CDLRN
Canadian Dementia Learning and Resource Network

Canadian Dementia Learning and Resource Network

Dementia Interventions Playbook

RIA Research Institute for Aging
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Dementia Interventions Playbook

A Dementia Strategy for Canada

The National Strategy for Alzheimer's Disease and Other Dementias Act, passed in 2017, mandates the federal Minister of Health to develop a national dementia strategy, host a national conference and establish a Ministerial Advisory Board on Dementia. The conference, held in 2018, included diverse participants such as people living with dementia, care partners, researchers and health professionals. The strategy was further shaped by stakeholder roundtables across Canada focused on research and innovation.

The resulting strategy, A Dementia Strategy for Canada: Together We Aspire, outlines three priorities:

- Prevent dementia
- Advance therapies and find a cure
- Improve the quality of life of people living with dementia and caregivers

In 2018, the Public Health Agency of Canada (PHAC) launched the Dementia Community Investment, a $4 million annual funding to improve the quality of life of people living with dementia and their care partners. The DCI investment supports community-based projects (referred to as DCI projects) to:

- Develop and implement tools, resources, programs, and other interventions to enhance the well-being of people with dementia and their care partners,
- Increase knowledge about dementia and its risk factors, and
- Support research to evaluate the effectiveness of project interventions.

Production of this project has been made possible through funding from the Public Health Agency of Canada (PHAC). The views expressed herein do not necessarily represent the view of the Public Health Agency of Canada.

Le présent projet a été produit grâce à la contribution financière de l'Agence de la santé publique du Canada. Les opinions exprimées ne représentent pas nécessairement celles de l'Agence de la santé publique du Canada.

The Canadian Dementia Learning and Resource Network Supports Dementia Community Investment Projects

Funded by the Public Health Agency of Canada's Dementia Community Investment, the Canadian Dementia Learning and Resource Network (CDLRN) is a knowledge hub that facilitates collaboration between the DCI projects across Canada and amplifies their successes. Led by the Schlegel-UW Research Institute for Aging (RIA), CDLRN is supported by a staff and research team at the RIA and is guided by a Community Advisory Committee.

How can this Playbook help you?

This Playbook was created to summarize, share, and showcase the work of the Dementia Community Investment projects in a way that will allow individuals and organizations to learn about and from their work, their successes, and the end products created through their projects. This Playbook is for individuals and organizations who engage with, support, and provide services to people living with dementia and care partners.

In this Playbook, each project is presented as a "Play" from which you can learn from the successes and challenges of the DCI projects. This might mean sharing DCI projects' toolkits or eLearning modules with the community and clients you work with. This could also mean adopting an existing project that is suitable for the needs and priorities of your local community.

Alternatively, for researchers and organizations, this could mean applying lessons learned by these projects, allowing them to avoid pitfalls and leverage the key learnings identified by projects that have done similar work.

Tips for navigating the Playbook

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Before You Begin: Foundational Knowledge for Everyone

Members of Canadian Dementia Learning and Resource Network (CDLRN), including Dementia Community Investment (DCI) project teams, people living with dementia and care partners, worked together to identify the foundational knowledge - or information that everyone needs to know - for a dementia initiative. This foundational knowledge was assembled through a collaborative process during the 2022 Annual Forum, an annual opportunity for members of the CDLRN to gather for capacity building workshops, discussion panels, and relationship building. Attendees worked in groups to identify background knowledge they found to be crucial to any dementia initiative. This foundational knowledge is presented below, organized into several categories/themes:

- Equity, Empowerment, and Hope
- Fostering Community Partnerships
- Meaningful Engagement of People Living with Dementia
- Stigma and Dementia
- Flexibility and Adaptability
- Accessibility
- Sustainability

Each of these themes are presented below with examples, links to resources, and practical ideas for implementing these considerations in your initiative. The sections on adaptability and flexibility, and sustainability were co-created with content expert Dr. Julia Moore and her team at the Center for Implementation.

Equity, Empowerment, and Hope

Equity, empowerment, and hope are essential pillars of any effective dementia intervention, promoting a more inclusive and supportive environment for individuals living with dementia.

Equity means recognizing and upholding the right of people with dementia to have their physical, cognitive, social, and spiritual needs met, engage in community opportunities, and access lifelong learning, aligning with the United Nations Convention on the Rights of Persons with Disabilities for equal rights, opportunities, and protections. This approach combats discrimination and ensures equitable access to support, resources, and care for everyone affected by dementia.

Simultaneously, **empowerment** is crucial, offering people living with dementia a sense of agency and control over their lives. In a dementia intervention, empowerment is supported by involving people living with dementia as equal partners in decision-making processes and breaking down stigma and misconceptions. Empowerment fosters dignity, independence, and a higher quality of life for people living with dementia, inspiring others through positive role models.

Approaching dementia with a sense of **hope** for living as well as possible each day is a core value that connects people living with dementia, project teams, and networks involved in DCI projects. Improving hope for living well with dementia provides a sense of purpose for team members.

Through an equity-focused, empowerment-driven, and hope-inspired approach, dementia projects can create a more optimistic outlook and supportive environment for all individuals living with dementia.

Resources for equity, empowerment and hope

- Forward with Dementia
- The Canadian Charter of Rights for People Living with Dementia
- The United Nations Convention on the Rights of Persons with Disabilities
- Finding Hope in Dementia (Canadian Consortium on Neurodegeneration in Aging webinar)

Fostering Community Partnerships

Community partnerships are essential to develop, implement, evaluate, and sustain dementia initiatives. Partnerships with people living with dementia should be a feature of all initiatives. Considerations for the meaningful engagement of people living with dementia are explored in the next section.

The partnerships needed will depend on the local context, available resources and the goals of the initiative. Partners can include community organizations, health and service providers, academic and research institutions, local businesses, advocacy groups, and local leaders. Fostering diverse partnerships increases the likelihood that the initiative will be relevant to the community.

Partners can bring expertise, share resources, raise awareness, and contribute to the sustainability of initiatives. Partners can help ensure that an initiative is tailored to meet the needs of the intended population.

Each partnership is unique and will have a different level of engagement. The National Implementation Research Network outlines different levels of engagement and processes for considering how you will engage.

Key considerations for fostering partnerships:

- Building relationships is time consuming but crucial for long-term success. In-person interactions can help to strengthen relationships more quickly.
- Prioritize relationship-building first with underserved communities before asking for commitment to a specific initiative. Provide opportunity for mutual benefit.
- Collaboratively define and commit to project goals.
- Leverage team members' networks to expand partner base.
- Use social media to engage and connect unfamiliar communities.
- Express gratitude and appreciation for partner involvement.

Resources for fostering community partnerships

- Partnerships in Dementia Care (PiDC) Alliance
- Working Together in Research: Jim's story as a person living with dementia, Lloyd's story as a care partner
- Embracing Diversity Toolkit
- Behavioural Supports Ontario (BSO) Indigenous Land Acknowledgement Guiding Framework
- Alzheimer's Disease and Related Dementias Clinical Studies Recruitment Planning Guide

Meaningful Engagement of People Living with Dementia

Engaging people living with dementia in the planning and implementation of dementia initiatives is essential. True partnership with people living with dementia collaboration and trust. Representing diverse experiences of dementia is ideal, with people of different backgrounds, challenges, and strengths.

The Authentic Partnership approach, developed by the Murray Alzheimer Research and Education Program (MAREP), outlines principles and enablers for engagement of people living with dementia in research and other initiatives. Authentic partnerships emphasize genuine inclusion, respect and and valuing of diverse perspectives regarding dementia, and especially of the experiences and perspectives of people living with dementia and their family care partners.

The DCI projects echoed many of these principles and enablers. The teams identified several crucial elements for engaging people living with dementia:

- **Building trust** is vital and requires respect, patience, and empathy. Sharing our personal backgrounds that brought us to this important work enables trust.
- **Fostering collaboration** with people living with dementia from the outset of the project is critical. This may involve creating advisory or steering committees that champion the inclusion of people living with dementia and recognizing the contributions of people living with dementia with honorariums and titles that highlight their pivotal role.
- Dementia initiatives are avenues to **amplify the voices** of people living with dementia. Initiatives should encourage and prioritize the voices of lived experiences to reduce stigma and promote inclusion.
- Providing opportunities for **peer support** where people with lived experience of dementia engage and share experiences can foster camaraderie, acceptance, and understanding.
- **Ensuring representation** from diverse groups is a fundamental principle, as initiatives should include those they aim to serve, embracing diversity in ethno-cultural identity, gender identity, age, sexual orientation, and other identities.

Resources for meaningful engagement of people living with dementia:

- Authentic Partnership approach
- Forward with Dementia
- Meaningful Engagement of People Living with Dementia
- I live with dementia
- Enhancing Communication: a By Us For Us guide
- 2SLGBTQI Dementia Networks of Support – Where do you fit?

Stigma and Dementia

People living with dementia often experience stigma. That is, they are treated differently based on their diagnosis of dementia. It is common for people to make incorrect assumptions about a person's abilities or assume that a diagnosis of dementia means that someone can no longer make decisions or meaningful contributions. This is not true. Media representations of dementia often portray a narrow, stereotypical experience of dementia that fails to show the range of diverse abilities and experiences of people living with dementia.

Stigma perpetuates misconceptions of dementia and can result in the exclusion of people living with dementia from their communities. Stigma of dementia can also negatively impact the way people living with dementia view themselves and their own abilities.

Recognizing your own preconceptions of dementia and working to overcome stigma is an essential step for anyone involved in dementia initiatives.

There are many ways to challenge stigma and create a supportive environment within and through your initiative. Here are suggestions and helpful resources:

- **Language**: Words are powerful and can change how we see ourselves and others. Person-centred language focuses on the person and not their diagnosis, helping to lessen stigma and fear of dementia.
- **Understand the rights of people living with dementia:** Read and apply the principles outlined in the Charter of Rights for People Living with Dementia.
- **Challenge stigma:** The Flipping Stigma On Its Ear toolkit provides resources for people living with dementia, researchers, family, friends and care providers. The toolkit helps people to recognize and respond to stigma.

Resources for understanding and challenging stigma

- World Alzheimer Report: Overcoming the stigma of dementia (2012)
- Dementia in New Light
- 10 easy ways to fight stigma against dementia
- Reimagining Dementia
- Forward with Dementia
- Dementia Risk and Stigma (video)

Flexibility and Adaptability

Dementia initiatives need to accommodate the needs of the community or context where they are being implemented. The initiatives should also consider accommodating diverse abilities, preferences and needs of people living with dementia, care partners and other community members who may participate.

Adaptability: Teams must recognize and respond to the needs of the communities and contexts where they occur. This may include selecting appropriate 'Plays' for your context. Alternatively, the 'Plays' in this guide may be a starting point that need adaptation to suit the needs of the communities and context. Being attuned to the needs in the community will help the long-term success of dementia initiatives.

Developing a deep understanding of the needs of the community and the participants you are serving is a critical step before finalizing the plan for your initiative. Understanding community needs includes learning what other organizations are delivering dementia initiatives, what resources are available and what gaps people are experiencing.

