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Medical Concerns for Women Lifetime Survivors of HIV

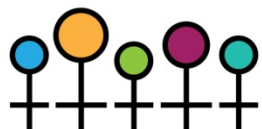
Last updated: February 5, 2025

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

#onewomanatatime

www.thewellproject.org

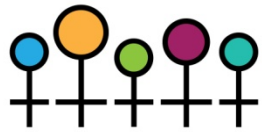
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Who Are Lifetime Survivors of HIV?

- HIV testing, treatment advances, blood product screening
 - Fewer transmissions to babies now
 - People who have acquired HIV early in life are aging
 - US 2021: 13,000 lifetime survivors of HIV, mostly over age 13
- *Lifetime survivors of HIV* are a unique group with their own concerns and medical issues
 - Medications taken from early age for rest of their lives
 - Shifting from pediatric to adult HIV care
 - Starting to date as a person living with HIV
 - Impact of life-long medications



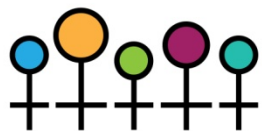
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Treatment Experience and Challenges

"I know my HIV medication is keeping me alive. I know how important it is. I know it's working against my virus and keeping me from getting sick. But like most people I had to grow up and learn the hard way. ..."

~ Porchia Dees, "Attention Health Care Providers: Insight into Why Young People May Be Not Consistently Engaging in HIV Medical Care (from *A Girl Like Me*)"

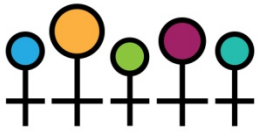




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Adherence

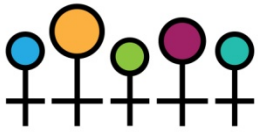
- Low adherence is No. 1 factor for drugs to stop working
- Reasons for not taking medications:
 - Busy schedules
 - Forgetting to take drugs
 - Leaving drugs at home
- Other concerns:
 - Feeling well (likely *because* of taking the drugs)
 - Treatment fatigue
 - Complex treatment schedule



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Adherence

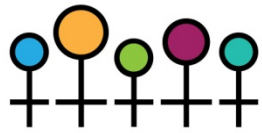
- Reasons for low adherence in high-resource areas:
 - Low self-efficacy
 - Low outcome expectancy
 - Experience with systemic injustices
- Young people's special concerns:
 - Physical growth and changes can affect how drugs work
 - Worry about disclosure to friends
- Provider relationship important for good adherence
 - Challenges with providers or institutions
- **Adherence is very important for HIV management!**



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Resistance

- Low adherence -> drug levels drop too low -> drug resistance develops
- More likely to develop in lifetime survivors
 - Have already taken various HIV drugs
 - May have been on earlier, more toxic drugs
 - May have been exposed to HIV drugs in the womb
- Provider recommendation: simple drug regimens
 - But: may need complex regimens because of previous treatment history
 - Newer classes of drugs may permit simple regimen anyway

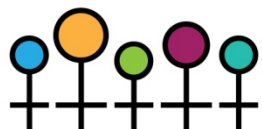


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Transition from Pediatric to Adult Care

"Transitioning out of pediatric care was a very significant—and extremely difficult—moment in my life. Entering into adult HIV care felt cold and distant. That transition made it easy for me to fall out of care in my young adulthood. I had built such a strong bond with my pediatrician that anything less than that was hard to accept. ..."

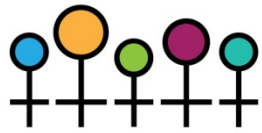
~ Porchia Dees, "Attention Health Care Providers: Insight into Why Young People May Be Not Consistently Engaging in HIV Medical Care (from *A Girl Like Me*)



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Transition from Pediatric to Adult Care

- Different training for providing HIV care to children or adults -> transition necessary
- Can be difficult for teen to move to different provider
 - Lifetime relationship with pediatric provider
 - Friendships with other kids at the clinic
 - Pediatric provider may be aware of difficult family history
 - Young person may not want to explain this to a new provider
- Important that adult provider **understands HIV care for lifetime survivors and takes interest in their lives**
 - Includes nonjudgemental environment for youths



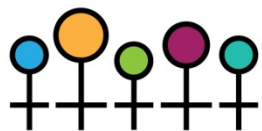
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Sexual Lives and Reproductive Health



“... My fear of passing HIV to another has caused me to experiment with my sexuality, and my fear of being alone has caused me to tolerate domestic violence, because I thought I deserved the abuse, and I thought I couldn't do better. ...”

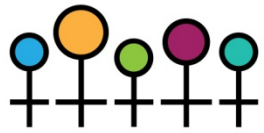
~ Lynnea, “My Cup of Tea” (from *A Girl Like Me*)



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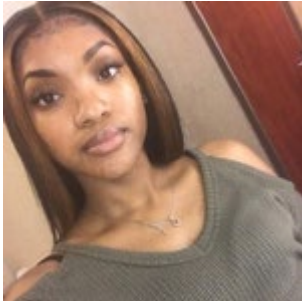
Sexual Lives and Reproductive Health

- Lifetime survivors of HIV can:
 - Have fulfilling sexual lives
 - Become parents
 - Well-controlled HIV:
 - No sexual transmission to partner
 - Very low risk of transmission to baby
- But there is still stigma around family-building
 - Especially around breast/chestfeeding while living with HIV
 - 2023 change to US guidelines: shared decision-making
- Need more research on breast/chestfeeding
 - Advocacy: BEEEEBAH program



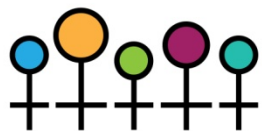
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Other HIV-Related Medical Challenges



I want to add so much about body image and self-esteem but there's no studies to support all of the physical issues and concerns expressed by my peers. I listen to so many of my perinatal friends that complain about physical deformities that stem from early antiretroviral use. ...”

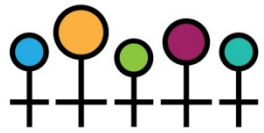
~ Ieshia Scott, founder, Positive Support



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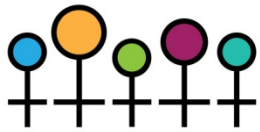
- Health concerns at younger ages than people who acquired HIV as adults
- Challenges include:
 - Liver health
 - Bone health
 - Dental health
 - Cardiovascular health
 - Weight gain associated with certain HIV drugs
 - Problems related to HIV not under control
 - Neurocognitive concerns



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Women Surviving and Thriving Over a Lifetime with HIV

- More research is needed into issues related to early-acquired HIV
- Lifetime survivors need spaces to connect
- Listen to women who have lived with HIV for their entire lives and figured out how to thrive!



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Learn More!

- To learn more:
 - [Medical Concerns for Women Lifetime Survivors of HIV](#)
 - [Lifetime Survivors of HIV](#)
 - [Mujeres con VIH adquirido a edad temprana](#)
- For more fact sheets and to connect to our community of women living with HIV:
 - www.thewellproject.org
 - [@thewellprojecthiv.bsky.social](https://bsky.app/@thewellprojecthiv)
 - www.facebook.com/thewellproject
 - www.instagram.com/thewellprojecthiv/
 - www.threads.net/@thewellprojecthiv
 - www.youtube.com/thewellprojecthiv