



COMPASSIONATE
HAMILTON

Report

January 2024

Inaugural Event: Living in the Gap



Summary Report

On November 1st, 2023, with community partner Good Shepherd Centres, Compassionate Hamilton held their inaugural event, Living in the Gap. The purpose of the event was to 1) raise awareness around Compassionate Communities; 2) explore ways in which death, dying, loss, grief, and bereavement (DDLGB) are experienced in Hamilton as well as identify gaps and potential solutions; and 3) assess interest within the community for moving Compassionate Community initiatives forward in Hamilton. A total of 44 exhibitors, representing a broad cross-section of community resources for those experiencing DDLGB, attended the event (see Appendix).

Event Feedback

Feedback from the event was overwhelmingly positive. In particular, participants were happy with the following:

- Broad representation of community stakeholders as exhibitors
- Opportunities for networking and learning about local community resources
- Sense of community and optimism for future impact

Approximately 200 people showed up to the event, consistent with our most frequent suggestion for improvement... “You’ll need a bigger venue for next year!” We also received some exciting suggestions for changes to the format of the event, as well as suggestions for future exhibitors, allowing us to continue to grow and be inclusive of the many voices and perspectives in our community.

The Three Questions

We asked all exhibitors and attendees 3 questions to gain a better sense of what is happening in our community:

1. How is DDLGB experienced in Hamilton?
2. What are the gaps in supporting those experiencing DDLGB?
3. What are some potential solutions for supporting those experiencing DDLGB?

We received dozens of responses, however a few key themes emerged:

- Social isolation (particular amongst seniors) is a major concern
- People DO want to talk about DDLGB and more opportunity to do so is required
- System and community navigation is overwhelming, and more supports are needed
- There is a great deal of potential and need for more partnerships and resource-sharing between individuals and organizations
- Equity-deserving groups (Indigenous peoples; 2SLGBTQ; racialized; and people impacted by poverty, homelessness, mental health and addictions) in our community require opportunity for expression and self-determination around DDLGB supports

Other examples are summarized below:

How is DDLGB experienced in Hamilton?

- Caregiver burnout
- Crisis many years after unresolved grief
- Inequitable access to end-of-life care
- Re-telling of medical history and associated stories
- Difficulty making complex decisions around treatment
- Lack of care coordination between providers
- Youth: parental absence; child as caregiver; financial concerns; lack of emotional support; tragic sudden loss of peers; substances to cope
- Lacking information to prevent a crisis
- Isolation
- Not knowing how to support someone or what is needed
- Inconsistent competencies between care providers
- Fear, avoidance, anger, resentment, family denial
- Trauma's impact on grief in those who marginalized
- Medicalization of death and dying
- Coroner involved because there is no care provider
- Late referrals
- Increased medical complexity
- Professional burnout
- Palliative care not offered
- Loss of independence
- lack of support to die at home well
- More attention to those with young children or spouse
- The long goodbye of dementia; dementia not linked with palliative care
- Racism, Islamophobia
- Death doula not seen as part of medical team
- Cultural shame and isolation, "unacceptable" reactions forcing need for privacy
- Unfinished business
- Not meeting criteria for income loss programs and benefits
- Fundraising resulting in a focus on only the "good" stories
- Dichotomies- caregiver/receiver; white vs. person of colour; professional vs. non-professional; diagnosis vs. no diagnosis/ socially compliant vs. not
- Public announcements of death and use of social media
- Difficulty in planning for the future for those who are homeless vs. prioritization of today's concerns; unjust death
- Medical Assistance in Dying (MAiD) pursued because of lack of supports
- Rights of the dead/dying prioritized vs. expectations/realities of the survivors

- Belief that more funding is required to move forward; more hospice beds the answer and only place to die well
- Trauma experienced by newcomers exacerbated by DDLGB
- Reliance on phones and electronics for medical access challenging for homeless

What are the gaps in supporting those experiencing DDLGB?

