

# Richmond Times-Dispatch

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Wednesday, September 2, 2009 |

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## With new medications HIV not an automatic death sentence



P. KEVIN MORLEY / TIMES-DISPATCH

Joy Blathers was diagnosed with the HIV virus in 1989. She has dealt with the disease with help from family, friends, her doctor and her faith.

*Text size: [small](#) | [medium](#) | [large](#)*

By [TAMMIE SMITH](#)

Published: August 23, 2009

Mark Baker's fitness routine sounds as if it could be that of any other 41-year-old approaching midlife concerned that the years ahead are lived in relative wellness.

"I work out three to four days a week," said Baker. "I do yoga. I don't eat a lot of fried foods. I try not to eat after 7 o'clock [p.m.]. I drink a ton of water. I haven't smoked a cigarette in 15 years. I have never done any type of recreational drugs."

What's different in Baker's wellness routine is that he also takes medication to keep the level of HIV in his blood in the range of low to

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undetectable.

Twenty-one years ago, at age 20, Baker was diagnosed with HIV. At that time, an HIV diagnosis often meant a person progressed to AIDS in a short time and died within a few years.

Medication combinations known as highly active antiretroviral therapy, or HAART, introduced in the 1990s have turned that around. Today the life expectancy of someone infected with HIV is about the same as that of someone without HIV.

"Before, that was not the case. There was a sense of urgency," said Baker, formerly of Richmond, who now lives in Washington. "Now, it's not that way. It's a good thing, but then it's a bad thing, because people don't take it as seriously. They think, 'Oh, I can just take a couple of pills and be fine.'"

"For the people I know who have been living a long time with HIV, they understand that it is more than just pills. HIV is a lifestyle change. I always tell people in order to live well with HIV and to be healthy with HIV, you only have to do three things. If you are on meds, take your meds like you are supposed to. Keep all of your doctor's appointments. And the third thing: Reduce your risk that got you infected to begin with. It's not rocket science."

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The early days of the HIV/AIDS epidemic were a time of stigma, fear, shame and many unknowns. People refused to be in the same room with someone with HIV for fear they would catch it. Children infected through blood transfusions were banned from schools.

Even 10 years into the epidemic, when basketball star Earvin "Magic" Johnson disclosed in 1991 that he was HIV-positive, there was some of the same disbelief and distancing. Even today, people are refused jobs because they are infected with HIV. The ACLU is challenging one such alleged instance, that of a U.S. Air Force veteran turned down for a job as a federal baggage screener after passing aptitude and preliminary screening tests.

"I still get stories from patients who say when they go to a doctor's office or hospital the demeanor of the medical staff changes dramatically," said Bob Higginson, a physician assistant who has worked more than 20 years in HIV care, currently at the VCU HIV/AIDS Center.

"I think part of it is there is still a lot of fear. Even though people are educated, I think there is still the general feeling people who are infected are gay or using IV drugs."

Discrimination is real, said Susan Tellier, HIV testing services coordinator at the Fan Free Clinic.

"There are a lot of people who don't get tested because of the stigma attached to it," Tellier said. They worry

## AUDIO

Hear patients and a doctor talk about the symptoms, the stigma and changing treatments.

- [Joy Blathers](#)
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## TESTING

**HIV testing sites:** [hivtest.org](http://hivtest.org)

**Hotline:** The Virginia HIV/STD/Viral Hepatitis Hotline, (800) 533-4148, also provides information on resources and testing locations.

## RESOURCES

Virginia HIV/STD/Viral Hepatitis Hotline: (800) 533-4148

[Transformation Retreats Inc.;](#)  
(804) 353-0060

Minority Health Consortium:  
(804) 225-0820

[VCU HIV/AIDS Center;](#) (804)  
828-2210 or (800) 525-7605

[The National Association of People with AIDS](#)

[Centers for Disease Control and Prevention](#)

[National Institute of Allergy and Infectious Diseases](#)

## FROM THE NEWSROOM

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that someone will see them.

"If you ever had sex one time with one person, you're at risk," said Tellier. "We've got to move away from that whole thing where unless you are participating in injecting drugs or gay men having sex with other gay men, that that's the only thing that puts you at risk. That's false, and it's ridiculous information like that that continues to fuel the virus."

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The shift to longer life expectancies for people with HIV has created all sorts of new issues and dilemmas. People with well-controlled HIV infection are able to get organ transplants whereas years ago such a thing would not have been considered. They are also living long enough to develop chronic conditions of aging, such as heart disease, increasing the need for health-care providers to expand what they know about HIV care.

HIV medications taken long term carry their own risks and side effects. The drugs take a toll, in particular, on the liver and kidneys.

Baker is reluctant to elaborate on a serious health issue he had just before his 39th birthday.

"I don't want to scare people from taking their medications, because medications do work. I would not be here for 21 years were it not for the medications," said Baker. "And that just was my experience. Someone else could be on the same regimen and not have a problem."

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In Virginia, 26 percent of the approximately 21,000 people living with HIV/AIDS are women.

Joy Blathers was 19 when, as she puts it, she was given a death sentence.

