



Life Stories
Voices of Women with HIV



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Introduction

Over the course of the month I have sat down with eight women to talk about their lives with HIV and their advice for high school students. Life with HIV is more than simply life with HIV but is life with children, spouses, parents, work, school, hobbies, and life in general. Their stories were incredible, often uplifting and sad at the same time, but always more positive than negative. I've tried to keep what I've written as true to what they expressed as possible but I haven't been able to show the hugs and congratulations I receive from them when I see them or the conversations we've had since they've let me, a stranger, see more of their lives than, in many cases, those closest to them have.

Each of these women has gone through at least one extremely difficult time and even now when HIV is seen as a chronic disease rather than the death sentence it was twenty-five years ago, a positive test result is a very difficult experience to go through. I admire these women, both collectively and individually, for coming out of the hardships they've faced and finding, or returning to, stability and success. I am also very grateful and honored that they spoke with me.

Each story begins with a brief introduction about the woman and then moves on to her voice, first with her advice and then with her story. I hope that you take something away from reading them like I have from meeting the women they came from and that, most importantly, you see and understand the positive undertone in words that at times sound harsh or depressing.

All names used are fictional and some basic details were changed to protect the women's anonymity.

ANNE IS A WOMAN IN HER LATE FORTIES WHO HAS BEEN LIVING WITH HIV FOR A NUMBER OF YEARS. SHE IS A MOTHER OF FIVE. SINCE TESTING POSITIVE FOR HIV, SHE HAS WORKED AS AN HIV/AIDS ACTIVIST AND HAS CONCENTRATED ON GETTING THE MESSAGE OUT AND KEEPING HERSELF HEALTHY. SHE SAID THAT SHE HOPED THAT TELLING HER STORY COULD HELP AT LEAST ONE PERSON, THAT AT LEAST ONE PERSON WOULD LISTEN TO WHAT SHE HAD TO SAY AND EDUCATE HERSELF TO STAY HEALTHY.

Always use a condom. Never assume 'he don't cause you don't.' He might not tell you [if he is HIV positive]. Look for the signs because there are signs you can see that might tell you. And abstinence makes the heart grow fonder—that's what my mother always told me.

I got HIV because I was very promiscuous. When I found out, I cried. I cried for about half an hour then I pulled myself together and asked “how do I deal with this?” My case manager told me that life has to continue as usual and I just had to keep doing whatever I would have done if I hadn't just come in and been tested. It was hard to take in at the time but life goes on. It was raining—I'll never forget that. It was pouring down outside. But I'm sitting here. I'm a survivor.

I look at things very differently now. I try not to let it [HIV] take its toll on me though. I'm ok. I'm not wearing a t-shirt that says it [that I'm HIV positive]. I look at myself differently but my children don't. Everyone worries about me but I worry about them more. I have to worry about their germs making me sick and worry about keeping them safe too.

Talking about it, being an advocate, have been challenges. It's hard to talk about it because I don't want it to come back to my kids. I don't want people to talk about how their mom is HIV positive and say things behind their backs and not want to spend time with them. I don't want to alienate my children.

I haven't been treated differently by anyone. My 'stinking thinking' will set me off, but I do that, not anyone else. Hearing someone talk about it [HIV] always hits a nerve though. People are so negative about HIV. It shouldn't always be a negative conversation. Either we're infected or we're affected but no one wants to talk about it—I was like that too.

The Community Health Center has been very supportive. Some days I wish I didn't have this because if I didn't have this then I wouldn't have everything that came with it. But The Community Health Center and everyone they've set me up with—The Living Center, AIDS Action Committee—I'm connected. I've had no difficulties.

I have five children. My youngest two were there when I got tested so of course they wanted to know the result. I told them but then I said we were going to go home and make popcorn because that was what we were planning to do anyway. To a certain extent their lives have been affected. They're not wondering when God's gonna take me but it has to be weighing on the back of their minds. Especially with my youngest daughter cause she lives with me. She goes to bed and wakes up with me every day. HIV won't be my death. God will take me, not some *disease*.

[Whether I'd tell my partner my status] all depends on if the relationship goes as it should. If I'm comfortable with him I'll tell him. I'm single cause I don't wanna tell. That's my biggest fear—he'd probably run and take off somewhere.

I will not tell the members of my church my status. God hasn't laid that on my heart yet. I don't think I ever will—they're not open to it and they're not ready. The churches should be more open—it's in our community. Like I said, you're either infected or you're affected. I think about the Scarlet Letter—they stoning me and throwing me out. I'm good with God. That's where I get my strength. But that's not to say that there aren't a few church members I have told. I'm close with them and they understand because they're affected by HIV.

