





Promising Practice: Palliative Outreach Resource Team (PORT)









Healthcare Excellence Canada (HEC) and the Canadian Partnership Against Cancer (the Partnership) would like to formally acknowledge the generosity of PORT in sharing their skills, knowledge, expertise and experiences to form this promising practice document. For our program team, it is a privilege to share the details of this work; however, we recognize that the contributions PORT has made to equity in palliative care reach far beyond what can be captured in this brief document. PORT has graciously shared their work and their time with us and for that we are deeply grateful.



About Healthcare Excellence Canada

Healthcare Excellence Canada (HEC) works with partners to spread innovation, build capability and catalyze policy change so that everyone in Canada has safe and high-quality healthcare. Through collaboration with patients, caregivers and people working in healthcare, we turn proven innovations into lasting improvements in all dimensions of healthcare excellence. Launched in 2021, HEC brings together the Canadian Patient Safety Institute and Canadian Foundation for Healthcare Improvement.

The views expressed herein do not necessarily represent the views of Health Canada.



About the Canadian Partnership Against Cancer

The Canadian Partnership Against Cancer (the Partnership) is an independent organization funded by the federal government to accelerate action on cancer control for all Canadians. The Partnership is the steward of the Canadian Strategy for Cancer Control (the Strategy) and works to implement the Strategy to reduce the burden of cancer on Canadians. The partner network-cancer agencies, health system leaders and experts and people affected by cancerbrings a wide variety of expertise to every aspect of our work to support multi-jurisdictional uptake of the knowledge emerging from cancer research and best practices in order to optimize cancer control planning and drive improvements in quality of practice across the country.





The Promising Practice

PORT is a mobile service in Victoria, BC, for people who have progressive life-limiting conditions and who have challenges accessing palliative support as a result of homelessness, poverty, racialization, stigma, discrimination and lack of social support.

PORT is a partnership between the University of Victoria, Island Health and Victoria Cool Aid Society along with multiple community collaborators.

Program goals

PORT's goals are to:

- Improve the quality of, and access to, palliative care for people who are structurally vulnerable and their chosen supporters.
- 2. Educate, support, build capacity among healthcare providers on palliative approaches to care for people who experience health inequities.

- Educate, support, build capacity among inner city health, housing/shelter and social services on palliative approaches to care for people who experience health inequities.
- Improve coordination and delivery of palliative care among providers and agencies as it relates to structurally vulnerable populations.
- 5. Bear witness, capacitate and support the whole person who is dying and their chosen family including biological and street families, and service providers.
- 6. Provide resources, direction and bereavement support to people caring for structurally vulnerable people facing progressive life limiting illness and end-oflife.
- 7. Advocate for accessible, high quality, upstream, integrated palliative care for structurally vulnerable populations.
- Advance the body of knowledge for palliative care in structurally vulnerable populations (Stajduhar & Mollison, PORT Interim Report, 2020).

Model

PORT staff meet clients where they are, working alongside their friends, family and service providers to ensure that the client has support if they are facing advanced, progressive illness and are nearing end of life. Clients continue with their primary care providers (if they have a primary care provider), and PORT consults and helps coordinate access to various health and social services. As an example, if there is someone in the community who is living in the shelter and they are approaching the end of their life, PORT will help facilitate access to community-based services and will attempt to build capacity to enable a palliative approach to care wherever clients are located. In the event that this cannot be achieved, the PORT team will help facilitate entry for the client into inpatient palliative care or another appropriate inpatient facility.

PORT services include addressing physical, psychological and spiritual needs, including developing Advance Care Plans, providing bereavement support, providing direct care, providing resources and addressing barriers in accessing health and social services. There is a strong emphasis on addressing the social determinants of health as a precursor to enhancing quality palliative and end-of-life care.

Program history

PORT began as an informal collaboration in 2011 for service providers working in the inner city of Victoria who wanted to improve access to palliative care, and quality of this care, for people who were nearing the end of life and who were experiencing homelessness or were vulnerably housed. In 2013, Dr. Kelli Stajduhar was approached by a nurse working at an inner city health clinic with whom she had worked previously to ask for help in making the needs more visible for people who were vulnerable and at the end of life through documenting their experiences. Dr. Stajduhar and a group of inner city health and social service providers collaborated to develop research that would begin to shine a light on the issues facing people who were dying while structurally vulnerable. Following eight years of research, advocacy, partnership building and planning, Saint Elizabeth Health Community Enterprise provided two years of catalyst funding for clinical services for PORT and an evaluation of the PORT program. In January 2019, meetings began to develop PORT's infrastructure and PORT officially launched in September 2019.

