

# AGE-FRIENDLY COMMUNITIES: DEMENTIA-FRIENDLY COMMUNITIES

## WEBINAR 6

### QUESTIONS AND ANSWERS

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**Date:** March 8<sup>th</sup> 2016

**Presenters:** David Webster

**Host:** Age-Friendly Community (AFC) Planning Outreach Initiative

#### TOPICS COVERED

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##### Empowering Local Businesses

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##### Lived Experiences of those in Dementia Friendly Communities

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##### Policy Change

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## **Dementia Friendly Communities and Age- Friendly Communities**

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## GENERAL QUESTIONS

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### **01. Is there any information on the number of unpaid family/friend caregivers that would otherwise be working?**

- The Alzheimer Society of Ontario is currently pulling together this data. We will share as soon as it is available.

### **02. On the topic of stigma, I'm wondering if the change in social attitudes that is needed is a parallel to work ongoing in the Mental Health Sector. Is it helpful to try to tag team somehow?**

- There is lots to learn from the mental health movement, and other movements, that has happened in the past, and continues to be current. It makes sense to learn and work from others to develop our strategy and move forward. Stigma has and will continue to be an ongoing issue for many different populations.

### **03. I was also interested in your comment on dementia friendly communities being designed more for younger age groups - can you say more?**

- There is recognition that Age-Friendly is changing its dynamic, when its original focus was on supporting seniors. The piece that is important for people with dementia is that we are seeing more people getting diagnosed under the age of 65, which is under the age of what we would typically call someone a senior person. I personally feel that this number will increase as more people are comfortable being diagnosed and know that they can still live well. We need to have that attitude and supportive shift in the community in order to support someone early. Right now, there are people whose real or perceived external threats may restrict them from being diagnosed, say if I disclose my diagnosis to my boss and I'm only 50, I may get terminated. So there are some fears that we need to work on through our campaign as well.

### **04. Have you looked into Universal Design?**

- We are having a look at many different model designs to help us find the one(s) that will most help us with bringing together a collective approach. This will be one to further explore. We want to ensure, in any one or combination of models, that we remember inclusion of people with dementia is very key, and to ensure that we appreciate the cognitive needs of people with dementia, just as valuable as the other components of the environment.

**05. Have you worked with MedicAlert for distributing information on dementia friendly initiatives?**

- The Alzheimer Society has been working with MedicAlert for a combined effort MASH ([Medic Alert Safely Home](#)):

## EMPOWERING LOCAL BUSINESSES

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### 01. Who provides the instruction to businesses about this program?

- The 1.5 hour session is done jointly by a staff or volunteer with the Alzheimer's society and a staff or volunteer with dementia. This Blue Umbrella Program is currently in its pilot stage. However, Alzheimer Societies across Ontario all have education staff and volunteers who can help in the meantime, to deliver sessions tailored for specific audiences.

### 02. Are there resources available to educate community partners (businesses, schools, etc) on dementia and how to best assist individuals with dementia in various settings?

- The Alzheimer Society [website](#) is a great place to start your search for information. I would also encourage you to connect with the Alzheimer Society providing service in your community. Educators are available to deliver sessions tailored for specific audiences.

### 03. Are there any financial numbers for businesses for the cost and benefit for training?

- No there are not. At this point in the blue umbrella program there is no cost to the businesses to take the training program, so there is no cost and all benefit to the business in that way. The anecdotal stories that we are collecting are from the people who have Dementia provide some perspective. For example, "I'm standing on a street corner, and there are two businesses one with the blue umbrella and one without, which one do you think I am going to go to?" And so the business with the blue umbrella will get the business from that person.

### 04. Would you be including transit staff, dental clinics, recreation centre staff, search & rescue staff, and grocery stores in these educational initiatives?

- Yes to all! We did a survey about a year ago to a number of Alzheimer's societies across Ontario and we had conversations with some people with Dementia and support groups. We asked them where they most frequent and where they most run into challenges, and that's how we got our first run at target audiences. That being said, some of our societies are already responding to needs in their own communities. For example, the Alzheimer's Society of Toronto has been working with the transit staff to develop a package for that group. The [Finding Your Way program](#) which is about reducing the risk that comes with wandering has been targeting retirement homes and emergency personnel. Guides have also been created from around the world, from British Columbia to Australia. We can borrow those until we have developed ours.

