

# Where is the Mysterious Dementia Strategy?

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In 2016 the NB Council on Aging listed creation of a provincial Dementia Strategy as a top priority for government. Prior to the council meetings, there had been periodic calls from the Alzheimer Society and other knowledgeable leaders in the system for such a strategy for the province.

The reason for the push from care delivery persons and families is that the growth of Dementia (there are at least 85 different forms of which Alzheimer's is the leading one) is rapid and placing incredible stress on Emergency Departments, family doctors' offices, the long term care system, and, most importantly, caregivers.

The Alzheimer Society of NB estimates the cost of treating this disease is \$479 million per annum and by 2029 it will rise to \$1.042 Billion. In the first six months of this year, the Society received 405 new clients and that is less than half of the known new cases being managed in New Brunswick in some manner.

In the absence of a full strategy, the Province of Ontario and the Alzheimer Society of Ontario have had a vibrant partnership for many years resulting in several relevant, timely programs across the province aimed at helping families and professionals trying to cope with the rapid increase of care volume.

As a result of the partnerships and the recognition of the issues, initiatives such as the Linda Lee Clinics have changed the face of the care of persons with Dementia and have given families hope.

In the Linda Lee clinic model, the patient and family go to regular clinic sessions where they may or may not need to see the doctor because all the other participants in care are at the clinic including the Alzheimer Society, home support personnel, Occupational Therapists, Social Workers and more.

In New Brunswick, by contrast, there appears to be no apparent planned approach to caring for this rapidly growing cohort of people. The Department of Social Development has a piece of the service, the Department of Health yet other pieces; family doctors offices cope with very imperfect information that often results in protracted periods required for diagnosis and care. Worse still, those who would innovate receive little encouragement; as a matter of fact, some key innovators tell me that they actually feel very discouraged "by the system."

In the absence of any apparent plan, services occasionally get developed when squeaky wheels become irritatingly noisy or when interest groups flex their political influence. But nothing seems to happen for the right reasons nor as a result of serious collaboration with the right people.

In the New Brunswick model of care, the family has to work through a minefield of strange offices and phone numbers in order to obtain, renew, or modify elements of the care program. Not so with Linda Lee!

In New Brunswick there have been many innovations adopted by progressive organizations, sometimes with a bit of encouragement by regulatory authorities but most often despite them. Indeed, it has often

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been nearly impossible to simply get a hearing on some proposed innovations that had the promise of radically changing the model of care and moderating the Alternate Level of Care population.

And so it was hoped, by the leaders of the Aging Council, that a Dementia Strategy would provide an umbrella for much more planning and program development. Council members had no illusion that a full blown plan for Dementia Care could be accomplished in a short period. But there is a huge difference between Strategy and Plan.

In 1992, for instance, there was a Strategy to automate the administrative functions of all the hospitals in Region 3. The idea was birthed after the need was identified. Then a vendor was selected, financing put together then implementation commenced. No one at that time had any real idea how such automation would roll out but we were committed to the concept.

Similarly, with Dementia Strategy. Families across the province know what is needed! The elements of good strategy commence with identification of probable caseload, diagnostic processes, support processes, various steps in the long term care process in which there are many minefields.

A Dementia Strategy should not pretend to be a plan to provide all the services that one could imagine the public to need. But it must be a starting point that says that we do need a plan to fix all that is broken in our system. A strategy would simply point us in directions, identify boots already on the ground, establish priority areas of focus, and, in the process, serve to empower those on the ground who are ever so hungry for leadership and frustrated that it has not been visible.

If we wait for the perfect plan we will simply serve to frustrate those hundreds of good people who are just saying “show me the way out of this mess”.

If your loved one is one of those many people afflicted with Early Onset Dementia, you will spend your early years in great frustration! You will look for good information and not find it easily. You will look for services targeted to younger persons with Dementia and you will not find that either. Some families go to Bangor, Maine and beyond to get the information they need to manage.

We can do ever so much better. Since the Council tabled its report on January 27, 2017 we have been repeatedly advised: “it is in progress in the Department of Health.”

This is one illustration of what is dreadfully wrong in our system: wait until we have a crisis then try to do damage control.

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