

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

#thewellproject



What Is an Advocate?

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





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



Self-Advocacy in Healthcare

To get the best care possible, <u>speak up for and support</u> 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



Self-Advocacy in Healthcare

Other ways you can <u>advocate for yourself with your</u> <u>healthcare team</u>:

- 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 HIVrelated 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



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



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



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
- 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)

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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



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!



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 <u>Voice in HIV Planning and</u>
 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: <u>Using</u>

Social Media as a Tool for Empowerment & Advocacy