Support volunteer bulletin

Fall 2022

Help us spread the word!

Happy fall everyone! This time last year, we were starting our return to in-person programs and with that, came our planning to invite volunteers back into an active role in Minds in Motion® and support groups.

Fast-forward one year and we are thrilled to have had many volunteers choose to return and re-engage in our programs once again. We've truly missed you all. As we add more in-person programs back to our offerings, we are again reminded of just how important volunteers are for increasing capacity as a Society. This allows us to offer more programs across the province and connect more families affected by dementia to the support they need.

As support volunteers, you understand the value of your role to the Society and the impact our programs can have on people living with dementia and caregivers. You bring your empathy, compassion and strong active listening skills to your role, so families have a safe space to learn more about dementia and connect with others on the dementia journey. Now, we are asking for your help.

Please help us spread the word about the many volunteer opportunities we have available at the Society. We are currently in immediate need of support group facilitators for in-person and online groups (particularly online).

If you know of others in your personal network who may be interested in volunteering with us, please direct them to our volunteer page to complete an online application, or connect them with your staff supervisor.

Volunteers are vital to the energy and success of the Society. We thank you for your support of our recruitment efforts to ensure we can continue to expand our program offerings to families affected by dementia across the province.

"I cannot do all the good that the world needs. But the world needs all the good that I can do."

- Jana Stanfield

IN THIS ISSUE

Skills training for support group facilitators

We are pleased to offer several live virtual trainings this year for support group facilitators.

Live practice for support group facilitators

Throughout the year we have offered several live trainings for support group facilitators hosted virtually in Microsoft Teams. We have received positive feedback from those in attendance and are happy to announce that we have one remaining training for the year coming up in November.

This skills training will provide an opportunity for you to meet with volunteers from across the province and practice your responding skills through a series of discussion scenarios and role plays. These sessions are designed to be highly interactive, fun and informative, so please ensure you join the meetings from a private space so you're able to fully participate in the discussions.

If it has been an extended period of time since you have actively facilitated a support group or you are new to facilitating, these live practice sessions will help build confidence and expand your existing skill set. Refresher trainings are optional but it is highly recommended that volunteers attend at least one of the sessions offered this year.

Registration is open to all support group facilitators, the only requirement is that you have completed the full support group facilitator training prior to attending the practice sessions.

Pre-registration is required, meetings with low registration will be cancelled, so early registration is encouraged.

Training topics

Listed below are some of the scenarios we can work through as a group during this interactive training:

- Advice giver
- Cross-talker
- Challenging behaviour
- Controversial topics
- Grief & loss/MAiD
- Reactivity/Facilitator is triggered
- Starting up a new group
- Use of non-person centred language
- Online facilitation
- COVID-19 safety measures

If you have any questions or requests for specific training scenarios, contact **Kim McKercher at** kmckercher@alzheimerbc.org.

MEETING DATE

Thursday, Nov 17,

10 a.m. to 12 p.m.

CLICK HERE TO REGISTER

Upcoming provincial meeting for support group facilitators: Supporting conversations around end of life

You're invited to the Alzheimer Society of B.C.'s fall 2022 provincial support volunteer meeting on **Wednesday, November 23**, **12 to 1 p.m.**

These meetings provide an opportunity for ongoing learning about dementia, facilitation and other topics relevant to support volunteers and allow us to highlight important updates to our programs and services. We hope these meetings will also facilitate interactive discussions and a chance for volunteers to connect and share their unique experiences and knowledge with one another.

Topic of this meeting:

Our fall meeting will focus on the topic of end of life and how to support conversations around this topic in a support group setting. We will cover:

- What end of life might look like for someone on the dementia journey.
- Overview of palliative & hospice care.
- Legislation around Medical Assistance in Dying (MAiD)
- Grief, loss and dementia .
- Available resources on end-of-life and dementia

Please register by Wednesday, November 9

This meeting is intended for support group facilitators only.

