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Long-Term Survivors of HIV

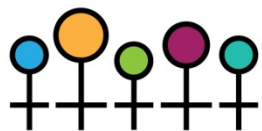
Last updated: February 6, 2025

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

#onewomanatatime

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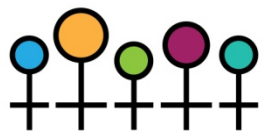
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Who Are HIV Long-Term Survivors?

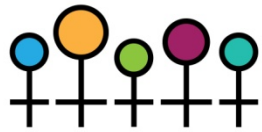
- Powerful HIV drugs now make it possible for people with HIV to live far longer lives than we could have imagined before effective HIV treatment became available
- Those who have lived with HIV for many years are often called **long-term survivors (LTS)**



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Defining HIV Long-Term Survivors

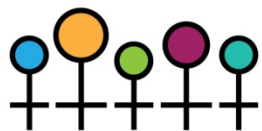
- **Pre-HAART LTS** (or “longest-term survivors”): Living with HIV since before 1996 – start of the modern era of "highly active antiretroviral therapy" (**HAART**)
 - Acquired HIV when it was, in most cases, a death sentence
 - Often spent early adult lives believing they would die young - and watching 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

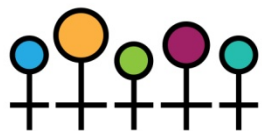
- **Lifetime survivors:** People who were **born with HIV** (perinatal acquisition), or **acquired it as young children**
 - Now in their 20s, 30s and early 40s, have lived with HIV for decades
- **HIV-negative LTS:** Partners, and others who supported people living with HIV in the epidemic's earliest 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)**
- 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



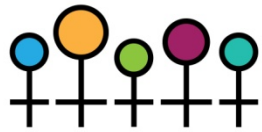
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Physical Health Concerns

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

HIV Treatment Challenges

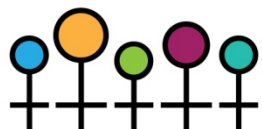
- Current treatments were tested in people who are now long-term survivors of HIV
- Many LTS deal with consequences of decades of HIV treatment
- Toxicity of early HIV drugs caused life-altering side effects, e.g.:
 - Lipodystrophy (body fat changes) and scars from lipo surgeries
 - Peripheral neuropathy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



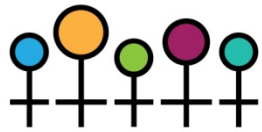
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Lifetime Survival

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

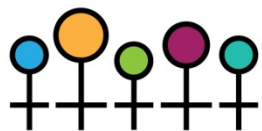
Very important for everyone to have trusting relationship with healthcare provider



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Inflammation

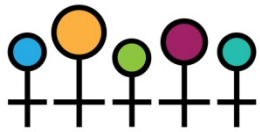
- Human body's natural response to threat or damage
- Immune system of a person living with HIV is always struggling to get rid of the virus
 - This means the immune system is always activated, or "on"
- After many years of being constantly activated, may produce inflammation
- Ongoing inflammation appears 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

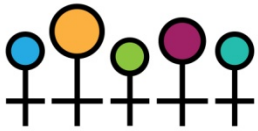


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Comorbidities

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

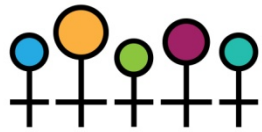
- Heart disease: LTS more likely to have taken older HIV drugs associated with body shape changes and increased blood fats
- Hepatitis C (HCV): Many LTS are “baby boomers”, CDC recommends testing for HCV; similar transmission paths as HIV
- Other liver diseases: Long-term use of medications can overwork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



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Comorbidities

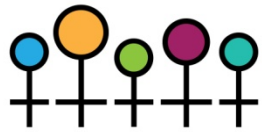
- Brain problems: HIV-associated neurocognitive disorder (HAND) may be more common among older people and LTS
- Cancers: Vital that LTS be regularly screened for AIDS-related cancers as well as other cancers not associated with HIV (e.g., breast or lung cancer)
- Bone disease: Some older HIV medications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



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Menopause

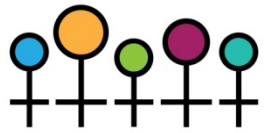
- Often called the "change of life"
- Point in time when a woman's menstrual periods stop
- Milestone that many women LTS may have thought they would not live to reach
- Effects of menopause can be treated with:
 - Hormone replacement therapy
 - Complementary treatments
 - Taking steps to stay healthy



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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

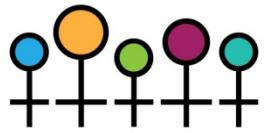


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Mental Health Issues

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

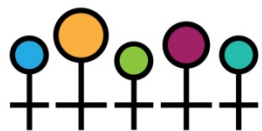


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Mental Health Issues

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

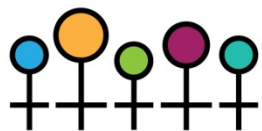


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Unexpected Long-Term Planning

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

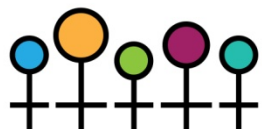


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Unexpected Long-Term Planning

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



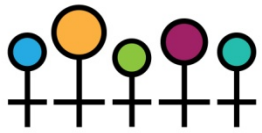
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Long-Term Survivors: Taking Care, Kicking Ass

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:

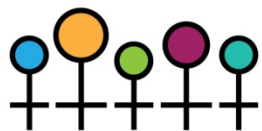
- **Take charge of your health.** Learn about your medications, have a good relationship with healthcare providers, keep on top of diet and exercise
- **Get support.** A health care provider, mental health counselor, peer mentor, or support group can provide support, help with connections to activities 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](#)
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