



Carol O'Rae
Terminal Ovarian Cancer (10:38)

My name is Carol O'Rae. I'm 56 years old, living in Torbay, Newfoundland. I was diagnosed with cancer of the cervix when I was 31 and 22 years later I was diagnosed with terminal ovarian cancer. I've currently finished all treatments and there are none scheduled on the horizon, so we're living with cancer.

Waiting for my cancer to return

In April of 2009, I went into emerg and they did a scan, or I don't remember if it was a scan or an x-ray. Anyway, they saw the tumour right there and actually the doctor came in, a doctor I hadn't seen before (you know, you're in emerg...) and he said: you have a very large, very unusual tumour on your colon and chemo is not going to help you. And that is how we found out. And he said "you don't even look surprised," and I said "I'm not really" because my first thought when he told me that was "it's finally happened." You know, you can stop worrying about it now. And I didn't worry about it all the time, but you live from checkup to checkup. Is this the checkup where they're going to find it again? And that was the way I lived anyway. And so, when they found it, it was a shock but it wasn't really a surprise because I had been really warned about it. In fact, one doctor I had told me that it was very likely that down the road, within 10 to 20 years, I would have a recurrence. So I chose to look at it as: "I'm living with it, not dying from it." I'm not really big on mottos but I just thought of it as that way.

Facing a terminal diagnosis

The first thing that I did with both doctors that I had seen, the first thing I said to them is "I don't want a hard death" and, you know, "are you the kind of doctor who believes in preserving life at all costs and if you are we are not going to work well together." So that was the biggest issue for me. I accepted right away that it was terminal... You know, not in a defeatist sense but the results were in and that was it, and so then it was like, well, how can I live with this for as long as I can. And my goal was always to buy time on this side of the bed. I wasn't looking to buy time to be bedridden for three years, you know? So that was the first thing that I did with regard to the doctors. That concerned me more even than the treatment. I knew the treatment was my choice and I could stop it at any time but I just did not want a hard death and I wanted to know that my doctor was going to take that journey with me, so that was the first issue I resolved.

My day to day

I have good days and bad days and for a while I was having good weeks and bad weeks. We're lucky, we're retired military and his children are grown, they're adults, and I don't have any. And we don't have to work, so I have the luxury of being sick. And so it's really just, enjoy good days and baby yourself on the bad, and that's it. You know, you kind of monitor things and you know what's right for you and what isn't. I've been living like this for 25 years anyway, because of the

previous one, where that caused so much damage that really the symptoms haven't really changed. So it's a little worse than it was, like I'm more restricted and my diet is bland but it's..., like I said, I have the luxury of it. It's just not really a big change for us. It wasn't a new experience. It's new that it's terminal – I wasn't told that it was terminal before but if you have cancer you're worried it's terminal anyway, so emotionally, it was really the same. Putting the word terminal on it didn't really change it a lot for me.

Being pragmatic about the future

One of the first things I did was get a medical directive and a living will and you got all that done and put it on file, understanding that they're not obligated in any way legally but it helps to have it. So I did all that and I made up, I call it my death binder. I put together things for my husband to do when I'm gone like who he has to contact. Because I take care of the finances and all that kind of thing. And I put the financial information in and who to contact and what's going to be available and what government departments... as much as I could. Basically a checklist for him. So that was one of the first things that... and I already had a will but I updated it. But putting together the information for him was I think really important because, you know, you see and hear of people who, especially if there's a sudden death, they're completely lost. They have no clue – especially if one partner did the finances, the other doesn't even know what bank they're at. You know, that kind of thing. I've seen it and so that... we're very pragmatic about it that way. I asked to go to the palliative care unit because you have the option of going there or being at home and so I said, well, I'd like to know, you know, what it entails and so I'm going to go down there and do a tour and talk to the people because I said, I didn't want the first time meeting these people to be when you're carried there by ambulance, you know. So, I've met the doctor there, so it's just... You know, I've got most things in place now which really takes a load off your mind. Or did off mine anyway.

Don't feel that you need to protect me

People, with the best of intentions, quite often end up isolating the patient and when the normal frustrations and irritations of the day... people don't tell you because what you're dealing with is so much heavier. And they don't realize that they're denying their wife or mother or whatever the opportunity to be supportive and to be there for you and to feel that maybe you're helping. Or that you're helping at least by listening and maybe you may have more concrete help to offer. But people say, "I don't want to tell her about that, she doesn't need to be worrying about that" and the end result is, you know, the patient becomes isolated and that's not good. Because you don't feel useful, you feel like your family doesn't need you. I mean there's all kinds of emotions attached to it and for sure it does more harm than good.

Providing Hope

There was a young woman in the chemo unit, her first treatment. And she was late 20s probably. And she had ovarian cancer so I told her, yes I have it too, and I'd been diagnosed in 2009 and they thought that would be my last Christmas if I saw it and all that, right? And I don't look sick usually, you know. It's not that I'm well all the time but you only go out when you're well. You know, so people don't see you when you're white as a sheet and that. But to her, she couldn't believe that I was terminal and she said to me, "you don't know how good it is to see and talk to somebody who looks totally normal, and healthy and so it gave her a visual of what it could be. You know that yes, you may go through a period where you lose your hair but you're going to come out the other side of it. So I try to make myself available that way and that's

become more important. I mean, there's not much you can do for me, is there a treatment or is there not? You know, that kind of thing. But there aren't many changes you can make really, so all I can do now is what I can for someone else.