Roundtable Discussion with the Minister of Health
DAC Speaking Remarks

Date: Tuesday, June 8, 2021
Time: 4:30pm AT, 3:30pm ET, 2:30pm CT, 1:30pm MT, 12:30pm PT

Goal: Help Minister understand the gaps and needs of Canadians impacted by dementia.

Mary Beth: Opening Remarks

Hello Minister, and distinguished colleagues. My name is Mary Beth Wighton, I live in South Hampton, Ontario. I am 54 years old and received a diagnosis of probable fronto-temporal dementia at the age of 46. I am the co-chair of Dementia Advocacy Canada. I've been a member of your ministerial advisory group on dementia for the last 3 years and was a member of the World Health Organization's Global Dementia Observatory. It took me 4 years to receive a diagnosis after seeing a plethora of doctors who did not understand dementia. Since that time, there has been no clear pathway for support and services for myself and my family, including end-of-life discussions.

Today, we are joining you as representatives of Dementia Advocacy Canada. Dementia Advocacy Canada is a pan-Canadian group of people living with dementia and family care partners that emerged following conversations, started over a beer, at the National Dementia Conference in May 2018. We remained in contact and eventually formed this group, in January 2019. We quickly grew to over 200 members and our numbers continue to increase. Today, on this call, we have representatives from coast to coast to coast. To maximize our time with you, we are not going to make introductions. Your office has been given our personal profiles for your reference.

I want to acknowledge and thank you and your team for your tremendous efforts over the past 18 months dealing with our current health crisis. On behalf of our members, we are grateful for your leadership. We are all looking forward to the pandemic being behind us so we can re-focus the public discussion on other urgent healthcare needs of Canadians.

Minister, I invite you to share some opening remarks….

The Honourable Patty Hajdu: Opening Remarks

Mary Beth: DAC "Scene Setter"

Thank you, Minister. The situation for our constituents – people living with dementia and family care partners and, indeed, all Canadians impacted by dementia, is that dementia is not a priority for this government. There is a lack of dedicated funding for dementia. There is a lack of access to supports and services and we do not see enough evidence that the principles outlined in the strategy are being followed. For example, in our experience, the human rights of people living with dementia are rarely acknowledged, even though human rights is one of the principles in the National Dementia Strategy. This can be seen in the COVID-19 pandemic. In Canada, people living with dementia have been more adversely affected than the rest of the population. The media has raised public awareness about the conditions of care including isolation, neglect, a lack of funding and insufficient human resources. These issues were well-documented concerns before the pandemic. This significant media attention has increased the urgency to accelerate the implementation of the National Dementia Strategy.

Dementia is a complex condition that does not fit into a neat and tidy box. It impacts Canadians across the age spectrum. While age IS the biggest risk factor, people as young as 30 have been diagnosed with dementia. As previously mentioned, I, myself, was diagnosed at the age of 46. I was in the prime of my life and my key earning years. I lost my job and my ability to support my family. Dementia has had a significant impact on the quality of life not just for me, but also my wife, our daughter, our grandson, and the rest of our family and close friends. Dementia impacts families, communities, our health AND social support systems and requires the co-ordination of multiple levels of government.

Myself, Christine Thelker from Vernon, BC and Faye Forbes from Windsor Junction, Nova Scotia, will be the main spokespeople on behalf of this varied group of individuals who are joining us today from across Canada.

Christine will now speak about some of the challenges, as we see it, for those impacted by dementia in Canada.

Christine: Challenges

Hello Minister and other distinguished guests. Thank you again for your time and attention today. My name is Christine Thelker, I live in Vernon, BC and I was diagnosed with vascular dementia in 2015. I represent a group of people who live alone while managing their dementia.

The challenge Minister, for those whom we represent today, is that the National Dementia Strategy is not working. The plan is not on target. From our perspective, if we were to grade the strategy's performance like a school report card, the strategy itself, is worthy of an "A", but, in OUR opinion, the IMPLEMENTATION of the strategy deserves a "D".

