



PALLIATIVE
APPROACHES
TO CARE IN AGING AND COMMUNITY HEALTH



Improving Access to Palliative Approaches to Care in Inner City Canada

Scottish Partnership for Palliative Care Conference: The Space Between

Ashley Mollison, PhD(c)

University of Victoria

Nov 6, 2024



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Institute on Aging and Lifelong Health,
Nursing

Equity in Palliative Approaches to Care (ePAC) is a community collaborative informed by a research program led out of the University of Victoria. Members of the collaborative work together to conduct research with local, national and international partners, and develop resources and tools, programs, and services aimed at improving access to quality care for people facing the end-of-life and who also face inequities like homelessness, poverty, isolation, racism, and stigma.





Presentation Overview

- Background
- What we did
- What we learned
- Audience participation



235,000
Canadians experience
homelessness
EACH YEAR

Canadian Definition of Homelessness

- Living outside or in places not fit for human habitation;
- Staying in temporary or emergency accommodations (e.g., emergency and transition shelters);
- Living in accommodations without security of tenure (e.g., 'couch surfing' or staying with friends or acquaintances); and
- Living at risk of homelessness due to financial insecurity or other factors (e.g., intimate partner violence, separation or divorce, etc.) that may compromise housing.

Gaetz, S.; Barr, C.; Friesen, A.; Harris, B.; Hill, C.; Kovacs-Burns, K.; Pauly, B.; Pearce, B.; Turner, A.; Marsolais, A. (2012) Canadian Definition of Homelessness. Toronto: Canadian Observatory on Homelessness Press.





“In the spirit of the Truth and Reconciliation Commission’s Calls to Action, the definition of homelessness recognizes the overrepresentation of Indigenous Peoples (including First Nations, Inuit, and Métis) amongst Canadian homeless populations resulting from colonization and cultural genocide. The Definition of Indigenous Homelessness in Canada highlights the necessity of considering the historical, experiential, and cultural perspectives of Indigenous Peoples, as well as the ongoing experience of colonization and racism as central to understanding and addressing Indigenous homelessness.

In addition, numerous populations, such as youth, women, families, people with mental health and/or addictions issues, people impacted by violence, seniors, veterans, immigrants, refugees, ethno-racial and racialized people, and members of LGBTQ2S communities experience homelessness due to a unique constellation of circumstances and as such the appropriateness of community responses has to take into account such diversity.”

Gaetz, S.; Barr, C.; Friesen, A.; Harris, B.; Hill, C.; Kovacs-Burns, K.; Pauly, B.; Pearce, B.; Turner, A.; Marsolais, A. (2012) Canadian Definition of Homelessness. Toronto: Canadian Observatory on Homelessness Press.



Stajduhar et al. *BMC Palliative Care* (2019) 18:11
<https://doi.org/10.1186/s12904-019-0396-7>

BMC Palliative Care

RESEARCH ARTICLE

Open Access

"Just too busy living in the moment and surviving": barriers to accessing health care for structurally vulnerable populations at end-of-life



K. I. Stajduhar^{1,4*}, A. Mollison¹, M. Giesbrecht¹, R. McNeil^{2,3}, B. Pauly^{4,5}, S. Reimer-Kirkham⁶, N. Dosani⁷, B. Wallace⁸, G. Showler⁹, C. Meagher⁹, K. Kvakic¹⁰, D. Gleave⁹, T. Teal¹⁰, C. Rose¹, C. Showler¹ and K. Rounds¹

Palliative care services are not designed for populations of people facing inequities. People's focus is on survival and immediate needs can mean that palliative care is not on the radar. Big silos in care in which people fall in between – social services, health services, mental health services, etc.

Stajduhar, K. I., Mollison, A., Giesbrecht, M., McNeil, R., Pauly, B., Reimer-Kirkham, S., Dosani, N., Wallace, B., Showler, G., Meagher, C., Kvakic, K., Gleave, D., Teal, T., Rose, C., Showler, C. & Rounds, K. (2019). "Just too busy living in the moment and surviving": barriers to accessing health care for structurally vulnerable populations at end-of-life. *BMC Palliative Care*, 18(1).

