



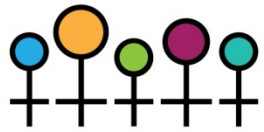
Session 1: HIV Advocacy: Awareness in Action

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

#onewomanatatime

#thewellproject

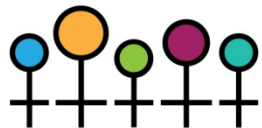
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About The Well Project

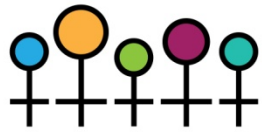
- Non-profit organization with a mission to change the course of the HIV/AIDS pandemic through a unique and comprehensive focus on women and girls across the gender spectrum
- Leverages technology to improve health outcomes and increase quality of life for women and girls living with HIV
- Our focus: education and information, community support, advocacy and leadership, collaborative engagement, and women-focused HIV research
- Access our resources and join our community at www.thewellproject.org



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About WATCH! 2.0

- Treatment advocacy webinar series, based on our successful 2015 series *A Place at the Table: WATCH!*
- 7 monthly sessions; 1 hour each
- Capacity building and training for women living with HIV and with reasons for HIV prevention across the gender spectrum
- Series topics will include advocacy basics, treatment and prevention, sexual and reproductive health, aging, research
- Participation in live sessions encouraged; recordings of sessions will be available to those unable to attend
- Certificates of completion will be issued to participants upon finishing the series and required evaluations/post-tests based on content of each episode



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Agenda

- Welcome
- What Does an HIV Advocate Look Like?
- Types and Levels of HIV Advocacy
- Language and Advocacy
- Claiming Your Place at the Table
- Taking Care of Ourselves
- Q&A

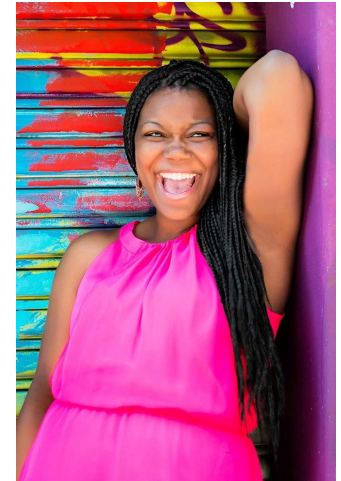
Today's Presenters



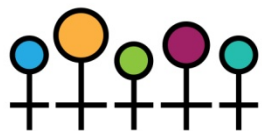
Tiommi Luckett
Transgender Law Center



Bridgette Picou, LVN, ACLPN
Moderator
The Well Project



Masonia Traylor
Lady BurgAndy



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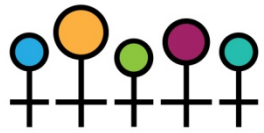
Being an Advocate for Yourself and Others

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

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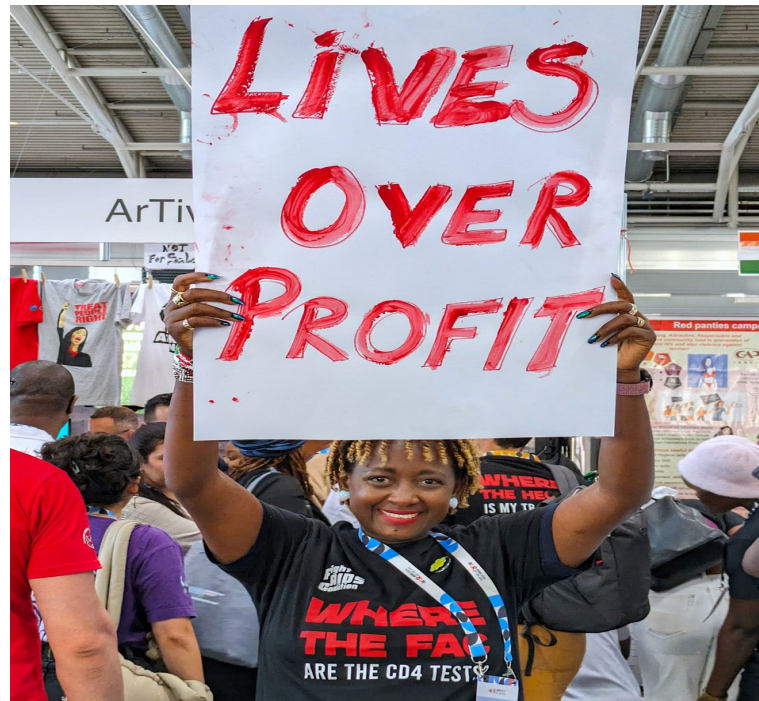
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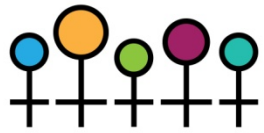


