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Executive Summary

RMA members voted in support of <u>Resolution 17-23F</u>: Sustainable Community Hospice Funding Model, which calls for the following:

THEREFORE, BE IT RESOLVED that the Rural Municipalities of Alberta advocate for the Government of Alberta to implement a sustainable operational funding model for the provision of hospice services by community hospice societies across the province.

In this report, RMA provides background information on how end-of-life and hospice care is organized and funded in Alberta, including the facilities where this care is available, before turning to a discussion on end-of-life care in rural Alberta. The report is oriented towards the creation of a sustainable community hospice funding model and concludes with recommendations on how to improve hospice in the province, and principles and recommendations for the creation and implementation of this funding model.

Hospice and palliative care are available in homes, hospitals, freestanding hospices, and in the community through community hospice societies. Care in homes and hospitals is funded through Alberta Health Services (AHS) agreements. Freestanding hospices and community hospice societies with agreements to provide clinical end-of-life care may have agreements with AHS or be funded by donations and fundraising, as is the case for many societies. Community hospice societies have historically had little if any access to grants or monies that fund their operating expenses.

Rural Alberta is ageing more quickly than the rest of the province and has higher mortality rates. Rural Canadians are more likely to be hospitalized at the end of their life and are more likely to die in hospital than urban residents. When it comes to end-of-life care, rural Alberta has a lower density of services, fewer allied and supportive care providers, fewer end-of-life services, and lower hospice and palliative care bed rates per 100,000 Albertan's. At the end of their life, rural Albertan's are faced with a choice Albertans in or near Calgary and Edmonton do not have to make; die in their community without the necessary supports for best practice end-of-life care or leave home to access that care. RMA supports no compromise and believes improved rural hospice care is attainable through the creation of a sustainable community hospice funding model.

This report provides three sets of recommendations.

- 1. Recommendations to improve hospice care in rural Alberta
- 2. Principles for the development of a sustainable community hospice society funding model
- 3. Recommendations for building a sustainable hospice society funding model



Recommendations for building a sustainable community hospice funding model include:

Recommendation 1: Government of Alberta funded

The sustainable community hospice society funding model should be paid for by the Government of Alberta, not rural municipalities.

Recommendation 2: Fund clinical care and grief and bereavement programs

Both clinical and grief and bereavement programs should be funded.

Recommendation 3: Options for the conceptual approach to funding model design

Funding should cover community hospice societies operational and capital costs.

Recommendation 4: Options for funding distribution design

RMA recommends funds be distributed through a combination of base funding and per diems.

Recommendation 5: Financial Transparency and Accountability

Ensure any sustainable community hospice society funds are fully transparent, reasonable, and accountable to the Government of Alberta, local governments, and members of the public.

Introduction

Access to palliative and end-of-life care services is an important issue for rural Albertans and rural municipalities. In Alberta, hospice care is delivered through a variety of streams and facility types.

These include freestanding hospices, within hospitals, long-term care centers, at home, and through community hospice societies, each of which has a distinct funding structure. Palliative and hospice services are predominantly located in Calgary and Edmonton, leaving much of the province with limited or no access to local palliative or hospice services. The lack of these services leads many rural

Albertans to have to make an unfathomable choice: die in their community without the necessary supports for best practice end-of-life care or leave home to access that care. RMA's position is that there should be no compromise. RMA believes that well-supported local end-of-life care is within reach through enhanced funding and capacity-support for a hospice delivery model that is better suited to rural communities. This type of approach would help ensure people facing end-of-life receive the care, comfort, and dignity they deserve in their own communities.



This report aligns with RMA member direction as reflected in <u>Resolution 17-23F</u>: Sustainable Community Hospice Funding Model, which calls for the following:

THEREFORE, BE IT RESOLVED that the Rural Municipalities of Alberta advocate for the Government of Alberta to implement a sustainable operational funding model for the provision of hospice services by community hospice societies across the province.

This resolution highlighted the benefits of palliative and hospice end-of-life care and its increasing importance given rural Alberta's demographic

change and the value community hospice societies contribute to their community and the delivery of end-of-life care in Alberta more broadly. To improve the present system and prepare for the future, rural municipalities know that a sustainable community hospice funding model is needed as an essential stepping stone towards enhancing rural end-of-life care.

Prior to Resolution 17-23F, RMA members voted in support of Resolution 20-19F: Policies for Supporting Community Hospice Associations. This resolution called for the Government of Alberta to develop standardized procedures and policies to interface community hospice societies with AHS to

better support these societies, and to recognize their important role in the healthcare system. Although the government did increase funding for end-of-life community care at the time of this resolution, the intent was not met as demonstrated by the very similar request in Resolution 17-23F.

This report provides recommendations on how to develop a sustainable community hospice funding model and provides context on the present state of hospice services in the province through a rural lens.

RMA and Community Hospice Society Advocacy

In 2023, the <u>Rural Municipalities of Alberta</u> and <u>Alberta Municipalities</u> members passed resolutions calling for the Government of Alberta to provide a sustainable operating funding model for community hospice providers. A sustainable hospice funding model would support rural Albertans' choice for end-of-life care, enhance the availability of hospice services, and alleviate healthcare costs and pressures from death and dying. The RMA sent Resolution 17-23F to Alberta Health, the Ministry of Seniors, Community, and Social Services, and AHS. Their responses indicated that they are taking action to improve access to palliative and end-of-life care in Alberta. For instance, the Government of Alberta (2024) provided funding in budgets 2023-27 for additional in-home end-of-life/hospice supports, the addition of 25 new community hospice beds across the province over three years, and funds that increase the number of funded care hours. Despite these investments, the actions taken by the Government of Alberta to this point do not fulfill the resolution request for a sustainable operational funding model for the provision of hospice services by community hospice societies across the province.

This report is one component of RMA's hospice advocacy. Along with increasing RMA's internal knowledge of Alberta's hospice operational and policy approaches, it provides members with an overview of hospice care services in Alberta, the work of community hospice societies in the province, offers background into how municipalities and hospice societies work together, and principles that should guide the Government of Alberta's (GOA's) creation of a sustainable community hospice funding model.

In addition to this report, RMA is collaborating with ABmunis to explore joint advocacy opportunities after identifying neighboring rural and urban municipalities sponsored identical resolutions. RMA and ABmunis have also engaged with the Alberta Hospice Palliative Care Association (AHPCA), an organization that represents community hospice societies across the province. RMA and ABmunis prepared a joint letter to the Health Minister with key messages on the role and potential of community hospice societies in the new healthcare model and a statement of principles for the creation of a sustainable community hospice societies funding model. To date, AHPCA has offered information on their work and community hospice societies across the province, which has been valuable to helping RMA better understand Alberta's hospice system.

Overview of Hospice in Alberta

Introduction

There are a few different ways to approach end-of life-care in Alberta. To understand different health system options, it is useful to differentiate between palliative care and hospice care. Each of these care models has a different outlook on death and dying and the clinical and social interventions that accompany it. AHS uses the following definitions:

"Palliative care - aims to improve the quality of life for patients and families facing the problems associated with a life-limiting illness through the prevention and relief of suffering by means of early identification, comprehensive interdisciplinary assessments and appropriate interventions." (Simon et al., 2024)

"Hospice care - is a specialized service that provides 24/7 facility-based care to those who are approaching end-of-life and whose needs can best be met in this location (based on assessed needs, patient preferences, and available bed capacity). It is provided in designated/supported community spaces, which may include a) standalone community hospice beds or b) designated/supported end-of-life care beds in long term care, designated supportive living, or other healthcare facilities located in the community. Hospice care is provided to both the adult and pediatric populations and may include respite. There are specific criteria for referral to hospice and access is determined by specialized palliative care clinicians (7)." (Simon et al., 2024)



RMA would add that hospice care is not only clinical care that people receive in an institutional facility, but an orientation to care they receive at home or through the community-based programs community hospice societies provide.

While palliative and hospice care are arguably more alike than unlike, the degree of accepted medical intervention differs. In the case of palliative care, people with a life-limiting illness may choose life extending interventions or care options, like a feeding tube or radiation therapy. Alternatively, hospice care does not hasten or postpone death; rather it allows a death with limited intervention to occur at its own time. The primary goal of hospice care is to manage symptoms, provide pain management, emotional support, and help meet other "complex"

needs of terminally ill patients." To accomplish this, the intent of hospice care is to tailor end-of-life care to individual preferences and help people live life fully until life's end. End-of-life care is more generally used to describe care required by "...patients and their families when they are approaching a period of time closer to death" (Simon et al., 2024).

Health services across Alberta are organized into five administrative "zones." These zones, shown in Figure 1, are the North Zone (green), Edmonton Zone (red), Central Zone (pink), Calgary Zone (yellow), and South Zone (burgundy). Each zone is responsible for local decisions and program management. Zones are divided into health advisory councils that allow for local feedback. The role and continuation of these zones in the transition to the four-pillar healthcare model is unclear. However, they provide part of the foundation for how end-of-life care is currently delivered in Alberta.