—Anne

KATE IS A WOMAN IN HER FIFTIES WHO HAS BEEN LIVING WITH THE VIRUS FOR THIRTY YEARS. SHE DID NOT MENTION A PARTNER OR ANY CHILDREN. SHE LET HER MORE TALKATIVE BEST FRIEND SAY MORE THAN SHE DID BUT SHE WAS VERY CLEAR IN HER MESSAGE OF KEEPING ANYONE ELSE FROM GETTING THE VIRUS.

Just say no. I know it's hard though. Women hear what they want to hear so if someone says they don't have HIV you won't question it.

I got a blood transfusion in 1976. I might have gotten [HIV] from IV drugs but I think it was the blood transfusion when I look back on it.

I found out because I was really sick. Someone took me to a hospital and when I woke up from my coma the doctor told me I had HIV. I cried a lot and I didn't want to leave the hospital. I did a lot of crying.

Before, I thought I was going to die. But I'm living with it. Sometimes I get an attitude cause I get sick. People should treat this disease the same way as cancer.

The biggest challenge has been rejection. My best friend has supported me.

I was brought up going to church. I like the gospel music and the feeling.

–Kate

GAIL IS A WOMAN IN HER EARLY FORTIES. SHE IS A MOTHER OF ONE. SHE CURRENTLY RESIDES IN A HOUSE FOR WOMEN WHO ARE HIV POSITIVE. SHE HAS NOT YET FELT ABLE TO OPENLY SHARE HER HIV STATUS WITH MOST OF THE PEOPLE IN HER LIFE BUT WANTED TO SHARE HER STORY AND ADVICE ANONYMOUSLY IN ORDER TO HELP OTHER PEOPLE.

Abstain from sex. When I had sex I didn't know what sex or a relationship was all about. A lot of responsibility comes with sex. You're young. During this time people should get to know you as a person, not your body. It's nice to know that people your age are looking into this because the epidemic is growing in the teenage population.

I got HIV from sex. I was using drugs. I was in a lot of pain and thought drugs were the way to deal with pain. Drugs just mask pain, they don't help it. If you have a problem, try to find someone, don't run from it. When I ran from my problems they just got bigger. Sex and drugs go hand in hand. Now I'm clean and there's no sex in my life. I'm trying to learn me. All these years I thought I knew me and I didn't. Today I'm dealing with me. A friend of mine just passed away and now it's hitting me that I have HIV—I need somebody supporting me.

It [my diagnosis] went in one ear and out the other. I heard it but didn't feel it. I knew but I didn't want to acknowledge it. Today is the first day I'm acknowledging it because of this guy's death. This will be the first death for me through HIV. I have a son that I have to tell. I think it's going to be hard but I don't think it will be as hard as I imagine.

I'm more concerned about everybody else now. I want to keep myself safe and learn as much as I can about it [HIV]. I'll probably always feel that way.

No one has treated me differently yet because I haven't really faced up to it [my disease]. Let me give you an example. I was telling someone about this guy who died and I said that he was in a program I'm in. And my friend said, he lived in that HIV house—I know you don't live there. And my son was right there and I haven't told him so of course I said no. I want to tell him privately. You can feel the reactions from people. I'm scared that someone would be scared to be around me. The Community Health Center people have been very supportive. They don't look down on me, they just treat me the same.

I think my son's life has been affected in a positive way. I stopped using and went into this house. I never let anyone help me before. It took me about a year to understand [my HIV status] and then four months later I moved into the house. I needed to learn how to live over. My son spends more time with me now. He's glad that I'm clean.

I told my partner when I found out. They told me I was positive and asked when I would tell him and I told them to bring him in right away. Otherwise I probably would have left; I would have gone down the back staircase.

The minister [at my church] doesn't know but most of the people I see here [at The Community Health Center] go to that church so they're aware.

My medical care has been excellent. I'm in the learning process right now.

—Gail

ANGELA IS A WOMAN IN HER FORTIES. SHE CURRENTLY WORKS IN THE HIV FIELD EVEN THOUGH SHE HAD A HARD TIME REACTING TO HER DIAGNOSIS WHEN SHE WAS FIRST TESTED. HER LIFE HAS ACTUALLY TAKEN A POSITIVE TURN SINCE BEING DIAGNOSED WITH HIV, BUT SHE WORKS TO MAKE SURE THAT OTHER PEOPLE DO NOT GET IT.

Stay in school and focus on school. I'm forty, I got my GED and am in college but I wish I could have done that earlier. Everything else is secondary. I'm not going to say stay abstinent but girls need to think about stuff before because the consequences are too high. Working in this field I see men who are positive who are dating young girls and don't tell them.