Hence, PORT was developed through a longstanding community development, participatory research process. The catalyst funding for research on flexible, mobile services in the inner city community was run through a communitybased organization, the Victoria Cool Aid Society. In the past three years, sustainable funding has been achieved via funding from the Island Health End-of-Life Program, which now has operational responsibility for PORT while maintaining close collaborations between Dr. Stajduhar at the University of Victoria, the Victoria Cool Aid Society (whose primary focus is on housing and services for people facing inequities) and several other community partners. In the past three years, the addition of the outreach worker has been key, since the primary intervention in palliative care for people who are vulnerable and marginalized is often addressing the social determinants of health (e.g. housing, food security, transportation to medical appointments). The outreach worker facilitates addressing these social determinants of health and advocates for clients.

Funding

Funding over the years has been provided by Saint Elizabeth Health Community Enterprise, Island Health's Palliative and End-of-Life Care Program, and Victoria Cool Aid Society (including private donors). All clinical services are now funded through the health authority. The health authority has provided funding for a part-time palliative care physician (shared by two physicians), parttime social worker and full-time nurse coordinator. A full-time health outreach worker, originally funded by Victoria Cool Aid Society, is now funded by Island Health. The University of Victoria and Cool Aid also raise funds and receive donations for PORT. The University of Victoria, through Dr. Stajduhar's research program, raises extra funding for holiday gifts, cell phones, grocery cards/Boost and equipment for clients, and provides the necessary infrastructure for ongoing community development, participatory research

and staffing to develop tools, resources and educational materials that are used to support integration of palliative approaches to care for people who face inequities. There is a PORT car that is collaboratively funded between the partners (e.g. gas and upkeep). This is an essential component of the work, as previous to this, the outreach worker was using their own car to provide services.

Referrals

The PORT model is designed as a capacity building model. PORT receives referrals from family members, self-referrals, community agencies and healthcare providers. PORT is designed to create a low-barrier referral process. Anyone can refer to PORT including people with life-limiting conditions, their friends and family, and service providers. See the <u>community referral</u> form and the health provider referral form.



Population served

The definition for clients is very broad and includes anyone who has a life limiting condition which is progressive and they are challenged for whatever reasons to get access to services that they need to support a good quality of life until their death. PORT has no firm expectation in terms of life expectancy. In some cases, once a client has their social determinants of health needs met, they may no longer be palliative and may transition from the program. In this case, the PORT team links the client with services and supports that they need.

Outcomes and Impacts

Ongoing data collection

Routine data are collected on an ongoing basis including on the number of clients, demographics (e.g. age, health conditions, housing status) and service utilization (e.g. referrals to allied health and social services).

Evaluation

An evaluation of PORT was recently completed and will be available on the Equity in Palliative Approaches to Care <u>website</u>. The Interim Report (February 2020) showed PORT had provided services to 47 people, 68 percent of whom were male, 16 percent identifying as Indigenous, and with an average age of 59. The majority (70 percent) of referrals came from healthcare providers, with 25 percent from community care providers and five percent from family (broadly defined). Clients were with the PORT service for an average of 37 days, with 18 clients discharged (eight died and 10 were identified as no longer needing PORT services and were provided referrals for other services as applicable). Early data show that PORT clients may have lower hospital utilization rates (Stajduhar & Mollison, PORT Interim Report, 2020).

Qualitative data collection, including with clients

A large study (Equitable Access to Care Study) was done initially by the University of Victoria that led to the inception of PORT clinical services. Twenty-five people in the community who experienced structural vulnerabilities and who had declining health were followed in an ethnographic study, along with family caregivers and workers in inner city settings (Stajduhar et. al., 2019; Stajduhar et. al., 2020; Stajduhar et. al., 2020). The study examined where they were living, their access to health services (e.g. doctor appointments) and their palliative care experience. A surprising finding was how satisfied many participants were with their palliative care experience. For some, a palliative approach offered them an opportunity to feel cared for and believed. For instance, participants had experiences getting very late diagnoses and not being believed that they were in pain due to a history of illicit substance use. Flexible and individualized approaches rather than standardized "one size fits all" models were found to be facilitative for people experiencing poverty, homelessness, stigma and discrimination.

Other analysis for future

PORT is looking at how best to incorporate patient reported outcome measures. Analysis is underway with the health authority on the number of hospitalizations pre- and post-PORT, as well as visits to emergency departments.



Collaboration

PORT is a partnership and collaboration between the community, university and health authority (the University of Victoria, Island Health, and Victoria Cool Aid Society).

PORT takes a classic **community development**, **participatory approach** that has evolved over time. In the time leading up to and during the first year of PORT, team members met every two to three weeks with an **Inner-City Action Team led out of the University of Victoria** (with inner city workers from six community and health organizations) as part of building relationships, awareness and knowledge and understanding how palliative approaches can be adapted for inner city settings.

