Hamilton Council on Aging

What We Heard Report

Empowering Dementia-Friendly Communities Project

HAMILTON & HALDIMAND, JUNE 2021

Our Partners

The Empowering Dementia-Friendly Communities Hamilton, Haldimand project is a collaborative initiative, led by the Hamilton Council on Aging (HCoA), citizens and a multi-disciplinary team of organizations including people living with dementia, 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, Haldimand War Memorial Hospital and the Age-Friendly Hamilton Collaborative Governance Committee. This project is funded by the Public Health Agency of Canada.

With Gratitude

A special thank you to the valuable contributions of our partners, to everyone that assisted with the development and promotion of the consultations and to the project team and committee members *(see Appendix A)*. Finally, and most importantly, our sincere thanks to those who participated in the consultations – this project would not have been possible without you.

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Introduction

Why focus on dementia?

The Alzheimer Society of Canada indicates that there are more than 500,000 Canadians living with dementia today and this number will almost double by 2030[1]. It is estimated that 255,000 people are currently living with dementia in Ontario[2] and **approximately 12,000 people are living with dementia in Hamilton and Haldimand.**[3] A dementia diagnosis has an impact on the person living with dementia, their formal and informal caregiver(s) and whole communities. While dementia shortens the lives of people living with the disease, its greatest impact is upon quality of life, both for the individual with dementia and their caregiver(s).[4] Dementia-friendly communities are emerging as a promising approach to help improve quality of life for people living with dementia and their caregivers.

What is a Dementia-Friendly Community?

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.[5]

What is the Empowering Dementia-Friendly Communities Hamilton, Haldimand project?

The *Empowering Dementia-Friendly Communities Hamilton, Haldimand* project is a communities-based initiative led by the Hamilton Council on Aging, people living with dementia and a multi-disciplinary team of partners, funded by the Public Health Agency of Canada's Dementia Community Investment Fund. This four-year investment provides an opportunity to engage people living with dementia, their care partners, families and other stakeholders **to develop, implement and evaluate promising practices, programs or initiatives that improve quality of life for persons living with dementia within their communities.**

The global COVID-19 pandemic and ensuing safety protocols disrupted the lives of everyone, and even more significantly, people living with dementia, their care partners, and families. For many people, programs and services were cancelled routines of getting groceries and running errands were further complicated by new social rules such as masking and physical distancing. These have increased stress and confusion for people living with dementia due to new navigation challenges (e.g. physical distancing signs). Additionally, COVID-19 safety protocols have added strain on care partners and increased feelings of social isolation among people living with dementia, especially for those who are living alone. The work of this project commenced at the onset of the pandemic

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[1] Dementia numbers in Canada. (2020). Alzheimer Society of Canada.

[2] Developing Ontario's Dementia Strategy: A Discussion Paper. (2016). Government of Ontario.

[3] Hopkins, R, W. (2010). Dementia Projections for the Counties, Regional Municipalities, and Census Divisions of Ontario.

[4] Dementia Friendly Communities: Key Principles. (2015). Alzheimer's Disease International.

[5] Dementia Friendly Communities Ontario. (2020). Alzheimer Society of Canada.

and continued despite the COVID-19 challenges and uncertainties therefore, the design of consultations and the perspectives of consultation participants have been shaped by the current realities of the COVID-19 pandemic.

What is a What We Heard Report?

The What We Heard Hamilton, Haldimand report is a summary of the feedback that emerged from community consultations in Hamilton and Haldimand. **Our goal for the consultation was to gain insight on the experiences and challenges/barriers experienced by people with dementia living in Hamilton and Haldimand and their care partners.** We also asked participants to share ideas on how our communities can become dementia-friendly. This information will be used to promote the need for dementia-friendly strategies in Hamilton and Haldimand. Additionally, based on this summary, we will prioritize two to five specific community-based action strategies to fund, pilot and evaluate over the next two years in Hamilton and Haldimand County.

How Did We Engage the Community?

