



Photos by Gena Little

Tracy MacCharles

NAVIGATING HER NEW NORMAL

An Interview with Jeff Tiessen

Tracy MacCharles, the former Ontario Minister of Accessibility, never planned to be a politician until she saw a newspaper article reporting that the then-current MPP was going to retire. She wondered what it would take to work as a Member of Provincial Parliament. She liked public service and had worked for 10 years in the Ontario government before moving to the private sector as a Human Relations professional in financial institutions like National Trust and Manulife and climbing the ladder to a Vice-President position. She understood government from a bureaucratic point of view, but didn't have any political experience. She knew lawn signs but didn't know about political parties or even how to get nominated. AND SO, HER POLITICAL JOURNEY BEGAN.



Tracy MacCharles never planned to be an amputee since being just hours away from a scheduled amputation of her left leg. She was diagnosed with bone cancer in her left leg when she was a teenager. At the last minute, her surgeon connected with an American colleague who had developed a limb-saving surgery for young cancer patients. Her femur and knee were replaced by a rod and hinge cemented to her shin bone. Thirty years later, as a young mother of twins, she was diagnosed with breast cancer. More surgery and more chemotherapy. At age 59 she became an above-knee amputee. She knew disability well, personally and professionally, but didn't know much about living with an amputation. AND SO, HER LIMB LOSS JOURNEY BEGAN.

thrive: *You said that this interview would be a real coming out for you as an amputee. What do you mean by that?*

Tracy: What I mean is that I have not fully embraced being an amputee, partially because it's been a massive learning experience and somewhat overwhelming. And, also learning to deal with the fear of the unknown. Learning to accept my new reality when I didn't really understand what my reality was, and not wanting to tell my story over and over again. I feel like I'm just starting to come out through my work with the Amputee Coalition of Canada, connecting with other amputees and accepting my new normal. I've avoided a lot of one-on-one conversations with people I don't know well.

thrive: *Yet, there's irony in that. You were Ontario's first Minister of Accessibility. You've worked and volunteered in the disability community for years. Your husband has a disability, as have you since you were 17 years old. Disability is not new to you.*

Tracy: The irony isn't lost on me. Public figures, politicians, we do look for anonymity and privacy too. And in my situation, while I've had leg-saving surgeries for years, I was doing a smoke and mirrors routine, even in politics, because I didn't look "disabled". I looked "able-bodied", right? I had a leg made of artificial parts internally, but I don't know if I ever really embraced being a disabled person, then, and as of last year, becoming an amputee.

Being an amputee is all new to me. Getting stared at is new to me. My leg is out there. Hiding it under clothes would make things more difficult. But I see the contradiction. Not only did I spend a lot of time working and volunteering in the disabled community, but I advocated for our children who had different kinds of challenges. And I helped create Ontario's accessibility legislation.



Tracy with
husband
Stephen
Little

thrive: *Did you identify with having a disability before your amputation?*

Tracy: Yes and no. We're all different, right? Whether you have a physical, mental health, cognitive, sensory, or whatever challenge, everyone's experience is different. I was pleased and honoured to take the reins as Minister of Accessibility and move the agenda forward in Ontario. But I did struggle with the stereotype of the disabled person becoming the Minister for Accessibility. I remember a well-meaning person saying to the Premier, right in front of me, "that's so nice that you hired this woman to do this." I was like, what? Like, first of all, I got elected by my community, a duly-elected politician who won the nomination in my riding. I won a general election twice. Of course, the Premier decides who's going to be a Minister. I did have mixed feelings about the role though. Was I progressing on my own merits, or was it tokenism? I've always struggled with that. And because my former limitations as a disabled person weren't evident to people, I wasn't disabled in their eyes. So, I think I've always struggled with my identity.



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thrive: *Let's talk about your previous disability, before your amputation.*

Tracy: I always struggled with telling my story. I'm still struggling with it, maybe more now as an amputee, because my story is long and complicated. I don't feel I can do it justice in a few sentences when it's a story of a lifelong challenge. But here goes.

