Dear Senate Committee,

Bonjour – Good morning!

1. My name is Marc Wortmann and many thanks for inviting me to this hearing.
2. Alzheimer’s Disease International is the global federation of Alzheimer associations and the Alzheimer Society of Canada was one of its founding members in 1984 and has been a great supporter over the years. Our vision is to improve the quality of life of people with Alzheimer’s disease and other dementias and their families.
3. Dementia is a syndrome that affect now more than 48 million people worldwide when the prevalence in different age groups is not changing this number will increase to over 131 million by the year 2050. Most of the increase will take place in lower and middle-income countries, but we will still see the numbers double in your country. The global cost last year was estimated at US$818 billion and will soon reach the US$1 trillion.
4. In many countries we have seen a cross party collaboration to get it on the political agenda despite political differences.
5. All over the world there is a need for national dementia strategies and 24 countries have done that now. Dementia is more than a health issue and has an impact on social programs, housing, transport and financial systems as well! This can be brought together in an overall plan and this happened in a number of countries like (among others) Australia, France and Japan. The World Health Organization recommended in their 2012 report *Dementia: A Global Health Priority* that every country should have an action plan. The region of the Americas, Panamerican Health Organization (PAHO), adopted an action plan on 1 October 2015 and supports countries working on national plans like Chile and Argentina. Canada has supported the PAHO resolution and I strongly recommend your country should have a national plan as well, touching on national issues like research funding, insurance and the position of family caregivers, while respecting that care and services are arranged at the provincial and local level (which is not unusual when looking to other countries). As I understand some of your provinces already made their own plans.

6. We have done a study at national plans and can see that a national plan or strategy helps driving policy to the benefit of people with dementia and their caregivers. We identified a number of commonalities and also the elements that made them successful. The first of this being high level political support, ideally from a whole of government point of view.

7. A second very crucial success factor is the involvement of all stakeholders. Think of people with dementia and their families, the national Alzheimer Society, professional associations of neurologists, psychiatrists and geriatricians, but also of care workers and nurses, care providers, community program providers, researchers and all relevant departments of the government.

8. It is very important to listen to the voice of the people with dementia and the Alzheimer Society of Canada and include them in any plan design. A lesson to be learned from other countries is that needs of people with dementia are not always what the experts think they are, so let them speak for themselves.
9. Dementia is sometimes described as a journey of care by people who have to go through it, or the dementia care is also described as a chain of different related services that should fit together. This leads to the importance of care coordination and the need for a navigator or case manager. There is good experience with this in Japan and the Netherlands with this system of one key contact for the person with dementia and their family.

10. All the services that can be carried out in the community should be appreciated as cheaper than institutional care, although institutions can’t be missed for the later stage of dementia and those who don’t have a family that can support. There are many examples of what are called Dementia Friendly Communities where local businesses and public services consider what they can do to make themselves more accessible to people with dementia. One of the elements is a Dementia Friends program that now also started in Canada. This is a good start and I actually became a Dementia Friend by watching the video and signing up, but it could even have a greater impact with an in-person training as was done in Japan. Their Supporters programme changed the perception of the disease completely and there are now over 5 million dementia supporters of all ages in the country.

11. Another area to pay attention to is prevention and risk reduction. There is more and more compelling evidence that dementia shares many risk factors with other major non communicable diseases like diabetes, heart disease and cancer. Smoking cessation, managing hypertension and other cardiovascular risk factors, a healthy diet and physical activity seem to reduce or delay the risk of getting dementia which is a strong message now many people fear dementia more than any other disease.

12. We need more research to find the best ways to care for people with dementia or ultimately find a cure and prevent the disease. There are a number of good research programs in your country and we appreciate the work of the Canadian Institute of Health Research. With more funding, more can be done and research efforts are catching up in the world. We need to bring that to the level of cancer and HIV/Aids where we have seen that these investments have paid out. Dementia research is still far from that level but we have seen that the US Congress has increased the dementia research budget with 50% and is looking for further steps. At ADI, our rule of thumb is at least 1% of the global cost should be spend on public funding for research which would mean $8 billion globally and we are not yet there at all.

13. Canada is almost the only country that has supported Alzheimer’s and dementia projects in lower and middle-income countries through its Grand Challenges program. For instance by supporting an awareness project in Indonesia. Thank you for that, it has made a big impact in that country. Please continue! Chronic diseases are now the main cause of death in most parts of the world but that is not reflected yet in development aid. Also the World Health Organization is doing good work with the creation of a Global Dementia Observatory and the iSupport online training for caregivers. It would be great if Canada support those initiatives alongside other countries like the UK, Switzerland and Japan.

14. Monitoring and evaluation: systematic data collection is very crucial to monitor progress with these programs and that is why the WHO needs support for the Global Observatory to do that globally and develop some standards for benchmarking. Looking at national plans, France has done this probably best during its 2008-2012 plan with a number of indicators that were reported on every 6 months. PAHO has also developed some indicators that might be useful. I would strongly recommend looking at this carefully.
15. There has not been any new drug for Alzheimer’s or dementia on the market since 2003, but there is growing optimism that some compounds now in the pipeline will come through and provide better outcomes than the current drugs that are only symptomatic and in the best case delay the onset of the disease a little bit. Don’t underestimate the dynamic that will occur if a new treatment appears to be successful. Health systems all over the world are not ready for the demand that this will create from society in terms of diagnosis, prescription and post-diagnostic support. By creating a national plan for Canada, you can meet that challenge and benefit from the fact that you have a good health system which only needs to be adjusted.

Thanks again for giving me this opportunity.