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END AIDS. LIVE LIFE.

Who Are Long-Term Survivors?

In 1989, I was diagnosed with HIV. I prepared for my rapid death as my immune system slowly and inevitably collapsed. I watched as my friends and friends of friends died from AIDS. My family, church, employer, and neighbors all abandoned me. My parents disowned me when I shared with them that I was gay and facing a rapid death. Abandonment. Trauma. Made worse by the loss of my friends, most of whom were in their 30s.

But I saw my community fight back: ACT UP, APLA, SFAF, GMHC. They replaced my family. They became that extended family we gays always spoke about with pride.

In 1993, I was lucky enough to get into a clinical trial of one of the new “cocktails” of meds being studied. It worked! By 1994 my viral load, which had been in the millions, was below 100 and my CD4 count was climbing above 200. Of course, there were side effects and difficult dosing schedules, but I accepted them as a trade-off for life.

During the next two decades, HIV took a huge physical toll. Work was no longer possible, but I was able to secure health care and medications. Housing and food support came from the ASOs and city and state systems. My doctors gave me life. But then I confronted another trauma: aging. The HIV cocktail gave me the promise of life, but what about aging? Where is the cocktail for that?

A Long-Term Survivor

by Stephen Karpiak, PhD

The story above comes from an HIV long-term survivor (LTS). LTS are often defined as people who were diagnosed with HIV/AIDS before 1996 and who are now over 50. Many receive their health care from Medicaid, the Ryan White Care Act, or ADAP – and their medical care has been consumed with achieving an undetectable viral

load and a high CD4 count. This focus was akin to a religious mantra. If you took HIV medication, you had life – with a functioning, if not perfect, immune system.

Then this remarkable advance in HIV treatment became a tool of HIV prevention. People with HIV who took their meds were no longer able to pass the virus to others. And if those who were at risk

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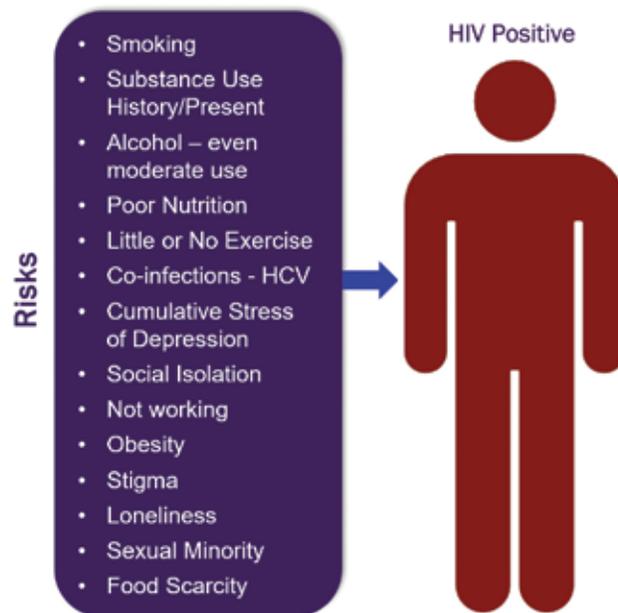
Long Term Survivors *cont. from first page*

for HIV took those same meds as PrEP, the epidemic would end.

The HIV Treatment Cascade

Guiding us in “Ending the Epidemic” is the Treatment Cascade, which assesses HIV testing, connection to care, and viral load suppression. The Treatment Cascade is a Public Health monitor. It is obsessive. And it is seen by many LTS not as a useful tool, but rather as a barrier to the critical care they need as they age. For the LTS, care begins after the Treatment Cascade.

Looking beyond the Treatment Cascade, research shows that LTS have high rates of multimorbidity (having two or more chronic diseases). Whether they are experiencing accelerated aging remains a question. If we use the number of conditions a person has as a measure of aging, then LTS are experiencing more aging. But whether it is occurring more quickly remains to be established.



Researchers have long known that the number of conditions a person has increases with age. For LTS, more of these conditions are being reported. Data show that older adults with HIV are at increased risk for heart disease, kidney disease, osteoporosis, non-AIDS cancers, and other conditions. LTS often attribute

this increased risk, as well as the increased frequency of comorbid conditions, to HIV.

But HIV is not the only factor that can lead to these increased risks and comorbidities. People without HIV also have increased risks and therefore high numbers of age-related conditions. Many LTS have several risks (see list below) that contribute to their higher rates of medical conditions. Managing these risks throughout life results in decreased multimorbidity. This is known as preventive health care. Unfortunately, such care has never been part of the Ryan White Care Act or other health insurance plans, including Medicaid.

HIV Inflammation

All the above risks are associated with increased inflammation in the body. At first, HIV infection leads to an extremely high level of inflammation. With HIV treatment, those levels are markedly reduced, but not eliminated.

High levels of inflammation are the basis for almost all the conditions associated with aging. Other infections, such as hepatitis B and C, along with unhealthy behaviors like smoking, poor diet, lack of exercise, substance and alcohol use, stress from stigma, sexual minority status, and social isolation all contribute to increased levels of inflammation. Add to this the stress caused by poorly managed mental health and it's no wonder that people with HIV feel they are aging faster than their HIV-negative peers.

Consider the effects of inflammation over many years. Data show that over 50% of older adults with HIV have a history of smoking, and up to 40%

continue to smoke, compared to only 13.7% of the U.S. population. Smoking is the number one risk factor for heart disease and cancer, while HIV itself is far down the list. Add to that high rates of past and present substance use (see graph at right), which also causes inflammation, and the increased rates of multimorbidity are not surprising.

LTS Data in ROAH

The contribution of HIV itself to the high rate of multimorbidity in LTS is seen in the preliminary assessment of data from the ROAH 2.0 study (Research on Older Adults with HIV). With almost 2,000 participants at multiple U.S. sites, the data show few differences in the number of comorbid conditions in LTS when compared to older adults diagnosed with HIV after 1996. The CD4 nadir (a person's lowest CD4 count ever), aging and other non-HIV risk factors appear to also have an impact on health outcomes, independent of HIV infection and duration. LTS, as well as other older adults with HIV, share a number of risk factors not specific to HIV.

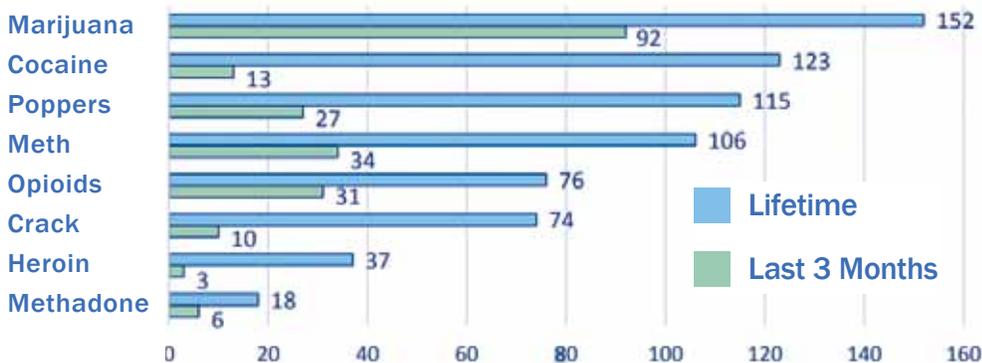
In recent years, HIV physicians and researchers began to note that more deaths of people with HIV were occurring from non-AIDS-related illnesses than from AIDS-defining ones. In one study of 9,858 people with HIV, 56% died from non-AIDS-defining illnesses like heart disease, end-stage liver disease, and non-AIDS cancers. So, the challenge for LTS is not only HIV inflammation, but other issues common to all people as they age.

AIDS Survivor Syndrome

“AIDS Survivor Syndrome” is a term proposed by activist Tez Anderson to describe the poorly managed overall health of LTS. Their mental health treatment has been, at best, dismal. High rates of depression were observed in the first decade of the epidemic, when there was no effective treatment. Many referred to that as reactive depression – something to be expected. But these high rates of depression remain today, and the mental health of LTS has been given low priority. That includes substance use that is too often seen in people with HIV.

AIDS Survivor Syndrome recognizes that many LTS are struggling to give meaning to their lives. They experienced the days when they planned to die while burying loved ones. The trauma of that first decade of the epidemic is accompanied by a strong sense of loss and grief. For many, this trauma has never been addressed. High rates of PTSD reflect this, as well as high rates of depression

Substance Use in ROAH 2.0 San Francisco Participants



“There are things that are *worse* than AIDS, like loneliness.”

ROAH 2.0 Focus Group Participant

and anxiety. The guilt of surviving when so many did not is another challenge. If not addressed, this trauma is likely the primary reason for the high rates of depression that persist.

Many LTS have a resiliency that has allowed them to move beyond the trauma of the early epidemic, yet many of the challenges that LTS confront can be traced to the persistent AIDS stigma, and now ageism, that pervades their lives. LTS continue to face challenges such as:

- Depression / Sadness / Anxiety
- Lack of Life Goals
- Suicidal Thoughts
- Sexual Risk-Taking
- Substance Use
- Social Isolation
- Survivor's Guilt
- Loss of Ability to Enjoy Life
- Emotional Numbness
- Sleep Difficulties
- Low Self-Esteem

Addressing these challenges requires empowering LTS so they can make better life choices and develop resilient behaviors. We must strengthen positive behaviors and create a sense of hope.

