

# *Soci t  Alzheimer Society*

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Mister Chair and Members,

The Alzheimer Society of Ontario appreciates this opportunity to discuss our priorities for the upcoming Budget. With me today is Karen Harrington, an advocate and friend of the Alzheimer Society and former care partner to her late husband, Grant Crosbie.

In the spring of 2015, for the first time, people with dementia visited Queen’s Park as a part of our “Day at the Legislature” and urged you as members to work with them “to do something about dementia.” Since this time, much work has been done to develop a dementia strategy for Ontario.

However, we still face a harsh reality in our province: dementia prevalence continues to increase, health care costs are climbing and those caring for people with dementia face immense stress and hardship<sup>1</sup>.

Good morning.

My name is Karen Harrington and I was the primary caregiver for my husband, Grant Crosbie for 7 years.

Grant was reluctant to talk about his condition and when he was first diagnosed did not want anyone to know about it. Because there is still a stigma around Alzheimer’s, telling family and friends that you have this disease that is slowly destroying your brain is very difficult.

It seems that we were always a step behind with the medical system in getting Grant the correct treatment. Our family doctor referred us to the Memory Clinic at Toronto Western Hospital – a process that took almost 8 months before we got an appointment with a Neurologist.

Grant did fairly well on his first test, was diagnosed with Mild Cognitive Impairment and then wasn’t seen again for another 6 months. By the time he got his second checkup his memory and cognitive skills had declined considerably.

It took over 3 months to get an MRI, which revealed that he did in fact have Alzheimer’s. We were shocked as Grant was the last person you would imagine to get this type of dementia. He was athletic, exercised daily, was a vegetarian most of his life, spoke 2 languages, and did everything else we’ve been told to maintain a healthy brain.

We attended courses at the Alzheimer’s Society in Oakville where we now lived. They helped us understand the disease better and just knowing we weren’t alone was comforting. However,

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<sup>1</sup> Refer to Appendix A.

they did not prepare us for the struggle we would have in dealing with the CCAC and long-term care (LTC) placement process.

Grant became more agitated and eventually he could not be left alone for even a few minutes at a time. The medication he was on wasn't keeping him calm and I could not get an earlier appointment to see our Neurologist.

Grant had an episode of delirium in August 2014 and became a danger to himself and to me. Not knowing what to do, I took him to the emergency department at Toronto Western Hospital.

We then began a 5 month long wait that severely affected his health and put undue stress on the entire family.

In the hospital, Grant was kept in an acute bed on a busy ward where he had very little stimulation. He was drugged to the point where he could not hold his head up or walk unassisted. The doctors reduced his medication but issues with aggression still occurred. There was an incident with a Personal Support Worker and this resulted in Grant being labeled as difficult to handle. The CCAC sent this report to all the Long Term Care facilities that had previously accepted Grant on their wait lists and they then refused to admit him. Our only choice was the Special Behavioural Support Unit (SBSU) at Sheridan Villa.

In early 2015 Grant finally got accepted into the SBSU at Sheridan Villa and spent the next 5 months being monitored by their doctors. He moved up to another floor in June but we were never able to get Grant into any of our 'preferred' LTC choices in Oakville.

By the end of the year, Grant had lost the ability to talk, walk and eat regular food.

In February 2016 I received a call late one night from his nurse telling me that Grant's breathing was laboured and he was gasping.

I then watched Grant gasp for breath for 3 days. I had to plead with the nurses to give him more painkillers to ease his distress. Being the weekend, no doctor came to see him for almost 2 days and finally on the 3<sup>rd</sup> day he stopped breathing completely and passed away.

Our story is sadly typical of a family dealing with Alzheimer's and the systemic problems in our medical system in dealing with dementia patients. A Dementia Strategy would help to increase awareness and educate the public and medical workers about this terrible disease for which there is still no cure.

Yes, there are great needs for certain. With 30 Societies across Ontario and 800 full and part time staff, we have learned a lot over the past 30 years about this disease and how we can address these needs in the most efficient and cost effective way: indeed we are proposing

solutions which will help reduce hospitalizations and ultimately reduce the healthcare spend. We have 3 priorities which we think will have the greatest impact per dollar spent.

Our first proposal significantly expands our **Dementia Friendly Communities** initiative. This is an integrated program of existing core services:

- Minds in Motion® : a train the trainer community-based exercise program delivered throughout Ontario at low cost to keep persons with dementia active, socially and physically, and to help stimulate their circulatory systems;
- Finding Your Way®: a program to prevent wandering, delivered in 14 languages through community in Ontario;
- Blue umbrella: a program to reduce stigma by training businesses and people in the community on how to communicate with people with dementia;
- ReThink Dementia: a campaign to reduce stigma, promote public awareness and prevention.

