



Covenant Health
Palliative Institute

Raising Public Awareness of Palliative Care

A 2021 Survey of Alberta Hospice
and Palliative Care Societies

January 2022



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Introduction

The Palliative Care Public Awareness Project was launched in 2020 to increase awareness and understanding of palliative care in Alberta. An important first step of this project was to identify, understand and engage with community organizations with an interest in and capacity for working together to realize this objective.

Non-profit hospice and palliative care societies are positioned as key palliative care stakeholders in numerous communities across the province. They offer a range of programs and services within their communities to support people living with serious, life-limiting illnesses. These include volunteer support services for patients and families, public education, grief support programs, and in some cases, residential hospice facilities for end-of-life care.

Hospice and palliative care societies represent a Compassionate Communities approach to palliative care. Compassionate Communities is a global movement premised on the belief that “death, dying, loss and care is everyone’s responsibility” (Public Health Palliative Care International). Its purpose is to expand community capacity to care for people who are seriously ill, caregiving, dying and grieving, broadening the networks of support that exist outside of professional health services.

In 2016 Alberta Health Services developed A Resource Guide for Community Development of Palliative and End-of-Life Care within Alberta to assist communities in building capacity and addressing local needs, and was developed with input from existing hospice and palliative care societies. Since that time, the type and extent of programs and services provided by these organizations has not been reviewed on a province-wide scale.

A survey of hospice and palliative care societies was undertaken in 2021 to fulfill three objectives:

- ♥ to identify and understand the programs and resources offered by Alberta hospice and palliative care societies;
- ♥ to learn about successful public engagement and public education initiatives; and
- ♥ to identify resource needs and opportunities for engagement of hospice and palliative care societies in Alberta.

This report outlines key survey findings and implications for implementing and sustaining public palliative care education initiatives.



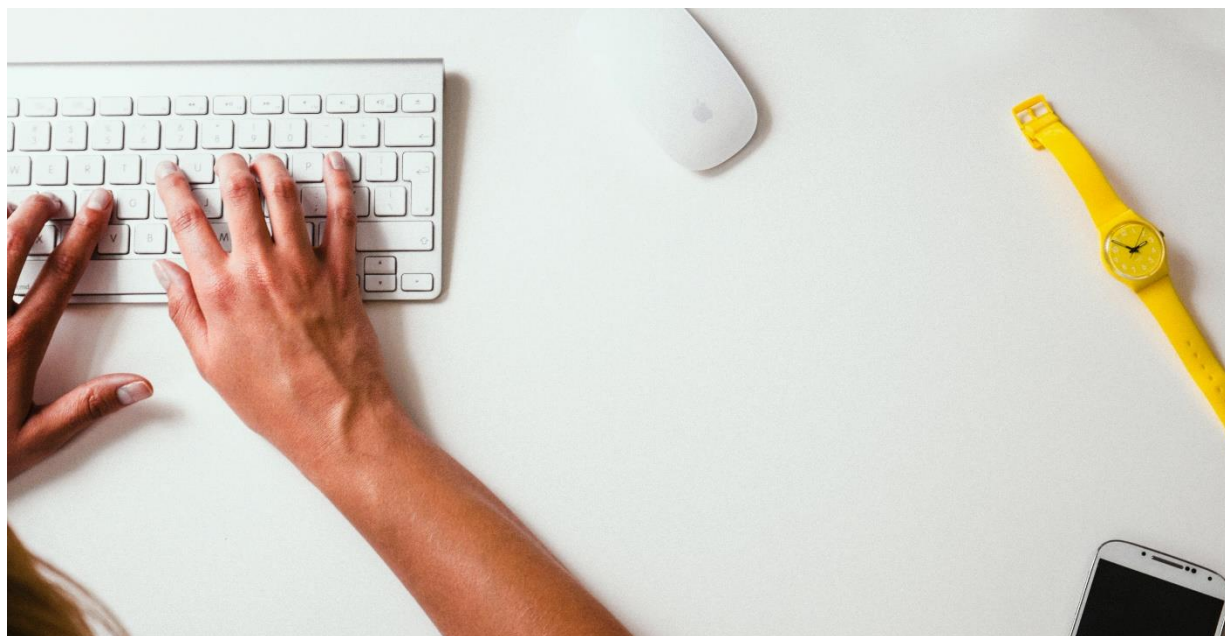


What We Did

Thirty-six active non-profit hospice and palliative care societies in Alberta were identified through the website of the Alberta Hospice Palliative Care Association and the government of Alberta's Non-Profit Listing. In June 2021, 35 organizations for which contact information could be identified were invited via email to participate in an online survey.

