



Questions Still Unanswered

A long-term survivor seeks more support for those aging with HIV.

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When the HIV epidemic began in the 1980s, we knew very little about the disease and the possibilities of living a long life with HIV. The focus was on saving lives and trying to survive. More than 40 years later, people who have been living with HIV are asking new questions: What toll has it taken on my body? How will the countless medications that I've taken over the years impact my organs, my memory, my lifespan?

I know the angst felt by this community of older adults because I have been living with HIV for 28 years, and I used to take up to 27 daily pills — almost every single day. This is a diverse community of older adults too, whose life experiences create different health realities for all. As for myself — a Navy veteran and member of the LGBTQ+ community — I think about these questions all the time. I have also worked with Washington, DC's most prominent health service practitioners and advocated for those silenced by the stigma of HIV. Sadly, we don't yet have answers for what our future holds.

We have seen major advancements in this area. For instance, pre-exposure prophylaxis (PrEP) and post-exposure prophylaxis (PEP) have proven to be remarkably life-enhancing and even lifesaving. With effectiveness rates [as high as 99%](#), young people with HIV today have a chance to thrive for many years. But [half of all people living with HIV are over the age of 50](#).

So, while it's important to focus on preventing HIV transmission, it's just as important to provide the right care for those living with HIV. This includes secondary prevention to stop HIV from advancing to later stages, as well as helping patients get to a place where their viral load is undetectable. There is an overwhelming body of clinical evidence to support Undetectable Equals Untransmittable (U=U). [The National Institutes of Health](#) (NIH) defines this as when a person with HIV adheres to antiretroviral therapy, and it is no longer detectable, so they cannot transmit it to others. Emphasizing these approaches within patient care will go a long way in supporting those living and aging with HIV.

The health system that miraculously carried us through the HIV crisis must now focus on the gaps in care for the millions of us aging with HIV, for both our physical and mental health needs. Care for HIV is already a highly complex process, so extending that care to aging patients will not be easy. A literature review from [the National Library of Medicine](#) proves this and shows that older HIV-positive adults who receive antiretroviral therapy do not recover nearly as quickly as younger

adults.

Having a relationship with a primary care practitioner (PCP) who knows your full life experience and medical history is crucial. This is also why I'm very encouraged to see programs such as George Washington University's [Two in One: HIV + COVID Screening and Testing Model](#).

This new program is designed with a combined health and racial equity lens to help PCPs routinize HIV screening, along with screening for COVID vaccines, for all their patients. By training PCPs to use culturally responsive communication, it promotes honest and frank conversation. Regular, open health screenings can go a long way toward addressing the whole person by covering cardiovascular diseases, cognitive impairment, osteoporosis and cancers.

The NIH needs to continue broadening HIV research funding in [geriatrics, immunology, neurology and social sciences](#). We also need to move beyond just medical treatment and focus on care for the "whole person" that will address a broad range of quality-of-life concerns involving a range of mental health issues, mobility challenges, and access to financial and technological services. The work I've done as a former board member of [at Mary's House For Older Adults](#) consistently reinforces the importance of mental health care and the importance of U=U among older adults in the LGBTQ+ community, as well.

Let us celebrate the historic progress made in fighting HIV, while also recognizing the gaps in care that hurt so many of those silently aging with HIV. It should not be a silent struggle. Let us raise our voices and demand a health care system that recognizes the long-term challenges we face and provides the necessary support to ensure a fulfilling and healthy life in our later years.

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