I got HIV through sharing needles. It was really shocking. I had no words when I found out I was positive. These are things you never think will happen to you despite unsafe behaviors.

HIV changed my life. It made me look at life differently. When they told me I was positive I wasn't ready to hear it. But I got clean and I started working in the field.

Because I'm Latina, I've had to deal with a big cultural stigma. It took a long time to tell my family. I started bringing home information about HIV without telling them that I had it, but they didn't even want to look at that so I was scared about what they'd say when they found out I had it. But I haven't been treated differently because I have HIV.

My family, now that I've told them and they're used to it, have been very supportive. My sister, my brother, my mom. My boyfriend, he's not positive which is another set of issues. My kids.

Yes [my children have been affected by my disease], especially my fifteen year old daughter. She's embarrassed about my status. She hasn't told any of her friends. Her best friend didn't know but she came to something for my work where I was speaking and that's how she found out. I didn't know she didn't know before that. I know [my daughter] is embarrassed because she didn't even tell her best friend who you're supposed to tell everything to.

HIV is not a priority for me right now, I have other priorities, but I would not want to infect anyone else because of what I went through.

My medical care has been good. I don't follow up as much as I should though. But I've finally found a provider that I trust and can work with.

—Angela

MARY IS A WOMAN IN HER EARLY FIFTIES WHO HAS BEEN LIVING WITH THE VIRUS FOR MANY YEARS. WHILE MARY HAS BEEN POSITIVE AND OPEN ABOUT HER STATUS FOR A LONG TIME, SHE STILL BELIEVES MANY MYTHS ABOUT THE VIRUS. IN HER INTERVIEW SHE MENTIONS THAT SHE WASHES HER HANDS MANY TIMES BEFORE COOKING AND THAT SHE THINKS THE VIRUS WAS MAN- MADE. SOMEONE WITH HIV DOES NOT NEED TO WASH THEIR HANDS ANY MORE THAN ANYONE ELSE BEFORE COOKING AND THERE IS NO EVIDENCE THAT HIV WAS CREATED IN A LAB ALTHOUGH THAT WAS A COMMON CONSPIRACY THEORY IN THE 1980S. WHILE IT IS DISHEARTENING TO SEE SUCH IGNORANCE IN SOMEONE WHO IS POSITIVE, HER OVERALL MESSAGE WAS POSITIVE AND SHE SEEMED TO BE A VERY HAPPY WOMAN DESPITE HARDSHIPS SHE HAS FACED.

Always wear protection. Treat every male like they have the virus. People lie.

The man I was seeing was really open and honest with me. I knew he had the virus but we used condoms. They were the sheepskin kind—now we know those don't work but we didn't know that back then. And the condom fell off. I wasn't mad at him though because he was open and honest with me.

When I found out I had HIV, I was upset; I was embarrassed; I was hurt; I was angry—all that good stuff at the same time. I was mad with the world. I was upset with my boyfriend but I was more mad with myself. I didn't know how to tell my children. Before I got tested I felt sick and tired all the time. I was working at a program to help people with HIV and people started saying that I had "The Sicky-Sick" so I got tested. After I found out I started selling and using drugs again.

Nobody wants to have this disease since there's no cure. It made me open my eyes to life and to people. Things like this let you find out who your real friends are. It's [having HIV] hard but I've learned to live with it. Read the book or see the movie *And the Band Played On*. I survived cancer and an abusive relationship; I can survive this. I'm a survivor.

The hardest thing to deal with has been that people judge you. Rejection. My oldest son is afraid to hug me. I always wash my hands a bunch of times before I cook anything. It's hard. Some people act like they're fine with me but then gossip about it later. I've found that the people who point fingers and talk about you the most probably have it [HIV]. I had some friends who made sure to tell everyone that I had it but that's why we're not friends anymore. Sometimes you just have to let people go. My best friend has helped me be able to be open about my status. There're a lot of people who have it but won't do anything about it. They won't be honest about it and they won't use condoms.

I think it's important to be honest. I would tell my partner my status.

I don't even know who's a Christian or what it means to be Christian. You say you're supposed to be forgiving and nonjudgmental—then why are you judging me? God didn't give it to us—it was man-made. I think they wanted to give it to certain people and it got out of hand.