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What Is an Advocate?

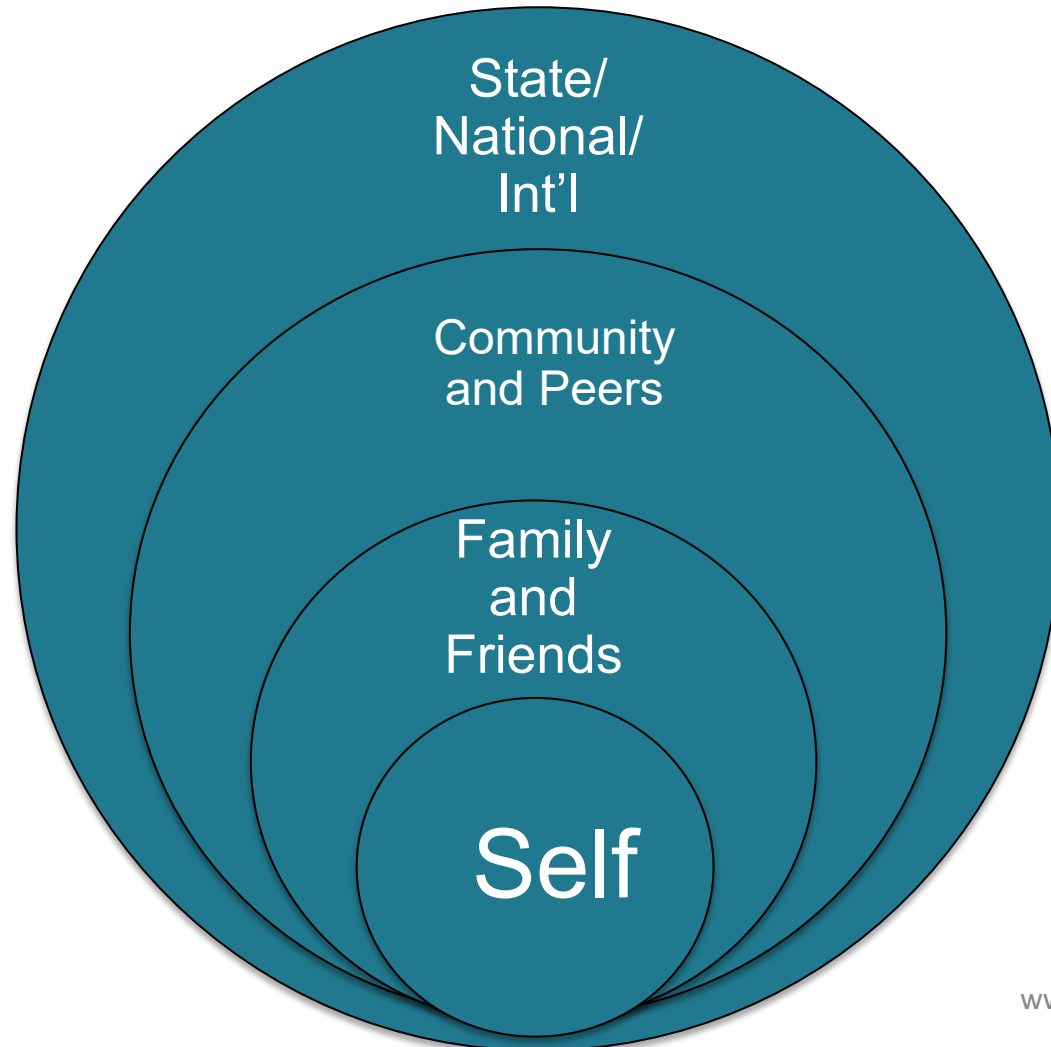
Advocate (n.): Person who takes steps to **support** **or recommend** a particular cause or policy





