

catching DIANE ATWOOD health

Tom Antonik, 63
Conversations About Aging
December 2, 2019

Diane: Welcome to Conversations About Aging. I'm Diane Atwood and I'm traveling around my home state of Maine talking to people 60 and above about what it's like to be getting older. Everyone has a story to tell and wisdom to share. Today I'm talking with Tom Antonik, who never thought he'd live to see 40. That's because at the age 30 he found out he was HIV positive. More than 30 years after passed and Tom is now 63 and doing well. I first met Tom in 1988 when he spoke at a school assembly in Scarborough that I was covering as a reporter. He did his first ever television interview with me and he made an impression. There was so much fear and lack of understanding about HIV/AIDS during that time and yet Tom decided early on to be open about his diagnosis and to share his story. We recently spent some time together at the Friends Meeting House in Portland, where he is a member and an adult volunteer and resource person with the New England wide Quaker youth programs, working mostly with high school aged youth. We talked about his diagnosis and how he has managed to live this long with AIDS when so many people succumbed early on? But before we got to that, Tom reminisced about his childhood.

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Diane: So you're from Maine.

Tom: Well, I lived mostly in Maine but my father was in the service. So I was born in Florida, my sister in New Jersey, my brother in upstate New York, but my earliest memories are from Maine. He was in the Air Force. I remember being at what was Dow Air Force Base in Bangor. We lived in France for three years and then came back. He was stationed in Topsham when that was still an Air Force installation and then retired from there. So I've lived most of my life in Maine, but I also went to school in New York City.

Diane: We sort of have parallel pasts because I'm an Army brat. My parents are from, they've both died now, but my father was from Westbrook, my mother was from

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Portland. I was born in Germany, another brother was born in Germany. There are eight of us. So a couple in Massachusetts couple in Maine, a couple in New Jersey. Yeah, it's quite a life, isn't it trying to adjust to making new friends all the time?

Tom: Well, you know, it was all that I knew, so I didn't really have anything to compare it with and I remember when we moved to Topsham, and it was not just a military school, it was a school for the community as well, and I met someone who at the ripe old age of 11 years old had lived in her house all her life, and I just thought that was astonishing.

Diane: I don't even have a memory of bedrooms.

Tom: Right. So, I, you know, I think in some ways, it gave me the advantage of being prepared for change. And knowing that I could be adaptable. So I think there were some benefits to it as well.

Diane: Here we are older and so well adapted.

Tom: Yes, and so much wiser.

Diane: So how old, how old were you when your father retired and they, the family settled down here in Maine. Were you still in the family?

Tom: Right. I was in I think the eighth grade so you know, maybe 12 at the time, but we had been living in Topsham and he bought a house in Lisbon falls, which my forgiveness to, begging forgiveness to everyone from Lisbon falls I refer to as my therapy years, because it was, it was not an easy place for someone who had a sense of, you know, my sexuality as a gay man that I was still, I was so afraid of being outed. It was and I think still remains a very conservative town. So there was some challenges about living there.

Diane: Well, that's a challenging time of life anyway, because you're in adolescence. Oh, absolutely. Trying to figure out who you are in general and on top of it, you're grappling with your sexuality, right? At what age did you suspect?

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Tom: I think it in a way I always knew, I think I didn't always have the language for it. I think perhaps as I got into, you know, puberty, I thought, well, maybe this is something you know, that might pass or that I could sort of find another place sort of along the sort of bisexual spectrum, but that never quite happened for me.

Diane: Tell me about your siblings. Where are you in the mix?

Tom: I'm a middle child. My sister is the youngest. She just lost her husband recently. My brother older than I am, and they both also live in Maine.

Diane: When you were growing up and you suspected but you didn't have the language, how did you work through that or did you just day to day, you were just Tom?

Tom: I think it was kind of a second sense of being very cautious of how much I revealed of myself.

Diane: Even at a young, young age?

Tom: Yeah, and I think it was mostly around gender roles. I remember you know, early on liking to play with dolls and getting the very clear message that that was wrong for boys. So that any sort of expression of femininity I had to hold back. So there was that sense around of, you know, sexuality, you know, expressed are, you know, connected to gender identity. And although I know, still, clearly I strongly identify as male, you know, working with youth now, and all the different options that there are for sexual identities and gender expression. You know, I wonder if I might have expressed it differently if I even knew those options existed?

