Support volunteer bulletin

Spring 2022

Our new hybrid model of programming

In our Fall bulletin, we provided an update on the return to our in-person programming. Since then, we have welcomed back care partners and people living with dementia to a number of in-person support groups, education workshops, and Minds in Motion® programs across the province. All in-person programs adhere to a number of safety measures, including the use of masks, physical distancing, and mandatory vaccinations—all measures are subject to change. A general overview of safety protocols can be found on our website, **HERE**.

While some areas have been slower to return, others are more eager to get back in-person. As such, some regional offices across the province may have more volunteer opportunities than others as programs are scheduled in response to client demand. For example, some regions are seeing event registration lists fill quickly while others may see cancellations as clients in that region may be more hesitant to return to in-person programming; we all feel comfortable in our own time.

Those not comfortable returning to in-person programs can continue to access our programs online, as we will continue to offer all of our programs — support groups, education workshops, and Minds in Motion® — online and in-person moving forward with our new hybrid model of programming.

As more volunteer opportunities become available, support and education coordinators will continue reaching out to volunteers with invitations to return. Your staff supervisor will also provide you with information on how to create a volunteer profile in our new Volunteer Portal and information on registering in upcoming live refresher training sessions.

If you have any questions about the return to your role, please contact your staff supervisor. We look forward to welcoming you back!

"If life were predictable it would cease to be life and be without flavor."
- Eleanor Roosevelt

IN THIS ISSUE

Alzheimer Society BRITISH COLUMBIA

Refresher training for support group facilitators

We are pleased to be able to offer refresher training to all returning programs and services volunteers, with additional program-specific training for returning support group facilitators. This training is offered in two parts:

Part 1: Recorded videos for all programs and services volunteers (*required)*

A series of short, pre-recorded training videos are organized into two eLearning modules and are available on the Volunteer Portal. These modules are a requirement for your return and must be completed within three months of returning to your role.

1. **Module 1 is for returning programs and services volunteers** and includes two videos: 1) an overview of the Society's new hybrid model of programming, and 2) an overview of the Society's person-centred philosophy and elements of meaningful engagement. This model will take approximately 25 minutes to complete.
2. **Module 2 is for returning support group facilitators** and includes seven videos, requiring approximately 90 minutes to complete. Topics include a review of the elements and roles of a support group facilitator, attending and active listening, modes of responding, working with a co-facilitator, screening and transitioning, privacy and confidentiality, and an update of the education and resources available to support group facilitators.

To access the videos, log into your Volunteer Portal account here. Click on **'My Profile'** then **'Trainings'** from the drop-down menu. After reviewing the orientation and training videos applicable to your role, contact your supervisor to let them know you have completed the training.

Part 2: Live practice for support group facilitators only (*optional)*

We are offering several optional live trainings this year. These sessions are an opportunity for you to practice your responding skills through a series of discussion scenarios and role plays. They are designed to be highly interactive, so please ensure you join the meetings from a space free of distractions so you're able to fully participate in the discussions. If there is a particular support group scenario or group member behaviour you would like to work through in one of these sessions, please email us in advance so we can incorporate it into the training.

You may register for as many live sessions as you would like; however, meetings with low registration will be cancelled, so early registration is encouraged. Information on how to register for these trainings will be sent to you by your staff supervisor once a volunteer opportunity is available.

Upcoming live training dates in 2022

- **Tuesday, May 17, 10 a.m. to 12 p.m.**
- **Thursday, August 18, 2 to 4 p.m.**
- **Thursday, November 17, 10 a.m. to 12 p.m.**

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

How to talk about self-care, without talking about self-care

Raise your hand if you have seen a caregiver roll their eyes or exhale a deep sigh at the mention of "self care." I sure have. So often caregivers are inundated with messages about the need to take time for themselves, prioritize their own needs and ask for help when it's needed. While all of these things are absolutely critical on the dementia journey, the reality is that many caregivers will secretly (and sometimes not so secretly) ask, "But how?"

> "How do I take a break when I can't leave my person alone for five minutes to take a shower, out of fear they will leave the house and get lost?"
>
> "How do I ask for help when the 'system' is so overdrawn that there aren't enough home support hours to meet our needs?"
>
> "If I had a break, what would I even do during that time?"