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The Many Forms of Advocacy



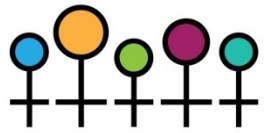


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How to Be an Advocate for Yourself and Others

- If being a public HIV advocate makes you nervous, other **types of advocacy** might be a first step
- Learning more about different forms of advocacy can help you realize that ...

You are already an advocate almost every day!



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Self-Advocacy

Every time you speak up for yourself or others,
you are an advocate





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Self-Advocacy in Healthcare

To get the best care, **speaking up for yourself**:

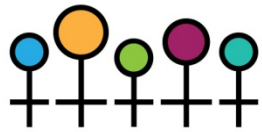
- **Learn** as much as you can about your options
- Make a **list of questions** before your appointment
 - Ask questions about medications
 - Ask your provider for an explanation
- **Take notes** during/immediately after visit
- Discuss any **health issues** with your provider
- Ask for **copies** of medical records
- Get **second opinion** for anything important
- Offer **feedback** to your healthcare team



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Individual Advocacy for Others

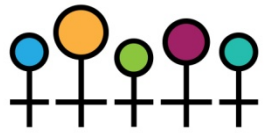
- Supporting someone when they need help, or trying to find a **solution** when someone has a problem
- Examples include:
 - Helping an elderly neighbor figure out local shuttle and bus schedules so they can continue to live independently
 - Writing or calling city officials to address an issue in your community



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HIV Peer Advocacy

- Supporting another person living with HIV around an HIV-related issue, based on your **shared experience**
- Examples include:
 - Linking a friend to a better healthcare provider after hearing they were not listened to
 - Volunteering at an HIV service organization as a resource for people who are newly diagnosed



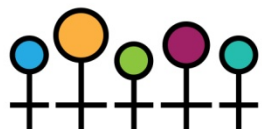
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Community Advocacy

- Involves groups of people acting together to bring about positive change
 - **When more than one person speaks up about an issue, the message can be even stronger**
- Examples include:
 - Speaking at a house of worship or other organization
 - Participating in an AIDS walk or other awareness event
 - Joining an advisory group at an HIV research site, service organization, or planning council
 - Using social media to speak up about your community

Whether you decide to go public with your status or keep it private, you can still be a community advocate

- Before getting involved, decide how comfortable you are disclosing your HIV status
- This is a personal decision that requires careful thought and discussion with people close to you



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Political/Public Advocacy

If you are interested in politics and want to help ***make a difference on a local, national or international level ...***

- You may consider becoming an advocate that focuses on policies that affect issues such as:
 - HIV treatment, funding, criminalization
 - Reproductive health/rights/justice, abortion rights, maternal health
 - Gender equity, LGBTQIA+ rights, gender-affirming care
- May involve calls, visits, or letters to government officials
- Most public or political advocacy groups provide some training



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Treatment Advocacy Through (Social) Media

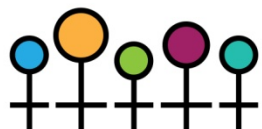
- **Social media** describes ways to communicate directly with large groups of people
 - Important tool to get information out to large groups at little or no cost
 - Allows you to write about issues in your own words
(Example: blogging on The Well Project's *A Girl Like Me*)
- **Mainstream media** distribute information via “gatekeepers” (journalists, producers, editors)
 - Requires going through gatekeepers
 - Can help communicate your message more widely



