



# MY UNEXPECTED LIFE

An International Memoir of Two Pandemics, HIV and COVID-19

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## POSSIBLE TOPICS, QUESTION IDEAS AND SAMPLE AUTHOR ANSWERS FOR *MY UNEXPECTED LIFE*

### TOPIC: HIV

**Question:** *What was it like to be tested for HIV before treatment was readily available?*

**Answer:** *Confusing. I was told I probably had five years to live so I decided I wanted to make those five years count. I became involved early on as an advocate for women with HIV and I think it saved my life because it made me feel I had a purpose. I figured that if I could share my story – I spoke frequently in high schools back in San Francisco in the 1990s – then maybe one person might learn something and not become infected themselves. That was a lot for me to hold on to and since we didn't yet have viable antiretroviral treatment, it was an excellent anchor.*

### TOPIC: HIV AND COVID-19

**Question:** *What similarities have you found between the two pandemics? What are the main differences?*

**Answer:** *I'd say the main similarity is the staggering, gut wrenching, numbers of deaths, both early on because we didn't know what had hit us or how to treat it, and again recently, because people refuse to believe the science and protect themselves. The trauma of so many deaths, so quickly, and so inexplicably, reopened the grief wounds for many of us living with HIV. Trauma never forgets.*

*And the main difference, for me, is that communities came together and changed the course of HIV. People living with HIV or AIDS. The LGBTQ community. The infectious disease medical workers. And so many others. They joined forces and made a difference. I do not see these sorts of alliances happening now because the country is so divided, and in a very different way than when the AIDS crisis took hold.*

**Question:** *You actually had COVID-19 in spring 2020, and if I understand correctly, you're now a COVID long-hauler. Tell me about that in relation to having HIV.*

**Answer:**

*Having lived for so long with HIV, I think I sort of felt COVID would not be my issue. But, of course, that was a ridiculous thought as viruses do not discriminate. When I first had it, I downplayed it but, in retrospect, it was awful. The main difference for me, however, was that I never felt like I was the only one dealing with it. With HIV I did.*

*And in terms of the long-haul issue, I'd have to say that COVID packed a punch in a way that dealt me more immediate issues than HIV. I was pretty healthy for the first 16 years with HIV before my health took a dive. With COVID, I'm still dealing with symptoms from day one, and that's been about 18 months.*

### TOPIC: UNITED NATIONS/PROFESSIONAL LIFE

**Question:** *Tell me about being the first openly HIV-positive person hired by UNAIDS.*

**Answer:** *It was like diving into the deep end, except the deep end was the middle of the ocean and I didn't really know how to swim.*

**Question:** *How did having HIV impact your professional choices?*

**Answer:** *Having HIV defined everything thing I did for decades after my diagnosis. Some opportunities were taken away, like my dream of joining the Peace Corps which, at the time, did not accept positive volunteers. But, since I dug my heels in, and had the good fortune to be guided by others wiser than myself, I ended up on a path that I could never have imagined. HIV, in many ways, afforded me a most extraordinary career and the chance to glimpse the realities of this pandemic all around the world. I would still rather not have HIV, but all things considered, I have been so blessed and my professional life has been no exception.*

**Question:** *After testing positive in 1992, you almost immediately dove into work as an activist and advocate for women living with HIV. Why? Why didn't you just live your life and work in a bookstore or something?*

**Answer:** *Because I didn't know what else to do. It's not a very glamorous answer, but it's the truth. If you're shoved off the shoulder of a highway down the embankment and into the sludge below, you don't just stay there. You muster every ounce of strength and climb back up and out. And if you can't find who or what knocked you down, then you at least try to make sure nobody else falls if they can avoid it.*

**Question:** *What advice would you give to anyone interested in working for the United Nations or in any other way undertaking a career in humanitarian work?*

**Answer:** *I'd say to start with what you can do close to home. There is so much need that we can't overlook our own back yards. Volunteer locally and see how it feels. If you like it, do more. If not, you know not to go into international humanitarian work. Do your homework and, with all things, think globally and (at least initially) act locally.*