This last question is a common one. Many caregivers experience a shift in identity as their caregiving role evolves. They may become so engrossed by the day-to-day needs of their role that they have difficulty identifying what they need help with, or what they even like to do for fun anymore if they do have the chance for a break. And then there's the 'big G' - GUILT.

It is common for caregivers to feel guilty when they take time for themselves, and this is a topic that will subtly weave its way into many discussions during a support group. Sometimes, by avoiding the language of "self-care," we can create opportunities for reflection that allow caregivers to explore the topic of self-care without getting over-run with feelings of guilt.

Facilitating natural self-care talk

Asking exploratory questions in a support group can be a powerful way to weave threads of self-care reminders into every meeting. It doesn't always have to be a focused conversation; sometimes a well-positioned question can be enough to get group members to reflect on their own identify shifts and what self-care looks like now for them. A caregiver may have always found a coffee chat with a friend to be an important self-care activity, but with changing caregiver needs, this may now look like a reheated home-brewed cup on the balcony while their person has a nap.

As facilitators, our role is to help group members reflect on their experience in a way that is meaningful to them. Supporting their connections with other group members is one way we do this; effective questions are another. Here are some examples of questions you can try in your group to help generate this reflection:

- What does a "good day" look like for you?
- What never fails to make you laugh?
- What have you learned about yourself in your role as a caregiver?

The value of closing rituals

Closing rituals are reflective activities typically introduced at the end of a support group meeting. One example of a closing ritual is to ask group members to identify something they appreciate about their support group, leaving them with a feeling of support and gratitude after the group. We will be discussing ways of using closing rituals and providing examples at our upcoming provincial support group facilitator meeting on April 26 (*see page 6 for more information).*

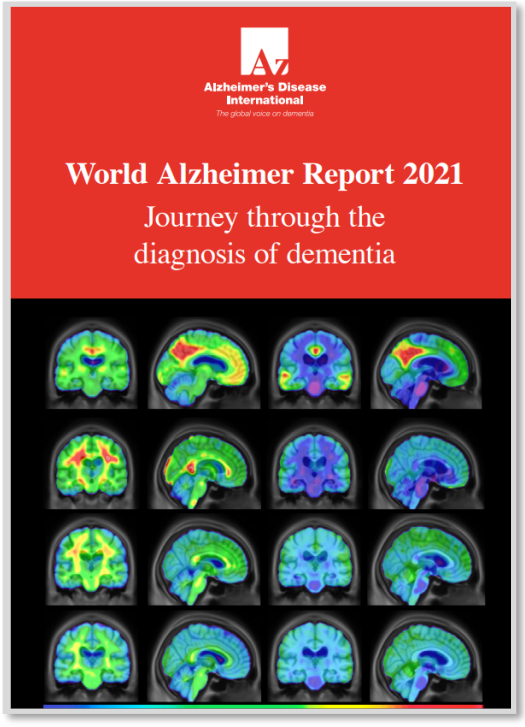
By working some of these questions and closing rituals into your monthly meetings, you can help to normalize conversations about self-care without ever using the words, thereby helping caregivers to feel a little less alone on the dementia journey.

World Alzheimer Report 2021

The following dementia updates were previously shared in a December email communication to you. If you did not receive the Research Ready email, and would like to receive updates like these via email in the future, then let us know at kmckercher@alzheimerbc.org.

On September 21, 2021, Alzheimer's Disease International released its annual *World Alzheimer Report 2021: A Journey Through the Diagnosis of Dementia*.

The report is a comprehensive look at all aspects of the dementia journey from clinical assessment, laboratory testing and diagnosis through to the consideration of individual circumstances such as access to medical professionals and resources. This year's report was led by a team at McGill University.



