

Begin with what's necessary, then do what's possible

It was the late 1990s. Candice Nelson was a high school student in Edmonton, and a guest speaker came to talk about HIV and AIDS.

"I don't remember much from the presentation other than feeling sorry for this man who looked healthy but was fighting a virus which would attack his immune system until it killed him," she recalls. "I do remember feeling a sense of relief; I was neither an injection drug user nor a homosexual man and felt I had no risk of contracting HIV."

Fast forward to nearly three years ago when she began working with SIGN Positive Impact and learned the latest about HIV. With nearly 15 years of experience in the medical field by then, it dawned on her: "If I was this uneducated about the basics of HIV, I was probably not the only one. Hair styles are not the only things to have changed since the 1990s!"

National HIV Testing Day began in Canada on June 27, 2018 as a way to start the conversation about the importance of testing for HIV and address the stigma surrounding this virus. After two successful years, the Canadian AIDS Society announced the expansion of the campaign this year to a national HIV Testing Week from June 21 to 27.

SIGN Positive Impact is dedicated to decreasing the stigma of HIV, Hepatitis C and other sexually transmitted blood born infections (STBBIs) through community engagement and education.

National HIV Testing Day usually comes with a week of testing events, BBQs, education sessions, and other activities. However, as with many things, the agenda changed with Covid-19. With those events not possible, Candice is doing something different but also important – sharing her experiences.

When I became the Impact Social Worker with SIGN three years ago, the new knowledge I gained about HIV seemed to bubble out of me. Any chance I got, I was sharing information and promoting getting tested for HIV. Know Your status!

People were offended when I suggested such a thing. Maybe they thought I was implying they were an intravenous drug user, had multiple sexual partners, or engaged in other high-risk activities. When I was a 16-year-old, I felt the same way.

Unfortunately, this stigma is debilitating. I would begin talking about HIV and people assume they are not at risk, smile politely, and tune me out. I don't blame them, but I'm also not willing to be quiet that easily! If I can educate people about the truths of HIV transmission risk factors, prevention, treatment, and routine testing, the stigma would be lessened to the point I may not need to advocate for people living with HIV. Perhaps I have rose-colored glasses, but I like to think big.

How do I do what I do? SIGN Positive Impact has offices in Yorkton and Kamsack, but I travel all over the former Sunrise Health Region including the surrounding First Nation communities. Before Covid-19, you'd find me on home visits, at drop-in centres, hospitals, or meeting with people on the street.

I drink coffee and listen to stories of resilience. I hold the hands of people going to long overdue dentist appointments. I help people obtain their birth certificate so they can open a bank account, apply for a job, get photo ID, or vote.

These tasks may not seem like they have anything to do with HIV, or National Testing Week, but they help build the foundation of looking after responsibilities we may find routine, but which for many are overwhelming barriers.

I get creative and am never bored.

I talk about wants, needs, and priorities. I fill out paperwork with people who have low literacy or simply cannot see the small print. I meet people in crisis and try to help them make sense of their chaos. I celebrate the little victories even if they are surrounded by multiple setbacks. I help people figure out what hoops they need to jump through and cheer them on while they jump. I get frustrated with policies designed for the benefit of the majority but which fail others in many ways.

I bite my tongue more often than not.

I've sat with someone and encouraged them to keep breathing while we waited for what was ultimately a positive HIV test. I put my values aside and do things that are difficult to explain but are making a difference. I celebrate when people are willing to call detox and are lucky enough to get a bed, and then struggle to find them a ride to the city.

I plant community gardens, not because I have any idea what I am doing, but because as I weed and spend time with clients, we learn to be patient with change and with carrots. I have a "deceased" folder in my filing cabinet of clients who will not get the chance to recover.

I cry with people. But I also laugh with people.

I blush as I say the words blood, breastmilk, semen, vaginal and anal fluid to grade 9 to 12 students because I want them to know how HIV can be spread and that it's okay to talk about these things, even when it makes us blush.

I attend flu clinics and health fairs where people actively avoid me like I am trying to get them to sign up for a credit card. I repeat the phrase "everyone has a status, you are either positive or negative, and until you know, you cannot know, so just get tested" to anyone who will listen and do an inner happy dance when I see the wheels turning. Let's be honest, I do a real dance sometimes as well!

I remind people this is not about "us" and "them" but that it's important we advocate for our own health and get tested.

With treatment, HIV no longer leads to AIDS. Medication puts the virus to sleep, making it undetectable and untransmittable. I have held a healthy HIV negative baby born to healthy HIV positive mother. I aspire to keep sharing with anyone who will listen, because I believe one day there will be a cure for HIV. I try to decrease the debilitating stigma of HIV in hopes to remove some of the many barriers my clients face, simply because of a diagnosis. If you are ever diagnosed with HIV, I will be in your corner.

What can each of us do? To quote St. Francis of Assisi, "Start by doing what's necessary, then what's possible; and suddenly you are doing the impossible."

This year for National HIV Testing Week, I challenge you to begin with what's necessary, by educating yourself about the HIV of today, not relying on information from your youth.

Then do what is possible by getting tested. Ask for it to be added to your next blood work requisition or call your local public health office. Then we will be doing the impossible because the HIV stigma will fade away and testing will be seen as routine.

Me? Until we're at that point I'll keep going, one coffee at a time, one application at a time, one phone call at a time, one presentation at a time, and one client at a time.

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