Side by Side

Getting the most out of your relationship with your doctor or health care provider

January 17, 2017 By Tim Murphy

Eric Roberson of Houston has an anecdote that sums up his relationship with Joseph Gathe, MD, who has been his HIV care provider for 20 years. “When I told him that I’d married my boyfriend, Kenneth,” recalls Roberson, 41, an IT professional, “he said to me, ‘You might be married to Kenneth outside, but in here, you’re married to me.’” And then Roberson laughs. (Gathe is heterosexual but has worked with LGBT patients for decades.)

In a separate phone call, Gathe repeats the story. It’s part of his effort to underscore the fact that, like a good, long-term marriage, a good, long-term doctor-patient relationship is based on mutual honesty, communication, trust and respect. “Eric is very involved in his own care,” says Gathe, who is known nationally for his HIV care and research. “He tells me everything that’s going on. I always say to my patients, ‘It’s not just about your lab numbers but also about your goals. What kind of life do you want for yourself? Eric is very engaged. He brings in lists of questions asking about how different medications interact.”

It’s a working relationship that started shortly after Roberson was diagnosed with HIV in 1996. “A friend looked up Gathe for me and confirmed that he took my insurance,” Roberson recalls. “I went to him and said, ‘I don’t know what to do,’ and he said, ‘You’re in the right place.’” It turned out Gathe was right. He and Roberson have stuck together for 20 years since then, getting Roberson through various challenges including starting and eventually switching HIV meds, a tonsillectomy, MRSA (a tough-to-treat staph infection) and a back injury. “He gave me steroid shots for that to keep me out of the hospital so I could go to my graduation ceremony for my associate’s degree,” recalls Roberson.

Gathe says working with patients like Roberson who play an active role in their own care makes his job easier. “Once I know what’s important to my patients, I can better care for them.”

And that’s not just Gathe’s take on doctor-patient relations. Numerous studies over the years have shown that communication, honesty and trust between HIV patients and doctors play a crucial role in terms of how well folks with HIV adhere to their med regimens or show up for doctor and lab visits.

“If we’re able to talk honestly about everything, including whether you’re taking your meds and whether you have other things going on like depression or drug use, I won’t judge you, but I’ll be

able to help us figure out a solution that works for both of us," says Antonio Urbina, MD, a professor at the Institute for Advanced Medicine at New York City's Mount Sinai Hospital who's been treating HIV patients for 25 years.

Getting Started

But let's face it: If you're going to be 100 percent honest with your doctor, you have to trust him or her. Even if your doc isn't going to be your best friend, you still have to feel that you're being heard and that you are a person—not merely the next 15-minute slot being crammed into that day. And the sad truth is that because insurance reimbursement rates are so low these days, doctors are under the gun to see as many patients as they can.

Still, says Gathe, "even when I'm behind—and I'm always behind—I try to give each patient the time that they need."

Your doctor should too. When you're shopping for a health care provider, be on the lookout for someone who will adequately address your needs. For a while, Ruby Ingram, 54, of Brooklyn, who was diagnosed with HIV in 1996, was seeing a certain doctor. "But I didn't feel like she was listening to me," she recalls. "I would tell her about things that were really bothering me, like a lump I had on my neck, and she would just say, 'Don't worry about that' and dismissed it without referring me anywhere else. When I told her about the chronic pain I had from my fibromyalgia, she said to me, 'I don't want to discuss that with you, because I didn't diagnose you with that. And I don't prescribe pain meds.' And I hadn't even asked her for them!"

So Ingram asked around, made some calls and switched for several years to nurse practitioner Natacha Baron at Housing Works, a large New York HIV/AIDS agency that offers primary care. Soon, she'll start up with yet another doctor.

She's like many folks with HIV who've had to switch doctors multiple times in the search for a better bedside manner or as a result of changes in their health care coverage. Since he was diagnosed with HIV in 2008, Jeremiah Johnson, a research and policy coordinator at New York City's HIV advocacy Treatment Action Group, has had three doctors. The first, Ben Young, in Colorado, was terrific. "When my parents were afraid of using the same toilet seat as me, Dr. Young invited them into the office and explained to them in scientific terms why and how HIV is not transmittable that way. That solved the problem."

Upon moving to New York, Johnson ended up seeing a prominent doctor for three years who was not as gentle as Young, especially with respect to Johnson's issues around sex and drug and alcohol use. "He was very brusque, and I had to manage my expectations about how much emotional support I was going to get from him." When that doctor closed his practice, Johnson moved to a new medical group, where he is currently seeing an HIV-trained nurse practitioner. "That meets my needs at the moment," he says.

