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Long-Term Survivors of HIV

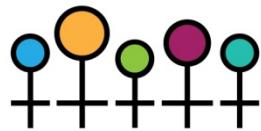
Last Updated: June 3, 2021

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

#onewomanatatime

www.thewellproject.org

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Who Are Long-Term Survivors of HIV?

"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*



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Who Are HIV Long-Term Survivors?

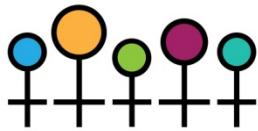
- Powerful HIV drugs now make it possible for people with HIV to live far longer lives than we could have imagined in the epidemic's earliest days
- Those who have lived with HIV for many years are often called **long-term survivors** (LTS)



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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



Other Definitions

- Perinatal infection: People who were **born with HIV, or acquired it as young children**
 - Now in their 20s and 30s, having lived with HIV for decades
 - May have experienced loss of many loved ones
- **HIV-negative LTS:** Partners, companions, activists, healthcare providers, etc., directly supporting people living with HIV in the epidemic's earliest days
 - Many experienced tremendous losses, had their lives deeply affected by the epidemic



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AIDS Survivor Syndrome (ASS)

"I feel like we are soldiers coming back from a HORRIBLE WAR and we are still battling it."

– Maria T. Mejia, on A Girl Like Me

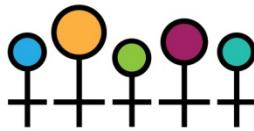
<http://www.thewellproject.org/a-girl-like-me/aglm-blogs/survivor%E2%80%99s-guiltptsdanxietydepression>



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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 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 & self-worth
 - Substance abuse
 - Social withdrawal & isolation
 - Survivor's guilt



Perinatal Acquisition

Studies of people who acquired HIV at birth (**perinatally**) found younger LTS ***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 (including pre-HAART LTS)
- Young people may find adherence more challenging than adults



Physical Health Concerns of LTS

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

- Important for LTS of all ages to have trusting relationships with healthcare providers
 - Can work together to find effective, ***tolerable*** treatment options

HIV Treatment Challenges

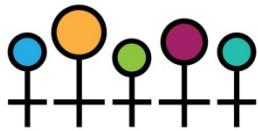
- Many LTS deal with consequences of decades of HIV treatment
- Toxicity of many early HIV drug regimens caused life-altering side effects; include but are not limited to:
 - Lipodystrophy (body fat changes) and scars from lipo surgeries
 - Peripheral neuropathy



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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 several pills each day for HIV and other health conditions (**comorbidities**), plus vitamins, supplements, birth control methods, pain relievers, etc.
 - More pills increases likelihood of drug interactions



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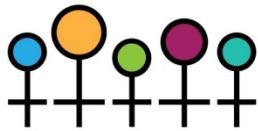
Inflammation

- 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 "turned 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.)



Accelerated Aging?

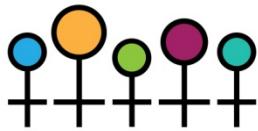
- Scientists exploring whether inflammation causes people living with HIV to experience signs of aging earlier (**accelerated aging**)
- Some professionals believe that signs of 'accelerated aging' may be less about HIV, more about higher rates of **traditional risk factors**
 - Smoking and stress are 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



Comorbidities

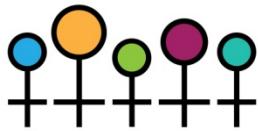
Many non-AIDS-related health conditions are more common among LTS and other aging people with HIV, including:

- Heart disease: LTS more likely to have taken older HIV drug regimens associated with body shape changes and increased blood fats
- Hepatitis C (HCV): Many LTS are **baby boomers** (born between 1945 and 1965); CDC recommends they be tested for HCV
- Other liver disease: Long-term use of medications can overwork the liver; certain HIV drugs also linked to liver damage