Diane: Are you able to do an exercise where you could imagine what how you might have expressed your identity, given the options that people have today?

Tom: Right, I think I probably might and to some degree today, like the identification of queer, rather just as gay and part of it is that sometimes I do like to have a little bit of feminine expression of, you know, wearing some, you know, costume jewelry or you know, something that's just a little bit, you know, tweaks the masculine, you know,

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sense. I remember being at an opening once in New York and a young man had, you know, a traditional suit, but he had a string of pearls and I just thought it was striking. I just really loved that and that's sort of the sense of expression that I really appreciate.

Diane: Help us to understand the difference in the terminology. You said queer versus gay. So is it just in how you express yourself?

Tom: I think for me, queer is a larger encompassing term and many people can use that identity. I think the term gay is just being, you know, a man who is sexually attracted to other men. There's some truth to that about me, but there have also been times where I've been attracted to women. And I think queer speaks to just not fitting into that mainstream sort of dichotomy of men being attracted man, woman being attracted to women and those who are bisexual and then there's pansexual and all sorts of others that — please don't ask me to define some of them because I...

Diane: I thought about it, but actually, I said no, I'm not gonna make him do that.

Tom: Right, because the definitions change, change a lot, and especially in the last few years with gender identity. I mean, those who don't identify on either gender and use either they, their pronouns or other pronouns that are not he, him or she, she hers.

Diane: So there's certainly a much more heightened awareness and sensitivity, do you think? And that's a good thing?

Tom: Oh, I think that is a good thing and I think it continues to expand. And there's still, you know, pushback, too. It's not easy for, you know, especially, you know, the murder rate among, you know, trans people and especially trans women of African American descent is just horrific. So there's, I mean, we still have a long way to go, but I think the possibilities are now opening up more.

Diane: Because we are all opening up more. We, by we, I mean, human beings are willing to be more open to talk about things to ask questions?

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Tom: I think so. And I think particularly the younger people who are finding that some of the terms that they grew up with weren't satisfying to them. And I think as one term expanded and then maybe another way of saying, well, that doesn't quite fit me but this might or I am in a place where I can't identify my gender binary. So I consider myself non-binary. What I think it's a combination of awareness, I think some growing acceptance, but as I said, you know, when I was younger there wasn't even the language for this.

Diane: I want to talk about that. But I am going to ask you to define non-binary.

Tom: Being neither, identifying neither as male nor female.

Diane: It's all about choice rather than having society or other people decide how you should be labeled.

Tom: Right. It's choice and I think it's also just more about an authenticity. I just kind of want to avoid the sense of choice and the sense that, again, you know, my early years and probably still, for many people, they think that being gay is a choice. It was never a choice for me. It's just how I'm made up and I think to give people, the expansiveness to say, oh, I don't have these two choices, I might have these multiple choices. They can, you know, fall somewhere in the spectrum or and sometimes go back. There is also the term gender fluidity where, you know, at some points in their lives, they might identify more as male and sometimes more as female. I think given the, it's, I think now we have the opportunities for a more expansive expression. So yes, it is a choice in how they want to be or any of us want to be, you know, addressed by pronouns, but it's not a choice in that I'm choosing not to be male.

Diane: Sometimes frequently, more so lately, I feel really discouraged about the human race. There are so many wonderful people out there but I don't understand people who aren't even willing to understand. You know, there's prejudice, there's racism, there's all of this stuff. What is it about us humans that we can't just accept somebody for he who he or she or they is?

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Tom: Or, you know, I wish I had a good answer for that. But I believe, you know, many people get into some very locked paradigm of what the world looks like in terms of, you know, gender, race, ethnic identity, and there's a kind of a threat to, you know, how that challenged really does threaten I think people's worldview and they get very defensive about it.

