We Were Here: Missing Men
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We Were Here is an oral history project documenting just a few of the tens of thousands of lives lost to both the ongoing opioid crisis in Canada and the AIDS crisis of the 1980s and 90s. The two have much in common, though I'm not seeing comparisons in the media. Both have been political hot potatoes, stigma and misinformation thwarting what should have been a swift and effective public health response.

When my daughter Sophie died from a fentanyl overdose, someone said to me, "Fentanyl? But that's something in the news!" Well, I've got news for you - it could have been your kid. The gay men who died thirty odd years ago were my peers. I can still feel the empty space where they should be.

A quote from Toronto AIDS activist Michael Lynch struck me hard as I embarked on this project: "Most Canadian PLWAS (people living with AIDS) find their illness must be kept secret. Survivors routinely erase the cause of death in memorial services or death notices." When I wrote Sophie's obituary, I was clear about how she died. She was outspoken about her struggles, and would not have wanted me to be vague. This was an unusual enough choice in 2020 that I got calls to do media interviews. One headline read, "This mother penned a brutally honest obituary." All I could say to reporters was that silence = death. Always has, always will.

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The first person I want to introduce to you is John Helliwell (1950 - 1996). But before I tell you about John, I will relay what my friend Jim Tennyson said to me when I asked him if he'd care to be interviewed for this project:

> "The reaction to the fentanyl/opioid crisis has much in common with the AIDS crisis of the eighties. Of course, the most depressing parallel is the apparent hope, on the part of the powers that be, that if they ignore the issue, it will just go away like an unpleasant

dream. Some would say that those affected have only themselves to blame. This view seemed particularly prevalent at the Reagan White House; they did not appear concerned when gay people were the ones getting sick and dying from a mysterious illness. People talked callously at the time about AIDS affecting only members of the 4H Club: Haitians, Hemophiliacs, Heroin Addicts and Homosexuals.

It wasn't quite as bad up here but the attitudes weren't pretty. I was a founding member of the AIDS Committee of Toronto so I was on the front lines. I was also part of a University of Toronto epidemiology study - one of the earliest in the world - which followed the health of a group of about forty guys who were either infected, or had been with those who were. I was certain that I was HIV-positive, but by a twist of fate, this was not the case. I remember when the first antibody test results arrived about six months after the study began. The doctor said, 'Well, Jim, you're negative.' I thought I was going to faint. I had certainly had unsafe sex with guys who would soon be dead. You have to remember that *unsafe sex* was just *sex* up to this point.

I watched most of my close friends die or come very close to it before the introduction of antiretroviral therapy. But in terms of an interview, I'm going to respectfully back out, unless you're really stuck for subjects, and I'm sure there are some of us still stumbling around. It's not something I don't talk about, but to have to confront in a serious fashion the utterly tragic events of those years is still too draining. I always say that my experiences beside deathbed after deathbed would fill a script for a miniseries. One of those beds held a man with whom I was in love and he with me."

In not being interviewed, Jim spoke volumes, and he gave me permission to share his reasons.

I met Jim years ago through the Toronto queer theatre company Buddies in Bad Times. I later served on its board with Gordon Floyd. Both men are in their seventies now, and both gave innumerable hours to HIV/AIDS peer support and political activism from the beginning. Gordon agreed to tell me about his dear friend John, and shared with me the detailed records he kept pertaining to John's life, palliative care and death.

Gordon prefaced his memories by describing a line from the play *The Inheritance* by Matthew López, mounted in Toronto last year. A character cries out to the younger players, "Don't you understand? I don't have any contemporaries!" This is Gordon's truth too. His current gay friends are all fifteen to twenty years younger than he is, because his former gay friends are all gone. He's been HIV-positive for thirty years and considers himself one of the lucky ones because he was infected late, once antiretroviral drugs were available and effective. Shorthand for this historical milestone is "post-cocktail," which contrasts starkly with the deadly years "pre-cocktail."

In the mid-1980s, John Helliwell wrote an award-winning personal computing column for *The Globe and Mail*, touting the potential of email to save on courier costs, and the futuristic prospect that cellular telephones combined with microcomputers would create an "office in a briefcase." He was way ahead of his time and a leader in the field, becoming an executive editor at PC Magazine based in Boston. His career then took him to New York, where he was living when he became ill.