Canada has an aspirational dementia strategy but there are insufficient resources allocated to the implementation. How many people in the Public Health Agency of Canada are working full-time on the dementia portfolio? Are they able to deliver attainable results? Can we realistically expect these people to have the resources needed to implement the National Dementia Strategy? Nobody seems to be taking responsibility for the lack of quality care and social support for people impacted by dementia. We're looking for accountability. It doesn't have to be complicated, but we need to know that progress is being made. We are not seeing any results at our level.

Dementia is a global health crisis that impacts a growing number of Canadians - both those who are being diagnosed and their care partners.

Dementia should be a priority for this government, but dementia was NOT even mentioned in the Prime Minister’s most recent mandate letters.

Now Minister, Faye will speak about our recommended actions.

Faye: Recommended Actions

Hello Minister and other distinguished guests. Thank you for the opportunity to speak to you today. My name is Reverand Faye Forbes. I live in Windsor Junction, Nova Scotia and was diagnosed with dementia, specifically early onset Alzheimer’s Disease at the age of 55. Prior to being diagnosed, I lost my job, my ability to learn a living and my self respect.

We have a 3-point action request for the federal government which is the following:

1. Access to rehabilitation immediately upon diagnosis to help people retain their independence, remain employed, where applicable, and stay at home as long as possible. Recreation programs like YouQuest which was founded by John McCaffery, who is on this call today, and his wife Cindy, should exist in every city.

2. Creation of a clearly defined health and social support pathway from diagnosis through to end-of-life that includes dementia-specific system navigators with local knowledge and the ability to make referrals, that ensures treatment & social support is equitable across the country, regardless of postal code or socio-economic status. This model of disease pathway management is being used by other health conditions within Canada such as cancer. Other countries, such as Scotland, are successfully using this model to support people impacted by dementia.

3. Recognizing the needs of people impacted by dementia beyond healthcare. Letters we send to other ministers generally result in the response that it’s been forwarded to YOUR office, failing to recognize that dementia DOES impact the ministry that they’re in charge of. Dementia is about much more than health. Dementia is emotionally

and financially devastating and has a tremendous impact on families and communities. Dementia intersects not only with the Ministry of Health, but also with the Ministry of Aboriginal Affairs, the Ministry of Infrastructure and Communities, the Ministry of Finance, the Ministry of Employment, Workforce Development and Disability Inclusion, the Ministry of Diversity and Inclusion and Youth, the Ministry of Families, Children and Social Development, the Ministry of Seniors, and, as dementia disproportionally impacts women, this is an issue for Ministry for Women and Gender Equality and Rural Economic Development, just to name a few. One of the aspirations of the National Dementia Strategy is integrated, person-centered quality care. All these ministers should be aware of dementia, and it should be included in their portfolios.

Dementia is a non-partisan crisis that requires the collaboration of ALL federal ministries, and ALL levels of government, including those in the provinces and territories.

Minister, we would like to formally request the formation of an All-Party Dementia Caucus to support the provision of supports and services for people impacted by dementia across Canada that includes people living with dementia and family care partners in a leadership role.

Minister, we believe that, should you initiate the actions we recommend; they will result in a significantly improved quality of life for Canadians impacted by dementia. Thank you.

Mary Beth –

Mary Beth: Closing remarks

Thank you, Faye. Minister, we ask that dementia becomes a priority for this government, the Health Ministry as well as all other ministries. There has to be the political will to move the National Dementia Strategy forward.

Once again, we formally request that the government form an All-Party Dementia Caucus with a cross ministry focus on dementia that includes the provinces, territories and indigenous communities, to address dementia in a comprehensive way, including physical, emotional, financial health and social support needs of people living with dementia and their family care partners. We would like to emphasize the importance of including people living with dementia in a leadership role.

Minister, we know that you are very busy, and we very much appreciate your time. We now look forward to hearing your comments and questions.

The Honourable Patty Hajdu: Comments & Questions

Mary Beth: Minister, John McCaffery from Calgary Alberta wants to share his insights on the biggest challenge of living with dementia.

