

DEMENTIA

You **CAN** do something.



Solutions That Will Make a Difference

Introduction

The Alzheimer Society is striving for a Dementia Strategy for Ontario that will make a difference. All Ontarians want to enable people touched by dementia to live with purpose, dignity and meaningful relationships. People want to remain in their homes and to delay institutional care for as long as possible. With adequate supports and services in the right place and at the right time, this can be achieved.

We have some specific suggestions that will make a difference and help make this happen.

Our proposals:

- touch a broad range of activities because dementia affects a person's whole life
- enable quick implementation
- are affordable
- address both government and our service partners

Our solutions promote **Living Well**, not only for persons with dementia, but also for care partners and persons at risk of developing dementia. We are taking a prevention approach that promotes health, reduces risk and lessens negative experiences for everyone involved. Through prevention, the burden of disease (dementia) can be reduced significantly at every stage.

Proposals

1. Healthy People/Healthy Communities

The risk of some types of dementia, particularly when caused by vascular disease can be reduced through healthy eating and active living. In some instances, healthy active living can influence the course of the disease. Several Ontario communities are working to become dementia friendly. By doing so, they are more able to support people living with dementia and their families to live independently and remain active.

Volunteerism is one way to help ensure people are meaningfully engaged and active in their community of choice. People living with dementia have much experience, skills and knowledge to contribute to their communities and should have opportunities to do so. Volunteers contribute positively to their communities and volunteering is associated with physical, mental and social benefits that contribute to overall wellbeing and a sense of belonging.

Some organizations and researchers are seeking ways to better understand the needs of people with dementia and how to better support them in volunteer roles and community engagement. Providing these opportunities benefits everyone in the community. Alzheimer Societies can build on the success of Finding Your Way and Minds in Motion to partner with Ontario communities and services to become more dementia friendly.

Solution

Our suggestion is to merge the Finding Your Way/Living Safely in the Community program, the Blue Umbrella program, which trains customer service staff, along with our successful Minds in Motion program to **allow for more active participation of people living with dementia and care partners in community life.**

As a result, more people will learn how to live more safely, become more active, and be able to continue to use services for longer periods of time. In addition, a greater number of customer service staff will be made more competent to provide services that are more accessible.

It is also recommended that investment be made to support volunteer management initiatives. Assistance in connecting people with dementia to the most appropriate volunteer positions as well as supports to fulfil and maintain these roles are necessary to ensure people are able to remain active and involved members of their communities. Benefits of this will be shared by both individuals and communities alike.

A modest increase in government support will allow more partnerships to be formed with more private and public sector organizations. We recommend an investment of **\$3 million** over 2 years in addition to the existing investment of \$750,000 by the Ontario Seniors Secretariat.

2. Early Detection and First Link

Dementia can be better managed when it is detected early. People with dementia and care partners can take advantage of opportunities to live well and adopt approaches to maintain health and activity. Care partners who are well informed and supported throughout manage their roles better than those who experience a crisis situation before reaching out for help.

Resources for detection and making a diagnosis vary across the province, with many people missing out on a timely diagnosis and early treatment. As well, most people with dementia have, or will develop several other chronic conditions. Primary care is the most accessible resource for increasing the number of accurate diagnoses and for improving the care of people with multiple conditions.

Successful partnerships have emerged between the Alzheimer Societies and Memory Clinics. Connecting people to both medical and community-based treatment resources helps ensure positive outcomes.

Solution

Increasing the capacity of primary care will give access so that every person with dementia would have a timely diagnosis. In addition, every person would have access to the First Link program to become connected to education, community resources and support.

As a result more people will be diagnosed in a timely manner and primary care's ability to manage not only dementia, but also accompanying conditions like diabetes, will enable people to remain in the community in more satisfying circumstances. People will have access to community resources earlier and will be better able to live well, in whatever setting they reside.

We recommend an investment of **\$4 million** over 2 years to help support the enhancement of the First Link program. In the context of the rapidly growing number of people diagnosed with dementia in Ontario, this investment will help to ensure that **every person with dementia and their care partners has access to the right supports at the right time** along the dementia journey and are better supported in the community.

3. Supports that work for Care Partners

Ontarians value family life and the bonds that deepen over time. Nowhere is this more evident than in the care provided by family and friends to people with dementia. The vast majority of care and support is provided by people who have close relationships to those needing help. Services that supplement this care enable people to carry-on.

