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African-American HIV/AIDS Resource Center



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PROFILES IN COURAGE

Mel Byrd

Personal Bio

Tell us a little about your life.

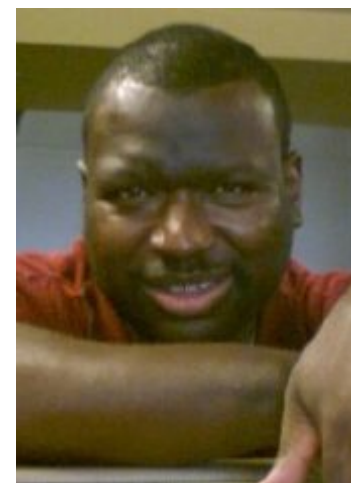
I live in Garland, a suburb of Dallas. It has that not-really-large-town feel that I was used to, growing up in West Texas, which is literally in the middle of nowhere. But it has access to the urban things that Dallas has to offer, and I like that as well. I live alone, I don't have a partner -- I never have had a partner, actually. That would be nice to change, but I don't know if it ever will. I work in the IT [information-technology] industry, doing support for one of the internal groups.

What did you want to be when you were a kid?

I always wanted to be a dad, but I never really thought about a vocation. I did well in school, so I just expected that I could take a natural progression, but I was never very ambitious.

What kinds of work have you done?

The job that I have now is my second "grown-up" job. The first, I worked in a community college setting as a counselor/adviser/



- What is the most critical HIV/AIDS issue facing the African-American community?
- What are the top myths that you encounter about HIV/AIDS in the African-American community?
- How have your relationships with family and friends changed since you were diagnosed?

NEWSROOM

- Chicago Black Gay Men's Caucus Launches
- California: New Center Helps Blacks Access AIDS Services
- NPR's "All Things Considered" Examines HIV/AIDS Epidemic in Washington, D.C.
- Florida: HIV Testing for Blacks Is a Unifying Mission
- New Jersey: Blacks Still Bear the Brunt of AIDS
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what's YOUR OPINION?

African American and living with HIV? Do you feel you've received unequal care from your doctor or other health professional because of your race?

- Yes
- No

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financial aid officer type. It gave me an opportunity to get some experience under my belt, which I discovered was one of the things, every time I went for an interview, that people were asking for. So I worked in that environment, and had to learn a lot of the computer skills that allowed me to make the jump into the IT arena.

What work did your parents do?

My father was in highway construction and my mother had various jobs: a nursing aide, hairdressing, food services -- she was a jack-of-all-trades.

Who are the most influential people in your life?

I spend most of my time, and have always spent most of my time, alone. So there weren't very many people I even interacted with, let alone allowed myself to be influenced by. I spent too much time doing my best not to draw attention to myself.

There are people I've encountered in the field in which I worked who I was honored to have the chance to meet. And as much as I could, I tried to emulate their example, but it was more of an organic movement toward this and that. I never really felt that "influence."

What do you like to do in your spare time?

I don't have any hobbies. I wanted pictures of my grandnieces and nephews, and they have youth sports, so I learned to use a video camera. And I make videos and DVDs with all the current desktop publishing and video-making programs out there.

Are you a religious or spiritual person? Do you attend a church?

I never thought of myself as such, no. I grew up in the tradition of a Baptist background, and that formed the basis of, "Here are the rules of how you're supposed to behave." But I never really bought into it, because I had far too many questions that I needed answered that I couldn't get from that. I haven't been to church since I was 13.

HIV Diagnosis

How did you find out you were HIV positive?

It was about a month before Princess Diana was killed in an accident. The glands in my cheek had started swelling, and I ignored it until I just couldn't ignore it anymore -- I waited till it got to crisis mode and then went to the doctor. And, thankfully, he immediately tested me.

I didn't know at the time that was what he was testing me for. He just said there was something he wanted to check. And then I got the call and that's when I found out.

He didn't use the word "HIV," he just said he wanted to test for something. He was probably fairly sure, but without knowing for certain, it's not the thing you want to drop on somebody.

What were your feelings?