Pre-registration is required and early registration is encouraged. **Meetings with low registration will be cancelled.**

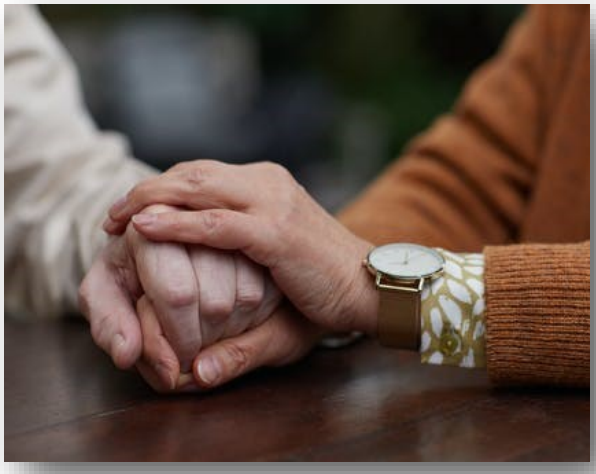
This meeting is hosted in Microsoft Teams. If you would prefer to call into the meeting, you can join by connecting to the audio from your phone using the information emailed to you when you register.

If you have any questions or specific topics you would like addressed at the meeting, please submit them using the online registration form when you register, or contact **Kim McKercher at kmckercher@alzheimerbc.org.**

MEETING DATE

Wednesday, Nov 23, 12 to 1 p.m.

CLICK HERE TO REGISTER



Research update: Alleged data tampering

In our programs, it is not uncommon for participants to ask about something they have read or heard about in the news, particularly if it is controversial. In this section of the Support Volunteer Bulletin, we aim to inform you of a topic of current interest in the news that may come up in discussion during a support group or Minds in Motion® session.

On July 21, *Science* published an article alleging manipulation of evidence in favour of a potential cause of Alzheimer's disease. The research being called into question – originally published in 2006 – suggests that Alzheimer's disease is potentially caused by a protein called Amyloid-beta. This study is considered foundational and concerns are being raised that the alleged misconduct has negatively affected the validity of subsequent studies and funding contingent on this theory.

While the allegation that the study may be inaccurate has the potential to affect subsequent research that relies on this theory, it is important to note that the amyloid-beta protein is only one of many possible causes being explored in research. This situation reminds us of the importance of funding multiple areas of diverse study, including those that seek to improve the quality of life with those currently living with dementia. This is practiced through the Society's Proof of Concept grant program, which was developed to fund innovations and research with lesser explored theories.

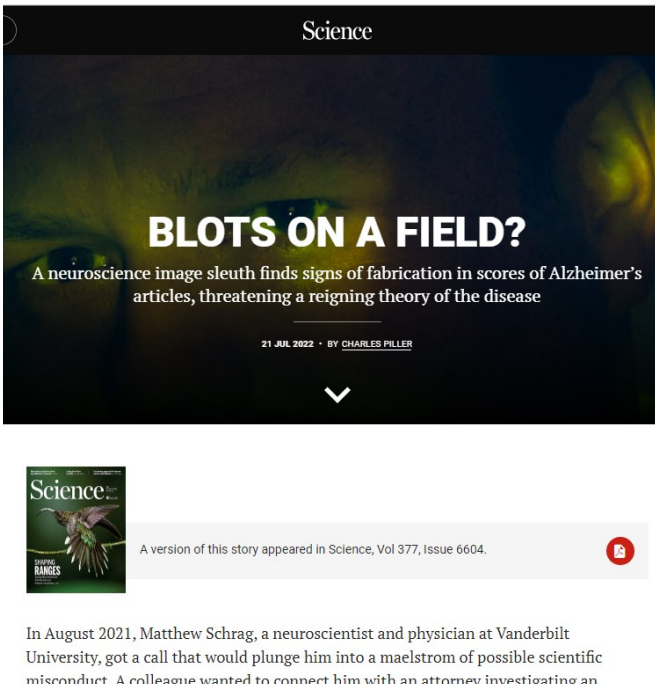
To read the article in *Science*, CLICK HERE

We understand dementia research is a source of hope for people affected by dementia and this news may be distressing to some. However, we hope that you can remind group members that the landscape of dementia research continues to advance each year and that other theories on the cause of Alzheimer's disease continue to be explored.