Comorbidities

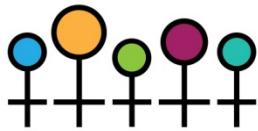
- Brain problems: HIV-associated neurocognitive disorder (HAND) may be more common among older people and LTS
- Cancers: Vital that LTS be regularly screened for AIDS-related cancers as well as others not associated with HIV (e.g., breast or lung cancer)
- Bone disease: Some older HIV medications have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



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Menopause

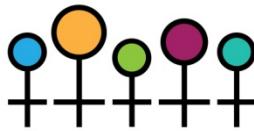
- Often called the "change of life"
- Point in time when a woman's menstrual periods stop
- Milestone that many women LTS may have thought they would not live to reach
- Effects of menopause can be treated with:
 - Hormone replacement therapy
 - Complementary treatments
 - Taking steps to stay healthy



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Sexual Health

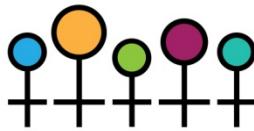
- Older women remain sexually active
 - May date and become sexually active after ending a long relationship or partner's death
 - Sexual risk-taking can be an effect of past trauma; can be a symptom of AIDS Survivor Syndrome
- Providers must talk about sexual health with their LTS clients
 - Important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



Mental Health Issues

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

- Already a significant concern for HIV+ people, 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 young people born with HIV



Mental Health Issues

Isolation from community and family

- Has numerous negative health effects, including higher rates of death from chronic health conditions
- 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 are key ways to decrease isolation, improve mental health



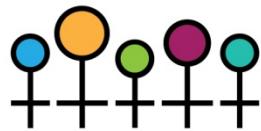
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Quality of Life Concerns for LTS

“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, on A Girl Like Me

<http://www.thewellproject.org/a-girl-like-me/aglm-blogs/surviving-unknown-age>



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Unexpected Long-Term Planning

Financial Considerations

- Faced with much longer life expectancy, LTS have now had to ask themselves, "What's next?"
 - Panic about the future, and inability to plan for or conceive of the future, are symptoms of ASS
 - Many LTS may have once seen no point in saving money
 - May now find themselves in dire financial straits as they grow older
 - 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 public assistance force HIV+ people 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



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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



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Long-Term Survivors: Taking Care, Kicking Ass

*“An ordinary woman, who has lived an **extraordinary life** ...*

*“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, on A Girl Like Me

<http://www.thewellproject.org/a-girl-like-me/aglm-blogs/ordinary-woman>
www.thewellproject.org



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Long-Term Survivors: Taking Care, Kicking 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 health care 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 (NHLTSAD).** 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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Long-Term Survivors: Taking Care, Kicking Ass

"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

http://letskickass.org/hiv-long-term-survivors-declaration-a-vision-for-our-future/#.V646_ZgrJhF



Learn More!

- Please read the full fact sheets on these topics:
 - [Long-Term Survivors of HIV](#)
 - [Women with Early Acquired HIV](#)
 - [Menopause](#)
 - [Older Women's Sexual Health](#)
 - [Mental Health](#)
- For more information, please visit:
 - [www.thewellproject.org](#)
 - [www.facebook.com/thewellproject](#)
 - [www.twitter.com/thewellproject](#)



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Resources for LTS

- [Let's Kick ASS](#)
- [The Reunion Project](#)
- [ACRIA](#)
- [Graying of AIDS](#)



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LTS A Girl Like Me Bloggers

- [Angel S.](#)
- [Tranisha Arzah](#)
- [Dawn Averitt](#)
- [Maria T. Mejia](#)
- [Robin Barkins](#)
- [BornHIVPoz89](#)
- [Angelena Cortello](#)
- [Nancy Duncan](#)
- [LovingLife101](#)
- [Sara Thapa Magar](#)
- [Wanda Brendle Moss](#)
- [MumbaiyyaGal](#)
- [Neen](#)
- [Sandra](#)
- [Ieshia Scott](#)
- [Stigma Warrior Princess](#)