We need person-centered health-care, in which survivors are partners in their care. Trauma-informed care is also vital. Online social networks are helping

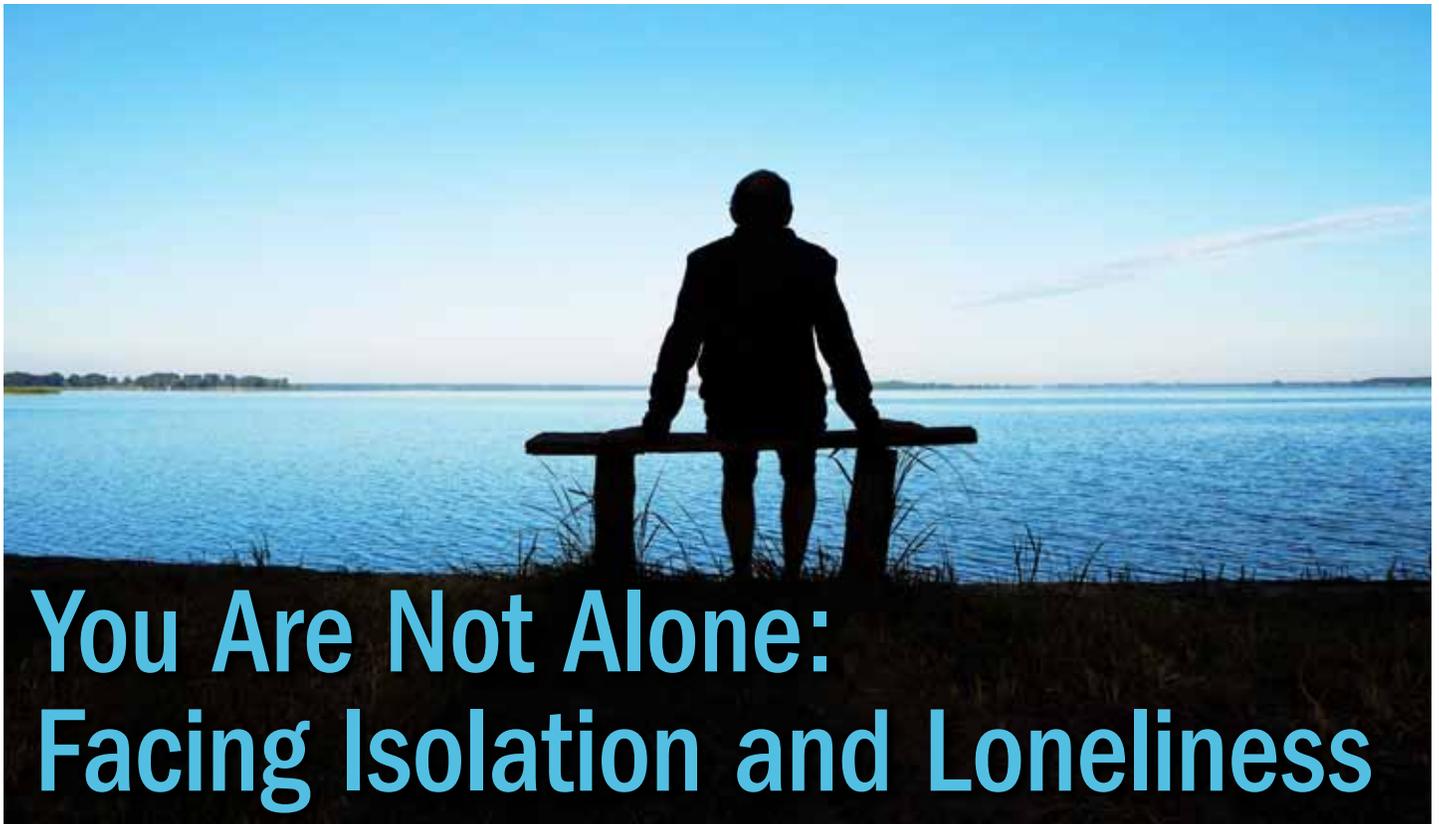
survivors create communities that meet in-person, but more needs to be done to reach those who are isolated. Finally, we must find ways to overcome the financial difficulties that exclude survivors from participating in the community.

Conclusion

The challenges are considerable for older adults with HIV, including LTS. But this group remains “young” on average, with most not having reached the age where they are classified as “seniors”. In 2017, 9% of people with HIV in the U.S. were over 65. They still have time to change their risk levels, which can improve their health outcomes. The steps they can take include early detection and treatment of illnesses, stopping smoking, minimizing weight gain, engaging in exercise, and making concerted efforts to break the bonds of social isolation.

They need to advocate for better mental health care and increases in ASO and CBO supportive services. By becoming advocates for their own health, they can break their social isolation and loneliness, and reap the rewards of having a purpose in life. ■

Stephen Karpiak is Senior Director for Research at GMHC.



You Are Not Alone: Facing Isolation and Loneliness

by Tez Anderson

When I was asked to write about isolation and HIV long-term survivors, I began by researching the topic online. I found that Googling “isolation” brought up many articles about both isolation and loneliness. It seems they are kissing cousins – they travel in pairs and interact with each other. But while they are interlinked, they are not the same. Isolation can sometimes have benefits, but loneliness serves no useful purpose. Living a full life means confronting both isolation and loneliness.

Isolation is an objective measure of the number of regular contacts people have. It is about the quantity of relationships, not their quality. Loneliness is subjective; it is the feeling of being alienated, excluded, and without quality connections. Some people experience loneliness even though they have frequent contact with friends and community. We all know the feeling of being utterly alone in a crowd. This is

likely because existing relationships are not providing the emotional support needed. Other people have few contacts but are not lonely – it’s all about how you perceive yourself in relation to others.

But when you are struggling, it can be hard to see the daylight between isolation and loneliness.

so we listened. Again and again, we heard survivors say they felt invisible, isolated, and forgotten by their community – and by AIDS service providers. Each survivor thought they were the only one who felt that way. The power of the numbers was a revelation – this was a shared experience.

As we approach the fourth decade of the AIDS pandemic, long-term survivors are facing another epidemic: one of isolation. Too many survivors feel forgotten and abandoned. It’s time to treat isolation like the epidemic it is.

A Widespread Problem

I first learned how common isolation is when “Let’s Kick ASS” (AIDS Survivor Syndrome) held our first town hall in 2013. We wanted to know what was on people’s minds and what challenges long-term survivors (LTS) were facing,

It became clear that as we approach the fourth decade of the AIDS pandemic, long-term survivors are facing another epidemic: one of isolation. This second epidemic poses a significant danger to our well-being and physical health. At a time when we have HIV medications that prolong

life, too many survivors feel forgotten and abandoned. It's time to treat isolation like the epidemic it is.

Ending isolation became part of the mission statement of "Let's Kick ASS". When I traveled across the U.S., I heard the same refrain from survivors who felt they were out of sync in a world focused on "Ending the Epidemic" and creating an "AIDS-Free Generation." In other words, saving the next generation – not the aging survivors of this plague. While no LTS would wish the horrors of the early AIDS epidemic on anyone, it is tough to feel sidelined.

In the 2015 HIV Long-Term Survivors Declaration, the first document to lay out the challenges facing LTS, I wrote: "As survivors age, we tend to isolate. Those living longest with HIV pull away just when we need to lean in and lean on our community. Living in isolation makes finding a sense of meaning and purpose difficult. It contributes to our feelings of invisibility and alienation. Isolation accelerates depression to despair that sometimes leads to suicide."

We Met the Challenge

Contributing to our isolation is the fact that we lived through a time when our community was dying horrible deaths – very young and very quickly. We were ostracized, stigmatized, and blamed for a pandemic. Many of us internalized that stigma. We lost entire social circles, as concepts like "midlife" and "old age" were scrambled and made no sense. We did all this while facing indifference, stigma, and rejection by families and society, as well as the stark reality of our own impending deaths.

What we did then was nothing short of epic. It was also traumatic. In his book *Out of the Shadows*, psychologist Walt Odets puts it perfectly: "Trauma typically leaves survivors isolated, and this has clearly been true in the aftermath of the early epidemic."

As we were preparing to die young, a funny thing happened: we didn't. And we didn't plan for our old age. Retirement plans were for the living, not for us. As a result, many of us live in poverty. Poverty limits survivors' participation in society, and ageism makes

them feel useless and invisible. Mental health providers are ill-equipped to treat a generation with a history of enormous loss, grief, guilt, and anxiety. There is often little knowledge of the early epidemic among service providers who are too young to understand what we went through and how complicated survival can be.



HIV survivors have good reasons for isolating. It is often hard to make new connections, given our history of mass casualties, multiple losses, and unprocessed grief. Many of us lost an entire circle of friends to AIDS early in the epidemic. Those losses make it tougher for us to make meaningful connections. Finding true friends is a little like finding a boyfriend: it takes a little luck and a lot of work. But making those connections is vital – it must be a priority.

We Are More Than Our Viral Load

ACRIA's groundbreaking 2005 Research on Older Adults with HIV (ROAH) study found high levels of isolation and loneliness. When ROAH 2.0 was done in 2018, 43% reported feeling "lonely" or "very lonely". Loneliness and isolation were the chief complaints among focus group participants, sometimes traced to a lack of family support.

Strikingly, one focus group participant said, "There are things that are worse than AIDS, like loneliness."

ROAH found that 70% of survivors live alone, compared with only 30% of the general population. In addition, there is a real difference between urban dwellers and people in rural areas, where survivors often know no one else

with HIV, much less anyone who has lived with it for over 20 years.

Many studies link isolation and loneliness to an increased risk of stroke, heart disease, high blood pressure, and earlier onset of dementia. Isolation increases stress hormones and inflammation. In people with HIV (who already have high levels of inflammation), the risks from these are much greater. One study stated, "Feeling isolated may be as bad for a person's health as smoking 15 cigarettes a day."

But as the focus on PrEP and prevention took center stage, invisibility became even greater for many survivors. We embraced the mantra of "Undetectable = Untransmittable" when studies showed that people with an undetectable viral load could not pass on HIV. We are finally in a time where HIV is seen as "no big deal" and "just one-pill-a-day."

With HIV now seen as a chronic manageable illness, the urgency and

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attention shifted. Some in the community began to say “You’ve got good medications. What do you have to complain about?” Medical providers use our viral loads as the be-all and end-all. If we’re undetectable, we’re doing well. They don’t have the time, or often the expertise, to dig deeper and ask about social connections, loneliness, or isolation.