The Society takes these concerns very seriously and will continue to monitor the latest research and developments surrounding this case.

If you, or any participants in your program(s) are in need of support, we encourage you to call the First Link® Dementia Helpline (1-800-936-6033).

Questions about this story or other research inquiries can be sent to research@alzheimerbc.org.



Medical Assistance in Dying (MAiD)

End-of-life care is a complex and highly personal issue. Because dementia is a progressive disease, a person's ability to communicate their needs and preferences will diminish over time. People living with dementia may worry about what their own end-of-life care will look like, or their caregivers may wonder what the person they are caring for will experience.

In June 2016, the Federal Government of Canada passed legislation (Bill C-14) to amend parts of the Criminal Code that prohibited Medical Assistance in Dying (MAiD). Since then, additional legislation (Bill C-7) was passed on March 17, 2021, introducing a "waiver of final consent" clause. This means that eligible people living with dementia whose natural death is considered reasonably foreseeable and who have been assessed and approved for MAiD and have set a date, can submit a "waiver of final consent" if they are at risk of losing capacity prior to their set date for MAiD. This amendment will hopefully mean that people living with dementia will no longer have to schedule MAID earlier than they may have wished for fear of losing the ability to consent. The waiver is not the same as an advance request for MAID - that is still not permitted under law. This has and continues to be a sensitive issue for many of whom may choose to enact MAiD.

It is recommended that people looking to learn more about MAiD and their eligibility discuss their options with a health-care provider, typically their family doctor or a nurse practitioner. In addition, every B.C. health authority has a designated person to help connect people requesting information on MAiD with a doctor or nurse practitioner who can provide guidance.

Support group members may have questions or concerns about this topic that they bring to the group for clarification, guidance or exploration of how others might feel about MAiD.

Here are some strategies for responding, should the topic of MAiD come up in a support group:

- Ask the group if they would like to have the conversation before proceeding; some group members may be uncomfortable with the topic and not wish to discuss it.
- Before starting a discussion, remind the group of the ground rules, specifically to, "*Respect the opinions of others, even if you do not share them.*"
- Focus on and acknowledge the emotion of the person raising the topic. Are they concerned? Curious? Relieved? Distressed?
- Guide the discussion away from a specific situation and toward the general issue (e.g. the group's feelings around MAiD as opposed to a specific case).
- Know your own triggers and limits. If *you* are not comfortable facilitating the discussion, it's okay to let the group know. Debrief after with your supervisor; if the topic is of high interest to the group, there may be an opportunity for your supervisor to visit the group to have the discussion on your behalf.

For more guidance on responding when a controversial topic is brought up in a support group, review the handout, **"Controversial topics: Guide and script for facilitators"** linked to in the *Support Volunteer Resource Binder.* To access the resource binder, sign into your profile in the Volunteer Portal. Under "**My Profile**", click "**Files**" to download the PDF under "Support Volunteer Resources".

For more information on MAiD, visit the following online resources:

- Alzheimer Society of B.C.'s website on MAiD
- Dying with Dignity Canada website
- BC Ministry of Health website on MAiD

Closing ritual guide

What is a closing ritual?

Closing rituals are reflective activities, typically introduced at the end of a support group meeting. They can help bring closure to the meeting, allow a moment to reflect on what has been shared and build deeper connections between group members. Closing rituals can also provide an opportunity for the group to get to know each other on a personal level, seeing each other as unique individuals separate from their caregiver role or diagnosis. They work well to bond newly formed groups or those in transition.

At our spring 2022 provincial meeting for support group facilitators we discussed the value of incorporating closing rituals into support group meetings and how they can naturally encourage conversations around self-care.

