

Minutes

Caregivers Focused Coalition

January 20, 2021 | 10:00 – 11:00 am | Location: Zoom Link

Agenda Items

Topic	Presenter/Actions
1. Welcome and Introduction	Sandy Sereda
2. Presentation re: Changing Continuing Care Legislation <ul style="list-style-type: none"> a. Anita would like to request input and feedback that she can take back to her work b. Working over the last year around refreshing the continuing care legislation, want to add a bit more robust around caregivers support c. Survey is available to the public, please complete d. Respite – not contained in a long care facility, early stages of dementia, other places are small cottage like, missing piece, respite increases stress. May have been given a limited choice in care homes that had open beds. e. Expanded in-home and respite is a good option but need to be more available, criteria needs to be more flexible, needs to be offered by the people coming to the homes, people offering respite need skills and foundational education f. Healthcare professionals need to know how to engage and interact with the client. If client is not happy you are adding more stress. g. Challenge if English is not the first language, person offering respite needs to speak language and understand culture h. Give the client choices. Case Mangers said that once they had the option to go to other agencies and choose and had training, the caregivers started to access respite i. The Rules for Respite in Care are really tight. Family feels they are burnt out and that should be the only rule, shouldn't need a test to qualify. j. Provide overnight respite as a choice, need communication, put a family member in and then walk away for 4-7 days and hear nothing and hope it is going well or they have multiple calls saying to talk to family member. That is not respite if you are spending all your time talking to the family member. k. If care partner is getting surgery, the timing doesn't always work out 	Anita Murphy, Manager Program Policy, Continuing Care Branch, Health Service Delivery Division Email feedback to Anita.Murphy@gov.ab.ca

- l. Choice of Settings, if you are leaving home and going to a bed, pick the same place each time, need flexibility to find their own organization or a family member who can receive an honorarium
 - m. Respite is not a "service", it is an "experience". Not always a bed or a homecare provider. This supports that we need to think outside the box of what respite is and ask caregivers. Basically will provide funding for whatever the caregiver believes is a respite experience is for them, even going to the hairdresser. It is an experience that provides a relief from the caregiver responsibilities. Think outside the "in facility" labor.
 - n. In terms of services, tell the caregiver they can select an agency but there is a huge shortage in the sector, it is another burden for the caregiver
 - o. Develop a toolkit to address the caregiver needs, what could be beneficial and meaningful for the caregiver, how do we engage the loved one in a more meaningful way, how do you feel comfortable to take a break
 - p. The needs of the caregiver is not flexible, they want to spend time in their own homes and have the loved one taken out of the house, caregivers want to take part in their own personal activities, time granted is very minimal
 - q. Shifting the conversation from caregivers needs to their goals is important because caregivers often put their own needs behind those of the person they are caring for
 - r. Need to remember that not all people are on homecare
 - s. Managing money needs to be addressed
 - t. Rural family caregivers are not getting the same homecare services as urban family
 - u. When people are offered respite, some of the services are reduced because they only want respite, not other services, might not be a cost issue
 - v. Integrate caregiver in the agency and need to work with the team to navigate the care, need to "ask", it is not an "offer"
 - w. Caregivers need to identify their OWN needs, this shift needs to happen, can work into legislation
 - x. The goal is also to support the caregiver, not just the care receiver (these are in conflicts)
 - y. Treat each person as a client, if they say they don't need any assistance
 - z. Advantages to having the same person coming in all the time because they feel comfortable leaving, the first visit should be the person going out, not the case worker
 - aa. Need a Caregivers Centered Approach
 - bb. Advanced level of education for the providers of the care, need mentorship, put this in the legislation
3. Presentation re: Study to examine the impact of COVID and its diverse challenges on assisted/supportive living facilities and affiliated family/friend caregivers
- a. Study involves a Facility Survey and Family/Friend Caregivers Survey
 - b. <https://sites.google.com/ualberta.ca/covcaresab-bc/home?authuser=0>

Matthias Hoben, Assistant Professor, University of Alberta and Colleen Maxwell, Universities of Calgary & Waterloo

- c. Asking for help with either recruiting facilities or recruiting family members
 - i. Research focuses on assisted/supportive living residents
 - ii. Advocates for family members
 - iii. Media is focused on long-term care and not looked into assisted living issues
 - iv. Ask a key contact in the facility (SURVEY), PPE, Staffing, measures, how they were affected, pre and post situation,
 - v. Family Caregivers (SURVEY), what capacity were they involved, how has that changed, how has the change affected them, how has the communication been
 - vi. Survey will be Alberta and BC, so we can collaborate
 - vii. Also focus on practices that have went well, does not get reported in media
 - viii. Need discussions on what needs to change, involving multiple provinces will assist
 - ix. Promising approach is going through the facility, the home sending out the survey
 - x. Hard to recruit family members
 - xi. Collect data until April to May, 2021
- Promote study
Send out link for participation

4. Questions and Closing Remarks

Sandy Sereda

Other Information

Next Meeting Date: Tue, Mar 16, 2021
 Time: 10:00-11:30 am

If you want to invite additional members to join the coalition, send the information to Morene Lamaitre at MLamaitre@caregiversalberta.ca