John returned to Toronto to die. Gordon says, "He was sick, he was weak, he knew it was over." Gordon went to New York, rented a van, and drove him back. He assembled and led his palliative care team, and agreed to serve as executor of his will.

The two met in university and bonded over politics and theatre. When they were both still in Toronto, they often travelled to New York for long weekends jam packed with Broadway shows. They caught Liberace's holiday extravaganza at Radio City Music Hall, where the flamboyantly campy but closeted star had the audience in the palm of his hand. Gordon recalls with a laugh, "The blue-rinse ladies from New Jersey hadn't a clue what they were witnessing." The two rather serious and sophisticated men would let their hair down at The Saint, the cavernous East Village club at the epicentre of gay nightlife in the 1980s. Like many of its patrons, the place fell victim to the AIDS crisis, closing in 1988.

In a lot of ways, the gay community invented the good death inside our grief-illiterate culture. “There was no blueprint,” notes Gordon. He’d lost a couple of dozen friends, which gave him enough exposure to lead John’s care team. Having put on hazmat suits to visit friends in hospital, and carried their meal trays in from the hall when staff wouldn’t go in the room, he says he had the stomach for it. In the absence of proper health services, amid the swirl of fear and bigotry, dying men and their friends designed their own end-of-life care.

The log books filled in by John’s caregivers include tender observations from his final weeks. One writes that, “John has promised no more macho cowboy stuff” after he went to the bathroom on his own and fell. There are records of the numerous visits from friends, who keep him sitting up a bit too long. Someone notes that John would like to reread *A Hitchhiker’s Guide to the Galaxy*, but time runs out before a copy can be acquired.

John was an only child, predeceased by both his parents. He was still close to the family of his former partner, who joined the care team along with some of John’s recent friends from New York and some very old friends from his high school in Marathon, Ontario. One of those classmates happened to be the CEO of a hospital, who surreptitiously helped the team access medical equipment and other essential resources.

I asked Gordon why he thought so many people from different periods of John’s life would volunteer for such a heartbreaking task, some dropping everything to travel to Toronto for a week or more. He thought about it for a minute, and said, “John was a person of incredible integrity and passion. He was successful because he was brilliant, but also great fun, with a wide range of interests that he shared with a wide range of people.” I think the same could be said of Gordon, who would have received a similar outpouring of support had he not been one of the “lucky” ones.

It took Gordon a good decade to process the aftereffects of attending nearly weekly funerals for several years. He acknowledges that loss of this magnitude makes one reluctant to get close to people. He made a sharp career turn in the mid-1990s, leaving both public service and business behind to move into the charitable sector. The last ten years of his career were devoted to

children's mental health. Gordon had lost faith in government, and become cynical about the private sector. While grateful for the drugs that kept him alive, he was dismayed by the egregious opportunism and profit-driven actions of pharmaceutical companies in the face of a public health catastrophe. And this was long before the opioid crisis.

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It was Jim Tennyson who mentioned one of the many friends he lost, Bill Dendy (1948 - 1993), piquing my interest when he told me,

> "Bill had that fierce light of conviction in his blue eyes. He wrote a study of the architectural gems Toronto had torn down. He was a charismatic protectionist for all things to do with city planning. His ideas had clout. I'm sure the downtown would be a more attractive place than it is at present had he not died in 1993."

I went looking for more information about Bill and discovered the vast William Dendy fonds at the University of Waterloo - an invaluable resource for architects, architectural historians, heritage conservationists and urban planners. His work was nowhere near done. In fact, he would have been at the peak of his career when he succumbed to AIDS at the age of forty-five. He was in the middle of a comparative study of domestic architecture in Toronto neighbourhoods.

There is a wonderful photograph of Bill from 1987 in the Toronto Public Library's Special Collections. He is sitting in front of an enormous wall of books and the caption reads: "William Dendy's favorite room has over 500 shelf-feet of books relating to architecture." Bill bequeathed 3,500 books, 2,500 periodicals and over 38,000 slides representing architecturally important structures and features to the University of Waterloo.