John: Some of the biggest challenges for people living with dementia are transitions. There are big, life-changing transitions – from employment to disability, from independence to dependence, from living at home to living in extended care.

Day-to-day life is also full of transitions. Morning routines that get the day started, changing from one activity to another - such as from fitness to lunch, or deciding what to wear if the weather changes.

Transition is a key theme for people with dementia. Challenges are common and stressful. Many people become lost in transitions.

Dementia is a constantly changing, progressive condition – it affects you emotionally, physically and financially. People living with dementia, their families and care partners need support to help with transitions.

Mary Beth: Minister, Roger Marple from Medicine Hat, Alberta wants to share some thoughts on stigma.

Roger: In a recent report by Alzheimer's Disease International, stigma was identified as the number 1 top issue WORLDWIDE for those living with a form of dementia.

People walking this dementia journey want empathy and understanding. But having said that, we, who are walking this journey need to extend that same empathy by understanding WHY people say what they say.
I have had several epiphany moments when advocating for a better understanding in our society about dementia stigma. One thing I've noticed is that when I see stigma and challenge it, often the reply is "I never thought of it that way."

When we respond to stigma, it should not be done from a condemnation point of view. Rather, we should respond with the same understanding, kindness and empathy, we expect towards changing perceptions in a non-confrontational, positive way. Empathy is a two-way street.

If we look towards the perfect solutions to addressing stigma, I promise we will get lost in the conversations and it will end there, as I have seen so often. Instead, we can easily identify the many low hanging fruits and take action such as putting out simple pointed messages on bus benches, billboards and subway stations in order to provoke thought towards the demographic of people who need to hear this messaging. My number one pet hate is dementia jokes in public media. You do not need to understand everything about dementia to know that telling jokes about a condition without a cure is not cool.

Before we can change stigma, we need to change stigma -related behaviors. For example, stigma drives us into culture of silence. We must install the infrastructure towards changing the culture around dementia so that people and that includes all of us living with dementia or not, are comfortable speaking OPENLY about dementia. Stigma will go away with the voice of the many, not the voice of the few.

I have thought long and hard on how we can approach this effectively with our government's help and have many more well thought through suggestions that perhaps you haven't thought of. I certainly hope that we can have more actionable conversations about reducing stigma going forward. I have often heard the catch phrase "let's rethink dementia". So then, let's "really" re-think how we can approach dementia stigma in an expedited way.

Mary Beth: Minister, Len Carter from Cambridge Ontario would like to describe his experience with getting a diagnosis.

Len: Minister, it is obvious to the people on this call and many others across the country that the dementia-specific skills and knowledge of health care professional are not adequate.

The PSW's and other non-degree-holding persons that provide care for us often have limited training or experience with dementia as a condition

Many General Practitioners pass dementia-related issues off to geriatricians or other cognitive "Specialists" because they do NOT have enough knowledge to make a diagnosis of dementia.

I am one such example. I was sent to a geriatrician after asking my GP for a recommendation for a memory program. I had been a lead character in every aspect of my life up to that point.

We would like to see more training for non-degree holding healthcare persons that are tasked to deal with people living with dementia

We believe that there should be more dementia-specific medical education for healthcare professions and that all doctors should have some aspect of their annual medical license require knowledge and understanding of dementia.

There should be a requirement for Family physicians and any medical professionals who work with people living with dementia to have the knowledge and understanding needed to make a diagnosis.

Mary Beth: Minister, **Myrna Norman** from Maple Ridge, BC wants to tell you about the health services that are currently unavailable for people impacted by dementia.

Myrna: Your time is so appreciated, Thank you.

It is vital to offer strategies that make tangible differences in the lives of persons living with a dementia and their carers.

I submit that an educational binder including pertinent information about one's diagnosis, one's prognosis, available therapies, support groups, and more to allow a life to be well lived.

Occupational therapy, pharmaceutical therapy, social and recreational therapy, are some of the opportunities that we don't have access to. After a TIA, a few years ago, appointments were made for me immediately to aid my physical symptoms however nothing is offered for the dementia diagnosis.

