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# Long-Term Survivors of HIV

*Last Updated: December 6, 2023*

*Together, we can change the course of the HIV epidemic...one woman at a time.*

#onewomanatatime

[www.thewellproject.org](http://www.thewellproject.org)

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# Who Are HIV Long-Term Survivors?

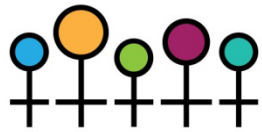
- Powerful HIV drugs now make it possible for people with HIV to live far longer lives than we could have imagined before effective HIV treatment became available
- Those who have lived with HIV for many years are often called **long-term survivors (LTS)**



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# Defining HIV Long-Term Survivors

- **Pre-HAART LTS** (or “longest-term survivors”): Living with HIV since before 1996 – start of the modern era of "highly active antiretroviral therapy" (**HAART**)
  - Acquired HIV when it was, in most cases, a death sentence
  - Often spent early adult lives believing they would die young - and watching many friends die
- **Post-HAART LTS**: Living with HIV for more than 10 years
  - Includes those diagnosed after 1996
  - Considered a very different experience than being diagnosed earlier in the epidemic



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# Other Definitions

- **Perinatal infection:** People who were **born with HIV, or acquired it as young children**
  - Now in their 20s, 30s and early 40s, have lived with HIV for decades
- **HIV-negative LTS:** Partners, and others who supported people living with HIV in the epidemic's earliest days
  - Many had their lives deeply affected by the epidemic
- **Long-term non-progressors:** A few people live with HIV without getting very sick even without medications



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# AIDS Survivor Syndrome (ASS)

- Refers to the psychological results of living through the most brutal years of the HIV pandemic
- Pre-HAART LTS especially vulnerable
- Sometimes compared to **post-traumatic stress disorder** (PTSD)
- Not many published studies
- Symptoms may include:
  - Anxiety, nervousness, or sense of feeling constantly ‘on guard’
  - Depression
  - Irritability or flashes of anger
  - Lack of future orientation
  - Low self-esteem & self-worth
  - Substance abuse
  - Social withdrawal & isolation
  - Survivor’s guilt



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# Physical Health Concerns

Some relate to common *effects of aging*; others to the unique *realities of surviving with HIV*

## HIV Treatment Challenges

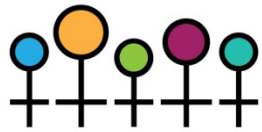
- Current treatments were tested in people who are now long-term survivors of HIV
- Many LTS deal with consequences of decades of HIV treatment
- Toxicity of early HIV drugs caused life-altering side effects, e.g.:
  - Lipodystrophy (body fat changes) and scars from lipo surgeries
  - Peripheral neuropathy (nerve pain)



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# Treatment Fatigue and Tolerability

- **Treatment fatigue:** physical or emotional weariness with taking HIV drugs
  - May cause LTS to have difficulties taking their HIV treatment regularly (**adherence**)
    - Can eventually cause HIV drugs to stop working (**HIV drug resistance**)
- **Multidrug-resistant HIV (MDR-HIV)** is reality for many LTS
  - Makes effective treatment options difficult to find
- LTS may take many pills each day for HIV and other health conditions (**comorbidities**)
  - More pills increases likelihood of drug interactions



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# Perinatal Acquisition

People who acquired HIV at birth (**perinatally**) may be ***more likely to have unsuccessful HIV treatment*** than adults, in part because:

- They may have been exposed to HIV treatment in the womb
  - Increased chances of HIV drug resistance
- Treatment histories tend to be just as complex as those of older-adult LTS but fewer medication options for children
- Young people may find adherence more challenging than adults

Very important for everyone to have trusting relationship with healthcare provider

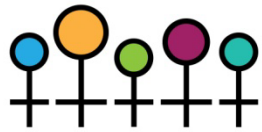




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# Inflammation

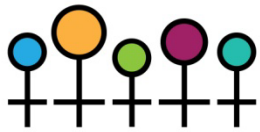
- Human body's natural response to threat or damage
- Immune system of a person living with HIV is always struggling to get rid of the virus
  - This means the immune system is always activated, or "on"
- After many years of being constantly activated, may produce inflammation
- Ongoing inflammation appears to be related to many health conditions (heart disease, cancers, etc.)



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# Accelerated Aging?

- Scientists exploring whether inflammation causes people living with HIV to experience signs of aging earlier (**accelerated aging**)
- Some professionals believe that signs of 'accelerated aging' may be less about HIV, more about higher rates of **traditional risk factors**
  - Smoking and stress are examples of traditional risk factors for heart disease that are more common among people living with HIV
- Eating well, exercising, managing other health conditions, and taking HIV drugs can all help reduce levels of inflammation



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# Comorbidities

Many non-AIDS-related health conditions are more common among aging people living with HIV, as well as LTS who were born with HIV:

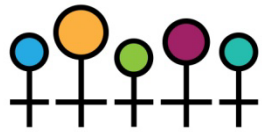
- Heart disease: LTS more likely to have taken older HIV drugs associated with body shape changes and increased blood fats
- Hepatitis C (HCV): Many LTS are “baby boomers”, CDC recommends testing for HCV; similar transmission paths as HIV
- Other liver diseases: Long-term use of medications can overwork the liver; certain HIV drugs also linked to liver damage



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# Comorbidities

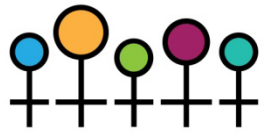
- Brain problems: HIV-associated neurocognitive disorder (HAND) may be more common among older people and LTS
- Cancers: Vital that LTS be regularly screened for AIDS-related cancers as well as other cancers not associated with HIV (e.g., breast or lung cancer)
- Bone disease: Some older HIV medications have been linked to bone loss



