

Episode 1: Finding Your Voice

Guest: Louise Binder

(Host) Michelle Jobin: Dialogue in bold

So many Canadians are engaged in the fight against cancer every day. Not just patients and those who care for them, but also healthcare professionals and researchers and people who work for hospitals, insurers, and governments. Cancer is so widespread that it affects almost everyone. At the same time, the fight against cancer is one that everyone can join. And that means patients, their caregivers, and healthcare professionals. Ultimately, everyone who gets involved in this fight wants the same thing, a better outcome for patients. Our determination to help people brings us all together and it gives us a common purpose. With this podcast, we are giving Canadians a look behind the scenes.

This is *My Time, My Voice*. I'm your host, Michelle Jobin.

In *My Time, My Voice*, we're going to hear from some of the people working on the frontiers of cancer care. But first, I'll tell you a little about myself and my family's cancer story.

Gosh, how do I talk about my mom? My mom is great. My mom has always been one of those people that is very interested in health and wellness. She's always been very active and wanted to instill that in myself and in my brother.

So in 2006, my mom noticed something that felt wrong in her mouth actually. And she went to an ear, nose and throat doctor who was quite certain that what it was was a stone or a calcification in her salivary gland, which he assured was quite routine and would just be a quick surgery to take care of that.

Upon going into the surgery, it was discovered that this was definitely not the case and that it was in fact a tumor. So what this was, was called a mucoepidermoid carcinoma of the submandibular gland. So she went through a surgery that was called a radical neck dissection, which is as life-altering as you might think it is. But she was definitely one of the lucky ones. The cancer did progress from something less serious to a little more aggressive during the time she was waiting for her diagnosis. But we are now 14 years on and despite a few concerning incidents in the years immediately following her surgery, she is cancer-free. So we're very happy for that and she had a very good result from the surgery.

But if we move a little bit further into the future and talk about my dad, it was a bit of a different situation for me.

This is the tough one. In 2015 was a very busy time for me and for my family. I was pregnant with my son and it was my first grandchild for both of my parents, very exciting time for everyone. And I was

quite wrapped up in that as people would be, especially with it being my first pregnancy. So there was a lot going on. I did notice that my dad seemed to be getting a little bit thin and I do remember Christmas of 2014 him coughing quite a bit. And I was like, "Dad, do you think you should maybe go see someone about that?"

He did go to the doctor in the meantime and was referred to a specialist for an ultrasound. And the results of the ultrasound were taking a very long time, during which my dad felt ill enough that he stopped going to work, which is definitely not like him. And then June 3rd 2015, I received a call from my dad finally with the results. I definitely remember that day quite vividly, where he told me that he had been diagnosed with lung cancer. And the first thing he said was, "It's not good." I said, "Okay, tell me a little bit more." And he did try to hide from me how serious things were for quite some time, because I had a newborn and I was very wrapped up in being the sleep-deprived new parent that I was. And there was a lot to learn and a lot going on. But he had been diagnosed with Stage 4 non-small cell lung cancer, which it was a huge shock and he deteriorated quite quickly.

So I remember in that time after my dad had been diagnosed, there were a few friends that I bumped into where I would tell them what was going on, because it's all-consuming at the time. There are wonderful friends that maybe don't have a connection to any of this and they just listen, and then there are some that get really uncomfortable and want to move on to the next subject.

And then there was the other group of people that I would talk to and they would say things like, "Are you prepared? Are you ready?" And I would shrug that off at the time. But now, I understand that they were all the people that had been through something similar. So it was in that time that I realized just how widespread these experiences were and how many people it affected, because the amount of people that had been through something similar far outweighed the group of people that just wanted to move on. I think it is really something that affects us all at one point or another in some way.

It was through my family's experiences that I came to understand just how many lives are touched by cancer in Canada, and how many people are fighting it

Today we're going to hear from someone who joined this fight not because she had cancer — but because she's HIV-positive.

Louise Binder, thank you so much for being here today. Can you please introduce yourself and tell our listeners a little bit about you?

(Guest Louise Binder — dialogue in regular type)

First of all, thank you very much for the invitation to chat with you today about this important topic. I've been living with HIV for nearly 30 years, and at the time of my diagnosis in 1994, there were no authorized treatments for HIV and it was a death sentence. So I was told at that time that I had about

two years to live. You can imagine the shock and terror for me. I decided to plan for the worst, but hope for the best, and that has been my philosophy ever since.

I became involved with groups of other people living with HIV and their supporters to learn what I could about the disease, about the science, and about the state of research at that time. And of course, we worked together to demand clinical trial sites for our community in Canada.

So we worked banded together and we met with governments first at the federal level, because that was the first block was actually getting the drugs authorized for sale in this country. And then to provincial governments and private payers to make them understand the value of reimbursing for these drugs.

Here I am with a two-year death sentence and with the extraordinary outcome that I'm now 24 more years and counting from the time I was supposed to have died and I've had the opportunity, I'm very honored to say, to help other people living with HIV and with other diseases. I've had the opportunity to travel, to really lead a very full life. And most importantly, in my opinion, to see the birth of two great grandchildren, one who's three years old and a boy who's two years old.

