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# How to Be an Advocate for Yourself and Others

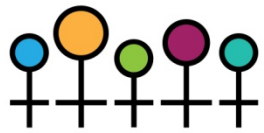
*Last updated: August 19, 2022*

*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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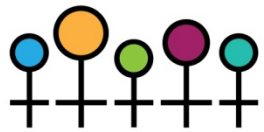


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# What Is an Advocate?

*Advocate (n.):* A person who **publicly supports** **or recommends** a particular cause or policy.



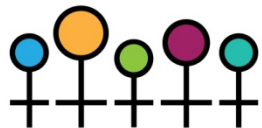


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# How to Be an Advocate for Yourself and Others

- 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!***

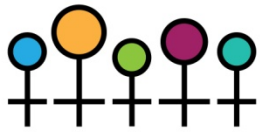


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# Self-Advocacy

**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

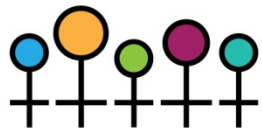


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# Self-Advocacy in Healthcare

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

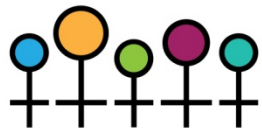
- Learn as much as you can about your options
- Make a list of questions before your appointment
- Ask questions about medications
- Ask provider for an explanation
- Take notes during/immediately after visit
- Discuss any health issues with your provider
- Ask for copies of medical records
- Get second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



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# Individual Advocacy for Others

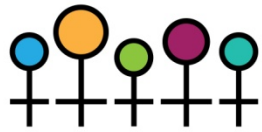
- Supporting someone when they need help, or trying to find a solution when someone has a problem
- Examples include:
  - Helping an elderly neighbor figure out local shuttle and bus schedules so she or he can continue to live independently without driving
  - Contacting school officials after learning 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 health care 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



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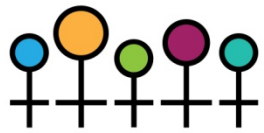
# Community Advocacy

- 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**

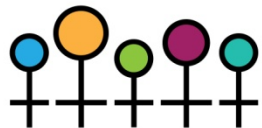
- Examples include:
  - Speaking at a house of worship or other organization about the needs of people living with HIV or HIV prevention
  - Getting involved with local HIV awareness and fundraising events by participating in an AIDS walk or another event
  - Joining a patient advisory group at an HIV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



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# Treatment Advocacy Through Social Media

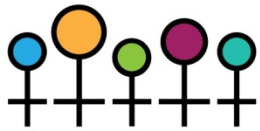
- Social media describes ways to communicate or share information with large groups of people
- Examples include: blogs, chatrooms, videos  
Facebook, Twitter, Instagram, LinkedIn, YouTube
- Important tool for non-profit organizations, individual advocates to get information out to large groups at little or no cost



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# Social Media: To dos

- 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

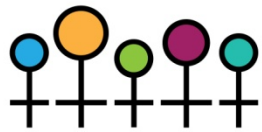


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# Political/Public Advocacy

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
  - HIV funding
  - Gender equality
  - Women-centered health care
  - HIV criminalization
- May involve calls, visits, or letters to government officials
- Most public or political advocacy groups provide some training



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# Advocacy Groups

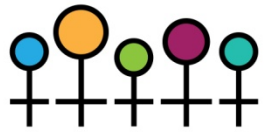
There are many amazing advocacy organizations *fighting for the rights of people with HIV*

## Global advocacy groups:

- ATHENA Network
- CARE
- Global Coalition on Women and AIDS (GCWA)
- International Community of Women Living with HIV (ICW)
- Frontline AIDS

## US-based advocacy groups:

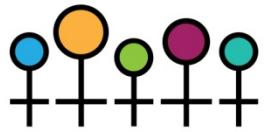
- Advocates for Youth
- AIDS United
- Black AIDS Institute
- Housing Works
- National Minority AIDS Council (NMAC)
- National Women and AIDS Collective (NWAC)
- Positive Women's Network - USA
- SisterLove
- Treatment Action Group (TAG)



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# Self-Care for Advocates

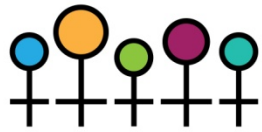
- If you don't take time to refill yourself, you put yourself at risk for burnout and depression
  - Burn out: feeling cynical about your advocacy, doubting your effectiveness, feeling overwhelmed, numb, frustrated, bored, unappreciated
  - Depression: feeling hopeless, lacking interest in many activities,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

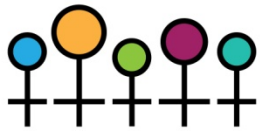


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# Many Possibilities

- *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!

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](#)

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

- [www.thewellproject.org](http://www.thewellproject.org)
- [www.facebook.com/thewellproject](https://www.facebook.com/thewellproject)
- [www.twitter.com/thewellproject](https://www.twitter.com/thewellproject)

Want more info on social media? See our webinar: [Using Social Media as a Tool for Empowerment & Advocacy](#)