<https://doi.org/10.1186/s12904-019-0396-7>



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© Palliative Approaches to Care in Aging and Community Health



Where barriers persist, people facing health inequities seek care outside mainstream health and palliative care with people they trust.

Inner city workers (e.g., housing/shelter, outreach, support, peer) are caring for people who are dying filling gaps in the Canadian healthcare system that relies on family caregivers to provide unpaid and invisible support work.


Palliative Medicine
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<https://doi.org/10.1177/0269216320917875>



Original Article



Caregiving at the margins: An ethnographic exploration of family caregivers experiences providing care for structurally vulnerable populations at the end-of-life

Kelli I Stajduhar ^{1,2}, Melissa Giesbrecht¹, Ashley Mollison¹, Naheed Dosani³, and Ryan McNeil^{4,5}

Background: People experiencing structural vulnerability (e.g. homelessness, poverty, racism, criminalization of illicit drug use and mental health stigma) face significant barriers to accessing care at

Stajduhar, K. I., Giesbrecht, M., Mollison, A., Dosani, N. & McNeil, R. (2020). Caregiving at the margins: An ethnographic exploration of family caregivers experiences providing care for structurally vulnerable populations at the end-of-life. *Palliative Medicine*, 34(7), 946–953. <https://doi.org/10.1177/0269216320917875>





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[Palliative & Supportive
Care](#)

"Everybody in this community is at risk of dying": An ethnographic exploration on the potential of integrating a palliative approach to care among workers in inner-city settings

Published online by Cambridge University Press: 07 May 2020

[Kelli I. Stajduhar](#), [Melissa Giesbrecht](#) , [Ashley Mollison](#) and
[Margo d'Archangelo](#)

[Show author details](#) ▼

Death and dying is all around, but there is a lack of preparation, recognition, and support for the mostly invisible role workers are playing as formal/informal caregivers.

Workers are drawing on principles and approaches that are aligned with palliative care such as harm reduction and trauma-informed care.

Stajduhar KI, Giesbrecht M, Mollison A, d'Archangelo M. "Everybody in this community is at risk of dying": An ethnographic exploration on the potential of integrating a palliative approach to care among workers in inner-city settings. Palliat Support Care. 2020 Dec;18(6):670-675. doi: 10.1017/S1478951520000280. PMID: 32378499.





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Nursing



***“Once you open that door, it’s a floodgate”:
Exploring work-related grief among community
service workers providing care for structurally
vulnerable populations at the end of life through
participatory action research***

Melissa Giesbrecht¹ , Ashley Mollison¹, Kara Whitlock¹
and Kelli I Stajduhar^{1,2} 

Palliative Medicine

1–9

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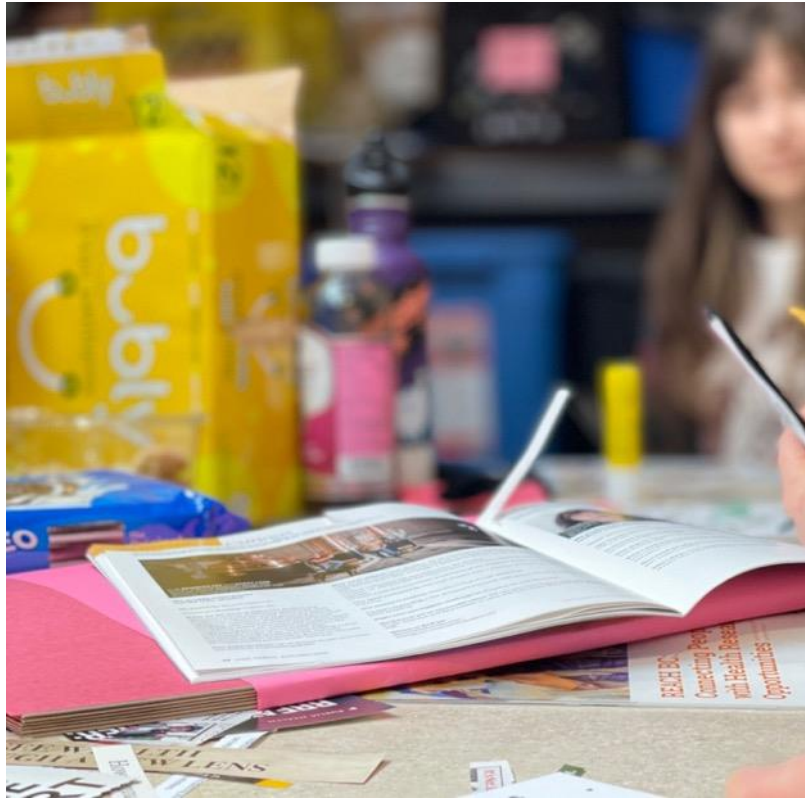
Grief experienced by community service workers (de facto family) is unrecognized, invisible, and profound.