Changing language, terminology and acronyms for a different context are ways to incorporate **adaptability**. When adapting an initiative to a different language or ethnocultural group, invest time in learning about the language and terminology preferred by the community. Consider what terms related to dementia are preferred and understood by the communities you are engaging.

To successfully adapt an initiative, experts recommend working through six steps:

1. Clearly define what is being done (who is impacted by the initiative, who should be involved, what is the initiative, and how the initiative is being implemented)
2. Engage with the people who are implementing and impacted by the initiative
3. As a group, discuss why the initiative matters now and what can and can't be adapted
4. As a group, define what you are adapting using the responses from step 1
5. As a group, identify who will be impacted by the recommended changes
6. As a group, identify the impacts of the recommended changes

Past DCI projects suggest building in buffer time in timelines to accommodate challenges or unanticipated needs that are likely to arise. When unexpected obstacles arise and a change in approach is needed, communicate changes and rationale for changes clearly with project partners.

Read some of the lessons learned from projects like Our Dementia Journey Journal and the Cummings Centre Therapeutic Dementia Care Program for examples of flexibility and adaptability in action.

Flexibility and Adaptability

Fidelity: While adaptability to community needs and flexibility to individual needs are important, it is important to recognize that the evaluation of the 'Plays' in this Playbook depend on 'fidelity' to the original initiative. Fidelity refers to implementing the initiative as it was previously done (and evaluated upon). If you are adopting something that is evidence-based and want to achieve the same results as the original initiative, fidelity may be important. It can also damage the credibility of an initiative if it isn't used as designed and doesn't achieve its intended effects.

Choosing an initiative that most closely matches the needs and goals of your specific community will likely require the fewest adaptations. All contexts are different and there may not be an initiative that is a perfect fit. It is likely that some adaptations will be needed for your community but know that deviations may impact the effectiveness of the intervention and whether existing evaluation results apply.

If you think that substantial changes are needed for your context, consider consulting with the team that developed the intervention to understand their experiences, to ask for their advice, and to consider whether adapting their initiative or simply learning from their experience is the best approach.

Flexibility: Flexibility in dementia initiatives is also important at the individual level. Like everyone, people living with dementia have diverse abilities, preferences and needs that may vary day-to-day and over time. The social and physical environment can also influence the abilities and needs of people living with dementia. Teams should consider how they will support the unique needs of each participant in their programs.

Resources for remaining adaptable and flexible

- 5 Tips to plan for adaptations
- How-To-Guide: How to adapt social and behavior change communication materials
- Hexagon Tool: an exploration process to help you understand community needs

Sustainability

Why does sustainability matter? Planning early for sustainability increases the likelihood of maintaining the dementia initiative after implementation ends.

What is sustainability? Sustainability means different things to different people. Sustainability can refer to the project team's ability to deliver some or all aspects of a dementia initiative beyond the funding period. Sustainability can also refer to efforts to sustain the outcomes and benefits achieved over a defined period of time. Recipients of Dementia Community Investment (DCI) funding recommend planning for the sustainability of an initiative from the start of the project.

Who should be involved in sustainability planning? When teams start thinking about sustainability, they should take the time to consider who should be involved in these conversations. At minimum, it is advisable to involve: people who will be involved in implementation of the initiative, people who will make decisions about the initiative (after the project is finished), people impacted by the initiative, and subject matter experts.

What should you consider for sustainability planning? There are a number of tools available to help teams plan for sustainability. Identifying who should be involved in sustainability planning, clearly defining the long-term vision and goals for the initiative, and considering how it might continue and/or evolve are helpful first steps.

Successful approaches to sustainability used by DCI projects:

- Consider creating collaborative partnerships with people living with dementia, local community groups, and organizations that can help champion your initiative, like the Building Capacity project. Time to develop these partnerships should be planned for in your initiative.
- Consider how an initiative might be scaled up or modified to be used in a different context (for example, a capacity building approach or a "train-the trainer" model, used by the Together for Fun project). These groups can then continue to deliver the initiative after the funding has ended.
- Some DCI projects used an online education model to support the sustainability of their initiative, as these online education resources can be accessed beyond the funding period.

Resources for sustainability

- The 5 components of sustainability
- The Program Sustainability Assessment Tool (PSAT)
- The StrategEase Pathway
- The Long Term Success Tool

Accessibility

- Accessibility is an evolving topic with considerations that vary depending on the setting. When planning a dementia initiative, it is important to consider how to minimize barriers to participation and maximize accessibility. Barriers to participation can be physical, social, financial, and more. Accessibility also includes aspects that can be invisible, such as creating a safe environment where people living with dementia feel welcomed and supported. Reflect on potential barriers to your initiative and strategies that may help overcome these barriers.
- When implementing your dementia initiative, consider how you will promote accessibility for diverse groups, including people living with dementia who are diverse in abilities, geography, ethno-cultural identity, spoken language, and/or sexual and gender identity. You may not be able to specifically engage all these groups, but you should carefully consider how your choices influence accessibility across groups.
- Accessibility standards or legislation may exist in your region. At the time of this publication, provincial standards were in place in Alberta, British Columbia, Manitoba, New Brunswick, Newfoundland and Labrador, Nova Scotia, Ontario, Prince Edward Island, Quebec, and Saskatchewan. The Resources for accessibility below include considerations related to services and products (such as written materials) that are the most likely to be encountered when implementing a dementia initiative.

Resources for accessibility

- Planning for accessibility considerations
- DEEP Guide: Writing dementia-friendly information
- Creating accessible Microsoft Word documents
- Why is digital design important for someone affected by dementia?
- Dementia-Friendly Canada: Tips for dementia-friendly spaces
- Dementia-friendly environment checklist
- Becoming Dementia Friendly: Checklist for a physical environment
- Dementia-friendly communities environmental assessment

The Plays

The previous section outlined the foundational knowledge that is essential for any community-based dementia initiative.

Next, learn from the Dementia Community Investment projects about their unique and innovative work. Each project is presented as a “Play”, beginning with a short description of the project and suggestions of who could benefit from reading this Play, to help readers easily identify the projects that may be useful or relevant to them.

Each Play includes 4 main sections that outline:

- Key information, including:
  - Who was this project designed for?
  - Project lead
  - Project partners
  - Project status
- Project story, including:
  - Background
  - Goals
  - Milestones and achievements
- Impact, including:
  - Project findings
  - Experiences
  - Insights, including:
- Lessons learned
  - Recommended resources
  - Get in touch

Building Capacity for Meaningful Participation by People Living with Dementia

Promoting the full social citizenship of people living with dementia through practical resources and approaches, collaborative community programs and partnerships.

Who could benefit from reading this Play?

- Community organizations who want to improve the inclusion of people living with dementia in their existing programs or programs being developed.
- People living with dementia or care partners in Vancouver, BC and Thunder Bay, ON who would like to become involved in initiatives developed through this project or develop similar initiatives.
- Individuals and community organizations who want to use the lessons learned and resources developed from this project to create or modify a similar program.

Review the Before you begin section for foundational knowledge that will be helpful for any dementia community initiative.

Key information

Who was this project designed for? people living with dementia and their care partners and the community at large, including community organizations that provide support and programming for older adults

Project lead: University of British Columbia and Lakehead University

Project partners: Westside Seniors Hub and the North West Dementia Working Group

Project status: DCI funding (2019-2023) is complete, with phase 2 underway (2023-2025)

Building Capacity for Meaningful Participation by People Living with Dementia

Project story

Background

Driven by a commitment to inclusivity and empowerment, researchers from University of British Columbia and Lakehead University collaborated with local organizations to create, foster and sustain opportunities for people living with dementia and care partners to maintain engagement within their communities. Acknowledging the unique challenges and strengths in each community, this project used an asset-based community development approach to support initiatives in arts, social participation, fitness, and volunteering. Beyond introducing new programs, this project explored how to adapt and improve established resources, such as existing programming in community and seniors centres, to create communities and spaces that are inclusive of people living with dementia.

Goals

To improve the well-being of people living with dementia by supporting and creating opportunities to remain active and socially connected by:

- Creating community-led initiatives and events that engage, support and empower people living with dementia
- Supporting and empowering partner organizations to build their capacity to offer inclusive programming and services
- Developing educational materials and resources to promote understanding, inclusion and reduce stigma
- Identifying, evaluating and sharing practices and approaches to make communities more dementia-inclusive

Building Capacity for Meaningful Participation by People Living with Dementia

Milestones and achievements

Development of resources, tools and knowledge mobilization products:

- Flipping Stigma toolkit and resulting training (in partnership with the Flipping Stigma Action Group), website, and awareness campaign using bus advertisements
- Monthly newsletter highlighting opportunities, resources and events
- Dementia Ventures Soundbytes series, featuring highlights and words of wisdom from people with lived experience of dementia and community partners
- Documentary: The Building Capacity Project
- Community partner pillars exhibit showcasing the work of partner organizations
- Through our eyes video series: awareness building and education tool
- A comprehensive portfolio of knowledge translation products

Building Capacity for Meaningful Participation by People Living with Dementia

Milestones and achievements (continued)

- Creation of new dementia initiatives, including events offered weekly, bi-weekly and monthly:
  - Dementia Sisterhood facilitated peer support group
  - Dementia Ventures events
  - Happy Memories Café, offered in Spanish and English
  - Tablet lending program
  - Fireweed Club, a regular social gathering in the summer months
  - Gardening workshop series
- Special events including:
  - Intergenerational storytelling event with Vancouver poet laureate Fiona Tinwei Lam
  - End of Year community celebrations
  - Field trips
- Training, education and awareness initiatives:
  - Adaptation of the Flipping Stigma toolkit into a community training initiative used to train staff and 200+ volunteers from senior day centers, church groups and community gathering spaces (such as Neighborhood Houses)
  - Memory buddy training
  - Dementia and stigma awareness for Vancouver Public Library staff, in partnership with the Alzheimer Society of British Columbia
  - Bilingual (Mandarin and English) workshops, dementia education and training including topics of brain health and stigma
- Support and capacity building of ongoing initiatives including:
  - Monthly North West Dementia Working Group (NWDWG) meetings
  - Dementia Café (held several times a month)
  - Taking Control of Our Lives facilitated peer support group

Building Capacity for Meaningful Participation by People Living with Dementia

Impact

Project findings

Community partners (including seniors centres, community centres and religious organizations) experienced:

- Increased understanding of dementia and the impact of stigma
- Improved capacity and confidence to be supportive and inclusive of community members living with dementia

People living with dementia and care partners experienced:

- Increased feelings of social inclusion
- Improved well-being

Building Capacity for Meaningful Participation by People Living with Dementia

Insights

Lessons learned

- Building and maintaining relationships with individuals, communities, and organizations is essential for initiatives like Building Capacity. This relationship building requires time, flexibility, and commitment to building lasting partnerships.
- Stigma is a barrier to creating dementia-inclusive spaces. By fostering community dialogues and promoting awareness about dementia and its associated stigma, organizations can begin initial steps toward enhancing their capacity to deliver inclusive support and services.
- Leveraging the established partnerships and structures of partner organizations, such as utilizing the existing physical space, practices, and partnerships of a seniors centre or community gathering space, can allow initiatives to be trialed and can open doors to potential additional partnerships. The development of additional partnerships can be supported by making intentional connections and encouraging collaboration between partners.
- Prioritize activities and initiatives that promote and build on participant's feelings of enjoyment, social connection, and sense of belonging.
- When implementing new initiatives, flexibility, and a willingness to trial approaches is helpful and allows work to progress, rather than waiting for ideal conditions. Taking small steps then reflecting on the success of the approach is recommended.
- Community development coaching provides invaluable support by empowering communities and organizations to identify their individual and shared goals and leveraging available resources to create mutual support. This approach can be facilitated by a backbone organization to guide and coordinate efforts, maximizing impact and sustainability.
- Champions are extremely valuable, including at the organizational level to promote the cause, as well as people who are living well with dementia who can decrease stigma and act as role models for new members.