Tom: Makes me think of a story I'm going on a little tangent, but many years ago after I moved back here but I was still going back to New York for many years and would attend the the Gay Pride festivals there. And I was sort of walking in between groups and really enjoying myself and I was doing it one of those very beautiful and not too hot June days. But the area in front of St. Patrick's is where usually all the protesters are. And there's good police presence and their are barricades, but I'd gotten separated between groups. So I was walking pretty much alone in that area in front of, you know, all the protesters and being you know, hearing just some pretty horrific things, you know, slung at me, and part of what happened was my thought they don't know me. They're throwing these words and this hate and this fear towards some idea of who they think that I am. And so yes, it was a little scary. I have to admit, I was grateful for the police presence there and it was also kind of an opening for me to realize, to not take it personally. That it was Yeah, they didn't know me. But I was a symbol.

Diane It would be hard not to take it personally in those moments, though, probably.

Tom: Curiously, I think it was, was easier because, again, they can, they didn't know me whatsoever. I was just this anonymous person walking through. And, you know, I think if I were doing, you know, a talk and you know, there might have been someone who knew me from high school or something and, you know, yelled out some slurs that would have been, I probably would have taken that more personally. But I am curious. I was a very curious experience. Yes, you might think that would be the case. But, I was I think that that sense of that's not me.

Diane: Back to your childhood, when you said that you had to be careful about expressing your feminine side in particular. Was that within your family, outside of the family? Both?

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Tom: I think a little bit of both. I think my my mother probably always suspected that I was gay. I think it was more of a surprise to my father. You know, I'm sure my father didn't quite know what to do with this young man who wasn't interested in sports or would much prefer, you know, to play with dolls or his crayons.

Tom: He didn't know, really, how to relate to me in some ways, and I to him. Curiously, when I did finally come out, I think in many ways my father was much more supportive in the largest sense than my mother who probably had I know she had undiagnosed mental health issues. So it seemed alright I was gay at home, but somewhat not so much in front of the neighbors and there would be almost a double standard.

Diane: This is where your mother's concerned?

Tom: Correct. So that, you know, she was comfortable when I brought home partners but when a neighbor visited and I remember one time, it was just a friend of mine, it was someone I was not in relationship, but I had my arm around him, good friends and this neighbor said she was uncomfortable with it and my mother reprimanded me for that and I was really, really hurt by that.

Diane: Were you able to have a conversation with your mother about your feelings?

Tom: I don't think so. I don't think I really sort of grasped what was going on at the time. But I was definitely hurt by it. I think I might have expressed that.

Diane: Did your brother and sister know you were gay before you came out to the family?

Tom: No, I think they all sort of learned pretty much the same time maybe my sister was the first and they were very supportive. I don't think it was you know, a terrible surprise but I don't think they went like oh, of course we're just waiting. They didn't do that? Right, I think some families go yes, we knew we're just waiting for you to say so.

Diane: What about in school?

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Tom: Well, in high school is very, you know, very cautious about being found out, although, you know, when I think of, you know, you know, the red wide wale corduroys that I made at one point, I'm thinking how do people not know? I finally went to the School of Visual Arts in New York. It was just such a, you know, amazing place that I could be open and just felt, I think I needed to get that distance. I know some people I knew might move to Boston or in Portland was a big draw for, for many, you know, gay and lesbian people because it was safer than being in rural areas.

Diane: Are you saying that you left Topsham and you went to New York and finished high school there?

Tom: No, no, no. For my for my undergraduate work.

Diane: Okay. So you were in what grade, did you tell me eighth grade when you moved to Topsham, when you settled in Topsham?

Tom: Eighth grade when we moved to Lisbon falls. So I was probably six, seven for the first half of eighth grade in Topsham and then we moved to Lisbon Falls.

Diane: And that's where you finished high school. And that's where you hid your true self? Absolutely. Yes. Did you ever have any kind of confrontations or painful moments?

Tom: No, I think there was some bullying of you know, not sort of horrific, but I was aware that they sort of had their eye on me. And I think keeping my head down was my idea of keeping safe.

Diane: And New York City, was that a wonderful place for you to be?

Tom: Oh, it really was. I started in the School of Visual Arts in New York in 1979.

Diane: Because you are a visual artist?