This team is a group of people with lived/living experience of structural vulnerability including workers (housing, shelter, outreach, harm reduction) who are integrated into all aspects of the work PORT does. The PORT outreach workers sit on the inner city action team and the team is designed to contribute to planning, implementation and evaluation of PORT's work. PORT is one part of a collaborative/collective partnership with PORT clinical services intersecting with the community-based action team, and research and knowledge mobilization/translation is embedded in all that PORT does as a collective. An informal Island Community of Practice, with which PORT participates, is also in place to collaborate, consult about clients and do case review, provide education and collaborate with other palliative consultation teams across the Island.

There are many collaborative partnerships that have been developed from research projects. **Research projects** have been used to bring together people in very participatory ways.

Given that PORT acts as a bridge between clients and various social and health services, PORT works closely with many **community organizations,** as well as **primary care providers.** Housing providers are also key partners given the importance of housing for health, and as mentioned, also refer clients to PORT.

PORT has a weekly connection in rounds with the clinical nurse leader from the BC Cancer Agency, as many clients followed by PORT have cancer. PORT has monthly rounds with the Liver Care Clinic, given that many PORT clients have advanced liver failure. These rounds are also a place from which PORT referrals occur.

Lessons Learned

Key principles

- PORT follows a harm reduction and trauma-informed approach.
- PORT has a **low-barrier process** for referrals, where anyone is able to refer someone to PORT.
- PORT meets people where they are at, whether this is in different types of housing or a location of the client's choosing if they are people experiencing homelessness, such as a tent, shelter or vehicle.
- PORT advocates for interventions that address the social determinants of health (housing, food security, transportation to medical appointments), laying the groundwork for good quality care at the end of life.
- PORT also advocates for good symptom management and overall care, as well as works to address issues of stigma on the part of healthcare providers and inequities in the healthcare system.
- PORT works closely with partners as a bridge to health and social services. PORT aims not to go in and take over the work of other providers. PORT has strong, trusting relationships with clients. Clients often do not have primary care providers. PORT bridges the patient with services in the community.
- PORT ensures flexibility in meeting the needs of the client and is nimble in addressing needs. PORT does what needs to be done to meet the goals of a patient. This can be quite varied. In some cases, the team cares for the client where they are at (e.g. supportive housing) where housing organizations are receptive to keeping

people in place. PORT does bridging work to try to ensure a client can stay in place, but this is not always possible given the need for physical care, and pain and symptom management.

Enablers

PORT is a community-led intervention, working from the ground up. People working with community organizations (e.g. not for profits, housing organizations) came together to address this challenge and bridge the gap. The community exerted its own expertise and authority based on what they were seeing. Facilitated by researchers from the University of Victoria, these organizations put aside past histories and lack of trust with working with the health authority to address this issue. People were willing to sit together and hear from each other, keeping clients at the centre of the work. A community development approach is important, and the roll-out of projects such as this needs to be very mindful, thoughtful and strategic. Hiring people that work in the inner city and who have community development capacity ensures that the work is credible.

A large research project completed by the University of Victoria was the impetus to support the advocacy efforts to establish PORT and secure funding (Stajduhar & Mollison, 2018). The advocacy efforts were helped immensely because of previous relationships that Dr. Stajduhar held within both the health authority and many of the community-based agencies. Based on the research, a number of articles have also been published including at least one that involves people with lived experience of homelessness and progressive chronic illness. The research has also identified many recommendations in working with service providers, clients and their families on palliative care for vulnerable populations.

Relationship building and trust building cannot

be underestimated. Listening, acting from a place of humility, learning from people on the ground and working alongside partners to develop a sustainable model is key.

Breaking down silos and barriers between mainstream healthcare services and community has been important.

Small quality improvement-type interventions (that are often low cost) have been underway as well to address challenges that have arisen. For example, Advanced Care Planning was implemented to identify peoples wishes and help communicate this to others. Another example is in fall 2023, an educational toolkit was launched for inner city workers to integrate palliative care into their work. There is funding now for equipment for clients, and the University of Victoria and PORT partnered with a local equipment business to store, maintain and clean the equipment. The PORT partnership organizations engage with news and social media (e.g. press releases, op-eds, newsletters) to highlight and build support for the work underway. These are some of the areas that are critical, but that the health system does not have capacity or funding to address. PORT has been responsive and nimble to address these challenges as they arise.

Another key enabler is **strong connections to other organizations.** There is coordination at rounds with organizations like the BC Cancer Agency and the Liver Care Clinic. This helps to coordinate care. Collaboration with housing providers is also important, and they are a source of referrals.

Challenges

Lack of trust based on past interactions: The community that is being seen by PORT are often people who have faced discrimination in the healthcare system and have been treated poorly.



The community-based organizations that work with these clients often have limited time and funding, and there is not always a lot of trust between organizations and the health system, nor between clients and the healthcare system. People working in the healthcare system often do not have capacity to carry out the community development work in the way that is needed to build partnerships and gain trust.