**05. Has there been any thought to bringing this program into our schools?**

- This would be a great opportunity that would fit well as we get going with our Dementia Friendly Community collective impact strategy. I am sure you are aware there are many opportunities for young people to interact with people with dementia, including employment situations, but also as caregivers for parents and grandparents. We are starting to have conversations about building in new content, or enhancing current curriculum, with college and university level programs that have the potential for interacting with people with dementia. And we do have a few examples of high school intergenerational programs where students spend recreational time with people with dementia as part of their volunteer requirements.

**06. Could such an educational resource be shared with the Accessibility Directorate? This could help with compliance and training for the AODA Customer Service Standard.**

- We are still developing the tools, practicing with them, and engaging with experts in the field. We are working with specific staff member in each sector (banking staff helping us develop banking educational resources, restaurant staff helping us develop the restaurant educational resources, etc.). It is our goal with the Dementia-Friendly community model and the Ontario Trillium Foundation to include those tools to be distributed world-wide.

**07. Does the AODA legislation cover the need for dementia friendly services by and through larger organizations? If not, what additional components need to be added specifically for dementia?**

- We are exploring this right now – Accessibility for Ontarians with Disability Act does require businesses to ensure their environments are accessible to customers and clients – you can check their [website](#) for more specifics. One reason for having the dementia disability/disease conversation is to better be able to ensure that the unique needs of people with dementia are recognized as being important within this legislation, so that education and changes can happen. Another piece, once this can happen, is that the education needs to be more inclusive of the cognitive and communication, or invisible, disabilities, that people with dementia live with.

**08. As you decide how to encourage businesses to be more welcoming to people with dementia, have you considered promoting general gentleness with customers having a hard time regardless of trying to diagnose, anyone as needing “special” levels of gentleness?**

- This is our hope for down the road – wouldn't it be nice for everyone to receive this same compassionate “gentleness” regardless of what they do or do not present as a condition? Until we get there, it will remain important to educate and provide some

resources to help businesses understand and appreciate people and all their diversities, and the benefits that come with treating everyone the same. The use of the term “diagnosis” in our approach for dementia friends and within business education, is not about identifying that someone has dementia – that is for a health professional – but to recognize some of the signs as indicating that someone might have some cognitive challenges, and might need some help. The approach is very much like you would follow for anyone (with some tailored considerations for people with dementia) – ask if they would like help, make eye contact, help them to a quiet spot, ... things you should be doing for anyone who doesn’t quite seem like themselves, or who doesn’t quite seem like they are performing a “normal” action.

**09. I would love to learn more about how you advertised the Blue Umbrella educational sessions for businesses in Bobcaygeon and how did you attract businesses to attend?**

**Host-** With the concept of Age-Friendly businesses sometimes it’s a bit harder getting your foot in the door. Could you expand on the Dementia-Friendly experience?

- It’s a multi-directional approach to get in. Sometimes, you have the opportunity to meet with a chamber of commerce group to do a presentation and usually you get access to that group from someone internally. The cold calls and walk-about in Bobcaygeon is how they got their foot in the door. Our group in Paris developed a short 5-10 minute CD that they left with store owners putting a background story and face to dementia. It’s really just an introduction to say “hey, have you thought about these people?” and inform them of the opportunities to attend meetings and learning sessions. Sometimes you need to be flexible with scheduling and schedule something unique to that group. Bobcaygeon for example, has a high tourist season in the summer, so you will not get into those businesses in the summer. The education should happen pre-summer when you get your summer staff hired or in the quieter months. And different people have different days of the week or times of the month that work better for them. I think the walk-about were key because people have a visual image of people with dementia in a LTC home, but they don’t imagine that that person would be standing in front of them. Some of the volunteers talked about having arguments with storefront people being accused of not having dementia and having to prove it because they don’t fit that visual. Having a local champion also helps – if there is a person with dementia who has been a business owner, or has significant relationships, who can open the door, this will help for sure.

## LIVED EXPERIENCES OF THOSE IN DEMENTIA-FRIENDLY COMMUNITIES

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### **01. Has the stigma associated with dementia been a deterrent for people to declare themselves?**

- Yes, this will be the major focus of moving forward with dementia friendly communities – reducing the stigma, both for the person with dementia, as well as their care partners. The experience, after disclosing, is that the social circle around them shrinks. If employed, there is a fear of loss of job. There are all the myths out there, for example dementia transfers by touch ...
- This is also why we are having the discussions about dementia as a disability rather than a disease – with a disease, the person is considered sick, not up to standard, and that is not the case, especially for those diagnosed early.
- We are seeing more younger people (40's to 60's) who are very courageous and not only sharing their diagnosis with family and friends, but also being very public to help dispel the myths. I think I mentioned earlier how some people with dementia get into arguments when others don't feel they are really with dementia – they don't look and act like the visual of someone in a bed in a long term care home – this courage and these people are helping everyone in a very significant way.

