Project profile:
Expanding services to improve access for palliative care clients and families

A joint effort of Paramedics Association of Manitoba and Interlake-Eastern RHA with funding and support from Canadian Foundation for Healthcare Improvement and Canadian Partnership Against Cancer

*We fell through the cracks.*

**Patient advisor testimonial**
Karen Rose, retired nurse

*My husband George made a conscious decision to end his kidney dialysis and he wanted to die at home. He wanted to die at home with his cat and me by his side – probably in that order.*

The palliative care nurse that came to the house was fantastic. All the paperwork was signed. I thought the meds had been ordered... I thought everything was lined up. Here we are now, four o'clock on Friday - no meds, no doctor to sign the meds, the pharmacy won’t give us the meds. There we are with no palliative care support.

I had no support from anybody and I think the toxins were beginning to take their toll. Needless to say George was confused and agitated, and I had nothing. Nothing. I was forced to take him to the ER. He stayed there for two nights before he died.

*I don’t think he knew he was in the hospital at that point – but, I knew he was there.*

The bottom line is that the system failed. We dropped through the cracks; but at the same time, each of the disciplines I was happy with – the palliative care nurse, the EMS, the ER - always good. So I have that as somewhat of a consolation. But, ultimately the system failed.
Purpose

Improving care options for people wanting to die at home

Clients in Interlake-Eastern RHA's palliative care program are not experiencing the program integration required to provide the care and support they need to fulfill their expressed wishes to die at home.

This project will establish new systems and connections among care providers. When clients or their families call 911 for after-hours care, care providers will be aware of people's wishes to die at home and the care they provide will be with that objective in mind.

Building upon the success of similar projects in Nova Scotia, Prince Edward Island and Alberta, the project in Interlake-Eastern RHA is part of national efforts to improve health system responsiveness to patient and family needs and improve access to home and community care, including palliative care. The Canadian Foundation for Health Care Improvement and the Canadian Partnership Against Cancer are contributing over $700,000 to this project and providing additional supports through their Paramedics and Palliative Care: Bringing Vital Services to Canadians program.

Regional statistics

- Primary care providers register approximately 20 new clients with the regional palliative care program every month.
- At any given time, the palliative care program is supporting 100-110 clients and their family members. The vast majority of clients (75 to 85 per cent) have identified a desire to die at home.
- The palliative care program supports 200-250 clients annually. Approximately 80 per cent of clients are living with cancer diagnoses.

Project Benefits

Clients and Families

- Expanding care options to improve palliative and end of life care for clients who wish to die at home
- Medical and emotional support available when needed

Care Providers – General

- Increased ability to support client’s desired care
- Increased collaboration among care providers and improved pathways to support integration of care and access to patient information

Care Providers – Paramedics

- Increased knowledge, comfort and confidence in providing palliative care in clients' homes within current scope of practice
- Increased access to necessary supports for delivery of care
- Increased job satisfaction

Health Care System

- Reduced palliative care client visits to emergency departments for clients who prefer to remain at home
- Ongoing improved delivery of palliative care services to meet growing demand
Current State

Gaps exist in the care continuum to support clients’ wishes to die at home

Medical care is not accessible at all times
Primary care providers (physicians, nurse practitioners) register clients with the palliative care program. Primary health care is not available 24-7 but this model of care does apply to emergency medical services (EMS). As a result, palliative care clients who need medical attention after hours often require transport to an emergency room for care even though they’d prefer to remain at home. In Interlake-Eastern RHA, there may be times when a physician may not be available in the closest emergency department. Long transports may be required to reach medical care.

Home care is not equally accessible
Home care services are structured to align with palliative clients’ needs. Visit frequency increases as a client’s health deteriorates. While this care is valuable to clients and their families, home care services are limited or not available in parts of the region due to the region’s geographic expanse and lack of access to home care resources even though recruitment is ongoing.

The process to share and maintain client records is fractured.
- The palliative care team maintains a registry of clients who want to receive palliative care at home. This information is not readily accessible to other care providers who are unable to deliver care in the context of clients’ expressed wishes. This puts clients or their family members in the position of conveying this important information to care providers at what is already a stressful time.
- Primary care providers develop care plans for palliative care clients that include prescribed medication. Inability to access primary care providers after hours means clients are seeking care from other care providers, typically emergency department physicians, who may modify medications based on the clients’ evolving care needs. The care plan documentation process is not robust enough to capture, update and reflect these changes in care so that all care providers are working from current information.

Current EMS models are designed based on transport to care
While the 911 EMS model of care is responsive to calls for help from palliative clients and families, paramedics don’t have the supports they need to deliver care in clients’ homes. The current model of EMS care focuses on stabilizing patients and transporting them to a hospital. As a result, palliative clients are regularly transported away from their homes for care where they may spend their final days which may not align with their preferred choice.