Community engagement for the dementia-friendly communities project took place from April to November 2020 in Hamilton and Haldimand. We used open-ended, semi-structured interviews offered via phone or video conference, and close-ended multiple-choice and open-ended survey questions offered online and in print. **Interviews and surveys were designed with feedback from people with lived experience** and all questions were made optional allowing flexibility for participants. The consultation process provided valuable and rich insight into their experiences and challenges related to living with dementia in Hamilton and Haldimand. We also offered a follow-up satisfaction survey to learn about what participants thought about our process.

Individual interviews and surveys were offered in both official languages. Language translation and accessibility accommodation requests, including access to technology, were encouraged, and welcomed. Resources were mobilized in advance of consultation to respond to the diverse and unique needs of people living with dementia in Hamilton and Haldimand, their care partners, family, and friends.

Initial participant recruitment for individual interviews were primarily through the Alzheimer Society of Brant, Haldimand Norfolk, Hamilton Halton and the Haldimand-Norfolk Community Senior Support Services. In October 2020, we launched a three-week public campaign which included paid print and online advertising, newspaper articles, an editorial, and social media promotion to encourage broad participation in the survey. Additionally, we identified and promoted the survey to over 300 diverse faith community groups, community-based and health organizations, and advocacy groups to encourage participation of Indigenous Persons, the LGBTQ2S+ community and diverse ethno-cultural groups in Hamilton and Haldimand.

Who Did We Hear From?

From July – November 2020, we consulted with a total of 305 people (234 Hamilton and 71 Haldimand) affected by dementia.[6] Of those, 71 individual interviews (49 Hamilton and 22 Haldimand) and 234 surveys (185 Hamilton and 49 Haldimand) were completed with people living with dementia and care partners. The preferred method of interview participants was by phone and most of the surveys were completed online.

The people interviewed and surveyed lived in many neighbourhoods throughout Hamilton and Haldimand County. We heard from people living with dementia residing with family or care partners and others that live alone, the youngest being 41 years old. Many care partners indicated that they live in proximity, while some care partners indicated that they provide care from a distance, some as far away as Ottawa and Arizona.

Project Challenges and Limitations

It is important to consider the project limitations within social distancing and COVID-19 safety measures that influenced the methods of engagement. The lack of in-person engagement resulted in a loss of representation from people who are socially isolated, without access to the internet, those who are not involved with organizations, those who need to prioritize meeting their basic needs, and communities of Black, Indigenous and other visible minorities. We recognize that the voices of these individuals are important, and that an increase in representation and diversity of perspectives is needed to fully understand how to empower people with dementia living in Hamilton and Haldimand and their caregivers, and how to develop inclusive, dementia-friendly communities that respect and support diversity.

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[6] Completed surveys that were received after the closure date are not captured in these numbers.

Additionally, we acknowledge the important work that advocates are doing to improve quality of life for people living with dementia in provincially governed long-term care homes and other complex systems such as hospitals. COVID-19 has publicly surfaced the significance of care systems on the health, safety, and quality of life for those living with dementia. The work of this project aims to evoke a community-based response for the improvement of quality of life for people living with dementia within the community, although the notion of living well and the importance of community-facing public institutions throughout the whole dementia journey must be recognized. We gained some insight through our conversations and felt it important to recognize the need for transformation across sectors and systems that intersect with the lives of people with dementia, their care partners, and families.

Highlights of What We Heard

Our conversations and consultation with people living with dementia, families/care partners in Hamilton and Haldimand revealed the uniqueness of their individual experiences and some shared and common experiences of community life.

Our overarching goal was to present this material in a way that best reflects and respects *what we heard* from people living with dementia and their care partners, and to present their experiences and ideas in a format that would be accessible and useful to them and the communities in which they live, work, receive care and play.

Five key themes emerged from the public consultations:

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

The summaries included describe each theme; provide an overview of the consultation feedback highlighting some of the survey and interview responses; and identify the challenges and barriers to living with dementia in the community. Based on the public consultations, action strategies were identified for each of the five themes. Lastly, consultation participants provided some specific ideas as to how the communities of Hamilton and Haldimand can become dementia-friendly.

Empowering people living with dementia

“Nothing about us, without us!”

