How to Be an Advocate for Yourself and Others

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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.): A person who **publicly supports or recommends** a particular cause or policy.
• 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!*
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
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 *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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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
  – 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
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 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.

- 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.
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
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 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
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)
- 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, 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 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
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!
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](http://www.facebook.com/thewellproject)
- [www.twitter.com/thewellproject](http://www.twitter.com/thewellproject)

Want more info on social media? See our webinar: **Using Social Media as a Tool for Empowerment & Advocacy**

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