I had bone cancer when I was 17, the same year that Terry Fox was running across Canada. I was scheduled for an amputation. I had the NPO sign at the end of my hospital bed... "Nothing by Mouth. Amputation." Canada wasn't doing limb-saving surgery yet, but my surgeon at Sick Kids had a relationship with a surgeon in Philadelphia who did. Dr. Hugh Watts, who amputated Ted Kennedy's son's leg, was tired of amputating young people's limbs. Osteosarcoma, the bone cancer I had, was more prevalent in young people. So, he developed this new internal limb-saving prosthesis. And so, instead of the amputation the next day, I was whisked off to Philadelphia for limb-saving surgery. My femur and my knee were replaced by a steel rod and a metal hinge cemented to my tibia. I came back to Sick Kids in Toronto for chemotherapy and watched Terry Fox run down University Avenue in front of my window.

thrive: *Any regrets in going the innovative procedure route?*

Tracy: Honestly, I was a selfish teenager and wanted everything over with. I would have just gone with the amputation because I wanted to get whatever was happening to me behind me. My father insisted that I do the limb-saving surgery. "You can have your amputation later if you want," he said. It turned out to be the best decision. The internal prosthesis that Dr. Watts put in lasted for 30 years before it broke. So, I had a good run with it. I carried my twins on it before my troubles with it began. I got it replaced in Canada but immediately after my first election, it snapped in two. Thank goodness I was at home and not at an event. While doctors were figuring out how to get that 30-year-old prosthesis out of me, and replace it with new technology, I was also recovering from a second cancer surgery, breast cancer, a year prior.

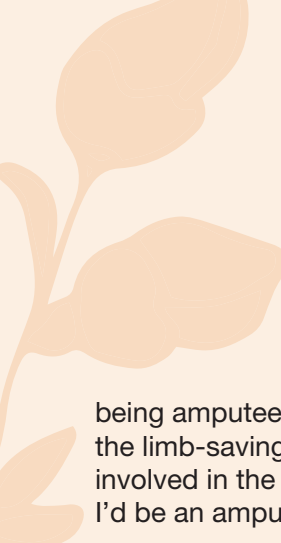
All of that said, I could walk, but not quickly, especially with the replacement. Every step took a lot of energy, mentally and physically. That's part of my irony. I appeared able-bodied, but I wasn't. If I chose amputation initially, I probably would have had a more carefree lifestyle and would have been able to do more sports. I chose the internal prosthesis, and it was a good decision, but it also came with a lot of limitations that I accepted but maybe didn't reveal.

thrive: *I know that you never planned on becoming an amputee, but at any point did you start thinking that it was inevitable?*

Tracy: My leg replacement surgery worked well for about six years, until 2017 when some of the cement that was binding things together cracked. I had to have some revision surgeries. Infections ensued, and a couple of operations. That's when I decided not to run for re-election. I was on a series of suppressive antibiotics and didn't think I'd have the energy to mount a successful campaign. In 2022 I had massive reconstruction. All the parts came out and I went into a wheelchair with basically a nail for a leg inside. The new prosthesis started dislocating. It wasn't the fault of the new technology. I was older. I didn't have the muscles and tissues to sustain the new one. With the dislocations and infections, which can be catastrophic, my surgeon started talking about quality of life, because at that point, my quality of life was not good. Another tough decision, but it was the right one.

I bought a lot of time, and I'm very grateful for it, but I never imagined being an amputee. I knew intellectually that it was the right decision, and my surgeon was spot on. It was time for quality of life; time for a new normal. But I hadn't thought about





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being amputee since I was 17. I was always on the limb-saving journey, acting able-bodied, very involved in the disabled community, never thinking I’d be an amputee one day.

thrive: *You talk about a new normal. What does that mean to you?*

Tracy: I didn’t know it would be an opportunity to redefine myself. I look at it – my whole journey actually – as survivorship. I mean, two rounds of cancer, two rounds of treatment and a mechanical leg that worked magnificently for 30 years.

I’m learning to navigate that new normal. Learning to be an amputee. It’s hard. It’s way more complicated than I understood. And I think I’m a reasonably intelligent person who knows how to navigate systems from my personal and professional experiences in life and work. But it’s a hard journey that no one is really helping you navigate. You have to figure it out. But I’m very grateful that I have an amazing team to rely on, including my surgeon, my prosthetist, and my physical therapist who works almost exclusively in the amputee community. I need a massage therapist for some radiating spinal nerve pain associated with the amputation. And my chiropractor helps with that nerve pain and my hip contracture which is probably from improper walking for so many years.

I’m learning to embrace my amputation. I’ve always taken pride in myself for being independent. I get through things. Politics is a team sport and so is being an amputee. Having a team around you is critical. My new normal also means accepting that everything takes me longer to do and takes more energy. I wasn’t always the most patient person.

thrive: *You talk a lot about learning and navigation. What were some of the first things you learned as part of your new normal, that being a new amputee?*

Tracy: I need to accept setbacks. This is not a linear process. Adjustments to the prosthesis. Volume management. Skin problems. I thought that “you have an amputation, recover, slap on your new limb, and off you go.” Way more complicated, way more involved. It takes a lot of patience and time. You have to accept help, and you have to figure out how

to navigate it all, and you have to give yourself the time to do that.