Empowerment of people living with dementia is a confidence building process whereby people living with dementia are respected, have a voice and are heard, are involved in making decisions about their lives and have the opportunity to create change through access to appropriate resources.[7] To support the quality of life of people living with dementia, communities need to encourage and foster their empowerment.

Empowerment is:

- Respecting the rights of people living with dementia.[8]
- Countering dominant narratives about dementia, by making space for their valued knowledge and expertise and centering their voices in all decisions that impact their lives.
- Having accessible information about dementia and dementia-specific support.

We recognize the lived realities with the progression of dementia, however people living with dementia are far too often disempowered by the label of the disease. People living with dementia have the right to be supported throughout their journey so that they can actively participate in personal, organizational and community decision-making for as long as possible.

What We Heard

We heard that there are varied experiences of empowerment and disempowerment. Through the survey we learned:

- 50% of survey question participants in Hamilton and Haldimand felt that people living with dementia do not have local opportunities to participate in the development and implementation of policies and programs that affect them.

The consultation further revealed varied experiences of people living with dementia of being involved in making decisions about their lives. These experiences had an impact on shaping their sense of self-efficacy and worth.

- Only 20% of survey participants in Hamilton and Haldimand indicated that people living with dementia feel like they are a valuable part of the community.

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[7] McConnell, T., Sturm, T., Stevenson, M. et al. (2019). Co-producing a shared understanding and definition of empowerment with people with dementia. Research Involvement and Engagement, 5, 19. https://doi.org/10.1186/s40900-019-0154-2

[8] Canadian Charter of Rights for People with Dementia. (n.d.). Alzheimer Society of Canada.

One interview participant reflected on getting the diagnosis, and how from that moment she felt like her autonomy to make decisions was taken away,

> *“The doctor did not look at or speak to me. He spoke to my husband and said, ‘Your wife has early onset Alzheimer’s’. I was angry because they were not talking to me. The doctor made me feel like I was totally incompetent, right from that moment.”*

Having access to information and support was viewed as critical to enabling people to have power over their lives, yet survey questions responses indicate that,

- Only 30% of survey question participants felt people living with dementia have easy access to information regarding their local community.
- Less than half (43%) of the participants who answered the survey question, felt that people living with dementia have easy access to information and services regarding their health.
- 40% of survey participants felt they do not have the supports that they need to feel safe and to live well in their home.

People living with dementia that participated in the interviews, expressed appreciation for the well intentions of their care partners as well as concern for their diminishing autonomy. Making decisions about daily living and care are essential to those living with dementia. As one person living with dementia stated,

> *“Being challenged to make decisions about our lives and care and to be as independent as possible is good for us.”*

More broadly, people living with dementia and care partners expressed that there are limited opportunities and/or support to be involved in community, program, and policy planning and decisions. Some of the challenges and barriers to empowerment include:

- Diminishing autonomy and self-efficacy.
- Inconsistent person-centered approach to care.
- A lack of opportunities and support to participate in organizational/community advisory and consultation processes.

What We Can Do

✓ Encourage and foster the empowerment of people living with dementia.
✓ Create empowering environments, including the involvement of people living with dementia in personal, organizational and community decisions that affect their lives.
✓ Enhance access to information and support.

Challenging stigma and building understanding

“[The public] needs to understand that people living with dementia are honourable and should be treated with dignity and respect.”

Stigma is the negative assumptions and attitudes towards people living with dementia that lead to stereotyping and discrimination. According to a recent study, over two-thirds of Canadians agree that people living with dementia generally face a lower quality of life than people without dementia. The same proportion agree that people have negative assumptions about the abilities of people living with dementia.[9]

Stigmatization can have numerous negative consequences for people living with the disease, their care partners, and their families, such as rejection and exclusion from participation in various areas of social life.[10] Stigma and discrimination can happen due to a lack of understanding about dementia and its effects.[11]

What We Heard

People living with dementia and their care partners shared with us that they experience stigma from family, friends, and social networks. Some interview participants disclosed experiences of stigma and lack of understanding about dementia that led to disengagement from social networks. One interview participant living with dementia described,

> *“I was playing cards with a group of friends a few years ago and I got told that I was doing it wrong. They said, ‘thank you, goodbye’. I don’t play cards with anyone anymore.”*

Additionally, survey participants indicated that they experience stigma and a lack of understanding when visiting local businesses.

