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## Long-Term Survivors of HIV

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## Who Are HIV Long-Term Survivors?

*"We were a group of people who were willing to stand up for ourselves and for others and face what the world had to offer. ... Those living with HIV today can never [imagine] the horrors many of us had to endure in the early days of this epidemic. I wish I didn't remember – I wish I could forget." Vickie Lynn, [Drawing Lines in the Sand](#), A Girl Like Me*

Powerful HIV drugs now make it possible for people living with HIV to live far longer lives than could have been imagined before effective HIV treatment became available. This is one of the greatest successes of modern medicine. Those who have lived with HIV for many years are often called long-term survivors (LTS).

There are a few definitions describing HIV LTS. One definition of LTS refers to those who have been living with HIV since before the modern era of effective HIV drugs, or "highly active antiretroviral

therapy" (**HAART**). They are sometimes known as **pre-HAART LTS** or "longest-term survivors." They acquired HIV when the condition was, in most cases, a death sentence. They often spent their early adult lives believing they would die young - and watching scores of friends die of the health condition with which they themselves were living. This kind of [traumatic experience](#) can leave a lasting mark on people's lives, and affect mental and physical health, as well as financial stability and overall quality of life.

Another definition refers to people who have been living with HIV for more than ten years, and who were diagnosed after 1996. This group is sometimes known as **post-HAART LTS**. This is considered a very different experience than being diagnosed earlier in the epidemic.

Due to longer survival with HIV, the percentage of [older adults living with HIV](#) is increasing in all regions of the world. However, not all HIV LTS are older adults. People now in their twenties, thirties, and even early forties, who acquired HIV at birth or while very young, have also lived with HIV for decades. For more information about lifetime survivors (also known as Dandelions), a unique group of long-term HIV survivors, please see our fact sheet on [lifetime survivors of HIV](#).

Another group of long-term survivors that tends to be left out of conversations about long lives with HIV are the HIV-negative partners, companions, caretakers, community members, activists, and frontline professional care providers who directly supported people living with HIV in the earliest days of the epidemic. While this fact sheet will focus on people who have lived many years with the virus in their bodies, many **HIV-negative LTS** also experienced tremendous losses and had their lives deeply affected by the epidemic.

A few people may live with HIV for a long time without taking HIV medications and still not get very sick (progress to AIDS). They are called "**long-term non-progressors**." The chances of being such a non-progressor are very slim. The vast majority of people who acquire HIV will eventually progress to AIDS, if they do not take HIV medications. That is why medical bodies across the world recommend that people start taking such medications as soon as they are diagnosed with HIV.

People who have lived with HIV for decades are known as HIV long-term survivors. Learn about the unique experiences of those who lived through the epidemic's most brutal, unjust years.

*[Click above to view or download this fact sheet as a \*\*PDF slide presentation\*\*](#)*

## **AIDS Survivor Syndrome (ASS)**

[AIDS Survivor Syndrome \(ASS\)](#) is a term describing the psychological results of living through the most brutal, unjust years of the HIV pandemic. Pre-HAART LTS are especially vulnerable to ASS. Symptoms of ASS include, but are not limited to:

- Anxiety, nervousness, or sense of feeling constantly 'on guard'
- Depression
- Irritability or flashes of anger
- Lack of future orientation
- Low self-esteem and self-worth
- Substance abuse

- Social withdrawal and isolation
- Survivor's guilt

Survivor's guilt is common among survivors of natural disasters, violent conflicts, and epidemics. It refers to the feeling that many survivors have that they have done something wrong in surviving a traumatic event when others did not survive.

ASS is sometimes compared to [post-traumatic stress disorder, or PTSD](#), which is often associated with soldiers returning from war. However, ASS may have more in common with what is called complex PTSD, which results from enduring multiple traumas over a long period of time.

