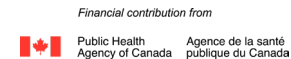




IMPACT REPORT 2020-2023

Empowering Dementia-Friendly Communities Hamilton, Haldimand Project

Special Edition: Fall 2023



A message from the Hamilton Council on Aging

Every day in Canada, 685 people are diagnosed with dementia. The number of Canadians affected by dementia is expected to triple to 1.7 million people over the next 25 years. There is a critical need to shift negative stereotypes about dementia and promote actions that create inclusive and accessible opportunities for continued involvement in community life.

In 2020, The Hamilton Council on Aging (HCoA) was awarded funding by the Public Health Agency of Canada to pilot innovative and promising community-based approaches for building dementia-friendly communities.

We are delighted to share this 2020-2023 Empowering Dementia-Friendly Communities Hamilton, Haldimand Impact Report that highlights our collective work, its impact, and lessons learned along the way.

Despite launching amid the challenges of the COVID-19 pandemic, the initiative successfully:

- Consulted over 300 individuals impacted by dementia in Hamilton and Haldimand County.
- Developed the 2021 “What We Heard Hamilton, Haldimand Report.”
- Informed Hamilton’s inaugural Age-Friendly/Dementia-Friendly Community Plan (2021-2026).
- Piloted strategies and campaigns that reached millions of people.

We respectfully honour and acknowledge that the lands on which we carry out this project are located on the ancestral and unceded land of many generations of Indigenous Nations.

This land is to be protected by the Dish With One Spoon; a treaty that connects and bounds us to share and protect the land in the spirit of peace. It is also covered by the Two Row Wampum, a living treaty between settlers and Haudenosaunee Nations to co-exist forever in friendship and respect, without interference in each other’s way of life. We acknowledge the significant harm caused by colonization and broken treaties. We are committed to the revitalization of these Nation-to-Nation agreements, reconciliation, and restorative justice for First Nations.

- Engaged individuals with dementia to actively contribute to the development, implementation and evaluation of training workshops, the Faces of Dementia campaign and local awareness-raising projects organized by new Engagement & Empowerment groups.

As project colleagues, people living with dementia enriched innovation, influenced policies and practices, and challenged misconceptions about dementia. They assumed leadership roles within the project and became inspiring role models for others facing similar challenges. Their resilience, determination, and achievements instilled hope and motivated others. In honour of these collective achievements, HCoA received the 2023 Dementia-Friendly Communities Award by the Alzheimer Society of Canada.

It is with great pride and gratitude that we reflect on the dedication, passion, and unwavering commitment of the Public Health Agency of Canada, project partners, staff, volunteers, and colleagues living with dementia that inspired, challenged, and transformed the trajectory and outcomes of this project. We extend our heartfelt gratitude to Six Nations of the Grand River Health Services for their guidance and support

to amplify the representation of Indigenous perspectives and experiences. Without your contributions, none of this would have been possible.

Please join us by delving into our Impact Report and celebrating the extraordinary progress we have achieved together. As we do so, let us renew our commitment to co-create a world where everyone, regardless of age and cognitive abilities, is acknowledged, heard, and empowered to actively participate in shaping their own lives and communities.



Dr. Lori Letts
HCoA Board President



Mary Burnett
HCoA Board Lead

Empowering Dementia-Friendly Communities Hamilton, Haldimand Project

A Dementia-Friendly Community is a place where people living with dementia are understood, respected, and supported. It is an environment where people living with dementia will be confident that they can contribute to community life. In a Dementia-Friendly Community, people will be aware of and understand dementia, and people living with dementia will be included and have choice and control over their day-to-day lives and level of engagement.

The Empowering Dementia-Friendly Communities Hamilton, Haldimand 2020-2023 project was a communities-based initiative led by the Hamilton Council on Aging, people living with dementia and a multi-disciplinary team of partners and funded by the Public Health Agency of Canada's Dementia Community Investment Fund. The project aimed to develop, implement, and evaluate promising practices, programs or initiatives that improve quality of life for persons living with dementia within their communities.