Bill's popular works, *Lost Toronto* (1978) and *Toronto Observed: Its Architecture, Patrons, and History* (1986), both won Toronto Book Awards. Activist, writer and historian Ed Jackson describes Bill as "tall, handsome, gregarious, energetic and passionate." Their paths crossed when Ed was a researcher in the 1970s. He was working on a survey of heritage buildings at Sherbourne and Dundas, just east of the downtown core, and Bill willingly volunteered to help. The buildings were saved, with low rise rent-geared-to-income apartments infilled behind them.

It was a successful project that gave equal priority to historical preservation and affordable housing. In the decades since, Toronto and many other North American cities have done a poor job with both.

Bill intended his work to be a call to action. In the introduction to his 1976 book, he wrote:

> "*Lost Toronto* is not meant to be a depressing litany of destruction and loss. It is rather a filling-in of the gaps in our streets, of the blanks in our understanding of the city. Instead of 'depressing,' I would hope that it would be acutely 'distressing' for many readers - encouraging a vehement and committed argument in favour of preservation… It is to be hoped that *Lost Toronto* will make unnecessary an additional publication detailing the losses of the last quarter century."

The *Toronto Star's* architecture columnist Christopher Hume described Bill as one of Canada's most knowledgeable and committed architectural scholars. He wrote,

> "The breadth of his knowledge was amazing. He was the kind of person a newspaper reporter could call with a specific question about a specific building - and get a specific answer… The underlying purpose of his scholarship was to make us cognizant of the facts of architectural life. In so doing, he believed, we would develop more sophisticated tastes and be less willing to settle for the built mediocrity that surrounds us."

Housing expert Carolyn Whitzman, author of the 2024 book *Home Truths*, notes:

> "I never met Bill Dendy personally but I have used *Lost Toronto* to summon stories of buildings, streetscapes and neighbourhoods that are now gone. Toronto is very good at erasing its past, along with any lessons the past may hold for the present and future."

Humans are, as a whole, very bad at learning from our history.

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Carolyn has been my friend since university. The story she told me about her brother Peter Whitzman (1947 - 1995) takes us from Canada to London, England, where he spent most of his life.

Their mother, Sheila Kastner, had a clear plan to get out of Cornwall, Ontario and become a journalist. At the age of seventeen, she was accepted into Carleton University in Ottawa. The only other Jew in the program was Earl Whitzman, back from WWII and starting his post-secondary education on a military scholarship. Instead of earning their degrees, the young couple promptly had a baby.

It's fair to say that Peter Whitzman hated Cornwall and Cornwall hated Peter back. At an early age, he gave off a vibe of otherness. Instead of taunting him with homophobic slurs, which were perhaps too exotic for that time and place, his classmates relentlessly chased him down the street shouting, "Jew Boy!" His younger brother Stephen wasn't bullied, though he was also a boy who was a Jew.

When Peter was ten, he shone as Ebenezer Scrooge in the school production of *A Christmas Carol*. He decided at that moment to pursue acting. The Whitzmans were theatre buffs and supported his aspirations. They travelled to the Stratford Festival in its early years, and to New York for all the big Broadway shows. The soundtracks from *Carousel*, *Guys and Dolls* and *My Fair Lady* were in constant rotation on the family turntable. Peter and Stephen, like their mother before them, were bright enough to skip grades and also hightailed it to university ahead of schedule.

It becomes even clearer why Peter was eager to get away when Carolyn shows me an assortment of family photographs, each with an obvious slice where Earl has been cropped out. By the time Carolyn was born, sixteen years after her eldest brother, their mother loathed their father "with the heat of a thousand burning suns." Their scathing verbal abuse and constant passive aggression would put them in the same league as George and Martha from *Who's Afraid of Virginia Woolf*. They finally separated when Carolyn was four.

Peter left to study drama at McGill University when his baby sister was still in diapers. At a distance of a hundred kilometres, Montreal was still much too close to home. He travelled to Israel and spent time on a kibbutz, where he experienced the freedom to start living as an openly gay man. He won a scholarship to attend the Royal Central School of Speech and Drama, and remained in London for the rest of his life.