On the other hand, solitude is the foundation of many spiritual practices, so it can’t be all bad. We need occasional solitude to reflect, regroup, and recharge. I need to isolate from time to time just to stay grounded and sane. I think we all need solitude as much as we need

“Let’s Kick ASS” has reached many LTS – it may be into the tens of thousands now. But I know there are still too many who have few or no social interactions. David Fawcett wrote: “I think a lot of older people living with HIV, especially in the gay community, may feel less energetic, less attractive, and invisible in the community. That can result in isolation.”

The ultimate tragedy is that when isolation goes too far into the danger zone, it leads to hopelessness, despair, and even suicide. Severe isolation usually happens slowly and can be hard to notice. Your brain tricks you into thinking you’re fine, but nothing could be further from the truth. People are social animals. We need human interaction – people to interact with, to listen to, to talk with.

Many studies link isolation and loneliness to an increased risk of stroke, heart disease, high blood pressure, and earlier onset of dementia. One study stated, “Feeling isolated may be as bad for a person’s health as smoking 15 cigarettes a day.”

human connection. But reaching out and finding connections is vital to our well-being. Even introverts need people, just as we need time alone to recharge.

Addressing the Problem

After living with HIV for 26 years, approaching my 50th birthday, I became overwhelmed by the challenges of surviving. It was a bad time. I was unable to communicate this to other people. I became nearly agoraphobic. I forgot how to have a conversation and pushed everyone away. I was physically isolated.

I lived for four years isolated and so alienated that I was nearly a recluse. I knew I had to do something to change that, so I found a new life purpose: to improve the lives of survivors. In the seven years since then,

Empathy

Empathy can be an important tool for breaking free of isolation. It is the ability to understand the world through others’ eyes and cut to the heart of what they are feeling. Empathy breeds compassion, connection, and love. It is the miracle drug of humans (and elephants, dolphins, etc.). It is the simplest, sweetest attribute one can possess, and the one most worth cultivating for social success. Empathy brings people closer, and makes others feel understood and less alone. And if there’s one thing we’re all looking for, it’s to be a little less alone.

When I see truly empathetic people, I see people who genuinely care. People who remind us that it’s okay to be still with someone and not invade their space. But as we age,

cultivating this quality can become harder. There’s no community service requirement in the real world – no one forces you to care. You’re free to live in neighborhoods with people who are exactly like you, and send your kids to the same schools, and narrow your concerns to what’s going in your own little circle.

As then-Senator Barack Obama said in 2006, “I think we should talk about our empathy deficit – the ability to put ourselves in someone else’s shoes; to see the world through those who are different from us. Cultivating empathy, challenging yourself, persevering in the face of adversity – these are the qualities that I’ve found to be important in my own life.”

To make matters worse, we live in a divided world where it can seem like everyone is hostile. An environment like that makes being vulnerable tricky. But vulnerability is the key to meaningful connections, and too often people are silenced by the fear of saying the wrong thing and being attacked. We need a movement devoted to empathy.

Addressing Isolation

It would seem that isolation could be overcome relatively easily: by simply contacting someone. It can start with something as simple as going to the grocery store and interacting with others. But people often don’t know where to start. One solution is attending the growing number of events for HIV survivors. These can be as simple as weekly coffees. Julie A. Fast, author of *Get it Done When You’re Depressed*, writes:

I force myself to plan events with other people, no matter how I feel. My brain will come up with so many excuses: I need to work. I’m tired. There’s a show I want to watch—but NO! I say to myself, “I am going out!” We often have to fight our own brains to get what we want in life. Planning outings when I’m depressed is never fun. But once I’m out, I almost always feel better!

If you’re reading this and you think, “I can’t do that, I’m not like

Julie, I'm an introvert and being social is hard for me", then I have a suggestion for you: Put aside what you think and feel now, and make yourself do something social anyway.

Focus on how you feel after the event – that is your measuring stick, not how you feel before you do it. Remember, depression will tell you that what you're doing is pointless. It will heighten your loneliness and lead to more isolating behavior. Do what you need to do anyway and focus on the outcome instead of on your feelings in the moment.

Unfortunately, some never leave the house or are isolated because of geography. Older people experiencing isolation need practical help and resources, like transportation. They need social support and extended social networks that can offer rides, which might be provided through group activities.

Experts on aging say it is important to spot signs of social isolation in ourselves and in others and to take steps to combat it early, because it can become a serious hazard to not only mental health but physical health, too.

E.A. Casey, an AARP Foundation expert, points out that one factor driving isolation is that many people who lack social connections are reluctant to ask for help. In such cases, friends and loved ones can reassure the person that they want to help and don't see it as a burden. It's also important to not push a particular solution but to ask questions to determine what interests the person who is isolated.

AARP sees isolation as so important that they created a website, connect2affect.org, to help older adults combat it. Its goal is to create a network of resources that meets the needs of anyone who is isolated or lonely, and that helps build the social connections older adults need to thrive. The site has a number of resources available.

Another factor in overcoming isolation is meaningful involvement. To



go deeper to find people with whom you connect takes work. But when it happens it is a game changer. Perhaps our post-ACT UP motto should now be: "Connection = Life". My fellow LTS Mark Milano faced a year-long period of depression and isolation when he first moved to New York City. He writes:

I was all alone in the city, so I quickly found a boyfriend. When he broke it off, I went into a deep depression, but had no one to turn to. Since I had no job yet, I was spending most days and nights alone at home. I could feel myself spiraling down, so I made a plan.

First, I forced myself out of the house. I went to the park, I went to museums, I went to the gym, or to a show. I did anything to make sure I wasn't at home watching TV. Then I came across this quote from playwright George Bernard Shaw:

"This is the true joy in life, being used for a purpose recognized by yourself as a mighty one. Being a force of nature instead of a feverish, selfish little clod of ailments and grievances, complaining that the world will not devote itself to making you happy.

I want to be thoroughly used up when I die, for the harder I work, the more I live. Life is no brief candle to me. It is a sort of splendid torch which I have got hold of for the moment and I want to make it burn as brightly as possible before handing it on to future generations."

Those were tough words, but they woke me up. I joined ACT UP, Body Positive, The Healing Circle, and a choir. I made sure that I had something to do every evening, so I wouldn't have to face that awful loneliness at night.

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Finally, I realized that I would never get past this if I kept focusing only on myself. I signed up for the East Harlem Tutorial Program and tutored a high school student for four years. Not only did I have a major impact on his life (he told me this recently), but I felt stronger. I felt that I did have power: the power to help others and to help myself. That got me out of my own head and back into the rest of the world. It saved my life.

Addressing Loneliness

Loneliness is a tougher nut to crack. What is needed are quality relationships. One or two people who get you, who see you for who you are and are there to lift you up. There are also different types of loneliness, which may

or close friend). Social loneliness is the lack of a wider social network of friends, neighbors or colleagues.

In his book *Lost Connections*, Johann Hari says, “Protracted loneliness causes you to shut down socially, and to be more suspicious of

tions, don’t write off people who are younger. One of the ways we might tackle this problem is through cross-generational interaction – two or more people who have a lot to learn from each other. We tend to pair peers of the same age and gender.



If we silo ourselves with older people like ourselves, we are limiting our pool of potential support and love. We also may need someone more agile to help us get by as we age. Most of all we need to step into our status as survivors of the worst epidemic of the modern age and own our strength.

require different interventions: emotional loneliness and social loneliness. Emotional loneliness is the absence of a significant other with whom a close attachment is formed (a partner

any social contract. You eventually become afraid of the very thing you need most and eventually develop a warped view of communal ties.”

In your search for connec-

Then we complain that the younger generation “doesn’t understand what the early decades of AIDS were like.”

My best friend is the same age as my virus. They were both born in 1983. If we silo ourselves with older people like ourselves, we are limiting our pool of potential support and love. We also may need someone more agile to help us get by as we age. Most of all we need to step into our status as survivors of the worst epidemic of the modern age and own our strength.

Mentoring need not be a student-teacher relationship but rather an equal relationship where exchanging ideas and experiences is mutually beneficial. We can tell them about our lives and they can share theirs. We knew a world before AIDS – they



don't. It's about excitement – what we can learn from another person instead of focusing only on ourselves. How does a person of another generation see the world? What are things of interest to them? What can you learn from their experiences?

The act of nurturing can also help. In her paper “Emotional Benefits of Dog Ownership”, Eve Beals writes: “Pet owners remain engaged socially, have less depression, suffer less loneliness, feel more secure, have more motivation for the constructive use of time and require less medication than non-pet owners. Animal companionship facilitates establishing friends, is a social lubricant, gives a reason to get up in the morning, and is an icebreaker.”

Conclusion

Of the 1.2 million people living with HIV in the U.S., over 300,000 have been living with the virus for 25 years or more. It's time to lean in and on our community and reach out to folks isolated by space: people in rural areas and people in urban

areas who have withdrawn. Let's end the isolation together.

If you are of a certain age, you know the power of the goddess Bette Midler. I've had the pleasure of spending time with Bette, who is also a long-term survivor of the plague. She played the New York City bathhouses in the '70s and experienced the deaths of the '80s and '90s. She sang the words of John Prine:

You know that old trees just grow stronger, and old rivers grow wilder every day, but old people, they just grow lonesome waiting for someone to say, “Hello in there, hello.”

So if you're walking down the street sometime and spot some hollow ancient eyes,

Please don't just pass 'em by and stare as if you didn't care, say, “Hello in there, hello.”

Bette also reminded us that “You got to have friends.” She is speaking to isolation in the first case and connection in the other. It's important to remember that, while it may be dif-

icult to find people who “get it”, it is worth the effort. My experience is that it's up to me to set the tone.

We must work to improve the quality of life of older adults with HIV. The goals established by the CDC, NIH, UNAIDS, etc., focus on viral suppression. But we also need to ensure access to mental health services that are designed to address issues such as trauma, PTSD, isolation, and depression. We need to make sure that all providers are sensitive to the unique issues affecting older adults with HIV.

