



# Airdrie & District Hospice Society Community Engagement Report

November 2016

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## Executive Summary

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**Background:** Historically palliative care developed out of local communities' responses to improve the quality and sustainability of end of life care. "Bill's Story" from the "Let's Talk Series" (Appendix I) illustrates this concept by exemplifying the difference communities can make by uniting to provide care and support for people nearing end of life.

**Project Focus:** The aim of this project was to collaborate with the local community of Airdrie to identify perceptions surrounding end of life care and how to use this information to support further development of community end of life care in Airdrie.

**Methods:** A small team from the Cumming School of Medicine met with members of the community on three occasions, in total talking with twelve different people with various roles in the community. Each focus group was two hours long.

**Results:** The community discussed six important themes throughout the three focus groups: services, support, advocacy, education, collaboration and engagement.

**Conclusions:** Community members would like to see the Airdrie and District Hospice Society take on an advocate role for end of life care in Airdrie. This could be done in two core ways: 1) having a coordinator to connect individuals with services and organize support and 2) focusing on community education surrounding end of life care.

## Demographics

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Of the twelve community members that we talked to, ten were female (83%). Individuals' ages ranged between 36 and 74, with an average age of 54.

## Participant Experiences

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In the focus groups, there was a wide diversity of experience with end of life care. Many of the participants were actively involved in Airdrie's community, worked in a field related to end of life care and/or had experienced being close to someone at the end of their life. One thing all the participants had in common was that they were passionate about improving the support for community members nearing end of life.

## Services

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Many members in the community felt that the current end of life supports and services available in Airdrie were inadequate. Individuals described the distance between Airdrie and Calgary as a barrier to care and support; this divide creates tension between the two communities. Many participants described traveling to Calgary to access services like hospice and grief counseling made an already difficult time more stressful, especially for individuals with young

**“I believe in[Airdrie’s] community and the necessity of meeting end of life care needs where people belong”**

families, as it removed them from their community. The community expressed that Airdrie is in need of a building that focuses on providing end of life care supports and services that can grow with the community. However, the community also realized that Airdrie needs to build its community's involvement in end of life care. ADHS could act as a catalyst to increase community involvement in end of life care.

## Supports

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Bereavement support for people who have lost someone as well as mental health support for caregivers were identified as important needs by the community. Currently available services are often not convenient to access and are primarily advertised solely to the individual's close family. Many community members stated that they felt people approaching the end of their life receive a lot of support, but their loved ones did not. Some individuals felt they were rushed out of hospital after their loved one died and consequently did not receive closure. The community suggested that having open peer support groups would help them work through their grief and feel more connected to their community.

**“It’s [about] a lot more than having a physical building”**

Supporting individuals experiencing grief was identified as very important to the community.

Supports need to be in place before they are required,

because many people feel lost in this situation and do not know where to find guidance. Often individuals felt uncomfortable asking for help as they did not know what they needed and/or did not want to burden their community. One participant stated that “the community needs to

reclaim death” and that this should start by supporting each other. Individuals identified that having regular support groups where people could discuss their grief would guide them through difficult times and help them feel like part of the community.

## Advocacy

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Community members who experienced losing a loved one described the experience as overwhelming. They stated that having a centralized resource guide would have been an invaluable tool to them. When going through the process of losing someone, many individuals did not know what they needed, and said that having someone offer support instead of asking what was needed would have been helpful. Community members related back to wanting a resource similar to “Bill United” (Appendix I), where the community could come together and support one another.

The community suggested that it would be valuable for the Airdrie and District Hospice Society (ADHS) to have an advocate who would help organize volunteers and connect individuals to important resources.

Community members stated that they learned a lot from other people who had already gone through losing someone.

Having an experienced advocate helped

them navigate through things that needed to be done. Sharing this type of knowledge could be done through community networks, which could be initiated and supported by an ADHS

**“Airdrie & District Hospice Society’s role should be to provide the means for volunteers to contribute to their community”**

advocate. Having an informal support network similar to “Bill United” (Appendix I) would help fill service gaps and help access the strong resourcefulness of Airdrie’s community.

## Education

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The community identified education surrounding end of life as an important resource that ADHS could provide. Community members were unaware of the services and supports available surrounding end of life and suggested that ADHS could be a resource to resolve this knowledge gap.