Peter had an equivocal relationship with the English, who perceived him as “ethnic,” but was in the right place to pursue the life he wanted. He became one of the founding members of the Gay Sweatshop Theatre - a gutsy move in 1971. That same year, he met the man who would remain his partner for the next quarter century.

When Carolyn was eleven, her mother took her to London for a visit. En route, Sheila said to her, “You need to understand that being an actor doesn’t pay very well. Peter has to share a tiny one-bedroom flat with his friend Alan.” Carolyn rolled her eyes, as she was wont to do around her mother. But this was the story Sheila stuck with for another five years, until Peter finally wrote her a coming out letter, ending all attempts at obfuscation. Sheila was initially furious with herself for somehow causing Peter’s homosexuality, but eventually adjusted, even joining PFLAG.

Carolyn got herself back to London two years later, using her Bat Mitzvah money for the plane ticket. She established a pattern, staying with Peter and Alan every other summer until she was nineteen. She was only too willing to receive some alternative parenting from her big brother. He and Alan modeled the kind of relationship Carolyn aspired to, listening to one another and working through their issues. While non-monogamous, they were deeply committed to one another.

Carolyn was in awe of Peter. They bonded during those London summers over their fondness for old movies. Peter had a huge collection of VHS tapes and was something of a film savant. He could tell you who won the Oscar in every major category in any given year. And he had the requisite abiding love for Bette Davis and Judy Garland.

Though he went by the name Whitman professionally, Peter tended to be typecast as a neurotic Jew. He had a fine singing voice, and once shared the stage with Topol in a production of *Fiddler on the Roof.* Carolyn pointed him out when we watched *Yentl* one winter evening. Amazingly, Peter never had to work a day job. He supported himself as an actor, sometimes on stage in London's West End, occasionally with small parts in major movies, often with voiceover and narration gigs.

Carolyn remembers meeting Simon Callow and Ian McKellen at parties, where Peter would invariably be inside a circle of people hanging on his every word. Carolyn says, "He was the most loved person I ever met - he had *that thing*." He was brilliant with accents and a superb mimic, sometimes to Carolyn's chagrin. He had a perennially popular party piece in which he portrayed their parents as a dog and a cat. At the same time, he was a bundle of nerves, throwing up before every live performance he ever gave.

Peter knew he was HIV-positive at least eight years before he started to become ill. It was a rough waiting period, especially given that he had always been prone to hypochondria and convinced he was coming down with something. The family made hay out of Peter's assertion one morning, when he woke up feeling a bit peaky, that he'd had a mild stroke. To this day, when one of them is under the weather, they'll say,, "Staying home today, I've had a mild stroke."

In 1994, Peter brought Alan to a family reunion, which was highly unusual. Carolyn sensed that his anxiety was about more than just the event, and soon learned that it was due to his declining health. He was recovering from a bout of pneumonia, but rallied to play Shylock in Manchester a few months later. He won an award for his performance, which was a high note to finish on, as it would be his last acting job.

In January of 1995, Peter was diagnosed with Creutzfeldt-Jakob disease, which has symptoms similar to ALS. Carolyn visited him that March, when his body was beginning to shut down. She had to interpret the situation for her parents, pressing upon them the urgency to visit him. They were by his side when he died in July, having mustered the decency to be in the same room.

The year Carolyn turned forty-seven - the age Peter was when he died - she found herself reflecting on her brother's life. He should have had decades ahead of him, but the years he had were good. She says he would have made the perfect "alte kaker" - he was already kind of a fussy old fogey, in a mostly charming way.

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The next story I'll share starts out on Cape Breton Island. Chris Aucoin grew up in Glace Bay, Nova Scotia, where his father was a coal miner. As a kid, he was a competitive figure skater. He unintentionally came out at seventeen. Someone had pressured him into saying what was on his mind and then "the genie was out of the bottle." He came out to his mom and classmates in grade twelve, which was highly unusual in 1981, and not without its challenges. Chris never had a conversation about his sexuality with his dad, even after his partner started attending family gatherings in the early 1990s.

Once at university in Halifax, Chris realized he didn't have to figure everything out right away. He took some time to unpack what he calls the luggage of growing up working class and Catholic. He got involved in campus theatre, where he got to be himself among his first openly gay friends.

