

If not you, who?

Advance Care Planning Day is April 16



Life happens when you least expect it - Jas's story

"Life is what happens when you are busy making other plans."

– John Lennon

For Jas Cheema, a single mother with two teens on the cusp of adulthood who was also managing a busy professional life, community leadership responsibilities and an active extended family, this statement couldn't have been truer. With Advance Care Planning Day coming up, we sat down with her to discuss how having a plan supported her in navigating a very difficult time.

In the few weeks between Halloween and Christmas in 2014, Jas's life took a drastic turn when she was diagnosed with cancer. Always a go-getter and used to taking a leading role in her family and community, all of a sudden Jas was faced with balancing her already busy schedule with a full year of medical appointments, surgery, radiation and chemo... and the uncertainty that goes along with such an illness.

"Worst Christmas present ever!" Jas is able to laugh about it now.

"The irony is that I had just come through some very big changes in my life, and I felt that everything was finally falling into place, I was looking ahead with hope."

Breaking the news

Jas, who comes from a closely connected Punjabi-Canadian family, now had to figure out a way to tell them the news, and talk – really talk – about what was ahead.

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"I just called everyone together and made one big announcement... which was met by dead silence, and then my sister and a cousin tried to joke it off," says Jas. "I didn't realize just how big a shock it would be for them, and how much they just weren't ready to hear it."

The next morning (at 7am!), her parents who weren't able to attend the night before, were at the door. "My mom kept saying things like 'it's nothing, probably just a cyst', 'you're so healthy', 'doctors can make mistakes'. I just kept repeating 'I've done all the tests...Mom, I have cancer'...over and over until finally she was able to digest the news, bringing her to tears..."

Sharing her wishes

One of the first worries Jas had was making sure all her estate documents and health care wishes were up to date so that the kids wouldn't need to worry about anything and that they would know how to handle things if she wasn't able to speak for herself.

Jas was already familiar with advance care planning (ACP): she had been involved with advance care planning training in the South Asian community and had worked at Fraser Health developing and translating culturally sensitive ACP information into Punjabi.

"It's one thing to know about the Think, Talk, Plan steps of advance care planning, and another thing to walk through the process," says Jas.

Although I never needed to rely on my advance care plan through my cancer surgery and treatment, it brought me a great deal of peace of mind to know it was there.

She says that thinking about 'what ifs' and reflecting on what her wishes would be was a very moving experience... and a valuable one, since it encouraged her to look inwards to explore what mattered most in her life. Before her diagnosis, she had been so busy and focused on other people that taking time for this kind of reflection wasn't a priority.

Once she was clear on her own wishes, beliefs, and values, it was time to talk to family members about what she wanted and who would speak for her if decisions needed to be made and she wasn't able to make them.

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The conversation continues

Like any life plan, advance care planning isn't a 'one-and-done' event; it needs to be revisited, reviewed and revised when your life circumstances or wishes change.

In the years since Jas's illness, the conversation about advance care planning has continued within her family.

"My illness took a real emotional toll on the kids, seeing their mom needing care wasn't something they had faced" says Jas "I was always the glue that held things together, seeing my vulnerability and strength taught them some important life lessons on going with the ebbs and flows of life and trusting that 'this too shall pass'".

"Having conversations around my health care wishes and advance care planning is a bit more comfortable now, and now that they are older, they are more able to understand and value the process.

They've also seen the consequences of unfinished business and a family not knowing someone's wishes, so they understand the benefits of having ACP conversations, even when it's hard."

"Both of the kids know what I want and although culturally, the more natural choice would be to have my son as my substitute decision maker, I have chosen my daughter to speak for me... she is a Social

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Worker who understands the healthcare system, is well-spoken and self-assured, so a good substitute decision maker for me."

When Jas talks about lessons learned through her experience, she shares a few good ones: "One truth is that, in life, things happen, and some of those things

can be challenging. Being prepared will help you ride those waves. Another truth is that, when it comes to family, the more comfortable I can be talking about being vulnerable and my healthcare wishes, the easier it is for others to hear, and the richer those conversations become."

Finally, Jas says she would encourage everyone to start their plans today! The BC Centre for Palliative Care has some [great resources that can help you get started](#).