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Developing an Ontario Dementia Plan **A proposal for engagement from the Alzheimer Society of Ontario** **13 Nov 2014 – Updated 8 Jan 2015**

The Ontario government has shown leadership in addressing dementia in our province and our country. Premier Wynne's support in raising the issue of dementia with her fellow Premiers at the Council of the Federation shows this leadership and is appreciated by the Alzheimer Society. Minister Hoskin's initiative in calling for a dementia strategy nationally helped promote discussions among our nation's health ministers. The mandate letters to the Cabinet Ministers reassures us that Premier Wynne's government will follow through on commitments made.

As Ontario recognizes the impact of dementia and moves towards investing in dementia and caregiver supports, we are proposing that the government lead a process of engagement with people directly affected by dementia to inform an Ontario Dementia Plan.

We all know the statistics. The number of people living with Ontario is growing at an alarming rate. The number of Ontarians that are caregivers is also increasing and has an impact on our health system, our social welfare system, and our economy. Dementia affects a person's entire life. It affects more than just their health. It undermines their capacity to be involved in their communities. It can result in needs for specialized housing. It can lead to unfortunate encounters with the police and safety risks like going missing. It calls upon health providers to have special skills in responding to persons with dementia and to support families. Many times families are still working, raising children and supporting older members with dementia. Workplaces, municipalities, schools and universities, housing offices and police services all have dementia on their agenda. Women experience exceptional rates of dementia and provide exceptional services as wives, daughters and service providers who provide care.

One of the most significant changes in our conversations about dementia is that people living with dementia want to talk. For the first time people are being diagnosed at early enough stages that they want to be involved in decisions that will affect their lives. They are shunning the stigma of former times and speaking up. Families who once hid their family member from view are now actively supporting social engagements with old friends and new friends. Community organizations like churches, synagogues and temples, retiree and cultural groups are looking for ways to serve members with special needs. People with dementia and their families want to talk about living well with dementia and their communities want to join the conversation.

The government's commitment to addressing issues related to dementia requires a plan to coordinate existing supports while recognizing that it needs a plan to respond to increasing numbers of people with dementia. A sound plan will reflect the wisdom of people living with dementia and their caregivers. Governments lead when they seek out "the wisdom of the community". Dementia is a "whole of life" challenge and our response needs to be equally comprehensive, and the process of developing a plan must be inclusive of people with dementia. We might think we know what needs to be done, but we aren't living with dementia. Without people with dementia at the heart of planning, we risk making

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assumptions about their needs. This leads to investments in solutions that miss their target and result in wasted efforts.

The Alzheimer Society envisions solutions that engage the whole community – kids in schools, high school volunteers, and college and university students embracing careers sensitive to dementia. We envisage workplaces that support caregiving and treat workers who may develop dementia while employed with dignity. We envisage housing that fosters independence and social connections. We envisage communities where people with dementia can safely live and be supported within their communities. All of this is possible.

Ontario needs a dementia plan that looks beyond health. To develop a comprehensive plan that responds to needs and engages non-government sectors to join the movement we are proposing that you lead a “whole of government” conversation with communities about what we can do as a society about a problem that will touch us all. Many government ministries will be called upon to address dementia and we suggest a broad, multi-ministry approach will be most effective in finding societal solutions.

To move forward on platform commitments and to broaden the reach, we are proposing a 2-yr grassroots engagement approach to planning that would place people with lived experience of dementia (people with dementia and their care circles) at the centre, and which would mobilize the greater community to consider and take up its role in supporting people affected by dementia.

Below is the proposed timeline for this grassroots engagement process:



Through a grassroots engagement plan, we can develop an Ontario Dementia Plan rooted in wisdom from people with dementia and their caregivers. To achieve this we are proposing that you lead a process to nurture these community conversations and to help the grassroots find solutions to the

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challenges that dementia brings to their community members. Government needs to put in place specific plans and programs around dementia but it also needs to talk with the people affected by dementia and those who want to contribute to solutions.

Let's build on the important work underway in health, and commit to creating a dementia-friendly province through the creation and implementation on an Ontario Dementia Plan.

As people with dementia have said, "Nothing about us, without us".