Added funds would go a long way to delivering these programs more broadly throughout Ontario. All Dementia friendly communities programs are designed to increase a sense of inclusion and reduce the sense of isolation amongst people with dementia and their Carers. This initiative enables people with dementia to live longer and more satisfying lives in the community and reduces pressure on long-term care.

Our second proposal is for incremental funding for perhaps the most established and effective dementia focused program in Ontario today. **First Link**® which is already delivered by all 30 Alzheimer societies in Ontario is initiated at the primary care physician level. Once diagnosed, doctors ask people with dementia and their caregivers if they can be contacted by their local Alzheimer Society.

Once registered in First Link, people with dementia and their families receive education, family counselling and are connected to social groups and community services. From 2011-15, referrals into our First Link® program have doubled to 12,700 per annum! Our goal is that every Ontarian diagnosed with dementia will have access to First Link.

But there is a problem with this success. In the past 5 years we have partnered with **100 new Primary Care Memory Clinics** across Ontario where we work with teams of healthcare professionals to enable earlier diagnosis. This has dramatically increased our intake to First Link. Unfortunately, most local societies are working with the same budgets they had 10 years ago and as evidenced by the 8 month wait experienced by Grant and Karen to get a diagnosis and a proper connection to community services. We are struggling to manage the growth.

Research in the US shows that a program similar to First Link enabled participants to live in the community with a higher quality of life for significantly longer and reduce admission to LTC by 500 days.

Our third proposal is to create new ways of offering respite care for people with dementia and their caregivers. While more money is needed for respite, it's not about providing more and more money into the existing respite programs. We need to get smarter with the money. We propose to use this investment to force choice ranking available programs out there, measure their effectiveness and then encourage that only the best programs are leveraged to provide a minimum standard of respite care across Ontario. Care partners need the right support at the right time along this journey.

With an investment of \$3M, the Alzheimer Society would achieve an Ontario-wide expansion of our Dementia Friendly Community's initiative beyond the current 11 municipalities involved. An investment of \$4M in First Link® would enable us to reach every person with dementia at the time of diagnosis.

Our third priority would be for \$20M to the most innovative home and community providers to deliver "New Directions in Respite Care".

We have provided the clerk with detailed information on these including financials.

Premier Wynne has made an **Ontario Dementia Strategy one of her Government's priorities** and we welcome Minister Hoskins' leadership and that of Minister Damerla.

We are encouraged by the inclusion of the Strategy in the Fall Economic Review.

People with dementia account for nearly 50% of home and community care usage by complex older adults and 60-80% of LTC. Minister Sousa in his 2015/16 budgets committed to an investment of \$250 million toward improving Home and Community Care for the province. We feel that funding for an Ontario Dementia Strategy falls under this area. These investments together will improve community and home care for families touched by dementia and will reduce demand for LTC.

The above proposals are within our expertise to design, cost and/or deliver. There are other much needed services provided by our partners that warrant investments and we suggest that a total investment of **\$100 million will ensure that the Ontario Dementia Strategy** will increase the capacity in Primary Care to detect and diagnosis; improve training for the dementia workforce; and invigorate a more coordinated and collaborative research/industry enterprise, among other areas needing improvement.

The Alzheimer Society and its partners have time-tested tools to help. Rather than reinvent the wheel lets expand and re-energise the programs that we know are working and invest only in focussed innovations so that all Ontarians can benefit from them. Today we seek your support to reach even more Ontarians whose families have been touched by dementia.

## Appendix A

More Ontarians are developing dementia; today more than 220,000 Ontarians aged 65 and above - **1 out of 10 older adults** - live with the disease. In 2020, three years from now, one quarter of a million older adults in Ontario will be living with dementia. This is a 13 per cent increase from today. Most will be living in the community where family and friends will be supporting and caring for them. Among persons living in the community, with a diagnosis of dementia in 2013, almost 9,000 are under the age of 65.

In Ontario, over 7 per cent of community-dwelling persons with a dementia diagnosis—over 7,200 individuals—had at least one inpatient hospitalization with ALC days in 2013/14 compared to 3 per cent in the general population and, on average, ALC stays were 8 days longer for people with dementia. This is a significant expense, costing our health system, on average, \$19,000 per hospitalization for a person with dementia.

People caring for someone with dementia provide 75 per cent more care hours than other care partners and experience 20 per cent greater stress - many of whom are working people. Health Quality Ontario 2016, reported a 20 per cent increase over the last 6 years in feelings of distress, anger and depression among people providing unpaid care.



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