The survey consisted of 16 questions pertaining to organizational characteristics, programs and resources offered, successful public engagement initiatives, organizational challenges, and local needs and opportunities (see [Appendix 1](#)). Twenty-five respondents representing 23 different hospice and palliative care societies completed the survey (66% organizational response rate).

Twenty-two survey respondents indicated interest in follow-up engagement and provided their contact information at the end of the survey. These respondents and other interested members of their organizations were invited to attend a virtual "What We Heard" session in October 2021 to hear and discuss survey results. Fourteen individuals representing eight hospice and palliative care societies attended the meeting; their insights are reflected in this report.





What We Heard

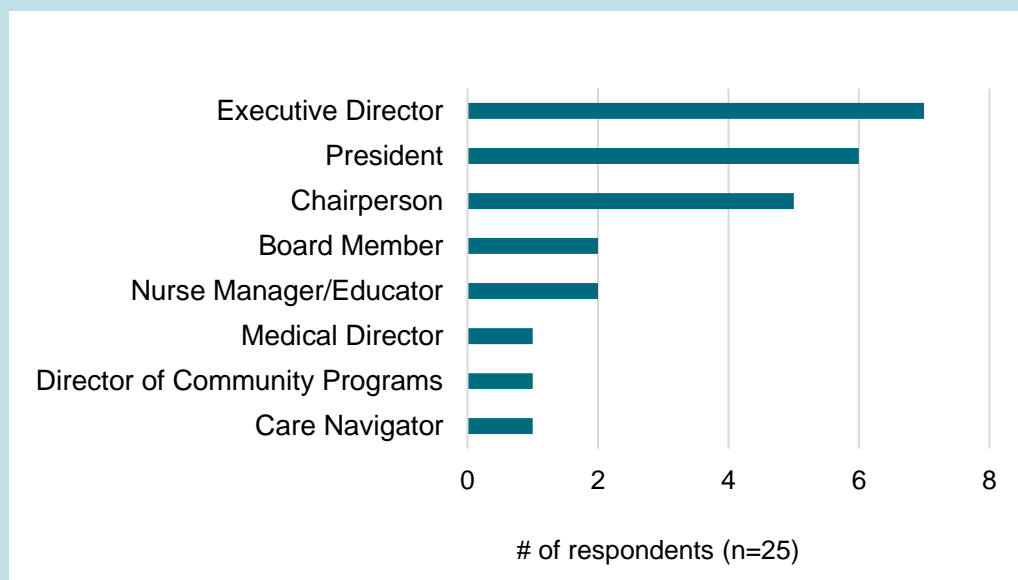
Part 1: Hospice and palliative care societies & their communities

Participating Organizations



- ♥ Rural and urban Alberta were well represented, with participating organizations located in 10 cities and 13 towns across the province.
- ♥ Four of the participating hospice societies offer residential hospice care.

Survey Respondents



- ♥ Survey respondents held a range of roles within their organizations, some volunteer and others paid.



