

# DEMENTIA INFORMED VICTORIA: AN INITIATIVE TO CELEBRATE THE POTENTIAL OF PERSONS LIVING WITH DEMENTIA

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West Coast Conference on Aging  
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April 2, 2022



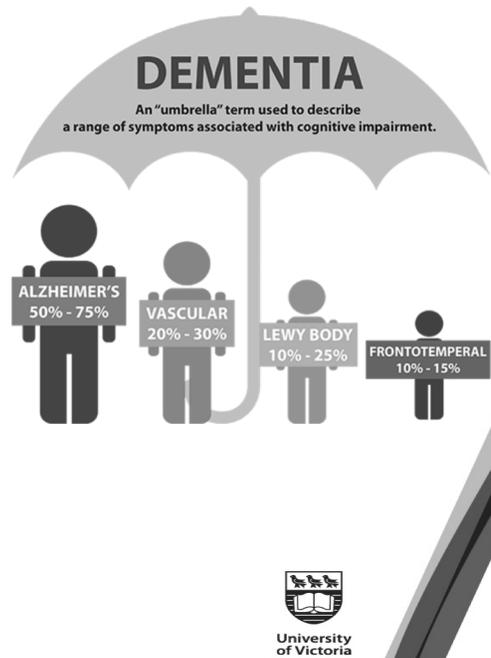
## Overview

- **Background**
  - Dementia: stigma and social isolation
- **Dementia Informed Approaches**
  - Voices in Motion
    - Findings
  - Memory Café Victoria
  - Call To Mind Podcast
- **Next Steps**
  - Momentia Victoria
  - RX Connect: Social Prescribing
  - Re-Connect: Creating Pathways to Inclusion



## Background

- The rising prevalence of dementia
  - 564,000 Canadians are living with dementia
  - Numbers will nearly double by 2030
- High risk for **stigma and social isolation**
  - Impacts health and quality of life
- **No medical cure** expected soon
  - Approaches that foster **social connections**
  - Create **community** through inclusive and **meaningful activities**



## Dementia Research Priorities

Report of the  
Canadian  
Dementia  
Priority Setting  
Partnership  
(2017)



- 1 STIGMA**  
What is the impact of stigmas associated with dementia and mental health issues on persons with dementia and their families? What are effective ways of reducing the stigma experienced by persons with dementia and their friends, family and caregivers/care partners?
- 2 EMOTIONAL WELL-BEING**  
What can be done to support emotional wellbeing, including maintaining a sense of dignity, for persons with dementia?
- 3 IMPACT OF EARLY TREATMENT**  
Among persons with dementia, what is the impact of early treatment on quality of life, disease progression and cognitive symptoms?
- 4 HEALTH SYSTEM CAPACITY**  
How can the health system build and sustain the capacity to meet the health and social care needs of persons with dementia and their friend or family caregivers/care partners?
- 5 CAREGIVER SUPPORT**  
What services, supports and therapies for friend or family caregivers/care partners of persons with dementia would improve or maintain health, wellbeing and quality of life for persons with dementia and their friends or family caregivers/care partners?
- 6 ACCESS TO INFORMATION AND SERVICES POST-DIAGNOSIS**  
After dementia is diagnosed, what would help persons with dementia and their friends, family and caregivers/care partners get the information, treatment, care and services they may need?
- 7 CARE PROVIDER EDUCATION**  
What dementia-related skills and knowledge should health and social care providers have? What are effective ways of providing them with these skills and this knowledge? How can the number of health and social care providers who have these skills and this knowledge be increased?
- 8 DEMENTIA-FRIENDLY COMMUNITIES**  
What enables the creation of dementia-friendly communities? What impact do dementia-friendly initiatives have on persons with dementia and their friends, families and caregivers/care partners?
- 9 IMPLEMENTATION OF BEST PRACTICES FOR CARE**  
What would ensure implementation and sustainability of best practices for dementia care within and across health care settings, including effective approaches to providing person-centred care?
- 10 NON-DRUG APPROACHES TO MANAGING SYMPTOMS**  
Among persons with dementia, what are the effects of non-pharmacological treatments compared to pharmacological treatments on behavioural and psychological symptoms of dementia? Can non-pharmacological treatments replace, reduce or be used in conjunction with pharmacological treatments for managing behavioural and psychological symptoms of dementia?