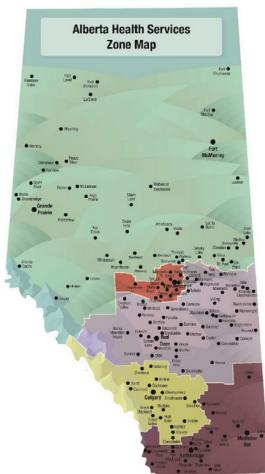


Figure 1 Alberta Health Services Administrative Zones

Image from albertahealthservices.ca/assets/about/publications/ahs-ar-2018/zones.html

In Alberta, patients may or may not receive palliative and hospice care in the same setting. A number of different palliative care services are offered in different care settings.

At home

- □ **Home care.** Specialized palliative home care teams provide palliative care in Calgary, Edmonton, Airdrie, Red Deer, and Camrose. General home care teams provide palliative care elsewhere in the province.
- Palliative End of Life Care (PEOLC) Assess Treat and Refer Program. This program uses Advanced Care and Community Paramedics to support end-of-life patients' ability to remain at home. In collaboration with home care nurses and a consultant physician, paramedics add skills, services, and capacity to the care otherwise available at home.
- Outpatient care clinics. "Alberta's two tertiary cancer centres and most of the four regional centres operate clinics or have consult services staffed by SPC [specialist palliative care teams]." These teams exist to provide additional support to the patient's primary care physician and/or oncology team. Some of the specialists have additional training in PEOLC, while others have experience and/or a special interest in the area, referred to here as 'champions' of palliative care in their specialty. As indicated in Table 1, there are notably fewer specialist palliative care teams and champions in Zones outside of Edmonton and Calgary (Simon et al., 2024).

Table 1. Alberta Outpatient Clinics with Palliative Specialist Support					
Zone	North	Edmonton	Central	Calgary	South
Cancer	SPC	SPC	SPC	SPC	SPC
Cardiology		Champion	Champion		
Respirology		Champion	Champion	Champion	
Nephrology		Champion		Champion	
Neurology		Champion		Champion	
Hepatology		Champion	Champion	Champion	Champion
ALC Clinic		Champion		SPC	
Geriatric Clinic				Champion	
Gastroenterology					Champion
Complex Chronic				SPC	
Disease Management					
Clinic					

In hospital

Palliative care units. There are five palliative care units with capacity for 87 patients in Alberta (Table 2). Palliative care units may be used temporarily to help manage a patient's symptoms and put supports in place for someone to return home, or on a longer-term basis until a patient dies. These units offer specialized palliative care physicians and a "comprehensive interprofessional team" that includes "...spiritual care providers, recreational/ music therapists, specialized pharmacists, occupational therapists, physiotherapists, social workers, nurses, and physicians." These units vary from primary care to tertiary or intensive care units for the patients in need of most support.

Table 2. Palliative Care Units in Alberta, 2023					
Facility	Level of Care	Location	Bed Count		
Grey Nuns Community Hospital	Tertiary Palliative Care Unit	Edmonton	20		
Foothills Medical Center	Intensive Palliative Care Unit	Calgary	29		
Red Deer Regional Hospital	Unspecified	Red Deer	18		
Center					
St. Michael's*	Unspecified	Lethbridge	10		
St. Joseph's*	Unspecified	Medicine Hat	10		

*These South Zone units function as both hospices and Palliative Care Units (PCU).

Data taken from Canadian Palliative Care Atlas Alberta Edition 2023.

Other

Specialist Palliative Care Teams. These teams are available to palliative Albertans and their physicians across the province in-person, over the phone, or through a virtual consultation 24/7. Depending on the Zone, teams "...may include physicians, nurse practitioners, nurses, spiritual care and allied health providers" (Simon et al., 2024). These teams are available to patients regardless of whether they are at home, in hospital, or in a community care setting such as long-term care.

Although Albertans of all ages, life stages, and places may benefit from palliative or hospice care, the majority of those who use these services are seniors with cancer or chronic illnesses. In Canada, 90% of "... deaths are caused by a chronic condition such as cancer, heart disease, organ failure, dementia or frailty"



(Government of Alberta (a), 2021). An Alberta report noted that while cancer is a leading disease where people choose palliative care at the end of their life, the end-of-life care model must also be prepared to manage a growing number of other chronic diseases. "A growing and ageing population will inevitably increase the number..." of people with a life limiting illness. Red Deer Hospice Society (n.d.) noted that 73% of residents in their 16-bed facility had a cancer diagnosis. Their average resident age was 75.4 years, but resident ages ranged from 36 to 99 in 2022-2023.

The information above suggests that palliative services are highly concentrated in the Calgary and Edmonton regions. We do not have information on population and/or demographic differences in end-of-life care users in rural versus urban parts of the province or AHS Zones, although "seniors are the fastest growing population in rural areas" (RhPAP, n.d.). This suggests that the proportion of rural Albertans likely to need end-of-life care will increase more quickly in rural Alberta than elsewhere. Conversations with our members tell us that existing local programs and services do not presently have the capacity to meet a large increase

in demand. Community hospice societies are one realistic means through which to increase provincial hospice capacity.

In recent years, the GOA has produced several publicly available reports on palliative and end-of-life care, listed here:

- Government of Alberta Advancing palliative and end-of-life care in Alberta Palliative and End-of-Life
 Care Engagement Final Report November 2021
- Alberta Health Services Palliative and End of Life Care Alberta Provincial Framework Addendum
 2021
- Alberta Health Services Palliative and End of Life Care Alberta Provincial Framework 2014

The Government of Alberta's most recent recommendations related to end-of-life care focus on increased use of a palliative approach to care, standardizing end-of-life care best practices and education, growing the availability of PEOLC services via increased support for home care, "community care programs," and "facility-based continuing care, and better integration of end-of-life care into the health system."

End-of-Life Facilities

Patients can receive end-of-life care at several different locations and facilities in Alberta. The emergency room, acute care hospital units, long term care or designated living facilities, freestanding hospices, at home, or in a hospice facility operated through a partnership between a community hospice society and care facility or a contract with AHS. Each is explained below:

Emergency Room and Acute Care

Although most Canadians would prefer to die at home, it is not always reality to receive the entirety of the end-of-life care someone might need outside of a hospital (Airdrie & District Hospice Society, n.d.). While some end-of-life patients prefer to receive care in the emergency room and/or acute care, others turn to it when their symptoms and conditions cannot be reasonably managed with home and/or community resources. Despite patient preferences, "data shows that slightly more than half of Canadians die at home or in the community (54.5%) rather than in hospital" (CIHI, 2023). Alberta sits around the national average at 54% (CIHI, n.d.). The proportion of Albertan's dying in hospital is down from 85% in 2014 (AHS, 2014). While this is undoubtedly a positive step towards meeting patients end-of-life wishes, the availability of non-hospital end-of-life care availability still lags behind the proportion of people who would prefer this approach.

Hospitals will continue to play an important role in end-of-life care in some situations. Patients often access hospitals for temporary stabilization and management support intended to allow them to return home and/or to community care. Research has shown that "the top four reasons palliative care patients were admitted to hospital were shortness of breath, weakness, abdominal pain and altered level of consciousness," which are often end-of-life symptoms that may be managed at home with adequate education, preparedness, and resources (CIHI, 2023). However, just under 50% of hospitalized end-of-life patients do not return home as they die while waiting for community placement. Alternatively, "not everyone wants to die at home, as it can put considerable stress on patients and their families" (CIHI, 2023). Accordingly, "... many people who are severely ill tend to favour institutional care, such as a hospital, when they get closer to death."



Regarding the disadvantages of end-of-life hospital care, patients receive more life saving/extending interventions that "...can be painful, cause unnecessary stress for patients and their loved ones, and use scarce health care resources" and do not always receive the high standard of personalized end-of-life care that includes the enhanced attention to their physical and emotional well-being they expect (CIHI, 2023). Additionally, end-of-life care in hospital is more costly than home or community care.

Long Term Care

Long term care and designated supportive living facilities present a common institutional alternative to hospitals. For many seniors who reside in these facilities, this may be considered similar, or as comfortable as dying at home. Some facilities, such as Foyer Lacombe in St. Albert, operate a combination of long-term care beds and hospice beds. Palliative care may be considered a routine part of primary care in many facilities. Alternatively, some end-of-life patients awaiting placement in hospital may be placed in a long-term care facility.

Freestanding Hospice

Freestanding hospices are standalone residential facilities that exclusively deliver hospice services. They provide an alternative to end-of-life care in another institution or at home. Each facility has its own history, often originating from a local grassroots end-of-life movement. As will be discussed later in further detail, freestanding hospices may be funded via contracts with AHS and supplemented with community fundraising and grants, while others primarily rely on fundraising and grants. Table 3 shows the AHS Zones where freestanding hospices are located. Apart from two of the Calgary hospices, all other freestanding hospices are operated by community hospice societies.