About Mel Byrd

Age: 41

Home: Garland, Texas

Diagnosed: 1997

Nobody knows that Mel Byrd has HIV. Not because he's afraid to tell anybody, he says -- it's just that there's nobody to tell. A self-described loner, the thoughtful, well-spoken Texas native has always turned inward for solace and understanding. Whether it was dealing with intense racism as a black kid growing up in rural Texas, or coping with an HIV diagnosis that blindsided him even though he realizes he should have known better, Mel has always kept his own counsel, looking to himself for the healing he needed. But lately, as he has come to terms with his HIV status and his situation in life, Mel has started to come around: "More and more recently, I've felt very much that I don't want to be anonymous anymore," he says. By sharing his story here, he may have taken the first step.

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I felt absolutely devastated. I took a couple of minutes to feel sad, then sucked it up, took a deep breath, and had to go back to work -- as if nothing had happened.

How did your feelings change over time?

Initially, I felt diminished by being infected. I was on this road of feeling sorry for myself and just waiting for whatever came to come. And then my truck broke down one day on my way home. There was no one to help me, so I had to push the truck out of the street and into the parking lot where I could get it towed back to my place, get it fixed. And having to push that truck by myself reminded me that in spite of the fact that I now have this new information about the state of my being, however I came to be that way, it did not suddenly unmake who I am. Something as simple as a breakdown of a mechanical device, and it kicked me in the pants.

How long do you think it takes to process a diagnosis?

The diagnosis took half a day to integrate into my psyche. The thing that still takes me a great deal of time and energy and effort is how do I integrate that into the wider aspect of my entire life? Do I want people to know? Do I tell my family? If I should find someone, do I want to bring this into a relationship if they aren't positive? If they are positive, how do I feel about that entire situation? All that is more of an issue than the actual diagnosis.

What advice would you offer someone who has just found out they are positive?

Take a deep breath, first of all, because it's going to hit you emotionally. And if you can get past the initial few moments, then you can get to the moments that follow that.

What conditions in your life put you at risk for getting infected with HIV?

Engaging in anonymous sex for most of my 20s.

When you look back, what would you have needed in order not to get infected?

If I had found a committed relationship and not engaged in the unsafe and unsavory actions I engaged in because I needed someone. Even my own psyche has its limits in terms of how much solitude I can take. And there were moments where I needed someone, even if it was only for a little while, to try and fill that -- whether it was right for me or not, I never stopped to consider.

It would have been a very different thing, I think, in my early 20s, if I had felt open enough to pursue a relationship with someone. That would've given me an opportunity to make better choices in the matter.

What is the first thing someone who has just found out they have HIV should do?

When I found out, the doctor said, "Well, here are the medical things that we need to do," and I understood the practical nature of that. But I never even wanted to address anything else about it because even the very fact that I was gay and was attracted to men was something I tried to not really address. If I didn't look at it too hard, maybe it wasn't so.

I felt somehow as if I needed to be further away from people because now I'm infected with HIV, and how would people feel if they knew they were sitting in the room with somebody who was infected? And what would the results of that be? And what would I do then? All this paranoia started to seep in. If I had addressed a lot of my personal issues before that, I don't think [dealing with my diagnosis] would have been nearly as paranoid as it was.

How has having HIV changed you?

Again, the medical issues obviously were something that had to be integrated into my day-to-day routine, so initially it just felt very alien. I never took a lot of medications or pills for anything, so now here I am, every day, having to do this. I had to learn to accept that: If you're going to hold onto the hope, the thought, the belief that you're not ready to die yet, then you have to do this.

African-American Identity and HIV

When did you first realize that you were an African American?

I have always had an awareness that I was black, and I choose the word black consciously. To say African American -- to me, it just feels like a sociopolitical assertion that I'm not really interested in making. I'm black -- that is what I grew up as and feel that I always am.

By definition, African American excludes any group of people who are not in this country, [even if] they are also African-derived populations. Up to the last 10, 15 years of my life, whenever I thought "black," I thought *all* black people. I never thought in terms of, "I'm an African American, and they're African Caribbean." As far as I'm concerned, they're just other black people.