His first awareness of HIV/AIDS came from a TV report about gay men dying in San Francisco. A few years later, he remembers walking down the street in Halifax and seeing an acquaintance a year younger than him, who shared that he had AIDS. That brought the reality of the disease home.

After his undergrad degree, Chris needed to make some money to pay off his student loans. His most marketable skill being skating, he got a gig with the Ice Capades. Touring took him all over the States, including to San Francisco, where he immediately felt the heaviness of AIDS in the air. He remembers the Ice Capades bringing in a speaker to give a rudimentary talk about safer sex. After Chris left the company, another member of the touring group died of AIDS. Chris

recalls that this young man was on the gaunt side of thin, but that body shape was not unusual for a skater, so no one suspected he was sick.

Back in Halifax, Chris saw a job posting at the Gay and Lesbian Association of Nova Scotia. It involved program development, financially supported by the local gay bar, which the association owned - an early example of social enterprise. Chris found himself going back and forth across the street to the Nova Scotia Persons with AIDS Coalition to use the photocopier. Spending time in their offices, he soon got to know many people living with HIV or AIDS.

Chris notes that people assumed he was HIV-positive long before he ever was, just by virtue of being part of that social scene. Chris consulted his doctor, who strongly discouraged him from getting tested because there was no treatment at the time. The doctor said he was seeing patients emotionally destroyed by what felt like a death sentence while they were physically asymptomatic. He told Chris that as long as he kept taking all the precautions he was already taking and being proactive about his health, there was no point in knowing. Chris couldn't find fault with his logic at the time. The same doctor gave him the advice to dump his HIV-positive boyfriend, which Chris disregarded.

Chris met his first long-term partner in 1991. Bill was HIV-positive, and had decided to use whatever time he had to follow his dream of studying marine biology in Halifax. He expected to be dead within a year or two. So when he and Chris quickly got serious, there was a lot at stake. When Bill told Chris he was HIV-positive, Chris put his arms around him to let him know he wouldn't be going anywhere. (Bill is a pseudonym. His family was determined to keep his sexuality a secret, even after his death, and Chris has reluctantly respected their wishes.)

Luckily, Bill was still alive when the drug cocktails that saved so many lives became available in the mid-1990s. He and Chris were together for ten years. Tragically, their break-up had everything to do with Chris's eventual HIV-positive diagnosis. Bill was convinced he had infected Chris, and could not cope with the guilt. In point of fact, the couple had an open relationship and Chris is sure he contracted the virus elsewhere, on a very specific occasion that

involved an unforeseen risk. Even though Chris told Bill all this, Bill was unable to believe he wasn't to blame.

When they split up, Bill moved away to Ottawa. A few years later, the two of them were starting to talk about reconciling and Chris was preparing to leave Halifax to give their relationship another go. Before Chris was able to make the move, Bill was killed by a drunk driver.

Twice when they were together, Chris thought Bill was going to die. He struggled to recover from a flu virus about a year into their relationship, but eventually bounced back. Then, when he first took an experimental drug cocktail, he had a life-threatening allergic reaction. Such stress in early adulthood takes a huge toll. Chris also went through the heartbreak of watching friends die, taking part in their home palliative-care teams, as many gay men did.

Chris pursued a Master's degree in educational psychology, and has always been a student of human behaviour, quietly watching everyone around him even as a young kid. He did a great deal of internal work to sort out the feelings of shame that came with his Catholic upbringing, as well as the impacts of having an alcoholic father. Once he was settled into a job he loved and a caring relationship with Bill, he realized he still wasn't happy and sought treatment for depression, with positive results.

Chris has been in the not-for-profit sector for many years, his work leading him to his current role as Executive Director of HEAL Nova Scotia, formerly the AIDS Coalition of Nova Scotia. Like many such organizations, its mandate has changed and continues to evolve with time. Chris tells me that having AIDS in the name always made fundraising harder. In any case, AIDS has not been the main focus of their work for about twenty years, but rather one aspect of the group's support and education around HIV, hepatitis and sexual health. Chris has also studied graphic design, his posters gracing the walls of many gay bars and businesses over the years. He is part of the Halifax Gay Men's Chorus and is working on a play about the loss of Bill and how that grief shaped who he is today.