Table 3. Freestanding Hospices by Zone				
Zone	Freestanding	Freestanding Hospices		
	Hospice Count			
North	0			
Edmonton Zone	1	Pilgrims Hospice Society		
Central Zone	1	Red Deer Hospice Society		
Calgary Zone	3	Salvation Army Agape Hospice, Rosedale Hospice, Foothills County		
		Hospice		
South Zone	0			
Total	5			

At Home

Along with patient preference, the choice to receive end-of-life care at home comes with several advantages. Palliative home care is a less costly alternative to hospital care, results in fewer intensive care admissions and emergency room visits, less diagnostic testing, and more comfort over curative interventions. As noted previously, the palliative and end-of-life care model in Alberta is set up to offer end-of-life care at home. However, while end-of-life care at home saves costs from lower rates of hospitalization, a Government of Alberta ((a),2021) report noted that costs were shifted elsewhere. More specifically, while health-care professionals play a role in home care, many of the care responsibilities and costs shift to families and caregivers. In addition to their time, families and caregivers often experience lost income and lost professional opportunities, along with the cost of the equipment and supplies their loved one requires.

Community Hospice Societies

Community hospice societies provide a diverse range of end-of-life services and support for hospice patients and their families and friends. No two hospice societies in Alberta are alike. Community hospice societies provide services ranging from home visits, grief support, education, clinical care, and more. Community hospice societies have varying organizational structures. For instance, some societies have contracts with AHS or Covenant Health to operate a freestanding hospice or community hospice bed. Other societies do not provide clinical care, but provide other services in hospitals, long term care facilities, in the community or a combination of locations. According to the Government of Alberta ((a), 2021), "many of the societies are volunteer-run and operate via donations and fundraising, which results in a strong grassroots presence."

Table 4 organizes community hospice societies by AHS Zone. Calgary is home to the most societies (12) and South Zone the fewest (1). When organized by RMA district, District 1 has the fewest (2) and District 2 has the most (10). Note that most physical hospice facilities are located in urban municipalities but serve residents of the surrounding rural areas. Other organizations, like the Alberta Hospice and Palliative Care Association supports community hospice associations across the province.

Table 4. Community Hos	pice Societies by AHS Zone
North	Edmonton
Elk Point Palliative Care Society	Pilgrims Hospice Society
Fairview and Area Palliative Care Society	Roozen Family Hospice Centre
Grande Prairie Palliative Care Society/Points West Living Hospice	Heartland Community Hospice Foundation
High Prairie & District Holistic Palliative Care Society	Foyer Lacombe – St. Albert/Sturgeon County
Manning & District Palliative Care Society	St. Albert Sturgeon Hospice Association – Sturgeon County
Peace Palliative Care Society – Peace River/Grim-	Light Up Your Life Tri-Community Palliative Hospice
shaw	Care Society
Central Peace Palliative Community – Spirit River	
Where the Rivers Meet Palliative Care Committee - Whitecourt	
Central	Calgary
Hospice Society of Camrose and District	Agape Hospice
Akasu Palliative Care Society – County of Minburn	AgeCare SkyPointe Hospice
Peace Hills Hospice Society – County of Wetaskiwin	Calgary's Allied Mobile Palliative Program (CAMPP)
Lacombe Palliative Care Society	Chinook Hospice

Table 4. Community Hospice Societies by AHS Zone					
Mountain View Hospice Society/Olds and District	Dulcina Hospice				
Hospice Society					
Ponoka/Rimbey Palliative Care Council	Hospice Calgary				
Red Deer Hospice Society	Rosedale Hospice				
Compassionate Care Hospice Society	Southwood Hospice				
Stettler Hospice Society	Palliative Care Society of the Bow Valley				
Sundre Palliative Care Association	Airdrie & District Hospice Society				
	Wheatland and Area Hospice Society				
	Foothills Country Hospice Society				
South	Other – Province Wide				
Prairie Rose Hospice Palliative Care Society -	Alberta Hospice Palliative Care Association				
Brooks					
	Canadian Hospice Palliative Care Association				

End-of-Life Care Standards

Given the variety of end-of-life care options and facilities where end-of-life care can be provided, its perhaps unsurprising that there are not more Government of Alberta standards around hospice care. While RMA is unaware of existing standards and best practices around clinical end-of-life care, conversations with the AHPCA informed RMA that there are no standards for community hospice societies, which is why existing community hospice societies provide highly variable types and levels of services and programs. More broadly, a lack of standards or the diversity within the hospice and end-of-life delivery model creates complexity around best practices. AHPCA compared Alberta's model to Ontario's model where freestanding hospices are considered the ideal end-of-life care setting. AHPCA thought this was one of Alberta's strengths, albeit a strength with limitations. For example, end-of-life clinical care should be standardized and clinical and soft skill training for healthcare professionals should be standardized. For instance, AHPCA was in the process of investing more in standardizing volunteer training programs and resources for community hospice societies to better support their members and ensure everyone had access to the same high-quality training.

Undoubtedly, flexibility and local programs can be a good thing and a sustainable hospice funding model could support this to a degree. For example, funds to develop local resources and/or adapt training to the local context could be developed. Additionally, community hospice societies could use funds to select and deliver a certain number of programs from a bank of available approved programs. Ultimately, it is RMA's understanding that many community hospice societies would like to deliver more programs and to do more than they currently do, and a steady operational funding stream and clearer standards could help make this possible.



Overview of Hospice Funding

Given the variety of hospice care and facility options available, it is likely no surprise that there are multiple funding options for these services. What is clear is that existing hospice funding has not provided adequate operational support for community hospice societies.

There are two ways through which the Government of Alberta currently funds hospice care: through annual budgets that fund AHS programs and services, and through special grant programs like the 2021 competitive grant program.



In the 2024-2027 budget, the Government of Alberta (2024) designated \$70 million in annual funding for "Home and Community Care initiatives, including activities/programs to enhance access to palliative and end of life care at home or in hospice, increased support for caregivers, and enhancements to home care infrastructure" (Government of Alberta, 2024). While this is a positive step, its benefits for end-of-life care in rural Alberta are minimal. More specifically, the funding does not fulfill the ask of Resolution 17-23F because it does not include funding for community hospice societies, outside of those freestanding hospices with contracts, or funding for a community hospice funding model. As such Resolution 17-23F is currently assigned a status of "intent not met."

In 2021 (b), the Government of Alberta created a one-time \$11 million competitive grant pool with funding for community hospice societies. According to the government, the grant was intended to raise awareness about palliative care, develop caregiver supports that enable care at home, educate healthcare professionals, and fund research that supports moving hospice from hospital to community (Government of Alberta

(b), 2021). Although community hospice societies were eligible to participate, the fund did not provide any funding for operating expenses, such as salaries, materials and supplies, equipment, training, or for the grief programs that many societies provide (Government of Alberta (b), 2021). The \$11 million was distributed to 25 different projects. Nine of these projects had a province-wide reach, six had a rural or partial rural focus, while the remaining projects were targeted to Edmonton, Calgary, or a First Nation. RMA is unaware of the other government, private, or community-based grants regularly available to community hospice societies. Combined, there is a lack of provincial funding for hospice through consistent operational support or one-off grant funding. Information on how other health services that may incorporate or connect end-of-life care is provided below.

Emergency Room and Acute Care

The Government of Alberta funds emergency room and acute care services in Alberta. They provide funding to AHS and Covenant Health to operate hospitals and deliver these essential services. In 2024-2025, the acute care operating budget is \$4.4 billion (Government of Alberta, 2024). The Government of Alberta operates 106 acute care hospitals across the province with 9,090 acute care and sub-acute care beds (AHS, 2023). As described previously, the relative lack of intervention that comes with a palliative level of care designation has been found to save money (Government of Alberta (a), 2021). More specifically, palliative care is less expensive than emergency or acute care because fewer interventions and diagnostic testing are ordered, and patients are not admitted to hospital or have shorter stays. In a non-hospital institutional setting such as a long-term care facility or alternative care at home, the cost is seven to eight thousand dollars lower per patient than care in an emergency room or hospital acute care setting (Government of Alberta (a), 2021). RMA was unable to determine the specific amount AHS spent on palliative and end-of-life care in Alberta. Albertans do not pay for the services they receive in hospital due to the Alberta Health Care Insurance Plan.

Long Term Care

The Government of Alberta is responsible for the medical costs of all long-term care residents, and may choose to subsidize accommodation costs such as rent, meals, housekeeping, and routine building maintenance. Continuing care is delivered by AHS in some facilities/communities and through contracted providers such as the Good Samaritan Society, Bethany Group, or Points West.



