Long-Term Survivors of HIV

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

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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).
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, 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
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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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)
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
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
• 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.)
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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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
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
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
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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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
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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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
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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• 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
  – https://www.facebook.com/thewellproject
  – https://www.twitter.com/thewellproject
Organizations of Interest

- Let's Kick ASS
- The Reunion Project
Women Kick ASS!

- AhmazinAshley
- Angel S.
- arnoldmom
- BornHIVPoz89
- Dawn Averitt
- EnoughIsEnough
- Godschild77
- Harmony Rey
- HIVictorious
- HIVstigmafighter
- IeshiaDKScott
- JoDha
- JustineDD
- KatieAdsila
- KimberlyC
- LovingLife101
- Lynnea
- Marcya Gullatte
- MariaHIVMejia
- María Natalia Sáenz Agudelo
- Nancy Duncan
- OneKidneyNina
- PDEES
- Positive Sunbeam
- Stigma Warrior Princess
- Zora Voyce