A product of systemic oppression, unjust deaths, and a lack of organizational support, responses are needed beyond ‘emotional’ support.

Giesbrecht, M., Mollison, A., Whitlock, K. & Stajduhar, K. I. (2022). “Once you open that door, it’s a floodgate ”: Exploring work-related grief among community service workers providing care for structurally vulnerable populations at the end of life through participatory action research. Palliative Medicine, 026921632211397. <https://doi.org/10.1177/02692163221139727>



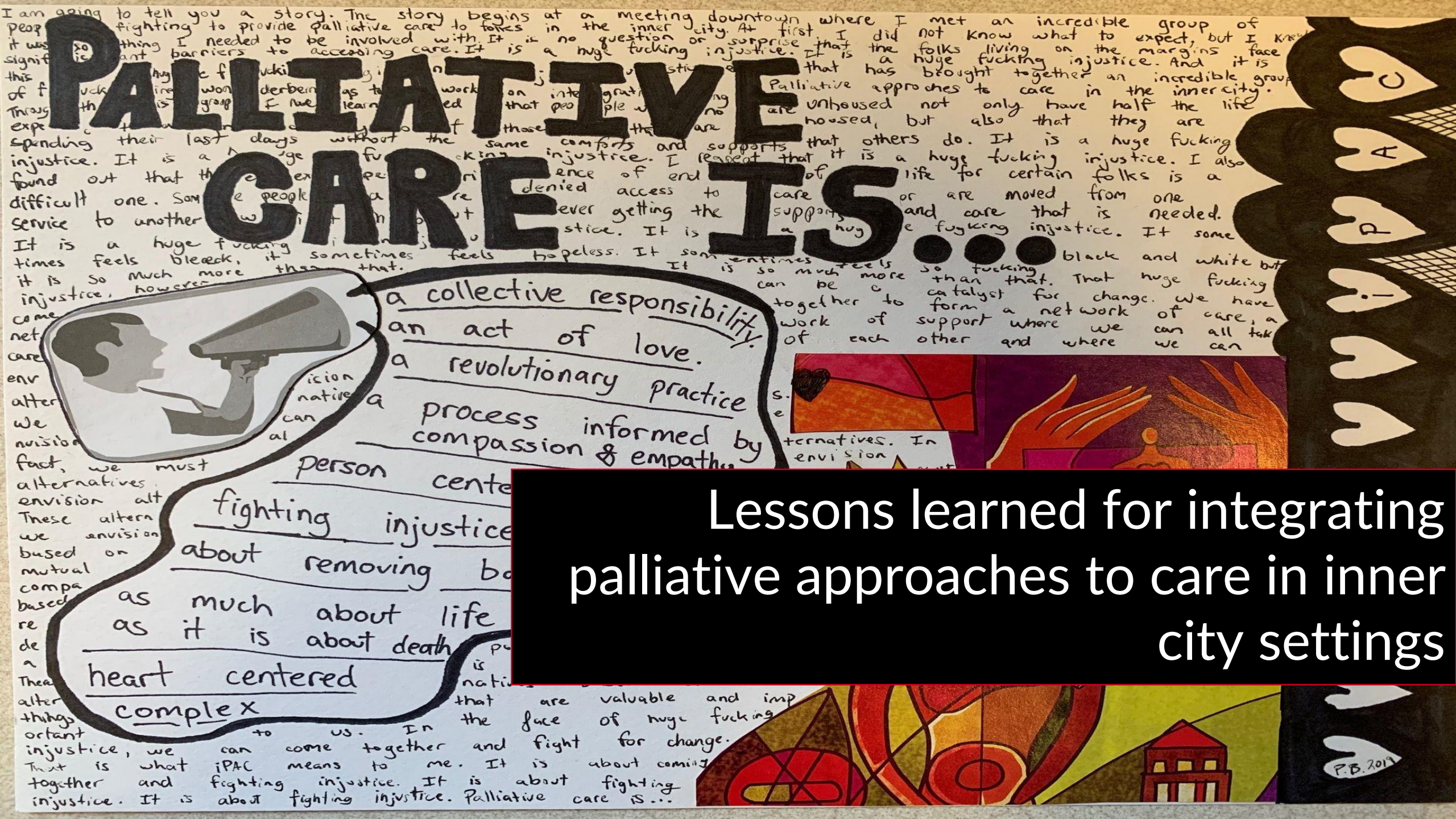
Building Palliative Approaches to Care in the Inner City