Building Capacity for Meaningful Participation by People Living with Dementia

Recommended resources

The following resources are recommended by the team who developed this program:

Toolkits and guides:

- By Us for Us Guides
- Flipping Stigma toolkit

Organizations:

- Westside Seniors Hub
- Dementia Australia
- North West Dementia Working Group
- Momentia

Dementia Dialogue podcast, including episodes:

- Season 3, Episode 20: Grassroots Changemakers
- Season 3, Episode 32: Women Living with Dementia
- Season 4, Episode 53: Building Capacity Project
- Season 5, Episode 57: Community engagement- Safety in numbers
- Season 5, Episode 58: Community partners and their journey of discussion and inclusion

Webinars and videos:

- Research Matters interview with Dr. Elaine Wiersma and Bill Heibein
- Healthy Aging CORE Canada webinar: The Case for Engaging People with Dementia in Community Support Efforts

Get in touch

Building Capacity project

Dr. Alison Phinney, University of British Columbia

Dr. Elaine Wiersma, Lakehead University

Coming Together to Support 2SLGBTQI People Living with Dementia and their Unpaid Primary Carers

Research-based and community informed education and resources designed to foster inclusivity and promote improved support for 2SLGBTQI people living with dementia and their care partners.

Who could benefit from reading this Play?

- Healthcare and service providers who want to enhance their knowledge and capacity to provide safe and supportive care for 2SLGBTQI people living with dementia and their care partners.
- Individuals and organizations who want to use the resources developed by this project to increase their ability to act in allyship towards 2SLGBTQI people living with dementia and their care partners.
- 2SLGBTQI people living with dementia and their care partners who want to learn about available resources.

Review the Before you begin section for foundational knowledge that will be helpful for any dementia community initiative.

Key information

Who was this project designed for? 2SLGBTQI people living with dementia and their care partners, as well as those who support them (including healthcare and social service providers)

Project lead: Egale Canada

Project partners: National Institute on Ageing (NIA) and Toronto Metropolitan University, with an advisory committee composed of representatives from the Alzheimer Society of Toronto, Rainbow Elders Calgary, ElderBerries, Nova Scotia Rainbow Action Project and the Queer Seniors of Saskatchewan.

Project status: complete, 2019-2023

2SLGBTQI Dementia Networks of Support – Where do you fit?

Coming Together to Support 2SLGBTQI People Living with Dementia and their Unpaid Primary Carers

Project story

Background

Clear gaps in research and knowledge related to the unique experiences and needs of 2SLGBTQI people living with dementia (PLWD) and their care partners led to the development of this multi-phase project, the first national research study focused on 2SLGBTQI communities and dementia. Researchers used focus groups, interviews and expert consultations to identify common challenges, areas of opportunity, and learning needs required to build the capacity of unpaid care partners, healthcare and social service providers to provide inclusive and supportive care for 2SLGBTQI PLWD. Reports, eLearning modules and resources were created to meet this need, with unique offerings tailored to different roles. A nation-wide awareness campaign highlighted the specific needs and increased risks faced by 2SLGBTQI PLWD and championed the use of the education materials developed through this project to address this growing need.

Goals

To enhance the provision of care, services, and support for 2SLGBTQI PLWD and their care partners in Canada by:

- Identifying and addressing gaps in knowledge, understanding and critical inquiry
- Creating shared understanding of their lived experiences, perspectives, and needs
- Developing education and resources to address identified gaps
- Promoting awareness of the unique needs identified and the resources available to address them

Coming Together to Support 2SLGBTQI People Living with Dementia and their Unpaid Primary Carers

Milestones and achievements

- 2SLGBTQI Dementia Networks of Support – Where do you fit? (also available in French)

Reports:

- Coming out and coming in to living with dementia: report
- Acting in Allyship with 2SLGBTQI People Living with Dementia — Guiding Principles for Healthcare And Social Service Professionals

eLearning modules:

- 2SLGBTQI Identity and Dementia: An Introduction for Unpaid Carers
  - Additional Learning Resources
- 2SLGBTQI Identity and Dementia: An Introduction for Healthcare and Social Service Professionals
  - Additional Learning Resources

Resources:

- How to be an Ally to 2SLGBTQI People Living with Dementia
- Nice to Meet You: What I'd like Healthcare and Social Service Providers to Know About Me
- Recommendations for Supporting 2SLGBTQI People Living with Dementia and their Carers through Systemic Change

Coming Together to Support 2SLGBTQI People Living with Dementia and their Unpaid Primary Carers

Impact

Project findings

- 100% of family/friend care partners who completed the eLearning modules reported improved wellbeing
- 97.3% of participants reported increased knowledge and/or skills (Healthcare and Social Service Professionals and unpaid carers/family/friend care partners combined)

Experiences

"This has really opened my eyes to 2SLBGTQI need for support in healthcare when ageing. No matter what our place is in this world, we all have red blood." - **eLearning module user**

"This is an excellent training, I oversee the training, learning & development program in my organization and have already incorporated into our training plan, and have assigned it to our Caregivers Education Team." - **eLearning module user**

"I work with people who have dementia and identify in many different ways. I feel that this experience has taught me many of the ideas this training was designed to address." - **eLearning module user**

Coming Together to Support 2SLGBTQI People Living with Dementia and their Unpaid Primary Carers

Insights

Lessons learned

- When planning research involving 2SLGBTQI groups, direct engagement with community members is critical. This can include having community members be part of your research team, engaged in an advisory committee, and/or be involved directly as research participants. This approach helps ensure that research efforts are more culturally sensitive, relevant, and aligned with the real experiences and needs of the community.
- The eLearning modules in this project were directly shaped by the perspectives, stories, and recommendations shared by 2SLGBTQI individuals living with dementia, their care partners and providers. This user-centric approach to creating educational materials is recommended, as it allows for users to be engaged throughout the development process, ensuring that the resulting materials are effective and tailored to the specific needs and preferences of the target audience.

Get in touch

- Dennis Quesnel, Project Management Officer, Egale
- Kendall Forde, Director of Project Management, Egale

Cummings Centre Therapeutic Dementia Care Program

Comprehensive and specialized day program for people living with dementia that includes support and respite services for care partners.

Who could benefit from reading this Play?

- Individuals, community organizations, day program service providers, managers and policy makers who want to use the lessons learned and recommended resources from this program to create or modify an existing day program for people living with dementia.
- People living with dementia and their care partners who are interested in attending a day program, and/or learning more about its potential impact.

Review the Before you begin section for foundational knowledge that will be helpful for any dementia community initiative.

Key information

Who was this project designed for? People living with dementia (or varying cognitive impairment levels) and care partners in Montréal, Québec, with a special focus on women, English-speaking older adults, individuals with low socioeconomic status and cultural minorities.

Project lead: The Cummings Centre

Project partners: Concordia University's Centre for Research on Aging (engAGE), the Centre for Research and Expertise in Social Gerontology (CREGES), the City of Côte Saint-Luc, and the Integrated Health and Social Services University Network for West-Central Montréal (CIUSSS Centre-Ouest de l'Île de Montréal), and an advisory committee composed of care partners involved in the program.

Project status: complete, 2019-2023

Cummings Centre Therapeutic Dementia Care Program

Project story

Background

The Cummings Centre is a multi-dimensional membership-based organization offering programs and services to the Montréal community. This program was delivered by recreation therapists and student trainees using a holistic approach to create a supportive and engaging environment for participants while addressing the unique challenges associated with dementia and caregiving. Originally intended to be delivered in-person in a community centre, this program evolved in response to the Covid-19 pandemic to offer both virtual and in-person programming including physical, cognitive, and creative arts activities. Respite care, dementia education, psychosocial support, and resources were available to care partners through the program. Training, workshops, conferences, and educational resources to raise awareness about dementia and its risk factors within the community were also available through the Cummings Centre as part of this program.

Learn about current Day Services offered at the Cummings Centre

Goals

The goal of the Therapeutic Dementia Care Program was to enhance the well-being of people living with dementia and their care partners through:

- Individual assessments to understand and address each participant's unique needs
- Specialized programming that meets the needs and preferences of participants
- Group activities that build relationships and foster a sense of belonging and community
- Equipping care partners with knowledge, skill and capacity building

Cummings Centre Therapeutic Dementia Care Program

Milestones and achievements

Members of the Cumming Centre Therapeutic Day Program team developed resources to support the delivery of this program and provide care partners with education and tools related to dementia.

- Download: Dementia Care Partner Resources Manual
- Download: Fostering Musical Engagement
- Download: Leisure Stories: “How To”

Impact

Project findings

- Both people living with dementia and care partners had high levels of satisfaction with the program. In particular, the program had a positive impact on the well-being of 131 people living with dementia and 156 care partners who participated in the Therapeutic Day Program.
- 452 members of the general population were reached through student internships, webinars and events that promoted awareness and knowledge about dementia and its risk factors.

Cummings Centre Therapeutic Dementia Care Program

Impact

People living with dementia

- 100% were satisfied with the program and kept their minds active
- 100% reported improved well-being
- 91% were energized by the program
- 88% felt less lonely
- 81% kept their bodies active

Care partners

- 92% reported improved well-being
- 93% reported an increase in knowledge and/or skills
- 85% agreed that they were happier
- 76% agreed that they avoided burning out
- 75% agreed that they enjoyed life more

Want to know more? Download this supplementary resource outlining how this program was evaluated.

Experiences

"[My wife] has an AMAZING time with you. She cannot stop saying how much she enjoys herself ("such nice people"). I am so very, very grateful that this program exists. It is literally helping me become more mentally stable and confident in my 24/7 caring for [my wife]!" - **Care partner**

"Thank you for making me feel right at home". - **Person living with dementia**

Cummings Centre Therapeutic Dementia Care Program

Insights

Lessons learned

- Intake assessments help understand the client's interests and requirements. Plan for extra time and effort to complete intake assessments and onboarding of new clients and families. Prioritize completing assessments in person (including home visits, if necessary), even for clients who may only attend virtually.
- Encourage socialization among people living with dementia during programming and consider grouping guests based on social fit. Creating opportunities for participants to befriend each other enhances engagement and fosters a sense of belonging within the group.
- Facilitate ongoing group opportunities for care partners to participate with a consistent core group, fostering connections and a sense of belonging. This is preferable to activities that are time-limited (e.g. 10 week series) which can deter potential attendees from joining if they are unable to commit long term.
- Plan care partner leisure activities thoughtfully, avoiding activities that require a certain number of attendees. This can inadvertently pressure care partners to register just to support the program.