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Social Media: To-Do's

- Educate yourself about HIV using resources and websites like The Well Project
- Use an alias if you are not comfortable using your real name in online HIV groups, forums or websites
- Consider the platform's privacy settings
- Becoming a successful social media activist requires a lot of time and dedication (often voluntary)
- Just getting started? Consider joining an existing group or social media campaign



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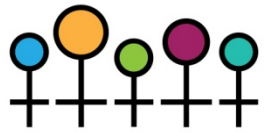
Why Language Matters in HIV Advocacy

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

#onewomanatatime

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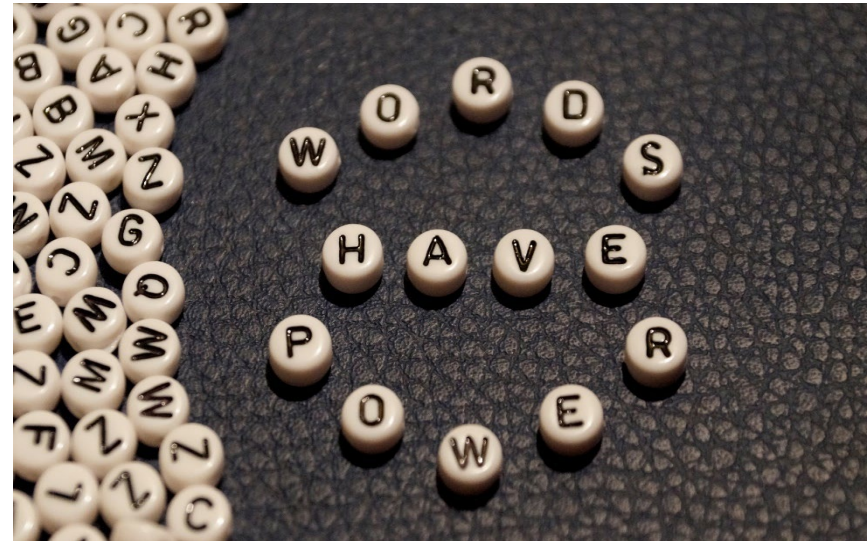


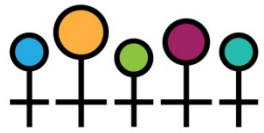
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Why Language Matters

The words people use to talk about HIV affect the way people living with HIV feel about *themselves*

These words also have an impact on how others *view* people living with HIV

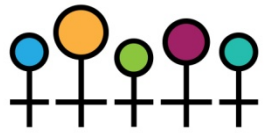




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Why Language Matters

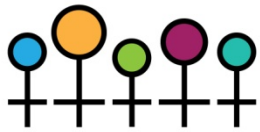
- Women may experience multiple forms of oppression, discrimination
- Often reinforced through language
 - An aggressive, powerful woman may be called “bitch”
 - A man with same qualities respected, considered “ambitious”
- Adding an HIV diagnosis can magnify this oppression
 - Affects self-worth, confidence, self-identity



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Why Language Matters

- Language that reinforces stigma and discrimination, repeated over years, affects health and well-being of women living with HIV
 - Stigma and stress can affect family, job, pregnancies
 - Stress of stigma can affect immune system
- HIV-related stigma affects prevention, deters people from being tested for HIV, makes disclosure harder
- ***Rare to find a woman living with HIV who has not felt stigmatized in some way***

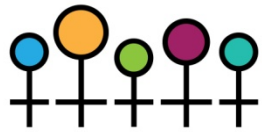


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What Is

People-First Language?