From that discussion, we developed a closing ritual guide for support group facilitators. In this guide you will find information on how to introduce a closing ritual to your group and things to be mindful of when trying one for the first time.

The guide also provides a page of examples of specific questions and activities you can try with your groups. Remember that this is only a few examples so we encourage you to take note of what works well with your group and build upon your own repertoire of rituals.

CLICK HERE to view the closing ritual guide

Do you have a favourite closing ritual not listed in the guide? We'd love to hear about it, contact **Kim McKercher at** kmckercher@alzheimerbc.org

Closing ritual guide

For support group facilitators

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Example of a closing ritual

Ask: Describe in one word how you are feeling in this moment?

Each group member is given an opportunity to respond before closing the meeting.

How to get started

As its title implies, a closing ritual is traditionally an activity that takes place at the end of the support group meeting, but you can also start your meeting with a 'getting to know you' question to set the tone. Regardless of the timing of the ritual it can be helpful to provide an explanation to the group before introducing it for the first time.

Consider the following strategies:

- When starting the group let everyone know that you would like to reserve approx. 10 minutes at the end of each meeting for a closing ritual or reflective question.
- Highlight some of the benefits of a closing ritual and why you think it is important for this group to try one (i.e. bonding, connection, reflection, deeper learning).
- Provide an example of a time when you or a colleague successfully used a closing ritual with another group and discuss the value it brought to the meeting.

It is not mandatory to utilize a closing ritual at every meeting. It can be helpful to gather feedback from the group after using a ritual 2-3 times to see how they are enjoying the practice. As the facilitator use your judgement, each group may respond differently. Be flexible and try different options. Take note of what activities worked well with each group.

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Closing ritual options

Reflective questions

- What is one thing you appreciate about this support group?
- Can you share one thing you are grateful for today?
- What has caregiving or living with dementia taught you about yourself?

Deeper learning

- Try tying a question to what was shared that meeting: *In today's meeting we spoke a lot about therapeutic activities and reminiscing, name one activity you enjoyed doing as a child?*
- What is one strategy or tip you've learned from this group that has had a positive impact on your life?

Exploratory questions to encourage self-care

- What does a "good day" look like for you? *This can help caregivers to think creatively about what's most important to them and how they might be able to incorporate that into their current routine.*
- What never fails to make you smile? *Sometimes caregivers get so wrapped up in the day-to-day, they might forget certain elements of their identity, like what makes them laugh, or what they like to do for fun.*
- What activity do you wish you could do more of?

'Getting to know you' questions

- Where is your favourite place to go on vacation? Why?
- What type of music do you enjoy listening to?
- What is your proudest accomplishment?

Affirmations

The facilitator may wish to start with an affirmation that the group repeats and then encourage members to share their own.

- "I am not alone on this journey"
- "Self-care is not selfish"
- "I will do something for me today"
- "I am doing the best I can in this moment"

Activities

- Close the meeting by reading a quote or poem and encourage group dialogue. Members may wish to bring their own poem/quote to share each month.
- Bring a photo or memento that represents something meaningful to each member (this may require more time and would only be done on occasion).

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Volunteer spotlight: Sadia Sharmin

Sadia joined the Society in June in a new volunteer role as a practicum student in Simon Fraser University's Master of Arts in Gerontology program. Her previous work experience as a physiotherapist for a non-profit organization that supports older adults with neurological conditions inspired her to pursue a career in Gerontology. Below, Sadia shares with us her reflections on her experience as a practicum volunteer with the Society.

What interested you about volunteering with the Alzheimer Society of B.C. for your practicum?

I chose to do my practicum at the Society for a variety of reasons. First, working with people with dementia drew my interest given my professional background. When I discovered that the Society offers a variety of support groups for people with early-stage dementia, I decided that being a volunteer for the organization would be a worthwhile experience. Second, my Master's research is focused on dementia in long-term care, so it felt like a great opportunity to learn more about the Society and the people they support.

Can you provide a short overview of the project you're working on?