Some of the report's key findings include:

- Globally 75 per cent of people living with dementia are undiagnosed and in some low- and middle-income countries, where stigma and lack of awareness of dementia remain major barriers to diagnosis, the estimate could be as high as 90 per cent.
- Clinical stigma remains a barrier to diagnosis. One in three clinicians surveyed believed that diagnosing dementia was futile as nothing can be done anyways. Over 55 million people live with dementia worldwide and this is estimated to reach 78 million by 2030.
- Culturally-appropriate cognitive assessment tools and awareness campaigns must be developed to improve diagnosis rates and access to treatment and trials.
- Available research suggests that Indigenous populations experience higher rates of dementia than non-Indigenous populations and face distinct barriers to diagnosis including a lack of culturally-appropriate care.
- COVID-19 disrupted access to health-care services for people with dementia symptoms. The full impact of COVID on diagnosis is unknown.

To read the report, CLICK HERE

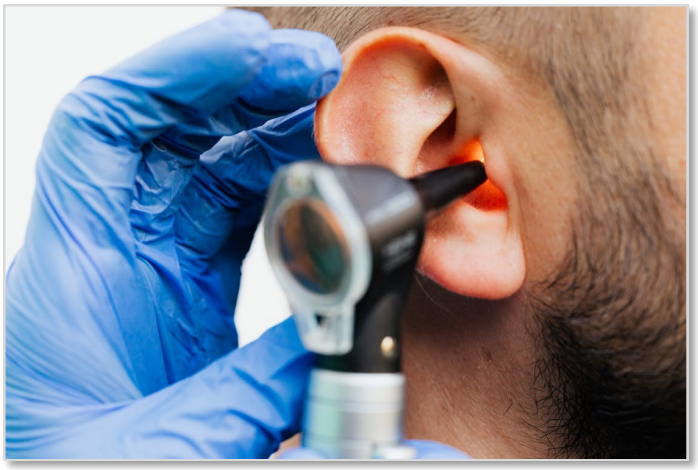
Citation: Gauthier S, Rosa-Neto P, Morais JA, & Webster C.2021. World Alzheimer Report 2021: Journey through the diagnosis of dementia. London, England: Alzheimer's Disease International.

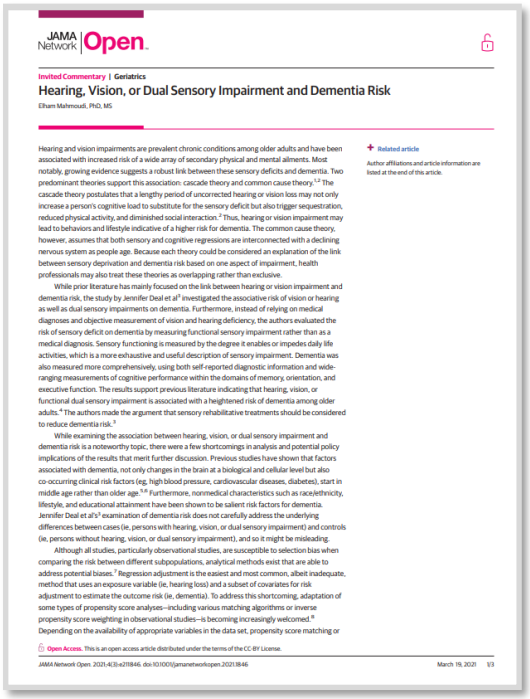
Sensory impairment and dementia risk

Impairment in hearing or vision are chronic conditions associated with aging. There is growing evidence that both are linked to an increased risk of dementia. The understanding of the combined effect of hearing and vision loss is still developing but recognizes that the loss of both is common in older individuals. The combined risk of both hearing and vision impairment may result in a greater risk of developing dementia.

A recent study looked at the combined effect of hearing and vision loss as a risk factor. This study is among the first to investigate the association between the combination of hearing and vision loss and dementia in a national sample of community dwelling older adults in the US. The longitudinal study included 4,546 participants.

Hearing and vision loss were assessed using functional sensory impairment which relies on participants to self-report perceived difficulties with vision and hearing in ordinary situations – for example, recognizing someone from across the street or hearing well enough to carry out a conversation on the phone.





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Invited Commentary | Geriatrics

Hearing, Vision, or Dual Sensory Impairment and Dementia Risk

Elham Mahmoudi, PhD, MS

Related article

Author affiliations and article information are listed at the end of this article.

