

Summary of August 2016 Provincial Live Chat Event/www.dementiacrossroads.ca

Question:

One of the key areas that the Provincial BSO Lived Experience Advisory has selected for this year is a focus on enhancing system navigation for older adults living with dementia, substance use, mental illness and other neurological disorders and their care partners. Our members expressed an interest in assisting in the development of a “navigational” tool or resource to help people find their way through what can be a confusing health care system.

Our question for tonight is: When you think about your experiences finding and accessing health care, what were the things you wish you knew that you did not know? Where and when did you find the resources you needed and how could that have been improved?

Participants:

There were twelve participants in this chat (this includes facilitators Sharon, Katelynn and Monica) as well as input sent by email prior to the chat. Participants were from: Chatham Kent, Perth, Sudbury, Champlain, Kingston, Mississauga, Thessalon and Brighton.

Key Findings:

Participants all expressed “feeling in the dark” when looking for answers about the diagnoses, medications, available services and processes:

- Key questions people had: “Where do I find information about this disease?, how do I cope with it all?, medication information, information about receiving respite, adult day programs and long term care and finally where do I turn when things go really really wrong?”
- “For us the issues began right at the doctor’s office level. The only place I feel we really got any “navigational” direction was at the Alzheimer Society.”
- “We didn’t know where to start, then we kept running into stumbling blocks....it seemed like a game where you are only given clues and you have to sort out where to move next.”
- The Alzheimer Society sent us to CCAC, we thought it was a province wide organization so we went to “the wrong one”, not the office that covers our town, so they wouldn’t help until I made a sort of scene and then they redirected us.”
- “For us, we were already familiar with CCAC, they had been coming to my Mom’s house for years to help with my older brother who had a physical disability. They recognized Mom’s dementia and got her into day sessions, but we were still pretty much in the dark until the day they called a family meeting to advise us that Mom needed pretty constant care and that we needed to get her into long term care as soon as possible. Six years later, I am thinking we were pretty much ill equipped and let others lead the way in what needed to happen. In a lot of ways I still feel pretty much in the dark. Seems the worse things get, the more questions I ask, I just keep getting the knowing nod and smile but no answers.”
- “ I wish there was a clear answer on the value of medication. You listen to the family doctor and he says one thing, the emergency doctor ends up saying another and medications are all changed, then geriatric physicians get called in and they make other changes in

medication but the entire time you are really at a loss as to whether you are agreeing to the right or the wrong things.”

- “I just didn't even know what services are available, like I never knew about foot care clinics, or day programs or even behavioural support for that matter. I have been at a loss searching and talking to anyone who will listen.”
- People found they waited and waited for information about services or long term care beds and then when things were ready it was instant – leaving no time to process or prepare for the changes: “CCAC was fantastic at communicating with me. My biggest issue was being told on a Monday morning there was no bed offer, so I went to Mexico my sister-in-law and got call Monday night that my mom had a bed - same Monday. Is there some way to delay the suddenness of moves and decisions – go from waiting and no info to next day they're in! - something in the middle?”
- “I remember how lost I felt -and how much of a crisis we were in with no direction - just me and the phone book.”
- “You really have to sleuth!”

The Value of informative, up to date, accessible and easy to use Online and Booklet Resources:

- “When I need to reach for help, I prefer doing that online. The Alzheimer’s Society website could have a menu on their page that has headings such as: Substitute Decisions Act, Health Care Act, Behavioural Support, Homecare, Day programs transportation etc.”
- “There needs to be better direction on CCAC websites and other community partners – with links to each other.”
- “Internet wise, there is information out there - but not simple easy to find or linked to each other so they are easy to use.”
- “Call it a resource page- add in a list of approved dementia-friendly places from diners to audiologists. They would meet the criteria of extra training to hold that title.”
- “I do know that Alzheimer Societies across the province are working very hard at having consistent resources to help people including navigation.”
- “I think the internet information is pretty much cookie cutter.”
- “True story: sadly I spent many types typing these words into a search bar "Alzheimers help" help, help.”
- “We still need things printed out for people too. Not everyone is internet savy – especially the over 70 crowd.”
- “If resources are presented on a web page, there needs to be a search button where I can type in my need, making it easier to find! I hate searching and often just hit the "contact us" button. The web page must have a contact us button. Oh oh wait a sec, how about a live chat operator screen that pops up.”

