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 www.thewellproject.org #thewellproject
"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
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

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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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"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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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
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
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.
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
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
“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
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
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 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
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!
• **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
  – 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
LTS A Girl Like Me Bloggers

- Angel S.
- Tranisha Arzah
- Dawn Averitt
- Maria T. Mejia
- Robin Barkins
- BornHIVPoz89
- Angeleni Cortello
- Nancy Duncan
- LovingLife101

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

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