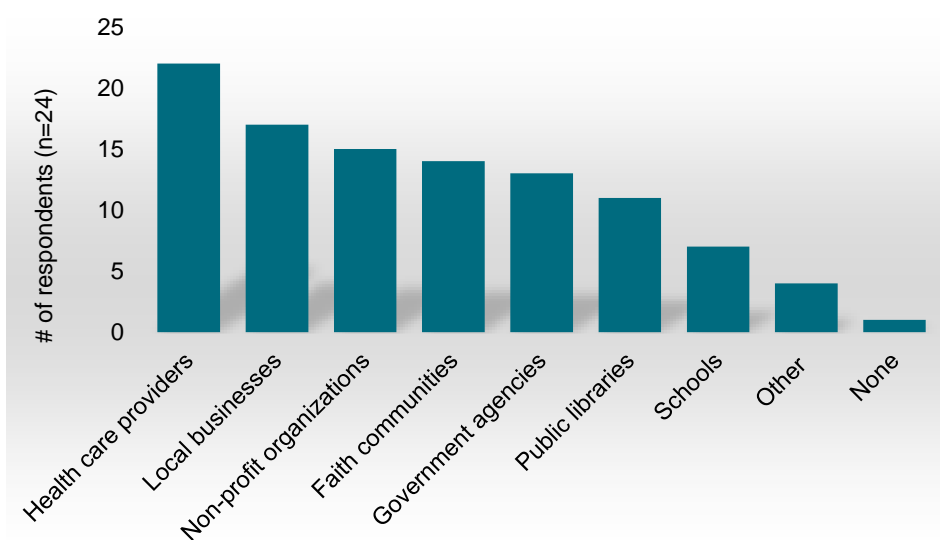


Organizational Characteristics

	Societies WITH residential hospice beds (n=4/23)	Societies WITHOUT residential hospice beds (n=19/23)
Number of full-time employees		
None	0 (0%)	11 (48%)
< 1	0 (0%)	3 (13%)
1 - 1.5	0 (0%)	3 (13%)
2 - 3	1 (4%)	2 (9%)
18	1 (4%)	0 (0%)
30+	2 (9%)	0 (0%)
Number of Volunteers		
1 - 25	0 (0%)	14 (61%)
26 - 50	0 (0%)	2 (9%)
51 - 75	0 (0%)	2 (9%)
76 - 100	1 (4%)	1 (4%)
101 - 125	1 (4%)	0 (0%)
250	2 (9%)	0 (0%)

- ♥ Alberta hospice and palliative care societies vary significantly in size.
- ♥ Roughly half are powered entirely by volunteers.

Community Partnerships



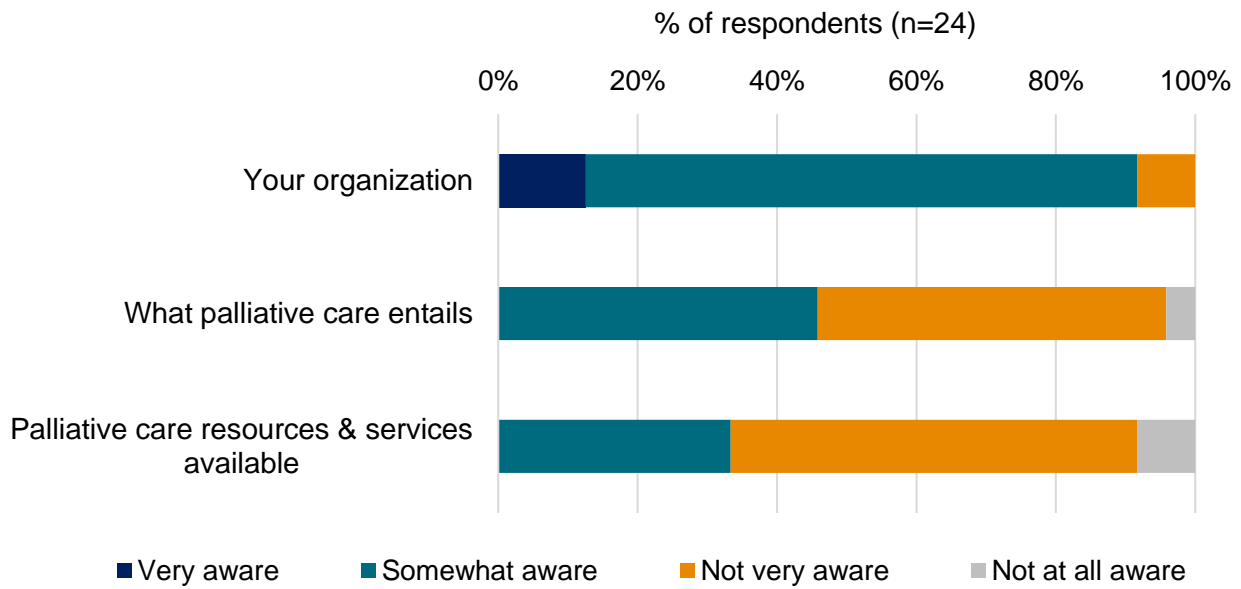
- ♥ Hospice and palliative care societies have cultivated broad partnerships in their local communities.