I challenge you to say “Hello, in there” to long-term survivors, acknowledge that their story of survival is epic – Shakespearean – and is still playing out. They – we – need all the support and love we can muster. Otherwise, ending the epidemic will be hollow rhetoric for the next generation. ■

Tez Anderson is the founder of Let's Kick Ass – AIDS Survivor Syndrome and HIV Long-Term Survivors Awareness Day (HLTSAD.org) on June 5.

Choosing Life

by *Graham Harriman*

I started on an antidepressant this week. It took me over a year to realize that I needed this help: I've lost a lot of the energy I once had, and I'm often stuck in negative thinking patterns about the state of the world (though I'm not alone in that these days). I can tell I need to get some perspective on my life and to open myself up to new possibilities. I've now lived with HIV for three decades – more years with HIV than without it – and it's time to reflect on my experience and how it has led me to where I am today.

I tested positive on February 2nd, 1990, in Portland, Oregon – the day after I first got health insurance. I was 23 years old. It was a turning point in my life, in regard to my health, my relationships, my profession, and my commitment to create a life, regardless of what I was told about my lifespan.

At the time, I was working the graveyard shift at a supportive housing program for people with serious mental illness. I immediately reached out to my boss, Mica Smith, who at the time was already a long-term survivor. He gave me the best advice I've ever received: "Think positively." Mica had seen how a person's outlook affects their approach to living with AIDS, especially during that era when the disease was seen as a death sentence and carried tremendous stigma. Keeping his advice front and center was key to my spiritual life and my ability to have hope – to try anything that crossed my path to seek health.

So, I chose not to live as though my life was over. I applied to a Master's degree program in counseling psychology. And while in school, I worked on an HIV study at the Cascade AIDS Project. Nothing was going to slow me down!

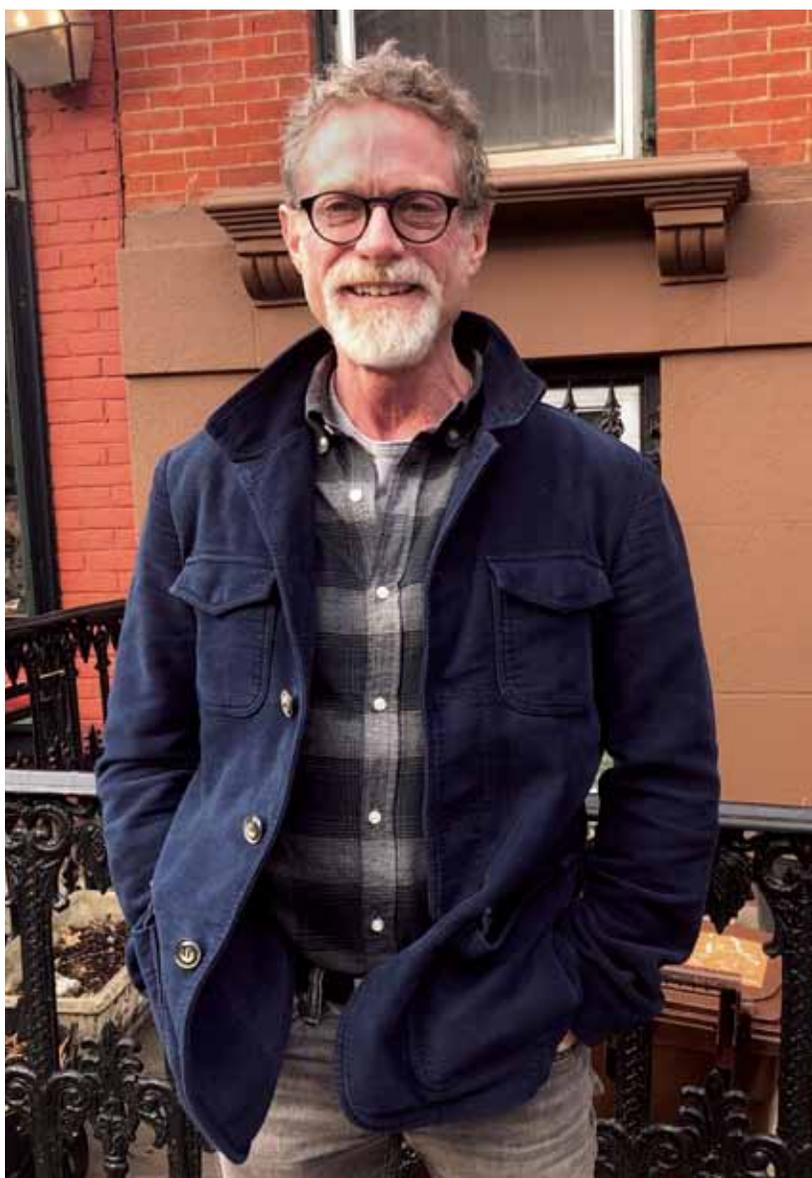
Mica had seen how a person's outlook affects their approach to living with AIDS. Keeping his advice front and center was key to my spiritual life and my ability to have hope – to try anything that crossed my path to seek health.

Unfortunately, in 1992, I was diagnosed with AIDS, which began a decade of health challenges. I started treatment with AZT, became resistant to it, and then did the same with each new drug as it appeared: d4T, ddI, ddC, and 3TC.

But I kept going. I began working as an openly gay, HIV-positive therapist, creating programs that addressed community needs like sexual health, self-management and wellness, smoking cessation, etc. and I was inspired by my HIV-positive brothers and sisters to lift my body and spirit by mountain climbing in the Cascades..

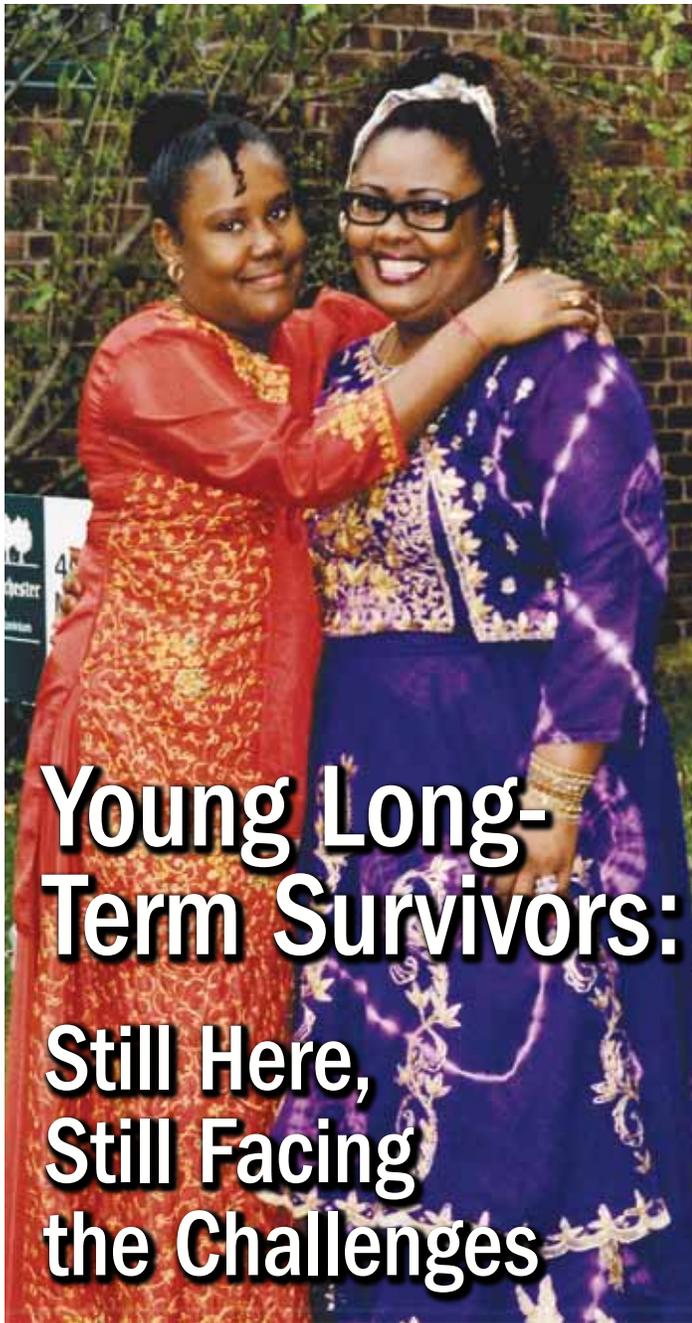
My CD4 reached an all-time low of nine in 1998. I had to start “salvage therapy,” which meant taking seven HIV meds at the same time! This was so toxic it led to serious kidney and liver problems, and then to wasting. When even this regimen failed, I developed CMV retinitis, which required IV infusions twice a day for two years to prevent me from losing my sight.

But I was able to face each challenge and even continue working (with limited hours and long stretches of time off). There were times when I didn’t think I’d make it, but I had a core support group: my family (who grew with me as I faced challenges), friends by my side at every turn, and my doctor, Diana Antoniskis, who stood by me no matter what decisions I made. She arranged access to experimental drugs before they were FDA-approved. That was lifesaving, since I didn’t find a regimen that suppressed my viral load until 2001.



When I reflect on everything I’ve experienced, I feel I’ve been given a gift: a perspective on life that allows me to value my time on earth and to spend it doing work that is valuable, while also enjoying life and the company of others. My experience from that earlier era of HIV led me to my work today as the Director of Care and Treatment at the New York City Health Department’s Bureau of HIV. I always strive to support the next generation in building programs that meet the needs of the many different communities affected by HIV today.

