Making It Work

Finding a doctor once you've been diagnosed with HIV and educating yourself about the virus will help you live a long and healthy life.

November 28, 2016 By Rita Rubin

When Mark S. King tested positive for HIV in March 1985, he gained insight about doctors that has served him well for more than three decades.

Back then, "doctors didn't know a whole lot more than any well-informed patient did," recalls King, who turns 56 in December. "I entered health care as someone who saw myself as an equal to my doctor in terms of what we both knew. He was not infallible. He was actually grasping at straws."

In 1985, few people knew their HIV status. After all, the United States Food and Drug Administration had licensed the first commercial blood test to detect HIV only days before King opted to be tested.

"You weren't even supposed to get tested in '85," he says. "It was not politically correct." AIDS activists opposed testing because with no treatments available, "there were only negative consequences to finding out your status."

People feared discrimination if word got out that they were HIV positive, but King says he had a "morbid curiosity" about whether he'd be dead in two years. "I also had a feeling I'd be positive." Still, not wanting any record of his test, he had a nurse friend draw his blood after office hours.

Because he was such a rarity—an HIV-positive person who learned he was infected before coming down with an AIDS-related illness—King had no playbook to follow.

"Discussing treatment options with my doctor was not a luxury I enjoyed, because there were none," says King, a married Baltimore resident who blogs about "My Fabulous Disease" at MarkSKing.com and on POZ.com. "As a community, we learned that doctors don't know everything, that they can be challenged, that you can disagree, that you can participate fully in your health care."

Even with all of today's treatment options, King says he views his relationship with his physician from the perspective that they are partners, not leader and follower. "I've certainly had doctors who had egos," he says. "If you seem helpless, then I think there's more of a tendency for them to walk all over you and be dictatorial."

Your relationship with your doctor is one of the most important tools you have in fighting HIV, so it's important to find the right one. Ask your primary care doctor for recommendations. You can also compile a list of prospects by searching online or contacting your local AIDS service organization (ASO) listed in POZ's online directory (directory.poz.com).

You'll need a doctor with experience treating people with HIV; if you're a woman, you'll also need a gynecologist who's informed about HIV. If you have another health condition, like hepatitis or heart disease, you might also need to see
another specialist.

The Affordable Care Act has expanded coverage and provided Americans with access to affordable health insurance. Plus, Medicare and Medicaid still cover eligible individuals, and the AIDS Drug Assistance Program provides drugs for people who can't afford them. In addition, many pharmaceutical companies offer patient assistance or copay programs that reduce or eliminate out-of-pocket costs. (Visit the "Basics" section on POZ.com for information about how to pay for HIV drugs.)

If you're not a legal U.S. resident, your local ASO can help you find programs and clinics that provide free or low-cost care and/or medications. Even without health insurance and regardless of your immigration status, you have the right to treatment in the event of an emergency.

An HIV diagnosis can be an eye-opening introduction to the complexities of the U.S. health care system and the variety of sources of care, King says. "I've had it every way. I've gone to a community-based organization. I've gone to clinics. I've gone to private doctors." Currently, he sees a doctor at a federally qualified health center (FQHC). Among other requirements, FQHCs must serve an underserved area or population, offer a sliding-fee scale and provide comprehensive services.

Even long-term survivors such as King sometimes have to find a new doctor. Several years ago, he had to switch doctors when he moved from Atlanta to Fort Lauderdale. He made the most of the situation by filming an interview with his Atlanta doctor about what patients should look for in a physician and intercutting it with his first visit to the man who would become his new doctor in Florida. The information is still relevant, and you can watch his video on the "My Fabulous Disease" YouTube channel.

It's important that you feel comfortable with your doctor and that you discuss any issues you may have.

"Even though HIV is now fairly easily treatable, it's also true that we as people with HIV are more likely to have other issues, such as being gay, being transgender, having a history of substance abuse," says King, who is a recovering addict. "I have to be able to talk about that with my doctor."

Here are some of the questions King suggests you ask prospective doctors:

- Are you credentialed as an HIV specialist by the American Academy of HIV Medicine?
- Where do you have hospital admitting privileges?
- Can you provide all my primary care needs plus treat my HIV?
- How quickly can I get in to see

  you when I'm not feeling well?
- Can I share information "off the record" if I don't want it noted in my medical chart?

Plus, King says, it's a good idea to bring a hard copy of your medical records to your first visit with a new doctor.

He practices what he preaches. King stopped going to one Baltimore clinic because he was kept waiting nearly an hour during each of his two visits and never got to see a doctor.

The health center where he now receives care assigned a doctor to him. "I had a lot of questions for her when I first saw her," King recalls. "I was interviewing her for the job of being my physician, and it's an important job." Satisfied with her answers, King stayed with her.

True, doing the legwork necessary to line up your care might seem daunting, especially just after learning that you're positive. King understands. "Go ahead and freak out," he advises. "It's a major life event. You're going to have all your friends telling you it's OK, there are plenty of medications. While that may be true, you still need time to process it and freak out."

But don't let your freakout drag on.

"You've got to be educated," King emphasizes. "You've got to become a student of what's going on."

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