Long-Term Survivors of HIV

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

#onewomanatatime

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"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)**.
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
"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
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

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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.

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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 others not associated with HIV (e.g., breast or lung cancer)
- **Bone disease**: Some older HIV medications have been linked to bone loss
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

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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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“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
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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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.
“An ordinary woman, who has lived an extra\text{ordinary} \text{ life} \ldots

“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, \text{hopeful}.”

– honeysplace2, on A Girl Like Me

\url{http://www.thewellproject.org/a-girl-like-me/aglm-blogs/ordinary-woman}
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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"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."


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

Learn More!
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
- Angeleno Cortello
- Nancy Duncan
- LovingLife101

- Sara Thapa Magar
- Wanda Brendle Moss
- MumbaiyyaGal
- Neen
- Sandra
- Ieshia Scott
- Stigma Warrior Princess

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