## HEALTH RISKS OF LONELINESS

- Social isolation significantly increased a person's risk of premature death from all causes, a risk that may rival those of smoking, obesity, and physical inactivity.
- Social isolation was associated with about a 50% percent increased risk of dementia.
- Poor social relationships (characterized by social isolation or loneliness) was associated with a 29% increased risk of heart disease and a 32% increased risk of stroke.
- Loneliness was associated with higher rates of depression, anxiety, and suicide.
- Loneliness among heart failure patients was associated with a nearly 4 times increased risk of death, 68% increased risk of hospitalization, and 57% increased risk of emergency department visits.

Source: <https://www.cdc.gov/aging/publications/features/lonely-older-adults.html>



## DEMENTIA-INFORMED APPROACHES



## Voices in Motion Choirs (<https://voicesinmotionchoirs.org/>)



An **intergenerational** choir program for adults with memory loss, their care partners, friends and high school students in Victoria, BC

- **Professionally** conducted
- Started in 2018 as a 2 year study to **research** the benefits of participating in a choir on those with dementia, care partners and high school students
- **Currently**-- a charity with three in-person community-based choirs and one online choir.



## Choir Program

- 12-week season, concluding with a concert performance
  - Weekly 60-90 minute rehearsals
  - 3-part harmony (Soprano, Alto & Tenor/Baritone)
- Music binders: “lyrics only” or “full score”
  - CDs given to participants to listen and practice at home
- Repertoires with a theme (e.g., “Songs of Love and Friendship,” “Living in Technicolor,” “People Who Need People”)
  - Popular songs from a variety of eras, e.g., “What a Wonderful World,” “La Vie en Rose,” “Colour My World,” “Yellow Submarine”

VOICES IN MOTION PRESENTS  
**so happy TOGETHER**

**WINTER CONCERTS: SO HAPPY TOGETHER**  
Enjoy the songs that celebrate the gift of community  
We'll take you back in history to some of the best: *That's What Friends Are For, Lean on Me, I'd Like to Teach the World to Sing* and many more.

December 12 @ 3:00pm at St. Mary the Virgin  
Anglican Church  
(1701 Elgin Rd, Victoria)

December 19 @ 2:00pm at Victoria Edelweiss Club  
(108 Niagara St, Victoria)

PROOF OF VACCINATION AND MASKS REQUIRED

**BUY TICKETS: DEC 12 CONCERT**



## Research Overview

- **Participants:** 35 "duets"
  - Age: Care partners: 69 yrs, Person with dementia: 80 yrs
  - ~50% were spouses, 30% were adult children
- **Findings**
  - **Quantitative data**
    - **Caregiver distress:** significantly decreased during the choir season and rose during summer break
    - **Depression:** rates for caregiver and persons living with dementia decreased
    - **Cognitive decline:** about ½ the rate expected based on national data
  - **Qualitative data**
    - increase **quality of life and sense of well-being**
    - reduced **stigma**
    - Increased **social connections**
    - aroused **positive emotions** and memories



## THE CHOIR AS A COMMUNITY: TRUST, RESPECT AND FRIENDSHIPS



- ViM as a community and a family—many people with dementia said they derived a strong sense of belonging from singing with others in harmony
 

*"This is... this is not campfire singing, you know, we do a reasonable job. But the absolute delight in singing is to hear the... other voices, you know, and hear where you fit in."*
- Factors contributing to sense of community
  - Choristers with memory loss were seated beside a student or a volunteer for support and interaction
  - Ice breakers in rehearsal breaks for sharing personal stories and the meaning the songs had for choristers
  - The close friendships that choristers developed with one another through other activities that brought choir members together (e.g. picnic, tailgate parties)