*"I feel like we are soldiers coming back from a HORRIBLE WAR and we are still battling it."* Maria T. Mejia, from "[Survivor's Guilt/PTSD/Anxiety/Depression](#)," on *A Girl Like Me*

There are few published studies looking into AIDS Survivor Syndrome. However, in recent years, LTS themselves have begun to come together and share about their lives in the aftermath of the epidemic's darkest years. The evidence that a particular condition has been affecting them is too overwhelming to ignore. Unfortunately, few published studies means few healthcare providers or therapists are aware of the signs that an individual is experiencing ASS. But the body of research in this area is growing.

This video from [The Reunion Project](#) features a diverse group of LTS sharing what the legacy of these powerful experiences means to them.

## Physical Health Concerns

Some health concerns faced by LTS relate to common effects of aging, while others have to do with the unique realities of surviving with HIV. Below is a list of some of the common issues LTS may experience. Click the additional links below for more information.

### HIV treatment challenges

Our current long list of [effective, tolerable HIV treatment options](#) would not have been possible without the HIV long-term survivors whose bodies were testing grounds for numerous HIV medications over the years.

Many LTS deal with the consequences of decades of HIV treatment. The toxicity of many early HIV treatment regimens caused life-altering [side effects](#), including [lipodystrophy](#) (fat accumulation or wasting, which change a person's appearance) and [peripheral neuropathy](#) (nerve pain, often in hands and feet).

*"[A]s I move into late middle age, I have come to accept that HIV and I will be in this together for the long haul. 'The long haul' is an American idiom which describes a long-term, ongoing commitment. The term 'long haul' also refers to a long distance trip, long period of time or even a long run. Something like a marathon."* Martha Lang, from "[We Will Have You Running Marathons](#)," on *A Girl Like Me*

### Treatment fatigue and tolerability

Treatment fatigue (physical or emotional weariness with taking HIV drugs) may lead many LTS to have difficulties [adhering to their HIV treatment](#), which can eventually cause [drug resistance](#). However, multidrug-resistant HIV (MDR-HIV) is already a reality for a number of LTS, for whom effective treatment options are difficult to find.

Many long-term survivors take a dizzying array of pills each day, for HIV and for other health conditions

they're managing (comorbidities). They may also take [vitamins](#), supplements, [contraceptive pills](#), and pain relievers, all of which can increase the likelihood of [drug interactions](#).

A review of numerous studies of [people who acquired HIV at birth](#) (perinatally) found that lifetime survivors were more likely to have their HIV treatment be unsuccessful than adults, for a number of reasons:

- They may have been exposed to HIV treatment in the womb that increased their chances of HIV drug resistance
- Their treatment histories tend to be just as complex as those described above for older-adult LTS, and complicated by fewer medication options for children due to fixed doses and the need for dose adjustment for weight
- Young people may find it more challenging than adults to [take their HIV drugs consistently](#) enough for the drugs to be effective

It is very important for LTS of all ages to have trusting relationships with their healthcare providers, so that they can work together to find effective, tolerable treatment options. This is a key step not only to improve long-term health outcomes, but also to improve quality of life.

## Inflammation

Inflammation is the human body's natural response to threat or damage. Because the immune system of a person living with HIV is always struggling to get rid of the virus, it is always activated, or "turned on," over many years. This is known as chronic low-level immune activation, which is a form of inflammation. Some research suggests that the body's response to complex trauma, as with ASS, may also increase levels of inflammation.

Ongoing inflammation appears to be related to many conditions, including [heart disease](#) and [cancers](#). Scientists are still exploring whether people living with HIV experience 'accelerated aging' due in part to inflammation. Some professionals attest that what gets called 'accelerated aging' may have less to do with the virus than with the fact that people with HIV also have higher rates of traditional risk factors (risks that are seen in the general population) for these conditions, like [smoking](#) or [stress](#).

Eating well, exercising, stopping smoking, managing other health conditions like high blood pressure and [diabetes](#), and taking HIV drugs can help reduce levels of inflammation in HIV long-term survivors and other people living with HIV.