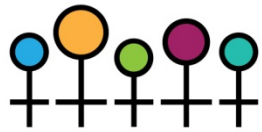
- Puts person before illness or label
- Describes and respects who they are, not what they happen to have been diagnosed with
- Helps eliminate prejudice; removes value judgments
- Describing people by labels or medical diagnoses devalues and disrespects them as individuals
 - Never hear “cancerous people” or “I am cancer positive”
 - Often hear “HIV-infected woman”
 - ***Woman living with HIV*** refers to person *before* mentioning their health condition



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The Denver Principles

- Document written by HIV advocates in 1983
- In opening words, Denver Principles called for use of person-first language:
*“We condemn attempts to label us as 'victims,' a term which implies defeat, and we are only occasionally 'patients,' a term which implies passivity, helplessness, and dependence upon the care of others. **We are 'People With AIDS.'**”*
- This narrative describes people living with HIV as human, valuable; shows respect, compassion



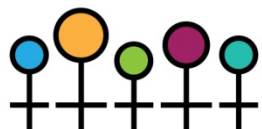
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Language and Empowerment

Important to note:

- Terms and phrases like “living with AIDS” and “I am HIV-positive” have been empowering to many people living with HIV; for others, may feel stigmatizing
- Words and language mean different things to different people, at different times in their lives

Allow others to define themselves as they wish; always ***start from a place of respect***



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Changing Language, Making Change

- For many women living with HIV, thinking about and making changes to their HIV language has been empowering
- For some, has led to pointing out stigmatizing ***language used by others***: family, friends, providers
- Others may begin ***reaching out to media*** when outlets use inappropriate language
- Some join campaigns working on language issues
 - HIV advocates have won changes to stigmatizing language used by ***large institutions*** (e.g., US CDC)



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Changing Language, Making Change

- These are powerful ways to be an advocate; they **don't** all involve being a loud voice in a big crowd
- Each time anyone questions (even to themselves) use of a phrase that fuels stigma and ignorance, they contribute to changing our culture from one that disrespects women living with HIV, to one that uses language to support ***power and dignity of all women***



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Taking Your Place at the Table in HIV Planning and Decision Making

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

#onewomanatatime

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Having a Voice in HIV Decision Making

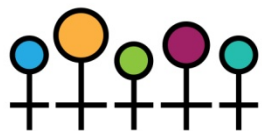
Your voice is important!

People living with HIV are experts of their own lives and what the response should look like

You can inform:

- How HIV funding is used
- What HIV policies are put in place
- How research studies are conducted
- How HIV organizations are run





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Having a Voice in HIV Decision Making

Due to hard work by HIV advocates, **most agencies involved in HIV work now include people living with HIV**

- Service organizations
- Planning councils
- Local and national HIV research networks



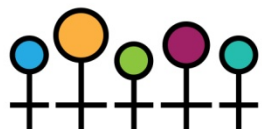


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Coalitions and Networks

- Population or issue specific
- Can be local, regional, national, or international
- Different levels of involvement
- Great way to learn issues important to people living with HIV
- Build community with others who share your passion





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Community Advisory Boards (CABs)

- HIV organizations, research sites, some health centers have CABs
- **Each type of CAB includes people living with HIV**
- Some CABs are very active; others meet infrequently and have little impact
- Government-funded clinical trials in the US must set up CABs



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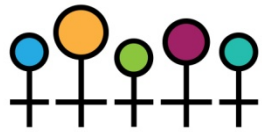
Community Advisory Boards (CABs)

- Participating in a CAB can also help you:
 - Make new friends
 - Get a better idea of what a project or organization provides
 - Build skills and knowledge if you are looking for a job
- If you're not sure whether you have anything to offer the CAB, **talk to current CAB members**
 - They may help you identify strengths that you didn't know you had!

HIV Planning Councils



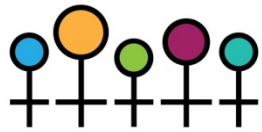
- Located in urban areas with many people living with HIV
- Set priorities for distribution of government funding based on services most needed by local people living with HIV
- Members attend full council meetings, usually at least one council committee
- *Time commitment: 4-10 hours/month*



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HIV Care Consortia

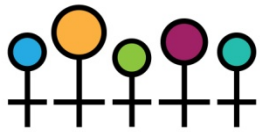
- Regional or statewide planning groups in rural areas
- Provide a broad-based community response to the HIV epidemic in their region
- Ensure that high-quality, comprehensive health and support services are available to people living with or affected by HIV
- Meet at least every 3 months; many members participate on at least 1 committee
- *Time commitment: 1-5 hours/month*