### **02. As people who reveal that they have been diagnosed with dementia find their friends fall away, how do you describe the population who decides to wear the dementia pin? Do they tend to have a later stage of the disease?**

- I wouldn't say its older people who are in a long term care home wearing the pin at this point because it's really designed (so far) for people in the earlier stages. People 40, 50, 60 who we have been in contact with who were volunteers. We don't know who's wearing the pins that have been distributed by the doctors' offices. Pins can also be picked up at the local Alzheimer's Society within participating communities, so we have some ideas of how many of those were distributed. But the only time we do understand where someone is wearing them is when it is a client of the organization who is wearing the pin. And so the people we know about tend to be 40, 50, 60 who are willing to step up, they are not afraid to declare themselves in the community, and so they are standing proud as a person who happens to have dementia, and who still wants to participate in the community doing great things.

### **03. I believe that the folks with Dementia may be taken over by loved ones, and they don't actually have a say in their own lives. What is the best way to educate the primary care giver?**

- Interesting observation. We hear the same thing, that people with dementia lose their voice with diagnosis. This can cause great tension for both the person with dementia and the caregiver. There doesn't seem to be a consistent response for this observation.

There are primary care professionals who really understand how dementia works, and there are some who could use more education. Many of our local Alzheimer Societies have opportunities to work with their primary care professionals through specific arrangements – as part of memory clinic teams, working with geriatric specialists, and these work well. Many of our education staff are invited to clinic and GP education sessions.

- Caregivers tend to want to protect their loved ones – any of us would want to protect someone who is not well. This fits the disease model – take care of those who are not well. The disability model would suggest that we change the environment so that the person with dementia still has a voice. Neither are perfect all the time. The trick is to be able to find the balance to providing the voice for people with dementia when it is safe, and being available to support the person with dementia when they need it.
- The primary care person has an obligation to ensure the privacy of information related to their patients – this is where we hear about caregivers being left out of doctor visits – with the risk then that the primary care professional doesn't get an accurate version of what life is like – example, the person with dementia could say everything is fine, not remembering that they had a fall that morning, or remembering that they were awake all night wandering the house with hallucinations.

#### **04. What challenges have been encountered in including people living with dementia in volunteer teams?**

- Another interesting question – we have formed an inclusion task force to explore that topic. There are some of the basic considerations, likely for many of us – notes have to be larger font and white space on pages, transportation has to be available to get people to meetings, help may be required to access phone and webinars (a communication buddy), meetings have to be at the right time based on when people with dementia are most able to interact, etc.
- However, the two biggest learnings I have grown to appreciate is that people with dementia want to contribute in a valuable way – whatever that is – so volunteer positions have to be meaningful. They have to be designed to recognize the talents and expertise that comes with a person (dementia or not).
- And finally, volunteer activities have to be what I would term episodic – there have to be successes and milestones that are achievable in timeframes that allow people with dementia to recognize their contributions and completion of a project.

## POLICY CHANGE

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### **01. Can you tell us more about what legislation is involved related to dementia friendly communities?**

- There is currently no legislation specific to dementia. So what we will be doing is exploring opportunities to work in a couple of focus areas – accessibility legislation focuses on the requirements of organizations, businesses ... to ensure that their environment is accessible to everyone. And accommodation legislation focuses on employer responsibilities to ensure that their environments can accommodate the disabilities/characteristics of their (paid and volunteer) employees. This is a very loose translation.
  - [Accessibility for Ontarians with Disabilities Act](#)
  - [Ontario Human Rights Code](#)

### **02. So many caregivers are seniors themselves, not eligible for Employment Insurance and if their loved ones are in LTC, there is no compensation for travels, hours devoted etc. Any advocacy happening for this?**

- Yes, the Alzheimer Society of Ontario, through work in developing a dementia strategy, is focused on many issues, including the appreciation for the reliance on informal caregivers, and their own financial, social and health costs, in supporting their loved ones. This strategy is being developed, and we look forward to its release.

