



# Promising Practice: Six Nations



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



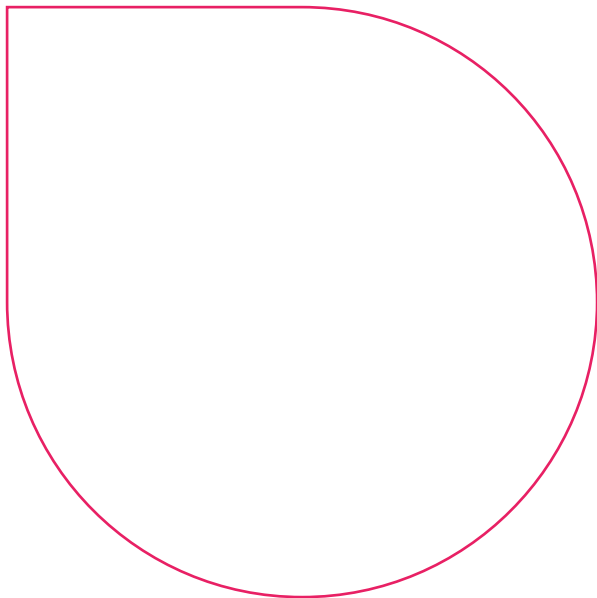
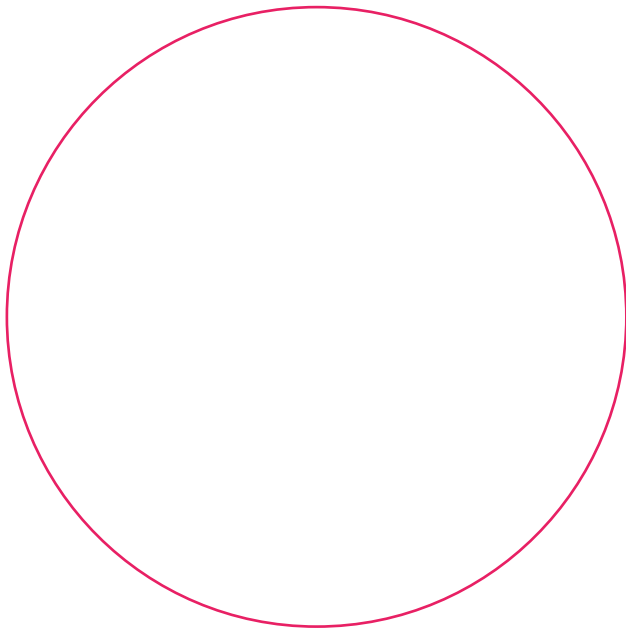
## About Healthcare Excellence Canada

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

This program began in 1999 in the Six Nations community located in Ontario. Historically, it sat with Home and Community Care, which had a single program manager for all home and community care services (with 90 staff). This included personal support services, community support services, professional services (such as foot care), health advocacy, dementia services and an alternative level of care facility with nine beds for people with a head injury, as well as palliative care. This was a challenge for resources for palliative care, and palliative care was not a focus given all the other areas.

An external review was conducted in 2018, and feedback included the need for more support and supervision for teams. It became clear that palliative care required focused attention. In early 2022, a program supervisor was hired who now oversees palliative care specifically. The focus is now on palliative day-to-day work, with a growth focus. A donor is interested in building a hospice but there is no funding to operate the hospice once built.

Recently, an external consultant was hired to conduct an overview of palliative care in Six Nations to identify any gaps, barriers and communication tools that might be needed. One area identified was the need for a checklist for families to understand what an expected death looks like in a home. The EDITH (Expected Death in the Home) form was created and implemented by the palliative care team and case managers. A communication tool was also developed that outlines the available list of services, contact numbers and the time that the services are available (e.g. 24 hours, 8:30 a.m. to 4:30 p.m.) to facilitate families in their navigation of the system.

## Team

The team is made up of clinical nursing services from Home and Community Support Services via the Ontario Ministry of Health and Long-Term Care. Six Nations has a case manager/care coordinator for palliative care and currently has two part-time personal support workers (PSWs) who are trained in palliative care. The PSWs are connected to a designated registered nurse (RN) virtually using a telemedicine model (through a program called eSHIFT). If the PSWs have any concerns, they convey this to the designated RN who can do any follow-up or assessment. There is also a project manager to develop the hospice program. It is hoped that the team can be expanded in the future with additional PSWs, a cultural advisor, clinical education and another spiritual care clinician.

