Close To You

Aging with HIV doesn't have to mean living without love.

August 14, 2017 By Tim Murphy

It started with a misunderstanding. Five summers ago, Anna Fowlkes of Baltimore, now 70, was doing HIV prevention outreach at an outdoor festival where musician Paul Johns, 72, was operating the sound system. Boldly, Fowlkes approached Johns and his buddies and asked them whether they'd been tested for HIV.

"I told her I didn't need to be tested because I'd been married for a long time, exclusively, to my wife," says Johns, who, like Fowlkes, had been widowed. He also thought she was hitting on him. "She was a little presumptuous, like standing in front of an ice cream truck and asking someone to buy you ice cream."

Fowlkes was just doing what she always does: getting the word out to seniors that age doesn't make them immune to HIV. But she also admits she found Johns alluring. "I'm a flirt," she says. "I like my men tall, dark and handsome, and that's what he was."

One thing she didn't share with him that day was that after the death of her longtime husband, she had tested HIV positive in 2006, having gotten the virus from a man she dated in the '90s who did not disclose his status to her.

Six months after they first met, Fowlkes and Johns ran into each other again, this time at a church HIV awareness event where Fowlkes publicly disclosed her status. "I realized that inquiries like the one she'd made to me were part of her promotion," Johns says, "so I told her I'd gotten the totally wrong impression."

"And I gave him my card and told him to call me," adds Fowlkes.

Five years later, Fowlkes and Johns, who is HIV negative, have built a life together—a life that they developed in slow steps, educating each other about both HIV and their own personal needs along the way.

"We had the tough discussions early on," Fowlkes says. "He said up front that he'd had three women propose to him! I told him that my home and car were paid for, just like his, and that I wasn't looking for a husband. But I did need companionship, a hug every now and then. I have my

girlfriends, my sister and my grandkids, but I needed a man friend."

And if Johns ever thought he might have to take care of Fowlkes because she has HIV, the tables turned two years into the relationship when doctors found a growth on his pituitary gland. They operated right away, after which Fowlkes, a former home health aide, looked after him. "She didn't need me," laughs Johns, "but there was quite a while when I needed her."

They've been living together for the past two years and doing everything else—from attending doctors' appointments and traveling to see local plays—together too. In the evenings, they're content to watch TV in separate rooms. (Fowlkes prefers British mystery shows; Johns is partial to Rachel Maddow.)

So when she was inducted into the 2020 Leading Women's Society by the Atlanta-based HIV/AIDS group SisterLove Inc., Fowlkes brought Johns along. She says: "Many other HIV-positive women came up to me and said that seeing me with him gave them new hope that they could find a good man."

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It's natural to want love, sex, romance, companionship and intimacy in our lives. Sadly, not everyone knows that the risk of HIV transmission from people who have an undetectable viral load is negligible and that people who are HIV negative can take PrEP (the HIV pill Truvada taken daily for prevention) to protect against the virus. Stigma, which dates back to the 1980s, dies hard. And that stigma can also turn inward, making us feel like damaged goods.

"A lot of us feel as though we can't even date HIV-negative men because we're afraid they'll try to criminalize us over HIV disclosure if the relationship doesn't work out," says Phyllis Malone, 58, who was diagnosed with HIV in 1996 and is a prevention specialist at SisterLove, which serves HIV-positive and at-risk Black women. "We have so many ladies who want relationships, but they're afraid to make that step. That person in line with you at Walmart may be your soul mate, so start a conversation. And if one person fails you, don't give up!"

With gay men, other issues arise. "Gay men over 50 did not grow up being socialized to have relationships or taught how to love each other, so we've had to muddle through those issues," says Perry Halkitis, PhD, who was diagnosed with HIV in 1998 and is the dean of the Rutgers School of Public Health in New Jersey and author of The AIDS Generation. "We spent so much time hiding who we were when we were young that we can still feel alone. Plus, we are probably living with some underlying trauma from surviving the AIDS crisis."