To what extent have you experienced racism in your life? How have you learned to deal with it?

I grew up in West Texas, and it's built in to the system. There's a lot of open racism there. It was nothing to hear the "n" word, or get that looking-down-their-nose feeling, or outright anger or hatred pointed at me, for no other reason than because I am what I was born.

College was very odd for me, because I had grown up in a predominantly black environment. College was the first time that wasn't true. And there were some things that occurred that completely caught me off guard. A number of times people tried to run me over with their truck, and I was just walking on the sidewalk. They yelled stuff at me that made it very clear why they were trying to run me over. So you had to pick and choose when you were going to walk around campus at night.

How have you learned to deal with it?

Mostly by my solitary existence. I just take myself out of harm's way, as it were. It's just easier not to deal with it than stand up and make myself a target -- especially in those situations where I wasn't immediately in imminent danger.

What do you think is the biggest challenge facing African Americans today in terms of HIV?

A lot of the people that I knew had issues not just with HIV but even with just being gay. If you don't fit the expected role -- if you're a man here's what you do, and anything outside of those rigid stereotypes can get you in a lot of trouble with your family and the social circles in which you travel. Getting to the point of not denying, and accepting these people, would be a huge move forward in that respect.

What HIV risk factors are of special concern to African Americans?

The whole denial/acceptance thing put me in a place of, "I can't let anybody know that I do this thing," so you keep it hidden, and you end up doing a lot of things that, if you were able to do it in a public manner, in a way that was acceptable, you could make better choices. You

could make safer choices. So that one thing alone would guarantee that a lot of the risk factors I engaged in wouldn't happen, because there would be better opportunities.

Are there any specific aspects of African-American culture or identity that give you strength as you learn to live with HIV?

Well, the thing is, I have only ever been black, so it's very difficult for me to understand what that means. For me, the only difference I see between black people and anybody else is that we're louder on occasion! I understand that my skin is darker and some of the cultural remnants that are "African-ness" have been brought through history to us and with us, but outside of that, it's no different than any other social or ethnic group. I simply am who I am.

What is the biggest change you'd like to see in HIV treatment, prevention or education care for African Americans?

It all goes back to that whole denial/acceptance thing. If they would acknowledge it, a lot of people might be more willing to help in getting information out there, and better prevention efforts, and the types of things that would go a long way in keeping this from becoming an even bigger pandemic than it already is.

Do you think the Bush administration is doing enough for the black epidemic?

I don't think they're doing enough for HIV in any community.

How would you grade Bush's performance?

I would give him an F, because the administration has had to be forced, embarrassed, to even make them acknowledge HIV and AIDS -- not just in this country, but worldwide.

What are some of the main myths about HIV that you hear in your community?

Before I became positive, I had a complete lack of understanding as to what was going to happen [or] what treatments were available. All I had were those images from the early '80s, all I could think about was, "This is a death sentence." But as it turns out, it isn't the death sentence it once was. The quality of people's lives is better, to be certain, even though a cure hasn't been found -- or at least a way to turn this into a long-term, manageable disease.

What are your fears and hopes for the next generation of African Americans as they face the risks of HIV?

That they become more informed. That they understand that making a choice to engage in less safe sexual practices is the same as saying, "I think this is worth dying for," potentially.

HIV, Health Care and Treatment

What has been your experience with HIV treatment?

I've not been sick from any HIV-related issues. I've had to deal with weight-related things -- high blood pressure, cholesterol, triglyceride issues and stuff like that. Some of the medications I've had to take have been far worse on me than the HIV itself. The medications continue to keep the virus suppressed and my numbers are fine. As soon as I started taking medications and my numbers started to come back in line, my swollen glands went away. They're still a little puffy, but I was like, huge -- like holding air in my cheeks. Other than that, I didn't feel sick. So as long as the medications continue to work, I'll be around for some time to come.

How do you feel about your meds?

It's a very odd thing to get up every morning and walk to the cabinet, and here are these pills that I have to take every day. It seems almost surreal, but I have to do it. And I understand that, intellectually and practically. It just feels somehow unreal because I don't *feel* sick.