Rather than give in to depression or despair, I will continue to seek a life powered by love, supported by community, and filled with meaning. As we are challenged by the current leadership of our nation, I believe understanding each other’s challenges will make us stronger and lead new generations to see outside of themselves. I work in this field because I’m grateful to have the ability to address health, community, empowerment, and social justice, and to create a better, more inclusive, and supportive world. ■



Young Long-Term Survivors: Still Here, Still Facing the Challenges

LTS Michelle Lopez with her YLTS daughter, Raven

by Reed Vreeland

In the 1980s and '90s, hundreds of U.S. infants and children with HIV died of AIDS. When effective HIV medications became available, thousands survived, thanks to a heroic national effort to create pediatric HIV regimens and to provide health and mental health services. But that's not the full story. Today, these long-term survivors (now in their 20s and 30s) are facing the effects of decades of living with HIV and of being on different HIV regimens. With higher than normal mortality rates and a higher risk of certain health and mental health conditions, what does the future look like for long-term survivors who have been living with HIV since childhood?

The Kids Are Not Alright

In April 2017, POZ magazine published an article titled “The Kids Are Alright”, with interviews of five young people born with HIV. Most of the article focused on the praiseworthy HIV education efforts of interviewees Jake Glaser and Hydeia Broadbent, but buried halfway through the article was a quote from Marc D. Foca, MD, a specialist in pediatric infectious diseases at Columbia University Medical Center. He said that in his practice he has found that people with HIV who have taken HIV meds since childhood have a higher rate of heart disease and diabetes, and at younger ages. Hydeia Broadbent shared her own experience with depression, her virus's resistance to certain medications, and difficulties over the years adhering to HIV regimens.

The POZ article focused mainly on positive stories that matched the cover's title, “Forever Young”, instead of folding the concerns of Dr. Foca and Broadbent into a look at the research on people who have lived with HIV since birth. What that research has found is that, far from being “forever young,” these long-term survivors are “prematurely old” in many ways. Some face serious physical and mental health conditions decades before the usual onset of these conditions. And the surge of resources that was there for them when they were children is now nowhere to be found.

Aging Out of Pediatric Care

“The transition from pediatric to adult care for a person who has been living with HIV since childhood can be an extremely challenging process,” explained Lori Wiener, PhD, who spent many years at the NIH working with children and young people in the pediatric AIDS unit. She is now co-director of Behavioral Health Core at the National Cancer Institute.

“In most cases the transition to adult care is dependent on age limits rather than developmental milestones, so young people might be required to transition when not being necessarily ready to do so,” she explained. When NIH's Pediatric AIDS Unit was phased out in 2005 and closed in 2006, Wiener helped develop a transition scale to determine the needs of young people with HIV who were being moved to adult care. The measure surveyed how ready a teen was to handle a higher level of autonomy in adult care. For example, it asked if the teen knew their HIV diagnosis, medications, dosages, CD4 count, viral load and comorbidities. Some young people had not been told they had HIV until their teens, and so had relied on their parents and providers to manage their treatment, without understanding the basics of HIV. The measure also looked at whether the young person was able to schedule doctors' appointments on their own, had a basic understanding of insurance, had an adult health care provider, and had access to transportation.

Unfortunately, despite pediatric health providers who were well intentioned, many young long-term survivors (YLTS) were pushed out of pediatric care because of their age, not because they were ready to switch to adult care.

Creating a Smoother Transition

“The transition to adult care hasn't gone well when a person doesn't have a provider they can really talk to and work with,

and this can lead to poor HIV medication adherence and poor health outcomes,” Dr. Wiener explained. The National Alliance to Advance Adolescent Health and the Maternal and Child Health Bureau have partnered to create GotTransition.org, an online resource dedicated to improving the transition to adult care for many health conditions. This resource center can be used by YLTS who have not yet made the transition to adult care.

YLTS who have already transitioned to adult care but are unsatisfied with it can also use GotTransition to evaluate their own needs and get information about how to move to a new provider. Doctors providing care to YLTS should be aware of the research on liver, kidney, and bone health in this group and their elevated risks for certain comorbidities, and they should take extra time to ensure that mental health and substance use services are in place and meet their needs.

Doctors of YLTS can also look to NIH’s COPE study (Clinical Outcomes for Persons with HIV Acquired Early in Life) for recent findings relating to them. Colleen Hadigan,

For some YLTS, HIV is an all-consuming part of their lives, while others have not come to terms with it or even deny it. This creates a barrier to forming relationships and getting close to people. YLTS who do best accept HIV as part of their life, but don’t let it define them.

MD, the principal investigator, discussed a recent article that investigated coronary blood vessel wall thickness in this group. “Using MRIs, we could see that the coronary walls were thicker in YLTS [compared to young people without HIV],” which could predispose them to developing plaque. This is an area that the study will continue to monitor as they age.

The good news is that, despite the difference in coronary wall thickness, no one with HIV had coronary artery narrowing or cardiovascular disease. “Even in adults with HIV, careful screening following standard cardiovascular guidelines for the general public should be adequate,” Hadigan said. “The low-hanging fruit that we can do something about includes identifying people who are smoking, counseling them, and monitoring weight gain – as well as identifying and addressing obesity and high blood pressure.”

The relatively small COPE study of approximately 65 individuals with HIV since early in life will continue to track a number of health issues in this group. “What our thinking is on cancer and other less common health concerns is that if we suddenly see several cases of a relatively rare illness, we would ring the bell and mobilize other networks to start looking for this in similar but larger HIV cohorts. Thus far, we have not

seen conditions such as cancer that are alarming or out of the ordinary of what we would have expected,” Hadigan explained.

Mental Health and Social Support

Mental health and social well-being must also be considered when looking at the transition to adult care. Dr. Wiener explained that many of the YLTS she worked with had lost family members to AIDS, and their primary support had come from their pediatric HIV team. “The new adult care team might not know the family member they lost – leaving the pediatric program might be experienced as another loss,” she added. A young person may not have had the opportunity to grieve for parents who died, and their new adult care provider might not understand this bottled-up grief. Dr. Wiener explained that it’s also important for providers to screen for cognitive impairment that might feel or look like depression.

Sadness, anger, depression, anxiety, PTSD, social isolation, cognitive challenges, worry about the future – these are all common among YLTS. “Being able to have individual psychotherapy is important, as is meeting other people who are also living with HIV and doing well,” Dr. Wiener said. It’s important for YLTS to have people in their lives who are aware of their diagnosis and whom they can talk to about their health, mental health, sexuality, and emotional well-being.

Dr. Wiener has found that for some YLTS, HIV is an all-consuming part of their lives, while others have not come to terms with it or even deny it. This creates a barrier to forming relationships and getting close to people. She has seen that YLTS who do best accept HIV as part of their life, but don’t let it define them. “Bottom line, the most important thing is human attachment and how we make meaning in our life. We need to balance connection to others while understanding what the future may bring. I’m very much alive today and I can make the most out of today. None of us know what tomorrow is going to bring,” she said.

Adherence and Viral Load

In 2017, JAMA Pediatrics published an analysis of the health data of 1,446 people who had been born with HIV and found that those between the ages of 13 and 30 had higher viral loads and lower CD4 counts compared with adults with HIV who had not had it since childhood. They were also more likely to have AIDS-related illnesses and were more likely to die.

According to Dr. Wiener, “Adherence is a huge issue for any teenager who feels invincible. It’s hard for people who are healthy to complete even a two-week course of antibiotics.” This is further complicated when HIV regimens need to be followed during adolescence – the time of life when obeying rules is often challenged.

The good news from the study is that serious health problems were rare among people who had sustained viral load suppression, according to study leader Anne Neilan at Massachusetts General Hospital in Boston. This means that when an undetectable viral load is maintained, it more or less eliminates the heightened incidence of opportunistic infections and mortality.

continued on next page

But adherence and viral load suppression seem to be especially difficult for YLTS. A 2019 study in the *American Journal of Managed Care* followed 381 young people who were born with HIV and found that the likelihood of adherence goes down with age. When children born with HIV aged from pre-adolescence (age 8-11) to young adulthood (18-22), their rate of nonadherence increased from 31% to 50%, and the prevalence of a detectable viral load increased from 16% to 40%. This should be an alarm bell, and it requires attention and resources that follow the principles of meaningful involvement and leadership for YLTS.

Plan for the Future. Demand Attention. Learn from Each Other.

As YLTS age out of pediatric care and are isolated from others like them, how can they get the help they need? Demand to be acknowledged and learn from others with shared experiences, is the answer of Grissel Grandos, who directed a 2015 documentary called *We're Still Here*. It focused on the lives of YLTS. After holding screenings when it was first released, she made the full documentary free to view on YouTube; search for “We're Still Here (2015) – Official.”

As a person born with HIV, Grandos grew up in the Los Angeles area and participated in summer camps for kids with HIV. As an adult, she felt she was well adjusted, but noticed that she didn't see herself reflected in spaces discussing HIV, or in the data and research she found. “Where are all of these other people that I grew up with?” she asked. When she met people and told them about being born with HIV, they were often shocked. They hadn't heard anything about kids with HIV since the early '90s. “I guess they assumed we died,” Grandos said. “No, some of us didn't die—we're still here, lost in the adult system.”

She started the documentary project trying to find other people who were born with HIV who had experiences similar to hers. “I learned about myself and my little community: the 10,000 people born with HIV living in this country. But we're all so separated and in small numbers in any jurisdiction. We grew up very isolated,” she said. Grandos also found that parents had a big influence on whether a YLTS met or socialized with other people with HIV, how they thought about their HIV status, and who knew about it. There were significant differences in experience, but also some similarities.

Grandos was raised to be optimistic by her mother (who was also HIV positive), and she began by looking for positive stories that supported her own narrative. But when she started conducting interviews, she instead found that many people were struggling. “I don't think it's that the kids are alright, or that the kids are screwed. I thought I was going to find that the other kids are alright but I learned it's not that black and white,” she explained.