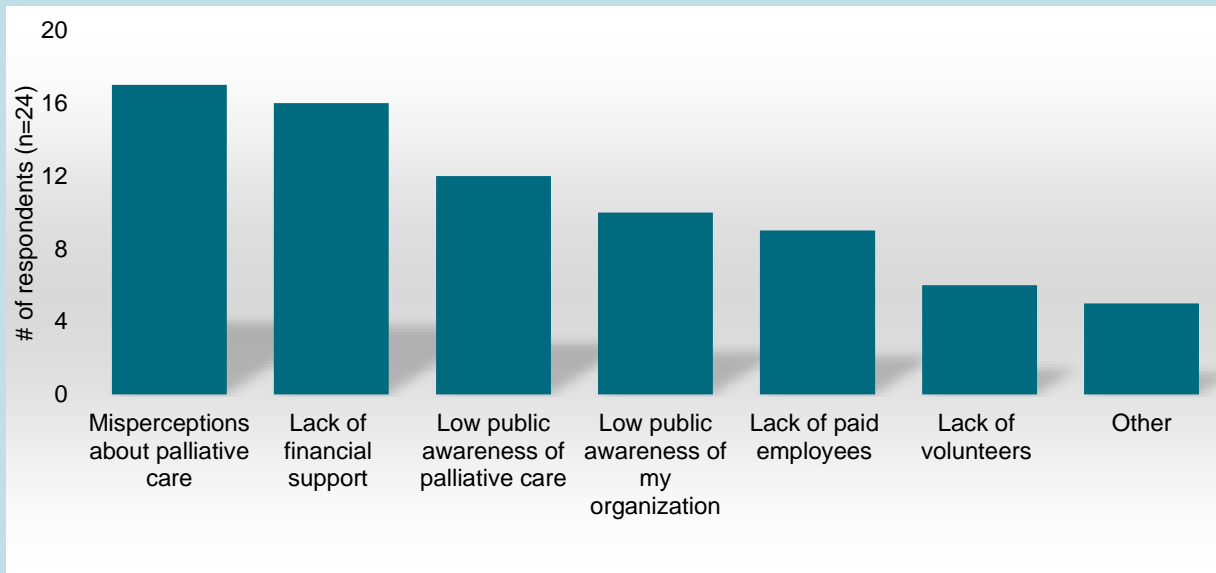


Community Awareness

How aware are people in your community of:



Barriers to the Work





Most Successful Public Engagement Initiatives

Category	Initiative	Frequency (n=24)
Marketing & communications	Social media	4
	Newspaper, radio & TV	2
	Brochures/newsletters	2
	Website & online resources	2
	Word of mouth	2
	Hospice tour	1
Fundraising	Walk/Hike for Hospice, Tree of Hope	10
Public education	Presentations, workshops & speaker series	9
Volunteer training & services	Training for volunteers, grief companion training, bedside respite, pen pal program	6
Grief support	Online & in-person bereavement programs and workshops	3
Memorial events	Remembrance Tree, butterfly release, memorial service	3
Partnerships	Collaborations with other organizations	3
Residential care	Hospice care & palliative care suite	2
Supplies	Comfort kits/supplies	2
None	No programs yet	2
Respite	Hospice day program	1

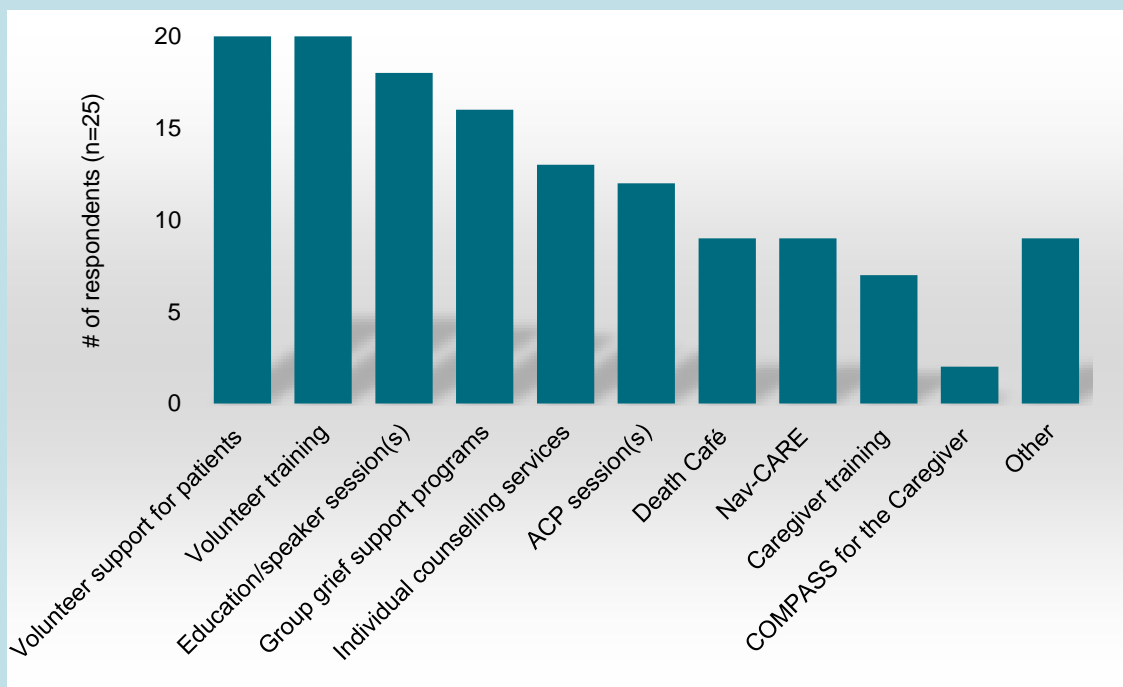
“We have seen that the topics of death and dying are of interest and concern to our community and that holding free public events for information sharing has made a safe space to begin... Raising awareness about palliative [and] end of life care, and a palliative approach to care, can give the person and their family hope for a more comfortable journey, where they want to be.”