Tom: Right, right. I think living in New York probably was much if not more of an education than being at the school itself. It was a very exciting time. As an artist, the

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artists of like the East Village, were just exploding There is still you know, find your reasonably priced theater tickets and you know the museums but also just that the mix of culture and also the gay and lesbian scene and that for the most part could feel comfortable if I were walking hand in hand with, you know, a boyfriend but there are also other parts in New York that was not safe and just kind of intuitively knew where and when that could happen. So it was a very exciting time for me. It was also pre-AIDS so I was also living there at the time where we started hearing about this mysterious illness that was affecting gay men and I was there for that time as well.

Diane: Were you afraid?

Tom: Well at the time I was in a monogamous relationship and probably stayed in that relationship much longer than I should have. It was not a healthy relationship but part of that was because I was afraid of then going out and trying to navigate the dating scene. It was not a good breakup. And I was in the place of like, well, I'm just not going to date again, ever, so I don't have to worry about that. But I think maybe a year later and someone was you know, expressing interest and I, you know, maybe I do want to and I participated in a research project with Columbia University that was looking into the psychological and sociological effects of this of AIDS on quote unquote healthy gay men and once the antibody test was made available, they offered that and, as an option, and optional, to find out the results and I I chose not to find out the results because I wasn't dating. But when, you know, this person expressed interest in me and I was feeling you know that interest myself, I thought maybe I'll go find out. And when I found out that I was HIV positive, it was really quite a shock to me. It was '86, and in '87 that I got the full AIDS diagnosis.

Diane: So when you're HIV positive, it just means that they detected the antibodies but you're not sick at that point. Correct. What was it that gave you the AIDS diagnosis?

Tom: Kaposi's Sarcoma, which is one of the secondary cancers that sometimes people would get at that time. I'm can't say at this moment what the criteria is, but I think at that time it was either one of the secondary cancers, PCP, which is a particular kind of pneumonia, a t-cell count, which is a measure of one's immune system, below 200. So when, when I was first HIV positive, actually first diagnosed, there were there were no

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treatments and AZT had just become available when I was diagnosed with AIDS and my doctor actually had to lie at the time because it was only available to people with like a cd count below 200 and mine was still higher than that, but I had the Kaposi's but that wouldn't have qualified me.

Diane: Maybe getting you on that early, maybe is what's helped you still be here today?

Tom: Well there's a mix with that. It actually in some ways it kind of backfired because I've had so many different treatments I have resistances to all sorts of different medications. So the medication, combination of medications I'm on now, if the, if this fails, there's actually nothing immediately available. There's something that might be released soon, because of where I have resistances and sensitivities, for you know, the science is amazing than the genotyping they can do with the virus now, but it does show that I have a lot of resistance is to a lot of the meds.

Diane: When I met you in the late 80s, then you'd been diagnosed you were you had AIDS. They used to call it full blown AIDS.

Tom: That was the term then.

Diane: So you had been diagnosed with AIDS. And right from the get go, you chose to be public about it, to talk about it, whatever motivated you to be so open?

Tom: I think in part I was a little bit of I guess paying it forward. When I was first diagnosed and then living in Connecticut, New York, or in New York, I started going to the People With AIDS coalition. I remember walking around the block a couple times before I dared go in. And I mean, there's just so much fear around it, but so many people because of their being a public made it that much easier for me to, you know, get the support that I needed. And so once I think the big initial shock wore off some, I think I still lived with it for quite a while and it's probably still there in some ways. I thought I wanted to do something to help those who are coming along. And I thought there was there's an opening on the board of directors of the People With AIDS Coalition in New York and put in an application and but I had never been politically active or much of an activist and you know, I think, always before I said, when I get to

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this point in my life I'll do this volunteer work but just never got around to it. I thought, well, maybe this this is a time and I did not think that they would accept me onto the board of directors. But what was so powerful about it is just being listened to for my experience and that gave me the authority to be part of this sort of groundbreaking organization that really wanted to combat the sense of victimization and that, that we as people living with AIDS, you know, had a voice and say in our treatment. And I remember the very first speaking engagement I was asked to do through the speaker's bureau there, it was at the Parsons School of Design Fashion Institute. So, you know, I was up almost the night before and not so much worried about what I was going to say but what I was going to wear, and I think I dressed very, very smartly. But I think there was a woman from Gay Men's Health Crisis, which is still the preeminent AIDS service organization in New York and talking about the facts and statistics and then I got up and told my story and, and then, you know, okay, it here comes when, are there any questions? I just have no idea what's going to happen. But, you know, one hand raises after the other, but I remember one question about, you know, we, you know, in our fashion work, we often share piles of, you know, sewing pins. What if someone, you know, sticks a finger on that, and I hadn't even thought about that. But the questions that I got were respectful or, you know, out of genuine curiosity, and it just really gave me that opening of, again, by sharing my personal story, you know, I was making a difference for others.