Freestanding Hospice

Most freestanding hospices in Alberta are funded through a combination of a contract with AHS, which provides medical operating expenses, and community fundraising to supplement residents' stay costs (Table 3). At the Red Deer Hospice residents are only responsible to pay for certain medications and personal comfort items. Currently all five freestanding hospices in Alberta have some sort of funding agreement with AHS (Table 3). While RMA could not locate budgets for the Salvation Army Agape Hospice or Rosedale Hospice in Calgary, annual reports or other financial information was available for Red Deer, Pilgrims, and Foothills Hospice Societies. The proportion of the operating budget that AHS funding covered ranged from roughly 40% at the Pilgrims Hospice Society to roughly 70% at the Red Deer hospice. AHS provides contracts to freestanding hospices on a voluntary basis, but it is unclear as to why exactly AHS has entered into agreement with these facilities, but not others. Should a group not have a contract to provide hospice services, they are entirely reliant on community funding and grants.

AHS (2014) noted that a freestanding hospice can be a more costly route to deliver hospice care than care offered at home or in a shared facility, particularly in rural communities where demand and vacancy numbers may not parallel costs of shared end-of-life care spaces in pre-existing, staffed facilities, like long-term care. While this may be the case, like many rural services, the limited population and long distance to population centres means that service justification cannot be measured purely on a per capita cost basis, but rather must consider the impacts of not providing the service locally.

At Home

The Government of Alberta funds home care through Continuing Care services. Home care is intended for people whose needs can be reasonably met and managed in their private residence, including those who reside at a suite in a senior's lodge. The range of available services includes palliative care. The 2024-2027 budget estimated \$921 million dollars for home care in 2024-25, increasing to \$998 million target in 2026-27 (Government of Alberta, 2024).



Community Hospice Societies

There is considerable variation in how community hospice societies are funded, in large part because of the differences in the services they provide. For example, some community hospice societies such as the Stettler Hospice Society almost exclusively provide supports for a hospice bed, while others such as the Camrose and District Hospice Society provide almost exclusively community-based grief and end-of-life community services. Other societies such as the Prairie Rose Hospice Palliative Care Society in Brooks and the Compassionate Care Hospice Society in Clearwater County/Rocky Mountain House offer a combination of hospice bed and community grief supports and services by combining their services with clinical care in a long-term care or hospital setting. Table 10 shows a list of community hospice societies that receive some funding from AHS or have various other agreements in place. For example, in Mountain View, Clearwater, and Stettler counties, AHS provides clinical and/or residential support, while the society provides grief support, other end-of-life supports for the patient and their family and sometimes covers residential costs, such as renting or owning a unit in a seniors' facility.

RMA could locate publicly available community hospice association financial information from five community hospice associations: Camrose & District Hospice Society, Red Deer Hospice Society, Olds & District Hospice Society, Wheatland & Area Hospice Society, and Foothills Country Hospice Society. Three of these five organizations operate hospice beds and listed staff payroll as an expense (Table 5, Table 6, Table 10). The presence of hospice beds and the availability of financial reporting may indicate that these organizations provide a relatively comprehensive level of service and may have above average revenues and expenses compared to other societies. However, evaluating revenue and expense data may provide useful insights into how these societies operate and subsequently be used to inform recommendations on a sustainable community hospice funding model. Different societies list different financial categories for both revenue and expense. RMA has attempted to combine categories where appropriate, but also not to change categories when unclear on similarities and differences to maintain the integrity of each category.

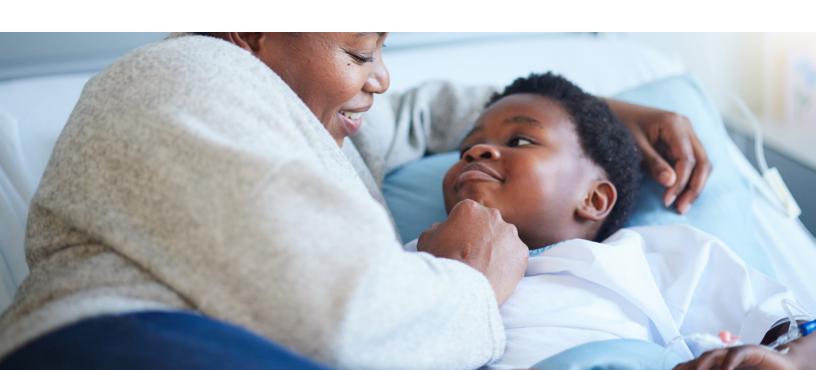


Table 5 shows the dollar amount and proportion of community hospice society revenue. RMA obtained the most recent available financial information from four community hospice society websites, which are all of the community hospice society budgets RMA could locate online. Organizations relied on a combination of donations, grants, clinical funding and more for revenue. Donations came from individuals, corporations, estates, donations made in memorial, donations from an unspecified source, or donations that were the result of fundraising (Table 5). As table 5 shows, it takes hundreds of thousands, if not millions of dollars in community fundraising to sustain community hospice society operations and capital plans. Wheatland and Area Hospice Society earned roughly 96% of their revenue from donations and fundraising, Red Deer Hospice Society as little as 25%, and the others somewhere in between. While these communities' generosity is noble, it undoubtedly takes a toll on residents and municipalities, particularly in a time of economic hardship. A sustainable community hospice funding model would ensure the continuity of these vital health services is not dependent on the necessity of donors' generosity.

Table 5. Community Hospice Society Revenue								
Category	Camrose (2021)		Red Deer (2023)		Olds & District	(2023)	Wheatland (2022	-2023)
	\$	%	\$	%	\$	%	\$	%
Donations	Donations							
Individual Dona-	31,119.74	16.53						
tions								
In Memorial	10,975.00	5.83			3,483.00	1.19		
Donations								
Corporate Dona-	17,122.00	9.1						
tions								
Estate Donations	1,000.00	0.53						
Service Clubs/	4,961.13	2.64					78,220.66	5.19
Donations from								
Other Charities								
Other Donations	8,545.73	4.54			162,010.00	55.23	1,188,441.00	78.9
General Dona-			813,352.00	20.26				
tions								
Fundraising			211,362.00	5.27	33,727.00	11.50	181,166.33	12.03
Other Revenue								
Membership	95.00	0.05	300	0.01	320	0.11		
Fees								
Government	4,789.07	2.54			15,000.00	5.11		
Grants								
Other Grants	18,564.00	9.86			57,248.00	19.51		

Table 5. Community Hospice Society Revenue								
Category	Camrose (2021)		Red Deer (2023)		Olds & District	(2023)	Wheatland (2022	-2023)
	\$	%	\$	%	\$	%	\$	%
Wage Subsidy	35,273.23	18.74						
Funding								
Rent Subsidy	1,877.48	0.99						
Funding								
Honorarium	100.00	0.05						
Fees								
Critical Benefit	2,583.84	1.37						
Funding								
NAV-Care	30,000.00	15.94						
Funding								
AHS			2,759,260.00	68.73	21,544.00	7.34		
Casino Revenue	21,203.07	11.27						
Capital Contri-			198,452.00	4.94				
butions								
Gifts-in-Kind			17,977.00	0.45				
Meals			13,407.00	0.33				
Investment							58,379.97	3.88
Income								
Total	188,209.29	99.98	4,014,110.00	99.99	293,332.00	99.99	1,506,207.96	100.00

Information from: Hospice Society of Camrose and District 2021-2022 Annual Report, Red Deer Hospice Report to the Community, Olds and District

Hospice Society Report to the Community, and the Wheatland and Area Hospice Society.

Other prominent revenue sources for community hospice societies include government and community grants (Camrose and Olds) and funding from AHS (Red Deer and Olds) (Table 5). The Camrose and District Hospice society provides some innovative examples of where community hospice societies can look for funding support, including various government subsidy programs, and working with the NAV-Care program. Other innovative examples include the Red Deer Hospice Societies gifts-in-kind (Table 5).

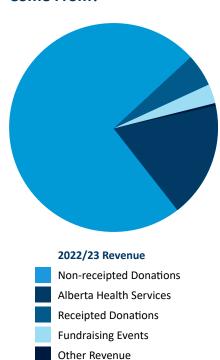
Table 6. Community Hospice Society Expense								
Category	Camrose (2021)		Red Deer (2023)		Olds & District	(2023)	Wheatland (2022	-2023)
	\$	%	\$	%	\$	%	\$	%
Communica-	31,119.74	16.53						
tions/								
Advertising and	2,001.58	1.45			6,668.00	3.13	1,722.06	1.79
Promotion								
Fundraising	3,646.94	2.65	62,531.00	1.59	3,562.00	1.67	69,695.94	72.56
Education	2,792.97	2.02						
Payroll & Bene-	113,648.71	82.56	2,939,996.00	74.53	151,074.00	70.97		
fits								
Program	2,366.37	1.72						
Overhead/	13,19.50	9.56	262,449.00	6.65	16,507.00	7.75		
Facility								
Administration			208,798.00	5.29	23,581.00	11.08	8,170.47	8.51
Direct Care Cost			102,420.00	2.6				
Other			347,149.00	8.8	298.00	0.14	12,380.80	12.89
Investment Loss			21,244.00	0.54	3,629.00	1.7	4,045.01	4.21
Total	137,656.07	99.96	3,944,587.00	100.00	212,865.00	99.98	96,014.28	99.96

Information from: Hospice Society of Camrose and District 2021-2022 Annual Report, Red Deer Hospice Report to the Community, Olds and District

Hospice Society Report to the Community, and the Wheatland and Area Hospice Society.

