Healthcare Excellence Canada

CANADIAN PARTNERSHIP AGAINST CANCER

Promising Practice: Thunder Bay Palliative Advocacy & Care Team (PACT)

PACT
PALLIATIVE ADVOCACY CARE TEAM

Healthcare Excellence Canada (HEC) and the Canadian Partnership Against Cancer (the Partnership) would like to formally acknowledge the generosity of the PACT team 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 PACT has made to equity in palliative care reach far beyond what can be captured in this brief document. PACT has graciously shared their work and their time with us and for that we are deeply grateful.

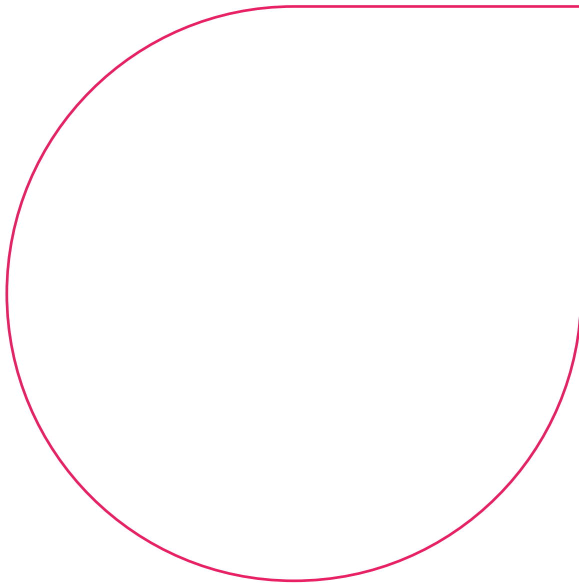
About Healthcare Excellence Canada

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 cancer—brings 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

Program history and current model

Hospice Northwest is a visiting hospice, with no residential space. Volunteers go wherever end-of-life cases might be – in long-term care, in personal homes and in hospitals. Hospice Northwest also has a Journey Home Team, made up of a small group of volunteers, who go into shelters, including the Managed Alcohol Program, to play cards, games, paint, garden and do other activities to get to know clients. Clients then tend to open up about grief and bereavement, including anticipatory bereavement, over time as trust increases.

In the past three years, Hospice Northwest has increased their involvement with vulnerably housed populations, leading the Vulnerably Housed Working Group in Thunder Bay, ON. A group of healthcare professionals (front-line providers including palliative care providers and those working in housing or in shelters) meets every two weeks on Wednesday mornings to do palliative care rounds, similar to clinical rounds (called Rocket Rounds). They discuss each client and ask how they are doing, who has seen the person most recently, and what steps may need to be taken to assist the person (e.g. a volunteer or a healthcare professional may agree to go to the shelter at closing to try to find someone to encourage them to go to the hospital). New cases are added to the rounds as they come up. There is no formality to the process. A list of contacts is updated and sent out to people so they can communicate between rounds. This work helps to ensure that people who are already involved in caring for vulnerably housed people are aware of palliative care and are connected to resources as needed, with wraparound care for the client. The model also builds on leveraging the relationships already in place to ensure palliative care services are provided.

A larger group of leaders meets bi-monthly to move the dial forward on palliative care for the vulnerably housed in Thunder Bay.

When this work started, rounds consisted of only one client. Now there are five to eight clients discussed during each round. The activities have been evolving over time, and interviewees noted that there is more to be done. As things evolve, the meetings are becoming more formal (in terms of a structured working group) rather than ad hoc calls.

When the team involved in doing rounds received temporary funding, they rebranded as PACT. Thunder Bay Palliative Advocacy & Care Team (PACT) provides primary healthcare and social services in the Thunder Bay community and surrounding District. PACT aims to:

- improve access to care through an outreach worker dedicated to vulnerably housed palliative care clients.
- increase knowledge about palliative care among healthcare providers and people experiencing homelessness.
- inform future programming though community engagement sessions and then build capacity to address identified needs in the community.

PACT is partnering with Hospice Northwest, St. Joseph's Group Northwest Regional Palliative Care Program, Thunder Bay Palliative Care Associates, the Centre for Education and Research on Acting and Health, and NorWest Community Health Centre.

