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How to Be an Advocate for Yourself and Others

Last updated: April 21, 2025

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

#onewomanatatime

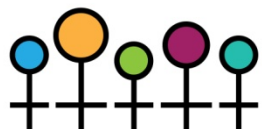
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What Is an Advocate?

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



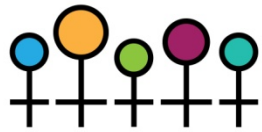


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How to Be an Advocate for Yourself and Others

- If being a public HIV advocate makes you nervous, other types of advocacy might be a first step
 - You may know that you want to do *something*, but you may not know what to do or where to start
- Learning more about different forms of advocacy can help you realize that...

You are already an advocate almost every day!

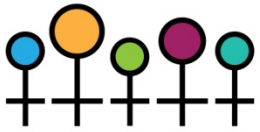


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Self-Advocacy

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

- It may be as simple as:
 - Letting the cashier at the grocery store know that she overcharged you for an item
 - Telling your children not to speak to you disrespectfully
- It can also be more difficult, like:
 - Fighting for disability status
 - Filing a complaint with human resources for discrimination or harassment at your job

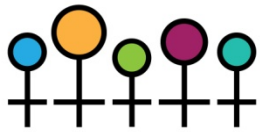


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Self-Advocacy in Healthcare

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

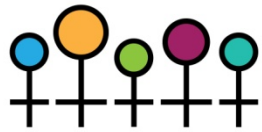
- Learn as much as you can about your options
- Make a list of questions before your appointment
- Ask questions about medications
- Ask provider for an explanation
- Take notes during/immediately after visit
- Discuss any health issues with your provider
- Ask for copies of medical records
- Get second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



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Individual Advocacy for Others

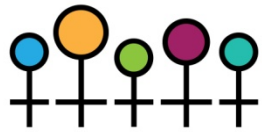
- Supporting someone when they need help, or trying to find a solution when someone has a problem
- Examples include:
 - Helping an elderly neighbor figure out local shuttle and bus schedules so she or he can continue to live independently without driving
 - Contacting school officials after learning a child was bullied at school
 - Practicing or role-playing a difficult conversation that a friend expects to have with her boss
 - Writing or calling city officials to improve or 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:
 - Helping someone in your support group who is having trouble understanding HIV treatment materials
 - Linking a friend to a better healthcare provider after hearing she was not getting her questions answered or did not get the care she needed
 - Volunteering at an AIDS Service Organization (ASO) to be a resource/peer advocate for people who are newly diagnosed
 - Helping people who are in prison or jail get their HIV medications, either by advocating for someone you know or by volunteering for an organization that is involved in this work



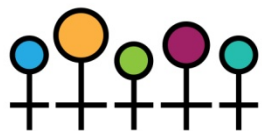
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Community Advocacy

- A larger version of the individual advocacy that you may already practice in your daily life
- 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**
- 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

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

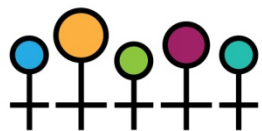
- Examples include:
 - Speaking at a house of worship or other organization about the needs of people living with HIV or HIV prevention
 - Getting involved with local HIV awareness and fundraising events by participating in an AIDS walk or another event
 - Joining a patient advisory group at an HIV research site, an AIDS service organization, or an HIV planning council
 - Advocating on behalf of your community through the media, including social media



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Treatment Advocacy Through (Social) Media

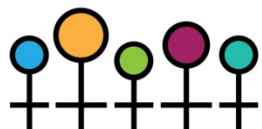
- **Social media** describes ways to communicate or share information with large groups of people
 - For example: blogs, chatrooms, videos Facebook, X (Twitter), Instagram, LinkedIn, YouTube
 - Important tool to get information out to large groups at little or no cost
- **Mainstream media** distribute information via gatekeepers (journalists, producers, editors):
 - You must go through the gatekeepers
 - Responding to interview requests can help communicate your message more widely



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Social Media: To Do's

- 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
- Educate yourself about HIV using resources and websites like The Well Project
- 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

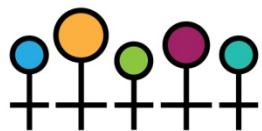


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Political/Public Advocacy

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
 - Gender equality, women-centered health care
- May involve calls, visits, or letters to government officials
- Most public or political advocacy groups provide some training
- Advocacy for reproductive rights and justice, including abortion rights, has become very important



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Advocacy Groups

There are many amazing advocacy organizations *fighting for the rights of people with HIV*

Global advocacy groups:

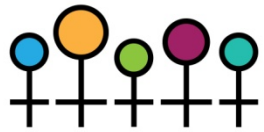
- ATHENA Network
- CARE
- Global Coalition on Women and AIDS
- Int'l Community of Women Living with HIV
- Frontline AIDS

Provider-based advocacy groups:

- Ryan White Medical Providers Coalition
- HIV Medicine Association
- American Academy of HIV Medicine

US-based advocacy groups:

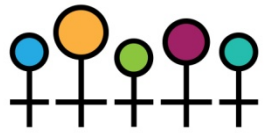
- Advocates for Youth
- AIDS United
- Black AIDS Institute
- Housing Works
- Iris House
- National Minority AIDS Council (NMAC)
- National Women and AIDS Collective (NWAC)
- Positive Women's Network - USA
- SisterLove
- Treatment Action Group (TAG)



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Self-Care for Advocates

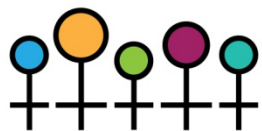
- If you don't take time to refill yourself, you put yourself at risk for burnout and depression
 - Burn out: feeling cynical about your advocacy, doubting your effectiveness, feeling overwhelmed, numb, frustrated, bored, unappreciated
 - Depression: feeling hopeless, lacking interest in many activities,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



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Self-Care for Advocates

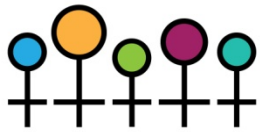
- Self-care can break stress cycle leading to burnout, enable you to recover energy and passion
- What drains you? What re-energizes you?
 - Do you need more sleep? Time outdoors? A good laugh? Time to journal? Connecting with friends?
- You will have so much more to share with others if you take time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

To learn more about these topics, please read the full fact sheets:

- [How to Be an Advocate for Yourself and Others](#)
- [A Place at the Table: Having a Voice in HIV Planning and Decision Making](#)
- [Advocating for Women Living With HIV in Prisons or Jails in the US](#)
- [Sharing Your Expertise in Mainstream Media](#)
- [Social Media, HIV Advocacy, and Your Voice](#)

For more fact sheets and to connect to our community of women living with HIV, visit:

- 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