Community hospice societies report their expenses along with their revenue (Table 6). There are several similarities in the expenses each society incurs. For example, all societies spent money on fundraising. With the exception of the Red Deer Hospice Society whose similar funds may have been in another category like fundraising or administration, organizations spent money on communications or advertising and promotion. Three out of four societies paid for staff payroll and benefits, overhead and/or facility costs, and administration. For societies with staff, payroll and benefits was the largest expense, amounting to 70% or more of their total expenses. For the society with no staff, fundraising was the largest expense. Other common larger expenses were overhead/facility, administration costs, and other (Table 6).

Where Does Our Money Come From?



Where Does Your Money Go?

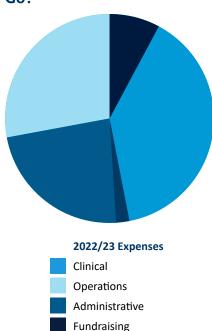


Figure 2 Foothills County Hospice (2022-2023)

Programs

Although Foothills Country Hospice does not provide specific budget information on their website, they do provide a breakdown of where their funds came from and how they were spent (Figure 2). Most of their funds come from non-receipted donations or AHS. Most of their expenses were related to clinical costs, operations, or administrative expenses (Figure 2). RMA will use this information to inform what should be included in the community hospice society funding model.

Budget, revenue and expense information can be supplemented with information from hospice websites that describes their fundraising efforts and the programs and services they provide. For example, websites confirm the prominent role of fundraising to support community hospice societies. Examples of community hospice society fundraisers included "Farming for Hospice" where people could sponsor an acre of land for a \$300 donation, "Hike for Hospice," and raffles. Donations made in memorial or raised at annual grief events like Christmas memorial services, are another common fundraising stream. One society even owns and operates a thrift store to supplement their activities.

Arguably this financial information does not tell the full story of actual costs to operate a community hospice society. More specifically, volunteers play a huge role in these societies. Societies without paid staff are entirely volunteer run, from their board of directors to the people who organize and deliver programs. Societies with staff, all of which spend the majority of revenue on payroll and benefits, still rely heavily on volunteers to perform a variety of essential organizational and programming roles that include administration, hospitality, entertainment, bereavement, event planning, and fundraising.

Table 7. Community Hospice Society Volunteers				
Hospice Society	Number of Volunteers	Volunteer Hours		
Camrose (2021)	228	3,140.5		
Olds & District (2023)	138	9,155		
Foothills (2022-2023)	99	8,389		
Total	465	20,684.5		

Information from: <u>Hospice Society of Camrose and District 2021-2022 Annual Report, Olds and District</u>

Hospice Society Report to the Community, and the Foothills Country Hospice Society.

Table 7 shows the number of volunteers and total volunteer hours contributed at three community hospice societies for which information is available. Even though these three societies had staff, approximately 100 or more



volunteers contributed thousands of hours of their time. On average, volunteers at the Olds and Foothills hospices contributed 66.34 and 84.74 hours per year per person respectively (Table 7). The number of Camrose & District Hospice Society volunteers may count the same person more than once if they volunteered with multiple programs. Camrose's volunteer hours may be lower than Olds or Foothills given their data comes from 2021 when hospice activities were impacted by the Covid-19 pandemic (Table 7). Volunteer information from more community hospice societies would be ideal to better and more fully understand the very prominent role volunteers play in operating community hospice societies and how much they contribute to their bottom line. Undoubtedly, tracking volunteer hours is challenging and adds yet another administrative task and cost.

It is possible to assign a rough financial value to these volunteer hours by translating them to hours of work for a full time position and assigning a salary value. RMA assigned full time hours to be 40 hours per week over the course of a 52-week salary year. RMAs estimations include a conservative annual salary at \$65,000 for an administrative or non-clinical hospice position (Table 8). Volunteer positions at the Olds and Foothills societies translate to more than four full time positions per society for a combined salary value of nearly \$550,000.

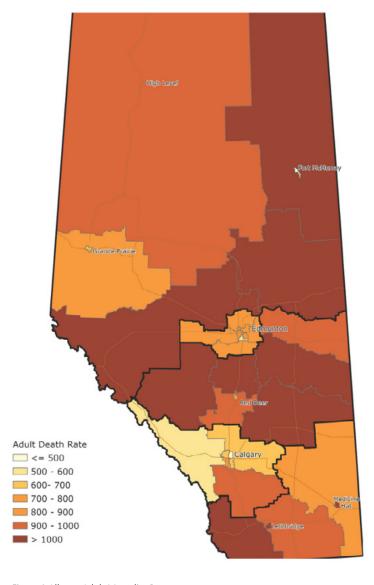
Table 8. Community Hospice Society Volunteers					
Hospice Society	Volunteer Hours	Number of 40 Hour	Number Full Time	Salary Value (\$)	
		Weeks	Positions		
Camrose (2021)	3,140.5	78.51	1.51	98,150	
Olds & District (2023)	9,155	228.86	4.40	286,000	
Foothills (2022-2023)	8,389	209.73	4.03	261,950	
Total	20,684.5	816.67	9.94	646,100	



The Rural Case

Introduction to Hospice in Rural Alberta

As noted earlier, rural Alberta is ageing quickly. Ageing populations need increasing end-of-life supports. Along with the prevalence of cancer and other chronic illnesses, there are a few other notable rural mortality trends. Figure 3 shows the adult death rate across Alberta (Simon et al., 2024). The highest death rate



is shown in a dark orange/red and the lowest death rate in white/pale yellow. The death rate is highest outside of Calgary and Edmonton, particularly in the southwest corner of the province, much of central Alberta, and a strip that runs from west of Edmonton, to north of Edmonton, to the northeast corner of the province. Mortality rates outside of Edmonton and Calgary were highest for males with some variation across the province, while there was somewhat less variation in females' mortality rate across the province. Children had different leading causes of death based on their age (Simon et al., 2024). While this information is useful to better understand the context of death and dying in rural Alberta, it does not directly speak to the number of people requiring or choosing end of life services in a hospice.

Figure 3 Alberta Adult Mortality Rates Data from Simon et al., 2024.

AHSes to AHSes, Dust to Dust: The Nitty Gritty of End-of-Life Care in Rural Alberta

Geography and distance are other differentiating factors in delivering and accessing hospice and end-of-life care in rural Alberta. Rural Alberta has a relatively lower population and population density than urban areas of the province (Simon et al., 2024; Table 9). The AHS North Zone is the least dense, Central and South Zones similarly dense, while Calgary and Edmonton have the greatest population density (Table 9).

Table 9. AHS Zone Population Size and Density					
AHS Zone	Population Size (2021)	Population Proportion (%)	Population Density (/km²)		
North Zone	474,696	11.14	1		
Edmonton Zone	1,451,927	34.06	120		
Central Zone	476,092	11.17	5		
Calgary Zone	1,727,705	40.53	43		
South Zone	312,255	7.33	5		
Alberta	4,262,635	100.00	6.7		

Data taken from <u>Canadian Palliative Care Atlas Alberta Edition 2023</u>.

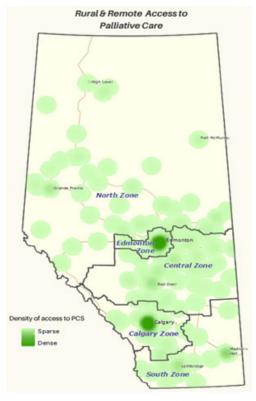


Figure 4. Rural & Remote Access to Palliative Care
Data from Simon et al., 2024.

Population density has historically been used to justify a regionalized healthcare model where specialized services are delivered in a centralized urban setting and general care is available in the surrounding areas. As a result of the lack of rural palliative and hospice care services, many rural Albertans leave their community to access care. A Canada wide report by the Canadian Institute for Health Information (CIHI, 2023) found similar rates of palliative patient designations in "urban and rural/remote settings," and similar access to home care. There were, however, a few key differences. Namely, rural palliative patients "were more likely to be hospitalized" for palliative care than urban patients and rural patients were more likely to die in hospital (CIHI, 2023). This suggests that the difference between rural and urban palliative care is not the label or designation of palliative care as a treatment status or goal of care, but differences in the quality, variety, and accessibility of end-of-life services and programs. This difference in care levels and availability is confirmed by the information in Figure 4. Figure 4 shows rates of palliative care access in rural and remote areas of Alberta. The darker green shows a high density of access to palliative care, and the lighter green lower density. There is only density of access, or the greatest access to palliative care, in Calgary and Edmonton. There is some lower density access outside of those urban centers, or fewer supports and services. Alternatively, some areas of the province are pale yellow, indicating no access or the requirement to travel to access any services. This is the case for much of the North Zone.