"Back then, people with the virus, they caught AIDS and they died," said Blathers, who lives in eastern Henrico County.

Married in October 1987, she had a son in December 1988. She and her husband later separated. In April 1989, she went to the doctor complaining of a sore throat and swelling.

"Three days later, the nurse called me and said she wanted to come to the house because she had the test results. By then, I am really thinking it's cancer," said Blathers. "She said I was HIV-positive. When she left, I was thinking, 'It can't be right.' Here I was 19. I haven't lived my life. I didn't take it well. I went into a serious case of denial, just pretending this was not happening to me."

From 1989 to 1997, Blathers said she didn't tell anyone she was HIV-positive. Her son tested negative. She told the public health workers who called to check on her that she would find her own doctor, but she never did.

"Too scared, too ashamed," she said. "I was really ashamed I had done something so stupid to ruin my life."

She had joint custody of her son but sent him to live with his father, thinking she would not live long. She continued to act as if everything was OK until it obviously wasn't. In 1997, she developed pneumonia and was hospitalized.

"While I was in the hospital, I was thinking, 'This could have killed you, and it would have been your own fault,'" Blathers said.

"After the pneumonia, I found a doctor, who I am with to this day. It still took me a couple of years after that to tell anybody. I kept getting sick. I told this man I was seeing first. He kind of knew something was wrong. He told me, 'You need to tell your family.' I told my family. I told my best friend at church. I had him tell my pastor. To me, that was all the people who needed to know."

By then, HAART, the antiretroviral therapy, was becoming available, and she was able to take advantage of the simpler medication regimens. There were some bumpy spots as she tried different drugs. One medication she took for six months in 2003 has left her with neuropathy, or nerve pain, primarily in her hands, legs and feet.

"Everything that could go wrong, went wrong . . .," Blathers said. "When [the neuropathy] was first diagnosed, it was so severe I could not walk. I was on bed rest for six months."

She took powerful drugs to control the pain and continued to work in her job as an administrative assistant at the state until 2007, when she left on long-term disability.

"I am considered a retired employee," said Blathers, who wants to return to work. "I never thought after 18 and one-half years with the state, I would be without a job. It's not a good time to look for a job."

Last year for the first time, Blathers talked openly about her HIV status, addressing the congregation at her place of worship, Mount Olivet Church.

"It took a lot of courage for her to do it," said Bishop Darryl F. Husband Sr. "That day was a day we'd talked about for maybe a year or two, about making public what she had gone through because it would help to change the life of some other persons who were sitting there listening. She said, 'I am ready.' We set a date for her to come up and tell her testimony. . . . They gave her a standing ovation. Since then, we've had other people come and tell their stories as well, and some people being healed from just hearing her testimony."

In the congregation that day was her son's girlfriend. She made her promise not to say anything to him. Her son, whom she never expected to live long enough to see grow up, is a man now, enlisted in the Navy. It wasn't until he was in seventh grade, she said, that she realized she wasn't dying, and she brought him to live with her.

"I cried the first day he went to high school. I cried his senior year," said Blathers. "I took him to get his tuxedo for the prom; I cried then. He said I was embarrassing him. He didn't know I never thought I was going to see him even enter high school."

She finally told him last December. Not face to face, but by e-mail. He was on duty and would not be back for a few months. Blathers had been interviewed by a national magazine about health-care costs and didn't want to chance him finding out from someone else. It turned out he had some inkling already.

"He said to me, 'I kind of knew it, Mom, because of all the books you had around the house.' I had a couple of books about support groups. A couple of medical books. I would leave evidence everywhere.

"My desire now is to help someone else who is HIV-positive or living with AIDS. I know how lonely the disease can be when you think you have no one to turn to, nowhere to go."

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For Baker, HIV changed the direction of his life.

"I always feel like I have been living in two worlds: life before HIV and life after HIV diagnosis," said Baker. At 20, he had plans to be a physical therapist, but he was also enjoying life.

"I was a wild child. HIV put me on a different course of loving myself. I have better relationships with my siblings. I am kinder to myself. Pre-HIV, my life was wrapped up in material things," he said.

Life after HIV diagnosis has been very deliberate and very focused.

Baker became an advocate, outreach worker, peer counselor and spiritual supporter. He serves on the board of Richmond-based Transformation Retreats, which for 20 years has offered emotional and spiritual support for people living with HIV. Baker has helped lead the Thursday-Sunday programs that offer people with HIV a place to retreat. He credits the program with saving his life.

"You're coming into an environment where you are accepted for whoever and whatever you are automatically," Baker said.

"Our approach has changed. When we first started out, we were doing more accompanying the dying, getting them prepared for that transition. Now we accompany the newly diagnosed though the initial fear, isolation, questioning and shame."

Baker's work as a peer treatment navigator at a Washington hospital also brings him in contact with people newly diagnosed with HIV infection. Some of the people who call or come into his office are young, in their teens and early 20s.

"Every teenager I counsel, that means that somehow I did not reach that person or people in his community," Baker said. That drives him to work even harder.

"There are a lot of things still left for me to do. I live every day being thankful, being grateful for the people who got into clinical trials, who advocated for programs. I just don't take my life for granted."

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