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# Menopause

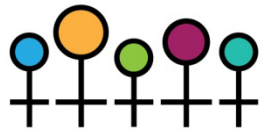
- Often called the "change of life"
- Point in time when a woman's menstrual periods stop
- Milestone that many women LTS may have thought they would not live to reach
- Effects of menopause can be treated with:
  - Hormone replacement therapy
  - Complementary treatments
  - Taking steps to stay healthy



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# Sexual Health

- Older women remain sexually active
  - May date after ending a long relationship or partner's death
  - Sexual risk-taking can be an effect of past trauma; can be a symptom of AIDS Survivor Syndrome
- Providers must talk about sexual health with their LTS clients
  - Important for women growing older with HIV to continue to visit gynecologist
  - For lifetime survivors and other LTS of childbearing age, sexual healthcare should include:
    - Respectful safer conception resources
    - Conversations that affirm women's sexual expression

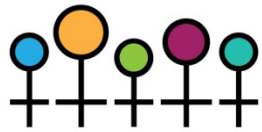


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# Mental Health Issues

**Depression** (prolonged emotional symptoms that affect physical health and wellbeing)

- Already a significant concern for people living with HIV, particularly older women
- Prevalent among HIV LTS, along with other serious mental health issues
- Also high rates of depression, other mental health conditions found in studies of mental health in lifetime survivors



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# Mental Health Issues

## **Isolation** from community and family

- Has numerous negative health effects
- Contributors to isolation include:
  - Multiple losses
  - Trauma
  - Decreased ability to leave home or get around town
  - Substance use
  - Financial concerns
  - Caregiving duties (especially for women)
- Working with mental health providers, social support, a sense of purpose in life can improve mental health





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# Unexpected Long-Term Planning

## Financial Considerations

- Faced with much longer life expectancy, LTS now must now ask themselves, "What's next?"
  - In LTS community, "retirement" has been a euphemism for being on permanent disability
    - Unstable form of income that is also difficult to get off
  - Eligibility requirements for some forms of public assistance force people living with HIV to keep incomes low
    - Nearly impossible to save for the future
  - Long gaps in work histories, ageism, etc. pose challenges for LTS returning to work
  - Panic about future and inability to plan for it are symptoms of AIDS Survivor Syndrome

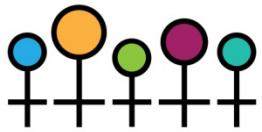


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# Unexpected Long-Term Planning

## End-of-Life Planning

- That end will most likely be much farther off than once expected
- Can be an empowering process when, earlier in the HIV epidemic, there was not time or space to be thoughtful about plans at the end of life
- Means deciding not just where belongings will go, but how a person wishes to be treated, medically and otherwise, if a time comes when they are unable to make such decisions on their own
- People living with HIV used not to be able to get life insurance – that's changing now



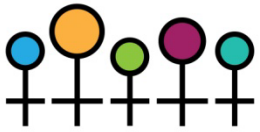
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# Long-Term Survivors: Taking Care, Kicking Ass

Advocacy group: [Let's Kick ASS](#)

If you are a LTS, you can stay resilient and ***not only survive, but thrive*** throughout a long life with HIV:

- **Take charge of your health.** Learn about your medications, have a good relationship with healthcare providers, keep on top of diet and exercise
- **Get support.** A health care provider, mental health counselor, peer mentor, or support group can provide support, help with connections to activities and community
- **Tell your stories.** Speaking your truth is part of healing!



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# Long-Term Survivors: Taking Care, Kicking Ass

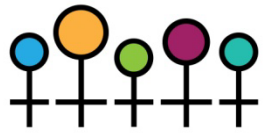
- **Find your purpose.** Committing to an activity that excites you, working or volunteering on something you believe in, and rediscovering your talents are just a few ways to experience pleasure, be productive, and find purpose
- **Take your rightful seat at the table.** LTS are experts in living a long life with HIV, and must be part of organizational and policy decisions that impact their lives. Become a community advocate!
- **Commemorate June 5, National HIV Long-Term Survivors Awareness Day (#HLTSAD).** Not just an awareness day, but a call to action to keep needs and demands of HIV LTS front and center in the HIV community



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## Learn More!

- Please read the full fact sheets on these topics:
  - [Long-Term Survivors of HIV](#)
  - [Lifetime Survivors of HIV](#)
  - [Menopause and HIV](#)
  - [Older Women, Sex, and HIV](#)
  - [Depression, Women, and HIV](#)
- For more information, please visit:
  - [www.thewellproject.org](http://www.thewellproject.org)
  - <https://www.facebook.com/thewellproject>
  - <https://www.twitter.com/thewellproject>



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# Organizations of Interest

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



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# Women Kick ASS!

- [AhmazinAshley](#)
- [Angel S.](#)
- [arnoldmom](#)
- [BornHIVPoz89](#)
- [Dawn Averitt](#)
- [EnoughIsEnough](#)
- [Godschild77](#)
- [Harmony\\_Rey](#)
- [HIVictorious](#)
- [HIVstigmafighter](#)
- [IeshiaDKScott](#)
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- [JustineDD](#)
- [KatieAdsila](#)
- [KimberlyC](#)
- [LovingLife101](#)
- [Lynnea](#)
- [Marcy Gullatte](#)
- [MariaHIVMejia](#)
- [María Natalia Sáenz Agudelo](#)
- [Nancy Duncan](#)
- [OneKidneyNina](#)
- [PDEES](#)
- [Positive Sunbeam](#)
- [Stigma Warrior Princess](#)
- [Zora Voyce](#)