

# If not you, who?

Advance Care Planning Day is April 16



## A family caregiver and the gift of conversations: Della's Story

Della is a palliative care nurse with over 25 years' experience in British Columbia with a wealth of palliative care knowledge and expertise in serious-illness conversations and advance care planning. She is also navigating through a unique situation – she is a caregiver for both her father and her sister.



*Della Roberts and her dad share a laugh.*

Stressing the importance of education and support around advance care planning, Della shared her experience of working with the health care system to develop a care plan and determine next steps for her 92-year-old father who has many chronic conditions including vascular dementia. She found his health team provided limited advance care planning guidance. Luckily, she had the experience and the understanding of how important these conversations are in determining a care plan and was able to align father's wishes with his care, drawing on previous talks with her dad about questions such as, "who do you want to speak for you, and what abilities are so important that you can't live without?".

Della shares that with her father and sister, the conversations about advance care planning were about similar questions but felt very different: "In these conversations I am not a nurse, I am a daughter and a sister, and as family members we feel first with our hearts and then with our heads," Della says.

**"IN THESE CONVERSATIONS, I'M NOT A NURSE ... I AM A DAUGHTER AND SISTER, AND AS FAMILY MEMBERS, WE FEEL FIRST WITH OUR HEARTS AND THEN WITH OUR HEADS"**

### **Della's Tips:**

*Questions can help when navigating the unexpected.*

*ACP resources are very helpful. They allow you to know the questions to ask. There are lots of emotions and feelings present and these practical resources are extremely helpful in having these conversations.*

*Start these conversations from where you are. Ask yourself if the people, situation, or place are the best combination for a fruitful conversation. And remember that this conversation will be one conversation among many... and they'll be influenced by the connection you already have with your family member or friend.*

*Have conversations early since early conversations create guided decisions.*

*We worry about the health of our loved one and about having these conversations because they feel hard. Worry is just a message to tread carefully, respectfully and to be mindful. Don't close the door and walk away because you are afraid. Just proceed cautiously.*

Her sister, who is in her sixties and has advanced frontal lobe dementia, was a particularly challenging and emotional situation for Della and her family.

DELLA EMPHASIZES THE IMPORTANCE OF NOT ONLY KNOWING THE TYPE OF QUESTIONS TO ASK, BUT ALSO MAKING SURE THAT THE CONDITIONS ARE RIGHT TO ASK THE QUESTIONS.

“It is a family member who is ‘dying at the wrong time’. It isn’t natural” she states. “Situations like these can become emotionally challenging for family caregivers and advance care planning conversations become even more important. These words are a gift to guide us through the emotional transitions to come.”

Della emphasizes the importance of not only knowing the type of questions to ask, but also making sure that – as much as possible – the conditions are right to ask the questions, such as who is in the conversation, whether the location is quiet or busy, even what time of day. Family caregivers may find themselves navigating through changing relationships. Whether it’s due to your loved one’s wishes or other factors, you might not be the best person to lead the conversation. If you are having challenges, get support from others - health care providers, friends or family members.

“Families can be complicated, and we need to understand how relationships evolve,” Della says. She shares that her father found love again after her mom passed away, and as his health began to decline a conversation was necessary with his partner. Her father’s partner advised that she did not want to make decisions on his behalf and felt that his family would be more appropriate. Della shared that the advance care planning questions not only helped in this situation, but that the “the questions can inform you, as the decision maker, down the road”.

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For Della, advance care planning conversations, while unfamiliar, are gifts that can create an even greater bond within our families. “What advance care planning does - these conversations equip us to support future decisions and brush away tensions and worries that might interfere with time and enjoying the present.”

### **About Della Roberts**

*As Special Projects Manager, with the BC Centre for Palliative Care, Della uses her impressive experience to inform and lead the development of priority projects for the Centre, advancing its mission and taking on roles that are critical to the Centre’s success and growth. With over 25 years’ experience with three BC health authorities, Della brings important perspective and insight to her work at the Centre. As a palliative care and end-of-life care leader, Della played a key role in creating systems to support the practice of palliative care, notably the BC After Hours Nurse Line, a community palliative care operating model and a decision guide for timing home care nursing visits for palliative care.*