I am working as a Programs and Services Project Assistant for the Society's early-stage programs (Minds in Motion®, early-stage support groups and early-stage Coffee and Chat). The main goal of my role is to develop a guide for early-stage group facilitators that would consist of three elements: research summary of best practices for early-stage facilitation**,** environmental scan (to learn from other organizations delivering similar programs) and the development of discussion questions and engagement activities.

What is one thing you'll take away from your time with the Society?

I previously had the opportunity to assist in resolving the physical concerns that people with dementia face thanks to my professional training as a physiotherapist, but I was never able to explore the psychological problems they deal with.

I am incredibly appreciative of the Society for giving students the opportunity to volunteer here and for allowing me to witness the challenges people with dementia go through. I've read about the psychological challenges and impairments associated with dementia, but this is my first experience observing them first-hand.

Do you have any words of encouragement or other comments that you would like to share with other support group facilitators?

The facilitators are doing a novel job. The way they lead the discussion and stimulate communication helps people with dementia to cope with loneliness and psychological challenges. Many of the group participants I've observed have expressed gratitude for the opportunity to join these support groups and mentioned that they remain happier the rest of the day after participating in the group. They added the groups make them feel that they are not alone. I think the best way to thank and encourage the facilitators would be through participants' feedback.

On behalf of the Programs and Services team—thank you, Sadia, and all our skilled volunteers for your support of families affected by dementia across B.C.

Students interested in a practicum opportunity are asked to send inquiries to Sarah Eveneshen at seveneshen@alzheimerbc.org.

All webinars now presented in Microsoft Teams

In July, we transitioned from using Cisco WebEx for presenting our Wednesday webinars to Microsoft Teams, bringing more consistency to how families access our online programs. In addition to our in-person education, we now offer two types of education online:

- **Lecture-style webinars (Wednesdays, 2 p.m.):** In these sensory-friendly sessions, discussion is limited to the chat box and participant cameras are turned off to allow those joining to focus on the information being shared.
- **Interactive workshops (various days and times):** In these online workshops, groups are kept small to allow for participant discussion and interaction throughout the workshop. Those joining have the opportunity to ask live questions and share their own experiences as they relate to the information being shared.

To ensure a seamless technical experience, it is best for all participants to join webinars or workshops from the downloaded Teams app (click here for instructions on how to install the Teams app) or via the Microsoft Edge web browser (click here to download the Edge browser).

Focus on end-of-life upcoming online education

The Alzheimer Society of B.C. is hosting various webinars and workshops focusing on the end of life over the next several months. Join us as we explore topics that impact families affected by dementia at the end-of-life.

Planning for health-care, legal and financial decisions **Monday, September 19, 2 p.m.**

Plan now, before dementia affects the ability to communicate. Learn how to begin early legal, health-care and financial planning to prepare for your future.

What is palliative care? **Wednesday, September 21, 2 p.m.**

Join Della Roberts RN, BSN, MSN, CHPCN (C) from the BC Centre for Palliative Care to learn more about what palliative is and how it differs from hospice care. Sharing her experience as a certified hospice and palliative care nurse, Della will discuss what palliative care may look like for someone living with dementia and their family and who can access palliative care in B.C. *For caregivers and people living with dementia.*

Additional upcoming topics on end-of-life include Medical Assistance in Dying (MAiD) and Grief, loss and the dementia experience. For more information visit alzbc.org/end-of-life

Recently recorded webinars on end-of-life

Preparing for end-of-life on the dementia journey

Presented Wednesday, August 24

Learn what to expect when transitioning from advanced dementia to end-of-life. The physiological signs of dying, key decisions to be made, ways to discuss end-of-life wishes in advance, and strategies to maintain connection throughout the end of the dementia journey are discussed.

Introduction to Advance Care Planning

Presented Wednesday, September 7

Guest presenters from the BC Centre for Palliative Care discuss advance care planning and provide information and resources to help families to get started.

Visit: alzbc.org/webinars for the most current schedule and information on how to register.