From April to November 2020, we engaged over 300 people affected by dementia in Hamilton and Haldimand County to learn about their experiences, challenges/barriers, and their ideas on how to create dementia-friendly communities. The information gathered was used to develop specific community-based action strategies aimed at creating dementia inclusive communities.

Visit www.coahamilton.ca to learn more about the consultation and to read the What We Heard Report.





Addressing key themes identified in the community consultation the project engaged in the following activities:

- Development and public launch of a “Faces of Dementia” Campaign to showcase the lived experiences of persons living with dementia as part of awareness raising efforts and the development and launch of local community exhibits to promote the Faces of Dementia Campaign.
- Development and implementation of a Dementia-Friendly Community Education Program.
- Creation of Engagement and Empowerment Groups, in Hamilton and Haldimand to identify, direct, and implement dementia-friendly projects.
- Evaluation of all project activities, gathering the feedback of all stakeholders involved through interviews and surveys, identifying key project outcomes/ impacts, and learning about how to implement dementia-friendly community projects.



**Empowering
people living with
dementia**



**Challenging
stigma & building
understanding**



**Fostering social
inclusion &
participation**



**Creating dementia-
inclusive built
environments &
transportation**



**Improving
community
responsiveness to
crisis/COVID-19**

A photograph of three women standing together, smiling. They are wearing dark jackets and light-colored blouses. The woman in the center is wearing glasses and a grey blazer. All three are wearing circular badges that say 'FACES OF DEMENTIA' and rectangular name tags that say 'HELLO'. The background is a blurred indoor setting with a whiteboard and a lamp.

Challenging Stigma and Building Understanding: Faces of Dementia Campaign

The Faces of Dementia Campaign was created and co-designed with people living with dementia to challenge negative perceptions and increase awareness about the experience of living with dementia. Compelling videos, beautiful posters, and imagery tell the stories of seven individuals living with dementia, with an overarching message that they are *so much more* than their diagnosis. Their stories explore lived experiences with stigma within the community and opportunities for creating more dementia-friendly communities.

To view their stories, visit www.FacesOfDementia.ca

Faces of Dementia was launched in May 2022 with a virtual online event and shared broadly through various media outlets and presentations. Two in-person launch events were held to introduce six-week interactive gallery exhibits at the Sackville Hill Seniors Recreation Centre in Hamilton and the MINGA Café in Haldimand County.

“This program that we have started, its aim was for dementia, but really, it’s going to benefit everybody. Anybody that has any kind of challenge, it’s not about tolerance, it’s not about being friendly, it’s about acceptance. To me, it’s about being inclusive and accepting.”

Faces of Dementia was inspiring, empowering, and impactful.

People living with dementia who co-created the campaign felt that it:

- Empowered them to engage in community advocacy
- Increased their confidence
- Increased their desire to contribute more in the community
- Reduced their social isolation

Faces of Dementia transformed community perspectives.

Campaign audiences indicated a positive change in:

- Community understanding of what it is like to live with dementia
- Awareness of the need for and interest in dementia-friendly community education
- Interest from other communities in creating dementia-friendly communities
- Acceptance of any persons experiencing challenges
- Advancing dementia-friendly communities

The Faces of Dementia campaign garnered over **16 million views!**



“It’s broadened my horizons in the key areas that affect me and that I want to do further advocacy work.”

[Campaign Team]



“I appreciate the attention to diversity and representing the individuality of the dementia experience.”

[Community Member]



“There are many situations where people living with dementia got a message of hope, received a message that this isn’t the end of the world...there are lots of other people out there living with this disease and I am not alone.”

[Participant]





“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!”

[Community Member]



“For sure I enjoyed it and it gave me lots of support. In a way that I’m not going to stop anything, and it gives me courage to live, and they are doing so much. If I stay back and depress about my stuff, and just say: ‘I’m not going to do anything’, its not good.”

[Participant]



“I’ve been so isolated for years here and then finally being part of a program, it’s been great.”