**“Everyone is going to come to the end of their life at some point, therefore everyone should be informed”**

Individuals felt that the young demographic of Airdrie removed people from death and created a stigma around end of life. Therefore, they felt it was essential for ADHS to foster discussion and

awareness surrounding end of life. Having individuals tell their stories has the potential to be a powerful tool in educating the community. Individuals expressed that hearing other people’s stories helped them feel less isolated as it made discussions surrounding end of life more comfortable. It was suggested that this could be done by facilitating “grief groups” for people who needed support as well as educating the general public by sharing stories in the newspaper, on the radio and at community events such as trade shows. This would not only make community connections stronger, but also generate more support for ADHS.

## Collaboration

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The community identified that current changes regarding health care occurring in Airdrie are due to local people taking action. However, a lack of communication between different groups and services negatively impacts care.

**“Every organization has their own focus, but together health care is everyone, we’re all connected. We need to respect everyone’s focus and support each other”**

Individuals believed multiple community groups needed to come together and support each other in order to harness outside support for increased services in Airdrie. The Airdrie Resource Council was mentioned as an important initiative to connect and strengthen different community groups in Airdrie. Collaborating with other groups has the potential to help grow the support for end of life care initiatives in Airdrie, increase community support and address disconnects between existing resources. Additionally, the community felt it was important to connect with other hospice boards outside of Airdrie to learn from their communities’ experiences.

## Engagement

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Community members expressed confusion surrounding the different community initiatives in Airdrie. Increasing AHDS’ online presence may help better define their initiative and increase support from a wider demographic. By further developing a stronger community presence, ADHS could become an essential asset to Airdrie’s community. Focusing on educational



initiatives, such as the speaker series that ADHS currently runs could help increase community awareness and support.

Individuals who were eager to be involved with ADHS expressed frustration as they had contacted ADHS multiple times and never received a response. As a result, potential volunteers committed their time to hospice organizations outside of the community.

Some of the community members described ADHS with disaffection partially due to their lack of understanding of ADHS goals. This perspective is beginning to influence community support and should be addressed to prevent negative influence. Further learning about the

**“Airdrie and District Hospice Society needs a stronger presence in the community”**

characteristics and complexities within Airdries community could make ADHS a better resource to the community. Community members who did not have young families felt excluded from the

community. In order to truly play a role in enriching the community of Airdrie, ADHS must engage with the community in a relevant manner. This is particularly important for engaging with people who do not consider themselves part of the community. Exploring alternative avenues to reach diverse populations within the community could help increase support for ADHS.

It was suggested that having a community advocate could help ADHS navigate community networks and keep potential volunteers engaged by focusing on communication with individuals who expressed interest with ADHS.

## Conclusion

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While the community brought up the need for increased services in Airdrie, the main focus was on the role community should play in supporting each other one someone is nearing the end of their life. Community members would like to see ADHS take on an advocate role for end of life care in Airdrie. This could be done in two core ways:

**“It takes a community”**

1) having a coordinator to connect individuals with services and organize support; and 2) focusing on community education surrounding end of life care. Collaborating with other community groups and engaging with the community would support these two areas and help ADHS achieve their goals.

## Next Steps

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It is hoped that the community’s perceptions and suggestions captured in this report will provide insight for ADHS to reassess their strategic direction and approach. The community expressed strong interest in a community night where this report could be presented and discussed. SPaCE at the Cumming School of Medicine is interested in continuing this dialogue and working towards increasing community capacity collaboratively within Airdrie with ADHS and community members.

## Appendix I: Helpful Resources

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- Information and support on palliative and end of life care, loss and grief:  
[http://www.virtualhospice.ca/en\\_US/Main+Site+Navigation/Home.aspx](http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx)
  - <http://www.mygrief.ca/>
  - <http://www.livingmyculture.ca/culture/>
- Milford Care Centre, Bill's Story: Talking Together, Facing Death and Dying.  
<https://www.youtube.com/watch?v=5tJGaWjRZk>
- Volunteer Alberta: <http://volunteeralberta.ab.ca/volunteer-police-information-check-program/>
- Serving Communities Internship Program (SCIP):  
<https://www.joinscip.ca/organization-faqs>
- Funding option: <http://www.culture.alberta.ca/community/community-grants/community-initiatives-program/>
- Funding option: do a casino to pay for administration support:  
<http://www.aglc.ca/casino/>