Have you experienced side effects from your medication?

From my first combination, I was fine for a few months, and then one day, I just started to get nauseous, and it would not go away. Every day was nothing but all-day-long nausea. And once that happened, it was like, "Oh god, I've gotta live the rest of my life like this?" And so I called the doctor's office and talked with them for a while, and he asked me to stop taking those. The nausea went away after a few days, and after a few weeks I went on a new combination. And I've been on it for almost seven years now.

How would you rate your ability to take your meds on schedule?

I'm very good at it -- my entire world is centered around having a routine.

Do you have any special rituals or preparations that help you remember to take them?

I keep the medications in the same cabinet in the kitchen next to the refrigerator. It's better not to have them in the bathroom cabinet because of all the moisture that can get into them from the shower. I always look at the refrigerator in the morning, so I've gotten used to this visual cue. When I'm on vacation, I'm more likely to forget.

How did you choose your doctor?

I'm under an HMO [health maintenance organization], so it wasn't really a choice.

How often do you see him?

Every three months.

Do you think you are getting the best care possible?

Yeah, I'm getting the best care possible, but again, it's an HMO, so in a couple of years I could be seeing a different doctor. This is my fourth doctor in almost eight years: I get a doctor, and I get comfortable with them, and then for whatever reason they move or pull out of the HMO, and I go back to ground zero. So this year I changed to a PPO [preferred provider organization], because I can go outside the network if my doctor does.

Is your doctor an African American?

No. He is gay, though. I discovered quite by accident. I feel a lot more comfortable somehow with a gay doctor than with the straight ones. He seems to understand better -- not in terms of medical training and background, but there's just an additional level of comfort. There are issues that I have that may not quite be medical, they might contribute to or be a consequence of [something medical]. I feel more comfortable communicating that to him than [I would from a straight doctor].

Does your doctor treat you like a partner in terms of making decisions about your health?

Yes he does -- and that's something the first two doctors, who were straight, didn't. I would

say, "Here are my feelings on this, and this is how I would like to work on this," and it would turn into -- it felt like talking to my dad when I was little, like, "I know what's right, and this is what we're going to do." I understand I had a right to disagree, but it always felt like such a confrontation.

Whereas, with [my current doctor], it just feels more like I'm having a conversation with him than anything else. And he makes the extra effort on occasion to reach through if I'm feeling unapproachable. And I enjoy that very much.

Do you have a particular health regimen that helps you stay well?

No, but I do feel better if I do anything that contributes to my health, even if it's just walking 30 minutes a day. I don't do it consistently, though, because I always get myself caught up in work projects that need to get done and there's this deadline, so health issues get pushed onto the back burner. But even when I'm taking medication that makes me feel bad, I feel a lot *less* bad if I'm doing exercise. And it doesn't have to be, "I'm going to the gym and I'm pumping iron and I'm doing aerobics." Just doing something where I get a chance to do this thing and I'm *breathing*. It helps me feel better physically and psychologically.

Do you participate in an AIDS service organization?

I don't participate in any organization. Well, the football parents' organization, but that's not quite the same thing.

Disclosure, Relationships and Sex

How have your relationships with family and friends changed since you were diagnosed?

It's the same as it has always been. I was never very close with my family. I don't have any friends -- that was a non-issue.

Have you been able to be open about your HIV status with the people closest to you?

I don't have anybody closest to me, so again, it's a non-issue. I'd like to think that if I did have somebody close enough to me, I would be willing, but if you don't have any friends, you're not close with your family, that narrows down my choices.

Is there someone that you would want to tell if you felt safe doing so?

Not at this point, no. The only people that I even continue to interact with are a couple of nieces and nephews and grandnieces and nephews. Some are in their mid-20s now, but they've got their own issues to deal with and there's nothing about my dropping that information into the equation that could be of any real benefit to them at this time, so I don't really care to. And the little ones, they're just happy to see you. That may change in due time, but right now there's just no profit in throwing it out there.

Do you feel that if you practice safe sex, it is necessary to tell a sex partner that you are positive?