Diane: You became educated about how HIV spread. And so you went out and you tried to educate people, the doctors tried to educate the people. There are still some people who don't understand it. So educate us again.

Tom: Well, it can't be passed casually. It needs to be you know, passed you know, either you know blood to blood or through you know sexual fluids and and then a significant amount of exposure, too. Something like the pins and the sewing pins would not likely, you know, if someone pricked themselves with a pin that someone else was HIV positive pricked themselves before would likely not have you know, almost infinitesimal. Can't say it's impossible but it had to be, it has to be a significant exposure. And what's also developed recently with the new medications where you know some people are, the HIV level is so low that it's undetectable. I don't think there's really any risk of transmission sexually. They're finding that you know, with a couple, one person is

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CR positive and one isn't and they may not have been as careful as you know, they might have but one person is on the antiretroviral treatments and at an undetectable level.

Diane: So their viral load is that the term is low is way below the acceptable ...

Tom: The sensitivity of tests that they have now, which are pretty sensitive, but I can't remember how many parts per million, the test just can't detect it.

Diane: Back when you were first diagnosed, AZT had just come out on the market and then there were these protease inhibitors. And that is like, how many years now? 20, 30?

Tom: Probably close to 30 I'm trying to think. It was 1990 that I'd just heard about the protease inhibitors, it might have been two years later, might have been 92 when they started combining them. And I remember being skeptical, took me a while before I went on them, because there were, there were many new treatments that came along that were, you know, hailed as this is the breakthrough drug and then, you know, six months later, not such a breakthrough as they thought it was. And so I was a little skeptical.

Diane: Were there side effects?

Tom: Not that they recognized immediately but one of the side effects was raising cholesterol levels. So suddenly, people who hadn't had heart conditions before were getting into having to have you know, bypass surgery or having heart attacks. So some long term side effects they're still not, not sure of and other different liver functions and so, but when I started seeing, you know, people who, you know, months before looked like they were at death's door, that I barely recognized them because they were healthy. Thought maybe I'll give it a try.

Diane: Because by then were you feeling pretty miserable?

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Tom: I was feeling pretty, pretty poorly and, and I had outlived, you know, you know, so many friends, so many sort of cycles of people in my support groups and so there was almost a kind of despair of you know, just let it be over with.

Diane: I was gonna ask you about that. You have the specter of death over you even all of these medications did offer some kind of hope. It wasn't hope of a cure was it at that point?

Tom: Not at that point. But it was sort of the hope of treating it better. So I think the so the it, the benefits sort of arose gradually, as I'm still kind of, I still sort of look back and you know, wonder at what point what did I have a little bit more hope that I might have more time. And one of them was after I was diagnosed, I kind of stopped doing my art work and devoted a lot of my energies towards the public speaking and activism work. And I thought, well, maybe I'll still be around for a while, but as a painter I was never terribly prolific. I thought I've always liked photography and I can get a lot more work done as a photographer in what I think is still going to be a short period of time. So that was really took my attention for many years and I really enjoyed that. And, and it was, there was some trepidation when I thought that well, maybe I can trust getting back to doing some painting again. There's still a little bit of sort of hold back a little bit here and there.

Diane: It's almost like every day you wake up and you think oh my gosh, it's another day.

Tom: My milestone birthdays. I remember particularly, like my 40th and again, like, I have finally reached 40, oh my god I'm 40 years old. How did this happen? Like I'd never thought I'd be 40 years old. My 50th birthday I decided to do a nine-week silent retreat at a Zen Meditation site, center in Barre. Friends of mine here at Portland Friends Meeting decided I needed a surprise 50th birthday party. I just want to put it out there, as much as I appreciate all the love, never give an introvert a surprise birthday party. I'm so grateful that you did but give us time to prepare.