Caregiving becomes more complex as the condition progresses, despite the best efforts of persons with dementia to maintain independence and for those around them to provide support. Stress levels can build up and social isolation becomes an all too common experience.

Respite services, as they are currently delivered, often seem to fall short of the mark in terms of meeting people's needs. As a result, rates of caregiver distress are on the rise. At the same time, there are some great examples in Ontario and elsewhere of how things can be done differently and of how people's experience of being a care partner can be improved.

Solution

More than money is needed to improve respite services so that they will make a difference. We propose to identify the services that seem to make a difference for families caring for a loved one living with dementia, understand the basis for their success, and then make them available to everyone who needs them. A principle-based approach that values the person and care partner is the foundation for assessing service models. **Services must offer choices, be sufficiently flexible, and responsive to the unique needs and circumstances of the care partners and the person living with dementia.**

Adult day programs are one such model of respite with proven success. Care partners frequently tout day programs as an invaluable source of support and respite; however, not

every community offers these programs and in those communities that do, long wait times are not uncommon. In addition, day programs that have the capacity to support individuals with more advanced forms of dementia or, at the other end of the spectrum, with an early-onset dementia are rare. More programs in more communities that serve the full spectrum of dementia are necessary to ensure that people continue to be meaningfully engaged in their communities and care partners are well supported to continue in this role.

Transportation is also an important component of supports that work for care partners. For persons living with dementia and care partners to have full access to the services and supports they need and to remain independent and integrated in their community of choice, affordable, efficient and accessible transportation must be made available in every geographical area and community. Cognitive impairment, like physical impairment, requires equal right to accessibility in such services.

We recommend an investment of **\$20 million** over 2 years to provide better, not just more, respite and to reinvest existing funds in delivery models with proven success, including caregiver education.

Better respite will improve patient and caregiver experiences and enable people to live in their community of choice for longer. Adverse outcomes like caregiver stress, anti-psychotic use and crisis admission to hospital or long-term care can be expected to decrease with excellence in respite care.

4. Building Capacity of the Dementia Workforce

Dementia affects all aspects of the lives of the individual person and their families - it is more than a health condition. Special needs in housing or transportation, banking or going to a restaurant, emerge over time. Many people are beginning to think of dementia as a social disability, not just a disease. As such, access and participation become rights of every individual, not benefits that are granted. There is an obligation for services to be provided in a way that makes possible full access to any service.

People living with dementia use many parts of the health care system: primary care, emergency medical services, home care, specialist care, etc. Workers, at every point of contact, need the necessary, basic ability to provide service in a sensitive and appropriate way.

To meet the challenge of preparing the majority of the workforce to care for, and provide service to people with dementia in a suitable way, more needs to be done in secondary and post-secondary training and in continuing education. Only with a competent workforce will we be able to make a difference.

Solution

We suggest that **health and education leaders put in place a set of core competencies in dementia care for each discipline and setting**, building upon previous work done in Ontario and other jurisdictions. Once in place, these core competencies will be implemented by the educational institutions, professional colleges, and the like.

Further, we propose that government invest in opportunities and offer incentives, on an ongoing basis, for health care workers to maintain and improve skills. An initiative such as the brainXchange could serve as a resource to coordinate training and stimulate continuous development and learning opportunities.

5. Research

Researchers in Ontario are a significant contributor to research, not only in Canada but at a global level as well. However, the impact of research is limited because it is diffused and disjointed. Efforts are underway to create more coordinated research efforts among individual researchers and Ontario research institutions.

Just as dementia impacts different aspects of a person's life, dementia research should also extend beyond health, especially into areas that reduce risk and enable people with dementia to be more independent and remain involved.

Applying new knowledge to one's life and one's work is important and improved effort to translate new research into applied practice will help research investments make a difference.

Solution

Priorities for dementia research should be articulated and investment in research should be designed to enable Ontario to be a leader in these articulated priority areas. These can be arrived at through deliberation within the broader research community, including health charities, funders, and other stakeholders and by listening to people with dementia and those close to them.

Ontario has a rich set of resources in mobilizing knowledge to action, not the least of which is the brainXchange, which has a specific mandate in the dementia sector. The brainXchange could be engaged to create improved knowledge translation and exchange among researchers as well as an integrated plan for translating new knowledge in Ontario to people with dementia, their care partners, healthcare providers and policy makers.