PACT hired their first dedicated staff person, an outreach worker, to work with palliative care clients. This position provides boots on the ground for people who come together for clinical rounds. This outreach worker has lived experience with homelessness and addiction. She was previously a front-line worker at Shelter House and an outreach worker at the safe consumption site. The outreach worker helps people to ensure their social needs are met, including transportation, accompanying them to an appointment, assisting with housing or getting identification or helping with food or other basic needs.

PACT focuses on advocacy as well as education. Education for palliative care providers includes how to better provide service to clients who are vulnerably housed, through providing trauma-informed, culturally safer, equitable care with a harm reduction lens. PACT also provides education for front-line social service providers (e.g. shelter, outreach workers) on the benefit of a palliative approach to care for clients. PACT is also starting to educate clients on their rights.

Funding

Funding is for direct clinical care only. There is no consistent funding for this work, with the only paid staff for PACT being the outreach worker via project funding through the Improving Equity in Access to Palliative Care program. The work, including working groups and rounds, is largely done off the sides of desks, or via volunteers.

Team

The bi-weekly rounds are attended by healthcare professionals including a street nurse and one palliative care physician (who works at the regional hospital and regional cancer centre), and representatives from various organizations including Hospice Northwest, NorWest CHC, Grace Place, Northwind, Getting Appropriate Personal and Professional Support from St. Joseph's Care Group, street nurses and nurse practitioners, home and community care, emergency medical services, and the Managed Alcohol Program.

The larger group meetings also include the staff from the Thunder Bay Regional Health Sciences Centre Emergency Department.

Referrals

There is a central referral form for all palliative care in Thunder Bay. Self-referrals can also be made to PACT, and referrals can be made informally (e.g. from people working with the vulnerably housed, for instance those working in shelters).

Population served

The population served is people who have a life limiting illness (usually cancer and liver failure). There is no specific limit on how much time they can have left (but typically with estimated one year or less). People are vulnerably housed, but this is an informal definition and includes people living in shelters or couch surfing.

These definitions have intentionally remained open to ensure people do not fall through the cracks. The intent is to be low barrier.

Outcomes and Impacts

Data from rounds have been collected since September 2021. The dedicated outreach worker uses an intake form with any client involved with the PACT team, collecting demographics, information on the social determinants of health, and any unmet needs that clients have.

A survey was completed with 18 respondents and 23 palliative and vulnerably housed intake clients. Liver failure and cancer were the primary life-limiting diagnoses for survey respondents. Barriers for 80 percent or more of survey respondents include transportation (100 percent), financial challenges (94 percent), uncertainty of resources available (94 percent), racism and discrimination (89 percent) and previous bad experiences (83 percent). There is a plan to conduct another survey, as well as additional client follow-up.

The lack of data and evaluations is noted as a gap, and it is understood that to get additional funding, additional data will be needed. However, how the data will be tracked in a meaningful way needs to be addressed.

Collaboration

Organizational partnerships

Partners include Norwest Community Health Centres (Palliative Carelink), Hospice Northwest, St. Joseph's Care Group, Palliative Care Associates (physicians), Home and Community Care Support Services, Thunder Bay Regional Health Sciences Centre, Superior North EMS (community paramedicine), Shelter House and Grace Place.

The partnerships are informal (including those partnerships between people at rounds noted above), and there are no formal memorandums of understanding. Work is done via goodwill, with Hospice Northwest leading the work. There is an ongoing effort to engage Indigenous partners in the work.

Partnerships with community

The community has been engaged via volunteers through Hospice Northwest. As noted above, the PACT outreach worker has lived experience.

Peer support

Peer support has not been looked at explicitly and needs more attention.

A 2018 needs assessment, which included surveys for service providers and interviews with service users, recommended: continued collaboration, funding and resources, increasing access, eliminating discriminatory beliefs, education for service providers, education for service users, and housing first. To date, PACT has looked at models for housing first, and continues to refer and assist with housing applications.

Lessons Learned

Enablers

- The work has been informal, and this works well in many ways, given the size of Thunder Bay.
- The people working on this have stayed the course, and this is a testament to the dedication of people working in this area.
- Having access to a provider (medical doctor or nurse practitioner) is critical.
- Being part of the Improving Equity in Access to Palliative Care collaborative across Canada to share best practices and tools and lessons learned, and receiving project funding support, has been important.
- Spending time with people who are vulnerably housed builds trust (e.g. doing arts and crafts together). This trust is needed to have conversations including on advanced care planning or grief/bereavement. Staff with lived experience also build trust quickly and allows the program to be quickly tailored to client needs.
- Past cases are looked at as a group to understand what could be improved next time.