Different challenges are loaded on when you're transgender. "People aren't stupid," says Tanya Walker, 54, who was diagnosed with HIV in 1997 and is the cofounder of New York Trans Advocacy Group. "They know that if you're older and you're Black and trans, you're many times more likely to have HIV. I've heard guys say, 'Hey, don't mess with that one, she might have AIDS.' I'd love to have a companion who likes house music, dancing and other things I like, but many men who date trans women are still in the closet. But," she adds, "my last boyfriend did."

Anna Fowlkes and Paul JohnsJustin Tsucalas

No wonder, then, that folks with HIV over 50 who are already in relationships work hard to sustain them. Since 2008, HIV prevention volunteer Franceina Hopkins, 54, of Lexington, South Carolina, who was diagnosed with HIV in 1995, has been in a relationship with Dan, who is HIV negative. He knew little about HIV when they met and even called her a “carrier” of the virus when she disclosed to him, but because he was drawn to her, he kept listening and learning—including about the fact that undetectable equals untransmittable. More than a year into their relationship, he finally felt comfortable enough to have sex without condoms.

She agrees that communication and compromise have been key. At one point, she says, Dan thought she was cheating on him because she was away so often at HIV conferences. The solution? He started joining her. In turn, she’s learned to share Dan’s interests, such as hunting and fishing. “You have to be quiet when you’re doing those things, and that’s not my norm!” she laughs. “I have to be attentive to him and listen. It’s a conscious decision on my part.”

In Connecticut, HIV prevention worker Bill Petrosky, 64, who was diagnosed with HIV in 1991, has

been with Oliver Smith, 67 and also HIV positive, since they met 17 years ago at a local gay bar. “I was 47 at the time and had just left a five-year relationship that was not working,” Petrosky says. “I was not feeling good about myself, down in the dumps about my HIV and possibly being alone the rest of my life.”

Now the two are preparing to retire. Their rules for making it work all these years? “Accept the other person for who they are and don’t try to change them into something that meets your ideals,” says Petrosky. “Never take advantage of them. Always express appreciation. And it’s OK to do certain things separately. Having your own space is healthy.”

Sometimes, what it takes to find that special someone is an open mind—or what Halkitis would call “not latching on to a heteronormative idea of what it means to be in a relationship. We as gay men have defined our own paths of what it means to love, and we know that one model does not fit all.”

Take Chris, 50, a New York–area instructional coach diagnosed with HIV in 1992. He was devastated two years ago when G., his partner of 25 years, died. So he started spending more time with D., a “fuck buddy” he’d had while G. was still alive. (He and G. had long ago transitioned into a “don’t ask, don’t tell” open relationship.)

“But after G. died, D. and I became more serious, more committed,” says Chris. Meanwhile, D. was in his own long-term open relationship. Finally, one night, D. and his husband invited Chris to dinner. Chris and the husband hit it off as friends, though not sexually. Now the three men spend weekends together upstate, with D. sleeping one night with his husband and the other with Chris.

“It’s very Mormon,” Chris jokes of his “sister wife” relationship with D.’s husband. But he also feels it’s exactly what he needs after losing G. “I’m not a big monogamy fan,” Chris says. “D. and I are also open. We work on boundaries to make sure it never becomes hurtful.”

That outlook isn’t unique to gay men. “I have one guy I see potential in and another who’s just a sex buddy,” says a straight Black woman in the South. “I wake up in the morning and decide which one I want to be with today! But,” she advises, laughing, “once you see real potential in someone, don’t keep him at bay. Slowly put a rope around him!”