Recommended resources

The following resources are recommended by the team who developed this **program:**

- Dementia - Your Companion Guide (available in multiple languages)
- Teepa Snow's Positive Approach to Care
- The Eden Alternative Approach
- Dementia beyond disease: enhancing well-being by G. Allen Power, M.D.

Get in touch

Sheri Stock, Program Manager, Cummings Centre Day Services

Dementia-Friendly Canada

Education and tools for the general public and professionals working in specific sectors to apply dementia-friendly principles in their work and communities.

Who could benefit from reading this Play?

- Professionals in sectors including recreation, library, retail, restaurant, and public transportation, who want to enhance their knowledge and confidence in supporting individuals living with dementia
- Individuals and organizations interested in using the lessons learned and resources created by this project to create or support dementia-friendly communities and workplaces, fostering inclusivity and accessibility.

Review the Before you begin section for foundational knowledge that will be helpful for any dementia community initiative.

Key information

Who was this project designed for? The general public and professionals working in the recreation, retail, restaurant and public transportation

Project lead: Alzheimer Society of Canada

Project partners: Alzheimer Societies of British Columbia, Saskatchewan, Manitoba, Nova Scotia and Ontario

Project status: DCI funding (2019-2023) is complete, with phase 2 underway (2023-2025)

Learn from Dementia-Friendly Canada

Dementia-Friendly Canada

Project story

Background

A dementia-friendly community is one where people living with dementia and their families, friends and care partners are included and supported. Building upon existing work across the country, the Dementia-Friendly Canada project created tools, education, and programming to support the development of dementia-friendly communities throughout Canada. This work was informed by consultations with people living with dementia, care partners and targeted professional groups (people working in recreation and library, restaurant and retail, and public transportation sectors). These consultations identified the characteristics that define dementia-friendly communities and the education topics, tools and resources needed to foster their creation. The resulting products and education include public service announcement videos (PSAs), online education modules, webinars, guidelines and tip sheets.

Goals

Three main goals guided the Dementia-Friendly Canada project:

- To train Canada's workforce to be dementia friendly
- To promote education and awareness of dementia among the general public
- Promote the sustainability and nationwide growth of the Dementia-Friendly Canada initiative

Dementia-Friendly Canada

Milestones and achievements

- Development of the Building Dementia-Friendly Communities course, a 75-minute interactive, self-paced and self-directed course.
- Building Dementia-Friendly Communities tip sheets:
  - How to be a Dementia Friend
  - Tips for Dementia-Friendly Interactions
  - Tips for Dementia-Friendly Interactions from Behind a Mask
  - Dementia-Friendly Language Guidelines
  - Tips for Dementia-Friendly Spaces
  - Tips for Dementia-Friendly Written Material
- Creation of the Dementia-Friendly Communities Awards
- Public service announcement videos:
  - Ways you can be dementia friendly: reducing distractions
  - Ways you can be dementia friendly: ensuring participation
  - Ways you can be dementia friendly: providing assistance
  - Ways you can be dementia friendly: responding compassionately
- Webinars:
  - Dementia-Friendly Canada: Building dementia-friendly communities
  - Dementia-Friendly Canada: Creating inclusive and supportive communities
  - Dementia-Friendly Canada Project
  - A dialogue about dementia-friendly public transportation
  - A dialogue about ensuring a dementia-friendly experience in retail and restaurants
  - A dialogue about ensuring a dementia-friendly experience in recreation and libraries
  - Dementia-Friendly Canada: Reflections and next steps
- Internal resources for Alzheimer Society staff:
  - Dementia-Friendly Communities Awards: Toolkit for Alzheimer Society Federation Partners
  - Building dementia-friendly communities: A guide for Alzheimer Society Federation partners

Dementia-Friendly Canada

Impact

Project findings and experiences

Sector professionals who completed the Building Dementia-Friendly Communities course were satisfied with the educational resources, finding them helpful in boosting their knowledge and confidence in supporting those affected by dementia.

- Increased self-reported knowledge/skills related to dementia
- Increased confidence in interacting with people living with dementia
- Felt that their own actions could increase their organization's ability to be dementia-friendly

Want to know more? Download this supplementary resource outlining the data collection methods, the evaluation evidence and the tools used. This report from the Alzheimer Society of Canada and their Federation Partners includes additional in-depth information.

Dementia-Friendly Canada

Insights

Lessons learned

- The involvement of people living with dementia and care partners throughout a project is invaluable. Support this engagement by creating a plan at the outset of a project for the continuous and comprehensive engagement of people with lived experience, allowing adequate time for meaningful engagement to occur.
- Translation of materials into other languages should include both a certified translator and team members or partners fluent in the language to verify translations for cultural accuracy and alignment with the organization's communication style.

Experiences

"As soon as the course was completed, I went into the lobby area of our library and removed additional furnishings and re-organized the space for a better flow. I looked for "visual noise" in the space and removed some unnecessary signage."

- Sector professional

"It's a well-designed, thoughtful course that outlines the different areas service providers can focus on. It empowers people in all levels of an organization to have conversations and destigmatize what living with dementia or caring for someone living with dementia means. We all have a role we can play and the barriers that we can chip away can help so many others and hopefully develop thriving and connected communities."

- Sector professional

"I think most people are willing to be helpful. Often, we/they just don't think of things we can do. The course provides ideas to recognize and help situations."

- Person living with dementia

Get in touch

Dementia-Friendly Canada

Dementia-Friendly Communities Supporting the Life Trajectory of People Living with Dementia

Implementation of tailored recommendations in two Quebec communities to adapt their environments to be more dementia-friendly, with a specific focus on supporting continued participation in community life and preferred activities.

Who could benefit from reading this Play?

- Individuals and community organizations who are interested in making their communities more dementia-friendly.
- Municipalities, first responders (including police and firefighters) and community organizations who would like to train their staff in dementia-friendly approaches.
- Care partners and support networks of people living with dementia who want to improve their communication and support they provide.
- Individuals and community organizations who want to use the lessons learned and recommended resources from this project to create or modify a similar program.

Review the Before you begin section for foundational knowledge that will be helpful for any dementia community initiative.

Key information

Who was this project designed for? People living with dementia, their care partners and first responders, volunteers, employees of community organizations and municipal authorities in the communities of the Huron-Wendat First Nation and Sherbrooke, Quebec.

Project lead: Research Centre on Aging, affiliated with the Université de Sherbrooke (Centre de recherche sur le vieillissement).

Project partners: The Estrie Alzheimer Society, the Sherbrooke Police Service, the Memphremagog Police Board, the Council of the Huron-Wendat Nation and the Marie-Paule-Sioui-Vincent Health Centre.

Project status: complete, 2019-2023

Dementia-Friendly Communities Supporting the Life Trajectory of People Living with Dementia

Project story

Background

The Dementia-Friendly Communities Supporting the Life Trajectory of People Living with Dementia project was developed to address the needs of people living with dementia and their family and friend care partners in Sherbrooke, Quebec and Wendake (the Huron-Wendat Nation). Community consultations, including surveys, interviews and focus groups, were used to understand the specific challenges experienced by people living with dementia and their families in each community. Steering committees in each community worked collaboratively with researchers to co-design community action plans tailored to the unique needs of each community, including events and training to raise awareness of dementia, the development of a vulnerable persons registry and provide dementia-friendly training to organizations who interact with and provide services to people living with dementia.

Goals

To implement community initiatives and training that will improve the well-being and quality of life of people living with dementia and their care partners by:

- Increasing knowledge and awareness of dementia among first responders, service providers and municipal employees
- Improving the ability of people living with dementia and care partners to participate in community activities and activities of daily living
- Increasing awareness of dementia and approaches to include and maintain inclusion of people living with dementia in cultural, recreation and community activities

Dementia-Friendly Communities Supporting the Life Trajectory of People Living with Dementia

Milestones and achievements

- Development and delivery of dementia-friendly training for police and firefighters
- Development and implementation of a vulnerable persons registry with the police service ("Let's get you home" program, also available in French)
- Educational videos:
  - "Living with a Neurocognitive Disorder", provides tips and insight into how to provide support for people living with dementia to remain engaged and supported in their communities; also available in French
  - "Strategies to communicate in a supportive manner with a person living with dementia" includes advice on how to promote communication with someone living with dementia; also available in French
  - "Tips for handling sensitive situations in the context of neurocognitive disorders" available on the project's YouTube channel
- Development and implementation of training designed to increase understanding and awareness of dementia, promote kindness and reduce stigma for 711 residents of long term care and retirement homes
- Delivery of community events focused on cognitive health and raising awareness of dementia, including a film screening and discussion

Dementia-Friendly Communities Supporting the Life Trajectory of People Living with Dementia

Impact

Project findings

Care partners and people living with dementia involved in this project reported:

- Improved well-being
- Improved protective factors

Participants who completed dementia-friendly training (including police officers and firefighters), reported:

- That they would recommend dementia-friendly training to others (83.5% - 100% of training participants)
- That they acquired knowledge and skills that are relevant to their work(88.6% of training participants)

Participants in community events reported:

- That their previous perceptions of dementia were changed through their participation (83.5%)

Dementia-Friendly Communities Supporting the Life Trajectory of People Living with Dementia

Insights

Lessons learned

- Building and maintaining strong relationships with partners such as police and firefighter organizations is a worthwhile investment of time. Allocating resources (both human and financial) to the continued implementation of a program can help ensure the initiative continues to be implemented as priorities and roles change.
- Stigma and cultural norms surrounding dementia support can have an impact on recruitment and involvement of people living with dementia, which can vary by region and culture. This project team experienced challenges reaching people living with dementia to participate in the study or their steering committees. Efforts to support stigma reduction and the promotion of opportunities for engagement and leadership of Francophone people living with dementia would be beneficial.
- Ensuring the long-term sustainability of interventions like this one can be improved by empowering involved organizations to collaborate on the development of sustainability plans to ensure buy-in and improve the feasibility of the plan.

Recommended resources

The project team identified the following resources that were helpful in the development of this project:

- Dementia-Friendly Canada resources, including tip sheets and the online course Building Dementia-Friendly Communities: Recreation and Library, Restaurant and Retail, and Public Transportation
- Dementia Dialogue podcast
- I'm a first responder: handbook, videos and resources for first responders, also available in French
- Resources from the National Collaborating Centre for Aboriginal Health website

Get in touch

Julie Lacerte, Centre de recherche sur le vieillissement

Véronique Provencher, Centre de recherche sur le vieillissement

Dementia Resources for Eating, Activity and Meaningful Inclusion

Education and resources to include and support people living with dementia in physical activity, healthy eating, mealtimes, and other wellness activities.

Who could benefit from reading this Play?

- Health and community service providers across Canada (and beyond) who deliver physical activity, healthy eating, mealtime, or other wellness programs and services.
- People living with dementia and their care partners who are interested in improving their well-being through physical activity and maintaining a healthy diet
- Organizations and service providers interested in using the lessons learned and resources created by this project to create or modify a similar program.