Part 2: Programs & Resources

Programs Offered in the Past Five Years



- ♥ Alberta hospice and palliative care societies offer varied programs, many of which are facilitated by volunteers.
- ♥ Several programs are offered in partnership with other organizations e.g. Volunteer training (AHS), Nav-CARE (UBC/U of A) and COMPASS for Caregivers (Caregivers Alberta).

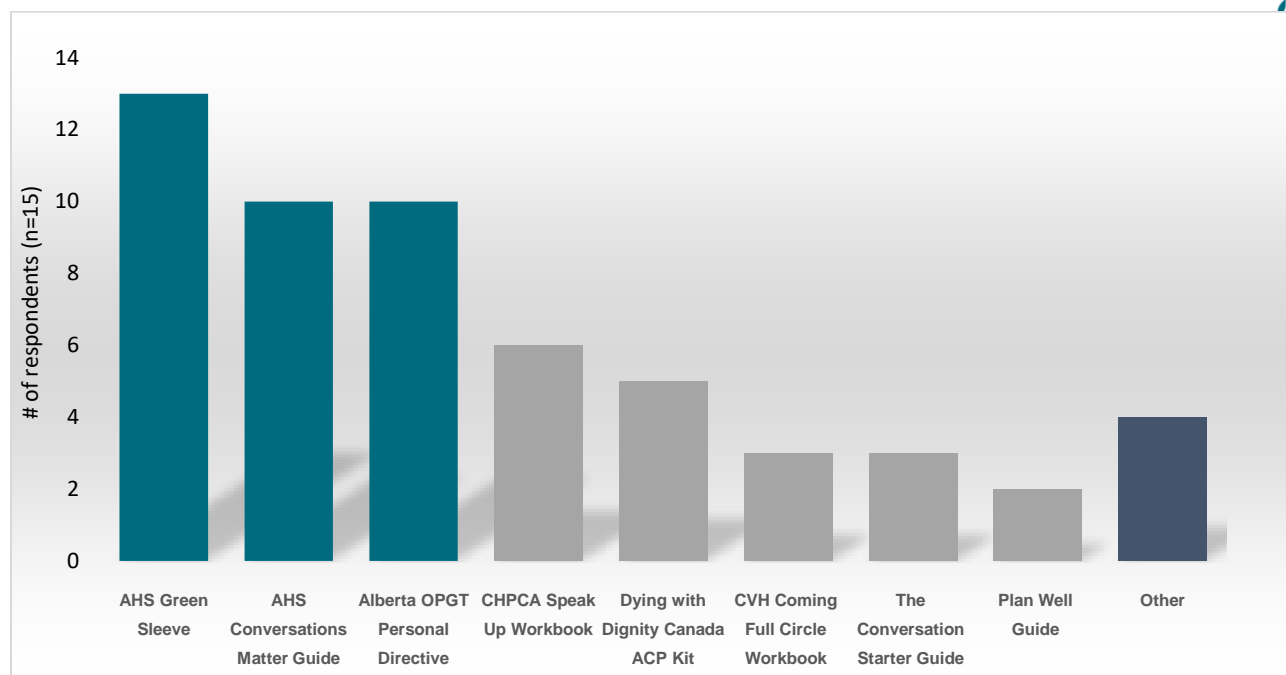
Topics of 'Education/speaker session(s)':

- ♥ Education about palliative care was most frequently offered (75% of respondents).
- ♥ Grief and advance care planning (ACP) tied as the second-most frequently highlighted topics.
- ♥ Education for caregivers and disease-specific sessions were also offered by several societies.





Use of Advance Care Planning (ACP) Materials



- ♥ Hospice and palliative care societies are utilizing a wide range of advance care planning materials, with Alberta resources (green bars) having highest uptake.
- ♥ Survey respondents also indicated high usage of various *interactive* ACP materials such as fillable workbooks and online tools (grey bars), though currently none of these contain Alberta-specific content.