## DEMENTIA-FRIENDLY COMMUNITIES AND AGE-FRIENDLY COMMUNITIES

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### 01. There has been a movement towards mixed communities (promoting social inclusion and changing cultures). What is your opinion on NORCs (Naturally Occurring Retirement Communities), which seem like a strategy to alleviate the need to integrate these special populations into the community?

- I'm not very aware of [NORCs](#) in order to comment on it in great detail. Wouldn't it be nice if we just had a community that did not need to identify people in a specific way and everyone was just accepting of everyone? One of the things we've talked about when implementing the blue umbrella identifier (or the white cane), is wouldn't it be nice if people were just respectful and just asked if something doesn't seem right, instead of needing a symbol to identify that someone may need extra care.

### 02. Do you see any challenges implementing this program in bigger cities; smaller communities are generally very accepting and willing to help people within their community; sometimes in bigger cities this is into the case, thoughts?

- The challenges and concerns in the bigger city include safety. It becomes a different definition of a community or a neighborhood. Waterloo or Kitchener for example, where we are piloting the blue umbrella program, chose Stanley Park; so a smaller division or neighborhood in that area to start with. When you look at different cities like Ottawa, Windsor, Toronto, you look at a different kind of community. It may be a different physical community or suburb, it may be one mall that decides to become dementia friendly with all of their stores, or it may be a sector (a credit union may decide that all of its credit unions across the city will become dementia friendly). So there are different ways depending on the different neighborhoods. It could be by churches so all the similar faith-based communities get together. I think there are many ways to break it down and make it more manageable. I want to remind people that the blue umbrella program is just one program within the bigger dementia-friendly community model. We are looking at awareness campaigns, looking at reducing stigma, all sorts of things.
- **Participant-** For bigger cities, a neighborhood approach is best- maybe like the [Jane's Walk](#) type of program to raise awareness (eg. Walking with Dementia?)

### 03. For small communities that do not have dedicated Alzheimer's society staff (or shared staff over a variety of communities) what is your plan for supporting these communities?

- As we continue through this process of developing a collective response, it will be important to recognize that we need to ensure resources are available. One of the benefits of a collective response is that no individual person or agency owns all the

responsibility for implementation, nor face the expectation of providing all the resources.

- As we dive deeper, we hope to identify new funding opportunities for those hard costs with any program implementation. We also hope that new partnerships will develop (that will reduce costs to any one agency by sharing resources).

#### **04. How do you foresee the dementia friendly and age friendly initiatives aligning themselves? Who will take the lead on this?**

- As we move through the Collective Impact funding stream with the Ontario Trillium Foundation, we hope to develop a Collective Impact model that would be approved by the Ontario Trillium Foundation for implementation. With this model there would be a dedicated “backbone organization” (currently proposed is the Alzheimer Society of Ontario), who would work with a steering committee. We would see the combination of the steering committee and the backbone organization, working with other stakeholders that would of course include those currently working in the age-friendly initiatives.

#### **05. Is there anything that cities who are going through the age-friendly design process can do right now to ensure that their city is also dementia-friendly?**

**Host-** This certainly speaks to the point that David made throughout the presentation that Dementia-Friendly communities is not simply an add-on piece. What would you suggest communities could be considering now?

- Certainly contacting a [local Alzheimer’s society](#) office and asking them if they have some tools. We are still developing these materials and will start to distribute these out to the different communities. As an example, a couple of the communities that have received an Age-Friendly planning grant (Peterborough and the City of Kawartha Lakes), their Age-Friendly staff member is an Alzheimer’s society staff member. So they are looking at Dementia-Friendly and Age-Friendly Communities together. As we develop these tools, we will be informing other groups such as the Ontario Seniors Secretariat, Accessibility Directorate, and to this provincial distribution list.

#### **06. How do you see dementia friendly reaching out and working with age-friendly communities - what do you want age friendly communities do to take on dementia friendly?**

1. Invite people with dementia onto your local age-friendly committees and action groups – they would know best what they need to build on the age-friendly work you are doing;
2. Invite representation from the Alzheimer Society providing service in your community, to your age-friendly committees and action groups;

3. Let me know how to reach you – as the model gets further developed over the next year, we would like to share information with you, as well as invite you to participate in our development work – David Webster [dwebster@alzheimeront.org](mailto:dwebster@alzheimeront.org)

**07. How can we get involved in collective impact model that you are working on with the Ontario Trillium Foundation?**

- Send me an email: [dwebster@alzheimeront.org](mailto:dwebster@alzheimeront.org)