Music therapy, (via headphones) for those in long term care and pet therapy have been shown to be valuable tools to ease anxiety.

Remaining social and having regular exercise have been proven to be essential for good health. Transportation is required for many of us. Just going outside for a walk around the block or to the neighbourhood park would be stimulating and a respite for a carer to recharge.

We ask for your consideration.

Mary Beth: Minister, **Susan Rae** from Whitehorse, Yukon would like to speak about the challenges of accessing supports and services in a rural community.

Susan: Thank you, Minister, for this opportunity. My husband, Dr. Andrew Kaegi, was diagnosed with dementia four years ago but I know it was an issue much earlier. My brother and his wife live in Calgary. She was diagnosed with early onset Alzheimer's. I listened over the years to his experiences, and how he searched out and found information and supports. My assumption was that there were all these supports everywhere including the north.

I was shocked when I spent days on the phone looking for support and information, being bounced from government department to government department and NGO's only to find there was nothing available. I did discover, through a small ad in the paper, a Dementia Caregivers support group and was surprised no one told me. Andrew was SO angry when I left for my first support group meeting saying "Where is my support group? I really need a support group if I'm going to beat this. This isn't fair." And it wasn't.

Once COVID hit, my health started to deteriorate, and Andrew's dementia started to progress rapidly. By last September I was burnt out and unwell so had to place him in care in October. I was diagnosed with bladder cancer in December requiring major surgery in Vancouver in March and we have no family up here to help. I did not see Andrew for 10 weeks which was the longest we had ever been apart.

Dementia has been devastating to both of us at all levels: physically, emotionally, and financially. We lost half our income to cover long term care expenses. My regular expenses stayed the same and this has plunged me into a financial crisis.

At the National Dementia Conference in 2018 Andrew and I discovered there was a complete lack of supports, resources and information in rural and remote communities across Canada. But we DID come back full of hope.

I pray we get the supports and services we desperately need up here, and soon.

Mary Beth: Minister, **Frank Palmer** from Toronto, Ontario has a comment about the need for increased support for care partners.

Frank:

~Hello Minister and PHAC Members:

Throughout the pandemic period, care partners and family members have earned the title ~ 'Essential Workers in Care' ~ providing various care, and support, for their loved ones living with dementia, whether it be within their own home or a long-term care residence.

The Canadian Healthcare System depends upon care partners - family or friends, who ensure both 'QUALITY of CARE and DIGNITY of LIFE' of those for whom they care.

During my tenure as a care partner, throughout the 14 years of Irene, my wife's journey with dementia, I often characterized myself as a CEO of a business, providing multiple and various care services for her at our home.

For example: ~ personal hygiene, feeding, arranging social and recreational periods, in addition to, the tedious and taxing administrative duties: ~ coordinating a care plan, finding and hiring qualified staff, dealing with both government and private agencies, and multiple other tasks.

Typically, these are UNPAID SERVICES, provided by care partners, family and friends, with little compensation, not even tax credits or other allowable business expenses, which would assist with the financial costs required to provide this QUALITY of care so needed.

Future planning for people living with Dementia in Canada should include Family Care Partners.

Minister: ~ The ROLE and the NEEDS of the "UNPAID CARE PARTNER", a critical aspect of the care of those living with DEMENTIA, is worthy of a separate discussion within your Ministry.

Mary Beth: Minister, **Ron Posno** from London Ontario has a question that he would like to ask.

Ron: Given the realities that policy and funding are largely federal matters, nothing is going change until the provincial decision-making authorities are playing an active role. How can we be assured that anything we recommend and agree upon with you and your office will ever be executed in provincial and territorial jurisdictions?

Mary Beth: Second Close

Minister, I hope you see that members of Dementia Advocacy Canada are action-oriented and highly motivated to find solutions to the urgent challenges faced by those impacted by dementia in Canada.

We want to be a resource for you. Please do not hesitate to ask should there be any way we can help further the implementation of the National Dementia Strategy.

Thank you again, Minister for the invitation to speak with you about dementia. We appreciate your time and willingness to have this conversation.