Diane: I know everybody's going to want to know. Exactly why have you lived so long?

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Tom: I don't know. I think there is a possibility of a partial immunity. There are, I forget what the percentage is of people of some Northern European heritage, Scandinavian, other places in Northern Europe that have actually an actual immunity to HIV.

Diane: And you don't have the immunity because you got it? Right. But you might have an immunity that's built up over the years?

Tom: Or there might be a partial immunity. So It's not like, you know, full immunity, but there might be a partial me that that slowed the progression of the disease. That's one one theory I hold. But you know, I know certainly other people who, you know, took much better care of themselves than I did, who know died many years ago. So I think there's no real reason that I can name. Just on as a piece of that natural immunity. I don't know if you're familiar with the Berlin patient and recently, I think the London patient, who was, the Berlin patient was someone living with HIV/AIDS, who also developed leukemia. And when they did the bone marrow transplant, I believe they specifically looked for a match with someone who had that natural immunity. And so they had the marrow transplant and he was probably the first person to be effectively, living free from HIV AIDS without any medications.

Diane: The procedure cleared him of the virus?

Tom: Right. And I think something similar happened to someone in London recently. So I mentioned you know, before we began recording about a medical protocol I engaged in was sort of falling on that science. They took some of my white blood cells out through plasmapheresis, they genetically altered those white blood cells to create that natural immunity, then cultured them. I had one course of chemotherapy, which was supposed to sort of shock out whatever, you know, HIV was left and then reintroduced, you know, again, billions of copies of those white blood cells that were originally mine, but then modified with that genetic immunity. And then after, you know, a few days after chemotherapy I went off meds, and I think it worked well for someone up to like 18 months or more. Eventually, it did not work. I think a few months later I remember, I was actually I'm visiting some friends out in California and just just not quite the night sweats, but something was just terribly wrong. And when I got back my viral account was like up to like 6 million.

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Diane: So what you're telling me is that you participated in a, was it a clinical trial?

Tom: Yes, that was the word I was looking for. Clinical trial in Connecticut and I knew some of the risks that might be involved. But I you know, again, this, you know, speaking of those who came before me, many people did clinical trials so that I am on the, you know, protease inhibitors I am on now. So, you know, I felt it was worth it. I had a little trouble getting viral count back down to undetectable consistently since that time.

Diane: That's kind of scary.

Tom: It's a little bit scary because as I said said it's, it's still very low, but you know, if it breaks through, there's not a lot of options right now and that there is something as I said, hopefully released the next couple months.

Diane: How long ago did you participate in this clinical trial?

Tom: I'm trying to think, you know, four or five years ago. It was a two-year study. So even though you know I did not respond to it, eventually, I think, no one did. I think the longest I knew someone was off meds and still undetectable was a year and a half. But they continued following me as you know, to make sure that, you know, other side effects did not happen.

Diane: So you have helped the people who come after you, haven't you? And I'm sure that it's a stepping stone to something that will work like that.

Tom: Yes, I think it's a very promising line of research.

Diane: How are you feeling now?

Tom: Physically with HIV/AIDS, that's probably the least of my challenges. You know, again, part of, I have type two diabetes and about a year and a half ago, I had a coronary event which really surprised me because I have like freakishly low cholesterol levels, had been mostly vegan or vegetarian beforehand. But also have family history

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and being a man over 60 and type two diabetes. So, yeah, that one took me by surprise. I ended up having two stents to correct three blockages and so grateful for my sister has worked at the Maine Med cardiac cath lab for many years I got they were very careful not to kill her brother there.

Diane: Thank the Lord, thank the dear Lord.

Tom: I know they're wonderful, wonderful people there anyway, but I think they're especially on guard.

Diane: They treated you with kid gloves. Absolutely.

Diane: Is it possible that both your diabetes and the heart issues could be connected to any medications that you've been on?

Tom: Yes, actually. Medications that affect the immune system including some different kinds of chemotherapies have a high propensity to trigger diabetes. I wish someone had told me that ahead of time. And I think I was a little annoyed when they told me that with such a casual, you know, my mother did have diabetes, so I do have the genetic propensity. But yeah, so that, I don't know about the HIV but I do know of even in the earlier some medications would trigger diabetes in some people.