## Singing to Challenge the Stigma of Dementia

- Students views of dementia evolved.  
*"In the beginning you're always just thinking in the bottom of your head they have Alzheimer's so you should be careful with what you say so they won't be so confused...but as weeks progressed you start to forget that they have Alzheimer's and like the beginning of rehearsals you're just like, 'oh hey come sit with me' and you start chatting with them and it's more comfortable being with them."*
- A sense of purpose in shifting views of dementia  
*"I think that the fact that we're on stage performing and people come from all walks of life, probably, come to hear us sing. And I'm sure they're observing us, hearing us, observing us and it probably does shift a few attitudes. And I think that's good. I think that's great! It's, yeah, just to be out, out in the world."*



## Count on Me



<https://www.youtube.com/watch?v=Lzjfi6OdWTM>



# MEMORY CAFÉ VICTORIA



## Background

- **Purpose**
  - Create a comfortable and supportive group for persons living with dementia and care partners to meet new friends, engage in creative activities, participate in learning and have fun.
- **Structure**
  - 12 week online program, 1 hour/week on Zoom
  - Professionally-led activities: poetry, drumming, music, story creation, art, and field trips to museums, art galleries and more.
  - Intergenerational—student volunteers



## Quotes

- **Social connections**

*“I feel getting to know others is important for two reasons: my partner (PwD) wants to get to know people who are like him (have dementia). I want to know other caregivers for support---get to know others who understand what we are going through.” (CP)*

- **In the moment**

*“My mother did not remember what happened afterwards but in the moment, it was like she was her old self, just laughing and engaging and getting to tell her stories, and I would be grateful to get to see her like that again.” (CP)*



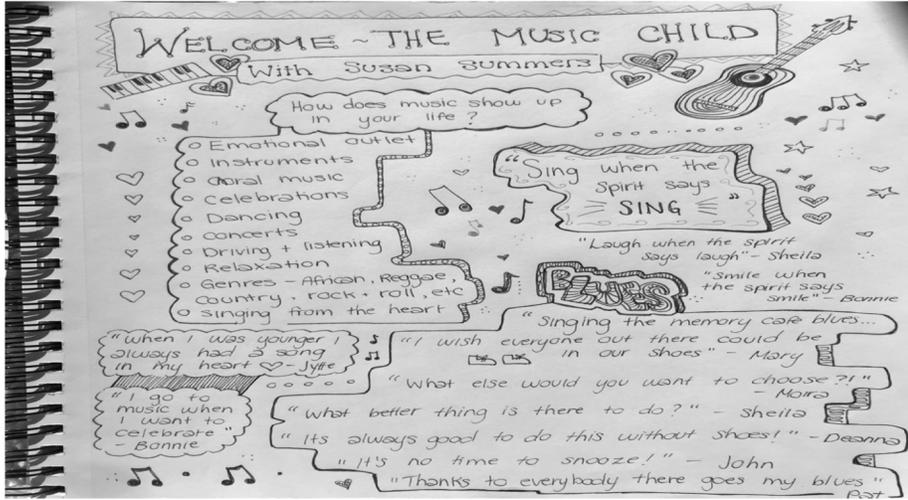
## Intergenerational Understanding

*“I love getting to hear about the participants’ weeks and hearing about their various interests. They all have such vibrant personalities and I feel as though a lot of individuals in my generation don’t recognize this enough. They often just assume that all elderly individuals are the same, and that they all have boring hobbies/stories.*

