

It's time to talk about advance care planning

Walking the Talk:

Advance Care Planning Conversations Get Personal

Kathy Kennedy is something much more important than an expert in advance care planning – although she certainly is that – she's a loving daughter who has seen its value up close with her own parents.

"Over the years, there has been a shift in the focus of advance care planning," Kathy explains. "Now, the emphasis is less on completing documentation and much more on the conversations about your values, beliefs and wishes for your future care. The conversations are what matter most."

Professional met personal 10 years ago when Kathy's increasingly frail mother was diagnosed with cancer. As a family, they had no documentation in place, and hadn't had any direct conversations about advance care planning, but one thing her mother was very clear about: she wanted to die at home.



Kathy enjoying family time with her dad, Hume, and her youngest grandson, River.

It was the family's north star guiding any care decisions, and the strength of that north star was tested a few months before Kathy's mom's death when a health crisis meant hospitalization. Because of her mother's clear wishes, the family, along with their palliative care physician, was able to ensure that every treatment decision was made with an eye to getting her home as soon as possible.

With Kathy's dad Hume, the advance care planning process began just a few months after his wife's death. For him, the first step was to get the documents locked down, including a representation agreement from a form they found online.

Kathy's tips

- ✓ Take into account the individual differences in decision-making and starting advance care planning conversations. They may like to include a large group, or keep it one-on-one.
- ✓ Understand that you won't cover everything at once.

 Think of it as an ongoing conversation, and it's okay to take it in small doses.
- ✓ Take some time to clarify your own thoughts before opening the conversation. You may not have all the answers, but it gives you a place to start.
- ✓ Think small, even while you're thinking big.
 Sometimes what's important to you are on the big bucket list but think about what's good about the everyday.
 Small things that we have control over are valuable and worth noting.

"In the 10 years since mom died, we have had lots and lots of conversations, and the conversations have changed over the years," says Kathy. "What was quality of life 10 years ago has shifted to accommodate changes in Dad's health. He's 95 now and as long as he's still enjoying life, he wants to be here."

Kathy and her family make a point of renewing the conversation when there is a change in Hume's health, but conversations can also be sparked by items on the news or by friends' experiences.

"We're really on the same page when it comes to values and wishes. And when a health crisis comes, we're not trying to establish common ground... we've already got it."

Kathy started with writing her adult daughters a letter, in which she talked about the things she appreciates day-to-day and giving them guidance on how to make decisions for her, if she can't do it herself.

With her own daughters, Kathy is already having those all-important advance care planning conversations, sparked by the COVID-19 pandemic. While she hasn't prepared any legal documents, Kathy started with writing her adult daughters a letter, in which she talked about the things she appreciates day-to-day and giving them guidance on how to make decisions for her, if she can't do it herself.

"Talking about advance care planning is ultimately about caring for people. It's a wonderful, intimate way to know someone, and is precious for both people involved." Writing and discussing the letter with her daughters was tough, says Kathy, and quite teary. "There is a lot for them to take in and think about. And there's one part that they strongly disagree with and have asked if that can be negotiable. Shows the importance of ongoing conversations!"

That's not to say starting these conversations isn't hard.

According to Kathy, it helps to allow yourself to talk in small doses over time.

"Ultimately, talking about advance care planning is about caring for people," concludes Kathy. "It's a wonderful, intimate way to know someone. Getting to know them on a deeper level and sharing wishes that may never have been articulated before is precious for both people involved."

About Kathy Kennedy

Professionally, Kathy Kennedy began work in advance care planning (ACP) more than 20 years ago with the Alzheimer Society of BC, where the focus then was on the broader area of personal planning and legal documents. In 2017, she joined the newly formed BC Centre for Palliative Care and became involved in developing, training and promoting advance care planning in British Columbia. She is still with the BCCPC and more passionate about ACP than ever.

Learn more

Find more information about advance care planning and Advance Care Planning Day 2021.