Two team members are also funded and supported via the Palliative Care Outreach Team, which is a regional team. They support the region, not Six Nations exclusively. One of these members is a clinical nurse specialist who is paired with a palliative care physician who works in the region. This clinical nurse specialist is assigned any patients who choose to work with the Palliative Care Outreach Team (a community member can work with their

own general practitioner or can work with the Palliative Care Outreach Team). The other team member is a psychosocial bereavement clinician who works during and after the process of a person's passing (for people in Six Nations as well as the broader region). Plans are to create a full-time palliative care nurse clinician role to bridge between the outreach team, which works primarily out of Stedman Community Hospice and the Six Nations Team.

Emergency medical services staff have been trained to provide palliative care when dispatched to a house with someone who is registered as palliative. This program started in September 2021.

## Referrals

Referrals come to the Home and Community Care Team (who work with Elders still living in the community in their own homes) once these patients are found to be palliative. At this point, a discussion is held on whether the patient gets referred to the palliative care coordinator or if they get moved to the Palliative Care Outreach Team. The Palliative Care Outreach Team works in collaboration with Six Nations case managers and the Home and Community Care Support Services care coordinator. Patients can also self-refer for palliative care. Other internal programs, such as the Family Health Team, also refer. Referrals also come from outside of the community in the event individuals want to come home to die.

There are two categories for what constitutes palliative in terms of receiving services: one is

that “you would not be surprised if someone died in the next year,” and the other is if the person is actively dying. Six Nations will see anyone in the wider definition. However, the Palliative Care Outreach Team works with those only who are actively dying.

## Population served

The focus is on palliative populations on Six Nations. There is no focus on people who are homeless specifically. The community as a whole is vulnerable, as they are not getting specialized care to support being more comfortable at end of life. Some people also come home after living away, as they would like to die at home.

There is no particular age range; there are some pediatric cases, but the majority are older. Many community members come to palliative care very late in their progression of their disease.

## Funding

The Six Nations palliative work is funded by a mix of federal and provincial funding.



# Outcomes and Impacts

## Ongoing data collection

Fulsome data are not being collected given resource challenges. There is a plan to have a clinical lead in place to conduct quality improvement.

A caregiver survey has been developed, which is a series of 11 questions, including ones that ask whether pain symptoms were eased, spiritual care was offered, the team asked about cultural preferences, meetings were held to discuss the loved one’s care, and the coordination of care and overall end-of-life care were provided.

Data on the number of visits and clients per month are collected. Data from a 2016 article (Fruch et al) show that the number of referrals increased 170 percent between 2012 and 2014 (from 30 to 81). In 2013–2015, there were 55 deaths at home, 22 in hospital and six in hospice. Data from fiscal year 2022–2023 show 2,301 total visits (not including emails and telephone calls), 1,247 total individuals served and 187 new referrals. In one of the interviews, it was noted that the 3PC (Paramedics Providing Palliative Care) program has helped to minimize hospital visits.

## Collaboration

### Partnerships

Partnerships include Indigenous Services Canada and the Ontario Ministry of Health and Long-Term Care for potential funding for the building and the Ontario Ministry of Health and Long-Term Care Health to secure funding for the operation of the hospice.

Partners in service delivery include the Ontario Government (Home and Community Care Support Services as discussed above) and the internal portfolio under the Portfolio Lead at Six Nations (which includes paramedics, long-term care, home and community care, the Family Health Team and another medical clinic).

The team also works with the Regional Palliative Care Network, which has subcommittees including a data committee to understand trends regionally.

Internal partnerships at Six Nations are also critical. This includes paramedic services, home and community care, long-term care, the Family Health Team and the child and youth team. The child and youth team has added new positions recently and collaborations have been strengthened with this group. A new dementia team has been added and the plan is to build that partnership so that palliative care can be provided early to someone living with dementia.