- 43% of Hamilton and Haldimand survey participants indicated that local businesses are welcoming and helpful. Alternatively, a total of 47% either felt that they were not welcoming and helpful (21%) or did not know (36%).

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[9] Dementia Survey: Final Report. (2020). Government of Canada.

[10] Rewerska-Juśko M, Rejdak K. Social Stigma of People with Dementia. Journal of Alzheimer’s Disease: JAD. 2020 Nov. DOI: 10.3233/jad-201004.

[11] Understanding and Challenging Stigma and Discrimination. (n.d.). DementiaUK.

Some participants indicated that they experience inconsistencies in service, “Depending on who was working [at the business], determines how you get treated.”

Furthermore, people living with dementia feared judgment should they disclose dementia or require any assistance from staff,

> *“I used to go to the gym, but I would forget to wipe down the equipment. I was afraid of being told ‘maybe you shouldn’t be here’. I was worried about negative responses from others. I felt like I would be seen as a risk.”*

It should be noted that this incident happened before COVID-19 and that fear of judgment has been exacerbated by the pandemic.

Experiences with stigma and a lack of understanding were also cited within health care system, community-based programs/services, and from groups such as youth and the general community.

Experiences of stigma and fear of judgment if diagnosis was disclosed were threaded throughout our conversations with people living with dementia and care partners in Hamilton and Haldimand. Participants shared how stigma around dementia has eroded their social relationships and led to an increase of social disengagement and isolation. Participants expressed that stigma was associated with:

- A lack of understanding about normal aging, dementia and its fluctuations and progression.
- Lack of patience and knowledge of what to do and how to support.
- General misconceptions about dementia among friends and social networks, businesses, community programs and services, healthcare, and the broader community.

What We Can Do

- ✓ Develop and implement an anti-stigma campaign in Hamilton and Haldimand
- ✓ Raise awareness through education about risk factors of dementia and stigma associated with dementia
- ✓ Create and distribute dementia-friendly tools and resources

Fostering social participation and inclusion

“I want to be able to talk to people. I still have a lot to offer.”

A dementia-friendly community should have affordable, accessible, and conveniently located events and opportunities for people living with dementia and their care partners to socialize, engage in meaningful activities and participate in civic life. The social inclusion of people living with dementia enables social connections and a sense of belonging that are essential to well-being and quality of life. Purposeful connections, and doing meaningful activities together are important to a person with dementia and their families/care partners.[12]

Disengagement leads to social isolation, feelings of loneliness and being generally disconnected from the world. Social isolation and loneliness have been shown to negatively impact health and quality of life. For example, isolation and loneliness increase risk of mortality, with loneliness being as damaging to a person’s health as smoking 15 cigarettes a day.[13]

What We Heard

People living with dementia and care partner responses confirmed that community participation matters and is essential to their quality of life. However, their responses also reflected that there is lack of local opportunities to participate in almost all aspects of community life.

- Almost half (47%) of the survey participants felt that there are no opportunities for people living with dementia to engage in community activities in Hamilton and Haldimand.

The lack of opportunity for social participation for people living with dementia result in social isolation, as a care partner describes,

> *“Their home becomes a prison. Social isolation for people living with dementia is very real.”*

On the other hand, there is no shortage of activities that people living with dementia identified that they would love to do. In fact, the kinds of activities people living with dementia would like to do are as unique as the individuals themselves and are based on a lifetime of doing what they love.

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[12] Hung L, Leitch S, Hung R, et al. Creating dementia-friendly and inclusive communities for social inclusion: a scoping review protocol.
BMJ Open 2020. doi: 10.1136/bmjopen-2019-035028

[13] Holt-Lunstad J, Smith TB and Baker M. Loneliness and social isolation as risk factors for mortality. A meta-analytic review. Perspectives on Psychological Science 2015; 10:2:227-237

The following graphic reflects the diverse and enriching activities that people living with dementia would love to continue to do.