Hearing and vision impairments are prevalent chronic conditions among older adults and have been associated with increased risk of a wide array of secondary physical and mental ailments. Most notably, growing evidence suggests a robust link between these sensory deficits and dementia. Two predominant theories support this association: cascade theory and common cause theory.[1,2] The cascade theory postulates that a lengthy period of uncorrected hearing or vision loss may not only increase a person's cognitive load to substitute for the sensory deficit but also trigger sequestration, reduced physical activity, and diminished social interaction.[2] Thus, hearing or vision impairment may lead to behaviors and lifestyle indicative of a higher risk for dementia. The common cause theory, however, assumes that both sensory and cognitive regressions are interconnected with a declining nervous system as people age. Because each theory could be considered an explanation of the link between sensory deprivation and dementia risk based on one aspect of impairment, health professionals may also treat these theories as overlapping rather than exclusive.

While prior literature has mainly focused on the link between hearing or vision impairment and dementia risk, the study by Jennifer Deal et al[3] investigated the associative risk of vision or hearing as well as dual sensory impairments on dementia. Furthermore, instead of relying on medical diagnoses and objective measurement of vision and hearing deficiency, the authors evaluated the risk of sensory deficit on dementia by measuring functional sensory impairment rather than as a medical diagnosis. Sensory functioning is measured by the degree it enables or impedes daily life activities, which is a more exhaustive and useful description of sensory impairment. Dementia was also measured more comprehensively, using both self-reported diagnostic information and wide-ranging measurements of cognitive performance within the domains of memory, orientation, and executive function. The results support previous literature indicating that hearing, vision, or functional dual sensory impairment is associated with a heightened risk of dementia among older adults.[4] The authors made the argument that sensory rehabilitative treatments should be considered to reduce dementia risk.[3]

While examining the association between hearing, vision, or dual sensory impairment and dementia risk is a noteworthy topic, there were a few shortcomings in analysis and potential policy implications of the results that merit further discussion. Previous studies have shown that factors associated with dementia, not only changes in the brain at a biological and cellular level but also co-occurring clinical risk factors (eg, high blood pressure, cardiovascular diseases, diabetes), start in middle age rather than older age.[5,6] Furthermore, nonmedical characteristics such as race/ethnicity, lifestyle, and educational attainment have been shown to be salient risk factors for dementia. Jennifer Deal et al's[3] examination of dementia risk does not carefully address the underlying differences between cases (ie, persons with hearing, vision, or dual sensory impairment) and controls (ie, persons without hearing, vision, or dual sensory impairment), and so it might be misleading.

Although all studies, particularly observational studies, are susceptible to selection bias when comparing the risk between different subpopulations, analytical methods exist that are able to address potential biases.[7] Regression adjustment is the easiest and most common, albeit inadequate, method that uses an exposure variable (ie, hearing loss) and a subset of covariates for risk adjustment to estimate the outcome risk (ie, dementia). To address this shortcoming, adaptation of some types of propensity score analyses—including various matching algorithms or inverse propensity score weighting in observational studies—is becoming increasingly welcomed.[8] Depending on the availability of appropriate variables in the data set, propensity score matching or

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JAMA Network Open. 2021;4(3):e211846. doi:10.1001/jamanetworkopen.2021.1846 March 19, 2021 1/3

Older adults with functional sensory impairments, particularly dual sensory impairment, were at increased risk for incident dementia. This highlights the importance of procedures and tools such as cataract surgery or hearing aids to modify both hearing and vision loss; however, further research is needed to identify optimal preventative measures.

Further research is also necessary to understand the link between functional sensory impairment and dementia.

To read the original article,
CLICK HERE

Citation: Mahmoudi E. Hearing, Vision, or Dual Sensory Impairment and Dementia Risk. *JAMA Netw Open.* 2021;4(3):e211846. doi:10.1001/jamanetworkopen.2021.1846

Upcoming provincial meeting for support group facilitators: Building connection in your group

You're invited to the Alzheimer Society of B.C.'s spring 2022 provincial support volunteer meeting on **Tuesday, April 26**, **at 2 p.m. or 7 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:

Building trust and connection between group members is an integral part of the peer support group experience. It is what allows group members to feel safe to share and realize they are not alone in their experience. In this meeting, we will:

- Identify signs of connection and disconnection amongst support group members.
- Discuss what closing rituals are, the value of using them, and strategies for integrating them into your monthly meetings.
- Provide examples of closing rituals that you may choose to adopt in your support group.