Participants Expressed the Need for One Local Point of Contact/A Navigator or Advocate:

- “It is difficult to navigate and find answers. Whatever navigational tool exists - it must be attached to a person or number who can help us wade through it. That person would be an advocate and navigator.”
- “It sounds to me like the group is looking for one very local point of contact for all services that would help to guide them through the entire dementia journey.”
- “I think that's a theme we hear all the time - one source, one navigator... someone who understands the local resources and can connect people to what they need!”
- “I needed one agency that would sort my concerns then direct me to all the different agencies according to what they govern.”

- "Online info is necessary but we are presently dealing with a big segment of the population that is not so computer savvy. Plus, you want a little hand holding when you get a diagnosis, not just the facts."
- "I see that we have different navigational needs some are in crisis which need quick fast response and others are more purposeful and planned navigation."
- "Even with a health care background my biggest frustration is being navigated to a resource the person on the phone knows nothing about or it is outdated. It gives false hope."
- "Things are changing so fast. The websites often can't keep up or keep updated - that is why the navigator needs to be LOCAL!"
- "Some of us need a person to support us and also have reliable electronic websites or documents we can access when needed at our finger tips - the ability to escalate and ask for extra help when needed."
- **Characteristics listed of a good navigator:** Trouble shooter, very knowledgeable and connected locally with key organizations that provide care, partnered, timely and collaborative as well as compassionate and empathetic. Responsive and action oriented.... A good navigator is a phone, booklet or website with access to a real person, one who listens to your story vs telling theirs. One with contacts for the correct agency for your needs. One who is knowledgeable and has the title to back it up... I believe the navigator we are designing is a specialist for our families and clients and works inter-collaborative and crosses LHIN boundaries. Universal service! like the OHIP card...We need a person sometimes to ask...what does that mean?...We do need a person to ask the hard questions of and we need that person to give us the facts, not sugar coat to save our feelings. The unknown is often worse than knowing what to expect next... And if that person can't find the answers they will find them for us - not send us away to find it for ourselves and get lost."

The need for peer to peer support:

"The most valuable help for me came from peers and friends first as they had hands on knowledge and my trust."

"In the North East, BSO is in the early stages of launching a peer to peer mentor/coach program facilitated by those with lived experience." (Participants expressed an interest in taking part in this program).

Examples of Navigational Supports that are Effective:

- The resource of a "coach" was recommended. People have found this helpful but some of the barriers were cost and questions about qualifications.
- Discussed the Benefits and need for First Link programs. First Link is an early intervention program that helps physicians and community service providers connect people with dementia and their caregivers to education, services and supports as early as possible after diagnosis.
- Someone shared information about a health link number to call in Alberta that is directing people to resources including peer to peer support.
- The Care Guide is a paper booklet and online website with a call-in feature that lists all Ontario contact information for Long Term Care Homes, Retirement Homes, Senior Products and Services, Community Support Services, Home Health Care, Assisted Living, Memory Care and Hospice Care. The booklets are free and the website is: www.THECAREGUIDE.com.
- Shifting Focus is a booklet made by the Alzheimer Society of Ontario. Listed as a helpful navigational tool.

- Canadian Mental Health is doing crisis video chats in the Mississauga region. It was recommended that we create something similar to help BSO care partners. Canadian mental health live video chat: here is the CMHA Peel link <http://peel.cmha.ca/247csp/>
- "In the Erie St. Clair LHIN we have BSO System Navigators who are the "go to" people for anyone experiencing behaviours. They are the hub and communicator to Long Term Care, CCAC, caregivers, doctors, pharmacists, psychiatrists etc. It is working very well according to the caregivers. It would be good to have system navigators outside of BSO for the community and those not affected by behaviours."