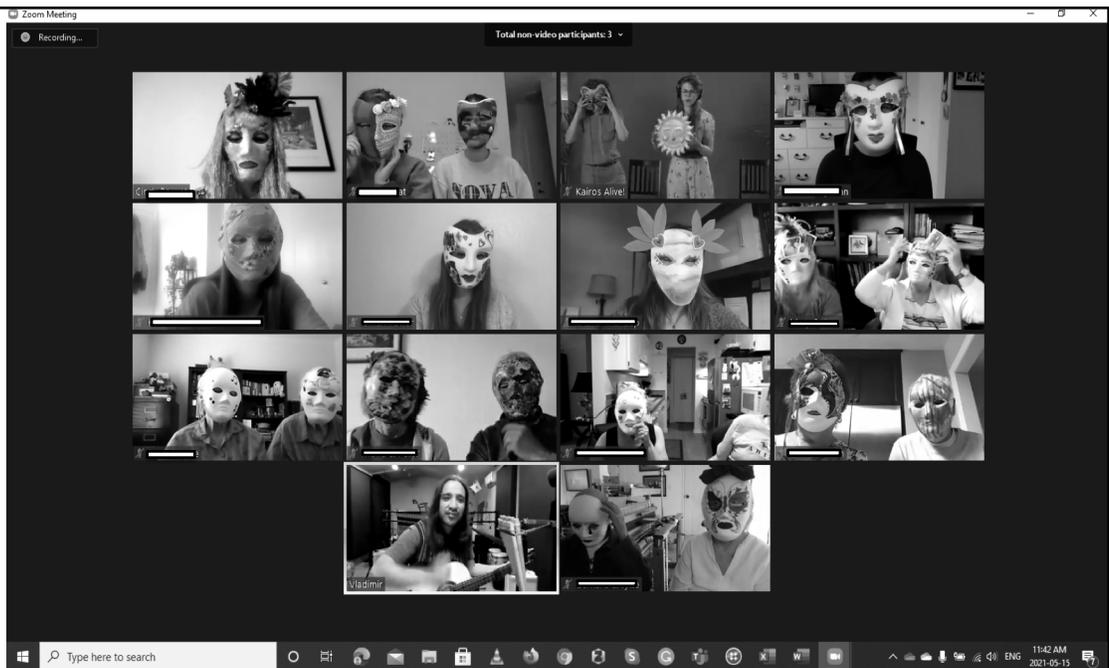
*But what I love about participating in the Memory Café is that I’m reminded of how untrue that is. I’m reminded that all of these individuals are so uniquely human; they all have stories to share, a sense of humour, and people whom they’ve loved and lost, and remembering this is, in my opinion, is of vital importance when connecting with people.” (Student)*



# Poster of Music Creation Activity



# Mask Making





Drumming Café



Painting





**HAPA ZOME**  
JAPANESE FLOWER  
PRINTING



CALL TO MIND PODCAST



## Giving Voice: Caregiver Diaries

- Four-part podcast series
  - Pandemic diaries to address the “narrative scarcity” of the voice of care partners and their family member
  - Personal stories to increase empathy for care partners who are expected to take on this role.
- **Goal:** shift narrative way from one of tragedy, continuous decline, caregiving burden, and fear
- Balanced stories that also show the love, tenderness and joy.