## Comorbidities

A number of health conditions that are not related to [AIDS](#) are still more common among people growing older with HIV. Long-term survivors born with HIV are also vulnerable to many of these comorbidities, such as heart disease, kidney problems, and [anemia](#). Key health concerns for HIV long-term survivors to be aware of include:

- **[Heart disease](#)**: LTS are more likely to have taken older HIV drug regimens associated with [body shape changes](#) and [increased blood fats](#), which are linked to heart disease
- **[Hepatitis C \(HCV\)](#)**: Many LTS are "baby boomers," or those born between 1945 and 1965, for whom the US Centers for Disease and Control and Prevention (CDC) recommends testing for HCV. Like HIV, HCV is transmitted by sharing needles or engaging in anal sex. It is therefore more common in people living with HIV than in the general population.
- **[Other kinds of liver disease](#)**: Long-term use of medications can overwork the liver, and certain HIV drugs have been directly linked to liver damage
- **[Brain problems](#)**: Research suggests that HIV-associated neurocognitive disorder, or HAND (a group of conditions that includes some combination of thinking, movement, mood, and/or

behavior problems) is more common among older people, as well as those who have been living with HIV for a long time.

- **Cancers:** It is vital that LTS be regularly screened for cancers - not only those known to be AIDS-related (e.g., cervical cancer), but others not associated with HIV (e.g., breast or lung cancer)
- **Bone disease:** Some older HIV drugs have been linked to bone loss (e.g., tenofovir disoproxil fumarate, or TDF; brand name Viread). Newer HIV drugs containing a different form of tenofovir (tenofovir alafenamide, or TAF) cause less bone loss.

## Menopause

Often called the "change of life," [menopause](#) is the point in time when a woman's menstrual periods stop. It is also a milestone that many women long-term survivors may have once assumed they would not live to reach. Effects of menopause can be treated with [hormone replacement](#) therapy, [complementary treatments](#), and by taking steps to stay healthy.

## Sexual health

Despite the myth that older people do not have sex, [many older women are sexually active](#). Women over 50, including long-term survivors, may be thinking about dating and becoming sexually active after the end of a long-term relationship or the death of a partner. Further, sexual risk-taking can be an [effect of past trauma](#), and can be a symptom of ASS. It is important for healthcare providers to talk about sexual health with their older clients, and for women growing older with HIV to [continue to visit](#) a gynecologist.

For lifetime survivors and other long-term survivors of childbearing age, sexual healthcare should include respectful safer conception resources, in addition to conversations that affirm women's sexual expression.

*"Doctors need to ask about young women's sexual practices without making assumptions," [writes Grissel Granados](#), a Los Angeles-based activist and service provider who has lived with HIV all her life. "I have met young women born with HIV who have grown up in such fear of themselves as sexual beings that they cannot even fathom dating, much less having healthy children someday."*

***Honoring Long-Term Survivors:*** *The Well Project's Ci Ci Covin moderates an important conversation among four long-term survivors from our community advisory board on this Long-Term Survivors' Day 2021 episode of A Girl Like Me LIVE!*

*View other episodes in the [A Girl Like Me LIVE series](#)*

## Quality of Life Concerns

Below is a list of some common issues related to quality of life that LTS may experience. Click the additional links below for more information on these experiences.

### Mental health issues

*"Why am I still here and my friends are gone!?! Not a few, THOUSANDS!!! MILLIONS!!!!"* Maria T. Mejia, from "[Survivor's Guilt/PTSD/Anxiety/Depression](#)," A Girl Like Me

- **Depression** is already a significant concern for people living with HIV, and particularly [older women](#). One study has shown that more than six in ten women living with HIV between ages 50 and 76 suffered from depression. Depression and other serious mental health issues are prevalent among HIV long-term survivors. A review of studies of [mental health in young people](#) born with HIV also found high rates of depression and other mental-health diagnoses in this group.
- **Isolation** from community and family is also a major concern for HIV long-term survivors. Multiple losses, trauma, decreased ability to leave home or get around town, [substance use](#), financial concerns, and caregiving duties (especially for women) can all contribute to isolation. This type of separation or aloneness can have negative health effects, including higher rates of death from chronic health conditions.