Register by Monday, April 11

This meeting is intended for support group facilitators only. If you volunteered as a support group facilitator before the pandemic and have not yet been able to return to an active role, we still welcome and encourage you to register.

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 future meetings, please submit them using the online registration form when you register, or contact **Kim McKercher at** kmckercher@alzheimerbc.org.

HOW TO REGISTER

Both sessions will be held on Tuesday, April 26.

Please only register for one of the following two times available.

To register for the 2 p.m. meeting, CLICK HERE

To register for the 7 p.m. meeting, CLICK HERE

Registration closes Monday, April 11, 2021, 11:59 PM PST.

Volunteer spotlight: Shirley Tam

Shirley first joined the Society as a volunteer in 2019 as a support group facilitator. Since then, Shirley has been instrumental in supporting the Society's efforts to provide culturally accessible support groups for the Chinese community in Cantonese.

When the opportunity arose for Shirley to facilitate a virtual caregiver support group, she jumped in and now facilitates several groups online and in-person. I recently had the pleasure of speaking with Shirley about her role:

What most interested you about facilitating a support group?

In 2018, my mum was diagnosed with Alzheimer's disease. I joined a support group and felt I got a lot of support from the group, seeing how others shared their experience, their frustration, and people offering strategies and coping mechanisms. It gave me a lot of reassurance knowing there is somewhere I can go. That helped me realize how important a support group is. Fast forward to now and I have the time. The first thing I wanted to do is volunteer with the Society, to help families not have to deal with it all by themselves.

What has been the most rewarding part of your role as a support group facilitator?

Seeing how people are able to empower or help others to gain confidence and get a sense of hope and control. I've seen people crying and eventually they get to a position where they can encourage other people. Seeing that transformation and change amongst the group members is most rewarding.

One thing I learned is to trust the process. If we follow the rules of the group, the process itself will work out. It will lead to the desired outcome because people find it safe to share and they know that confidentiality has been protected and they feel attended to and listened to throughout that process. There is a lot of wisdom, strength and resilience in each person and we just need to nurture that, and the support group is the place that we can do that. It is very encouraging to see the fruit of people's journey over months.

What words of encouragement would you like to share with your support volunteer peers?

I think it's a great privilege to be allowed to share these raw emotions [with caregivers] and witness the transformation of their experience. It's really important to trust that each person has it in them to have the strength and resilience to go through this. All that we need is to create the environment and the process for that to happen.

It's a privilege to journey with them - going through the ups and downs and the joy that they have finally managed and developed the coping skills - that itself is very rewarding.

Upcoming weekly webinars

Learn about dementia from anywhere by participating in one of our live one-hour webinars. All you need is a computer, tablet or phone! You can sign up for upcoming webinars in advance to receive a reminder or review our on-demand videos on a range of different themes related to living with dementia.

You can also subscribe to receive regular webinar updates.

What's coming up

Panel discussion: Commonly asked questions about dementia

Wednesday, March 30, 2 p.m.

Join us for a panel discussion where we respond to some of your most commonly-asked questions.

Lived experience: Walking the journey

Wednesday, April 6, 2 p.m.

Hear from families as they share the impact of dementia on their lives, and how involvement with the Alzheimer Society of B.C. has helped them find meaning along the way.

Targeted strategies for word salad, confabulation, wanting to go home, and asking for deceased relatives

Wednesday, April 13, 2 p.m.

Learn specific strategies for responding to behaviours that dementia caregivers often ask us about, including wanting to go home and asking about deceased relatives.

Coping with change, grief and loss

Wednesday, April 20, 2 p.m.

The dementia experience involves change and loss and uncertainty. Join us to explore strategies to help you and those around you cope in the face of these changes.

Staying healthy in a time of change and uncertainty

Wednesday, April 20, 2 p.m.

Self-care tips and techniques for both caregivers and people living with dementia.

Please note that the webinar schedule is subject to change.

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

To see a list of our upcoming in-person and online education workshops, CLICK HERE