“This story needs to be rewritten . . . instead of the responding paramedics saving a life, during this call, they save this moment. They have restored dignity to the patient and a sense of control to the family. The patient can stay and home and the family can rest in the fact that they have respected their loved ones’ wishes.”

-Wayne Bustard, Intermediate Care Paramedic, EMS Education Officer, IERHA
Current State

Information sharing and integration of services are limited among care providers. Client and family interactions with care providers are unique and not part of an overarching, all-encompassing patient-centric plan.

*Of Canadians who have a preference, 75 per cent would prefer to die in their home.*

*Only 15 per cent have early access to palliative home care.*

Future State

**After-hours palliative care in the home**

Clients and family members will be able to access after-hours palliative care from paramedics in alignment with their desire to receive palliative and end of life care at home.

**Primary care as the foundation of care**

Building upon the solid understanding that primary care providers have of their patients’ care needs; palliative care, home care and paramedic service delivery will be better integrated to ensure a consistent and collaborative approach to client care in support of clients’ wishes.

**Current client information accessible to care providers when and where it’s needed**

Clients and their families will be relieved from the responsibility of advising their care providers of the care plan in place and noting any required changes.

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2. Access to Palliative Care in Canada. Canadian Institute for Health Information. 2018. Available at: https://is.gd/AccessToPalliativeCare
Indigenous Partnerships

Palliative care service delivery in Indigenous communities reflects different models with varying jurisdictional responsibilities for care. The perspectives of Indigenous palliative care clients, their families and health care providers will be incorporated via a project advisory committee that will determine how Indigenous communities can benefit from the project’s objectives. In conjunction with Indigenous partners, communities will be selected to pilot improved access to palliative care services after hours, with the intent that service delivery be scaled up and extended to other Indigenous communities.

Interlake-Eastern RHA service profiles (Numbers provided will fluctuate)

Palliative Care: Provides comfort and quality of life for clients and families facing a life-limiting non-curative illness.
- 1 regional palliative program manager
- 3 palliative care nurse specialists
- 2 psychosocial specialists
- 2 palliative care physicians
- 70 volunteers
- 1 volunteer coordinator & community liaison worker

EMS: Direct operation of EMS in Interlake-Eastern RHA currently lies with the RHA. In April 2019, EMS staff transition to become employees of Shared Health, a provincial government organization.
- 1 regional EMS program director
- 5 EMS operations supervisors
- 1 regional educator
- 280 paramedics (full- and part-time and casual)
- 19 EMS stations
- 35 ambulances

Cancer Services: Interlake-Eastern residents have access to a number of cancer support services within the region.
- 3 community cancer program sites (Gimli, Pinawa, Selkirk) delivering chemotherapy
- Approximately 400 people annually are supported by cancer navigation services composed of:
  - 2 nurse navigators
  - 1 oncology social worker
  - 1 community liaison

Home Care: In-home support to individuals, regardless of age, who require health services or assistance with activities of daily living. At any given time, approximately 3,000 clients are receiving home care services in the region.
- 6 management team members
- 30 case coordinators
- 19 resource coordinators
- 14 scheduling clerks
- 434 home care attendants
- 70 nurses

Primary Health Care: Cradle to grave, holistic, prevention focused care that ensures quick access to an appropriate care provider for everyday health care needs.
- 80 primary care physicians
- 16 nurse practitioners
- 1 physician assistant
- additional staff in 40 home clinics
Project Status

The project is in the initiation phase. The project brief and project manager are in place. Work is underway to develop the project initiation document, complete current and future state analysis, gather detailed business requirements, complete the stakeholder analysis, and develop the benefits evaluation plan. Key stakeholder engagement and communication is initiating.

Next Steps
- Establishment of Steering Committee
- Key stakeholder engagement
- Development of next stage plan (Design/Build stage)

Project Background

The Canadian Foundation for Health Care Improvement (CFHI) and the Canadian Partnership Against Cancer (CPAC) are jointly providing up to $5.5 million over the next four years to improve patient care by expanding access to palliative and end-of-life care through projects in six provinces.

In February 2017, CPAC and CFHI issued a call for expressions of interest. The Paramedic Association of Manitoba (PAM), working with Interlake-Eastern RHA and the EMS branch of Manitoba Health Seniors and Active Living, successfully obtained approval to submit a detailed project proposal. PAM asked Interlake-Eastern RHA to assume the role of lead partner. In fall 2018, the project was approved and a tripartite agreement was established among IERHA, CPAC and CFHI to design, develop and implement a sustainable regional palliative care service to support the provision of palliative and end-of-life care at home incorporating established provincial and regional protocols and client specific care plans within 3.5 years and within the approved budget of $718,192.

Project Timeline

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“This innovative, new practice is a great example of the kind of work being done across the country to develop health-care delivery models that bring care closer to home for many patients.”

– Cameron Friesen, Minister of Health, Seniors and Active Living