Diane: What exactly are you on now for medications?

Tom: There are two antiretrovirals. One of them is a combination of three different antiretroviral, so I guess technically I'm on four, but those are just two pills, two oral medications for type two diabetes. I am on slow acting insulin, there is an anti cholesterol medication, a very small amount of blood pressure medication, some medications for my depression. So it's quite a full pillbox.

Diane: As I remember some of the earlier medications you had to take them day and night, didn't you?

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Tom: Right. Particularly with AZT, that was every eight hours. I was thinking about that not too long about these pill boxes that were available. Ivory colored and you know, at certain public events, you'd hear this familiar beeping. We, we know what that is.

Diane: So at some point in your life, you didn't think you'd see, you'd never see 40.

Tom: Right. Right. So, you know, again, I was thinking about this interview coming up, and you know, what an interesting relationship I've had to aging and my sense of mortality. Because, again, going back to, you know, the early years of, you know, my diagnosis and, you know, losing people around me and being with, you know, actually with some people as they died, and you know, it was something I discovered about myself that I didn't know that was easy that I could do that. And it was not, not everyone could.

Diane: To be with somebody as they're dying.

Tom: Yeah, in the dying process and you know, I found you know, those two times I was actually with someone to be just such an honor. And, you know, certainly heartbreaking but, um, so and I also did a lot of work around grief through different workshops and you know, did some work with Elizabeth Kubler Ross workshops and so I really thought and I think at that time, really had made some peace with my mortality, you know, feeling like, I'd gotten to achieve some things that many people hadn't. And, you know, if I suddenly started my decline that would be okay. Then a year and a half ago when I had a coronary event and I'm going, well, that was then and this is now. Sort of a different relationship. You know, I'm not quite ready yet.

Diane: What do you have left to do?

Tom: Well,, it's curious. There was sort of a reevaluation of what was really important to me and I, you know, thought about you know, you know, the artwork and the photography and I think that was was there a series of paintings or photographs that you know, I just really felt made a difference in my life or others and I'm not sure that that's where it was but I think it's my, you know, work with youth and now as a we sort of reminisce, you know, some of the public speaking opportunities, including some in the

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Maine Youth Center when it was a very different Maine Youth Center than it was now. Those were, you know, really moments of I felt like I was able to, you know, give something and make a difference in people's lives. So, so I really hadn't been doing much of any artwork in the last year and a half some of the youth work that I'm doing now I've, last couple of years I'm wondering, it's hard for me to sleep on the air mattresses at the overnight retreats and staying up as late and can I continue doing this sort of work in the way that I have in the past? So, you know, what, what is what is what might continue as as meaningful work for me? I'm still sort of questioning and I think there has been some sort of post coronary event depression around that.

Diane: And it's fall.

Tom: Yes, yeah. It is. It's a hard time of year for many of us.

Diane: But you now at this stage in your life can look forward.

Tom: Yeah, I can. But you know, when I think I have coronary artery disease. I have type two diabetes, I have HIV. Depression shortens lives. You know, how many years do I really have left in a very realistic way and also knowing I certainly got surprised before. So um.

Diane: Do you consider yourself an old man?

Tom: You know, I work with teenagers, so there's always going to be that, but I think there's this part of that, that you know, I don't always feel like I'm an old man. At the same time, there are some things I think I can get away with, you know, because of my age. Actually, I'm a big fan of Project Runway although I have these great ideas and I think you know, the, either the very young or the very old can wear outrageous things. So...

Diane: Do you dress outrageously still?

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Tom: No, not not often. I think that is still a part of me that shyness, an introvert that sort of wants to blend in but every once in a while I'll wear this like a ridiculous hat or something to youth retreats I'm going to. When you're old, it's called eccentric, so.

Diane: There's a poem, when I am old, I will wear purple.

Tom: Yes, I was thinking of that as well. So, I hope to embrace that more.

Diane: I haven't asked you for your words of wisdom now that you're so old ...

