

Resources for Further Exploration



Beacon *shining light on Dementia

Sunday May 16, 2021 via Zoom

1:30 – 3:00 pm

Lighting our way forward*

Small group discussions on:

- *Equipping the Saints
(Connecting Circles of Care)
- *Accessible Worship and Music
- *Public Advocacy
- *How might our Buildings Adapt
- *Quiet Space for Conversation

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Inspired by our congregational vision for:
Inclusion, Diversity and Identity

Equipping the Saints: Connecting Circles of Care

Start here: Each of these sites has a wide variety of resources both general and specific:

The Alzheimers Society of BC: <https://alzheimer.ca/bc/en>

The Westside Seniors Hub: <https://www.westsideseniorshub.org>

Vancouver Public Library: this link will bring you directly to a book list on Dementia

https://afa49033-9fa2-44a2-850f-d2a38a8ac3e2.filesusr.com/ugd/f7b74e_0bcda4431db14ef3a3ad08acf8dc2b35.pdf



[Family Caregivers of BC \(FCBC\)](#) “supports caregivers by providing access to information, education and supports that enable caregivers to feel more confident and successful in their important role. We understand the common feelings of isolation, grief, compassion, joy, and exhaustion faced by many family and friend caregivers. FCBC provides direct support to caregivers through one-on-one emotional support, caregiver support groups, health care system navigation, and free educational resources. Click [here](#) to learn more about our resources for caregivers.”

After visiting some of these starting points, we suggest you “start anywhere” in the following resources, since one thing often leads to another!

Magazines, memoirs, stories– a few samples



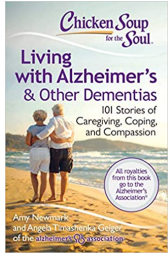
[Dementia Connections](#) (Dementia Connections Canada Ltd.)

“Dementia Connections is the only life-style magazine in Canada focused on supporting people living with dementia, care partners and families to live a good life, despite dementia... gain a deeper understanding of the lived experience of dementia.”

Still Alice. Lisa Genova. Simon & Schuster, 2009. Also available as an audiobook.

Will I Still Be Me? by Christine Bryden. Jessica Kingley Publishers, 2018. Firsthand story about finding a continuing sense of self in the lived experience of dementia. VPL: 362.19683 B91w

Childrens’ books: The Remember Balloons by Jessie Oliveros. Simon & Schuster, 2018. A 2019 Schneider Family Award Honor Book.



Chicken Soup for the Soul: Living with Alzheimer's and Other Dementias. Amy Newmark and Angela Timashenka Geiger. CSS Publishing, 2014.

Available through PSU (contact Sabina at sabharpe@gmail.com)

Podcasts and Web Resources

Dementia Dialogues In 2018-2019, the Alzheimer Society British Columbia hosted a series of webinars: *Understanding Dementia*; *Understanding Communication* (2-part); *Behaviour* (2-part). Search for *understanding dementia*.

TED Talks Anne Basting, *How to Meaningfully Reconnect with Those Who Have Dementia*; Lisa Genova, *What You Can Do to Prevent Alzheimer's* and more.

Caregivers Out Loud: A Podcast (Family Caregivers of BC)

"A series of conversations with caregivers that highlight the joys, trials, and self-discoveries that come along with this rewarding and taxing position... have support and balance through the stories of inspiring caregivers."

Dementia & Spirituality: Podcast Series (Dementia Dialogue, Lakehead University, Thunder Bay, ON)

"explores the many dimensions of spirituality along the dementia journey, as well as how our cultural background influences and nurtures spiritual perspectives. Our hosts have held interviews with a range of guests including people living with dementia, academics and researchers, spiritual care providers and care partners."

Research and community engagement



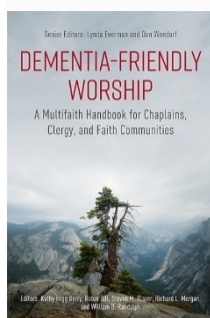
UBC Clinic for Alzheimer Disease and Related Disorders (CARD).
2021 Update on Alzheimer's Disease.