In addition to working with mental health providers and potentially seeking medical treatment, [social support](#) and a sense of purpose in life are key to decreasing isolation and improving mental health.

## Financial considerations and unexpected long-term planning

Many LTS, who may have once seen no point in saving money for a future they didn't believe they would see, now find themselves in difficult financial situations as they grow older.

- In the LTS community, "retirement" has been a euphemism for being on permanent disability, an unstable form of income that is also difficult to get off
- Due to eligibility requirements for various forms of public assistance, people living and growing older with HIV often have little choice but to [keep their incomes low](#), making it nearly impossible to save for the future
- Long gaps in work histories, as well as ageism, pose additional challenges for LTS returning to work
- Panic about the future, and an inability to plan for or conceive of the future, are symptoms of the compounded traumas of ASS
- Faced with much longer life expectancy, LTS now find themselves asking "What's next?"

*"I have been on Social Security Disability Income (SSDI) for the past 11 years; ever since my AIDS diagnosis. ... I have been told by many people 'Do not go back to work, it will screw everything up!' ... Why does this all have to be so complicated and stressful?"* Vickie Lynn, from "[Going back to work?!?](#)," on A Girl Like Me

Central to the movement supporting long-term survivors is helping them imagine a future – one that for years, even decades, was thought not to exist. That future includes, but is by no means limited to, planning for the end of their lives: deciding not just where their belongings will go, but how they wish to be treated, medically and otherwise, if a time comes when they are unable to make such decisions on their own.

**End-of-life planning** can be an empowering process when, earlier in the HIV epidemic, there was not much time or space to be thoughtful about such plans. Now, that end will most likely be much farther off than once expected. Recognizing this longer survival, some companies now offer life insurance to people living with HIV.

*"How will we be treated as elders in our twilight years? It's coming, for so many of us who were told we had 6 months to live. Now it's 25 years later and I am left to wonder, ponder and worry about the people who will tend to our needs as we start losing the ability to tend to them ourselves."* sologirl, from "[Surviving into an unknown age](#)," on A Girl Like Me

## Long-Term Survivors: Taking Care, Kicking Ass

In recent years, the advocacy of HIV long-term survivors, including many women living with HIV, has brought more attention to the unique needs of those who have been living with HIV and its dynamic challenges for decades. One such advocacy group, Let's Kick ASS, has several chapters across the US, and is growing; find out [more about Let's Kick ASS](#), and how you can become involved.

*"My attitude is of gratitude, for this life I have been given. The more I can share gives my life meaningful purpose. It is my daily mission to help inspire and motivate others to be kind, compassionate and above all, hopeful."* honeysplace2, [An Ordinary Woman](#), A Girl Like Me

There are many ways for LTS to stay resilient and not only survive, but thrive, throughout a long life with HIV. If you are an LTS, you can:

- **Take charge of your health.** Learning about your HIV drugs, having a good relationship with your healthcare providers, and keeping on top of your [diet](#) and [exercise](#) are all key parts of coping with the stresses of long-term survival.
- **Get support.** The importance of social support for HIV long-term survivors cannot be measured. A healthcare provider can be a source of support. So can a mental health counselor, peer mentor, or support group. They can help you connect with activities, family and friends, and even groups of other long-term survivors.
- **Tell your stories.** Speaking your truth is part of healing and makes important contributions to our community's history. You can share your story in a support group, with friends or family, at events and speaking engagements, online, and more. The Well Project's [A Girl Like Me online blog community](#) is one place where women living with HIV, including many long-term survivors, share their journeys with HIV. Join us! Positive Women's Network-USA also [welcomes blog submissions from women living with HIV](#).
- **Find your purpose.** Committing to an activity that excites you, working or volunteering for something you believe in, [continuing your education](#), and rediscovering your talents are just a few ways to experience pleasure and be productive, which can help you gain a sense of purpose in your life.
- **Take your rightful seat at the table.** Long-term survivors are experts in living a long life with HIV and must be part of organizational and policy decisions that impact the lives of LTS. You can help make sure LTS voices are heard by [becoming a community advocate](#). Learn more about organizations to get involved with in The Well Project's [Partners section](#).
- **Commemorate June 5, HIV Long-Term Survivors Awareness Day (#HLTSAD).** Acknowledged for the first time in 2014, HLTSAD is not just an awareness day, but a call to action to keep the needs, issues, and journeys of HIV LTS front and center in the HIV community.

