



Speak Up

In a blog post titled “How to Be an Advocate for Yourself and Others,” The Well Project shares how you can make a difference on an individual or community level. Here is an edited excerpt.

January 6, 2025 By [The Well Project](#)

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, other types of advocacy might be a first step.

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 at your job for discrimination or harassment. In one way or another, you are likely an advocate for yourself or someone else every day.

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 they say.
- 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 to take notes for you.

- Discuss with your provider any health issues that are on your mind, even if they do not seem like a big deal.
- Ask for copies of all your medical records, such as lab results.
- Get a second opinion about any important health issue.
- Offer your health care team suggestions and feedback 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 they 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 that her questions were not being answered or she was not getting the care she needed;
 - Volunteering at an AIDS service organization (ASO) as a resource/peer advocate for newly diagnosed people;
 - Helping people in prison or jail obtain their HIV medications, either by advocating for someone you know or by volunteering for an organization involved in this work.

Community Advocacy

It can be wonderful to advocate for yourself or on 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, the message can be even stronger.

Community advocacy is a larger version of the individual advocacy you may already practice in your daily life. The difference is that community advocacy involves groups of people acting together to bring about positive change. Before becoming involved, decide how comfortable you are about disclosing your HIV status. This personal decision requires careful thought and discussion with people close to you. Whether or not you decide to go public with your status, you can still be a community advocate.

You can advocate in a number of ways. For example, you can speak about the needs of people living with HIV or about HIV prevention at a house of worship or at an organization. You can raise HIV awareness and funds for an organization by participating in a local AIDS walk or other event. You can join a patient advisory group at an HIV research site, an ASO or an HIV planning council. You can also advocate on behalf of your community through the media, including social media.

Political/Public Advocacy

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

After the recent U.S. 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.

Many amazing advocacy organizations are fighting for the rights of people living with HIV:

Global advocacy groups: ATHENA Network, CARE, CHANGE, Frontline AIDS, the Global Coalition on Women and AIDS, International Community of Women Living with HIV;

U.S.-based advocacy groups: Advocates for Youth, AIDS United, Black AIDS Institute, Housing Works, Iris House, National Women and AIDS Collective, NMAC, Positive Women's Network—USA, SisterLove, Treatment Action Group;

Provider-based advocacy groups: While these groups are primarily for medical professionals, you can join them as a patient advocate: American Academy of HIV Medicine, HIV Medicine Association, Ryan White Medical Providers Coalition.

Serving From a Full Cup: Self-Care for Advocates

Serving as an HIV advocate can be very rewarding, 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'll be at risk for burnout. Burnout is a state of physical and/or emotional exhaustion often accompanied by a loss of passion or a sense of detachment from your advocacy work.

If you are burned out, you may feel cynical about your advocacy or doubt your effectiveness. You may also feel 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, talk with your health care provider.

Exhaustion is a normal reaction to high levels of stress and 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.

Self-care (caring for yourself)—which may include taking some of the very advice you are sharing with others—can break the stress cycle that leads to burnout and help you recover your energy and passion. It is important to pay attention not only to what drains you but also to what reenergizes you. This differs for each person. Do you need more sleep? Time outdoors? A good laugh? Some time to journal? To connect with friends? All of these are opportunities to reenergize.

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 both others and with yourself.

Many Possibilities

There are many ways to be an advocate. Some 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. Many other forms of advocacy are just as valuable. Take time to consider 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 nonprofit organization whose mission is to change the course of the HIV and AIDS pandemic through a unique and comprehensive focus on women and girls across the gender spectrum. For more information, go to thewellproject.org.