Johnson understands that living in a large, LGBT-friendly city like New York affords him a fair amount of choice in finding a doctor. "It's important to remember that your relationship with your

doctor, like all relationships, may not work out or be ideal," he says. "And you definitely should talk to HIV peers in person, online or through the community forums on POZ (forums.poz.com) and other places to find other options in your area. But if you have few choices, try to get your medical needs, like labs and meds, met through your doctor, then reach out elsewhere for spiritual and emotional support, to case managers, support groups or friends and family. Sometimes, with doctors, it really helps to manage your expectations."

Face to Face

But sometimes, if both parties bring their best selves to the table, doctor-patient relationships can evolve into a partnership that nurtures both you and the provider. Cecilia Chung, 51, a senior strategist at the Transgender Law Center in San Francisco and founder of Positively Trans, which advocates for HIV-positive transgender people, was diagnosed with HIV in 1993. But she did not have her own insurance until 1996, at which point she went to Virginia Cafaro, MD, whom she'd heard was experienced in trans health needs such as hormone therapy.

Her first phone chat with Cafaro's office manager set her at ease. "We had a really long, pleasant conversation about Dr. Cafaro and what she's like," remembers Chung, who felt that she would be treated as a human being there. And that's just what she found once she started seeing Cafaro. "She's very easygoing, and I like that she's part of the LGBT community herself, openly lesbian. She's not the type to sternly lecture you."

Still under Cafaro's care today, Chung says her trust in her doctor has only deepened over the years, allowing her to open up to Cafaro about her history of trauma and mental health needs so that together they can factor that into Chung's total wellness. Chung also liked that Cafaro embraced holistic tools, such as acupuncture and vitamins, alongside standard HIV meds. And years ago, when Chung desperately wanted to go off her HIV meds because the side effects of early HIV medications were so severe, Cafaro "was able to meet me where I was."

While Chung was off meds, Cafaro tracked her viral load and CD4 count, gently—and successfully—suggesting that Chung go back on meds once her viral load hit 1 million. "We go over my lab work together, and it makes me feel more comfortable asking questions. I feel like she's helped me earn my own MD!"

The admiration is mutual. "Cecilia has a good sense of humor, which I appreciate," says Cafaro. "She'll also own up when she didn't follow through on something we talked about." Such as? "Mainly self-care," says Cafaro. "Cecilia's doing a lot of good work for others, traveling a lot, which sometimes takes away from her looking after herself."

Chung says she feels like she can ask her doctor anything. You should feel the same way.

How to best maximize your time with your doctor? "Keep a running list of your health questions and problems that you take with you to your appointments, including things you might read online," suggests Urbina. "You can keep it on paper or on your phone. That'll streamline things once you're in the office with us. A good provider should help you understand why you have nothing to worry about instead of making you feel foolish. And if there is a problem, they should be

able to work with you toward a next step, whether it's pharmaceutical, extra lab work or maybe a change in lifestyle or diet."

And you, in turn, should feel that you can be completely candid with your doctor. That's how Gerald Walter of Fort Lauderdale feels about his provider, Jennifer Bartczak, MD, of Rowan Tree Medical. Walter, 51 and diagnosed in 1998, says that prior to her, "I had a very rude doctor who constantly misdiagnosed me." When he switched to her, "At my very first visit, she was very detailed, looking not just at my numbers but asking how my energy was, things like that."

Working with Bartczak, Walter got his HIV combo down from five meds to three and his viral load to undetectable (which he's been ever since), went on Ritalin for his ADHD, got his high cholesterol under control with meds and diet changes and quit smoking ("She said she could hear how clear my lungs sounded").

But best of all, Walter feels he now has a doctor he can share even the most personal, painful things with. Bartczak helped him through a bout of post-breakup depression, even calling him at home to make sure he was OK. The result? "I don't get embarrassed with her," even when his routine STD screen revealed syphilis, which Bartczak treated him for. "I'd just moved to Fort Lauderdale and didn't know it was a huge epidemic here," he says. "It's a big deal for me to be able to trust someone with intimate details and not feel judged. If you can't tell your doctor the truth, then you're not going to get the best care."

Making All the Difference

Dora Upchurch, 56, a St. Louis health care aide diagnosed with HIV in 1996, will never forget a horrible period three years ago. Not only had her son just died, but it had gotten out at the nursing home where she worked that she was HIV positive—and, she says, human resources did nothing to advocate for her. The HR department didn't even believe her claims that coworkers were gossiping about her. (Upchurch says she simply quit rather than deal with the subsequent workplace stress.)

All in all, "I was going through a mental stage," she says. "I couldn't stop crying and was ashamed." Luckily, she felt close enough to her care provider, Ernie-Paul Barrette, MD, at Washington University School of Medicine, to tell him about it. "He said the right things and gave me a hug and put me on the right antidepressant to get me through that time," she says. "He told me I'd be OK eventually."