—Mary

HELEN IS A WOMAN IN HER LATE FIFTIES OR EARLY SIXTIES. SHE HAS HAD HIV FOR A NUMBER OF YEARS AND WHILE SHE IS NOW MORE ABLE TO MANAGE IT MEDICALLY AND EMOTIONALLY, SHE INITIALLY HAD A VERY HARD TIME DEALING WITH HER DIAGNOSIS. HELEN HAS BEEN ABLE TO MOVE PAST AND LEARN FROM HER MISTAKES AND TO SEE THEM AS AN OPPORTUNITY TO EDUCATE YOUNG PEOPLE.

Practice safe sex. It's really rough out here. Hepatitis C—that's bad. It all depends on the atmosphere you're around and the groups you're with. Safe sex or none at all. Just be really careful. It's not nice out there, especially for females.

You have to be strong to deal with this. Try to stay close to home. Stay in school. Be careful. Be strong.

Just be true to yourself. Be true to your family. If you do get it don't hold it in cause that can be the worst thing you could do. You could be hurting yourself.

I got HIV by being uncareful. Taking a chance. All it took was that one chance. [When I found out I had HIV] I wanted to jump into the liquor bottle. I drank a lot, I did drugs and I tried to kill myself a couple of times. I didn't believe it when I first heard so I made them do the test again, and again, and again. Then I came back to Boston. I had really low self-esteem but my children and my grandkids kept me going. I live with my sister and we support each other.

All your friends start changing on you [when they find out you are HIV positive]. You start thinking about safe sex and all the shoulda, woulda, couldas. Some days I just want to give up.

[My children] worry more about me now. It [my status] affected my son real bad after his daddy passed [from HIV]. They've been strong and supportive. It hurts them but they say I'm going to be here for a long time. My daughter just worries so much. I try to tell her don't worry about it. I try not to think about it sometimes.

I would definitely tell my partner my status. Always be honest with yourself first. Always tell your partner.

My medical care has been pretty ok. Sometimes I miss my medication but I try to make it up later. I've had pneumonia a couple of times. I've been hospitalized a few times. God kept me here.

—Helen

SARA IS A WOMAN IN HER EARLY FORTIES WHO HAS BEEN LIVING WITH HIV FOR SEVERAL YEARS. SHE LIVES WITH, AND IS A CARETAKER FOR HER MOTHER, IS NOT MARRIED AND DOES NOT HAVE CHILDREN. BECAUSE OF PAINFUL PAST EXPERIENCES OF SHARING HER STATUS WITH PEERS, SHE HAS NOT FELT READY TO SPEAK PUBLICLY ABOUT HER STATUS WITH MANY PEOPLE. SHE REPEATED MANY TIMES QUITE FIRMLY THAT SHE WANTS EVERYONE TO BE EDUCATED TO AVOID GETTING SICK.

I want them to know about HIV/AIDS, protect themselves, get educated. Teach them not to get STDs. I never knew what HIV/AIDS was. I always thought it was old and gay people who got it. Know your partner very well. Get tested. This is not a death sentence for me. I'm still here going strong. Be safe. Get to know your partner very well before you get in bed with him. If he doesn't want to get tested or show you his record, drop him and find a new one. I want all the ladies and all the men to be educated. They should go to HIV/AIDS classes. Parents know more than the kids do so they should teach their kids too. Make sure you have an open mind about your partner, you never know what they could be hiding.

I wish I could talk to them but I don't want to throw myself out there. I wouldn't want them to know I had HIV and then think about me differently. It's good to listen. Maybe they would wake up and see what life is all about. They shouldn't take anything for granted; I never took anything for granted.

Were you scared when you found out I had HIV? [No] Really? I'm surprised you weren't scared. You're lucky you don't have this disease.

I got HIV maybe from not using a condom. My ex was using drugs which I didn't know. We both [my ex and I] went to [a Boston hospital] to get tested. I was upset and crying. I was more angry. I thought the test was wrong. We never talked about it in my family so I never thought I would get it. They did the test twice. I think he [my ex] knew he had it but was in denial so he didn't tell me.

HIV changed my life around because it changes your weight, your health. I've been to the hospital sixteen times. I had the flu and a bug that was going around. I can catch a cold really easily if someone sneezes on me. Other people will get the same bug I get but mine will be different. They're not in my shoes. Medication is no joke. You have to take them day and night until there's a cure. It's getting harder and harder to take them all the time. And there's no cure. I think there will be one. I pray they'll find one someday.

My family was hurt and upset. My family doesn't want to talk about it except my sister; she asks me how many medications I'm taking. If I get sick they don't visit me in the hospital cause I don't want them to get sick. My extended family doesn't know about it—I choose how far it goes. I'll tell them when I'm ready.

