

## **Coordinated Care - MARY BETH – 7 minutes in total**

### **What would make it easier for people with dementia, their care partners and care providers to navigate available services and supports?**

One of the biggest hurdles for people living in Ontario with dementia, partners and care providers is the ability to easily and successfully navigate available and supports. In order to understand what is needed to make it easier, we need to understand the current status quo.

Currently, there are gaps in dementia care including lack of support and training for care partners, poor care transitions and inconsistent access to community based services.

A result of this inconsistent quality of care is preventable episodes of emergency department visits and hospitalizations.

After years of seeing many doctors and specialists, I was finally given a diagnosis of probable frontotemporal dementia. With the diagnosis, I was told to get my affairs in order and my driver's license was revoked on the spot. To help my partner and I through this I was given a pamphlet after FTD and the instructions to contact the Alzheimer's Society as they are the experts.

Like many other people with dementia, I was contacted by CCAC to determine how they could help us. Much to my dismay, it too only had one pamphlet on FTD; the day programs were for people over 55 – I was only 45 and was told that I could not go to it; all other programs were geared towards people with Alzheimer's – which I don't have.

Not finding the support I needed, my partner and I began to comb the internet for information and support services. I mean there must be other people with FTD! The medical and support system failed us. And it is still failing us.

Each and every person, at the time of diagnosis, should expect the same type of support that any person with a disease would receive. For instance, a person with a diagnosis of cancer will automatically receive support based on the "Disease Pathway Management Program" that develops and maintains pathways that depict current evidence-based best practice for the diagnosis of all major cancers. Each person with a cancer diagnosis can expect a team of different health care professionals – doctors, nurses, pharmacists, dietitians, social workers and other. They are there to treat the cancer and to help the patient and family.

***Why do I not receive the same types of supports that a person with any other disease receives? I think this may be another event topic!***

So, the question is what would make it easier to navigate available services and supports. A great deal of research can be found on this topic. There are a number of proposed solutions. The one strategy that really stands out is the creation of a position, somewhat like a case-manager, called "Dementia Consultants." These positions are created in collaboration between local governments, health-care organizations, and health-care insurers.

The **Dementia Consultant** provides advice and support across sectors to different target populations and in the different phases of the disease with the aim to improve the quality of life of the person with dementia.

We know that there are many different supports available for both the person with dementia and their care partner. There is a need for more care continuity. The Dementia Consultant can coordinate the match between demand and provision across phases and sectors and ease the transitions between different care providers.

An example of a Dementia Team that could be coordinated includes:

- Family Doctor
- Nurse
- Patient Advocate
- Pharmacist
- Social Worker
- Dementia Specialist Doctor
- Art Therapist
- Dietitian
- Occupational Therapist
- Musical Therapist
- Physiotherapist
- Spiritual Care Worker
- Financial Adviser

### **Web-based Navigation**

In addition to a Dementia Consultant Role there are other possible solutions to help with the navigation of services and supports. Instead of having a person help in navigation, a single point of navigation for dementia can be web-based.

This site can direct users to web based community support and activities, peer-support groups, including web based community support and activities, online information and advisory services,

and an online dementia road map. For me and my partner, the internet has really been an important source of support and information. It could be even better, to have some type of dedicated web site.

Thank you.