, may be uncomfortable for another. It's important that we honour each individual's decision.

If you have received a diagnosis of dementia and aren't sure what to do next, contact the Alzheimer Society. A Client Support Coordinator can help you understand the illness and decide when and how to talk about it with your loved ones.