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Webinar Discussion Series - Community Dementia Care and Support:

Innovations supporting people living with dementia and care partners closer to home

February 10, 2021, Webinar Discussion Summary

Feb 10, 2021, Webinar Synopsis:

This webinar provided an overview of the [Community Dementia Care and Support webinar discussion series](#). Participants discussed two innovations:

1. Alzheimer Residences and Villages
2. [By Us for Us Guides](#) ©

The moderators for the session were Mimi Lowi-Young (Chair of the Board of Directors: AGE-WELL Network Centre of Excellence INC.) and Mary Beth Wighton (Chair & Co-founder: Ontario Dementia Advisory Group (ODAG) and Dementia Advocacy Canada (DAC); Member - Federal Ministerial Advisory Board on Dementia), who provided insights throughout the session, including these two quotes:

“We need a model that better enables integration services post diagnosis. Immediate access to post-diagnostic supports would ensure there isn’t a feeling of “now what” after someone has received a diagnosis of dementia. It is important to measure the effectiveness of post-diagnostic supports to ensure we are meeting the needs of people living with dementia and their care partners.”

- Mary Beth Wighton

“During the COVID19 pandemic, technology and virtual solutions have been highlighted to deal with critical issues such as loneliness and interactions with the health system. There are technologies that can be embedded in both residential environment and across communities to support older adults living with dementia at any stage of the disease as well as their caregivers. Technologies have been designed to be incorporated into the built environment of homes and facilities to support and improve the quality of life.

- Mimi Lowi-Young

Feb 10, 2021, Discussion Highlights:

Presentation 1: Alzheimer Residences and Villages

- Home living for seniors with cognitive issues without burdening family caregivers and residential settings that have been found to have positive results for residents.
- Facilitating home living – needs of family caregivers:
 - Flexible, customized services
 - Range of services
 - Services that are available quickly if required
 - Better integration of professional and community services
 - Cost is a significant barrier to access for health and social services
- Day Care Centres:
 - Seniors with cognitive issues:
 - Improve quality of life
 - Slow cognitive decline
 - Preserve independence
 - Reduce frequency of behavioral and psychological symptoms of dementia (BPSD) and use of psychotropic medications
 - Frail seniors:
 - Reduce rates of hospitalization, admission to long-term care homes, mortality
 - Caregivers:
 - Reduce burden
 - Improve psychological wellness
- Switzerland
 - Services are tailored to the needs of the caregiver and the person living with dementia and can include any combination of the following services:
 - Home Care
 - Protected housing
 - Day Care Centre
 - Evening Care Centre
 - Overnight Care Centre
 - Long-term care homes
- Chicoutimi – Association Québécoise de défense des droits des personnes retraitées et préretraitées (AQDR)
 - Provides respite care for family caregivers who want the senior to be able to stay at home. They are provided a short respite so they can continue to care for a loved one who is losing their independence in order to prevent caregiver burnout.
 - Services are provided at home and in private residences.
 - Services are offered Monday-Sunday from 8am – 10pm.
- Innovative residential settings for seniors with cognitive issues
 - Alzheimer Farm, Netherlands
 - Alzheimer Centre, Switzerland
 - Alzheimer Village, Italy
 - Alzheimer Centre, Austria
 - Alzheimer Centre, Norway

- GreenHouse Project, United States
 - They offer a house that is more suitable for people with cognitive issues. They promote having access to nature, social interaction and a home like feel.
- Other places with innovative residential settings for seniors with cognitive issues:
 - Some provinces in Canada
 - France
 - Belgium
 - Australia
- Family caregivers and nursing staff prefer house-style facilities because residents have control over their daily lives and communication with staff is easy and open.
- Quebec examples:
 - Humanitae
 - Floors are divided in households
 - Residents are provided with more freedom including access to the kitchen and outdoor areas.
 - Maison étincelle
 - Concept of front stage and backstage design. All the pieces of the residence that are operational that residents don't need access to are in the backstage, which means the front stage feels more like a home.
 - Access to outdoor terraces and balconies.