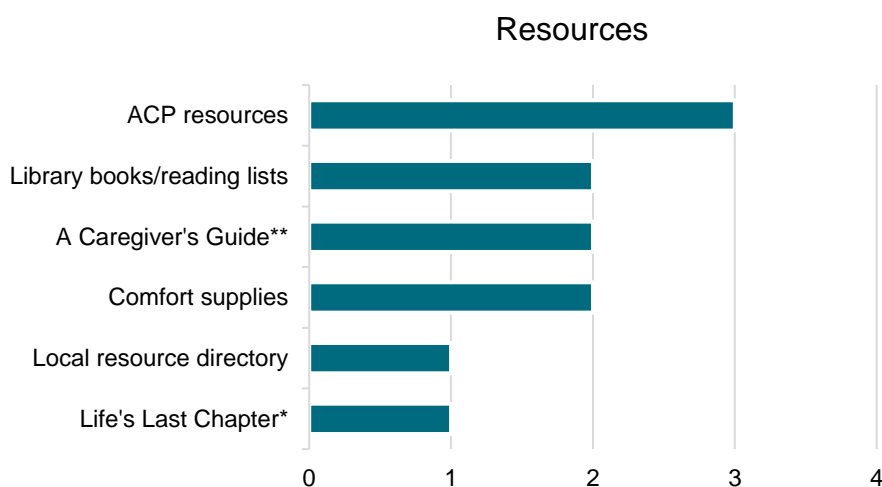
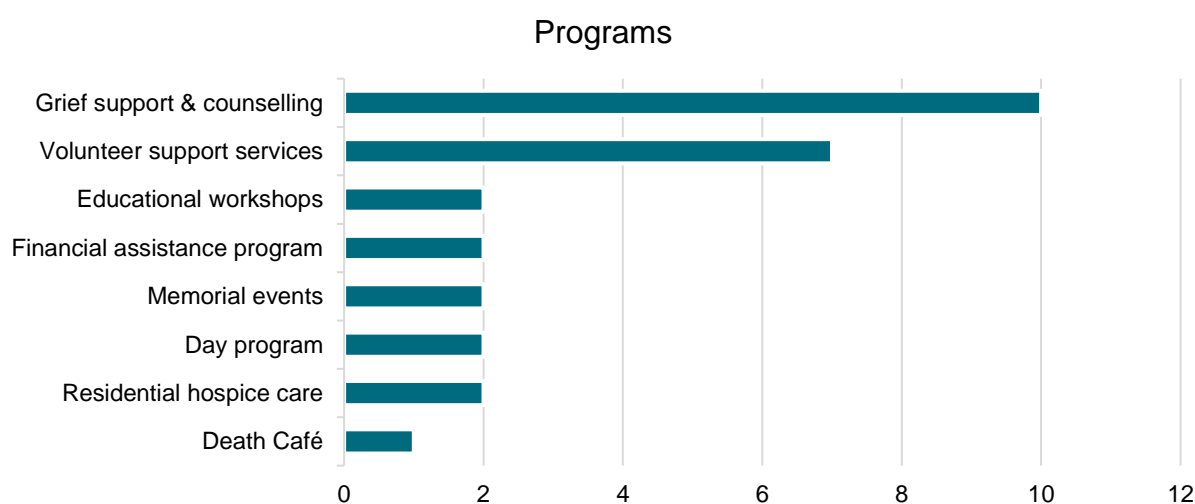


Locally Developed Tools/Resources

More than eighty percent of organizations reported creating their own tools or resources. Most frequently cited were websites, resources for volunteers, and library collections or recommended reading/film lists. Information for patients and families and directories of local resources have also been developed by several organizations. A smaller number offer brochures, activity books, a mobile app, and comfort supplies.

Most Utilized Programs or Resources

of respondents (n=21)



