



Rural Palliative Care In-Home Funding Program–Calgary Zone

A flexible approach to enhancing care for rural patients nearing end of life

While rural Canada makes up 95% of the country's landmass, it accounts for less than 20% of the population. Home care programs across the country are challenged with providing responsive, high-quality services to individuals residing in rural communities. **This High Impact Practice showcases an augmented service model in rural Alberta that is supporting clients nearing end of life to stay at home when desired, while ensuring they receive the required additional care.**

BACKGROUND

As the population ages and Canadians become increasingly aware that death can be better managed, the need for palliative care is expected to rise. Surveys of Canadians show that most would prefer to die at home if they can get the support they need.¹

The rural population is aging and the need for health care in these communities will remain high, particularly for home care and palliative care. Jurisdictions will need to develop alternative models for effectively delivering an appropriate mix and level of palliative and other health services to rural communities, which differ in size and type. According to a recent study by CIHI,¹ a higher proportion of residents from rural or remote areas were admitted to hospital primarily for palliative care in their last year of life (30%) compared with those who lived in an urban area (24%). This finding may be due to fewer care locations available outside of hospitals, such as hospices, and fewer home care services available for palliative care in rural and remote areas.

While it is generally accepted that access to palliative care in the home is more challenging for rural clients, research shows many positive factors are also associated with access to and delivery of palliative care in rural areas.²

Challenges:

- Distance and weather conditions impede travel for both clients and health care providers.
- Human resources shortages (both paid and volunteer are common), especially after hours.

- Health care providers often lack palliative care education and competency, especially around pain and symptom management.
- Dual relationships among rural health care providers, clients and families create unique ethical and emotional challenges (e.g., privacy of client information and blurring of personal and professional boundaries).
- Lack of residential care beds leads to increased family caregiver burden.
- Timely access to medications in the home is often lacking.
- Clients and health care providers experience procedural barriers to getting equipment for the home.
- Health care providers are often not aware of local resources such as volunteer networks.

Strengths:

- Informal networks provide for better care coordination.
- Good teamwork makes up for resource challenges.
- Relationships between health care providers and clients can result in providers going the extra mile.
- Volunteer networks and community support in rural areas are strong.
- Rural values of self-reliance and independence support client and health care provider resilience.
- Clients and families are comfortable using the telephone for communication and support.
- New programs are available for virtual consults with palliative specialists.³
- Rural hospitals can provide a more intimate and familiar space for end-of-life care.
- Health care providers are familiar with local culture and language.

HIGH IMPACT PRACTICES

Evidence-informed practices in home and community care that result in better care, better outcomes and better value.

Program Development

The working group developed the following tools to facilitate program implementation and evaluation.



Commencing in 2006, three Rural Primary Care Networks (PCNs) within Alberta Health Services (AHS) Calgary Zone provided funding to augment rural home care services and resources for palliative clients, with the aim to reduce rural-urban inequities. Each of the PCNs implemented the funding in varying ways.

This funding was discontinued in 2017, with a vision of shifting responsibility for resource augmentation to AHS. The Calgary Zone Palliative and End of Life Care program (PEOLC), in collaboration with AHS Rural Health services, assumed responsibility for evolving the rural in-home funding model. One significant improvement over the previous PCN program was the ability to ensure that in-home funding was equitable, accessible, and consistent across all rural Calgary Zone communities.

DEVELOPMENT

From the outset, it was recognized that the program needed to be tailored to meet the specific needs of rural palliative care clients in the context of rural communities. While other models of augmented care exist, these models were not appropriate for rural palliative care clients for the following reasons:

- Self-managed care programs are designed for stable clients with long-term prognoses and require families to have extensive training and financial responsibility for managing the care.
- Contracts with vendor agencies are not feasible in rural areas as few home care agencies serve palliative care clients outside of urban centres.
- Hiring and scheduling of additional rural home care staff are difficult to optimize due to fluctuating caseloads of palliative care clients.

A working group was established that included a broad representation from organizational and rural community-based health services, involving individuals from both front line and leadership roles. The development team met regularly and frequently. Fundamental to the success of the project was effective communication with AHS leadership to ensure support and endorsement. Rather than starting with a blank page, the team drew upon infrastructure and documentation from the previous Rural PCN Palliative Care

Program. With input from legal, financial and analytical subject matter experts, they developed operational processes and tools, roles and responsibilities of key stakeholders, and measurable indicators. Adaptation and development of the program based on the prior PCN program took 5 months.

Evidence-Informed Model

In developing the new program, the team examined research and evidence on issues in rural palliative care, including social values and ethical considerations, to ensure the program was tailored to best meet rural needs and honour rural culture. Current research shows that in order to support ethical rural health and palliative care, it is critical to consider the lived experiences of individuals and the values and strengths of rural communities, such as social solidarity, close-knit relationships and commitment to community.^{4,5}

Key Principles

To support an “outside-the-box” innovative approach, the working group established the following key principles that the new program had to meet:

- client- and family-centred
- community-centric
- rural-centric
- focused on palliative care

Innovations

The team was able to incorporate a number of innovations that honoured the program’s key principles, including:

- a simplified contractual relationship between the care provider and client/family, rather than the more complicated employer/employee relationship required in a self-managed care program.
- an expedited, streamlined invoice and payment process through AHS with an average turnaround payment time, to the family, of five days. This ensures the ability for families to not have to pay the care provider out of pocket in advance.
- a list of care providers for each rural area, along with a rate brochure, to help clients select and recruit care providers (developed with legal support).
- flexible eligibility criteria for care providers, meaning clients can contract with any individual, including relatives and those without a formal health care provider designation.

Rural Palliative Care In-Home Funding Program

To be inclusive, and ensure that Indigenous clients living on First Nation communities have access to this program, the working group is engaging with the First Nation communities to identify, and implement, a culturally tailored approach.