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Our next story takes us to the opposite coast, and is based on an interview with Dakota Descoteaux, part of the invaluable "HIV In My Day" oral history project, housed at the University of Victoria Archives and made available to the public.

When Dakota came out in the 1980s, he was in his early twenties and living in Ottawa. Much of the nightlife happened across the Ottawa River in Hull (now Gatineau), Quebec. One night, a co-worker at the hotel where he worked invited him to a spot across the bridge, where he remembers seeing a dance floor full of only men, "moving their butts to Donna Summer's *Love to Love You* – I thought I'd died and gone to heaven."

Dakota soon discovered that, "There were lots of gay-friendly clubs in Hull. The discos would spin their tunes and serve alcohol until 3:00, while on the Ontario side, bars would close at 1:00. So, there was a very entrenched thing in Ottawa that people would go to the bars and drink until 1:00 and then drive across the bridge and carry on."

Dakota was promoted by the hotel and transferred to Whistler, BC. After a year, he moved to Vancouver, where he was amazed to discover not just a handful of gay bars, but fourteen! It was what he imagined San Francisco to be like. The bathhouse scene was also thriving. Dakota met his first long-term partner at a bathhouse. He remembers the awkwardness of being asked by parents or straight friends, "Oh, where did you guys meet?" You'd have to say, "Um… We met at the gym." In the pre-Internet days, bathhouses or bars were really the only places to meet men. And they were where real community connections formed, in the absence of more mainstream queer spaces.

By the middle of 1985, Dakota and his partner André were starting to hear rumours and read about the mysterious illness killing gay men. As soon as testing became available, they learned that they were both HIV-positive. Dakota says their strategy was, "Well, let's just keep living our lives and not make any changes until we need to." They had heard that symptoms might remain at bay for ten years, so when André started getting sick in 1989, they felt cheated. André had to

stop working and Dakota moved from hospitality to a job in insurance, where he'd have at least some paid sick leave, even if he couldn't get his own life insurance policy due to his HIV status.

Before long, it became impossible for Dakota to care for André on his own. His physical symptoms could be severe, but his increasing dementia was the challenge that proved untenable. He was no longer himself, behaving erratically and becoming reckless with money. Friends took him in, but couldn't cope either. André's mother took him home with her to Montreal, where he soon died in palliative care. It was a harrowing end to their relationship.

Dakota had joined an organization called Positive Living, where everyone could talk openly and vent about the medications that often caused worse symptoms than those they were intended to treat. Dakota says, "The disease and the drugs and the pharmaceutical companies, they were all finding their way. And there were no answers."

A couple of years after André's death, Dakota received a package in the mail.

> "I start opening it and there – oh my god, it was André's ashes. His mother sent them without telling me. So he came back to me in a box. He told me before he got dementia that if he ever were to die - of AIDS - he wanted his ashes spread at the Southlands Riding Club down in the horsey part of Vancouver. He used to be an equestrian long before I met him and he loved horses. So, I went down under the cover of night, 'cause it's illegal to spread ashes on private property (and public property for that matter). I spread his ashes all around the riding circle. I was able to have closure with it all and then move on, so I felt lucky for that experience."

In 1991, Dakota met Robert, who had spent a year coming to terms with his HIV-positive status by living in a log cabin near Squamish, developing healthy habits which Dakota gratefully embraced. They moved to Robert's childhood home and undertook its renovation. They were in their early thirties. Before long, they both started feeling a bit unwell - nothing specific, but just run down. Sensing that their time was limited, they took a few cruises and hosted lots of dinner

parties. They had three great years before Robert started wasting away - becoming thinner and weaker until he died in 1996.

Dakota had spotted his first Kaposi's sarcoma lesion some months before Robert's death. Suddenly they were everywhere, including in his throat, causing trouble swallowing. He underwent treatment, travelling back and forth between the cancer centre and the hospital where Robert lay dying. He describes it like this: "The chemo and the radiation were external treatments that were like throwing a thimble of water on a forest fire. Something would shrink and a week later it would be back."