** Canadian Hospice Palliative Care Association & the Order of St. Lazarus

* Hospice Calgary





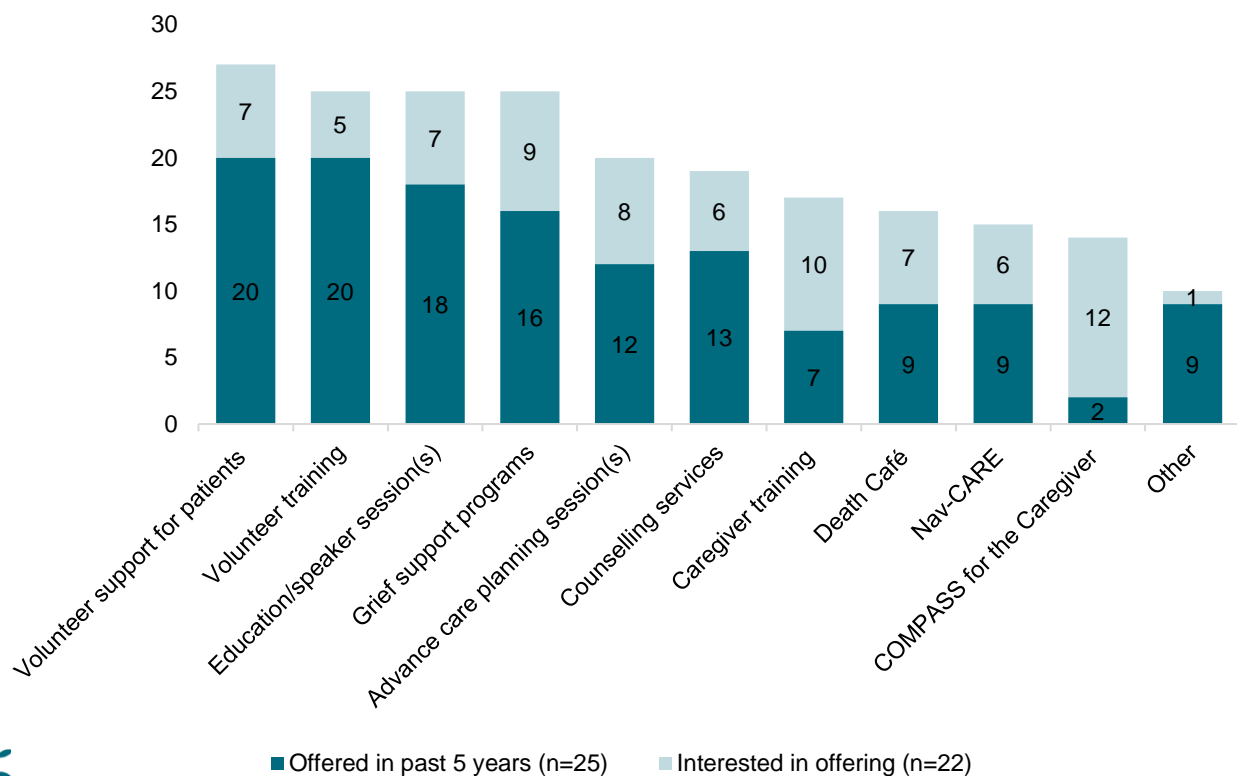
Unmet Needs for Public Education

Seventy-eight percent of respondents identified unmet needs for public education within their community. Among those respondents, general knowledge of palliative care emerged as the most commonly cited need. Knowing how to access palliative care, grief support training, and advance care planning were also commonly identified as unmet educational needs.

Educational sessions and collaboration with other organizations were identified as the top means of addressing these public educational needs. Other plans included offering additional professional support to patients and families, and more volunteer training and support.

“People are still very wary of palliative care and accessing supports earlier in their journey.”

Programs Offered & Interested in Offering





Key Findings

- ♥ **Hospice and palliative care societies provide invaluable support to their communities.**

Hospice and palliative care societies often function with very limited resources, and yet they manage to meet a significant need within their communities, particularly in providing volunteer and grief support to patients and families, as well as public education sessions on a variety of topics.

- ♥ **There is a need for continued education to improve public understanding of palliative care and dispel misperceptions.**

Hospice and palliative care societies have undertaken a wide range of community engagement initiatives, which have contributed to relatively high public awareness of their organizations. However, this awareness does not necessarily translate into optimal community awareness of what palliative care entails, or of palliative care resources and services. Misperceptions of palliative care and low public awareness were identified by hospice and palliative care societies as top barriers to expanding their work. Most survey respondents identified ongoing needs for public education.

- ♥ **Hospice and palliative care societies are keen to participate in additional public education.**

Although many hospice and palliative care societies offer public education, there remains significant interest in additional programming in this area. Survey respondents described a range of strategies planned to address public educational needs.

- ♥ **Community partnerships should be leveraged to expand the impact of hospice and palliative care societies.**

Hospice and palliative care societies have cultivated partnerships with many different community groups, and these are an important foundation for building Compassionate Communities. Prioritizing collaboration amongst hospice and palliative care societies and with other community organizations will help limit duplication of efforts, optimize the quality of programs and resources offered, and ensure all Albertans understand what palliative care has to offer.

“Education for caregivers, for community professionals, for physicians, for family, for school personnel - of those working with or impacted by people with advanced illness: people need the fundamentals so the community has greater capacity to serve people where they access help.”





Conclusion

This report reinforces the important role that hospice and palliative care societies play in raising awareness of palliative care in Alberta. It draws attention to the scope of the programs and resources these organizations provide, and the vital support they offer in communities across the province. These findings also highlight palliative care-related public educational needs and point to opportunities to work together to address the challenges that remain. We believe this information will be of value to hospice and palliative care societies and other likeminded community organizations, and encourage even greater collaboration in caring for those who are seriously ill, dying, caregiving and grieving, as well as strengthen community support for palliative care in Alberta.