There is more information to support this finding. AHS reports have found continued discrepancies in services and programs between AHS Zones (Simon et al., 2024; AHS, 2021). More specifically, there are several palliative and end-of-life services and resources that are available in Calgary and Edmonton that are not available elsewhere in the province. Programs not available in the North, Central, and South Zones include specialized palliative home care teams, tertiary and intensive palliative care units, the pediatric rural palliative care in-home funding program, and rural telehealth consultations (AHS, 2021). The regionalization of many healthcare services means rural palliative patients have limited access or must travel to access certain procedures or even benefit from telehealth.

Staffing presents another major concern. There is inconsistent access to allied health providers such as physiotherapists, occupational therapists, speech language therapists, and respiratory technicians, along with nurses and doctors with specialist knowledge and/or experience providing end-of-life services (Simon et al., 2024). The absence of rural end-of-life services was particularly pronounced in the case of palliative services for children (AHS, 2021).

The availability of end-of-life care beds is another indicator of an inequitable level of access in rural communities. As noted in Table 2, there are palliative care unit beds in Edmonton, Red Deer, Calgary, Lethbridge and Medicine Hat, but no beds in the North Zone. Table 10 shows the facility and number of available hospice beds in each zone. There are over 100 beds in the Calgary and Edmonton Zones and 15 to 22 beds in the North, Central, and South Zones. Over 79% of all hospice beds in the province are located in Edmonton and Calgary. Hospice beds in the North zone are exclusively located in continuing care facilities or hospitals, located in continuing care facilities, hospital, or hospice in Edmonton, predominantly by hospice societies in Central Zone, in hospice or continuing care in Calgary, and in continuing care facilities in the South Zone (Table 10).

Table 10. Hospice Location & Bed Count by AHS Zone				
AHS Zone	Bed Count	Proportion (%)		
North Zone	15	5.47		
Prairie Lake Seniors Community	10			
Fairview Health Complex	1			
The Manor at Whitecourt Village	2			
Grimshaw and District Community Health Centre	1			
La Crete Community Health Centre	1			
Edmonton Zone	104	37.96		
Edmonton General Continuing Care Centre	26			
Foyer Lacombe	10			
Norwood – Angus McGugan Pavilion	30			

Table 10. Hospice Location & Bed Count by AHS Zone				
Rivercrest Care Centre	6			
St. Joseph's Auxiliary Hospital	14			
Westview Health Centre	6			
Pilgrims Hospice Society	12			
Central Zone	21	7.66		
Red Deer Hospice	16			
Compassionate Care Hospice Society	1			
Stettler Hospice Society	1			
Olds & District Hospice Society	2			
Stettler Community Health Centre	1			
Calgary Zone	114	41.61		
Salvation Army Agape Hospice	20			
Rosedale Hospice	7			
AgeCare SkyPointe Hospice	15			
Intercare Southwood Hospice	24			
Dulcina Hospice at Marguerite Manor	26			
Intercare Chinook Care Centre	14			
Foothills Country Hospice	8			
South Zone	20	7.30		
St. Josephs (Medicine Hat)*	10			
St. Michaels (Lethbridge)*	10			
Total	274	100.00		

^{*}These South Zone units function as both hospices and Palliative Care Units (PCU).

2023 data taken from <u>Canadian Palliative Care AtlasAlberta Edition 2023</u>.

Comparing the proportional share of hospice beds by zone with the population of each zone provides a sense of the relative level of hospice availability across different regions of the province (Table 9, Table 10). For example, the the population proportion exceeds the proportional share of beds in the North, Central, and South zones, while the bed proportion is slightly higher than population in Edmonton and Calgary. This further supports the idea the rural patients must travel to Edmonton and Calgary to receive end-of-life care, or receive a lower level of care, or non-end-of-life specific care in the home healthcare setting. The fact that rural areas of the province are generally aging more rapidly than large cities further exacerbates this inequity.

While Table 10 offers valuable insights into the availability of hospice across the province, it does not indicate how the number of rural hospice beds compare to the number of hospice beds in Edmonton and Calgary, or whether the number of hospice beds is adequate for the population. The recommended number of hospice beds per 100,000 people is seven (Canadian Cancer Society, 2023). In 2014, AHS acknowledged a standard ratio of 7.7 hospice beds per 100,000 and claimed that only the Calgary Zone had

achieved this standard (AHS, 2014). This does not include palliative care beds.

Table 11 shows hospice beds for the entire provincial population. Alberta falls roughly half a bed short of the recommendation. Calgary and Edmonton are closest to the recommendation, falling just under or just over seven hospice beds per 100,000 people. The story is different for the North and Central Zones, where the rate is 3.16 and 4.62 beds per 100,000 people respectively. The situation is more complex in the South Zone. There are 6.45 hospice beds per 100,000 people in the South Zone, or 20 beds for roughly 312,000 people. Although that may suggest that there is no issue in the South Zone, the only hospice beds in the Zone are shared palliative – hospice beds; they are not exclusively hospice beds. We do not know how many hospice versus palliative patients occupy the beds at any particular time. Additionally, these beds are located in regional centers, Lethbridge and Medicine Hat. Figure 4 above indicates no access to hospice services for large swaths of the South Zone, indicating the extent to which access is centralized and the limited value that zonal data provides in emphasizing the rural/urban service access divide within zones.

Table 11. Hospice Bed by Zone and Population					
Zone	Hospice Beds	Population (2021)	Hospice Beds per 100,000 people		
North	15	474,696	3.16		
Edmonton Zone	104	1,451,927	7.16		
Central Zone	22	476,092	4.62		
Calgary Zone	114	1,727,705	6.60		
South Zone	20	312,255	6.41		
Total/Alberta	275	4,262,635	6.45		

Data taken from <u>Canadian Palliative Care Atlas Alberta Edition 2023.</u>

For Albertans who prefer to receive palliative care in hospital or have a higher level of care requirement, there are similar discrepancies between Zones (Table 12). Given that hospice-palliative beds are shared in the South Zone, it appears to have the most, followed by the Central Zone, Calgary Zone, Edmonton Zone, and North Zone where there are no palliative care unit beds.

Table 12. Palliative Care Units in Alberta by Zone and Population					
Zone	Palliative Care Unit	Population (2021)	Palliative Care Unit Beds per		
	Beds		100,000 people		
North	0	474,696	0		
Edmonton Zone	20	1,451,927	1.38		
Central Zone	18	476,092	3.78		
Calgary Zone	29	1,727,705	1.68		
South Zone	20	312,255	6.41		
Total	87	4,262,635	2.04		

Data taken from Canadian Palliative Care AtlasAlberta Edition 2023.

Report findings from the Canadian Palliative Care Atlas: Alberta Edition 2023 highlighted that single hospice and palliative care beds are a positive solution in the sense that they provide the option to stay close to home, but that there are benefits to facilities such as freestanding hospices that offer experienced staff who are comfortable with death and dying and related wrap around services (Simon et al., 2024). The result of these inadequacies in rural care means that it is common for rural Albertans to have to make a choice to spend the end of their life in their community with limited care or spend that precious time in a hospital or another residential facility some distance away (Simon et al., 2024). RMA's position is that there should be no compromise. Rural Albertans should not have to make the choice to die a moderately supported death in their community or a well-supported death elsewhere. Given the higher death rates and more rapidly ageing population in rural Alberta, the discrepancy in hospice bed access is especially concerning. The creation of a sustainable community hospice funding model is one major and essential step towards enhancing rural end-of-life care.

Rural Municipalities and Community Hospice Societies

Given the role of community hospice societies in supporting and bolstering the availability of hospice in rural communities, it is appropriate to consider how rural municipalities and community hospice societies work together. To begin, community hospice societies also have a relationship with the federal and provincial governments. Most, if not all, community hospice societies in Alberta have charitable status. Charitable status is a federal designation that enables organizations to accept certain donations and issue tax deductible receipts. Alberta has additional requirements for charitable organizations through the Charitable Fundraising Act and Societies Act. The relationship between community hospice societies and municipal governments is more ambiguous, consisting of both the legalities and technicalities of business licenses and land use permitting and zoning, and the advantages of having rich and varied social supports and community organizations.

Yet, there is more to the relationship than legalities and technicalities. Community hospice societies provide valued end-of-life services in rural municipalities across the province. In many rural communities, they provide hospice beds and grief support services that would not otherwise be available. Generally, municipalities want these organizations to succeed. In addition to Resolution 17-23F, RMA has heard frustration from members regarding inadequate provincial hospice funding and a lack of progress on approved and funded projects. Community hospice societies that are largely or entirely dependent on community fundraising may look to municipalities for grant funding, donations, emergency funding, or other support. The extent to which a municipality may choose to support community hospice societies is discretionary. Although RMA does not have specific data on which member municipalities have made financial or in-kind contributions to community hospice societies, multiple members do provide this type of support. Unfortunately, some members find themselves in a difficult position in relation to these societies. For example, RMA heard that despite supporting their local community hospice society, one member failed to see the society deliver on their promises or use donated funds appropriately. RMA has heard and attempted to address this concern in the creation of a sustainable community hospice funding model by supporting the installation of standards for community hospice societies and including a recommendation on service standards and financial accountability.