I’d say only a few friends and family really understand how challenging life is as a new amputee. I have a good team, and I’m very grateful for all that. But I quickly learned in the amputee world that it takes a lot for other people to understand it because it’s so foreign. People want to understand and want to support you but it’s complicated. Even simple things like going out for coffee. Well, okay, where are we parking? How’s the accessibility? How many steps are there to get in? Is the washroom accessible? How am I going to carry my coffee to the table because I’m still using a walker?

I’m learning that my job now is to work on my recovery and to embrace the team and the help, but that is very resource consumptive. Multiple appointments every week. I do it because I want to live my best life. It’s an investment in me right now. And I’m learning to be open with people who genuinely want to be supportive.

thrive: *Again, the irony. You were the Minister of Accessibility, had a lot of experience with disability and are married to a well-known advocate and wheelchair user in the disability community. Wasn’t any of this experience transferrable to your “new normal”?*

Tracy: It’s funny, when I started dating Stephen [Little] I was really nervous and at a loss for words. I was a bureaucrat when I met him, not a politician. He worked in the former Office of Disability Issues. We were both civil servants at the time. But there’s a huge delta between being involved in the disabled community, doing work in it, working with colleagues who have a disability, and developing a relationship and dating someone from the disabled community. A whole other ballgame. And remember, I’m not really accepting my own limitations, and here I am having a relationship with a paraplegic, right? I was very unsure how to navigate that at first. I was intrigued with his independence, his ability to navigate his work in the community, being an advocate, you know, all things that attracted me to him. But it’s really about the person and similar goals, one of ours being that we both wanted to become parents. That was our big joint initiative as a couple. And amputation is a whole new ballgame too. A whole new journey, even with my experience with disability.

thrive: *What's the next step for you? What does the near future look like?*

Tracy: Maybe it's an aging thing more than an amputee thing, but to pause and really take a hard look at what's next in my life. I'm a recovered – or recovering at least – workaholic. Right now, I teach part-time at the University of Toronto. I do volunteer work. I've been asked to consider becoming a Justice of the Peace.

My interest level is super high, but my capacity to do a lot of things has changed. I need to be accepting of that. I guess there's been a change in perspective for me during this last year of reflection and speculation. But it's not Pollyanna-ish in that "Oh, I'm so grateful to be alive. I kiss the ground every day." It's not like that, because I still have my faults and bad habits. I'm very compliant, but not perfect.

But I am reevaluating life as an amputee and how I spend my time. I think I'm bolder now in some ways. As a politician, there's a certain amount of caution. As a public figure, you have to, you know, keep your views within a certain framework sometimes. I think I feel a little more liberated to be myself and to do what I want to do at this stage of my life, and maybe battle hard for amputees by dealing with some of the systemic problems.

A lot of my goals are focused on my physical recovery and being able to walk well or as well as I can and reach whatever potential that is. But also, you know, doing things differently, embracing invitations to be involved in some projects. I work as a Peer Visitor with the Amputee Coalition of Canada, and I'm now a member of its Board of Directors and that's very exciting.

thrive: *Last question. You received peer support after your amputation and now you are a Peer Visitor, which is really valuable I think for a new amputee to hear from a peer like you who is relatively new too. What's your message to someone who is just starting on their amputee journey?*

Tracy: We're all different. And that it's a lifelong journey. A good team is key. It's a constant calculus of risk and reward in terms of your recovery... like, how much time can you tolerate on your artificial limb. Whatever assumptions people have about amputees, they may not apply to you or me, and you can't expect people to understand that. There will be challenges and there will be new opportunities too, in terms of new friendships and new connections.

The medical team can be really good at doing what needs to be done, but this system doesn't really address mental health, and you need to be open to getting that kind of support too.

You're going to have to advocate for yourself. Yes, there are professionals who can give you advice, whether it's a PT or a prosthetist, or other people in your circle, but amputee peers are so important too... someone around the same age or stage of life who is relatable in terms of what you're going through.

It's going to be hard, and you're going to have successes, but you're going to have setbacks too. It's so different for everyone, but learning to accept help and getting that good team around you are critical in those early days.



Photo courtesy of Tracy MacCharles