- Practical supports - meals, childcare, companionship
- Trans/LGBTW support
- Moving/decluttering services and costs
- Communication about resources, palliative care options, hospice
- Support for low-income or homeless when dying
- Transportation
- Home repairs
- Medical/home equipment and cost
- Number of hospices and access
- Care for those socially isolated or who cannot live independently (satellite facilities, temporary LTC)
- Housing programs
- Longitudinal support for a long time after a grief-inducing event
- Front-line care
- Collaboration between organizations
- Confidence in education children about DDLGB
- Support for children before death of a loved one
- Culturally and age-appropriate programming
- Peer support
- Access to technology for online supports
- People reaching out
- Policies around DDLGB
- Home care services
- Earlier connections for those with chronic diseases
- Vigil in final days with seniors who are isolated and dying
- Knowing what palliative care is
- Resources and supports for those who are neurodivergent
- Accompaniment along the entire journey
- Service provider knowledge re: resources and realities
- Poor transitions and hand-offs
- Medication availability in some pharmacies
- Support for caregivers administering medications
- No family physician

- No housing/shelters; poverty
- Honest communication from providers
- Awareness of and interaction with neighbors to enable support
- Language/cultural barriers; connection of groups with medical world
- Media attention and access to accurate information re: death
- Family and survivor supports re: benefits, financial
- Strategies for accidental deaths or those at risk
- Affordable access to counselling; how delivered in our city
- Mental health and healing groups in different languages
- Respite support for complex children
- Support around infant/child/youth death; sudden death
- Lower city grief support for children
- Legal support for low-income
- Encampment care
- Resources for complicated grief
- Continuity of care
- Inconsistent bereavement protocols (school board)
- Resources for those with disabilities, including psychological
- Schools and pivotal role of education in DDLGB
- Community engagement

What are some potential solutions for supporting those experiencing DDLGB?

- Legacy work programming
- Informal care coordinators; central referral source for resources
- More conversation around death in schools (curricula)
- Age- and culturally appropriate resources
- Low-cost tech access/rentals, support
- Roadmap for aging parents, navigation for help, hotline
- Flow chart for care providers with links, comprehensive
- Flexible volunteers for practical supports and guidance
- Training for church groups re: DDLGB
- Neighbourhood groups around DDLGB
- Mobile responding for palliative and supportive care
- Minimum standards of services
- Community and professional training for non-medical aspects of DDLGB
- Supports for formal caregivers
- Grief groups outside of the usual suspects
- Spiritual, art, music programs
- Online Community of Practice (CoP)

- Grants/funding for counselling that is specific to culture and language
- Grief support in libraries and schools, grief specialist
- Funeral homes doing community memorials
- Hamilton Bereavement Officer of Health
- Calendar of services/events
- Community experiences for medical trainees
- Community engagement and focus groups
- Mentors and lay leaders befriending those on margins (relational vs. transactional volunteering)
- Shared medical documentation for patients
- Longer absences from school for kinds grieving; reviewing policies
- Improving healthline.ca and awareness
- Training for teachers to speak with students
- Populatio-focused death cafés (example single people)

Panel Discussion

In addition to our community partner Good Shepherd Centres who sponsored our inaugural event, we would like to thank our panelists:

- Dr. Sammy Winemaker and Maggie Civak – The Waiting Room Revolution podcast
- Jammy Lo – Keeping Six, Hamilton Harm Reduction Action League
- Pam Blackwood – McNally House Hospice Compassionate Community Initiative



To watch the panel discussion from the event, please visit the following link:

https://youtu.be/VqIGX_Eic3U

We share this report with the hope it provides some insight into what is on the minds of members of our community when it comes to DDLGB. Not only will this inform Compassionate Hamilton's work moving forward but may also spark some compassionate ideas for you and/or your various organizations and communities.

Compassionate Hamilton will be busy over the coming months planning for our second annual event and additional opportunities for engagement, education and community-building throughout the year. We will continue to update you through e-mail and social media. We also continue to seek support and specific skillsets in getting this work off the ground. Please don't hesitate to reach out with any comments, questions, or feedback.

Wishing you all a compassionate 2024,

Compassionate Hamilton

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