



Jeff - First Nations Caregiver

You have to make some sacrifices in your own life to be able to spend some quality time and not have any regrets with that family member with cancer, but you have to take care of yourself too.

My name's Jeff Cook. My sister was Jean. She passed away from colorectal cancer on March 23rd, 2007. I was her baby brother and I helped her in her last two years of her life.

The diagnosis

I remember the appointment with the oncologist where he told her that she had two years to live. Being the family member with medical background, I was appointed — and it was also assumed — that I would be going to all of my sister's appointments with her. I'm glad I did because she heard half of it and I had to translate half and remember the other half. But I didn't mind doing it. I helped her with that. And I remember after that appointment having to tell her that meant she had two years to live. And that she was going to...die. So whether it was a reflex — where she didn't hear it and didn't think about it — and you know of course, it was quite a shock, so she didn't take it all in.

Different roles

There were certain things that I dealt with in a professional way, rather than a sibling/family way. I dealt in a professional way where it was a procedure, it was an interview, it was an appointment, and this was information, and so could distance myself to a degree and look at it professionally. But, obviously, when I was with other professionals, I could be professional. I'm surprised how quickly and easily potentially I could snap into that even though it's my sister. But at the same time too I'm not surprised because of the independent personalities that we're kind of guided to be. Because of the independent personalities we all have, I think it's one of those things where the whole is greater than the sum of its parts. I think that's the same with our family.

Conversations

Because my sister was given sufficient treatment to maximize her life, we were able to have these candid conversations about finances, about wills, about do not resuscitate orders — conversations that you don't have until you have to. The same sort of thing happened in terms of where she was going to be, where she was going to stay. She wanted to stay at home for as long as possible and that was fine. I tried to help her with that too with the work that I do, try to find equipment or give her techniques to stay at home for as long as possible. But she was aware, and again she had the time to accept where she was and what was happening, and so when the point came when the amount of attention and care that she required superseded the amount that was available to her in the community and homecare programs, she understood what was happening and where she was and she got excellent care at the palliative program where she stayed and her life ended.

Palliative care

When she went into inpatient palliative care it was mixed emotions you know, you wish she could stay at home longer. It was the fact that she had accepted where she was — didn't mean the rest of us had accepted where she was. It was...it's a pretty blatant, obvious slap in the face in terms of where she was within her life span. It

was a positive experience...it's funny to say but it was a positive experience because of the people that worked there. And I've heard those stories over and over again — that the people that work in these programs are exceptional people that, and I concur, not everybody can work in that setting. My mum stayed with my sister for the last weeks that she...my mum stayed with my sister for the last weeks that she was in the palliative program, night and day, stayed there...nurses getting her some lunch and extra tea, a teabag for her water and things like that, they took care of my mum almost as much as they took care of my sister. So when my sister passed away, you know it was emotional for my mum, saying goodbye to the nurses as well. So there was a lot of emotions around the time — positive and negative. Just because we had the opportunity to talk about it didn't necessarily make it something so easy that we slipped right into it seamlessly. There was plenty of challenges with that too.

Sharing your situation

It's a compromise that you have to make, in your own sort of way that you live your life, that you have to be able to communicate these things with the people around you. You can choose how far you want to talk about these things and people approach you in different ways. And people will want to hug you that you've never hugged before in your whole life and those things will happen. But you remember that I did this now to save me time later so that I don't have to communicate later. I can all of a sudden take these days off and it's not a surprise where I just all of a sudden don't show up for work... I think, you know, it's communicating. You don't have to tell everybody everything all the time but you do have to let some cracks happen and let some people see in. And I think that's a healthy thing. As advice, I think that's something that people should do too.

You just do it

You can't give advice to anybody about 'this is the plan', or 'read this book', and 'go to this website and this'll totally help you know every step that you need to do to help be a caregiver to somebody going, and fighting cancer'. You just do it. And nobody knows the strength they have until they're thrust into a situation like that. So we just did it. The fact that our family has had challenges in the past — like most families — but we've had some pretty unique challenges in our family, that helped make us stronger. That maintained or maximized communication. Those sort of things were established in the years prior to... Maybe those were the things that helped us so we were ready to —prepped us — so we were ready for the challenge of my sister with her cancer. We didn't sit down and have a family meeting and say, 'Okay, I'll do this, you do this, and we'll meet over here'. Like you do with a fire escape plan or something like that. Things change. Cancer is a diagnosis and how everybody fights it and how some people decline with the cancer is different and is the same but it's different for everybody. And so as it changes, then plans change. So you just do what you got to do.