

AIDS Survivor Syndrome: The Challenges of Long Term Survival



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Agenda

- Introductions
- NYC Background
- Defining Long-term Survivors
- AIDS Survival Syndrome
- Physical Concerns/Co-morbidities
- Sexual Health
- Taking Care, Kicking Ass
- Q&A

Speakers



Kim Canady, speaker, [Love Heals](#); community advisory board, The Well Project



Krista Martel, executive director, [The Well Project](#)



Susan Rodriguez, founding director, [SMART](#)



Terri L. Wilder, MSW, director, HIV/AIDS Education and Training, [Mt. Sinai Institute for Advanced Medicine](#)



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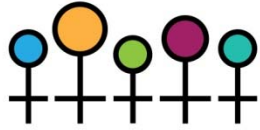
Jack Martin Clinic
Comprehensive Health Program
Peter Krueger Clinic
Morningside Clinic
Samuels Clinic



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About The Well Project

- Non-profit organization with a mission to change the course of the HIV/AIDS pandemic through a unique and comprehensive focus on women and girls
- Leverages technology to improve health outcomes and increase quality of life for women and girls living with HIV
- Provides accessible and comprehensive #information, #community support, and #advocacy building
- Access our resources and join our community at www.thewellproject.org



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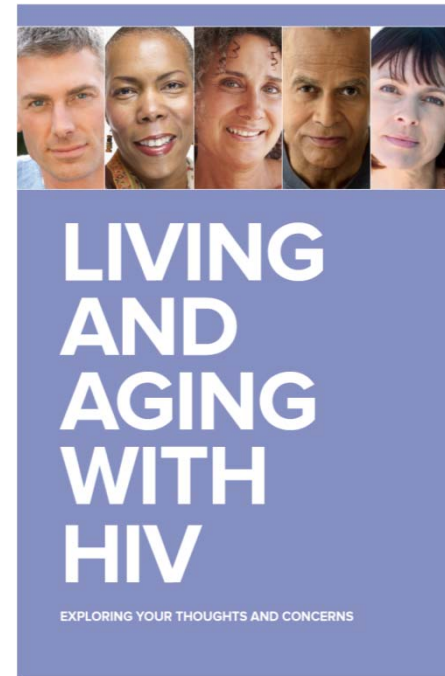
NYC Data

Data from New York City estimates that 26% of all people living with HIV in Manhattan are HIV Long-Term Survivors



NYS Data

By the year 2020, 70% of people living with HIV in NYS will be over the age of 50



Defining Long-Term Survivors (LTS)

- Powerful drugs make it possible for people with HIV to live far longer than we could have imagined in the epidemic's earliest days
- **Pre-HAART LTS:** Living with HIV since before 1996
 - Acquired HIV when it was usually a death sentence
 - Often spent early adulthood believing they would die young, watching friends die
- **Post-HAART LTS:** Living with HIV for >10 years
 - Anyone diagnosed after 1996
 - A very different experience than being diagnosed earlier in the epidemic

Other Definitions

- **Perinatal transmission:** People **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 due to the virus
- **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

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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LET'S KICK ASS AIDS SURVIVOR SYNDROME

The Original Grassroots Movement Since 2013.



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AIDS Survivor Syndrome

- Most commonly found in people diagnosed before 1996 (AIDS Generation)
- It is what happens after the AIDS tsunami recedes
- When survivors have had time to evaluate the loss, grief and fear of the tragedy that unfolded
- Life is going on but they are still traumatized
- It varies in degree of severity from very mild to chronic

What are the symptoms?

- Depression
- Personality changes
- Flashes of anger
- Survivor guilt
- Jumpiness or hyperarousal
- Anxiety
- Emotional numbness
- Insomnia
- Social withdrawal and isolation
- Hopelessness
- Substance abuse
- Sexual risk-taking
- Lack of future orientation

History

- **Survivor Syndrome:** Coined by Dr. William G. Niederland to describe what survivors of death camps went through 16 years after the Holocaust ended
- **Post-AIDS Stress Syndrome (PASS):** coined by NYC Psychotherapist Robert Levithan to describe the phenomenon of long-term survivors “outliving themselves”
- **1996 International AIDS Conference, Vancouver:** first conference after the technological advance of measuring HIV viral load
 - Conference introduced combination therapy using protease inhibitor
 - Within a week of the conference, >75,000 patients began taking an effective antiviral regimen
 - The treatment increased their immune system strength and health