Review the Before you begin section for foundational knowledge that will be helpful for any dementia community initiative.

Key information

Who was this project designed for? Community service providers, people living with dementia and their care partners

Project lead: University of Waterloo with the University of Northern British Columbia

Project partners: Active Health Solutions, Alzheimer Society of BC, Alzheimer Society of Ontario, Canadian Nutrition Society, Canadian Society of Exercise Physiology, City of Kitchener, Dementia Advocacy Canada, Muslim Social Services of Kitchener-Waterloo, Ontario Brain Institute, Ontario Kinesiology Association, Schlegel-UW Research Institute for Aging, Waterloo Regional Dementia Advisory Group, YMCA of Three Rivers

Project status: complete, 2020-2023

Dementia Resources for Eating, Activity and Meaningful Inclusion

Project story

Background

People living with dementia have the right to equitable support for their health, wellbeing, and function. Inclusion and support of people living with dementia should be a key priority for service providers. The purpose of the Dementia Resources for Eating, Activity, and Meaningful Inclusion (DREAM) project is to increase the number and quality of physical activity, healthy eating, and wellness programs and services accessible to people living with dementia. To accomplish this, the DREAM project co-developed a toolkit that includes a website, videos, resources and education modules to equip service providers with the knowledge and skills to include and support people living with dementia in their services and programs. The DREAM resources and tools also empower people living with dementia and their care partners with the knowledge and confidence to engage in physical activity and maintain a healthy diet. These materials were all co-developed with a steering committee that included people living with dementia, care partners, health care providers and community service providers to ensure that the resulting materials met the needs of the end users.

Learn from DREAM

Dementia Resources for Eating, Activity and Meaningful Inclusion

Goals

DREAM promotes the inclusion of people living with dementia in high quality physical activity, healthy aging and wellness programs by:

- Supporting service providers to learn about dementia, understand the rights of people living with dementia to inclusion, the benefits of physical activity, healthy eating and mealtimes to people living with dementia and ways to support people with dementia access and use their services
- Empowering people living with dementia and care partners with the knowledge and confidence to take up physical activity and healthy eating in order to improve health, function, and wellbeing.

Dementia Resources for Eating, Activity and Meaningful Inclusion

Milestones and achievements

The DREAM toolkit includes eLearning modules, videos and resources for both service providers and people living with dementia and their care partners:

- Tools and resources for people living with dementia
- Tools and resources for service providers

eLearning modules: accessible here

Videos:

- I Have Dementia but I'm Still Me
- Staying Active Helps Me Live Well with Dementia
- Eating Healthy Helps Me Live Well with Dementia

Handouts:

- DREAM Handout: Understanding Dementia
- DREAM Handout: The Rights of People Living with Dementia
- DREAM Handout: Dementia-Inclusive Communities
- DREAM Handout: Support for Physical Activity
- DREAM Handout: Support for Nutrition Risk and Malnutrition
- DREAM Handout: A Guide for Healthy Eating and Drinking
- DREAM Handout: Nutrition Risk Factors
- DREAM Handout: Strategies for Mealtime Challenges
- DREAM Booklet: Get to Know Me

Wallet cards:

- DREAM Wallet Card: Dementia-Inclusive Physical Activity: People with Memory Challenges
- DREAM Wallet Card: Dementia-Inclusive Physical Activity: People with Dementia
- DREAM Wallet Card: Dementia-Inclusive Healthy Eating and Mealtimes: People with Memory Challenges
- DREAM Wallet Card: Dementia-Inclusive Healthy Eating and Mealtimes: People with Dementia

All resources are available in English and French, with select key resources available in Arabic, Simplified Chinese, Portuguese, Punjabi.

Dementia Resources for Eating, Activity and Meaningful Inclusion

Impact

Project findings

People living with dementia and care partners reported:

- Improved attitudes and confidence for physical activity and healthy eating
- Improved physical activity and healthy eating
- Improved feelings of mental and physical well-being
- Improved feelings of inclusion

Community service providers reported:

- Increased knowledge of dementia, and understanding of physical activity and healthy eating
- Improved attitudes on inclusion, physical activity and nutrition for people living with dementia and care partners
- Increased confidence in supporting people with dementia and uptake of dementia-inclusive practices
- Increased adoption of dementia-inclusive practices on organizational level

Want to know more? Download this supplementary resource outlining the data collection methods, the evaluation evidence and the tools used.

Dementia Resources for Eating, Activity and Meaningful Inclusion

Impact

Experiences

"...what I found the DREAM modules helped me with was my confidence, getting that knowledge into play. So instead of just spitting facts at me, I found the whole training and all the information gave me ways to apply all these strategies and demonstrate techniques." - **Community service provider**

"Oh, using it, it was very informative. And a lot of the stuff into it, I very much liked because it told me stuff I didn't know and it told me stuff I should be doing and this sort of thing. That way I was very impressed with it." - **Person living with dementia**

"And I sort of got the feeling from him that it was like, it was a relief to find out some of these things. And the one thing that really came up was, when we were watching the one video, and they were shooting boats. David's comment was, "I didn't know I could still do that. I guess I am allowed to." And I said, "Well, yes."- **Care partner**

Dementia Resources for Eating, Activity and Meaningful Inclusion

Insights

Lessons learned

- Free, web-based education is a valuable approach to ensuring the long term sustainability of resources and tools.
- There can be seasonal challenges in recruitment during spring and summer months. Support from project partners' networks and formal/informal connections with people living with dementia and care partners (e.g., Dementia Connections) can help promote continued recruitment during these times, as well as year-round.
- While developing relationships with individual staff at an organization is valuable, developing a relationship with organizations as a whole can enable engagement of new representatives when others leave their role, the organization, or when priorities and workload change.
- Relationships with a range of project partners in different geographic areas and organizational types are valuable and require time to develop. For DREAM, having diverse project partners was helpful in spreading the toolkit across Canada, reaching as many community service providers as possible. Where possible, create mutually beneficial relationships where you can support one another's work.
- Invest in ongoing engagement efforts, particularly in underserved groups. This engagement requires continuous efforts to build relationships and involve partners.
- For similar wellness and physical activity-focused projects or initiatives, exploring targeted recruitment strategies that pair people living with dementia with trained service providers could be valuable for recruitment.
- When creating eLearning modules, offering a certificate of completion can encourage organizations to promote training to their employees as part of ongoing professional development.

Get in touch

Dr. Laura Middleton, Associate Professor, University of Waterloo

Empowering Dementia-Friendly Communities Hamilton, Haldimand

Community initiatives that are co-designed and led by people living with dementia to develop, implement and evaluate programs and approaches that improve the quality of life for people living with dementia.

Who could benefit from reading this Play?

- Municipalities, community organizations, service providers, and policy makers who want to use the lessons learned and recommended resources from this program to implement a dementia-friendly program in their local community.
- People living with dementia and their care partners who want to learn more about dementia-friendly communities.

Review the Before you begin section for foundational knowledge that will be helpful for any dementia community initiative.

Key information

Who was this project designed for? People living with dementia and their care partners and the communities of Hamilton and Haldimand County, Ontario

Project lead: Hamilton Council on Aging

Project partners: People living with dementia, a multi-disciplinary team of organizations including the Alzheimer Society of Brant, Haldimand Norfolk, Hamilton Halton, the GERAS Centre for Aging Research, the Regional Geriatric Program (central), McMaster University, Haldimand-Norfolk Community Senior Support Services, Hamilton Health Sciences, and the Age-Friendly Hamilton Collaborative Governance Committee.

Project status: DCI funding (2019-2023) is complete, with phase 2 underway (2023-2025)

Empowering Dementia-Friendly Communities Hamilton, Haldimand

Project story

Background

The Empowering Dementia-Friendly Communities project engaged with people living with dementia, their care partners and families in Hamilton and Haldimand County, Ontario, to learn about the experience of living with dementia in these communities, the challenges, and barriers encountered, and identify strategies to improve the social inclusion and quality of life of people living with dementia within their communities. Community consultations identified five key themes which were used to identify, fund, pilot and evaluate actions in the community over the course of the project. In both communities, people living with dementia led and supported the creation of a dementia-friendly education program and a public awareness campaign. Each community created Engagement & Empowerment groups, composed of and led by people living with dementia, who developed community events including an art festival, an ongoing newsletter and a public mural unveiling.

Goals

The Empowering Dementia-Friendly Communities Hamilton, Haldimand project aimed to improve the social inclusion and quality of life of people living with dementia through:

- Empowering people living with dementia to be active members, leaders and change makers in their communities
- Fostering social inclusion and participation of people living with dementia
- Challenging stigma surrounding dementia and promoting compassion and support
- Building understanding and awareness of dementia and modifiable risk factors for dementia

Empowering Dementia-Friendly Communities Hamilton, Haldimand

Milestones and achievements

- Community consultation report:
  - What We Heard Hamilton, Haldimand Report (2020)
- Creation of Dementia-Friendly Communities education:
  - Empowering Dementia-Friendly Communities Education Workbook
  - Empowering Dementia-Friendly Communities Infographic
  - Quick tips for starting your dementia-friendly journey
- Awareness campaign:
  - Faces of Dementia
- Engagement & Empowerment group initiatives led by people living with dementia:
  - Dementia Friends in Our Community
  - Memory Inclusive Communities Everywhere

Empowering Dementia-Friendly Communities Hamilton, Haldimand

Impact

Project findings

- 357 community members were educated through the Dementia Friendly Community education program
- 16 million viewers were reached by the Faces of Dementia awareness campaign

People living with dementia who participated as Lived Experience Leadership team members:

- 83% experienced an improved sense of well-being and belonging within their community
- 83% experienced a high level of empowerment as a result of their involvement

People living with dementia who participated as Lived Experience Leadership team members:

- 77% increased their knowledge of how to make their community more dementia friendly
- 73% improved their ability to reduce stigma through social and environmental factors
- 75% reported increased understanding of social isolation and strategies to minimize its impact

People living with dementia who participated as Lived Experience Leadership team members:

- 88% reported increased understanding of the stigma experienced by people living with dementia
- 75% increased knowledge and understanding of dementia and its impact

Empowering Dementia-Friendly Communities Hamilton, Haldimand

Impact

Experiences

"It is the first time since my diagnosis I have felt inclusion and self worth. Memory+ diagnosis can be difficult to understand if you don't have any connections to these disease progressions. People can become invisible, a person to hide. Other diseases may get 'championed', they are warriors. So are we, and this is an awesome opportunity for a voice. It is the first time in years I was welcomed and involved in a project. I love the experience."

- Lived Experience Leadership team member

"Incredible messages of hope and purpose. Thanks to all of you for sharing your stories and faces with us!! People living with dementia are LIVING, and this is what your video reminds the world about!"

- Faces of Dementia campaign launch attendee

"I had conversations with family members about increasing the autonomy of their loved ones. They tend to want to direct all things and I can see now how deflating can this be. I try to model this by giving the patient more choice and include them in decisions. And taking the advice I learned in the workshop - where appropriate, I don't talk to the caregiver or spouse - I direct my questions to the person with dementia. You learn so much doing this! I've talked to my coworkers about this".