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Institutional Review Boards (IRBs)

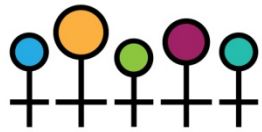
- Also known as Ethical Review Boards (ERBs) or Independent Ethics Committees (IECs)
- Protect study participants by making sure trials are safe and ethical – an IRB can stop a trial that is not run properly
 - All US research hospitals or centers conducting studies must have IRBs
 - All trials reviewed and approved by IRB before they begin
- Other countries also have ethics committees
 - Design and function vary by country



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Institutional Review Boards (IRBs)

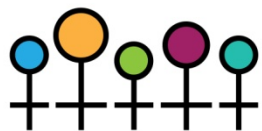
- As a member of an IRB, **be prepared to:**
 - Spend many hours reading trial designs, attending meetings, talking with other IRB members
 - Important that people living with HIV be involved in IRBs; members and researchers need to hear your concerns
- *Time commitment: **big***
 - An IRB is probably not the easiest way to get started in community advocacy, but it is a great way to learn a **lot!**
- Contact clinical trial sites where you live for IRB opportunities and requirements



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Boards of Directors (BOD)

- **All non-profit HIV service organizations have a Board of Directors (BOD)**
 - Legal and financial responsibility for organization
 - Sets policy, hires and fires the executive director
 - Makes sure the organization is serving its chosen mission
- *Time commitment: 2-4 hours/month*
- Many boards require members to give or raise a certain amount of money
 - Some BODs make exceptions to include people who have valuable things to offer but cannot help raise money



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Tips for Successful Advocacy

- Community involvement is an important way of helping HIV groups serve their purpose
- Being an advocate on a board/planning council allows you to give your opinion and stand up for what you feel is important to you and your community
- However, **it also adds extra responsibilities and takes up some of your time**



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Taking Care of Yourself: Self-Care for Advocates

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

#onewomanatathetime

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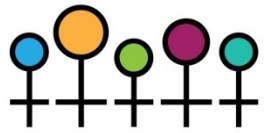
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Balancing Health with Advocacy

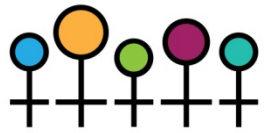
- Remember, you and your health come first
- Think about your goals before joining a group
- Limit yourself to only those projects you can complete
- Work with people who understand the issues and support your efforts
- Try not to let disagreements become personal
- Learn from long-time advocates
- Think before you speak!
- Be aware of power dynamics with others
- Recognize you have a voice. ***Your experiences are valid!***



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Self-Care for Advocates

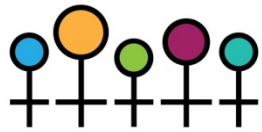
- If you don't take time to refill yourself, you put yourself at risk for burnout and depression
 - Burn out: feeling cynical about your advocacy, doubting your effectiveness, feeling overwhelmed, numb, frustrated, bored, unappreciated
 - Depression: feeling hopeless, lacking interest in many activities, having trouble sleeping or concentrating, not taking HIV treatment or managing your disease



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Self-Care for Advocates

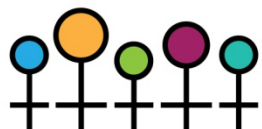
- Self-care can break stress cycle leading to burnout, enable you to recover energy and passion
- What drains you? What re-energizes you?
 - Do you need more sleep? Time outdoors? A good laugh? Time to journal? Connecting with friends?
- You will have so much more to share with others if you take time to care for yourself



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Many Possibilities

- *Becoming an advocate for yourself, another person, or large numbers of people can be rewarding and empowering*
 - Being an advocate does not have to mean speaking to the media, meeting with politicians, or participating in rallies and demonstrations
 - There are many ways to be an advocate that are just as valuable
- Take your time in looking at your options and finding the best fit for you!



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Learn More!

*Scan the QR code for **more resources** on this topic from The Well Project, and to access the **video and survey** following this session!*



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