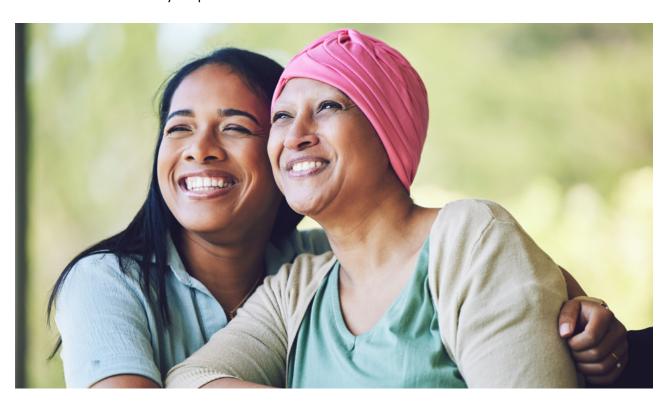
Recommendations to Improve Hospice in Rural Alberta

This report has covered a lot of ground, from an overview of hospice versus palliative end-of-life care in Alberta, how end-of-life care is funded, and some of the background information that makes end-of-life care unique and lesser than in the current model. Guided by the ask of Resolution 17-23F: Sustainable Community Hospice Funding Model, RMA has identified a series of areas where rural end-of-life care fails to meet rural Albertans need and does not offer the same end-of-life care available elsewhere in the province. RMA has prepared six recommendations to improve end-of-life and hospice care in rural Alberta.

Recommendation 1: Improve and publicize palliative, hospice, and end-of-life data

It is difficult to assess and comment on the state of end-of-life supports in the province if relevant data is not regularly collected or made publicly available. Given the number of organizations involved in delivering hospice and palliative care in Alberta, it is important to have regular and consistent measures and to ensure that organizations are compliant with providing this information.

Data collection and management practices could be initiated in the healthcare transition when a new oversight minister assumes responsibility for hospice. Alternatively, the GOA could provide AHPCA with funds to collect data on community hospice societies.



Recommendation 2: Carefully consider hospice's organizational placement throughout the healthcare transition

In November 2023, the GOA announced a plan to transition away from the present model where AHS is the primary organization to administer and deliver health services in the province, to a four sectors model that consists of acute care, primary care, continuing care, and mental health and addiction. Palliative and hospice care will fall under the umbrella of continuing care. Recovery Alberta, the mental health and addiction pillar has already been operationalized, with the others expected to follow in fall 2024.

The organizational placement of hospice and palliative services must be carefully considered because of how the existing hospice delivery model has close ties to acute care, primary care, continuing care, and even a large mental health and well-being component. Palliative care units and hospices are located in hospitals and continuing care facilities. Family physicians provide palliative and hospice care as a part of community primary care.

Given the present strain the healthcare system is under, increased hospice support, such as through the creation of a community hospice funding model that provides new and additional support for community hospice societies, would help to alleviate strain in the system where it is felt most acutely, emergency rooms and acute care. Hospices already support this objective and would do so to an even greater extent with a community hospice funding model, by providing specialized end-of-life care in a supportive, home like environment.

Recommendation 3: Increase the number of rural hospice beds

As demonstrated in table 10-12, the number of hospice and palliative care beds is a problem; there are not enough. The shortage is felt most keenly in the North, Central, and South Zones, but only Edmonton meets the recommended number of hospice beds per 100,000 people (7.7). One of the ways the number of rural hospice beds could be increased is through partnering with community hospice societies to introduce new hospice beds in facilities like freestanding hospices, long term care centres, or to expand the number of beds in existing facilities.

While the need for more hospice beds is greatest in the rural North, Central, and South Zones, there is room to increase the number of hospice beds across the province.

Recommendation 4: Improve the distribution of end-of-life services outside of Calgary and Edmonton

As tables 5-7 also show, the number of beds is not the only prob-



lem, location also matters. As seen in figure 4 and table 5, there are many rural areas of the province that do not have any palliative care resources, or if resources and care is available, it is present in a much lower density than can be accessed in Edmonton and Calgary.

Furthermore, in areas of the province like the South Zone, end-of-life care beds are exclusively located in regional centres that do not allow rural Albertans to receive those end-of-life supports close to home, as is the case for Albertans in and around Calgary and Edmonton. The location and distribution of any new palliative and/or hospice beds should be carefully considered to ensure it is meeting the needs of Albertans without or distant from access to these services and not only increasing the density of services that already exists in Edmonton and Calgary.

Recommendation 5: Remain grassroots strong. Value, consider, and collaborate with community hospice societies

Many community hospice societies have emerged from a local grassroots movement to support, enhance, or make hospice care available to residents in their area. These organizations belong to their history, their volunteers, their residents, and the community. They are ready and open to growing and offering their communities more, with support from the Government of Alberta. Any changes that are made to hospice care, local or not, should be made in collaboration with these societies or led by them, with recognition and appreciation for the local experience and expertise they bring to the table. To ensure community hospice societies are heard and have their perspective incorporated, RMA recommends that the Government of Alberta prioritize supporting societies in collecting and using data, making evidence-based decisions, providing sustainable funding, and creating a system where they can regularly provide their input into the system such as advisory committee.

Recommendation 6: Build and implement a sustainable community hospice funding model

Resolution 17-23F: Sustainable Community Hospice Funding Model got it right; the best way to improve hospice care in rural Alberta is through the construction and implementation of a sustainable community hospice funding model. RMA has prepared principles for the creation of this sustainable funding model and specific recommendations on what should be included in the funding model.



Principles for the Development of a Sustainable Community Hospice Society Funding Model

To build and implement a sustainable community hospice funding model, there needs to be forethought into what the funding model should look like. To help guide the province in developing an effective funding model, RMA and Alberta Municipalities co-developed a statement of principles. These principles are both standalone and interconnected with one another. Together, they form the foundation for the Government of Alberta to increase support for community hospice societies to enable them to increase their hospice provision capacity and provide essential services to Albertans at the end of their life. Now is the ideal time to introduce changes to the community hospice societies funding model precisely because of other changes happening, but also recognize that the introduction of such an important funding model must be thoughtful, collaborative, detailed, and aware of unintended consequences.

Principle 1: Patient, Family, and Provider Centered

Good hospice care treats Albertans with respect, support, and compassionate care. The community hospice society funding model should do the same. The funding model should be built around meeting patients and their families needs and ensuring this quality care is provided through a supportive working environment for staff and healthcare professionals.

Principle 2: Comprehensive, Holistic & Quality Care

The funding model must be focused on funding the wrap around supports for patients and their families that community hospice societies provide presently. These comprehensive supports recognize that hospice care is holistic, or attentive to the end-of-life patients physical, mental, social, and spiritual health and well-being.

Principle 3: Collaborative

The Rural Municipalities of Alberta and Alberta Municipalities are honoured to be two of the voices in the conversation for a community hospice funding model. We recognize that there are other stakeholders with experience and knowledge in this area, such as community hospice societies, Alberta Health Services, Covenant Health, and the societies that represent healthcare professionals. The creation of a sustainable community hospice funding model should be a team effort.

Principle 4: Integrated

The community hospice society funding model must promote a society's integration into the healthcare

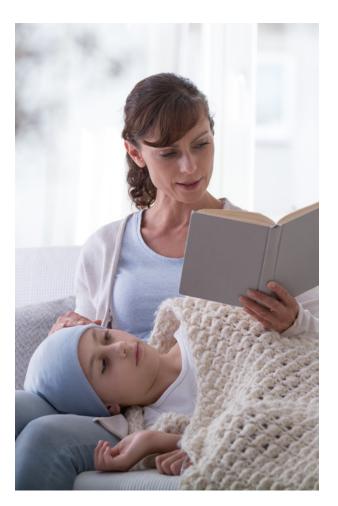
system as a health service delivery organization. Many of the hospice services provided are within the realm of primary care and continuing care. The model should have ties to the primary care and continuing care pillars, primary and continuing care services, and primary care networks. Community hospice societies engaged in clinical care should also have access to Connect Care for continuity of patient care throughout the healthcare system and continue to co-exist alongside home care and other hospice service providers.

Principle 5: Diverse & Inclusive

Albertans are a highly diverse population. Community hospice societies and their diverse staffs support Albertans choices in the end-of-life care they receive. Although many Albertans who receive end-of-life care are seniors with cancer or chronic illnesses, community hospice societies care for Albertans across the lifespan, children and adults of all ages with a vast array of terminal illnesses. Additionally, community hospice societies provide a diverse range of programs and services, across a varied and expansive province. Service options should be available to patients no matter where in the province they are located.

Principle 6: Grassroots Strong

Community hospice societies were founded by volunteers. They belong to the communities and organisations that founded them. It is important the funding model appreciate and respect that community hospice



societies are grassroots strong and that they maintain some autonomy in decision making and providing locally specific and relevant care.