Another realization she had while making the documentary was that the optimism that had served her well as a coping mechanism while growing up was actually hurting her as an adult. “It is really hard for me to sit with sad feelings. It's hard for me to sit with people's pain. It's something as an adult I'm trying to



Reed Vreeland

unlearn, so I can sit with feelings and connect with people when they're struggling or when I'm struggling,” she shared. She discovered that what had been a successful coping mechanism at one age was now leaving her a little emotionally stunted. Creating the documentary forced her to re-evaluate the coping mechanisms she'd used and to look at them as an adult, still living with HIV but with a different set of circumstances.

Grandos pointed out that there are many similarities between older long-term survivors and YLTS, but that the main difference is age. There are many things in common, such as: dealing with sickness, side effects, medications, fear of your mortality, losing parents and friends to AIDS, the trauma of surviving. But the age at which these experiences occurred was different. “Loss in this population is pretty deep, because we experienced it as children and to this day,” Grandos explained. “In general, whenever there is someone from my small community who passes away and deteriorates, there is a head in my voice that says that could happen to me,” she added, thinking of a young HIV-positive poet who had died recently.

Many YLTS didn't expect to live to 18 or 21. "They were living their lives as though they were going to die – for some it became a crisis. Now they are adults and have not been preparing for adulthood," Grandos observed. She sees YLTS in their 20s and 30s just starting to prepare for adulthood and considering their future, exploring the question: What does my lifetime look like now?

A lot of the conversations about long-term survivors begin with the assumption that they're in their 50s or older, so Grandos had open questions about what being a long-term survivor means when you're in your 30s. "We hear that HIV ages you faster, but what does that mean for me? What about menopause? Should I be checking my bones?" These questions and many others crossed her mind as she tried to understand what the research says about her near and long-term future.

Many YLTS didn't expect to live to 18 or 21. Now they are adults and have not been preparing for adulthood. Some YLTS in their 20s and 30s are just starting to prepare for adulthood and considering their future, exploring the question: "What does my lifetime look like now?"

In many cases, people who have lived with HIV since early childhood barely know a world in which HIV and its treatment was not in their lives. "Medication fatigue is real," Grandos emphasized, "particularly when you're a young adult and want to live your best life and go on with your developmental milestones." She explained that it is important to consider and not dismiss when people are not adherent. "We should support people's bodily autonomy, while also recognizing that this can be a sign people are struggling," Grandos said. She added that it's important not to shy away from a conversation about adherence and not to impose any shame, instead come from a stance of openness and understanding.

This summer Grandos and a number of other YLTS in Los Angeles took it upon themselves to connect, and formed a support group. Another group is forming in Puerto Rico. "We've started doing grassroots little meet-ups. I'm still meeting people today who say, 'You're the first person I've met [who was born with HIV or acquired it early in life].'" Strangely, 20 people in the Los Angeles group went to the same pediatric HIV clinic growing up but never met before. "There were a lot of missed opportunities of people who were growing in isolation," she said.



Kimberly Canady

Now, as adults, they are meeting on their own time, without resources, to support these groups, and are starting to build small networks of folks. "We're taking it upon ourselves to start connecting," Grandos added.

Back to Activism School

We have much to learn from the response to the pediatric AIDS epidemic in the U.S. Now, a second wave of worldwide pediatric AIDS activism has made it possible to end all mother-to-child HIV transmission in the near future. But YLTS and current HIV-positive babies, children, and teens will still be here long after that goal has been achieved. Ending mother-to-child transmission of HIV is quite different from extending and improving the lives of YLTS, which must be pursued with equal resources and determination.

What Grissel Grandos and other YLTS have beautifully demonstrated is that the interventions most likely to save and improve the lives of YLTS will be developed by them. But that doesn't mean they can get their plans off the ground without support. There needs to be a third wave of activism that is unafraid of the things that happen when kids with HIV grow up – and that starts by bringing together people eager to have those conversations. ■

Reed Vreeland is a young long-term survivor of HIV, and is director of NYC community mobilization at Housing Works.

Aging on the Black Side of the Red Ribbon

by *Waheedah Shabazz-El*

A good place for me to start is the day AIDS became my reality – in 2003, at the age of 49. The day when my first HIV test revealed I already had AIDS. I now know that older people in the U.S. are more likely than younger people to receive an AIDS diagnosis along with their first HIV test, and that more than half of people with HIV in the U.S. are over 50.

I had converted to Islam at the tender age of 19, and I shared my HIV status with a few Muslim women. Their reaction was to presuppose I was “polluted” and question if I was clean enough to pray on the rug in the mosque with the other believers. The hurt ran deep in that moment and I feared I was no longer socially or religiously acceptable. I isolated myself from the Mosque.

But the HIV community embraced me without hesitation. Jacqui Adams, a woman of trans experience, did my intake and needs assessment at the clinic. Afterwards, she took me under her wing and embraced me as a mentee, a sister, and a friend. She believed in me and helped me believe in myself. Through her support I found my way and my voice. Rest in Power, Jacqui.

I was incarcerated for six months in 2003 as a result of my drug addiction. Luckily, John Bell, a linkage specialist, provided resources to help me remain in care after my release. He was a member of ACT UP Philly and had lived with HIV for nearly 20 years. His strength kept me buoyant, and after my release I followed him to ACT UP meetings.

I can't say enough about being an advocate. I was so busy learning how to become a part of the solution to addressing HIV, my depression literally took a back seat. I became a facilitator of support groups, not just an attendee. I went from being a ghost writer to submitting articles in my own name.

My depression became more bearable. Advocacy helped me to stop allowing my mental health to be a barrier to living well with HIV.

“You have AIDS, you need to apply for SSI” is what they told me in the support groups. Having recently been released from prison, I was barely surviving on \$102.50 from public assistance. Advocacy also proved to be the ultimate weapon against recidivism. Since I had worked in the past, I began receiving SSDI – but then my advocacy took off and I was being offered positions that would pay me “my worth”.

Their reaction was to presuppose I was “polluted” and question if I was clean enough to pray on the rug in the mosque with the other believers.

A year after accepting a full-time position I informed Social Security that I had – before I did my taxes. But they took a year before they discontinued my benefits. So I had to return that overpayment and agree to a monthly payment plan.

In order to keep my Medicare, I had to make quarterly out of pocket payments. It was a huge challenge – dishing out nearly \$500 every 90 days. But once, my Medicare was discontinued for failure to pay. I can't tell you how scary that was, since I also have other medical conditions, like high blood pressure, high cholesterol, and sleep apnea. During this Medicare lapse I had to have emergency hernia surgery. I thanked God that once my Medicare was reinstated, the hernia surgery was covered. Because of all my age-related conditions, I decided to switch to a small pharmacy that would be more careful to warn me about interactions between my medications.

When I turned 65 in August 2018, I gave my employer a year's notice that I would retire as I approached my 66th birthday. My last day as a full-time worker was July 31, 2019, and I looked forward to receiving my retirement Social Security benefits. Instead, I received a letter saying I had to pay back the overpayment from the two years I had worked while receiving SSDI, and that my new benefits would not begin until October, 2021.

Believe me when I say my future life flashed in front of my eyes. I had just left a good paying job only to be informed that Social Security would withhold my benefits for two years! Suddenly, I was facing being homeless and having no healthcare as a 66-year-old black senior citizen with HIV. I reached out to the AIDS Law Project of Pennsylvania, who supported me in filing an appeal and negotiating an affordable monthly agreement. After three months I began to receive my benefits.

Amidst all my advocacy and education, there was also time for love.

I met man I really liked at a prison advocacy meeting in 2003. It was an instant mutual attraction. We connected over our advocacy and began getting close, talking for hours each night on the phone. I was thinking he may just be the one to liberate me from a life of HIV loneliness. Then, with no notice he suddenly stopped calling and stopped attending the prison advocacy meetings. It couldn't have been because I had HIV, since he did, too. As time passed, I moved on. Then in 2004 I met a gentle kind man in my support group and we married the next year, with my trans friend Jacqui as my maid of honor. Sadly, he passed away from lung cancer in 2006.

As fate would have it, in late December 2007 – a year after the death of my husband – the man I met back in 2003 re-appeared at the prison advocacy meetings as conspicuously as he'd left. I learned that he'd spent the past four years in jail for a parole violation. We married in 2010, so this year marks our tenth anniversary. Who would have known, right?

I started attending a different mosque in 2012 and this time I decided to keep my HIV status to myself. I needed the spiritual connection to balance my life. But my husband and I were interviewed on a local TV station for World AIDS Day,



and when I next attended the mosque one of sisters approached me and said she'd seen us on television. Then, with the warmest smile I have ever seen, she said to me, "That's good work you and your husband are doing. I'm so proud of you. I knew you were special the first time I saw you." And I thought, "Wow, what a difference. I'm home."

Community is the antidote to isolation. Spirituality, advocacy, education, intimate relationships, medical coverage, and finances are equally important when it comes to aging gracefully with HIV.

These issues prompted me to shift my advocacy to the formation of The National Alliance on HIV Long-Term Survival, through The Reunion Project. Regardless of my ethnic background or gender, I exercise my right to live and to love with dignity. I exercise that right not by passive aggression (taking whatever comes), but by carefully defining my path. Leading by example, I walk a well-worn path of service that doesn't merely benefit me, but that also benefits humanity and especially those people who, like me, are living with HIV. ■



Aging and HIV: The Role of Exercise

by Margaret Danilovich PT, DPT, PhD

As people age, everyone encounters age-related issues such as hearing and vision loss, memory problems, and body changes like wrinkles and grey hair. But people aging with HIV experience these changes along with other challenges as well.

However, with physical activity, exercise, and other healthy behaviors, people with HIV can age with good health and independence. This article will explore what people can normally expect with aging with HIV and how to get or stay active to promote optimal health as you get older.

What is Normal Aging?

It's often difficult to know what is normal aging and what is abnormal aging that requires additional medical attention. While there are milestones for babies that allow doctors and parents to determine if development is occurring at the normal rate, similar tools do not exist for people getting older. This makes it much more difficult to determine if, for example, a memory slip is a normal age-related change or an early sign of dementia or Alzheimer's.