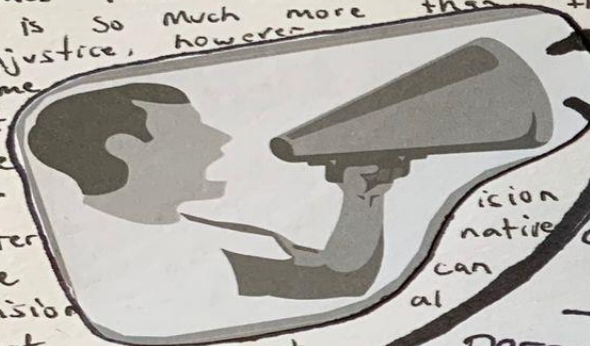
What We Did

- Participatory, community-based research beginning 2017
- Goal: Understand how to embed palliative approaches to care in places where people experiencing inequities live & die ... and do that.
- 15 workers from 6 organizations; 4 health professionals; research team members
- 5 years +





PALLIATIVE CARE IS...



a collective responsibility
an act of love.
a revolutionary practice
a process informed by
compassion & empathy



Lessons learned for integrating
palliative approaches to care in inner
city settings

person centered
fighting injustice
about removing barriers
as much about life
as it is about death
heart centered
complex



P.B. 2019



Credibility & Legitimacy

Members of our research team had long standing relationships in the communities we were trying to engage. Shared understanding and relational histories set the foundation for trust and engagement.



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STREET DEATHS ARE PREVENTABLE DEATHS

JUNE 15 - 20TH

**WEEK OF EDUCATION
AND ACTION**

JUNE 16TH

4TH ANNUAL PEER CONVERGENCE

FIRST MET. - 932 BALMORAL 9AM - 3PM

OPEN TO PEOPLE WHO USE(D) ILLICIT DRUGS

JUNE 17TH

**MOVING FORWARD: PUBLIC FORUM ON SUPERVISED
CONSUMPTION SERVICES**

FIRST MET. - 932 BALMORAL

6:30 - 8PM (DOORS AT 6PM)

JUNE 18TH

**DEATH AS A SOCIAL JUSTICE ISSUE: PERSPECTIVES
ON DEATH & DYING ON THE STREETS OF VICTORIA**

COMMUNITY ROOM, CENTRAL LIBRARY

735 BROUGHTON 2 - 4PM

JUNE 19TH

STREET DEATHS ARE PREVENTABLE DEATHS RALLY

PANDORA AND QUADRA 12PM

HOSTED BY: YES2SCS





The Unstructured Agenda

Importance of putting aside our own agendas to make space for what unfolds including anger and pain. Time is essential but can often conflict with our timelines and required outputs as researchers and practitioners.