This grassroots approach extends to the distribution of funds. Community hospice societies have valued partnerships and agreements in place that would allow them to adapt their services in a comprehensive and financially responsible manner. To maintain their decision-making power, contracts and agreements with community hospice societies should support the direct flow of funding from the Government to community hospice societies.

Principle 7: Standards & Flexibility

While community hospice societies must remain grassroots strong, as community hospice societies professionalize there is growing recognition of the need for more standards. For example, there are no standards for community hospice societies and the services and programs they provide. Additionally, there is need for standardization in areas like volunteer training. To support grassroots societies

and the locally specific programs and services they deliver, these standards must be flexible to provide the groundwork for a diversity of organizational models. Flexible standards would support and must guide the development of a community hospice funding model.

The introduction of standards and an intentionally flexible funding model both come with increased costs for community hospice societies. Community hospice societies must be financially supported as hospice standards are introduced. Any sustainable hospice funding model must be flexible to address the diversity of programs and care options that different societies offer.

Principle 8: Sustainable

The funding model must provide sustainable funding for community hospice societies. Sustainable funding is stable over time, predictable, reliable, and adequate to support the continuity of hospice services.

Principle 9: Transparent & Accountable

The community hospice funding model should achieve transparency through clearly communicating how funds are calculated, ensuring that the process for community hospice societies to be eligible for funds is clear and reasonable, conducting regular reviews and model revisions, and tracking hospice data, information gathering, and research that could in turn be used to improve the model. The completion of regular reviews and revisions is one means of accountability by having clear and measurable objectives, along with a means to verify funds are used as intended.



Recommendations for Building a Sustainable Community Hospice Society Funding Model

Guided by the nine principles for the creation of a sustainable funding model, RMA makes the following four recommendations on how to build and implement a sustainable hospice society funding model. RMA recognizes that the introduction of a community hospice funding model is complex, requires careful consideration and attention to detail, and most importantly, it requires ongoing consultation with the people and organizations it will affect most, including the Alberta Hospice Palliative Care Association (AHPCA), community hospice societies, and the rural municipalities that have supported them, amongst others.

Recommendation 1: Government of Alberta-funded

The Government of Alberta should provide the funds for the sustainable hospice funding model and the comprehensive work carried out by community hospice societies as they are responsible for health services in Alberta. Operational funding from the Government of Alberta should be consistent and adequate to sustain community hospice societies over time as opposed to ad hoc or project-based funding. Any municipal financial or in-kind contributions should remain voluntary.

Donations should also remain optional but become a non-essential component of hospice budgets. For example, volunteers could continue to provide homemade quilts or certain community programs like No One Dies Alone (NODA), similar to how volunteers currently donate their time and skills in hospitals and/or long-term care facilities.

Recommendation 2: Fund clinical care and grief and bereavement programs

Hospice is both a clinical orientation to end-of-life care and a philosophy of care that emphasizes wrap around supports for the patient and their family. The funding model should fund both clinical services and grief and bereavement programs.

Recommendation 3: Options for the conceptual approach to funding model design

RMA has considered two approaches to how the sustainable community hospice funding model could be designed.

- 1. Operational and capital funding model
- 2. Residential and community funding model

The associated costs would remain the same but vary in how they are distributed.

1. Operational and capital funding model

Regardless of whether a community hospice society is a residential or freestanding hospice, a community hospice society that support clinical beds in another facility, or a society that solely provides community care, all incur operational and capital costs. Cost have been listed in Table 13.

As community hospice societies would function as service delivery organizations in the new healthcare model, each society could choose to own their own land and building, or to rent a facility. Capital costs would allow the construction or modification of a facility for hospice along with regular maintenance and renovations.

Operational costs would include all the non-facility-based costs of running a hospice. For a society that provides clinical hospice services, these costs include the provision of clinical care, related equipment and supplies, and residential hospice services. Both community hospice societies that do and do not provide clinical services would require funding for staff salaries, administration, volunteer training, and comprehensive end-of-life programs and grief support.

Table 13. Operational and Capital Funding Costs	
Operational Costs	Capital Costs
Rent/overhead	Land purchase
Clinical care	Building purchase
Clinical equipment and supplies	Maintenance
Non-clinical hospice/bereavement/support programs	
Salary/benefits/payroll	
administration	
Residential hospice services (laundry, meal services, house-	
keeping)	
Communications and awareness	
Fundraising	
Volunteer education, appreciation, and support	
End-of-life and grief programs	

2. Residential and community funding model

An alternative to the same funding model for all community hospice societies would be to approach societies that provide clinical care separately from funding societies that exclusively provide community-based grief supports and programs. Each category of group would be subject to their own formula or ratios. Hospices that offer clinical care would continue to be eligible for all of the operational and capital costs listed in Table 13, while community-based societies would only be eligible for non-clinical costs with a lower formula ratio.

While either of these conceptual approaches may be effective, approach 1, the operational and capital funding design is the most straight forward, would likely involve the least administration and red tape, and would best support communities changing needs, such as the transition from an exclusively community based hospice to a society that also offers clinical hospice care.

Recommendation 4: Options for funding distribution design

There are several options for getting funds to community hospice societies. Here are a few general principles that should guide the distribution of funds:

- Funding should be based on community hospice society capacity not occupancy
- The funding model should both fund existing beds and programs and incentivize the creation of new beds and programs to help make hospice more equitable in rural Alberta and help meet the goal of 7.7 beds per 100,000 Albertans.
- The model should be flexible and adaptable to changing communities and changing community needs. For example, if a society that does not currently offer any clinical care wished to, there would be funding for them to do so. If a society wished to add another bed or a new program, there should be funding available that would enable them to do so without taking core capital or operational funds from another society.
- The government of Alberta should determine any base or per diem amounts with hospice partners including AHPCA, community hospice societies, and other stakeholders such as RMA and AB Munis.
- An application based model, as is the case for affordable housing, would not provide a sustainable funding model for community hospice societies and therefore should be avoided.

1. Base funding model

The Government of Alberta, AHPCA, community hospice societies and stakeholders such as RMA would work together to develop a funding model that provided community hospice societies with a base monthly or annual amount. This base amount would include dollars for both capital and operational expenses. It would consider factors such as the number of beds, clinical care service standards, and support program care service standards. Donations could be used to supplement reasonable standard service levels.

2. Per patient per diem

Several community hospice societies calculated how much it cost for someone to receive end-of-life care in one of their beds. This amounted to \$1,035 in 2023 at the Foothills Country Hospice (n.d.). A study using 2012-2015 data found that the mean cost of palliative care in hospital in Alberta was \$1,250 (Isenberg et al., 2021). While it is recognized that end-of-life care in an acute care setting costs more than similar care in another facility, given the similarity of the more recent number from the Foothills County hospice and the hospitalized care amount that is roughly a decade old, these numbers provide a reasonable estimate on the cost of a per diem (Isenberg et al., 2021; CHPCA, 2012).

The clinical per diem could include grief program costs, or clinical patients could be counted twice in a grief programming per diem calculated based on the number of programs and/or participants. The per diem amount would most likely focus more on operational costs but could also have a capital component.

Donations could be used to supplement care and programs over and beyond the reasonable service standards funded but should not be relied on to achieve reasonable care.

3. Combination – base model and per diem

A more realistic funding model that would help ensure sustainable funding and provide flexibility for changing communities and changing needs would be to combine the base and per diem models. For instance, base models could be developed based on the number of beds, such as a five, 10, or 15 bed facility etc., and number of programs with minimum attendance (i.e. three programs with 10 attendees per program). Per diems could be used to supplement the base model when the bed count varied from the base model or the number of programs or attendees exceeded the base funded amount.

4. Donation matching

In addition to any of the funding models proposed above, the Government of Alberta could introduce a donation matching program where they provided funds to a community hospice society in addition to any grant or per diem amounts made available that was equal to the amount of any donations received. Community hospice societies could use these funds at their discretion.

Recommendation 5: Financial Transparency and Accountability

To provide accountability to the Government of Alberta and municipalities that funds are used appropriately to support community hospice society operations, RMA recommends including the following measures within the funding model:

- Periodic audits of hospice societies to ensure funds are allocated in alignment with funding agreement terms.
- Annual financial reporting and publicly available financial statements
- Fully transparent funding application and allocation disclosures
- Provincial hospice reviews and regular data gathering

Conclusion

Community hospice societies provide valued end-of-life care that would not otherwise be available in many rural municipalities However, palliative and hospice services need improvements to better serve rural Albertans. Grounded in an understanding of end-of-life care in the province, RMA has clearly highlighted the shortfalls in rural access to hospice and palliative care, including the lack of rural access and comprehensive end-of-life supports. RMA's position is that there should be no compromise. RMA believes that well-supported and high-quality end-of-life care is within reach in rural Alberta, and begins with the creation of a sustainable community hospice funding model. RMA will continue to work to advance the principles and recommendations and to build and implement a sustainable community hospice funding model.



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