We do know that aging leads to a slowing in the amount or speed of processes in the body. But having HIV also causes changes in body systems. Some researchers hypothesize that HIV is contributing to advanced aging. We do know that even if people have an undetectable viral load, HIV inflammation can increase

the number of age-related conditions they have. Other factors – smoking, poor diet, lack of exercise, mental health, etc. – also contribute to this. So people with HIV are in double jeopardy – they face both the impact of aging and the impact of HIV.

Aging and the Body

What can we expect as normal parts of aging? In all people, sarcopenia (loss of muscle mass) affects all muscles at a rate of 1% per year after age 30, and 3% per year after 70. Everyone will have some reduction in their joints' range of motion, bone mass/density, and posture changes. We can expect to lose half an inch of height every decade after 40.

While aging can lead to declines in body systems, the good news is that exercise and physical activity can reduce these declines and improve strength, physical function, and quality of life.

Studies show that people with HIV have up to 60% less lower-body strength than their peers, due to structural and inflammatory muscle dysfunction. They can also have bone loss due to HIV itself, and to the effects of some HIV medications.

For people over the age of 65, walking speed has been proposed as the sixth vital sign since it predicts physical function, risk for falls, hospitalization, and loss of independence

(the other vital signs are heart rate, respiratory rate, blood pressure, temperature, and pain). All people should target a walking speed of at least 3.2 feet per second, as that is roughly the speed needed to walk safely in the community. Everyone’s walking speed decreases as they age, but for people with HIV it declines at a rate of one inch per second faster. These rates of decline are even more pronounced among minority populations and men.

Body composition also changes with aging. The total amount of body water decreases by 10-15%, body fat increases by up to 35%, and lean body mass decreases 10-20% due to the loss of skeletal muscle. People aging with HIV experience these changes, in addition to having increased risk for lipodystrophy (the changes in body fat due to HIV or HIV medications).

Older adults have decreased lung capacity, which contributes to earlier fatigue and less aerobic capacity. This means they have less physical endurance and tire more quickly, which can make it challenging to complete their activities of daily living.

Exercise and Physical Activity

While aging can lead to declines in body systems, the good news is that exercise and physical activity can reduce these declines and improve strength, physical function, and quality of life. Physical activity is defined as any body motion beyond sitting, while exercise is a structured and intentional form of physical activity like running, lifting weights, or taking a fitness class. The 2018 US National Physical Activity Guidelines stated that all people should:

- Avoid inactivity.
- Strive for 150 minutes of moderate-intensity activity each week or 75 minutes of vigorous intensity.
- Perform strength exercises for all major muscle groups two days a week.
- Add exercises to improve balance if at risk for falling.

There are no specific exercise guidelines for people with HIV at this time. However, research shows that aerobic and resistance exercises are beneficial for physical and mental health, and improve aerobic capacity and endurance. And the evidence shows a “dose-response” relationship with intensity, meaning that the greater the intensity of the activity, the greater the health benefits.

Measuring Intensity

A simple way to monitor the intensity of your physical activity or exercise is the Borg Rating of Perceived Exertion. As shown in the figure, the Borg RPE scale allows people to rate their feeling of how much effort they are exerting during an activity (see table above). Moderate intensity activity would be an RPE of 13-15 (somewhat hard to hard) while vigorous intensity activity would be an RPE of 15-17 (hard to very hard).

Borg's Rating of Perceived Exertion (RPE) Scale	
Perceived Exertion Rating	Description of Exertion
6	No exertion; sitting and resting
7	Extremely light
8	
9	Very light
10	
11	Light
12	
13	Somewhat hard
14	
15	Hard
16	
17	Very hard
18	
19	Extremely hard
20	Maximal exertion

Based on the US National Physical Activity Guidelines, people should get 150 minutes each week of activity that has an RPE rating of at least 13. However, for optimal health benefits, people should try to achieve activity at a level of 15 to 17.

One way of gauging your intensity is by measuring your heart rate (your pulse) during activity and comparing it to your maximum heart rate. You can measure your pulse by placing two fingers (not your thumb) on your wrist between the bone and tendon, near your thumb (see picture on next page). When you feel your heart rate (a beating sensation), count the number of beats for 30 seconds and double that number for your heart rate per minute.

People often use the formula “220 minus age” to estimate their maximum heart rate. But that formula is not accurate for older people. Instead, people over the age of 35 should use this formula: “209 minus (0.7 times age)”.

To determine your desired heart rate during activity, multiply your maximum heart rate by the intensity at which you want to exercise. Moderate intensity should be 50-70% of your maximum heart rate, while vigorous intensity activity should be 70-85% of your maximum heart rate. Here’s an example of how to do this for a 60-year-old:

First, calculate your maximum heart rate: $209 - (0.7 \times 60) = 167$. To exercise at an intensity of 70%, multiply 167 by 70% ($167 \times .70$). This gives a desired heart rate of 117.

Be aware that beta-blocker medications blunt the heart’s response to exercise, so people taking them should gauge intensity by their perceived exertion instead. For individual prescriptions, consult with a physical therapist.

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Getting Started

How should someone aging with HIV exercise? First, find activities you enjoy! If you like to do yoga – do it! If you like to dance – dance! Activities that bring enjoyment are likely to be done more regularly, so avoid inactivity by finding activities you enjoy doing.

For optimal health benefits, people should achieve at least 150 minutes of moderate intensity physical activity each week. This can be in the form of any kind of aerobic activity – walking, biking, running, dancing – activities that increase your heart rate and cause you to break a sweat. Research shows that higher intensity of exercise leads to more positive health outcomes.

In a study of treadmill exercise three times per week for men with HIV, people were randomized to moderate- or high-intensity groups. While both groups had improved endurance levels, people in the high-intensity group had improvements in their respiratory fitness levels, suggesting that higher intensity aerobic exercise is more beneficial.

Being active and exercising is not just good for the body – it also has significant impacts on one's mental and cognitive health. According to the CDC, people who regularly exercised had 43% fewer days of poor mental health, and participating in resistance exercise reduced depression symptoms. In a 2013 study of exercise for people with HIV, exercise was associated with better memory and information processing. These findings are particularly important as it is reported that 30-60% of people living with HIV have cognitive impairment.

Everyone should do resistance/strength exercise at least two days a week, working major muscle groups to build or maintain strength. According to the American College of Sports Medicine, the ideal strength training plan is to do 70-80% of the maximum weight you can lift, for two sets of 8-12 reps. While no specific guidelines exist for older adults with HIV, research shows positive benefits in improving muscle strength and muscle mass.

Where To Get Started

Becoming more active doesn't require joining a gym. Walking outdoors, in a mall, or even up and down a hallway are ways to get more aerobic activity. Riding a bike, playing sports, and even engaging in heavy housework or gardening will increase your heart rate and count toward a weekly physical activity goal.

There are also resources that may be provided through your insurance, such as the "Silver Sneakers" programs provided through Medicare Advantage plans. Area Agencies on Aging and senior centers are also great resources for low-cost fitness options. People can also do exercise in their own homes. There are a variety of on-demand fitness options on TV or online. The National Institute on Aging has a variety of free workout videos and resources on their Go4Life website: go4life.nia.nih.gov.



Given how many exercise and physical activity options are out there, the best advice is to try different classes, exercises, and activities and see what you enjoy the most – and do it consistently! Ongoing motivation for an active lifestyle can be difficult, so finding activities that you enjoy will make adherence easier.

Make an Activity Plan

Research shows that making a plan for exercise and physical activity leads to better adherence. Tips for creating an action plan include:

- Make a plan that is realistic about your current fitness level and how much time you can dedicate to physical activity each day.
- Make your plan specific: include the “who, what, where, when, why, and how” you will be active each week.
- Make physical activity a priority by scheduling time in your calendar each day.
- Include friends or family members as your activity or accountability partners to encourage and motivate you.

The online activity planner from the U.S. Department of Health and Human Services' Move Your Way (health.gov/moveyourway) provides an excellent way to track your physical activity and get ideas for other ways to be active.

Conclusion

The evidence is clear: everyone – every person and every body – needs to move. To age successfully, we need to move consistently in ways that challenge our bodies by engaging in vigorous physical activities. ■

Margaret Danilovich is a physical therapist and the Senior Director of the Leonard Schanfield Research Institute at CJE Senior Life.



Embracing Coordinated Care

by Stephen Karpiak, PhD
and Richard Havlik, MD, MPH

The health of older adults with HIV is a product of a care system that focuses mainly on suppressing HIV. There has been little thought given to preparing for the challenges of aging and multiple illnesses (multimorbidity). Care for serious mental health challenges like depression, anxiety, and substance use has not been a priority. Older adults with limited incomes who face HIV stigma can become isolated and sedentary, leading lives devoid of good nutrition and exercise.

If our health care system addressed all the components of good health, Long Term Survivors (LTS) would be ready to face the challenges of aging. They need care that goes beyond simple HIV management – care that addresses multimorbidity with a sustained focus on mental health and social networks. HIV physicians are often not trained in multimorbidity management, but geriatricians specialize in exactly that.

Geriatric Principles

The goal of geriatric medicine is to sustain function and therefore indepen-

dence. Unfortunately, there is a severe shortage of geriatricians in the U.S., even as the country ages.

In 2008, a group of experts on HIV and aging were assembled by the American Academy of HIV Medicine, ACRIA, and the American Geriatrics Society. They concluded that care for older adults with HIV needed to include geriatric care

HIV has morphed into a complex set of medical and social challenges, so the care of older adults with HIV requires the expertise of providers from multiple health care disciplines.

Geriatricians are very familiar with treating multiple health conditions that cannot be cured. Treatment must consider the fact that these conditions can

LTS need care that goes beyond HIV – care that addresses multimorbidity with a sustained focus on mental health and social networks. HIV physicians are often not trained in multimorbidity management, but geriatricians specialize in exactly that.

principles, and published guides to help clinicians better manage their health, at www.hiv-age.org.