## Call to Mind: Audio Stories of Love and Memory Loss



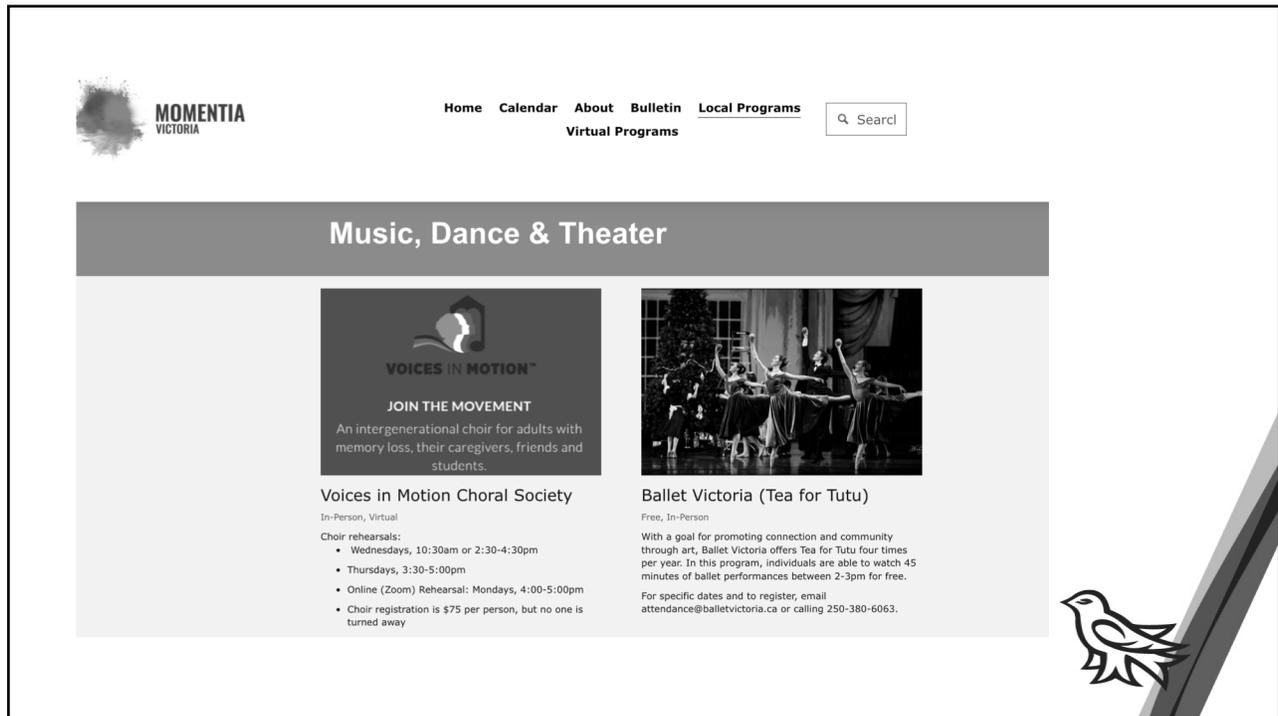
## NEXT STEPS



### **Momentia Victoria: Engagement in the Arts, Recreation and Social Activities**

- Map dementia accessible programs/activities in Victoria
- Identifying interested organizations who want to offer dementia informed activities
- Creating a “meet up” type website ([www.momentia victoria.org](http://www.momentia victoria.org)) to provide information on local and virtual programs
- Develop supports for dementia informed partnerships
- Ensure sustainability through “stewards”





**MOMENTIA**  
VICTORIA

Home Calendar About Bulletin Local Programs Virtual Programs

## Music, Dance & Theater



**VOICES IN MOTION™**

**JOIN THE MOVEMENT**

An intergenerational choir for adults with memory loss, their caregivers, friends and students.

**Voices in Motion Choral Society**

In-Person, Virtual

Choir rehearsals:

- Wednesdays, 10:30am or 2:30-4:30pm
- Thursdays, 3:30-5:00pm
- Online (Zoom) Rehearsals: Mondays, 4:00-5:00pm
- Choir registration is \$75 per person, but no one is turned away



**Ballet Victoria (Tea for Tutu)**

Free, In-Person

With a goal for promoting connection and community through art, Ballet Victoria offers Tea for Tutu four times per year. In this program, individuals are able to watch 45 minutes of ballet performances between 2-3pm for free.

For specific dates and to register, email [attendance@balletvictoria.ca](mailto:attendance@balletvictoria.ca) or calling 250-380-6063.



## RX Connect: Social Prescribing

- **Purpose:** referral of older adults with dementia to non-clinical resources to reduce social isolation and improve health and well-being
    - **Programs:** Voices in Motion, Minds in Motion, Memory Café Victoria
    - **Partners:** Seniors Outpatient Clinic, Primary Care Memory Clinic
    - Start up (pending funding): Fall 2022
  - **Key outcomes:** social connections, loneliness, caregiver distress, depression, purpose & meaning
- 

## Re-Connect: Creating pathways to dementia informed programs

- How can we support the development of self-efficacy in care partners and persons living with dementia?
  - Teach the skills necessary to navigate complex healthcare and social programs
  - Reduce stigma through empowerment and self-advocacy
  - Increase accessibility and choices for engagement







Pacific Alzheimer Research Foundation

*Société Alzheimer Society*

CANADA



ELDERCARE FOUNDATION

*Alzheimer Society*

BRITISH COLUMBIA



Canadian Frailty Network | Réseau canadien des soins aux personnes fragilisées

Known previously as Technology Evaluation in the Elderly Network, TVN



vancouver foundation



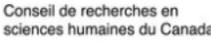
Michael Smith Health Research BC  
BC SUPPORT UNIT



island health



Social Sciences and Humanities Research Council of Canada



Conseil de recherches en sciences humaines du Canada



St. Andrew's Regional High School



PACIFIC CHRISTIAN SCHOOL  
EDUCATIONAL EXCELLENCE TO THE GLORY OF GOD

QUESTIONS?

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