There is also a position of Care for the Caregiver, who supports caregivers (whether the caregiver is caring for someone who is palliative or supporting someone with an illness). This position accepts referrals, supporting the caregiver and family, and helps to identify compassion burnout and refer to supports (e.g. grief supports, self-care resources). This position is akin to a caregiver navigator. This position is not with the palliative team but complements the palliative team.

## Partnerships with community

To develop the hospice, the community was involved to ask what they wanted the physical environment to feel like. There have been recent activities including a day where community members could drop in to see the conceptual design for the hospice and lunch was provided. Focus groups were also held in the past with Lakehead University on the palliative program, with communities being a part of the research.



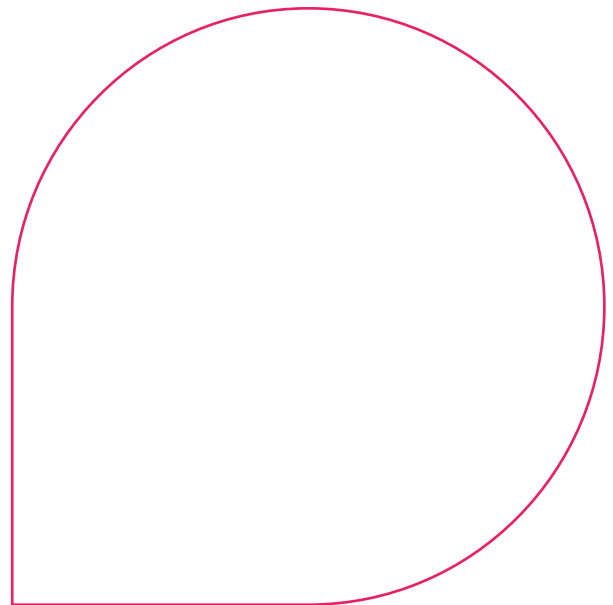
# Lessons Learned

## Enablers

- **Community engagement:** Community engagement is key in working with First Nations and this has been a large part of the work, including in the development of the hospice for the community. There have been effective opportunities to ensure people are engaged.
- **Engagement with partners:** There has been great engagement with the Ontario Ministry of Health and Long-Term Care to try to work well together.
- **Communication:** Open, concise and ongoing communication between all people working with a client is needed, given that multiple people can be working with a client. Weekly rounds are conducted, including with community paramedics, since they support palliative patients in the community. A palliative leadership committee has also just been restarted and consists of internal and external pain and symptom consultants and people providing palliative care or palliative resources.

## Challenges

- **Lack of integration between services:** One main challenge is to sort out which services sit with the team, which are outside of the community and how to ensure these services are seamlessly integrated. Organizations are currently very siloed in their work (internally and externally), and the system is complex, which can be a challenge to providing complementary care across services. There are examples where simple things like staffing a nurse practitioner (based on an opportunity that arose) at Six Nations was not possible as this role is already in the Ontario health system and there was confusion and questions raised over roles. This is a systems issue between the Ontario government and Six Nations.
- **Housing crisis:** There is a major housing crisis in communities, with lack of water and electricity, bed bugs and other issues. Home care is provided in homes with no running water or electricity and in places with issues of hoarding or drug use. It is not unusual to have many people in a home when providing palliative care. Safety of staff has not come up specifically as an issue in palliative care.
  - The challenge of “houselessness” (versus homelessness) is an issue in the community, as one author noted that all Indigenous people are “houseless” because of a disconnect with communities and culture. This increases vulnerability, including with receiving palliative care.
- **Racism and colonialism:** There is fear of healthcare institutions and the overall healthcare system due to racism and colonialism. This is a major reason to establish a hospice for Six Nations. Relationships need to be created, and a culturally safe space provided for community members and their families.
  - In addition, the Brantford hospice does not feel “like home” which is why Six Nations is developing their own hospice.
- **Lack of capacity to collect data:** There is limited capacity to collect data on the program. Therefore, it is difficult to plan for the future or know the major trends in the community in terms of palliative care.
- **Funding challenges:** While there was a donor to fund the building of a hospice, this donor has since backed out, and there is no funding for operations.
  - The federal government does not provide palliative care for First Nations. They fund personal support services (50 percent provincial and 50 percent federal) but no specific funding for palliative care.



This promising practice was co-produced with Six Nations. 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:

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