- Education program participant

Empowering Dementia-Friendly Communities Hamilton, Haldimand

Insights

Lessons learned

- The authentic involvement and partnership with people living with dementia is crucial for any dementia-friendly community initiative. Co-designing and leading project activities fosters meaningful engagement and supports the alignment of priorities and the relevance and impact of chosen project activities.
- 'Backbone' organizations (such as an Alzheimer Society or established community organization) are a crucial resource for supporting a group of diverse stakeholders and provide needed governance and structure (resources, funding, dedicated staff) to enable persons with dementia to actively guide community-based action plans.
- Partnering with individuals and organizations who share a common vision and commitment to building dementia-inclusive communities can facilitate collaboration. Diverse partners can bring unique skills and perspectives which can be used to support the project's success.
- Support for dementia-friendly community recommendations may be strengthened in communities where there is an existing Age-Friendly Plan, which can provide resources, momentum, and promotion for project activities.

Recommended resources

The following resources are recommended to groups interested in implementing similar projects:

- A Dementia Strategy for Canada: Together We Aspire
- Towards a dementia inclusive society: WHO toolkit for dementia-friendly initiatives (DFIs)
- The Alzheimer Society of Canada's The Landmark Study Report #1.

Empowering Dementia-Friendly Communities Hamilton, Haldimand

Helpful frameworks and practical examples:

- Asset-based Community Development
- Social Work Model of Empowerment
- Constellation Model of Collaborative Governance for Social Change
- Dementia Engagement & Empowerment Project (DEEP) Network
- Dementia Northern Ireland

Get in touch

Tracy Gibbs, Hamilton Council on Aging

Enhancing Minds in Motion® as a Virtual Program Delivery Model for People Living with Dementia and Their Care Partners

Community initiatives that are co-designed and led by people living with dementia to develop, implement and evaluate programs and approaches that improve the quality of life for people living with dementia.

Who could benefit from reading this Play?

- Individuals and community organizations who are interested in bringing Minds in Motion® in their community.
- People living with dementia and care partners who may want to become involved in their local Minds in Motion® program.
- Individuals and community organizations who want to use the lessons learned and recommended resources from this project to create or modify a similar program.

Review the Before you begin section for foundational knowledge that will be helpful for any dementia community initiative.

Key information

Who was this project designed for? People living with dementia and their care partners.

Project lead: Alzheimer Society of Ontario

Project partners: University of Waterloo, brainXchange and multiple Alzheimer Societies including Sarnia-Lambton, Toronto, Peterborough, Kawartha Lakes, Northumberland & Haliburton, Durham Region, and the Alzheimer Society Southwest Partners.

Project status: complete, 2021-2023

Enhancing Minds in Motion® as a Virtual Program Delivery Model for People Living with Dementia and Their Care Partners

Project story

Background

Minds in Motion® (MiM) began as an Alzheimer Society of Ontario pilot project in 2014. Now offered through local Alzheimer Societies across several Canadian provinces, this evidence-based program combines exercise, cognitive engagement, and social interaction for people living with early to mid-stage dementia and their care partners. This project is an extension of the existing in-person program, adapted to be offered virtually in English and French. A virtual approach broadened the program's reach by allowing participants to engage without the need to travel and avoided the impact of pandemic-related restrictions. People living with dementia and their care partners engage in the program together for 90-minute sessions once a week for eight weeks, conducted through Zoom.

Goals

To develop and deliver an adapted virtual version of the in-person MiM that provides physical activity, cognitive stimulation, health promotion and social interaction for people living with dementia and their care partners in a way that is:

- Evidence-informed
- Consistent
- Person centred
- Safe and effective

Enhancing Minds in Motion® as a Virtual Program Delivery Model for People Living with Dementia and Their Care Partners

Milestones and achievements

- An updated MiM manual that incorporates considerations for providing this program virtually and includes considerations for diversity, equity and inclusion.
- Strengthened safety procedures, registration and screening protocols for participants.
- Improved exercise delivery methods and standardized training requirements for certified exercise instructors.
- Compilation of an evidence base demonstrating positive outcomes for participants.

Impact

Project findings

Both people living with dementia and care partners had high levels of satisfaction with the virtual Minds in Motion program.

People living with dementia

- Improved mental well-being post-program
- Improved physical activity levels
- Enhanced mental activity levels

Care Partners

- Improved quality of life post-program
- Maintained physical well-being
- Maintained social well-being

Want to know more? Download this supplementary resource outlining the data collection methods, the evaluation evidence and the tools used.

Enhancing Minds in Motion® as a Virtual Program Delivery Model for People Living with Dementia and Their Care Partners

Impact

Experiences

"Well for me it was the awareness of how much strength I needed to regain in my legs and my legs are important because they're my independence. You lose them and you're really messed up. And I realized the benefit of taking time to do a program of some description for half an hour... it's made me more aware that you have to make the time to do this because it's what your body needs. You have to look at the body like an engine, you have to maintain it. It's made me more aware like that."

- Program participant

"I know I felt like my strength in general has really declined since I stopped working at the beginning of COVID. And I've noticed, even though I think the intensity of the classes has increased over time... I'm feeling stronger now and able to get through just fine compared to the beginning."

- Program participant

"The part that I found so useful was the motion part because there were exercises presented that I had never thought about before, that... clearly are important, but I just never thought about it. It had to do with the movement of feet and hands, and I just had never thought was so important to, you know, to move and that. So, it was enlightening for me."

- Program participant

Enhancing Minds in Motion® as a Virtual Program Delivery Model for People Living with Dementia and Their Care Partners

Insights

Lessons learned

- When delivering an exercise program virtually, a headset with a microphone is recommended so that participants can clearly hear the exercise instructor.
- Muting all participants is recommended; however, participants should keep their cameras on for safety so that facilitators can be aware of any falls or accidents.
- Optimal setup includes three facilitators: one for seated exercises, one for standing exercises, and one for tech support and emergencies.
- Encourage joint participation (care partner and person living with dementia) for better retention and satisfaction with the program.
- Recruiting during the summer months can be challenging as people are more inclined to spend time outdoors rather than participating in online programming.
- Alzheimer Societies delivering MiM are encouraged to:
  - → Complete abbreviated versions of the well-being questionnaires with participants, especially with new clients, so they can develop a baseline and track improvements. A lack of improvements among participants could be a signal that a Society is delivering MiM differently than demonstrated in the updated program manual.
  - → Conduct yearly fidelity observations to ensure proper exercise intensity.
  - → Follow the 90-minute session structure for virtual sessions.
  - → When advertising and recruiting new participants, highlight the improvements in well-being observed for people living with dementia.

Enhancing Minds in Motion® as a Virtual Program Delivery Model for People Living with Dementia and Their Care Partners

Recommended resources

The following resources are recommended to groups interested in implementing similar virtual programming:

- Dementia Inclusive Choices for Exercise (DICE) Training
- Tech Coaches - Zoom instructions and tools

A webinar presentation of this initiative is available: Exercise and Dementia: a discussion of lessons learned and best practices

Get in touch

Vanessa Barnes, Alzheimer Society of Sarnia-Lambton

Christina Stergiou-Dayment, Alzheimer Society of Ontario

My Tools 4 Care-In Care

Online toolkit designed to address the unique needs of family and friend caregivers supporting people living with dementia in long-term care homes.

Who could benefit from reading this Play?

- Caregivers of people living with dementia in long term care who may want to use the online toolkit
- Service providers, long term care homes and community organizations who could recommend the toolkit to caregivers of people living with dementia in long term care
- Individuals and organizations interested in using the lessons learned and recommended resources to create or modify a similar program.

Review the Before you begin section for foundational knowledge that will be helpful for any dementia community initiative.

Key information

Who was this project designed for? Family and friend caregivers supporting people living with dementia in long-term care homes.

Project lead: Led by the University of Alberta's Faculty of Nursing and a research team including Drs. Hannah O'Rourke, Wendy Duggleby, Pamela Baxter, Shelley Peacock, Genevieve Thompson, Véronique Dubé, Sunita Ghosh, Carrie McAiney, Jayna Holroyd-Leduc, Cheryl Nekolaichuk and Jennifer Swindle.

Project partners: Alzheimer Society of Alberta and Northwest Territories, in addition to an advisory committee composed of representatives from Alberta, Saskatchewan, Manitoba, Ontario, Quebec.

Project status: complete, 2019-2023

Access My Tools 4 Care-In Care

My Tools 4 Care-In Care

Project story

Background

Family and friend caregivers who are supporting individuals living with dementia in long-term care homes have unique needs and challenges that are often overlooked. An existing research-based toolkit (My Tools 4 Care, designed for caregivers of people living with dementia residing in the community) was adapted to cater specifically to these often-overlooked caregivers. This adaptation includes relevant resources, personal stories, Frequently Asked Questions and interactive activities designed to enhance the health and resilience of caregivers who are supporting individuals living in long-term care.

Goals

The well-being of caregivers can be enhanced by meeting their unique needs, which can ultimately contribute to improved quality of life for both people living with dementia and their caregivers. My Tools 4 Care-In Care empowers caregivers to:

- Navigate transitions
- Manage emotions
- Advocate effectively
- Make informed decisions

My Tools 4 Care-In Care

Milestones and achievements

- 45 family caregivers shared insights and feedback through focus groups across Alberta, Manitoba, Saskatchewan and Ontario
- 234 participants were given access to the toolkit and engaged in telephone interviews, assessing the toolkit's effect on hope, self-efficacy, grief, social support, loneliness, and quality of life
- Creation of a culturally relevant French version of the toolkit, supported by:
  - Use of the toolkit for 2 weeks by 12 French-speaking caregivers, followed by focus groups to capture their feedback and revisions to the toolkit based on their feedback
  - A feasibility study with 18 French-speaking caregivers to evaluate the acceptability and feasibility of the translated toolkit
- Delivery of public webinars and knowledge sharing events to share findings and raise awareness of the toolkit
- Creation of infographics and promotional videos demonstrating the impact of My Tools 4 Care-In Care:
  - My Tools 4 Care-In Care Promotional Video
  - My Tools 4 Care-In Care Promotional Video (short version)
  - Phase 2 infographic
  - Phase 3 infographic
- Creation of videos for inclusion in the toolkit that capture a caregiver's journey when a family member lives in long term care:
  - Cal's Story
  - Edith's Story
  - Jennifer's Story
  - Caregiver Experiences that Influence Feelings of Loneliness When a Family Member Lives in Long Term Care

My Tools 4 Care-In Care

Impact

Project findings

By using the toolkit, caregivers reported that:

- Their well-being improved
- Their knowledge and skills improved
- Their mental health improved

The My Tools 4 Care-In Care resource is available online in French and English through the ASANT Cafe.

Experiences

> "It reassures us in our situation. We can see that it's all about us, it puts words to situations, emotions, feelings, experiences in everyday life, in the concrete. It puts words on the difficulty, it clears the way a lot." - **Caregiver**

"It helps me to be able to access the sharing of other people's experience, in the videos among others, there is like a mirror effect, I recognize myself. It validates a lot in a way the feeling and the questioning." - **Caregiver**

My Tools 4 Care-In Care

Insights

Lessons learned

- Translation to French: translation into another language can be a complex process, not only for the word choices but for technical considerations when a product is web-based.
- Translation requires using user-friendly and culturally appropriate language which can prompt multiple rounds of revisions to ensure alignment with the dementia and caregiving community's needs. This project team ultimately included additional focus group interviews to ensure the translation was accurate and met the needs of their target audience.

