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# Lifetime Survivors of HIV

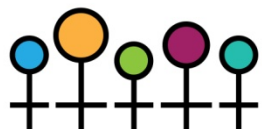
*Last updated: June 1, 2026*

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

#onewomanatatime

[www.thewellproject.org](http://www.thewellproject.org)

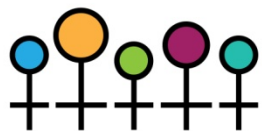
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# Female Lifetime Survivors of HIV

- Lifetime survivors: acquired HIV as babies
- 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 often not seen as a distinct group



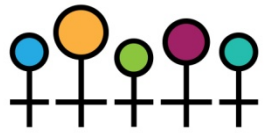
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# Treatment Experience and Challenges

*"[T]here are plenty of long-term survivors that can relate because we have the same chronic illness, but it's nothing compared to sharing the life experience of being born HIV-positive with others that were also born HIV-positive. Managing HIV as children and into adulthood is an experience and a bond that is difficult to describe."*

~ HIVictorious, "My First USCHA Experience" (from *A Girl Like Me*)

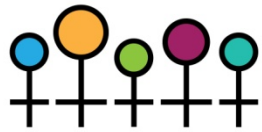




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# Some Language to Know

- Dandelions
- Early acquired HIV
- Lifetime survivors of HIV
- Long-term HIV survivors
- Perinatal HIV transmission
- Perinatal acquisition, perinatally acquired
- Vertical HIV acquisition
- Vertical HIV transmission

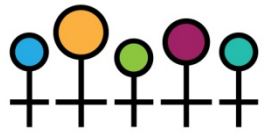


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# Terms to Avoid

These terms are considered stigmatizing but are still used:

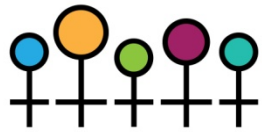
- Mother-to-child transmission of HIV (MTCT)
  - Use vertical HIV transmission instead
- Perinatal infection, perinatally infected
  - Use perinatal acquisition, perinatally acquired instead



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# The Dandelions Movement

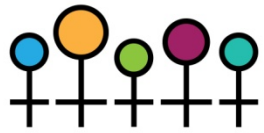
- Started in 2023 at Washington, DC gathering led by women of color with early acquired HIV
  - Spoken-word piece “Dandelions” by Mary Bowman
- Visit Dandelions Movement website to connect with that community
  - <https://www.thedandelions.org/>
- Watch special episode of *A Girl Like Me LIVE* on Lifetime Survivors of HIV
  - [https://www.youtube.com/watch?v=VsplK2\\_pgs4](https://www.youtube.com/watch?v=VsplK2_pgs4)



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# Individual and Social Challenges

- Disclosure
- Limited Support Systems
- Mental Health
- Substance Use and Sexual Activity
- Violence
- Intersectional Experiences of Oppression



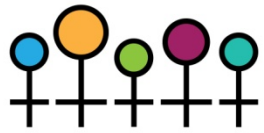
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# Disclosure

*"Disclosure has been one of the scariest things to navigate in my experience. You don't know how people will react—what they'll say, or if they'll freak out."*

~ 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*)

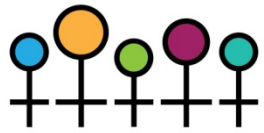




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# Finding Out HIV Status

- Parents/guardians may not tell young people that they are living with HIV
  - Teen may have internalized HIV stigma before knowing their own HIV status
  - Teen may find out on their own
- Knowing status is important for managing one's care
- Timing of disclosure to child may depend on:
  - Caregiver's concern for child's mental health
  - Caregiver's own internalized stigma
  - Surrounding social rejection of people living with HIV



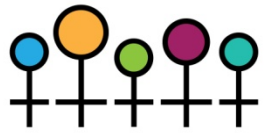
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# Dating and Sex



*“Growing up positive added its own layers of difficulty to the [dating] equation. I used to describe myself as poison ivy. I let the negative viewpoints of society and the stigma that I felt whenever people indirectly insulted me by joking about HIV alter the way I perceived myself.”*

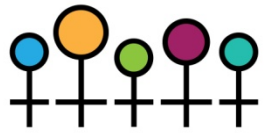
~ Lynnea, “My Cup of Tea” (from *A Girl Like Me*)



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# Limited Support Systems

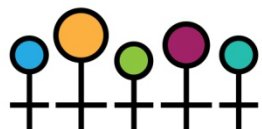
- Caregivers:
  - Primary caregiver may have died
  - Caregiver may have their own health struggle
- Young people:
  - May try to feel in control by stopping to take HIV medications
- HIV care institutions need to be “medical homes”:
  - Medicines & tests
  - Social support & emotional care
  - Strategies for coping with stress



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# Mental Health

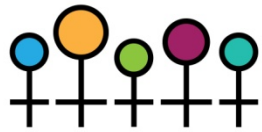
- Young women especially vulnerable to mental health concerns
- HIV and related stigma impacts mental health
- Move from adolescent to adult care stressful
- Survivor guilt over parents or friends with HIV who have died



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# Substance Use and Sexual Activity

- Substance use experiments like other teens
  - Effect on health of long-term survivors is greater
- Sexual activity
  - Fewer partners than other teens
  - But: condomless sex -> potential STI acquisition, HIV transmission
- Need to educate young people:
  - U=U
  - Effect of substance use on viral suppressio

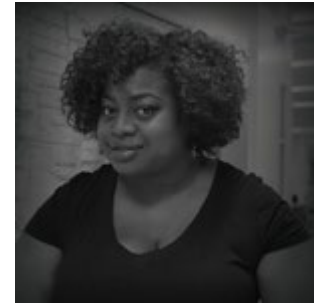


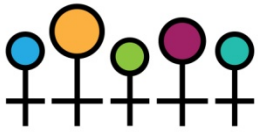
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# Violence

*“I think it's important to talk about sexual violence in intimate partner relationships as a barrier to being in a relationship while being positive. Being born with HIV can impact how you feel about yourself, but also what you might believe you deserve.”*

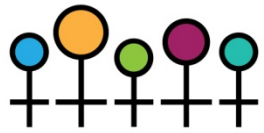
~ Kim Canady, Member of The Well Project's Community Advisory Board





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- Important: if you are feeling threatened right now:
  - National Domestic Violence hotline  
800-799-SAFE (1-800-799-7233)
  - Text START to 88788
  - Call 911 if that is a safe option
- Search for a safe space:
  - Domestic Shelters



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# Intersectional Experiences of Oppression

- Structural factors affecting lives and health outcomes:
  - Systemic racism
  - Sexism
  - Classism
  - Transphobia
  - Ableism



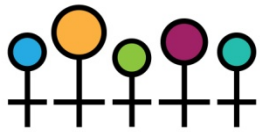
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# Women Surviving and Thriving Over a Lifetime with HIV



*“... Sometimes I even forget I have HIV! I have so many other things to do, I'm not really thinking about it – besides at night when I pop my pill – but otherwise, HIV is not my life. I refuse! I have too much else to think about and do. And I am loving the mom life!”*”

~ Kim Canady, Member of The Well Project's  
Community Advisory Board



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# Learn More!

- To learn more:
  - [Lifetime Survivors of HIV](#)
  - [Medical Concerns for Women 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](http://www.thewellproject.org)
  - [@thewellprojecthiv.bsky.social](https://bsky.app/profile/thewellprojecthiv)
  - [www.facebook.com/thewellproject](https://www.facebook.com/thewellproject)
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