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# How to Be an Advocate for Yourself and Others

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

#onewomanatatime

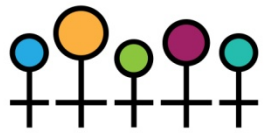
[www.thewellproject.org](http://www.thewellproject.org)

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# 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

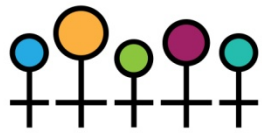
- If being a public HIV advocate makes you nervous, other types of advocacy might be a first step
  - You may know that you want to do *something*, but you may not know what to do or where to start
- Learning more about different forms of advocacy can help you realize that...

***You are already an advocate almost every day!***

# 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

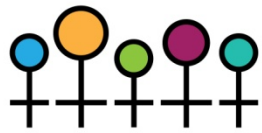


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# Self-Advocacy in Healthcare

To get the best care possible, ***speak up for and support 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

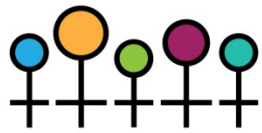


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# Self-Advocacy in Healthcare

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

# 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



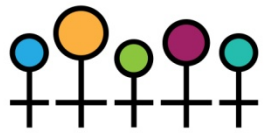
# Community Advocacy

- 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

# Community Advocacy

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

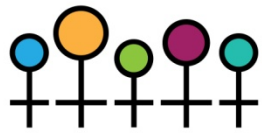
- Examples include:
  - Speaking at a church or other organization about the needs of people living with HIV or HIV prevention
  - Getting involved with local HIV awareness and fundraising events by participating in an AIDS walk or other AIDS event
  - Joining a patient advisory group at an HIV research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

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

# 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
- Center for Women and HIV Advocacy (HIV Law Project)
- National Minority AIDS Council (NMAC)
- National Women and AIDS Collective (NWAC)
- Positive Women's Network - USA
- SisterLove, Inc.
- 30 for 30
- Treatment Action Group (TAG)

# 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

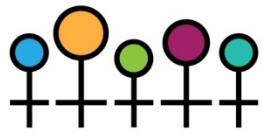
# Self-Care for Advocates

- 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



# 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](#)