In other words, Barrette treated Upchurch as he always has, she says, as a complete human being. "He's always down-to-earth," she says, adding that even if she sees another provider when she visits, Barrette always checks in on her. Plus, she says, case manager Caprice Johnson has got her back as well. (Tip: If your provider or clinic offers a social worker or case manager, take advantage of it. They can often help you with life issues your primary doc may not have the time or expertise for.)

"Be completely honest with your providers and be willing to work with them to ride out bumps in your life," whether they're medical or otherwise, says Cafaro. "Some things don't get fixed

immediately, so hang in there with us. My patients don't give up on me, and I don't give up on them. It's a two-way street." Conversely, says Cafaro, docs have to be honest with patients about how much time they have. "If we can't tackle a nonemergency problem in one day," she says, "I'll ask patients to make another appointment soon so we can really dig down on it."

That's just what Enrique Menendez, 51, a Manhattan entertainer diagnosed with HIV in 1989, had to do with his longtime doc, Michael Mullen, MD, when a decade ago Menendez learned he had hepatitis C. Says Menendez, "He saw me through three rounds of hep C treatment," only the last of which, using near-miracle meds that have come out in recent years, cured him—and without the harsh side effects of the older drugs.

Menendez says Mullen has also been patient with him as he struggled on and off with drug addiction the past few decades. "He's never like, 'You have to stop.' He's just supportive. He knows I've dealt with depression. I never feel judged by him. When I was using drugs, he'd even call when I missed appointments to ask, "Are you OK?'"

But, laughs Menendez, there are times when Mullen just says no to him. "I always joke with him, 'Can you prescribe me HGH please?'" says Menendez, referring to human growth hormone, which can give the body a muscular, ripped look but also can cause side effects such as muscle and joint pain and hand and foot swelling. "I want to have a fly body again, but he won't give it to me!"

Overall, though, says Menendez, he and Mullen have grown together. "Right now, he's really happy I'm doing well with health and sobriety, and he's curious about what's worked for me this time around." (Menendez attributes it to a steady combination of therapy, 12-step meetings and faithfully hitting the gym.)

"He's invested in me," continues Menendez, "as far back as 1992, when he made sure I got a private room when I was hospitalized for PCP." (Pneumocystis pneumonia, PCP, is a life-threatening lung disease that frequently killed people with AIDS in the days before effective HIV treatment.)

Take a Deep Breath

It's important to remember that not everyone will be lucky enough to have one great doctor for life. If you're with a doc you love, do all you can to stay with him or her. But don't panic if you have to change providers. Take a deep breath, do your research and ask others for suggestions.

"Try to take control of your life and be your own best advocate, or at least find someone, even a loved one, to help advocate for you," advises Robert Suttle, 37, the New York City–based assistant director of The Sero Project, which fights to remove laws in several states that unfairly criminalize HIV-positive people for having sex, even when they are on meds and undetectable and virtually uninfectious.

Suttle, diagnosed with HIV in 2003, is currently searching for a new provider because his doctor for the past few years, Roona Ray, MD, at New York's LGBT-serving Callen-Lorde clinic, is moving on.

“She understood me as a patient and always allowed me to express my concerns around medication, relationships, anything that was a barrier to my health,” he says. “She always took the time and asked questions. There were days I was not feeling happy or energetic, and she’d help me try to find solutions, like counseling.”

Ray also invited Suttle’s HIV-negative boyfriend into the office to discuss his going on pre-exposure prophylaxis, or PrEP, the HIV med Truvada taken once daily to prevent getting HIV. And perhaps, most of all, she helped Suttle overcome his fear of anoscopies, which are regular (slightly uncomfortable but not really painful) camera probes in the rectum to check for signs of precancerous lesions. (They are highly recommended for HIV-positive men, whose lesion rates are higher than average.)

“I just wasn’t ready for that,” he says, “but I trusted that she was looking out for me.”

In other words, fears and hesitations can be worked through with a good doctor, but it’s up to each of us to be honest, open and willing with our providers to nurture those relationships and get the most from them. From switching meds so you can manage side effects to dealing with stressful life events or mental health issues that can affect your medication adherence or overall wellness, it’s important to put everything on the table with your provider so they have the full picture—and can work with you to find solutions.

Back in Houston, Roberson and Gathe have learned that lesson together. “He’s always kept me healthy, whether we’re talking about the virus itself or other issues that pop up,” Roberson says. “I’m more comfortable telling him things than I am with most of the people I’ve ever had sex with! Just being in his presence, I start to feel better.”

Now that’s a doctor-patient relationship worth working toward!

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