AIDS Survivor Syndrome: Curious Phenomenon

- Patients became sloppy taking their medications
- Some Dallas doctors reported non-adherence rates as high as 75%, most saw at least 25% non-adherence



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 resulting scars from surgeries, implants, and injections
 - Peripheral neuropathy

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

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
- Hepatitis C (HCV)
- Other liver disease
- Brain problems
- Cancers
- Bone disease



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

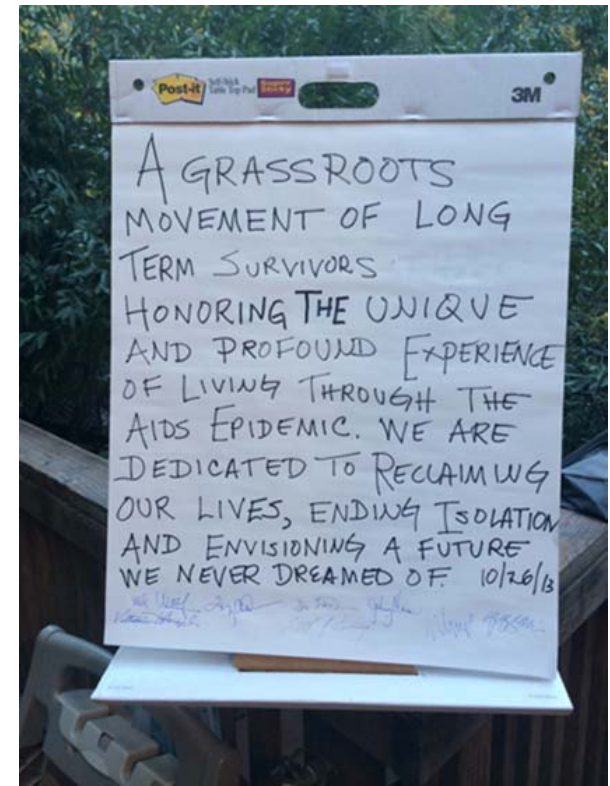
Long-Term Survivors: Taking Care, Kicking Ass

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 healthcare providers, keep on top of diet and exercise
- **Get support:** A healthcare 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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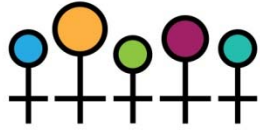


Long-Term Survivors: Taking Care, Kicking Ass

- **Find your purpose:** Commit to an activity that excites you, work or volunteer on something you believe in, rediscover your talents
- **Take your rightful seat at the table:** LTS are experts in living a long life with HIV, and should be part of the organizational and policy decisions that impact their lives
- **Commemorate June 5, National HIV Long-Term Survivors Awareness Day (NHLTSAD):** It's a call to action to keep the needs and demands of LTS front and center in the HIV community

Resources for Long-Term Survivors

- [Sage](#)
- [GMHC](#)
- [Let's Kick ASS](#)
- [The Reunion Project ACRIA](#)
- [Graying of AIDS](#)
- ["We're Still Here"](#)
- [Long-Term Survivor Group on The Well Project](#)



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Learn More!

- The Well Project fact sheets on these topics:
 - [Long-Term Survivors of HIV](#)
 - [Menopause](#)
 - [Older Women's Sexual Health](#)
 - [Mental Health](#)



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June 5, 2017

JUNE 5, 2017
HIV LONG-TERM SURVIVORS AWARENESS DAY
OUR HIV RESILIENT LIVES

2017 THEME HIV RESILIENT
HLTSAD.ORG #HIVRESILIENT
WHAT DOES IT MEAN TO BE HIV RESILIENT?



26% Of All People Living With HIV
Are Long-Term Survivors.

Empower. Engage. Unify. Elevate.
Originators and Lead Sponsor: LetsKickASS.org
The Original Grassroots Movement Since 2013.

Discussion

“With courage and compassion long-term survivors of HIV strive not only to survive but also to thrive into full, meaningful, productive, independent and connected lives, free from stigma, ageism and discrimination regardless of age, gender, race/ethnicity, sexual orientation, gender identity or socio-economic circumstance.”

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