Recommended resources

The Program Sustainability Assessment Tool (PSAT) was found to be particularly valuable in planning for the sustainability of this initiative.

Get in touch

My Tools 4 Care-In Care team

Our Dementia Journey Journal

An interactive tool that enables sustainable relationship building between care partners and care providers of persons living with dementia through information-sharing and care-role negotiation along the dementia journey.

Who could benefit from reading this Play?

- People living with dementia, their care partners and care providers who work in a variety of care settings and communities who could benefit from using the Our Dementia Journey Journal
- Members of Indigenous, Francophone and South Asian communities seeking a culturally relevant tool to support their own dementia journey or the journey of someone they care for
- Individuals and organizations interested in using the lessons learned and recommended resources to create or modify a similar program

Review the Before you begin section for foundational knowledge that will be helpful for any dementia community initiative.

Key information

Who was this project designed for? People living with dementia, family and friend care partners of people living with dementia and care providers, (including home care and long term care settings)

Project lead: SE Research Centre

Project partners: Representatives from First Nation and South Asian communities across Ontario , representatives from Indigenous communities across British Columbia

Project status: DCI funding (2019-2022) is complete, with phase 2 underway (2023-2025)

Project story

Background

The dementia journey is full of changes, including changes in function, care needs and the number and type of care providers involved in an individual's care. The roles of family and friend care partners and care providers change over time. The Our Dementia Journey Journal (ODJJ) is an interactive resource designed to address these changing needs and roles by improving how people living with dementia, care partners and care providers build relationships, communicate, share information, negotiate care roles and ultimately work together. The first prototype of the ODJJ was developed through six co-design workshops with care partners and care providers in a long-term care home in Ontario. The Journal has a variety of versions to meet the needs of different communities, including translated versions in English, French, Hindi and Punjabi, a First Nations version and a generic version. The ODJJ also includes sections for recording questions and answers between care partners and providers, an "All About Me" worksheet, a well-being log and assessment, information on dementia warning signs, symptom tracking, creative activities including joy journaling and care collages, and a collection of extra resources.

Goals

The ultimate goal of Our Dementia Journey Journal is to enhance the lives of people living with dementia, their care partners and care providers. In particular, it aims to

- Facilitate care role negotiation and relationship building through information sharing
- Improve relational, management, and information continuity
- Improve the mental health and quality of life of people with dementia, care partners and care providers
- Improve health care provider satisfaction and retention

Milestones and achievements

- Creation of an electronic (fillable PDF) version of the ODJJ
- Cultural adaptations as a result of field testing of the ODJJ in First Nations communities in Northern Ontario and British Columbia
- Cultural and language adaptations and field testing of the ODJJ in Francophone and South Asian communities, including versions in English, French, Hindi and Punjabi
- Identification of the need for a mobile application of the ODJJ (in development)

Impact

Project findings

Participants involved in the development and field testing of the Our Dementia Journey Journal reported:

- That their experiences/ideas/opinions were heard in the workshop (91-100% always felt or mostly felt)
- That their participation will change how persons living with dementia, their caregivers and health care providers work together (88-100% always felt or mostly felt confident)
- That cultural and language adaptations of the ODJJ would change how persons living with dementia, their care partners and health care providers work together

Want to know more? Download this supplementary resource outlining the data collection methods, the evaluation evidence and the tools used.

Experiences

"I found it to be useful to be able to connect with my mom on how she feels about this journey" - **Care Partner**

"I thought the journal was beneficial for [the person living with dementia] to reflect on and record important memories and I can also see how it would be beneficial in supporting communication between family and their care providers." - **Care Provider**

Insights

Lessons learned

Participants involved in the development and field testing of the Our Dementia Journey Journal reported:

- Partnership with community liaisons in the targeted First Nations communities was indispensable to this project's success. These liaisons brought profound understanding of the community's needs which allowed the project team to tailor their approach in each community, build trust, and conduct culturally safe workshops, leading to co-designed outcomes that are tailored to address the community's specific contexts and needs.
- Flexibility and adaptability are essential when partnering with different communities. For this project, the evaluation plan was adapted to collect evaluation data through interviews, rather than surveys, which better met the needs of the community. Recruitment approaches were also modified to include opportunities to participate virtually, lessening barriers to participation for communities that are geographically dispersed.
- Involving end users in the design process throughout is important for ensuring that the end result meets the user's needs. For this project, this involvement resulted in adapting the tool to be available digitally and selecting culturally appropriate language and terminology to be used in the tool.

Recommended resources

The following resources are recommended by the team who developed this program:

- Participatory Research to Action (PR2A) Framework
- ODJJ Research on the Run (project summary)

Get in touch

Valentina Cardozo, Research Associate, SE Research Centre

Supporting a Circle of Care

An Indigenous-led, culturally specific toolkit for Indigenous caregivers of people living with dementia.

Who could benefit from reading this Play?

- Indigenous caregivers of people living with dementia who could benefit from the toolkit
- Individuals and community organizations who are interested in sharing Circle of Care with their community or the clients they serve
- Individuals and organizations interested in using the lessons learned and recommended resources to create or modify a similar program.

Review the Before you begin section for foundational knowledge that will be helpful for any dementia community initiative.

Key information

Who was this project designed for? Indigenous caregivers of people living with dementia

Project lead: Native Women's Association of Canada (NWAC)

Project partners: Laurentian University, Schlegel Center for Advancing Seniors Care, Canadian Remote Access for Dementia Learning Experience (CRADLE), Dr. Jennifer Walker (McMaster University), Dr. Danielle Alcock, Nunavut Inuit Women's Association (North), Six Nations (South), Community liaisons in Saskatchewan (West) and New Brunswick (East)

Project status: complete, 2021-2023

Download Circle of Care

Supporting a Circle of Care

Project story

Background

Within Indigenous communities, care is commonly provided in the person's own home. The Native Women's Association of Canada recognized that while caregiving can be rewarding, there are unique needs and challenges experienced by Indigenous caregivers of people living with dementia. The Supporting a Circle of Care initiative engaged with First Nations, Metis, and Inuit community partners and Elders to develop and test a culturally safe and trauma-informed toolkit to provide caregivers with improved understanding and awareness of dementia, strategies for self-care, and approaches for establishing a support network.

Goals

This project sought to improve the social, cognitive, emotional, physical, and spiritual well-being of Indigenous women, Two Spirit, transgender, and gender-diverse caregivers of people living with dementia by:

- Increasing awareness and knowledge of coping strategies that promote caregiver well-being and decrease stress
- Improving awareness and understanding of dementia
- Improved awareness and knowledge of risk factors for dementia
- Improved caregiver capacity to understand and address the needs of people living with dementia
- Improved awareness and knowledge of potential symptoms of dementia

Supporting a Circle of Care

Milestones and achievements

- Extensive consultations with participating communities
- Creation of a toolkit that addresses the unique needs of Indigenous caregivers of people living with dementia
- Creation and delivery of virtual Sharing Circles to test the toolkit with caregivers and identify areas for improvement
- Participation in a public webinar and two Dementia Dialogue podcast episode reflecting on the project. (Episode 62, Episode 63)

Impact

Project findings

- Over 80% of caregivers who reviewed the toolkit and participated in a Sharing Circle reported increased knowledge and/or skills.

Caregivers reported:

- Improved knowledge about dementia
- Enhanced levels of support
- Decreased feelings of isolation

Supporting a Circle of Care

Insights

Lessons learned

- The presence of a Knowledge Keeper during Sharing Circles proved to be an invaluable approach for creating a comfortable and culturally safe space for participants to share their experiences.
- Engaging with Indigenous communities should involve the support of Elders or Knowledge Keepers, who should be compensated for their contributions and expertise, both as a gesture of thanks and as part of the ongoing process of reconciliation.
- Honorariums, incentives or other forms of financial compensation can improve recruitment and participant engagement and thank participants for sharing their time and lived experiences to improve a resource.
- Translating materials into Indigenous languages is a valuable investment. This is important for many reasons, notably as part of the ongoing process of reconciliation, and to improve access and uptake of the resource in communities where English is not the most commonly spoken language.
- Building evaluation components into the group activities can help motivate participants to provide feedback, rather than requesting that participants provide feedback on their own after the session is over.

Supporting a Circle of Care

Recommended resources

The team who developed this initiative identified several resources that were helpful, including:

- Dr. Danielle Alcock's PhD dissertation "I Honoured Him Until the End': Storytelling of Indigenous Female Caregivers and Care Providers Focused on Alzheimer's Disease and Other Dementias (ADOD)" (open access)
- Indigenous Cognition and Aging Awareness Research Exchange (I-CAARE)
- Addressing dementia related stigma with Indigenous specific strategies (also available in French)
- A Sacred Journey - The Long Goodbye (also available in French)

Many post-secondary institutions and community organizations have policies and guidelines for working with Elders and Knowledge Keepers, including:

- the University of Victoria's Guidelines for Protocol, Hosting and Payment for Elders, Knowledge Keepers and Community Members and
- the First Peoples' Cultural Council Working with Elders.

Get in touch

Native Women's Association of Canada

The New Brunswick Dementia Friendly Initiative

Dementia-friendly approaches to help communities in New Brunswick better support people living with dementia.

Who could benefit from reading this Play?

- Communities interested in gaining knowledge and understanding of dementia-friendly approaches to become more inclusive of people living with dementia.
- Individuals, communities and organizations interested in using the lessons learned and recommended resources to support the implementation of dementia-friendly initiatives in their local community.

Review the Before you begin section for foundational knowledge that will be helpful for any dementia community initiative.

Key information

Who was this project designed for? New Brunswick communities that are interested in becoming more inclusive of people living with dementia.

Project lead: New Brunswick Association of Nursing Homes

Project partners: Alzheimer's Society of New Brunswick, New Brunswick Continuing Care Safety Association, Seniors Healthy Aging Secretariat, Dr. Michelle Lafrance

Project status: complete, 2019-2023

The New Brunswick Dementia Friendly Initiative

Project story

Background

Led by the New Brunswick Association of Nursing Homes, this project supported communities in New Brunswick to be more inclusive of people living with dementia through the introduction and implementation of dementia-friendly approaches. Training in the Gentle Persuasive Approach was used to reduce stigma and equip care partners and community members with increased knowledge and understanding of dementia and strategies for supporting people living with dementia. Training sessions were conducted virtually to ensure broader accessibility and participation during the Covid-19 pandemic. An online community survey and interviews with care partners were used to better understand the experiences and needs of care partners of people living with dementia. The survey informed conversations and planning for approaches communities can implement to be more inclusive of people living with dementia. Interviews were used to understand the experiences and challenges of care partners supporting people living with dementia and to gather valuable insights into how their involvement with the project impacted their experience as a care partner.