Presentation 2: By Us For Us Guides

- When Brenda Hounam was diagnosed with Alzheimer disease at the age of 53, she realized that very little information was available for people living with dementia. The dominant view at the time was that people living with dementia could no longer learn and be involved in their own care. Brenda thought differently and was inspired to develop a series of resources specifically designed by and for people living with dementia. In 2004, she connected with various people living with dementia from all around Ontario and Murray Alzheimer Research and Education Program (MAREP) to work on what came to be called the By Us For Us Guides ©. The By Us For Us Guides are designed to provide people living with dementia and care partners the necessary tools to enhance their well-being and manage daily challenges.
- 14 guides and 3 unique series
 - Series 1: written by people with dementia
 - Tips and strategies for managing daily challenges
 - Memory exercises
 - Enhancing communication and wellness
 - Series 2: written by people with dementia and care partners
 - Safety
 - Food and mealtimes
 - Social connections
 - Coping with loss and grief
 - Series 3: written by care partners

- Before diagnosis
 - Roles
 - Health and well-being
- The guides are co-designed by people living with dementia and care partners using an authentic partnership approach
- Impact of the guides:
 - Making a difference for over 17 years
 - Over 100,000 guides have been distributed globally
 - Almost 4000 webpage views in 2019 alone
- Next steps:
 - Refreshing existing guides to ensure they are up to date and accessible
 - Creating a new guide focused on isolation and enhancing social connections for people living with dementia and care partners
- List of guides:
 - Memory workout
 - Managing triggers
 - Enhancing communications
 - Enhancing wellness
 - Tips and strategies
 - Living and celebrating life through leisure
 - Young onset dementia
 - Before/early diagnosis
 - Role, health, and well-being
 - Living and transforming with loss and grief
 - Food and mealtime
 - Living safely
 - Safety when out and about
 - Support matters
- To learn more about By Us for Us Guides © visit their [webpage](#).

Discussion and Participation: Questions, Answers, and Comments/Suggestions.

Participants were invited to ask questions and engage in a discussion. Below is the list of questions asked and the responses.

Q: How many residents are in a unit at the Quebec residences you mentioned?

A: 12-15 residents.

Q: How many staff for 12-15 residents?

A: A monthly assessment is conducted to determine how many staff will be required based on the needs of the residents that are currently living in the residence and adjustments are made based on the assessments. In these residences there can be a group of individuals with a broad range of disease progression who require different care. The assessment examines the level of autonomy among the residents, the level of behaviour problems or number of falls for example.



Q: In the home-like settings that you discussed; how do you balance safety with full access to kitchens (for example)?

A: These types of residences might not be for everyone as they operate in a more home-like setting. If you're looking for more structured care where residents have limited access due to safety concerns this might not be the type of residence you want to select. In a recent survey 20% of the participants would prefer safety over flexibility and taking risks. In this case we are not talking about big risks but we did present different scenarios like “would you allow your spouse with Alzheimer disease to be in the back yard of the residence and to freely walk around in a fenced area?” When a potential resident comes to these types of residences the risks are explained to them and their family or care partners and they get to decide if the residence is the right fit for them. The goal of these residences is to feel like a home.

Q: Are the guides also developed with input from Dementia researchers?

A: The Murray Alzheimer Research and Education Program (MAREP) Scientific Director Dr. Carrie McAiney is involved, and they receive REB for each guide, but they are not directed by researchers they are directed and created by people living with dementia.

Q: Are there sample pages to preview before making purchase?

A: All the guides can be freely downloaded on the website. There is a small cost for the printed copies.

Q: Will the guides be translated?

A: If funding was received to translate the guides the team would be happy to do so. New, refreshed, and accessible guides will be launched shortly. We will be looking for funding to translate the refreshed guides.

Q: Have any thoughts been given in providing more information around culturally specific care that is available in communities?

A: The guides are kept more general as they are distributed globally and nationally. None of the guides are specific to any individual community. We will be taking the considerations around culturally specific care to the group to consider for a future guide.