#### **TOPIC: CHRONIC ILLNESS, HIV OR OTHER**

**Question:** *You've been living with HIV for nearly 30 years. What impact has managing your health had on your day-to-day life?*

**Answer:** *I measure my life in two halves – before HIV and after HIV. And, within that, I also measure my life in two parts – HIV before I was on treatment and after I started. For the first 16 years, I was in remarkably good health. I didn't need to start treatment until the end of 2008 and making that transition was almost like being diagnosed all over again. What had once been an illness that I barely had to manage suddenly took over my life and each day, the pills remind me not to take anything for granted.*

**Question:** *What advice would you give to someone who has just tested positive for HIV?*

**Answer:** *Know that you are not alone. The people who you think should be there might not, but there are people who will support you. Don't isolate but, rather, find those people and let them be your family. Sharing your experience with other people living with HIV is invaluable.*

**Question:** *What advice would you give to someone who has been diagnosed with any other chronic and/or life-threatening illness?*

**Answer:** *I think it is probably very much the same. Know that you're not alone. Many people in our lives disappoint us when illness hits, but others often show up, people we would not have thought of, as long as we're open to being supported. Find others who want to be there for the right reasons.*

#### **TOPIC: LONG-TERM SURVIVAL WITH HIV**

**Question:** *Many people live for years, decades, even entire lifetimes with chronic illnesses. What makes being a long-term survivor with HIV any different?*

**Answer:** *Probably the main thing is that even though we're now 40+ years into this, we still don't know that much and those of us who are now long-term survivors are still the guinea pigs. We're learning more each day, but it is all still a work in progress.*

**Question:** *We've been hearing a bit more about HIV and aging. You're now in your late 50s and you've had HIV for more than half your life. How do those two realities converge in a way that might be different for anyone else approaching 60?*

**Answer:** *You know, when you're a kid, everyone seems old. And then as you age, old keeps shifting in our perspectives. When I tested positive, I sort of shut that switch off. I stopped imaging old because I didn't think I'd ever get to be this old. I didn't think I'd live to see 36 years old. And here I am. So aging with HIV is uncharted territory for me on all levels. I just know that each birthday that rolls around, I feel so blessed to still be here. Creaky joints and all!*

#### **TOPIC: TRAVEL**

**Question:** *To say that you've traveled a lot is an understatement. What were your best types of travel experiences? And, of course, your worst?*

**Answer:** *My best travel experiences were the ones where I got to work with my local colleagues. Having the opportunity to discuss something so sacred as sexuality and health, and getting to understand, even a bit, perspectives from around the world was a privilege. An honor.*

*The worst? That's harder to answer. I don't think any of the types of travel were better or worse, it all just depended on where I was at in my own life at the time, both in terms of my health and my emotional well-being. So the travel really just depended on the traveler.*

#### **TOPIC: WRITING A MEMOIR**

**Question:** *Writing a memoir is risky. In doing so, one puts their life out on display. What prompted you to write this memoir? Were you ever tempted to stop and, if so, why? And, if not, what kept you moving forward with the project?*

**Answer:** *When I finished my first full draft, I had to scrape Linda Blair-type gunk off my computer screen because it felt like an exorcism. But I had to do it. I knew that I had lived an albeit miniscule piece of the bigger history of the HIV experience within the AIDS pandemic. And, it is worth mentioning, that I've been open about my status almost from day one since diagnosis. So, it is just an extension of what as I see as an opportunity to share my own story in hopes that someone else might find a useful nugget of truth. I was tempted to stop many times, but it kept eating away at me, so it was kind of like I had no choice. And what kept me moving forward, probably more than anything, was the encouragement of others who believed in me, and this memoir, even when I didn't. So while my name is on the cover, a lot of people – a lot – made this book happen.*

#### **TOPIC: FINAL TAKE AWAY**

**Question:** *What is the one key message you hope your reader to take away from your memoir?*

**Answer:** *That you, the reader, matter. That your story matters. That your voice is important. And that if each of us makes a little effort every day, we can change things. But as Gil Scott-Heron so eloquently wrote, "The revolution will not be televised," because the revolutions starts from within each one of us.*