

## New study in service gaps provides 'hope' for Alzheimer Society of York Region

There are many gaps in the system that prevent Canadians living with dementia from getting the best care possible, according to a study published last week by the Brainwell Institute.

Mind The Gap: Closing the Care Divide for Canadians with Dementia notes that dementia is one of the top 10 causes of death in Canada and 'one of the fastest-growing health crises facing the country' but, as a whole, Canada is falling behind with dementia care.

'Supporting dementia is a growing concern worldwide,' says the study. 'While Canada has the potential to be a leader in innovative solutions, we were the last G7 country to release a national dementia strategy, and compared to our peers, we're lagging behind in turning strategy into action. Countries like Austria, Denmark, Germany, and Scotland have shown that with clear implementation plans, progress is not only possible, it's a must. These nations are seeing real system-wide improvements. Canada, by contrast, ranks just seventh out of 12 peer nations.'

'Since launching its national strategy, Canada has supported over 70 pilot projects in dementia care. Many have shown promise, improving access, outcomes and experiences. But without national coordination, pathways, or scale-up plans, these successes remain scattered and short-lived. We are innovating without integrating, which means life-changing solutions remain stuck at the local level with small-scale impacts.'

'Despite the investments, fewer than one in five Canadians believe dementia care has improved. Diagnosis still takes an average of two years, and services remain fragmented. Meanwhile, caregivers, who are most often women, continue to bear immense burdens, contributing to an estimated \$25 billion in lost productivity and indirect costs.'

One such organization that has stepped up to spearhead these pilot projects in dementia care has been the Alzheimer Society of York Region.

Reviewing the Brainwell Institute's study, they say they were 'thankful' for the findings as it shows that Canada has the capability to tackle the growing problem of dementia and make a real difference 'as long as everyone can get on the same page.'

'When I read this report, my first thought was I am thankful for it [as] it really does high-level explain what's happening in Canada and it is very hopeful where it shows we have the ability to within Canada to tackle this problem, and it also shows the urgency of which we need to do it,' says Kari Quinn-Humphrey, Executive Director of the Alzheimer Society of York Region, noting that she and her Society colleague, Andrea Ubell, have more than 50 years combined working in the field. 'We have been working within this lack of coordination for years and years, trying to fill the gaps [and] what their report is showing is that we have been filling the gaps for individuals, but we cannot do it alone.'

'[The report] highlights the inconsistency of services across Canada, and even across Ontario, and even within our own Region. You can live in a particular part of the Region and have access to certain services, but not in another area of the Region. The report also shows that we really have to create a care pathway that is accessible to everyone, no matter where you're living in Canada.'

Among the Calls to Action in Closing the Gap is the establishment of a Canadian Dementia Coordinating Body, modelled after similar approaches taken by the Canadian Partnership Against Cancer (CPAC) or the Stroke Network.

This, the study said, would 'guide policy implementation, set benchmarks for success, manage data, monitoring, and reporting and standards development and facilitate communication across Provinces and territories' while facilitating coordination of care and scale-up across the board.

Additional findings in the report, such as a lack of support for caregivers of those living with dementia, and an emphasis on brain

health overall, were also 'validating' for the Alzheimer Society of York Region and what they have been doing close to home.

'The thing that we have been at the table advocating and supporting for years and years that this system has lost sight of is the caregiver in general and providing that support to the caregiver,' says Quinn-Humphrey. 'If the caregiver is well, then the person living with dementia is as well. The report recognizes those caregivers and that's the gap that the Alzheimer Society has really filled for the system because the system has focused on the person living with dementia and providing that support to them. Meanwhile, the Alzheimer Society all along has been marching along with the system, providing that support to the caregiver through social workers, through respite, and through ongoing support, education and tools to support the caregiver.'

'When a person from very early in the disease process, to the very end, is only as well as the caregiver is. We've really filled that gap at all of these tables over the years to provide that support to the system that, until very recently, hasn't been overly recognized, but the vital piece to that is the wellness of that person living with dementia.'

Adds Ubell: 'We rely on those caregivers and the caregivers want to do the work for the most part. We rely on them. Our health care system relies on this informal caregiver, and the report points that out. If we are to be successful, you need to buttress the caregiver.'

Also needing structural support, as founded in the report, they agree, is better supports for home care.

'When I sit with caregivers and I'm having a casual discussion and we talk about what their needs are, it always ends back at, 'We need more support in the home,' says Quinn-Humphrey. 'They need more respite, and I would have loved to have seen that as a Call to Action and part of the urgent needs in Canada is that, from my perspective, is what I would have liked to have seen more of. Maybe that is too granular or too in-the-weeds for this report, but that is something I would like to see more readily available and consistently accessible to our caregivers.'

By Brock WeirEditorLocal Journalism Initiative Reporter