Goals

The New Brunswick Dementia Friendly Initiative worked to improve the inclusion of people living with dementia and care partners through:

- Education, training and tools that promote dementia-friendly approaches
- Increased awareness and understanding of the needs and experiences of people living with dementia and care partners

The New Brunswick Dementia Friendly Initiative

Milestones and achievements

- Development of a Community Toolkit to help communities become more dementia-friendly: English toolkit, French toolkit
- Development of a community conversation guide
- Delivery of Gentle Persuasive Approach training and education
- Delivery of Tai Chi classes to care partners and people living with dementia in targeted communities

Impact

Project findings

Participants who participated in Tai Chi classes reported:

- Enjoying the classes and being able to follow the movements (100%)
- Integrating Tai Chi into their daily routine (87.7%)

Participants who completed the Gentle Persuasive Approach training reported:

- Increased knowledge and/or skills after completing GPA

The New Brunswick Dementia Friendly Initiative

Insights

Lessons learned

- Establishing trusted community partnerships is essential for dementia-friendly initiatives, which can take time. Before implementing an initiative, assess the community's readiness to ensure that the community is able to support this work, which allows efforts and resources to be directed where they will have the most impact.
- Involving people with lived experience of dementia in the project team is crucial. Their insights and knowledge help shape the initiative to be more impactful and relevant for the target audience.
- When involving care partners, offering options such as online surveys and virtual education sessions can be helpful as they allow flexibility and reduce the need for travel.
- Social media is a valuable tool for engaging community members, raising awareness, sharing information about the initiative and offering classes or programs of interest to generate support for the initiative. Social media and email can be used for ongoing communication and reminders to support attendance; incentives and personalized reminders are also effective strategies.

Recommended resources

The following resources are recommended by the team who developed this program:

- Dementia Friendly Communities: Municipal Toolkit
- Creating Dementia-Friendly Communities: A Toolkit for Local Government
- Dementia-Friendly Communities Local Government Toolkit.

Get in touch

Samantha Hachey, New Brunswick Association of Nursing Homes

Together for Fun!

Leisure-based program delivered by trained facilitators to teach care partners of people living with dementia to create meaningful and enjoyable shared moments using simple recreation activities.

Who could benefit from reading this Play?

- People living with dementia and care partners who would like to participate in the Together for Fun! program at an established site
- Service providers and community organizations who would like to receive training to offer Together for Fun! in their local community
- Individuals and organizations interested in using the lessons learned and recommended resources to create or modify a similar program

Review the Before you begin section for foundational knowledge that will be helpful for any dementia community initiative.

Key information

Who was this project designed for? People living with dementia and their care partners

Project lead: Alzheimer Society of Granby and region

Project partners: Université du Québec à Trois-Rivières, Dalhousie University, Fédération Québécoise du Loisir en Institution (FQLI), Fédération Québécoise des Centres Communautaires de loisir (FQCCL)

Project status: complete, 2019-2023

Together for Fun!

Project story

Background

Together for Fun! focuses on the development of meaningful leisure experiences between care partners and people living with dementia by creating enjoyable moments of connection. Originally developed by researchers at the Université du Québec à Trois-Rivières, the program was offered by the Alzheimer Society of Granby and region for several years prior to the launch of this project, which adapted the program for implementation across different community settings. A virtual adaptation of the program was also developed in response to the Covid-19 pandemic.

Led by trained facilitators, dyads of care partners and people living with dementia attend this half-day program once per week where they learn and engage in simple recreation activities that can be repeated at home. The focus of the activities is to create enjoyable experiences, rather than achieving a particular outcome or completing an activity in a specific way. Following the shared activity, the care partners participate in a support group where they share their impressions of the activity and learn skills to replicate similar activities at home. During this time, participants living with dementia engage in a group activity together.

Goals

The Together for Fun! program improves the well-being of people living with dementia and their care partners by:

- Increasing care partners' knowledge and skills to use simple recreation activities to create enjoyable moments of connection
- Fostering a strengths-based approach to the skills and abilities of people living with dementia
- Promoting social inclusion and meaningful social interactions among participants
- Creating shared opportunities for success and enjoyment for both care partners and people living with dementia

Together for Fun!

Milestones and achievements

- Creation of comprehensive training, including activity binders, guides for participants and facilitators (facilitator guide available through completion of the training)
- Creation of tools and materials to support communities in their promotion, recruitment and delivery of the program
- Successful implementation of the program (in French) in 7 rural and urban community centres in Quebec and Nova Scotia
- Successful implementation of the program (in English) in 2 community centres in Quebec and 1 in Halifax, Nova Scotia

Impact

Project findings

The Together for Fun! program improves the well-being of people living with dementia and their care partners by:

- 90% of care partners who participated reported positive impacts from this program.

Care partner participants reported:

- Increased knowledge and/or skills
- Improved well-being
- Improved health behaviours
- Improved social inclusion

Participants living with dementia reported:

- Improved well-being

Together for Fun!

Experiences

"What I got out of this program is just good! It's not complicated. Personally, even for my mom, it's just positive because it's good for our minds." - Care partner

"I assure you that my [loved one]... he's waiting for Friday to come. It brings much happiness, a lot of happiness. He doesn't want it to end." - Care partner

"It's important for me not to hide…We want to paint a picture of a perfect care partner, but the facilitators have been like therapists for us. I thank them for making everyone very comfortable...and that's what makes me happy today with "Together for Fun". - Care partner

Insights

Lessons learned

- This program used a train-the-trainer model, where facilitators received training (either in person or via Zoom) to offer the program in their respective communities. In-person training was found to be most effective.
- When using Zoom to deliver the program to dyads of care partners and people living with dementia, the project team offered training and extra support to help participants learn to use the platform, which otherwise could have been a barrier to their participation.
- There may be concerns related to privacy and disclosing a dementia diagnosis for participants living in a small community where group participants might know one another.
- Hosting the program at a local community center is recommended, as participants felt a sense of belonging and community.

Get in touch

Community organizations interested in this program are asked to contact Hélène Carbonneau, PhD, l'Université du Québec à Trois-Rivières.

What Connects Us~Ce qui nous lie

An intersectoral collaborative partnership of healthcare, community-based organizations, government, media, and academic organizations whose aim is to create an inter-connected community for all.

Who could benefit from reading this Play?

- People living with dementia, care partners and social and health service providers
- Community organizations seeking to develop partnerships and collaborations with other sectors and organizations who can learn from the lessons learned and recommended resources identified by this initiative

Review the Before you begin section for foundational knowledge that will be helpful for any dementia community initiative.

Key information

Who was this project designed for? People living with dementia, their carers (personal and professional), and the public

Project lead: Culture & Mental Health Research Unit at the Jewish General Hospital and McGill University

Project partners: Volunteers In Partnership, Jewish General Hospital, National Centre for Dance Therapy, Les Grands Ballets Canadiens, Montréal Museum of Fine Arts, Les Arts et La Ville, Joyful Connections, Department of Psychiatry, Cummings Centre, Au Contraire Film Festival, Urban Pardes, Alzheimer Society of Montréal, Alzheimer Groupe Inc.

Project status: complete, 2019-2023

Visit What Connects Us~Ce Qui Nous Lie

What Connects Us~Ce qui nous lie

Project story

Background

The “What Connects Us~Ce Qui Nous Lie” project was a collaborative initiative aimed at enhancing the quality of life for individuals living with dementia, those who partner in their care and the community-based organizations that work with them. The priority concerns of key partner organizations were consulted to provide a blueprint for the project to establish local networks to cultivate enriched social and cultural environments. By connecting the realms of arts, culture, mental health, and academia, the project collaborated with community-based organizations, government bodies, media, and academic institutions to create a web of resources and decrease stigma surrounding dementia, mental illness, and aging through shared activities and events. The interventions were delivered both virtually and in the spaces provided by community-based organizations (e.g., non-government organizations, arts and culture institutions) and healthcare services.

Goals

Improve the quality of life of people living with dementia and their care partners through:

- The establishment of a comprehensive web of resources in the local community to provide support, connection and assistance
- Enriched and engaging social and cultural environments
- Ongoing partnerships between arts/culture, mental health, academic sectors and community based organizations that work with people living with dementia and their carers

What Connects Us~Ce qui nous lie

Milestones and achievements

- Increased awareness, visibility and accessibility of ongoing activities for people living with dementia and their care partners, including creative dance, laughter yoga, gallery visits at the museum and art therapy.
- Creation and hosting of community events including film screenings and discussions, both virtual and in person.
- Development of the Community Care Network, a volunteer-driven initiative which aims to reduce social isolation and connect older adults with community resources through regular phone calls.
- Development of a robust resource list and virtual map of the local community and resources available, including specific resources for older adults, crisis lines, shelters and specialized resources.
- In-house library of first-person narratives about living with- and caring in Alzheimer's and related disorders, including a curated collection of blogs and stories created by and for people living with dementia and their carers.
- Numerous publications, presentations and panels

Impact

Project findings

People who participated in dance, laughter yoga and/or film screenings reported:

- Improved attitudes towards dementia
- Increased quality of life
- Decreased feelings of loneliness

What Connects Us~Ce qui nous lie

Insights

Lessons learned

- This project supported the development of partnerships with various organizations to deliver shared activities and events for people living with dementia and care partners. A collaborative and relationship-focused approach was used to engage and sustain these partnerships in order to foster strong engagement, which begins with (and is sustained by) listening to the needs of local communities and creating a plan in response to those needs.
- When employing an emerging research approach, the focus should be on listening to what matters to those with whom we work, from their first person perspective and in their own terms.
- Staff turnover in partner organizations is likely, which requires a worthwhile investment of time and effort to cultivate relationships when a change occurs and help sustain the project work.

Recommended resources

The following resources are recommended to groups interested in implementing a similar project:

- Textbook: Evaluating Health Promotion Programs (Valente, 2002)
- Chapter: Centring What Really Matters: A Reasoning Heuristic for Promoting Occupational Participation (Park & Rouleau, 2022), In M. Egan & G. Restall (Eds). Promoting Occupational Participation: Collaborative Relationship-Focused Occupational Therapy, 10th Canadian Occupational Therapy Guidelines
- Survey platform: Lime Survey
- Web host: Koumbit.org

Get in touch

What Connects Us team

Conclusion

Thank you for reviewing the Dementia Interventions Playbook. This Playbook was created as an invitation to adapt, adopt, and learn from the successes of the Dementia Community Investment projects.

The comprehensive Before you begin section outlines foundational knowledge essential for any dementia initiative, which captures the collective wisdom and insights of the members of the Canadian Dementia Learning and Resource Network. The Plays highlighted in this resource offer insights, successes, and tangible outcomes achieved through the collaborative efforts of the DCI projects.

It is our hope that this Playbook serves as a comprehensive resource and testament to the impact of the Dementia Community Investment projects. By sharing and learning from their work, we hope this Playbook will contribute to the Government of Canada's vision of creating a Canada where people living with dementia are respected and included in all aspects of community life.

Get Involved in CDLRN

Sign up for updates and our newsletter

Stay in the loop with our latest news and updates by signing up for our mailing list!

CDLRN publishes a quarterly newsletter that includes details about upcoming events, resources, project spotlights, and a special feature on people living with dementia and their contributions to CDLRN.