Accessible Worship and Music

Worship focus

General tips and guidelines for dementia friendly worship:

<http://www.growingoldgracefully.org.uk/wp-content/uploads/2018/02/Top-ten-tips-for-Dementia-Friendly-Communities.pdf>



Dementia-Friendly Worship: A Multifaith Handbook for Chaplains, Clergy, and Faith Communities. Edited by [Virginia Biggar](#), [Lynda Everman](#), and [Steven M. Glazer](#). Jessica Kingsley Publishers

Religious faith is a powerful source of comfort and support for individuals and families facing dementia. Many faith leaders need help in adapting their ministries to address the worship/spiritual needs of this group. A product of Faith United Against Alzheimer's, this handbook by 45 different authors represents diverse faith traditions, including Christianity, Islam, Judaism, Sikhism, Buddhism and Native American. It provides practical help in developing services and creating dementia friendly faith communities.

It gives an understanding of the cognitive, communicative and physical abilities of people with dementia and shows what chaplains, clergy and lay persons can do to engage them through worship. Included are several articles by persons living with dementia.



families to discuss.

Spiritual Eldercare: a non-denominational worship site (from the US) for those living with dementia and their caregivers. Services are about 45 minutes long, with an emphasis on singing lots of older, familiar hymns, with the words on-screen, cues from the worship leader of what the next part of the service involves and reminders that words will be present; King James version of familiar psalms and Bible passages and interactive sermons for

<https://spiritualeldercare.com/2020/08/31/dementia-friendly-worship-service-work/>

Music Focus



Voices in Motion Choir: a multi-generational choir connecting people living with dementia, family caregivers and high-school students to make music. For general information go to:

VOICES IN MOTION™

<https://voicesinmotionchoirs.org/>

For training information on how to start a dementia friendly choir see:

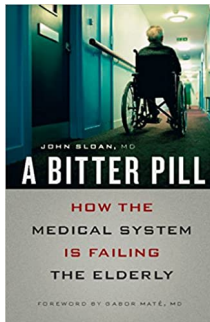
<https://voicesinmotionchoirs.org/training-program/>

And for the choir's latest online video see:

<https://www.youtube.com/watch?v=v7reLCS6Qq8>

Public Advocacy

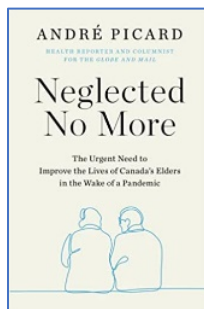
Print resources lending themselves to public advocacy group discussion.



John Sloan, M.D. (2009). *A Bitter Pill: How the Medical System is Failing the Elderly*. Vancouver/Toronto/Berkeley: Greystone Press.

“Dr. Sloan treated the elderly at home for many years. (Yes, he made house calls!) His recent book, *A Bitter Pill*, is an utterly convincing indictment of the way we're wasting money on useless care for the elderly, while making their lives worse. It's essential reading for anyone who's interested in health-care reform, as well as for anyone who's responsible for an elderly person or anyone who is or will become one.” —The Globe & Mail (2010-11-11)

Dr. Sloan recently served as a presenter and resource to Beacon 3's discussions.



André Picard (2021). *Neglected No More: The Urgent Need to Improve the Lives of Canada's Elders in the Wake of a Pandemic*. Toronto: Random House Canada.

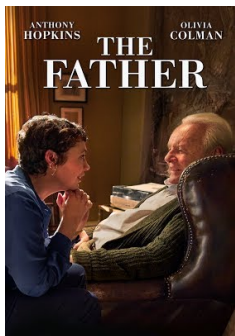
Although this recent book by The Globe & Mail's award-winning health journalist deals with the broad issue of current elder care in institutional settings, Chapter Five (pp. 76-91) will be of particular concern to Beacon participants and is titled “Forgotten: Caring for Elders with Dementia.” Also available as an audiobook.

Online print resources for education and public advocacy.

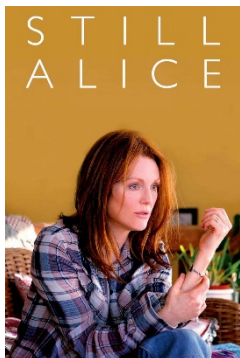
Change Minds. (2021). Alzheimer Society of British Columbia. A wide range of advocacy and education resources, many of which can be adapted across a range of dementias. A suggested starting point is their advocacy page entitled “Change Minds” which is found at: <https://alzheimer.ca/bc/en/take-action/change-minds> . Telephone 1-800-667-3742.