Challenges

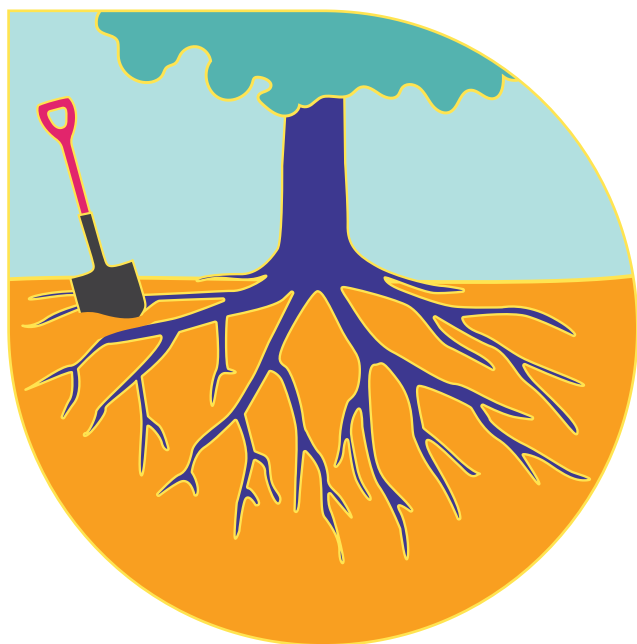
- There is **insufficient funding and services** for primary healthcare and harm reduction. Primary care is fragmented and inadequate for these populations.
- Housing, in particular appropriate housing for people with medical needs, remains a challenge.
- The **healthcare system and the social system are siloed**, with defined boundaries. As a result, clients may not have their needs met, or can fall through the cracks.
- There is a **lack of equity, diversity and inclusion** work done in healthcare in Thunder Bay, and it is unclear whose role it is to lead this work.
- The work on palliative care for the vulnerably housed is being done off the side of people's desks, with **no sustainable funding and only one paid staff**. People attend rounds as they happen to have clients they think are palliative or are passionate about the issue. Ideally, having additional dedicated staff in place (e.g. nurse) to support palliative care for the vulnerably housed is needed, and will help to move the model forward.
- Shelters are **not currently equipped for people to die in** (e.g. shelter staff cannot deal with incontinence, pain management or around-the-clock home care).
- Many people who are vulnerably housed and have a substance use disorder **do not want to go to a hospital** as they are not seen right away, and they will get agitated without alcohol/drugs.
- **Systematic racism and barriers** continue to be a challenge in Thunder Bay. Many clients who are vulnerably housed are First Nations, Inuit and Métis.
- Getting healthcare providers, including home and community care, to understand how best to work with people who are vulnerably housed is a challenge. **More training in core**

competencies of palliative care and the vulnerably housed, and understanding of this population, is needed to understand how to help the vulnerably housed. Clients may miss a call, or refuse services, and many healthcare providers do not know how to handle these situations. Oncologists are upset when someone does not show up for treatment. Home and community care will also refuse to go into some living situations. These are huge issues to be navigated.

Lessons learned

- It is important to **have a hospice space that is welcoming** to those who are vulnerably housed (i.e. to ensure there is no institutional feel if a stand-alone hospice dedicated to providing an inclusive space for all people and cultures were to open in Thunder Bay; currently there is a hospice in the hospital).
- It is important to have **staff and volunteers dedicated to providing care for this population**, including those who understand the complex needs of this population, are empathetic and understand harm reduction, trauma-informed care and culturally safer care.
- Additional resources need to be placed moving forward on **system issues, finding additional funding and monitoring and evaluation**.
- A **model for palliative care** for people who are vulnerably housed is needed that **works in smaller places**.

This promising practice was co-produced with PACT. 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:

Cherie Kok, Executive Director, Hospice Northwest
cherie@hospicenorthwest.ca

Brittany D'Angelo, Manager of Palliative Carelink & Safer Supply, NorWest Community Health Centres
bdangelo@norwestchc.org

Additional resources

2018 Needs Assessment