[Participant]



Fostering Social Inclusion & Participation: Dementia-Friendly Community Education Program

Community consultation highlighted a lack of awareness about dementia and misconceptions that contribute to the stigma experienced by people living with dementia, as well as the role that education can play in reducing stigma. The program was co-created and co-delivered with people living with dementia. Using a human rights approach, the program included workshops and resources to empower community sectors to create more socially and environmentally inclusive spaces — places and services for people affected by dementia.

Over 90% of participants valued the program and found it helpful. Participants also indicated that they now know more about dementia, stigma, and how to make their community more dementia-friendly. Further, participants indicated that they now have more dementia-friendly skills and information to support people living with dementia and to share with others.

To learn more about the Dementia-Friendly Communities training workshops, contact the Alzheimer Society of Brant, Haldimand Norfolk, Hamilton Halton at (905)529-7030.

“I had conversations with family members about increasing the autonomy of their loved ones. 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 [as well].”

Engagement & Empowerment Groups: A Promising Approach to Dementia-Inclusive Communities

Inspired by initiatives in the United Kingdom and Northern Ireland, the 2020–2023 Empowering Dementia-Friendly Communities project piloted the creation and evaluation of two Engagement and Empowerment Groups comprised of and led by citizens living with dementia; one in Hamilton, Ontario and one in Haldimand County, Ontario.

These groups provide opportunities for people with a shared experience of dementia to offer and benefit from peer support and to use their skills, knowledge and experience to collectively raise awareness through the development of localized projects and/or to influence policies, programs, and practices that affect their lives. These groups demonstrated significant benefits to their respective members and to their local communities.

“I’ve just been sitting at home. You go from working full-time to the diagnosis, and then the next thing is I’m not working anymore.... It [Engagement & Empowerment Group] gives me something to look forward to. I like having something to do that’s actually something [meaningful]...I kind of gave up on being any form of contributor to anything.”

“I think the community got to see a different side of dementia because when people think of dementia their minds automatically go to end stage. They don’t think of that whole period of living before they get to end stage, so maybe it opens their minds to the way they see things, that’s what I think. And I think that everybody is working so hard. I think it’s happening.”

Engagement & Empowerment Groups provided the opportunity to:

- Be involved in meaningful activities and meaningful use of skills
- Develop new knowledge, skills and new friendships
- Increase confidence, self-determination, and sense of accomplishment

Group members felt that their projects:

- Inspired conversations and improved access to information that reduces stigma about dementia
- Improved support for persons living with dementia when in the community
- Encouraged other people with dementia to become involved
- Generated interest in supporting the engagement and empowerment of people living with dementia

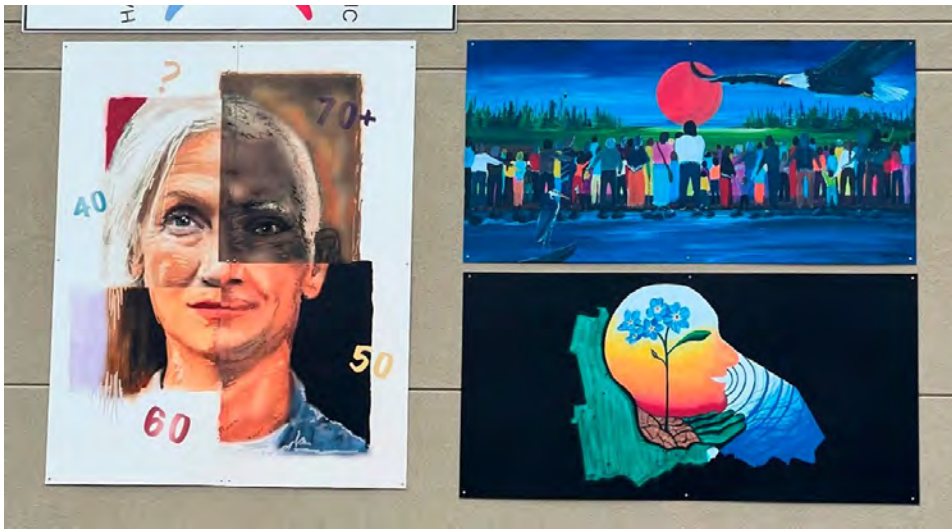


Engagement & Empowerment Group: Memory Inclusive Communities Everywhere (MICE+) Haldimand