中文小冊子及單張 | Online education resources (Chinese Language.) Alzheimer Society of British Columbia. Vancouver, BC. Available: <https://alzheimer.ca/bc/en/node/606>

Nonprint media lending themselves to public advocacy group discussion



“The Father” (2020). Sony Pictures Classics. Award-winning film follows an aging man, played by Sir Anthony Hopkins, who must deal with his progressive memory loss, and his daughter and caregiver, played by Olivia Colman. The film offers a unique perspective on the experience of memory loss: from the inside. View the trailer at: <https://www.youtube.com/watch?v=4TZb7YfK-JI>



“Still Alice” (2014). Sony Pictures Classics. Based on Lisa Genova’s 2007 novel of the same name, the film stars Julianne Moore, who plays a 50-year-old linguistics professor diagnosed with early onset Alzheimer disease. Its co-director, Richard Glatzer, had just been diagnosed with ALS when he began work on the screenplay.

View the movie’s trailer at: <https://www.youtube.com/watch?v=ZrXrZ5iiR0o>

While cinematic or dramatic treatments of dementia can often be more useful as general education and awareness tools, the argument for treating such a film as a stimulus for debate and public advocacy or action is advanced in Catherine Bailey’s essay in *The Conversation* (March 12, 2015). <https://theconversation.com/films-like-still-alice-are-crucial-to-keeping-debate-about-dementia-alive-38675>



“Supernova” (2020). Bleecker Street. Written and directed by Harry McQueen, and starring Colin Firth and Stanley Tucci, the story takes two partners of twenty years, one of whom is experiencing the inexorable advance of memory loss, on a journey across northern England in their RV to visit friends and family. Firth’s character

serves as advocate and novice caregiver while Tucci's character dreads what lies ahead.

View the trailer at: <https://www.youtube.com/watch?v=I4Vk0CVcDts>

Public advocacy in action: Local and Provincial levels



The Province of British Columbia's Seniors' Advocate. Isobel Mackenzie, "What does it take to age in place?" This webcast outlines the current status of older citizens, including those living with dementias, as a growing segment of the province's population and delves into the public health and care challenges triggered by that demographic shift. The 50-minute presentation was hosted by PSU's Catherine Evans as one of Vancouver Quadra MP Joyce Murray's "MP Brunch Connections" 2020-21 discussion series. The webcast also highlights some of the public advocacy that will be needed to address current shortcomings in both institutional and home-based support for elders. The presentation begins at the 11min 20sec point in the webcast <https://youtu.be/MSsUZtgpfN4>. See also reports at: <https://www.seniorsadvocatebc.ca/reports/>



Alzheimer BC (2015). "Jim's Story: Dementia Friendly Communities." Vancouver-based Alzheimer advocate Jim Mann, an airline executive who was diagnosed at age 58, demonstrates what it takes to create "dementia friendly" communities, and shares his experiences with stereotyping in his everyday activities. Featured in our Beacon session November 2020, it runs 6min 54sec. Find it at: https://www.youtube.com/watch?v=_ynYKMTkhs

Medical research and public advocacy

Canada's university-based research units, in their search for underlying causes of neurodegenerative disease, often offer services such as access for families to genetic testing and counselling for families of dementia patients. Enrolment in clinical research programs can often provide patients and families with a meaningful way of making a contribution to the understanding of neurodegenerative diseases and eventual prevention or therapies. Here are profiles of two internationally-renowned centres of dementia research that offer such opportunities, along with the international consortium to which they belong, plus a fine publication written for lay audiences that summarizes new Canadian research in brain health.



The University of British Columbia Faculty of Medicine: Alzheimer Disease and Related Disorders Program and Clinic (CARD). Based at the new UBC Djavad Mowfaghian Centre for Brain Health, this program serves as the main tertiary care referral centre in BC for dementia assessment and management, including genetic counseling, social work, neuropsychology, geriatric psychiatry and neurology. The multidisciplinary team conducts international collaborative research on drug therapies, medical genetics, and neuroimaging for neurodegenerative diseases including Alzheimer and

FTD. Learn more at: <https://neurology.med.ubc.ca/programs/alzheimer-disease-and-related-disorders-program/>

The CARD Centre also organizes annual research updates geared to the general public. “The annual forum is an opportunity for us to share our ongoing work at UBC towards new therapies and diagnostic tools for Alzheimer’s and other dementias and provide expert advice on various aspects of dementia care.”