People aging with HIV have a higher risk of a number of conditions, including liver disease, kidney impairment, heart disease, non-AIDS cancers, osteoporosis, cognitive decline, frailty, etc. Managing

build up, leading to unexpected effects on both physical and social health. In addition, many older adults take five or more medications (polypharmacy) which can reduce quality of life, increase the risk of falls and memory problems, and lead to drug interactions.

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Integrated Care

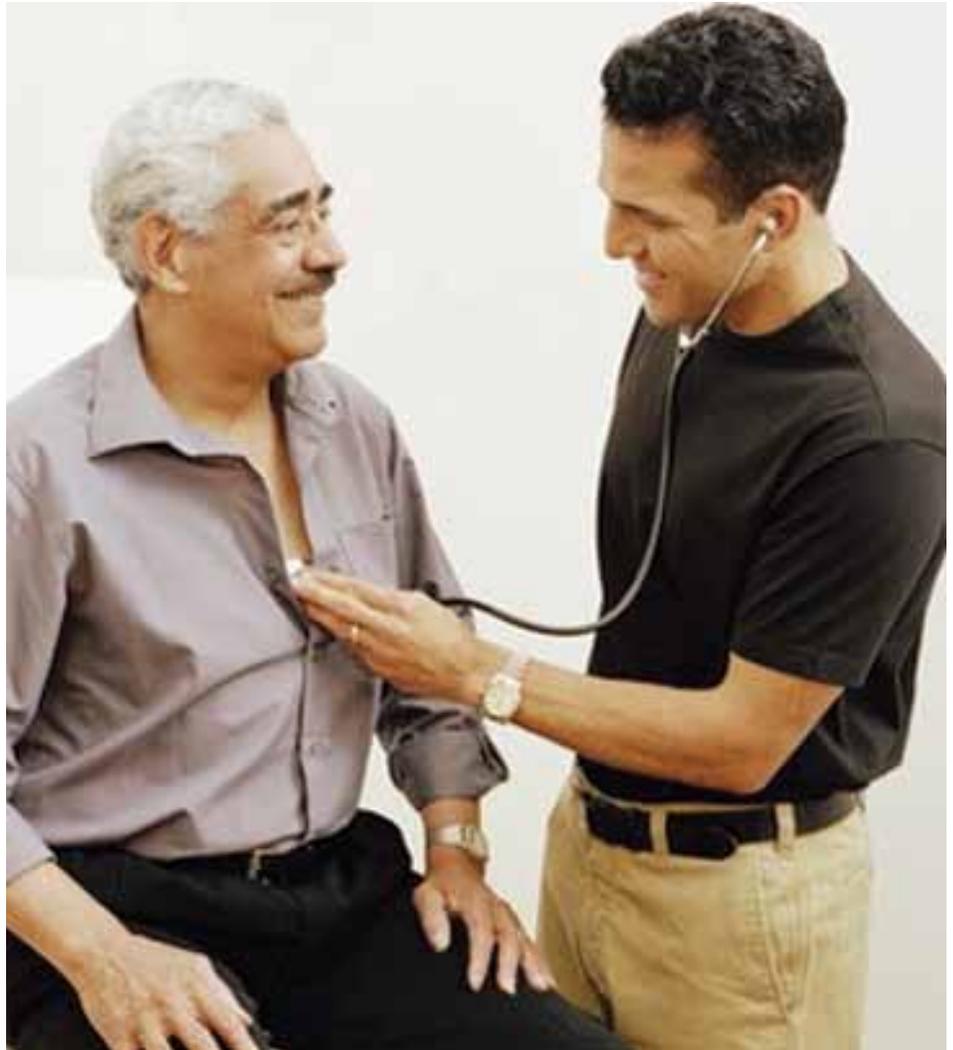
Clinicians and people aging with HIV should determine the meaning of a “healthy life expectancy” with the highest quality of life. Research concludes that LTS can benefit from the integrated care approaches developed by geriatricians. These focus on sustaining function. The complexity of aging is not best managed by treating each of the illnesses individually. Rather, the entire person must be considered. In addition, doctor and patient must be aware of geriatric conditions like frailty, dementia, lessened mobility, risk for falls, and polypharmacy. LTS are becoming aware of these changes in their health as they age, and they expect their providers to have similar awareness.

The geriatric literature provides guides for care of those aging with HIV. Geriatricians warn against the use of guidelines that were developed for people without any major comorbidity or complex chronic disease. Care should be tailored to each individual, with careful assessment of their risks for other illnesses. Once those risks are identified, everything should be done to minimize them. Geriatric care recognizes that aging problems occur as a result of multiple factors: clinical, environmental, and social. The chosen treatment, or no treatment, should match the goals the individual expresses (patient-centered care). People with HIV need to be part of health management decisions.

Stigma and Social Support

Using geriatric care principles for LTS is happening. It means giving priority to the mental health and social isolation older adults with HIV face because of the toxic impact of both HIV and aging stigma, especially ageism. Such stigma contributes to an increased risk for disability. In addition, health care is often hampered when LTS are referred to specialists who are not sensitive to their needs and the stigma they face.

Research has found that low social support leads to increased hospitalizations and overall mortality in LTS.



Data show that nearly 70% of older adults with HIV live alone, estranged from their families and friends due to HIV stigma. Consequently, they have fragile social networks that will not be able to give them the caregiving support they will eventually need. These poor social networks lead to social isolation and loneliness – predictors of poor health.

There are strategies that can prevent and even reverse losses in functioning as well as frailty. They include early HIV treatment, adherence counseling, decreasing alcohol, stopping smoking, avoiding obesity, and exercising. It's important to always check for drug interactions when adding a new med or switching to one. It's particularly essential with meds that have cognitive effects like opioids, benzodiazepines, sedatives, and sleeping pills.

Conclusion

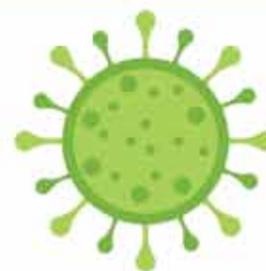
The need to expand care for LTS is clear, and their voices are needed to petition those who can change health care delivery. The National Resource Center for Aging and HIV (aginghiv.org) offers guides for older adults with HIV. For each condition, it suggests what to discuss with one's doctor and what steps to take to improve health.

Aging and the management of multimorbidity requires the participation of doctors and patients, together with community supports. This is a significant shift in care that will require the voices of every person who is committed to achieving optimal health outcomes for those aging with HIV. ■

Stephen Karpiak is Senior Director for Research at GMHC and the Director of the National Resource Center on HIV and Aging. Richard Havlik is a consultant to ACRIA.

WHAT OLDER ADULTS WITH HIV NEED TO KNOW ABOUT CORONAVIRUS

WHAT IS IT? Coronaviruses are not new. They can cause mild, severe, or no symptoms. The current pandemic of COVID-19 disease is caused by a new virus, first identified in late 2019. It can cause respiratory and other problems.



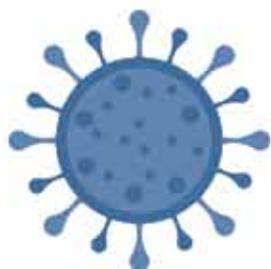
THE RISK FROM IMMUNE SUPPRESSION

is not known, but like other viral respiratory infections, the risk for people with HIV getting seriously ill is greatest in:

- People with a low CD4 cell count
- People not on HIV treatment (ART)
- People who are over 65
- People who have other medical conditions and illnesses

HOW CAN I PROTECT MYSELF?

Stay home! Wash your hands and keep them away from your face. Clean frequently touched objects like doorknobs, light switches or cabinet handles. Older adults with HIV and people with serious chronic illnesses should avoid all non-essential travel. Wear a face mask if you have to leave the house, and stay at least six feet away from other people.

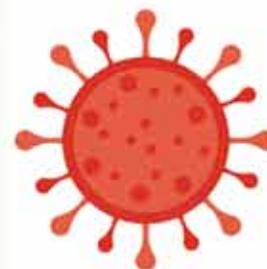


OLDER ADULTS WITH HIV & WITH CHRONIC ILLNESSES

like diabetes or heart, lung, liver, or kidney disease are at higher risk of getting seriously ill from COVID-19. They should take extra precautions. This includes having a supply of medications on hand and having a friend shop for household supplies and groceries.

PEOPLE CONSIDERED AT ELEVATED RISK are those who:

- Live in or have traveled to areas with a high number of cases
- Provide care for individuals with COVID-19
- Have had close contact with someone with confirmed COVID-19



COMMON SYMPTOMS CAN INCLUDE

Fever, cough, headaches, and loss of taste or smell. If you have symptoms, call your care provider before you visit them or before you seek care elsewhere. If your symptoms become serious (such as shortness of breath) contact your care provider immediately.

Adapted from IDSA

Infectious Disease
Society of America

achieve

GMHC
307 W. 38th Street
New York, NY 10018-9502

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The National Resource Center on HIV and Aging

The most comprehensive
patient-centered site
for older adults with HIV
and long-term survivors.

Register and become a part
of the growing community
of people aging healthy with HIV!

AgingHIV.org

The Terry Brenneis
hub for
Long-Term
Survivors

**The Terry Brenneis Hub
for Long-Term Survivors**
supports HIV long-term survivors
by connecting them to resources at
GMHC and elsewhere.

Programs and services include:

- Meals and nutritional counseling
- Workforce placement and job readiness services
- Assistance with managing healthcare benefits and Social Security-related issues
- On-site pharmacy and medication management
- Support groups and mental health counseling
- Social events and workshops
- The Buddy Program
- Wellness services: yoga, acupuncture, and massage

If you're a long-term survivor, contact Gregg Bruckno:
LTSHub@gmhc.org or 212-367-1063
GMHC hotline: 800-243-7692

GMHC
END AIDS. LIVE LIFE.