At this stage, because I am much more interested in having a relationship with someone, I would tell them, because I would want them to know: "Here's what you're getting into, so if you want to have this relationship with me, this is part of the territory." I would never have told that to someone I was having anonymous sex with.

Where do you go for support?

I don't.

What about online?

Oh, online it's very anonymous. I think that was part of what motivated me to click that link on The Body's site and send that e-mail [asking people to share their story for this African-American resource center]. More and more recently, I've felt very much that I don't want to be anonymous anymore. But beyond that, I can be anybody I want to be online, and do so quite often.

Have you ever tried any online support groups for people living with HIV?

When I was first infected, I hung out in an HIV-positive chat room. I hung out there for a little while -- there were people who were there in support of positive people, some who were positive themselves, some who had full-blown AIDS -- and that helped me become more comfortable with the entire arena of things. But it was just not quite the social world I wanted to be in. They just seemed to rehash the same things over and over, and I was past that point, like with the anonymous sex thing. I want something else.

Have you faced rejection from potential sex partners?

No. I found out I was positive after I had stopped engaging in sexual practices of any kind.

Is your celibacy related to HIV?

No. I made a geographic move, and I wasn't familiar with the area, and I'd get lost just trying to get home from work on a lot of occasions. So I had bigger issues than trying to find sex for the evening -- I'm trying to just find my way home.

I didn't make a decision -- there was no high moral ground or a conscious decision to be celibate. It just became the way things happened. And four or five years into it, I find out I'm also HIV positive, so that just built up on what already preceded it. And here it is, 12 years later, and I've not been with anybody in all that time. Not that I don't think about it, because I do. It would be nice to have an intimate relationship with somebody, but I just haven't.

Resolutions, Adventures and Wishes

Did you make any New Year's resolutions?

I was never one to make New Year's resolutions.

What's the biggest adventure you've ever had?

The biggest adventure I've ever had continues, actually: The first time I became an uncle. Because I understood early on, despite the fact that I didn't tell anybody in my family that I'm gay, that being gay means the probability is high that I would not have children of my own. So when I became an uncle, I found very much that it was a role I enjoyed greatly. And now with the grandnieces and grandnephews, I get little ones all over again. So that's been the best thing to come into my life. Short of actual fatherhood myself, that's been the greatest thing. I love the role of being the favorite uncle.

If you were granted one wish, what would it be?

To not be positive.

What books, movies, music or TV shows have had a big influence on you?

I like a lot of science fiction, in books, television and movies. I was never a major fan of splatter or gore -- but the ones that leave us with a message of the possibility of hope, that we can make it forward through to something.

Anything else you'd like The Body's readers to know about you?

Well, the one thing I'd like to communicate is, I hope no one misinterprets my composure on this matter as ease. The whole thing takes a great toll on my character. I just wanted to throw that out there -- that being able to deal with it practically is not the same thing as it being easy.

I mean, speaking about it now is not so difficult for me. If you had asked me these questions, or anything like them, in my 20s, it would have been an entirely different story. But at this point, I'm comfortable enough with the nature of who and what I am that it's not an issue. But I just wanted to make sure that people do understand not to confuse my composure with ease.

I don't have a great relationship with my family, I don't have any friends, I don't have a partner. And in spite of the fact that a lot of that is a consequence of my own choices, those choices have come to me because I had felt that, "Well, this is how my family has said things must be," and whether I like it or not, that's the game plan -- and what I think, how I feel, may not have any real value to them. It's not like I wouldn't like to have a better relationship with my family. It's not like I wouldn't like to have friends. And I throw these numbers -- I haven't had sex for 12 years, I've been positive for almost eight years -- and it comes out, and I'm reasonably articulate. But again it shouldn't be confused with ease in that entire matter.

Thank you for talking about all this -- you're doing something tremendous right here, I think.

You're quite welcome. And again, one of the reasons is that when I read articles about HIV, and about how few black people step forward, it made me think about the young kids in my family and the possibility of how someone else in somebody else's family might feel. I never had such images or heard any such voices in my growing up. I don't feel much like an activist, but it would be nice to put something back.

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