Getting sick all the time has been hard. I've been healthy so far but I was sick in December and January. I have ups and downs like everyone, even people who don't have the disease. Sometimes I'm happy and sometimes I'm sad when I think about my future. I wish I didn't have this disease. I thought I knew him but I guess I didn't know him that well. I wish I could turn back the clock but I can't. It's a painful thing to wake up with every day.

I told one friend and she was shocked and pissed. She treated me a little differently. I think she told a few of her friends who she lived with and they wouldn't hug me but I knew what was up. One of them wanted some of my chicken one time but she told him not to eat off my plate. And I told another friend, she was my best friend. Maybe she wasn't as educated as the other one. But I told her and she stopped calling. It bothered me but I just let it be. So now I'm alone. But I go to the women's support group. It keeps me going.

A lot of them [women in the support group] are recovering from drugs and alcohol. I support them and I can't knock them down. First I thought I was in the wrong group cause I don't do drugs. Some of them lie but not in the group; we're all honest with each other. We didn't deserve that [HIV]. If someone cares about you, they'll tell you. I want the women to be very careful about who they're with. Every guy won't be honest with you about everything.

I don't have children. I have dreams to get married, maybe adopt a kid or even have one of my own. But I'd worry that they'd get infected even though they say now they have medicines that can prevent that. If I found the right guy, I'd tell him. I'd want to be open with him, get tested together.

[Whether I'd tell my partner my status] depends cause I told someone I was seeing and he said he wasn't afraid, he was educated, he wasn't going anywhere, but then he stopped calling. I wanted to be honest. You have to tell him before he makes a move on you or you make a move on him. I made a mistake by telling him. I'm learning now not to tell too many people cause they're scared. I'd tell him when the time was right.

I haven't been to church for a while [for family reasons unrelated to HIV] but they don't know [my status]. I'm ready to go back to church but then I get sick. I am going to go back. I still have faith in God though even though I don't go to church. I pray every morning when I wake up and every night and every time I walk through the door.

My medical care has been pretty good so far. I go to the doctor every two months. The medicine works but you have to keep taking it. I'll stop if he [my doctor] asks me to but I don't want to. They're supposed to give you a break but I'm not ready for one yet.

—Sara

DENISE IS A WOMAN IN HER LATE FORTIES WHO WORKS AS A MEDICAL ASSISTANT IN A COMMUNITY HEALTH CENTER. SHE IS A MOTHER OF THREE AND TESTED HIV POSITIVE TWENTY YEARS AGO. NONE OF HER CHILDREN WERE BORN HIV POSITIVE. SHE HAS BEEN ABLE TO BE VERY OPEN ABOUT HER DISEASE. SHE DID NOT MENTION BEING AN ACTIVIST, AND DOES NOT GO OUT OF HER WAY TO MENTION HER STATUS, BUT SHE DOES NOT HIDE HER STATUS EITHER. SHE MENTIONED SEVERAL TIMES THAT “HIV IS NOT A DEATH SENTENCE” AND IT ISN’T; SHE HAS MOVED ON AND CONTINUED HER LIFE.

Stay in school. Take something in school you’ll enjoy and don’t settle for less. It’s [HIV] not a death sentence. You have to get clean and do what you’re supposed to do. If you keep using there’s no hope. You’ll get infected again and you’ll die. The best thing is your health. I take care of myself, take my medications when I need them and eat right. I can still do things.

I got HIV from sharing needles. I reacted to my diagnosis with denial. Now that I know more—I can still have a life. I don’t have to die because of it.

Telling my family was a challenge. My mother was very supportive. My eight year old doesn’t know obviously. I have a twenty-five year-old son and a daughter also. My daughter is nineteen and she was very concerned. She wanted to know if I was going to die. I’m not scared to tell people now though. It’s been twenty years now—I’ve been fine.

My fiancée and doctors at The Community Health Center have been helpful in supporting me. I'm also in recovery so people at NA [Narcotics Anonymous] and AA [Alcoholics Anonymous] have been supportive. I'm surrounded by good people.

I wouldn't say [my children's lives have been] *affected* but in the drug sense yes. Thank goodness I had my mother to watch them. My son was always supportive when I was trying to get clean. He would tell me that he knew I could do it this time but my daughter didn't want to talk to me. I mean she would talk to me, but I could tell she didn't want to when I would come by high or drunk. But I'm stable today.

I'm engaged. He knows my status and I would tell any partner my status.

I don't go to church very often. They don't know but I would tell them if it came up to let people know that there's hope. It's not a death sentence for me.

My medical care has been good. I get seen every three months and more often if something comes up. I've been very fortunate. I haven't been hospitalized.

—Denise