Nontraditional relationships can take other forms. In 2009, Fort Lauderdale’s Jay McLaughlin, 53, the HIV-positive founder of the HIV/AIDS nonprofit Project Link of South Florida, met a guy on a dating site named Chris who was living in Peru. Despite a language barrier, they hit it off. In a few months, McLaughlin was flying to Peru to meet Chris, who greeted him at the airport wearing a T-shirt with a photo of McLaughlin on it that read: My sweet Jay McLaughlin, welcome to Iquitos, Peru. “When I saw that, I knew I’d found the love of my life,” says McLaughlin.

Since then, they communicate every day via social media, Skype or phone, and McLaughlin visits Chris at least yearly, depending on his finances. Twice, Chris has been denied a visa to visit Florida, says McLaughlin, who is figuring out how they can spend the rest of their lives together.

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Of course, you don't have to be in a relationship at all. Gail Gonzalez, 60, of New York, who self-identifies as transsexual, has chosen to be celibate the past four years as she embraces being sober. "I just thought the journey would be less stressful if I didn't put sex into the mix," she says. "It's been an awakening experience. I feel a sense of calm and serenity. I'm not saying it's a permanent decision. I think when my higher power brings my soul mate to me, I'll be reactivated."

Then there's Sunshine Simpson, 52, of Oakland, California, who was diagnosed in 2013. She sees a guy every other week whom she'd like to see more. "I'd like to settle down with one person," she says. But she's not building her life around that goal. "I've been single for so long that I may just stay that way."

That attitude's fine, if you're really OK with it. "We tell ourselves that this isn't going to happen for us to protect ourselves," says Christopher Murray, a New York therapist living with HIV who runs groups at SAGE, which provides advocacy and services to LGBTQ seniors. "We take the veil like a widow. But you have to allow yourself to say, 'I wanna go on that ride, damn it' and amass as much compassion and love for yourself as you can. And also acknowledge that you really don't know what the future has in store for you. That's one way to manifest hope."

Another way? Take active steps toward meeting other people. In Portland, Oregon, Christophe Johnston, 56, who was diagnosed with HIV in 1987, is preparing to move to Palm Springs, California, to be among a bigger group of senior gay men, many of them living with the virus, for both dating and social support purposes. And yet he understands what RuPaul means when he asks, at the end of every episode of RuPaul's Drag Race, "If you can't love yourself, how the hell are you gonna love somebody else?" Says Johnston, who is part of Portland's #LetsKickASS support network for longtime survivors, "There comes a time when you finally recognize the person you see in the mirror as your long-lost soul mate. It's amazing how many of us fail to understand this and continue to denigrate ourselves."

That's all too true. So here's a double-edged challenge: Continue to nurture your established relationships with family, friends, colleagues and—most of all—yourself. But at the same time, be open to unexpected opportunities.

Take it from Anna Fowlkes and Paul Johns in Baltimore—suddenly, they're the custodians of Anna's 2-year-old granddaughter, Kwaja, while her mother is unable to care for her.

"Paul is telling his friends, 'I just had a baby,'" Fowlkes laughs. Then, more seriously, she says, "My whole family was worried about this child being too much for me, so I asked Paul, and he just said, 'We can do this.'"

Looking For Love? Here Are Some Tips...

- Strategize About Disclosing

If you tell people in person or on dating apps off the bat that you have HIV, you'll likely filter out HIV-phobes. But you don't have to disclose right away. "Feel people out and ask what they know about HIV," says Phyllis Malone (who also points out that you can choose to date only other positive folks). "But legally," she says, "you better disclose before the clothes come off."

- Take it Slow

  When together, hang out in groups or in public spaces, like the movies, to see whether you're a match, says Malone. "Start off as pals."

- Loosen Up

  Let go of some of your more superficial requirements in a lover, and broaden your comfort zone. "Everyone will have some flaw," says Perry Halkitis. "And you have to consciously place yourself in situations that are little unfamiliar."

- Stop the Pity Party

  Even if you're single, recognize other sources of love in your life. "We're nourished by all sorts of relationships, including family and friends," Christopher Murray says. "Love is happening around us all the time."

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