Outside the 9-5



The work often occurs outside the 9-5 with calls, texts, and showing up when we are formally or informally asked. By engaging people in our work we are also investing in their/our lives and communities. Reciprocity is essential!





Power Sharing & Partnerships



“I think one of the salient learnings has been around the value of defacto family and recognizing the **role of support workers** [...] They’re the, the ones who are, they are doing everything in the absence of our healthcare system providing accessible palliative care for them so I think that’s been a huge learning is recognizing the incredible amount of palliative care that happens **outside the healthcare system.**”

- Palliative Physician





Real not 'token' involvement

"I love the idea that we're **working toward something**, and we are implementing things...and huge things too! Like the advanced care plan, the PORT team, which I know had so many other people involved. But like that's like a **really tangible thing** like it feels like a thing that happened that **I was a part of.**"

- Inner City Worker





Valuing Multiple Knowledges

Not about “taking” palliative care to the inner city, but adapting palliative care knowledge for use in different settings and **IMPORTANTLY** recognizing how palliative care is already happening, and what inner city work can teach palliative care.



1.3 A palliative approach can happen anywhere

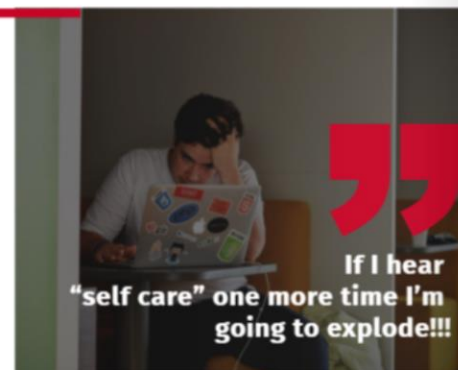
A palliative approach can happen anywhere

Palliative care is often seen as outside the realm of inner city work but the consequences of unexpected deaths fall on friends, family, and workers. A palliative approach recognizes that death is a normal part of life and must be attended to in all settings.

There are a range of experiences and responses in the face of dying and death, grief, and loss. So much of what is called bad boundaries, trauma, and burnout in inner city work is in fact, responses to injustice, grief, and loss. Rather than blaming workers, **we need a collective response.**



So much of what is called bad boundaries, trauma, and burnout in inner city work is in fact, responses to injustice, grief, and loss.



“If I hear “self care” one more time I’m going to explode!!!”

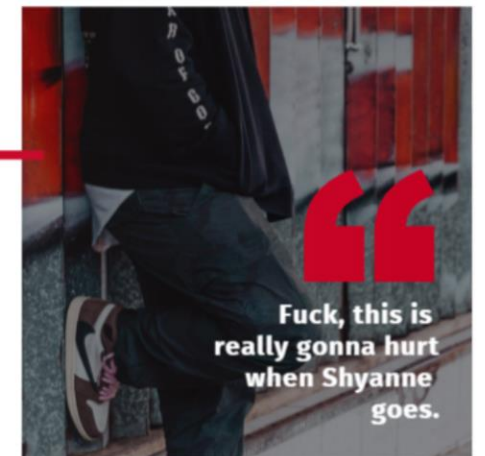
1.4 You are part of a palliative approach

Health care is often focused on the “individual” in need of care but living and dying through a palliative lens recognizes that a person’s friends, family (including “chosen” family), and community are central to the living and dying experiences.

A palliative approach seeks to reduce suffering by putting the person and their supporters at the centre of the health and social care relationship. This approach encourages people and their support networks to be active participants in care and support plans. Inner city workers are an important part of supporting people who are dying. You are likely paid to support people, but may also work outside your paid hours, scope or role to do so. These important yet sometimes complex roles deserve recognition and support.



A palliative approach can mean less suffering in illness and dying for both the person experiencing it and those witnessing it.