Our confidence may have been shaken when Covid stopped normal human activity for a while, but it's hard for people who didn't live through the beginning of the AIDS crisis to fathom just how helpless and furious people felt. Not just patients like Dakota, but doctors too. In his autobiography about practicing medicine in the 1980s in rural Tennessee, Dr. Abraham Verghese (now also an acclaimed novelist), writes, "Seven years into the epidemic, four years after the virus that causes AIDS was discovered, two years after I saw my first HIV-infected patient… I still had no treatment to offer. Hand-holding, counseling, moral support, platitudes, bromides, prognostications, homilies. But I had nothing in the way of a remedy."

Dakota had entered palliative care, anticipating that his cancer would be terminal, when a doctor came around and told him about some new medications, not yet widely available, that seemed to be suppressing the virus much better than AZT alone had ever done. Dakota started on a combination of the earliest versions of Crixivan, Stavudine and Lamivudine. They were very rough on the body. But they worked. Within a week, the cancer treatments that had seemed futile started having an effect. The doctor said, "You might make it."

Dakota's parents had come from Ottawa for Robert's funeral and took him back with them to recuperate for a year. He reflects, "As a thirty-eight-year-old grown man, I moved back in with my parents, which was a wonderful thing for me to do. You know, Mom's home cooking, and not having any responsibilities or worries really helped me heal. I started exercising and I gained

twenty pounds. From being really sick, it took a while for me to come into my full health. In ’98, I returned to Vancouver and started a completely different life.”

In the worst years of his partners’ illnesses and his own, Dakota had felt like he was barely keeping his head above water. He had no energy for marches and protests. But he did benefit from peer support within the HIV community, and when he resettled in Vancouver, he found his purpose as a volunteer, facilitating similar kinds of groups. During the decades before HIV became undetectable with treatment or untransmittable with PrEP (pre-exposure prophylaxis), Dakota describes many gay men he met as “living their stigma,” feeling frustrated and bitter about their situation.

And yet there he was, someone who had come back from the brink - the brink of death and the brink of hopelessness after losing two partners and countless friends. He married an HIV-negative man, remained close with his family and became strong in spirit as well as in body. Dakota reflects that an HIV diagnosis today just means taking some pills alone in your bathroom. There isn’t the need for support that was so crucial thirty or forty years ago. And that comes at a cost.

Nobody would choose to go through what Dakota did, yet he’s quick to state that he wouldn’t want to be a young man now and that he’s grateful for the path he wound up taking. With loneliness and isolation proving such a social scourge and health risk today, he observes:

> “This AIDS community has been my life for twenty plus years. I mean, this is the community I walk in… the community of my volunteerism, of my leadership, of my support, of being supported. I feel a connection to everybody that has been a part of this community.”

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The final story in this series takes place in PEI and is about both Allan Hickox and Stuart Hickox.

Imagine your lifelong friends - members of your close knit faith community - refusing to touch your ambrosia salad at the church potluck, for fear of contracting a deadly virus. Imagine being hounded by reporters outside your front door and avoided by neighbours at the grocery store. That's how it was for Jean Hickox, before and for some time after the death of her son Allan in 1987 - the first confirmed AIDS fatality on Prince Edward Island.

Now imagine you are a teenage boy watching this unfold within your own family. That's how it was for Stuart Hickox, whose father was Allan's cousin. He decided to get as far away as possible from that kind of judgement and scorn, and to deadbolt his own closet door. Stuart didn't come out until he was fifty years old. When he was finally ready, he did it while hosting a World AIDS Day event 2017, in the presence of MP Svend Robinson (Canada's first openly gay MP), the Secretary General of UNAIDS, and a room full of dignitaries. He had to make a speech in his role as Canadian director for the ONE campaign, an international not-for-profit started by Bono. He said,

> "I remember as a teen that the thing I heard most often was that if Allan really was gay and had AIDS, he was getting what he deserved. Even my dad called him the Family Shame. And then, of course, Allan died. His mother, Great-aunt Jean, wasn't allowed to see the body. For me, as an adolescent from a religious family in a small community, it was so traumatic that it took me another three decades to admit (even to myself) that I too am gay."

Although Stuart was profoundly shaken by this experience, he never forgot Jean's courageous response to the cruelty of her community. She went on CBC radio to say her son was gay, that he had indeed died of AIDS and that she loved and was proud of him.

