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How to Be an Advocate for Yourself and Others

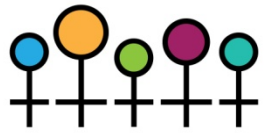
Last updated: March 18, 2019

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

#onewomanatatime

www.thewellproject.org

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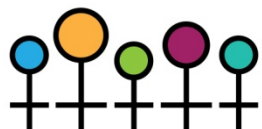


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What Is an Advocate?

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



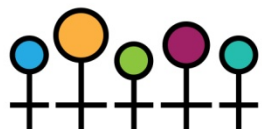


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How to Be an Advocate for Yourself and Others

- 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!

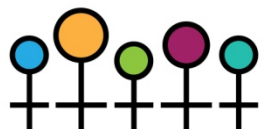


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Self-Advocacy

**Every time that 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

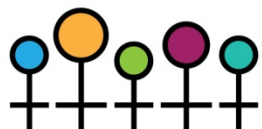


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Self-Advocacy in Healthcare

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

- Learn as much as you can about HIV, your health, and your treatment options
- Take notes during or immediately after your visit so that you can remember the important points when you get home **and/or**
- Invite a friend or family member to the visit who can also take notes, and help you remember
- Ask for and keep copies of all of your medical records, such as lab results
- Get a second opinion about any important health issue

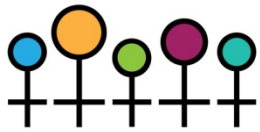


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Self-Advocacy in Healthcare

Other ways you can *advocate for yourself with your healthcare team:*

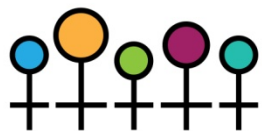
- Make a list of questions for your healthcare provider before your appointment
- Ask questions about the medications you're taking, or new medications you've heard about
- Anytime you don't understand something your provider says, ask for an explanation
- Discuss health issues that are on your mind with your provider – **even if they do not seem like a big deal**
- Offer suggestions and feedback to your healthcare team about ways to improve services for people with HIV



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Individual Advocacy for Others

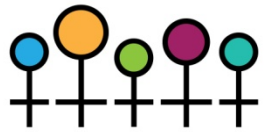
- Supporting someone when they need help, or trying to find a solution when someone has a problem
- Examples include:
 - Helping an elderly neighbor figure out local shuttle and bus schedules so she or he can continue to live independently without driving
 - Contacting school officials after learning a child was bullied at school
 - Helping a friend practice or role-play a difficult conversation she 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

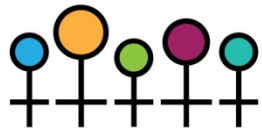
- Supporting another person living with HIV around an HIV-related issue, based on your shared experience
- Examples include:
 - Helping someone in your support group who is having trouble understanding HIV treatment materials
 - Linking a friend to a better health care provider after hearing she was not getting her questions answered or 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 to affect 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

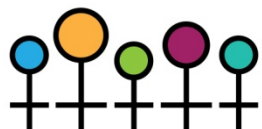


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Community Advocacy

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

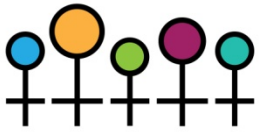
- Examples include:
 - Speaking at a church or other organization about the needs of people living with HIV or HIV prevention
 - Getting involved with local HIV awareness and fundraising events by participating in an AIDS walk or other AIDS event
 - Joining a patient advisory group at an HIV research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



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Treatment Advocacy Through Social Media

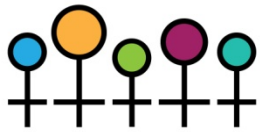
- Social media describes ways to communicate or share information with large groups of people
- Examples include: blogs, chatrooms, videos
Facebook, Twitter, Instagram, LinkedIn, YouTube
- Important tool for non-profit organizations, individual advocates to get information out to large groups for little 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
- 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

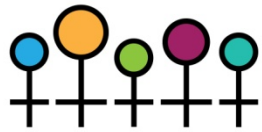


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Political/Public Advocacy

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

- You may consider becoming an advocate that focuses on policies that impact 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 form of training



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Advocacy Groups

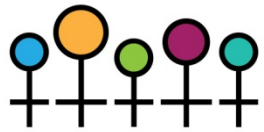
There are many amazing advocacy organizations *fighting for the rights of people with HIV*

GLOBAL ADVOCACY GROUPS:

- ATHENA Network
- CARE
- Center for Health and Gender Equity (CHANGE)
- Global Coalition on Women and AIDS (GCWA)
- International Community of Women Living with HIV (ICW)
- International HIV/AIDS Alliance

US-BASED ADVOCACY GROUPS:

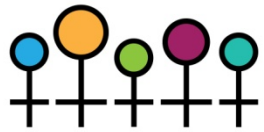
- Advocates for Youth
- AIDS United
- Black AIDS Institute
- Housing Works
- National Minority AIDS Council (NMAC)
- National Women and AIDS Collective (NWAC)
- Positive Women's Network - USA
- SisterLove, Inc.
- Treatment Action Group (TAG)



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Self-Care for Advocates

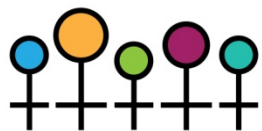
- Being an HIV advocate can be rewarding, but if you don't take time to refill yourself, you put yourself at risk for burnout and depression
 - Burn out: feeling cynical about your work, doubtful of your effectiveness or overwhelmed, numb, frustrated, bored, unappreciated
 - Depression: feeling hopeless, 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

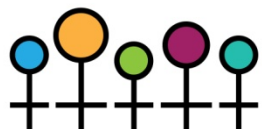
- Self-care can break stress cycle leading to burnout, enable you to recover energy and passion
- What drains you? What fills you up or re-energizes you?
 - Do you need more sleep? Time outdoors? A good laugh? Time to journal? Evening out with friends?
- You will have so much more to share with others 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
- www.facebook.com/thewellproject
- www.twitter.com/thewellproject

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