With the large range of activities that people would like to do,
we identified the five of the most frequently selected activities in the survey:

- Socialize with friends and family (82%)
- Enjoy the outdoors (55%)
- Exercise (46%)
- Going to restaurants (46%)
- Planned activities such as day programs (39%)

The challenge becomes how do we work with our communities to enable people living with dementia to engage in their "would like to dos"? Their responses reflect the barriers and challenges that prevent this engagement.

People living with dementia and care partners expressed serious concern for the lack of social interactions and increased social isolation. Stories of people living with dementia disengaging in meaningful activities due to barriers to participation were far too frequent. As one person living with dementia interviewed expressed,

> *"There is a lot of depression because you used to be super woman and now you are just a by stander, watching things go along."*

Through our consultation we heard that there is a need for more inclusive community activities, more program and activities options specifically designed for people living with dementia and more outreach to engage those affected by dementia.

- Only 6% of survey participants felt people living with dementia can engage in volunteer or paid work without worrying about any special requirements that they may have.

> *"I wanted to volunteer in my city, but the volunteer centre told me I didn't suit anything. I'm now 52 (diagnosed with Alzheimer's at 48). I feel like I have been sitting in my house alone all day for four years. […] I don't feel like I fit in anywhere."*

Notably, some participants indicated the absence of opportunities to connect with people of the same ethno-cultural background, with people who speak their first language, and with people who have shared experiences and interests.

People indicated that there are not enough dementia-specific programs. For example, a care partner stated,

> *"There isn't a lot for him to do here. There is a lack of activities for people living with dementia. He would love to participate in something like the Man Cave, where there are activities for men, where he can feel productive."*

Finally, the consultation feedback suggests that there is not enough outreach to people living with dementia in Hamilton and Haldimand,

- 43% of survey questions participants did not believe that there are programs and services that reach out to persons living with dementia to encourage participation in local activities.

> *"I wish more community groups would reach out to people living with dementia to be volunteers. It would give them a sense of purpose."*

Through our consultation, we heard a need for existing community activities to be more inclusive and dementia-friendly. We also heard a need for meaningful activities and programs specifically designed for people living with dementia. Social isolation impacts not only the person living with dementia but their care partners. We heard the desire of people living with dementia to continue to contribute to, and benefit from community, through paid work, volunteering, and mentorship opportunities for as long as possible. A component of creating a dementia-friendly community is the social inclusion and active participation of people living with dementia in meaningful community activities and civic life.

What We Can Do

- ✓ Support people living with dementia to participate in existing community programs and activities.
- ✓ Create local activities and programs specifically designed for people living with dementia.
- ✓ Enhance outreach to people living with dementia and care partners.

Creating dementia-inclusive built environments and transportation

“Not a lot of safe places for people living with dementia, they are hard to find. We need to create a map of dementia-friendly places.”

The built environment refers to the designed physical world that we live in. The notion of dementia-friendly built environments is often used to inform the design of residential care homes, but these same principles can be applied by the community to inform the design of independent home environments, gathering spaces, and public places. The built environment is intrinsically linked to transportation.

People living with dementia most often want to remain in their home in the community for as long as possible. Home adaptations and assistive technology provision are an increasingly attractive means of helping people to maintain their independence and enhancing their quality of life.[14] Many people interviewed focused on the outside environment, however one person spoke to the importance of the home environment,

> *“We don’t get the information that we need to make our homes dementia-friendly.”*

Additionally, some people consulted felt that there were not enough gathering spaces outside of the home for people living with dementia or that spaces were not accessible,

> *“Most of the community spaces available to us are in church basements or other places with lots of stairs.”*

- 53% of survey question participants felt that there are not enough places outside of their home to meet up with family and friends.

Many people that we connected with indicated that they enjoyed outdoor activities such as walking, biking, and hiking, however pointed out barriers to navigating these public places,

- 54% of survey question participants felt their local area/community is not accessible for people living with dementia, that they are not able to travel around without challenges.

