

This summary is result of dialoguing with community partners. We held a session in December 2016 to discuss a proposed End of Life Strategy. The goal of the dialogue was to begin discussion with key community partners in Richmond to gather feedback and a better understand of the needs of our community. We also had the opportunity to engage with the Richmond Intercultural Advisory Committee in January 2017. VCH Richmond wants to improve on and support the best quality of life and choices for individuals and their families when they are living with a life limiting illness. These opportunities for dialogue allowed us to share information about End of Life services and initiatives in our community and to ask participants to share their ideas on engaging our community on this topic.

What do you feel is important for VCH to know about your community, its cultural norms, beliefs and needs as they relate to health care and specifically to end of life care?

- Often the decision related to choices at end of life are not personal decisions; they are made within the family unit and intergenerationally. Approach these discussion with the family unit.
- Professional interpretation services are important to provide in order to support informed decisions.
- Generally people are not aware that support is available through the whole end of life trajectory; need to support advanced care planning and raise awareness of the services provided.
- There is a good level awareness of cultural norms and protocols within the funeral planning industry; tap into it.
- Consider partnering with funeral planning related to education on end of life .
- Need to be clear and direct with patients and families; ask what would you like to do next? who would like to talk to about a decision?
- There is lack of knowledge in communities on what medical and other care is available to patients at end of life.
- Consider how to integrate alternative therapies into palliative care.
- In the disability community many people have chronic health concerns but it is not often they discuss the topic of end of life.
- Concern exists that the health care community will pressure individuals to create DNR orders even if the individual is not ready to do so.
- Generally Asian cultures do not want to discuss end of life or know about what resources are available in the community. Family members who are 2nd or 3rd generation Canadians may be more approachable on the subject.
- Families would welcome knowing what services are available to support them and ease the burden of caregiving for their parents.
- The concept of a palliative model of care is not the norm; the curative model is still more accepted.
- People need to trust that they will be cared for and their wishes, related to care, upheld. This needs to be explicitly stated to comfort and assure patients and families.
- Within the HIV/ AIDS community the advancements in treatment have shifted the culture to be one of living with the disease instead of dying from it.
- In the Muslim community, generally, the will of God is the guide that people use for decision- making. This community would support dialogue to encourage understanding of how to align their options related to the palliative model with the will of God.
- Partner with faith communities to bring a deeper understanding to people of end of life options. Offering choices is easier than asking “what do you want?”
- Need to communicate the concept of pain management in a way that is understandable and relays the meaning of the treatment and how it can support people to manage their chronic conditions and maintain an acceptable quality of life.
- Gain understanding of how many residents/clients live alone or have family that lives away. Engagement with this population would need to be tailored to accommodate them.
- Are there options to accommodate families, who live out of town, and want to stay near family members who are at end stages of life.
- There is a need for a Wish Foundation for adults. There are two such organizations; Dream On Seniors Wish Foundation <http://dreamonseniorswish.org/> and Lasting Magic www.lastingmagic.org
- Clients, patents and families need tools and resources that can support them in the discussions; what to say, how to say it, what to expect. A guide to help them navigate through this phase of life.

What do you feel would be the most respectful and effective way to engage with the community on the topic of end of life care and services?

- Go out to the community to build relationships early. Before you want something from the community it is important to give something to the community.
- Acknowledge the vast range of diversity even within certain cultures; there is no one way to support one culture.
- Consider how to incorporate discussion on alternative therapies and practices that honour and respect honouring traditional beliefs.
- Consider the terms and words used to discuss end of life decisions. Palliative translates in Chinese to dying well. This may not be conducive to inviting conversation. Need to find a word that people can relate to and translates as relief or support to help patients and families feel better at this stage of their life journey.
- VCH needs to be open to seeking different terms/language to engage with our communities on the topic of end of life
- Consider the development of a brochure titled “How to Honour my Loved One” that can be provided to families early on in the planning trajectory
- People don’t want to just focus on the topic of death they want hope and to focus on living or quality of life. Consider using language that focuses on living well and respecting choices.
- Integrate the topic into community based info sessions.
- Set it into the context of the wellness and connect it to advance care planning sessions.
- Create mechanism for it to be discussed at various health care interactions not just at the stage of end of life
- Develop and deliver education to staff about cultural values and beliefs so they can communicate on end of life

What do you feel would be the most effective way to inform the community of these upcoming engagement sessions?

- Connect with Richmond Multicultural Community Services Seniors Group
- The temple on No. 5 Rd.
- Faith communities
- Community centre groups
- Richmond Youth Services Association Family night
- Join community committees
- Partner with City of Richmond Older Adult programs
- Provide education on the choices available to an individual and their family/caregiver
- Partner to deliver information alongside Advance Care Planning sessions.
- Provide training and support to GP’s and specialists to engage in the conversation with patients and families
- offer sessions at various times including weekends to increase access for family members to participate
- Find locations that are easily accessible and familiar to people
- Create a toolkit that will enable people to continue to have the conversation with loved ones following an information session

- Programs on wills, estate planning and funeral planning are very popular at local libraries. Partner with them to provide info on planning for end of life.
- Library can be a support to hosting discussion e.g “What does the Muslim community think about death?”
- Does our western approach where the individual is the autonomous decision maker impede our process to engage the community in these conversations in culture where as an example the eldest son is the decision maker.
- Shifting this culture and beliefs will take time.
- When engaging with communities it is important that VCH not come with an agenda but take an approach that through engagement the strategy will evolve.

How will this feedback be used to inform planning for community engagement on the End of Life Strategy?

In alignment with the Ministry of Health areas of priority the VCH Richmond Community of Care will continue to bolster the range and the scope of the care continuum for residents and families facing the end of life; supporting choice, access and quality of life.

The goal is to: *To provide safe, quality care at **the right time in the right place** with the **right resources** in place for all patients through strong acute and community partnerships*

This preliminary engagement with community leaders will:

- Change the way we will proceed to develop our overall community engagement plan to ensure the feedback and suggested ideas are integrated
- Ensure the input will be reflected in any information we develop and share with future groups
- Inform the principles guiding our team’s work in palliative care
- Ensure we are sharing the notes from this session with our whole team so that they can also incorporate relevant feedback into their day to day care provision

Community consultation and collaboration is essential to achieving our goal. This first stage will be about us consulting with community reference groups and cultural community leaders to inform our community engagement strategies. The second stage will be the implementation of community engagement strategies with the future vision of sustainment of community consultation and collaboration to better support our communities End of Life needs and goals.