IMPLEMENTATION

The new funding model was introduced in October 2017 and included a suite of tools to facilitate implementation and evaluation, such as process maps, guidelines, agreements, checklists, brochures, invoice templates, surveys and databases.

Target Population

The program is open to any client with a progressive, life-limiting illness living at home in the rural Calgary Zone. It provides additional funding when the home care service package and other funding sources are not sufficient to support palliative care clients who wish to remain at home longer and need extra care to do so.

Basket of Services

There is a cap of \$10,000 for the duration of the illness, with an emphasis on the end-of-life phase. The augmented funding covers personal care assistance, respite for caregivers and nursing care. Families are responsible for recruiting, contracting, directing, monitoring and paying care providers. AHS is unable to directly reimburse care providers as they are not in a position to verify their competency.

Staff Training and Education

To roll out the program, the team held orientation sessions with home care staff and palliative consultants that included practical training on how to complete documentation and where to find resources for clients and families.

A key learning from this innovative program was that even if clients and families did not take advantage of the extra funding and care, just knowing that it existed provided them with peace of mind and confidence to manage at home.

Communications and Engagement

The team implemented a multi-pronged strategy to encourage two-way communication and to provide user-friendly information for program users that included:

- information packages for clients, care providers and AHS clinicians;
- a dedicated email address to consolidate all communications and inquiries;
- targeted outreach to stakeholders to notify them of the program launch and facilitate the registration of potential care providers;
- simple online surveys for clients and families and AHS clinicians to measure satisfaction.

Process and Accountability

Program stakeholders follow clearly outlined processes, AHS staff have online access to a shared file system, while the PEOLC director's office manages program administration. Key program indicators are recorded in a database and shared through a detailed online dashboard. Clients, families, and home care teams are notified when clients have reached milestones in funding use (at \$5,000 and \$8,000). The development team continues to meet to address implementation issues.

Sample Dashboard of Program Indicators (used for monthly reporting)

Financials

- Total spend
- Med. \$ /client
- Med. \$ /day
- Avg. payee set-up time
- Avg. invoice turnaround time



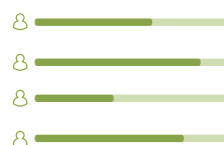
Clients

- # clients authorized and accessed
- # clients by rural area
- # cancer diagnosis
- # non-cancer diagnosis
- # deaths
- place of death
- # days of support
- # days survival from date of access and authorization



Care Providers

- Total hours of care
- Avg. hourly rate
- Invoice range



General Program Data

- Care provider hours by area
- Care provider hours by type
- Place of death
- Count by area
- Diagnosis breakdown
- Total days supported

OUTCOMES

From its launch in October 2017 until March 31, 2019, the program served a total of 104 clients and families. Of these, 82% had a diagnosis of cancer. Clients received extra care for an average of 4 days and survived a median of 21 days from the time the funding was first accessed. Out of a total of 94 deaths, 52% took place at home and 40% in a hospice. Only 7 clients died in acute care.

A total of 450 days of support and over 9,000 hours of care have been provided by the program. Health care aides have provided 72% of this care, while RN hours accounted for 2% and LPN hours for 11% of the total. With the flexibility in provider criteria, 15% of the care hours were delivered by providers with no formal health care designation.

The program's financials show that the median cost per client was \$2,727, with a median cost per day of \$90.88. The average time to set up a payee account was three days and the average invoice turnaround time was only five days.

Survey results show that clients and AHS clinicians are highly satisfied with the information materials and that the ability to hire 24-hour care is an important feature for many clients and families. Suggestions for improvement include simplifying the paperwork, adding a patient navigator, and including equipment as part of eligible expenses.

ENABLERS FOR SUCCESS

- **permanent funding** – to ensure sustainability.
- **dedicated, responsive administration office** – to coordinate communications, operations and data management and to support program users.
- **committed leadership role** – for stakeholder engagement, oversight, troubleshooting, promotion and reporting of outcomes.

- **engaged rural palliative consultants and home care clinicians** – to assess eligibility, identify care needs, walk clients through the process and provide support for ongoing needs and issues.
- **dedicated business intelligence team** – to develop and maintain an indicator dashboard and inform program evaluation.
- **involvement of accounts payable department** – to develop and maintain efficient payment processes.
- **legal advice** – to help develop sound procedures and agreements.
- **flexible approach** – to enable openness to unique circumstances.
- **inclusive, collaborative development process** – to ensure multiple perspectives are considered and rural values and culture are honoured.

NEXT STEPS

The team will conduct further evaluation to identify any possible ongoing gaps and/or barriers. Additionally, they will gather specific data to examine the use of acute care by clients who accessed the funding program.

As a result of the program's success, it will be implemented in all rural communities and zones in Alberta. This expansion is currently underway. Provincial standards will be established with enough flexibility to enable the zones to customize the program to meet their unique community needs.

While each jurisdiction will have its own operational requirements and constraints for providing home-based palliative care, this innovative program provides a model that can be tailored to provide effective and responsive palliative care to rural communities. It recognizes the practical challenges of rural health care and builds on the strength and values of our rural communities.

REFERENCES

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The CHCA Would like to extend a special thank you to the Alberta Health Services contributors:

Bev Berg, Director, Palliative and End of Life Care, Seniors, Palliative & Continuing Care, Calgary Zone

Linda Read Paul, Clinical Nurse Specialist, Palliative Care Consult Service – Rural, Calgary Zone

Alberta Health Services is the provincial health authority responsible for planning and delivering health supports and services for more than four million adults and children living in Alberta. Its mission is to provide a patient-focused, quality health system that is accessible and sustainable for all Albertans.