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[14] Rahman, S. (2016). Built Environments: Designing residential environments for living better with dementia. The Dementia Society. Retrieved from http://dementia-wellbeing.org/category/built-environments/

Some participants indicated a need for accessible walkways, easy to read and understand signage and dementia-friendly public places,

> *"We need to create outdoor spaces that aren't busy and overwhelming, where people feel safe."*

Consultation participants asserted that transportation is a big issue. Within urban Hamilton, people expressed varied concerns with public transportation and organized transportation support systems including a lack of on-demand service. In rural Hamilton and Haldimand, a lack of public transportation and affordable on-demand service is a barrier to community participation for people living with dementia. As a care partner describes,

> *"If me, or our family can't drive them to activities, then they can't go."*

Many participants rely on their care partners to provide transportation. The dependence on care partners limits the independence of, and options for people living with dementia. These findings suggest a clear need for affordable, on demand transportation for people living with dementia.

What We Can Do

- ✓ Promote information about dementia-friendly home environments
- ✓ Create more accessible, dementia-friendly gathering spaces
- ✓ Develop and promote dementia-friendly design principles for public places
- ✓ Develop on-demand, affordable transportation solutions for people living with dementia

Improving community responsiveness to crisis/COVID-19

“People living with dementia do not have the information that they need in a way that they can best understand. This is a source of fear and anxiety.”

Community and research organizations are rapidly working to assess the impacts of the COVID-19 pandemic on people affected dementia, including marginalized people, and people in rural communities. The pandemic has exacerbated all the themes identified above and requires enhanced and innovative community responses to address the needs of people affected by dementia.

A few key findings from our consultation during the COVID-19 crisis:

- 53% of survey question participants indicated that people living with dementia do not feel connected to their social supports during COVID-19.
- 54% of survey question participants felt that technology has not helped them to access health and community support during COVID-19.
- 40% of survey question participants indicate that people living with dementia are unable to follow and understand recommendations about wearing a mask, hand washing and physical distancing.
- 51% of survey question participants felt that people living with dementia do not have access to information about COVID-19 that is easy to read and understand and that is useful for people living with dementia.
- 42% of survey question participants indicated that people living with dementia have not had access to essential services and supports that they need during COVID-19.

Care partners shared that they had noticed a decline in the health and wellbeing of the person they are caring for, which they attribute to COVID-19 and physical distancing restrictions. In addition, care partners shared their experiences of increased stress and caregiving demands.

What We Can Do

✓ Ensure people living with dementia and care partners are equipped to handle long term crises such as COVID19 and other short-term crises such as floods, storms and events that unexpectedly disrupt care and social support systems.

Conclusion

Through our consultation process with hundreds of people affected by dementia in Hamilton and Haldimand, we heard shared stories of the experiences, challenges, and barriers to participating in community life for people living with dementia, care partners and families. We identified five overarching themes from what we heard and provided key insights from the consultation that support these findings.

We also wanted to learn from people who participated in the consultation about how they felt about the process. We invited consultation participants to complete a follow-up survey. 103 individuals to date have completed the follow-up survey and from that were learned the majority of participants were satisfied with their involvement in this community consultation; very few participants were dissatisfied. We also learned that 84% of participants felt that their community is somewhat, a little bit or not at all dementia-friendly. Additionally, when asked about the importance of this initiative, 97% survey participants felt that it is very important or extremely important.

Our goal for this work is to advance the rights and interests of people living with dementia in the community and to be a catalyst for change towards inclusive, dementia-friendly communities in Hamilton and Haldimand through the development and implementation of two–five community-based action strategies.

Lastly, the unforeseen pandemic has disrupted the world, especially the lives of those affected by dementia. Moving forward, we have learned that communities need to use a lens of emergency preparedness in the design and delivery of all programs and services to people living with dementia to ensure that they have the information they need and that their care and social ties are well supported during crisis events.

Appendix A
Project Team & Committee Members

Empowering Dementia Friendly Communities Hamilton, Haldimand

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