Lack of time and capacity to spread and scale: There is interest from the health authority to

There is interest from the health authority to broaden these kind of services geographically. However, spreading and scaling up these services can be a challenge when there is limited time and capacity. Much of the work is relational and it takes time to develop models that will work in different settings.

Need for further education and capacity

building: There is a need to continue to educate and build capacity amongst healthcare providers on providing palliative care for people who are marginalized and vulnerable (e.g. people experiencing poverty, homelessness, mental health and addictions).

Identifying substitute decision-makers: Another challenge noted in the Interim Report (2020) was that it can often be difficult to find someone who is able to take on a role of substitute decision-maker for the client if the client is unable to do so themselves.

Need for sustainable evaluation infrastructure:

Initially, PORT had a built-in evaluation mechanism. These data are no longer collected in the same robust way as they were in the initial stages when data were necessary to show proof of concept. This highlights the challenge of data collection (when the focus is on service delivery), as it is important to have infrastructure to sustain data collection over time.

Need for more formal connections with mental health and substance use colleagues: One

gap is that currently these connections are often informal, based on relationships, client by client. There is an opportunity for more robust systematic relationship building across the system, with formal integration in terms of models of care, service and resource planning.

Need for suitable housing: A lack of suitable housing remains a major challenge. It is difficult to support people through to the end of life even if supportive or temporary housing is available. Without housing, this is made even more difficult.

Need for services for non-palliative clients:

People who are vulnerably housed but are not facing a life-limiting illness lack access to services and are often seeking help where it can be found. These clients sometimes self-refer to PORT or are referred by community partners who may not be fully aware of their client's health situation. PORT partners with Victoria Cool Aid Society to try and help bridge these individuals to primary care. However, access to primary care services remains a challenge for these and other clients.

Lessons learned

It is important to **start from a place of sustainability** in developing a model such as this, including creating the infrastructure alongside the health service planning.

Care coordination is key for PORT clients, and better models for care coordination are needed to ensure clients' needs are met, including

PROMISING PRACTICE: Palliative Outreach Resource Team (PORT) with regards to determinants of health (e.g. assistance with appointments, groceries, housing, medical equipment, transportation). This may involve augmenting volunteer support in the model.

Hence, there is an opportunity to look at the role of **specifically trained volunteers** in supporting PORT. A major consideration is which organizations can host, coordinate and support these volunteers.

The **physical location of staff in the community** (e.g. office space) is an important consideration. It is important to consider how best to balance a physical presence in community health units as well as with hospital/hospice, so interaction can be facilitated.

In terms of **level of interventions in the advanced care plan**, the number of clients who express that they want to be a "full code" (i.e. receive resuscitation as part of their care plan) is high, despite many not feeling comfortable with hospitals and traditional healthcare.

Staff working for PORT note that **bereavement support** is critical for friends, family and healthcare and community providers.



This promising practice was co-produced with PORT. Information was compiled in the fall of 2023. In keeping with the changing and evolving nature of care the information may change in the future. We encourage you to reach out to this team for any further information that may be helpful as you work to improve access to palliative care for those you serve.

For more information

To learn more, contact:

The PORT Team
<u>PORT@islandhealth.ca</u>

Additional resources

- Equity In Palliative Approaches to Care
- <u>Palliative Approaches to Care in Aging and</u> <u>Community Health</u>

News articles

- What are the palliative care services available to the homeless population in Canada?
- <u>Comment: Homeless deserve end-of-life care, but</u> <u>aren't getting it</u>

Referral forms for community and healthcare providers

- PORT Referral Form: Community
- PORT Referral Form: Health Providers

Reports

- PORT Interim Report, February 2020
- Stajduhar KI, Mollison A. <u>Too little, too late: How</u> we fail vulnerable Canadians as they die and what to do about it. Victoria, BC: University of Victoria Institute on Aging and Lifelong Health; 2018.

Journal articles

- Reimer-Kirkham S, Stajduhar K, Pauly B, Giesbrecht M, Mollison A, McNeil R, Wallace B. Death is a social justice issue: Perspectives on equity-informed palliative care. *Advances in Nursing Science*. 2016;39(4), 293-307 doi: 10.1097/ANS.00000000000146
- Stajduhar KI, Mollison A, Gleave D, Hwang SW. When cancer hits the streets. *Current Oncology*. 2017; 24(3), 149-150. doi: <u>10.3747/</u> <u>co.24.3698</u>
- 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;18(6), 670-675. doi: 10.1017/S1478951520000280
- Stajduhar KI, Giesbrecht M, Mollison A, Dosani N, McNeil R. Caregiving at the margins: An ethnographic exploration of family caregivers experiences providing care for structurally vulnerable populations at the end-of-life. *Palliative Medicine*. 2020;34(7), 946-953. doi: 10.1177/0269216320917875

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