Memory Inclusive Communities Everywhere (MICE+) is a group of citizens from Haldimand County who live with Acquired Brain Changes (ABC), often referred to as dementia. Members have different diagnoses and journeys. Members are committed to using the insight they have gained through their experiences to inspire a more understanding, helpful and inclusive community.

In 2022, MICE+ launched a contest to engage Haldimand artists to create original artwork for a public mural. They successfully hosted the first MICE+ Festival, bringing over 150 people together, and unveiled the MICE+ Mural. Located on the exterior wall at the Medicine Shoppe, Caledonia, Ontario it features designs from three local artists who beautifully depict inclusive communities for everyone.

Recently, MICE+ launched a movement to “RENAME DEMENTIA” to raise issue with and challenge the negative origin and connotations associated with the word. Going forward they will refer to what was previously dementia as ACQUIRED BRAIN CHANGES (ABC).



“It is the first time since my diagnosis I have felt inclusion and self worth. It is also an important project. 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. Otherwise, I am alone and don’t do anything. Its hard to find a place where people understand you.”

Engagement & Empowerment Group: Dementia Friends in Our Community Hamilton

Dementia Friends in our Community (Dementia Friends) is a group of individuals from Hamilton, Ontario with different backgrounds, interests, and perspectives. Members share at least one thing in common: they have all been diagnosed with Alzheimer's disease. In 2022, Dementia Friends launched their quarterly newsletter, *Living with Alzheimer's & Other Dementias* – a publication written by people who live with dementia. It is for healthcare providers, family, friends, the public, and those who live with dementia to learn about what has helped the members on their journeys and to consider a different perspective about living with dementia. To date, over 6800 copies of the newsletters have been distributed electronically and in print.

Dementia Friends is committed to sharing their message of understanding, acceptance, and inclusion through their newsletter, public interviews with media, and organizations like the Twenty Place Retirement Community. Sharing personal stories to provide hope to others with or supporting people who live with Alzheimer's and other dementias.

"It's really been nice to have a place and a forum where I can feel like I'm actively contributing again. It is difficult to find your community and this is one place where its great, I have absolutely no problem saying: 'I forget what it is we talked about back then, can you remind me again?'"

Moving forward!

This project was focused on promoting awareness of dementia through innovative approaches that tackle stigma and promote inclusion and support that enhances the well-being of people living with dementia. Despite the limitations, delays and changes to project plans created by the COVID-19 pandemic and ongoing stigma about dementia, this project was able to achieve its primary objectives and project partners and participants are exceedingly proud of the accomplishments to date:

- The active and authentic involvement and leadership of people living with dementia
- The commitment and collaboration among all project stakeholders
- The positive impact of project activities including:
 - The positive psychosocial outcomes for people living with dementia who participated in this project
 - Increased awareness of dementia and the experience of living with it
 - Increased awareness of the value of engaging people living with dementia in activities and decisions that affect them

As we take a moment to reflect and celebrate these accomplishments with the release of this report, we acknowledge that there is much more work to be done. We continue to work with partners and funders to build on and share this work. We invite you to join us and many others in helping to make positive changes towards the inclusion of, and quality of life for people affected by dementia.

“I think what I’m the most proud of is being part of a team that has accomplished so much by being inclusive. [By that] I mean having people [living with] dementia at the table right from the beginning. I think that has made the biggest impact and I think that has informed everything else [turning] out so well.”

Thank you for your contributions and support!

Thank you to all of the advocates living with dementia, care partners, organizations, businesses, students, consultants, dignitaries, networks, and funders whose contributions helped to guide, amplify, transform and accomplish beyond what we ever imagined possible.

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