

Alzheimer Society

PETERBOROUGH, KAWARTHA LAKES, NORTHUMBERLAND & HALIBURTON

The **Client Advisory Committee (CAC)** is a dedicated group of client volunteers that are responsible for providing advice and guidance to the Alzheimer Society Board of Directors regarding issues of importance or concern to people with dementia and their partners in care, to ensure the work of the society remains informed, high quality and relevant.

One of the projects that the CAC recently completed was a generic letter that any person with dementia may provide to their friends and family to help others understand their condition and the challenges that they face. The CAC asked that this letter be shared with the hope of reaching as many people as possible. We ask that you take a couple of minutes to review their letter and to distribute it to those that you believe will find it helpful. ~Karen Beaney, Volunteer Coordinator

Dear Friend / Family Member,

As you may be aware, I have been diagnosed with a condition that causes me to experience dementia. The word “dementia” is a general term used to describe a set of symptoms that can be caused by disorders affecting the brain. Dementia involves a progressive decline in cognitive functions such as memory, communication skills, reasoning and judgement, and the ability to plan and organize. The level of difficulty a person experiences depends on the stage of their illness, however it will eventually affect my ability to perform everyday activities. As my condition progresses it will require adjustments in the way we interact and I want you to feel comfortable talking to me about the changes I am experiencing.

I have listed here, a few of the difficulties I may have now or in the future and suggestions for how you might best support me.

- When speaking to me, please speak slower than usual. I get easily confused and might need you to repeat what you have said. It is okay to ask if I am following what you have said if I do not seem to understand.
- Dementia affects short term memory. Please be patient; if you are referring to a previous conversation we have had I may need you to remind me of what we were discussing before I can proceed.



ALZHEIMER SOCIETY OF PETERBOROUGH, KAWARTHA LAKES, NORTHUMBERLAND & HALIBURTON

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CHARITABLE REGISTRATION NUMBER 12939 7980 RR0001

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- If I say something that does not make sense, please ask for clarification. It is common for people with dementia to make unusual word substitutions.
- Please don't interrupt me when I am speaking; I will lose my train of thought and might not be able to pick up where I left off.
- You may find that I interrupt conversations, because if I don't say what I am thinking immediately, I might forget what I wanted to say.
- I get easily frustrated with myself and can have "good" days and "bad" days. It is possible that I may be short tempered at times and seem depressed or out of humor; please don't take offense.
- There will be times when I just need to have a quiet day without a lot of activity or conversations with others.
- Situations with lots of people, multiple conversations and background noise are overwhelming for me. I may turn down invitations to these types of events or may need to limit the amount of time that I can stay.
- Bear with me if I do something unusual, for example – put the kettle in the refrigerator.
- I may no longer be able to be the lead person on important decisions, as dementia affects the ability to reason, problem solve and make choices where there are many possible options.
- I need more time to complete certain tasks and may become irritated if I am rushed or pushed to make quick decisions.
- Please don't minimize my condition with comments such as "you don't look like you have dementia", or "we all forget things". Symptoms appear and disappear at random and may not be evident at times when we have interacted.

It is very important to me to continue the connection with my friends and family. I hope that by having open conversations about my condition, it will assist in your understanding of the support I might need to maintain normal relationships with the people in my life.



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