



HIV & Aging: The Importance of Proactive Health Plans in Connecting to Care



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If I could help to support people who are aging with HIV, one suggestion I'd share would be: **Please remember, this is your body and your life.** This may sound obvious; however, in this “new normal” we are living in with COVID, we've all been turned upside down and inside out (to quote a famous song by [Diana Ross](#)). This may have some advantages, although the jury is still out for the final verdict on that.

We are still responsible for our lives, no matter how hard it may get at times. But this does not mean we have to do it alone. We also need to have health providers, doctors, nurses, insurance plans and others who see us as being at the center of our health care decisions while they are our partners, advisors who should be advocating for you as your support system.

If this does not describe your healthcare situation currently, then it's time for some self-care housekeeping. The most important mission each of us has is to take care of our health the best we can, with the help of those on our healthcare team.

In order to do this, we need to have providers who are user-friendly and who see us for who we are, as our authentic selves. We have to always be advocating for ourselves and what's in our best interest as well. Rule one is to always fight to stay connected to care.

These days, with all the barriers our healthcare system has in place, it does seem like a battle to access health care at times. However, if you are reading this, it most likely means that as a person living with HIV you are winning already in terms of navigating the health care system to some degree.

Another rule is to recognize the hard work and success you have achieved so far. How many people really understand the amount of courage and bravery that is needed once we leave the clinic or doctors office and go back out into the real world? As an HIV nurse and healthcare provider myself, I have learned so much from my patients, their families and loved ones.

I strongly recommend that you share your experiences and knowledge with everyone, because your experiences with HIV are the reality check we all need to hear in order to give you the most support we can.

One more fight we need to recognize is with ageism. Ageism is all around us: We walk into it every day, and it does not pass by any of us. Those people who were born with HIV and are now in their teens, twenties and above have aged with HIV. And those community members who have been successfully managing their HIV for many years after contracting it at in their 20s, 30s or 40s understand the faces of ageism as well. But for those who are now 55 and above who have recently tested positive, while you may have been able to learn a lot about your body's aging process up till now, going forward you'll need to learn many more important things about aging with HIV.

Because we live in a society that values youth to such an extent, people often fight so hard to remain youthful they don't recognize the value of other who have survived and won, and so walk right by them.

As a person who has HIV and who continues to age, please remember ***you are already winning***, and that we must all use each other the best we can to stay connected to care. We need to reach out to the person in front of us and help support them.

Unfortunately, for far too many Americans, that becomes harder — rather than easier — right at the time they enter their senior years and need the most help. That's because of a quirk in the health care and health insurance systems that can remove people with HIV from life-saving Medicaid Special Needs health plans (SNPs), replete with safety net care, when they turn 65 and become eligible for Medicare. Make no mistake, Medicare plays a vital role in keeping people connected to care as they age. But it should supplement — not replace — the proactive, special needs care that changes the trajectory of health for vulnerable Americans living with HIV.

I have seen all the care coordination that goes into — and all the good that comes out of — specialized Medicaid plans for people living with HIV, including the SelectHealth SNP offered by VNSNY CHOICE Health Plans (associated with the Visiting Nurse Service of New York, where I work).

For people with complex health needs, these kinds of plans cover not only high-quality medical care, dental, vision and prescription drugs, but also the care management and social work services that help weave that social safety net and make good health and hope possible. This can include connecting people to housekeeping and transportation to appointments; helping them manage medications and health care supplies; and even incentives to keep at-risk individuals connected to care. We've all had the experience of trying to get help by ourselves when we don't feel well. Now imagine trying to get help when you are experiencing a life-threatening illness and have no experience navigating the health care needed for this.

These SNPs' care management of people with HIV also includes committed door knocking and non-judgmental listening to meet people where they are and help them get to where they want to go. Take Gregory, whose body and spirit were wasting away when an outreach worker knocked on the door of his SRO — and changed his life. Gregory's insurance records showed he had a high viral load, poor medication refill rate, and no recent doctor's visits. Care workers from VNSNY SelectHealth and the Alliance for Positive Change assessed Gregory's health and told him point-blank, "You need to go to a doctor."

He agreed. They accompanied him to a clinic, where he saw a doctor for his HIV, had his medications assessed, received an inhaler for respiratory complications, and scheduled follow-up appointments, knowing the care team would help him with transportation. He enrolled in a pharmacy program that delivers medicines directly to his room, gained fifty-five pounds on the road to better health, resumed his love of bicycling through the city, and reconnected with his young grandchildren.

“People who live in extreme poverty are often in survival mode,” says SelectHealth nurse practitioner Dr. William LaRock. “Navigating the day or the week, it’s a lot of work. Going to the doctor, which may have been at the top of their list three years ago when they were really sick, has been bumped down to fifth or seventh. We help them walk the journey back to putting care at the top of the list.”

A SelectHealth team performed a similar service for Luis*, who had been taking his medication and regularly visiting a clinic in his Bronx neighborhood until a move to Far Rockaway, Queens, disrupted that connection. The 62-year-old stopped refilling prescriptions, couldn’t find a nearby clinic, and grew increasingly at risk for serious complications from HIV and underlying hypertension and cardiac issues. The SelectHealth team stepped in, located a small clinic in his new neighborhood, accompanied him on the first visit, and connected him with a cardiologist who replaced stents and went on to see him regularly. That connection to care helped Luis keep his condition under control and his viral load undetectable.

Mind the Gap

Transitions in care — going from hospital to home, or from one care plan to another — are often the riskiest times for patients or health plan members. I want to ensure that we don't leave older HIV-positive Americans vulnerable during this transition. I would like to see us as an industry continue with the life-changing oversight and care coordination of special needs plans even as Americans reach Medicare eligibility. Until that happens, I would urge us, as we reflect on how to support and care for Americans aging with HIV this September 18, to pay special attention to this transition, and make sure that those vital connections to and coordination of care remain in place at and after age 65.

After all, in the U.S., HIV is, increasingly, a disease of older people. According to the Centers for Disease Control and Prevention, more than half (51%) of Americans living with the disease are age 50+. Over the years, advances in medication and care delivery models have made the treatment of HIV equally or even more manageable than other chronic illnesses that commonly accompany aging, such as diabetes or hypertension.

Sometimes, you need a little extra care — Special Needs care — to bridge the isolation that living with HIV can bring, born of stigma or poverty or simply aging, when social circles narrow and mobility grows limited. Helping people remain connected to care — and keeping them connected — takes a lot of work. But the toll, both human and financial, of disconnecting from care would surely be far greater.

*This is a pseudonym to protect privacy