Tom: Words of wisdom. I think a former partner was asked about, you know, one of my qualities and he said, you know, really appreciated my curiosity. And, and I, I hadn't thought of that, but I hold on to that. And I think holding on to that, that sense of curiosity is sort of vital. It's, I mean, it's, it's part of that that Buddhist practice of just continuing looking in and looking in and looking in and also recognizing that everything is change. So I think, you know, to try to hold and nurture that curiosity. And also, I think if there were advice, you know, I give myself you know, to be a little more gentle on my own self.

Diane: I always ask people this question whether they're 63 or 93, or I've had one woman who was 100. What makes it a good day for you?

Tom: I was trying to prepare for that question and I do have a Buddhist practice we call that rehearsing mind. So I went through my rehearsing mind and and I think the, you know, my immediate answer was and they were I was being of service in some way that might include being of service to myself by learning something new. But I think in reality, I have to say, you know, really depends, particularly in light with struggling with depression because sometimes I have to set the bar really low. And that was some advice a couple of people gave me and it was sort of hard to take, but sometimes when I get out of bed and get dressed and shave, and sometimes even just, you know, get out physically out of the house, that's a good day for me. Other times, you know, when, you know, things seem to like really cooking at a youth retreat, and there's some kid having a meltdown that no one else seems to be able to work with that I just can be present to and and basically just empty myself out and listen to and then and hour or so

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later, something's happened. I don't know what and I don't, I often actually avoid trying to give advice, but just let them know that they're being heard and listened to and then something shifts.

Diane: We've talked about so many things. And you are the expert on you. Are there any things that you wish we had talked about? Questions that I have I failed to even think about?

Tom: Oh, I'm sure they'll come to me about, you know, 20 minutes or as I'm riding home. I think we've covered a lot of them. And again, you know, my, I think, you know, a lot of people just don't really fully imagine what it's like to to age and I think have a good excuse for that, that, you know, I was really given a diagnosis that most people would not ... the initial one was, most people did not live more than a year and a half.

Diane: So you're, you're really grateful that you're an old man now.

Tom: Well, I want to say there's mixed feelings because remember when my last boyfriend in New York was Vito Russo, who wrote the Cellulite Closet and just a lovely man. Neither loves of each other's lives but just, I don't think I'd like partner as much as I did here. I liked him so much. And he was having this banter back with his closest friend of, you know, I my foot hurts my back hurts and back and forth. And then finally Vito said I have AIDS and I'm going to die and his friend said, and I'm going to lose my best friend. So you know, who's who really suffers more than you know that person who dies earlier or the person who's, you know, living with the grief of their best friends lost that they've lost. I think one thing that I had thought about that I didn't mention is about five years ago, a very close friend of mine died of metastatic melanoma just shy of his 50th birthday and I was surprised how much I want to see a variation of PTSD came up because he was barely 50 and was to me, young and vital and he shouldn't have died that early and I think that, you know, that internal voice of you know, you shouldn't die this early sort of kicked that floodgate of, you know, so many, you know, people close to me that, you know, should not have died early so I think they're still kind of trauma that

Diane: you carry inside you. There's this term too, called survivor guilt. Do you ever feel that?

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Tom: I didn't think that I had, but I think there is a degree that I do. And I think part of that being hard on myself might be a little bit of like, I've survived all these people. And there are times when I'll run through some photographs of people who are long gone. And there's a sort of empty ache about that. I'm still here and and they're not.

Diane: I'm glad you're still here. What are you going to do for the rest of the day

Tom: I think I'm in Portland I've got a couple of errands to do is nice to have a you know a lovely clear day after you know still a windy you know blustery and rainy day yesterday. It's always nice to be here and get a few errands done.

Diane: Well, enjoy and thank you. Thank you.

You've been listening to *Conversations About Aging*, a Catching Health Podcast. I'm Diane Atwood and I've been talking with Tom Antonik, who was diagnosed with AIDS in 1987, the year before the World Health Organization declared the first World AIDS Day. This podcast episode was published the day after World AIDS Day 2019. A lot has changed in the past 30 plus years. When Tom got his diagnosis, it was considered an automatic death sentence. He is one of the few who survived those early years of the AIDS epidemic. Today, we're seeing fewer HIV infections, and because of new treatments, people who have HIV/AIDS are living longer, healthier lives.

If you enjoyed my conversations with Tom, please consider sharing it with a friend. You'll find more episodes on my blog Catching Health at CatchingHealth.com.

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