*"Ours is not a movement simply about nostalgia, pain and grief. It is also a testament to the resilience of the human spirit, to humans who rolled up their sleeves and refused to accept our death sentences."* from ["A Vision of Our Future: HIV Long-Term Survivors Declaration."](#) by Let's Kick ASS.

## Women Kick ASS! A Sample of Long-Term Survivor Voices on *A Girl Like Me*

- [AhmazinAshley](#) (Ashley Nicole Richardson)
- [Angel S.](#)
- [arnoldmom](#) (Lynda)
- [BornHIVPoz89](#) (Brittney Mosley)
- [Dawn Averitt](#)
- [EnoughIsEnough](#) (Stephanie)
- [Godschild77](#) (Derinthia Williams)
- [Harmony\\_Rey](#) (formerly Connie Rose)
- [HIVictorious](#)
- [HIVstigmafighter](#) (Eliane Becks Nininahazwe)



- [IeshiaDKScott](#)
- [JoDha](#) (Jyoti Dhawale-Surve, formerly MumbaiiyyaGal)
- [JustineDD](#)
- [KatieAdsila](#) (Katie Willingham)
- [KimberlyC](#) (Kim Canady)
- [LovingLife101](#) (Vickie Lynn)
- [Lynnea](#)
- [Marcya Gullatte](#)
- [Maria T. Mejia](#) (MariaHIVMejia)
- [María Natalia Sáenz Agudelo](#)
- [Nancy Duncan](#)
- [OneKidneyNina](#) (Nina Martinez)
- [PDEES](#) (Porchia Dees)
- [Positive Sunbeam](#)
- [Stigma Warrior Princess](#) (Sophie Jayawardene)
- [Zora Voyce](#)

## Organizations and Projects of Interest for Long-Term Survivors:

- [Let's Kick ASS](#)
- [The Reunion Project](#)

## Additional Resources

Select the links below for additional material related to Long-Term Survivors of HIV.

- [WRI 2019: Women Living with HIV over the Long Term and Across the Lifespan \(Wom...](#)
- [Who are HIV Long-Term Survivors? \(Let's Kick ASS\)](#)
- ["We Make a Statement Just by Living Our Lives": Women Long-Term HIV Survivors S...](#)
- [Aging on the Frontlines \(Positively Aware Spring 2021 special issue\)](#)
- [Long-Term Survivors of HIV/AIDS Speak Up About Their Legacy \(includes video\) \(M...](#)
- [What is AIDS Survivor Syndrome \(ASS\)? And Why It Matters. \(Let's Kick ASS\)](#)
- [Still Here \(Achieve, via POZ\)](#)
- [Everything You Need To Know About HIV Long-Term Survivors Awareness Day \(plus\)](#)
- [Not So Fast: Do People with HIV Really Experience Accelerated Aging? \(Positivel...](#)
- [Eight Characteristics of Long-Term Survivors of HIV/AIDS \(TheBody\)](#)
- [Hell in a Hot Flash? \(Positively Aware\)](#)
- [Alone Time: Two Long-Term Survivors Discuss the Risks of Social Isolation \(Posi...](#)
- [I Am a Long-Term Survivor of HIV \(HIV.gov\)](#)
- [Long-Term Survivors of HIV/AIDS Reflect on What They've Witnessed and Endured \(...\)](#)
- [Supporting Long-Term Survivors of HIV \(HIV.gov\)](#)
- [What Is an HIV Long-Term Survivor? Five People With HIV Grapple With the Questi...](#)
- [Long-Term Survivors \(National Resource Center on HIV & Aging\)](#)
- [Another survey with HIV long-term survivors. Have we learned anything new? \(San...](#)