That is really remarkable, and I can't tell you how happy I am to hear that outcome and to be sitting here and talking with you today. And I love the fact that you've taken your personal journey and your personal fight against what you were going through, and now you're using that to advocate for others. And you do advocacy work with cancer patients now. Can you tell us a little bit about that?

I work under the auspices of a group called Save Your Skin Foundation, which is a national patient oncology organization that was founded by a woman who, like myself, had been given a death sentence. But in her case, it was as a result of a melanoma diagnosis.

I think we all know that cancer is so widespread around the world and certainly in Canada that it affects almost everyone. It's the number one cause of death in Canada, and based on 2015 estimates at least one out of two Canadians are expected to develop some type of cancer in their lifetime with one in four dying from cancer.

This means that the fight against cancer is one that everyone should join in my view, including patients, their caregivers and healthcare professionals. As I said, because it's so widespread and so profound, I was asked and agreed to join the cancer patient community to do the same type of work that I had done in HIV.

I think it's just important to say to patients, and not to let them forget it, that nobody knows how long they're going to live, so when you get a diagnosis that says you're going to live this period of time that may be true in that moment, but everything else in the healthcare system could change, so what I say to myself every day, and what I said earlier actually to a group of cancer patients on a call today, is "Plan for the worst, but live with hope every day, and really live."

So what exactly does a patient advocate do? How would you describe your job?

So the word “advocacy” really refers to someone who is giving voice to the needs of patients as expressed by the patients. So it's not a job of telling people what they need, it's a job of hearing what they need and being able to translate that for policy makers, in terms of what policies should be. Of course, there's individual advocacy. We do that for ourselves all the time, including advocating for a treatment that we particularly want. But in the bigger picture, it's really giving voice to someone else's needs as well as, or instead of your own.

What do you feel that you achieve through advocating for patients?

Well, I mean, on our best day, we really do save lives by sharing prevention messages with our local communities. I worked with a group very recently of cancer patients with a rare cancer. We can also ensure that governments understand the importance of screening programs for people with oncology, of diagnostic programs that are effective, efficient, and available for everybody across the country, that new, novel treatments are made available as quickly as reasonably possible across the country. These are some of the things that we advocate for.

One of the things that we've been able to do is to convince governments, in many provinces and for many different types of cancer, to pay for genetic or mutational tests. So we've been very successful in a number of areas of cancer in achieving that.

And you've been doing that for over two decades now. What do you think, if anything, has changed in patient advocacy over the past 20 years?

I think a few things have changed in the last 20 years. I think one thing that's changed is that governments have recognized that they need to make some space at the decision-making tables, for patients to give their views and to understand the importance of treatments and diagnostics for them.

Unfortunately though, just inviting somebody to be there is not the same as them leading in terms of what are the best policies, decisions, systems for patients. And although we're there, and we are permitted to provide our input, we really don't get to have the deciding vote at these decision-making tables. And I think until that happens, we are not where we need to be for patients.

Let's talk about health technology assessment, which is also known as HTA and how patients can get involved in that? And this is the best way that people can contribute their input?

Absolutely. Health Technology Assessment is a process that the provinces and the federal government have put together to help make informed decisions about the optimal use of drugs and medical devices in our health care system. There are some ways that patients can get engaged with that system.

Why, in your opinion, are patient advocacy groups so important?

First of all, if there is a new drug that is being reviewed by the Health Technology Assessment process, there may be a patient organization in your area of cancer that is going to be permitted to make a

submission about the importance of that drug that that Health Technology Assessment organization should take into account. One thing you can really do is respond to your patient organization if they ask you about your involvement with that drug, if you've been on a trial for it, or why you might want to have that drug, even if you haven't had the opportunity to take it.

And what would you say to any patients out there, or their loved ones, who are thinking about getting more involved?

Please do. I would say we would love to have you join us in whatever way, and with whatever you feel are your skills, and abilities, and life experience is a skill and an ability, I assure you, and so anybody who tells you you don't have experience is absolutely wrong. Boy.

Please engage with your patient groups, for sure, in any Health Technology Assessment submissions they're making. You should certainly go to the website for the Health Technology Assessment organization. There are actually two in Canada, one for Quebec and a different one for the other provinces. If you're interested, go to their website. You can sign up for their newsletters. They send out regular newsletters. They often have webinars and other educational sessions that you can join to stay informed.

Certainly, if you can afford it, donate to the patient organization that's doing the work because we often don't have enough money to do these submissions. The HTA organizations, Health Technology Assessment organizations, do have committees as well. You can certainly put your name forward to sit on one of their committees, their patients.

Well, Louise, it was really, really a pleasure to speak to you today and I thank you for bringing all this clarity to a time that, again, may be quite difficult and overwhelming in people's lives. I'm sure you've heard the word inspiring before, but I'm going to say it again. It's inspiring to me and I thank you for the work that you do and I thank you for taking the time to talk with us today.

Thank you. The truth is it's the patients who give me the inspiration to do this work, and every story that I hear really inspires me to keep going, and I feel honored to have the opportunity to work with oncology patients and patients in general.

That's all for this episode, but join us next time when we'll be speaking with Dr. Gwyn Bebb, a lung cancer specialist who works at the Tom Baker Cancer Center in Calgary. Best of health until then.