“Fuck, this is really gonna hurt when Shyanne goes.”



The Side Door

7.3 Naming and responding to grief

There's no simple solution to grief, but these are some points workers have shared with us and reported as being helpful:

Finding your people

The type of support almost seems less important than who you do it with. Whether it is in a grief support group, your roller derby team, or community activism, there is a lot of power in 'finding your people.'



Benefit of preparing

There's no one way to fully prepare for death and dying, but it helps if we have a plan for what to do when it comes. Palliative approaches to care discussed in this toolkit can support workers to know how to work in line with the expressed wishes of the individual, minimizing moral distress felt after death.



Getting people support helps

Because so much distress is about people living and dying in unjust circumstances, identifying people who could benefit from a palliative approach, supporting them to get the things they need, and bringing in others (if wanted), can help workers share the load and burden and prevent them from feeling like they're not doing enough.



I'm not crying, you're crying

Doing grief together doesn't need to be labelled as 'grief support' at all. There can be a kind of 'side-door' that opens when we aren't trying to manage or fix the pain that people are experiencing. This kind of support happens when people just 'get it' through having shared experiences or context into your situation. Knowing you aren't alone in your experiences can help, whether talking about grief or not.

Memorial spaces at work

While reminders of people who have died aren't great for everyone, having a discrete space where people can share a memory or sign a banner can support remembrance and people have a choice when it comes to whether or not they engage with a resource like this.

Collective debriefing

Collective debriefing after deaths can help prevent workers from feeling like they're going through the loss or carrying a burden alone. Workers have shared that grief is made worse by feeling like they didn't do enough. Insights from good and bad experiences of death/dying can be used to inform future planning.

7.4 Public mourning: Grief and resistance

Public mourning: Grief and resistance

Publicly mourning the people we have lost is a way to respond to our grief collectively. When some people's lives are treated as disposable, openly grieving together can be a radical act. Pushing back against this idea of disposability means we can challenge the expectation that it is more professional or better for our health to carry on with business as usual.

Public mourning is a way to witness and support each other through our shared pain. When we join together and **acknowledge the significance of our losses**, we demonstrate how to be in relationship with each other and remember we aren't alone. These shared spaces are important to care work, to communities, and to our wellness, because connecting to others is vital to knowing how to grieve. **It shows everyone, including ourselves, that our distress matters, we matter, people matter.**

It doesn't always have to be formal, like in funerals or wakes, but can exist in forms like activism and spontaneous memorials. Banners or walls where people can write the names of their loved ones, public art displays, gatherings, or protests to fight against unjust deaths are all examples of ways to find and be with our people in collective grief.



Victoria, BC, National Day of Action on the Overdose Crisis, April 16, 2019.

“For me, this kind of feels like grief counselling because **we're working towards something together** and even though it's not explicitly us talking about challenges with grief, I feel lighter at the end of it.”

– Inner City Worker

CARE
rights issue

rise
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peer
worker

Uncommo
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t to the Community

Ascending
CARRIERS

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BLACK
& WHITE
THINKING.

PEER
WO
THANK YOU

COMPAS

 **Piotr Burek**
@burek75

I've said it before and I'll say it again, the amount of love and care I have for the humans in this group is beyond words.

Palliative care is about fighting injustice and caring for each other, and what incredible accomplices we have in doing so.

#ipac #yyj #justice #equity

 **Equity in Palliative Approaches to Care** @access2care · Sep 17

Just finished our iPAC zine workshop facilitated by the always amazing @burek75 ❤️ We are creating a zine about what palliative care in the inner city means for us. Stay tuned for the final product 📖





Contact Us!

- ✉ mollison@uvic.ca; palliative_approaches@uvic.ca
- 🌐 palliativeapproaches.uvic.ca
- 📍 IALH, University of Victoria
- 📞 X @access2care
- 📺 YouTube @palliative_approaches
- 📷 Instagram @palliativeapproaches



AUDIENCE PARTICIPATION

Questions? Comments?

