How to Be an Advocate for Yourself and Others

Learn about ways you can be an HIV advocate, speak up for yourself or others, and make a difference on an individual or community level.

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What is an advocate? By definition, an advocate is a person who publicly supports or recommends a particular cause or policy. However, if the thought of being an HIV advocate in public makes you nervous, there are other types of advocacy that 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. This is why 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

You might not think of yourself as an advocate, but in many ways you already are. 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 she overcharged you for an item or telling your children not to speak to you disrespectfully. It can also be more difficult, like fighting for disability status or filing a complaint with human resources for discrimination or harassment at your job. You are likely an advocate for yourself or someone else every day in one way or another.

Self-Advocacy in Health Care

Much of your advocacy as a person living with HIV may revolve around your health and the health care you receive. To get the best care possible, it is important to speak up for and support yourself. Below are some ways you can advocate for yourself with your health care team:

- Learn as much as you can about HIV, your health, and your treatment options
- Make a list of questions for your health care provider before your appointment
- Ask questions about the medications you are taking or new medications you have heard about
- Ask your health care provider for an explanation anytime you do not understand something he or she says
- Take notes during or immediately after your visit to help you remember the important points when you get home, or invite a friend or family member to the visit who can take notes for you
- Discuss health issues with your provider that are on your mind, even if they do not seem like a big deal
- Ask for and keep copies of all your medical records such as lab results
- Get a second opinion about any important health issue
- Offer suggestions and feedback to your health care team about ways to improve services for people with HIV

Individual Advocacy for Others and Peer

Advocacy

Individual advocacy refers to supporting someone when they need help or trying to find a solution when someone has a problem. You likely advocate for other people often in your daily life, yet you may not think of it as advocacy.

Examples of being an individual advocate for others:

- 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

Examples of being an HIV peer advocate:

- 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
- Helping people who are in prison or jail get their HIV medications, either by advocating for someone you know or by volunteering for an organization that is involved in this work. For more information, see our fact sheet on Advocating for Women Living With HIV in Prisons or Jails in the US.

Community Advocacy

It can be a wonderful thing to advocate on your own or someone else's behalf. It can also be very empowering to work together with a group of people; when more than one person speaks up about an issue, the message can be even stronger.

Community advocacy is a larger version of the individual advocacy that you may already practice in your daily life. The difference is, community advocacy involves groups of people acting together to bring about positive change. Before getting involved, decide how comfortable you are about 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.

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There are many things you can do. For example, you can speak at a houseof worship or other organization about the needs of people living with HIV or about HIV prevention. You can get involved with local HIV awareness and fundraising events by participating in an AIDS walk or another event. You can join a patient advisory group at an HIV research site, an AIDS service organization, or an HIV planning council. For more information about joining advocacy groups in the community, read our fact sheet A Place at the Table.

You can also advocate on behalf of your community through the media, including social media. To learn more, see our fact sheets on Sharing Your Expertise in Mainstream Media and on Social Media, HIV Advocacy, and Your Voice.

Political/Public Advocacy

If you are interested in politics and policy, you may want to help make a difference on a local, national or international level. In that type of advocacy role, you would focus on policies that affect HIV treatment, funding, gender equality, women-centered health care, criminalization, or other issues. You might be asked to call, visit, or write letters to government officials. If this is of interest to you, most groups will provide some form of training to help people learn how to become public or political advocates.

After the recent US Supreme Court decision against abortion rights and the passage of local laws limiting gender-affirming care, advocacy for reproductive rights and justice has become even more important. See our fact sheets on Abortion Laws and HIV in the US and on Sexual and Reproductive Health, Rights, Justice, Pleasure, and HIV for more information on these issues.

Around the globe, there are many amazing advocacy organizations fighting for the rights of people living with HIV. Below are some examples:

Global advocacy groups:

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

US-based advocacy groups:

- Advocates for Youth
- AIDS United
- Black AIDS Institute (BAI)

- Housing Works
- Iris House
- National Minority AIDS Council (NMAC)
- National Women and AIDS Collective (NWAC)
- Positive Women's Network - USA
- SisterLove
- Treatment Action Group (TAG)

Provider-based advocacy groups:

While these groups are primarily for medical professionals, you can join them as a patient advocate.

- Ryan White Medical Providers Coalition
- HIV Medicine Association
- American Academy of HIV Medicine

Serving from a Full Cup: Self-Care for Advocates

Serving as an HIV advocate can be a very rewarding experience, especially when you see the difference you are making in people's lives. However, if you are constantly giving and not taking time to refill yourself, you put yourself at risk for burnout. Burnout is not a clinical diagnosis, but rather a state of physical and/or emotional exhaustion that is often accompanied by a loss of passion or a sense of detachment from your advocacy work.

> Caring for yourself ... can break the stress cycle that leads to burnout and let you recover your energy and passion.

If you are burned out, you may find yourself feeling cynical about your advocacy, or doubt your effectiveness. You may also find yourself feeling overwhelmed, numb, frustrated, bored, or unappreciated. If you find yourself also feeling hopeless, lacking interest in many activities (not

just work), having trouble sleeping or concentrating, or not taking your HIV drugs, you may be depressed. Unlike burnout, depression is a medical condition. If you think you may be depressed, it is important to talk with your health care provider. For more information, see our fact sheet on Depression, Women, and HIV.

Just as each tide ebbs and flows, each person has natural and necessary periods of activity and rest. Exhaustion is a normal reaction to high levels of stress and is not necessarily a sign of illness. HIV advocacy can be particularly stressful because there are so many areas and people in need of advocacy, and people's lives are at stake. But denying yourself proper rest and replenishment, even when others are in need and the cause is worthy, can have serious negative effects on your mental and physical health.

Caring for yourself ("self-care") – which may include taking some of the very advice you are sharing with others – can break the stress cycle that leads to burnout and let you recover your energy and passion. It is important for you to pay attention not only to what drains you but also to what re-energizes you. This will be different for each person. Do you need more sleep? Time outdoors? A good laugh? Some time to journal? Connecting with friends? All of these are opportunities to re-energize and avoid burnout. For more ideas, see our fact sheet on Stress Management.

Consider what it would look like for you to take care of yourself before serving others. Imagine how much more you will have to share – with others and with yourself.

Many Possibilities

There are many ways to be an advocate. Some of them are larger and require a lot of time and commitment. Some are more public and may seem confrontational. However, being an advocate does not necessarily mean speaking to the media, meeting with politicians, or participating in rallies and demonstrations. There are many other ways to be an advocate that are just as valuable. Take your time to look at your options and find the best fit for you. Becoming an advocate for yourself, another person, or large numbers of people can be very rewarding and empowering.

The Well Project is a non-profit organization whose mission is to change the course of the HIV/AIDS pandemic through a unique and comprehensive focus on women and girls across the gender spectrum. Visit their website, https://www.thewellproject.org/, to access fact sheets (English and Spanish), blogs, and advocacy tools, and to join a global community of women living with HIV.

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