Information and registration for 2021 Update Saturday May 29, 2021, 8:30 – 2:15 [here](#). These updates are recorded: [Watch the 2020 Forum Talks on YouTube](#) .



The University of British Columbia Faculty of Medicine: Amyotrophic Lateral Sclerosis (ALS) Centre. Located at Vancouver’s G.F. Strong, the Centre offers trans-disciplinary clinical services to patients and their families throughout BC. Members also conduct leading clinical trials for the ALS Centre and investigate therapeutics and effective diagnostics for this neurodegenerative disease. Learn more at: <https://neurology.med.ubc.ca/programs/amyotrophic-lateral-sclerosis-program/>



STAR Institute, SFU – Science and Technology for Aging Research. <https://www.sfu.ca/starinstitute.html>
SIMON FRASER UNIVERSITY



ALLFTD
ARTFL LEFFTDS Longitudinal
Frontotemporal Lobar Degeneration

ALLFTD: This is the multi-site North American research consortium for clinical studies of another major group of neurodegenerative diseases, the frontotemporal lobar degeneration (FTLD) group that includes ALS. Many of the important Canadian dementia research projects collaborate with this consortium.

Their website’s tab “Patients and Families” tab not only offers one of the best descriptions of how current clinical research is conducted -- <https://www.allftd.org/research> -- but also offers descriptive links to a wide range of patient advocacy groups, mainly in the USA, at <https://www.allftd.org/patient-advocacy-groups>



[Mind Over Matter Magazine](#). Published by the Women’s Brain Health Initiative and supported by the Brain Canada Foundation and Health Canada, the magazine offers “insight into the latest research findings to combat brain aging diseases and the tools you need to stay brain healthy longer.” Attractive articles written in lay language highlight very current Canadian clinical and basic research in brain health that tackle questions around why brain aging inexplicably affects women disproportionately. WBHI offers book club resources, and the magazine can be read and easily shared online at the link above.

How Might our Buildings Adapt?

First, a reminder that you may “Start anywhere” on these resource lists. Each of these sites has a wide variety of resources both general and specific.

An interesting place to start for an overview: “Choosing a dementia friendly meeting space.” Available at: <https://www.dementivoices.org.uk/deep-guides/for-organisations-and-communities/>

Building design, signage and related topics: What two experts recommended

From Jim Mann, Vancouver advocate and a person living with dementia:

- A resource that may be helpful is "Is this INSIDE public space dementia-inclusive? A checklist for use by dementia groups." Available at: <https://www.dementivoices.org.uk/wp-content/uploads/2019/01/Audit-Checklist-%E2%80%93-Is-this-inside-public-space-dementia-inclusive.pdf>
- Another helpful document is "Supporting a sense of comfort and belonging in your living space" created by Schlegel-UW Research Institute for Aging (University of Waterloo, Ontario.) Available at: <https://the-ria.ca/wp-content/uploads/2021/01/Supporting-comfort-and-belonging-for-people-living-with-dementia-RIA-Resource-FNL-2.pdf>

From Kishore Seetharaman (kseethar@sfu.ca) of SFU:

For electronic copies of the following referenced (pdf) documents please email Susan at burns@sfu.ca.

- **Frost – Making it Dementia Friendly** (pdf). This may help you find areas within the church that could be improved to become more dementia-friendly.
- The **Dementia-friendly environment assessment tool** (pdf) is a similar checklist with a few additional issues to look out for.
- **Environmental Design Resources_2** (pdf) is a set of design guidelines to create dementia-friendly home environments, some of which are of relevance to public buildings.
- In **Improving the Design of Housing to Assist People with Dementia** (pdf) note part 6 in the PDF, which includes a number of case studies of how some care homes adapted dementia-friendly design principles into actionable strategies. Ideas and visuals on how dementia-friendly principles and guidelines could be translated into actual modifications of the environment.

- Fleming, R., Zeisel, J. & Bennett, K. 2020. **World Alzheimer Report 2020: Design Dignity Dementia: dementia-related design and the built environment. Volume 2: Case Studies.** London, England: Alzheimer's Disease International. Photos and some information from many more case studies of different care homes and community centres around the world that have taken design measures towards creating dementia-friendly environments.

Available at: <https://www.alzint.org/u/WorldAlzheimerReport2020Vol2.pdf>

Most recent update was on 2021-05-11.