Acknowledgements

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Appendix 1: Survey

Name of organization:

Your role within the organization:

Section 1: The following section asks about programs and resources that your organization has provided over the past five years.

1. Which of the following programs or services has your organization provided over the past five years? Select all that apply.

A. Advance care planning session(s)

B. Caregiver training (to provide care for others)

You selected B: Caregiver training. Please specify resources used for caregiver training:

C. COMPASS for Caregivers (self-care)

D. Individual counselling services

E. Death Café

F. Education/speaker series

You selected F: Education/speaker series. Please specify topics or themes of education/speaker series offered:

G. Group grief support programs

You selected G: Grief support programs. Please specify grief support program(s) offered:

H. Nav-CARE

I. Volunteer support for patients and/or families

J. Volunteer training

You selected J: Volunteer training. Please specify resources used for volunteer training:

K. Other

You selected K: Other. Please specify other programs or services offered:

2. What have been your organization's most successful initiatives to engage the public?

3. Has your organization created any tools or resources? Yes/No

If yes: What tools or resources has your organization created?

4. Has your organization provided materials, in person or online, to encourage advance care planning? Yes/No

If yes: Which materials have you used? Select all that apply.

A. Alberta Health Services Conversations Matter Guide

B. Alberta Health Services Green Sleeve

C. Alberta Office of the Public Guardian and Trustee Personal Directive





- D. Canadian Virtual Hospice Coming Full Circle Workbook
- E. CHPCA Speak Up Workbook
- F. Dying with Dignity Canada Advance Care Planning Kit
- G. Plan Well Guide
- H. The Conversation Project Your Conversation Starter Guide
- I. Other If I: Please specify:

5. What have been the most in-demand programs or materials that your organization offers?

6. Does your organization have paid employees? Yes/No

If Yes: How many full-time equivalent employees does your organization have?

If Yes: What are the role(s) of the paid employee(s) with your organization?

7. Approximately how many volunteers are active with your organization?

Section 2: The following section asks about unmet needs and opportunities for new initiatives in your community.

8. Has your organization identified any unmet needs for public education related to palliative care in your community? Yes/No

If yes: What are the needs that your organization has identified?

If yes: How does your organization plan to address these needs?

9. Is your organization interested in initiating any of the following programs or services that have not been previously offered? Select all that apply.

- A. Advance care planning session(s)
- B. Caregiver training (to provide care for others)
- C. COMPASS for Caregivers (self-care)
- D. Counselling services
- E. Death Café
- F. Education/speaker series
- G. Grief support programs
- H. Nav-CARE
- I. Volunteer support for patients and/or families
- J. Volunteer training
- K. Other





10. How would you rate people's awareness of your organization within your community?

- A. 1 – Not at all aware
- B. 2 – Not very aware
- C. 3 – Somewhat aware
- D. 4 – Very aware

11. How would you rate the awareness of people in your community of what palliative care entails?

- A. 1 – Not at all aware
- B. 2 – Not very aware
- C. 3 – Somewhat aware
- D. 4 – Very aware

12. How would you rate the awareness of people in your community of the palliative care resources and services available to them?

- A. 1 – Not at all aware
- B. 2 – Not very aware
- C. 3 – Somewhat aware
- D. 4 – Very aware

13. What are the biggest barriers to expanding the work of your organization? Select all that apply.

- A. Lack of financial support
- B. Lack of paid employees
- C. Lack of volunteers
- D. Low public awareness of my organization
- E. Low public awareness of palliative care
- F. Misperceptions about palliative care
- G. Other If G: Please specify:





14. Which of the following have partnered with your organization? Select all that apply.

- A. Faith communities
- B. Government agencies
- C. Health care providers
- D. Local businesses
- E. Non-profit organizations
- F. Public Libraries
- G. Schools
- H. Other: Please specify:
- I. None of the above

15. Is there anything else you would like to share with us?

16. Would you be willing to be contacted if we have further questions about your organization or about palliative care in your community? Yes/No

If yes, Please provide your name for follow-up (First Last): Your email address:

Thank you for completing this survey. We appreciate your time and input.



Appendix 2: Compassionate Communities Resources



Alberta Health Services: A Resource Guide for Community Development of Palliative and End-of-Life Care within Alberta (2016)

Alberta Hospice Palliative Care Association

BC Centre for Palliative Care: Compassionate Communities Toolkit

Canadian Hospice Palliative Care Association

Canadian Virtual Hospice

Compassionate Communities UK

Hospice Palliative Care Ontario: Compassionate Communities in Ontario (2020 Report)

My Health Alberta: Palliative and End-of-Life Care

Pallium Canada: Compassionate Communities

Public Health Palliative Care International