In 2022, Stuart took part in Dave Stewart's excellent "talkumentary" called *Positive: When HIV/AIDS hit PEI*. Dave Stewart describes himself as "an accidental queer archivist" with a passion for LGBT+ social history. Dave vividly recalls his own experience watching news of a deadly disease coming out of New York when he was in his early twenties. As a sexually active

closeted gay man, he was terrified that 1) he would be outed and 2) he would die an excruciating death. Dave's doctor was the first person he came out to, when he made an appointment to ask for an HIV test. The doctor made the process sound as threatening as possible, telling Dave he'd go on a government registry and have to contact every man he'd had sex with if his test came back positive.

Dave went ahead despite his doctor's dire warnings and continued to get tested every three months. He wanted to avoid spreading the virus without abandoning the joy of sex. The concept of harm reduction, through safer sex and programs like needle exchanges, really took hold in the early days of the AIDS crisis and continues to inform the response to the opioid crisis. It's a simple premise: if people are going to engage in certain behaviours - whether others approve or not - then we need to mitigate the risks involved, because everyone deserves to live. Straight people with multiple sexual partners started getting tested in the 80s and 90s as well, and condom use became the norm for everyone, with incalculable health benefits that continue to this day.

Stuart Hickox now lives in a lovely rural retreat in PEI that he shares with his adult sons (and occasionally his ex-wife). It's a family he never would have had, had he not been steered by his upbringing towards a traditional marriage with a woman. He says plainly, "My children exist because Allan died of AIDS. I saw what happened in my family when you're openly gay, and I couldn't do it."

Growing up, Stuart was aware that Allan was "not like the others." He was creative, artistic and often described as flamboyant. He was fun, in a family of prim and reserved aunts and uncles. Stuart isn't entirely sure how it came out that Allan was sick with AIDS, but the hysteria that ensued was borne of the particular kind of fear that can propagate on a small homogeneous island. Stuart notes that even during Covid, when PEI had extremely tight restrictions, people were very wary of their neighbours, going so far as to put warning signs on the lawns of those who were sick. "Go back forty years and make it about gay men," he says, "and you can just imagine what it was like."

When Allan died, Stuart's father refused to go to the funeral, where he assumed he could get AIDS by shaking hands with his (quote) "faggot friends." Stuart knew his attitude was wrong and mean-spirited but did not have the capacity to defend Allan. Nor did he have the wherewithal to escape the box he was in, for reasons that have become clearer as he's explored his family history. When Stuart did a university term in France, his grandfather, a conservative minister, wrote him a letter admonishing him to avoid the pleasures of the flesh. He was warning him, in no uncertain terms but without saying the words, not to be gay. Stuart got the message. On his wedding day, he knew he was making a conscious choice to deny who he was.

It turns out his grandfather had experienced parental rejection due to a terrible family tragedy. He filled the void with religious zeal. He moved his family from Wales to Alberta to PEI, ultimately wielding a great deal of influence from the pulpit but remaining sad and isolated his entire life.

While determinedly straight in his personal life - to the point of not knowing who RuPaul was - Stuart broke the mold in his professional life, becoming involved in the fight against HIV/AIDS in Africa… Which brings us back to that posh event in Ottawa on World AIDS Day 2017. Stuart remembers the silence that immediately followed his very public coming out (and then the thunderous applause and hugs).

His story about Great-aunt Jean's response to injustice and stigma perfectly reflected the theme of the evening. He told the crowd,

> "Keep in mind, this was a woman born before electricity in rural PEI in a fundamentalist religious society that didn't value women and where women were expected to stay in their place and be seen, not heard. Doesn't that sound familiar? As I considered this story for tonight, it occurred to me that these are the same circumstances we find women dealing with in communities we are struggling to help today. So while Great-aunt Jean's courage was remarkable in itself, it's only very recently that the full meaning of her actions has dawned on me, and why her story remains relevant."

A few years later, Stuart found himself in a pitched battle with the Canadian government over support for HIV/AIDS internationally. Much public intervention and a threat to embarrass the PM at the Montreal Pride parade ultimately paid off. Stuart happened to be visiting Allan's grave on the anniversary of his death on the day he got word that the funds had been approved.

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