

# Blow Your Own Horn

December 14, 2010

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Advocate for what you need—and deserve.

There's much more to living with HIV/AIDS than health care alone. Staying healthy requires decent housing, income, food, a job, maybe childcare and some kinds of therapy. These things are available, but you need to ask for them—sometimes loudly. Speak up, stand up, reach out—do what it takes to get the services you need. Your health and welfare depend on it, and you deserve it.

Mechelle Jones knows this from both sides of the coin. In 1995 she was told she had AIDS. “Not [just] HIV,” she says. “I had AIDS.” At the time, she was in the hospital with bacterial pneumonia (her third bout that year). When she got out, she returned to “my pacifier,” crack.

Today, Jones's virus is undetectable. Her drug use is a thing of the past, and she is an admissions coordinator at HELP/PSI, a large HIV care program in New York City.

But she didn't make the journey alone.

“At first it was really hard for me to ask people for help,” Jones says, “because I always thought I was smart; I knew how to do things. But now I needed a different kind of information and help.”

## **You Can't Do This Alone**

The first step, as Jones realized, is asking for help. Start at your hospital, clinic or doctor's office. Ask to talk with the case manager or social worker. They are trained to help you get financial support and find housing, food, a job, childcare and other services.

If your clinic or doctor doesn't meet your needs, turn to a local AIDS service organization (ASO) or community-based organization (CBO). At [directory.poz.com](http://directory.poz.com) you will find a national services directory. Type in your zip code and get information on all the nearest organizations and resources, including churches (many offer help for people living with HIV).

Jones's first requirement was housing, and her case manager helped. The U.S. Department of Housing and Urban Development (HUD) assists low-income people with HIV/AIDS and their families

through the Housing Opportunities for Persons With AIDS (HOPWA) program. If you don't qualify for HOPWA or can't find an agency that provides that program, don't give up. Housing is your right, and other government programs can help put or keep a roof over your head.

But advocating for yourself isn't easy. "You can't do this alone," Jones says. "Find a support network. It may be NA [Narcotics Anonymous], AA [Alcoholics Anonymous] or another group. You need support to stay clean, to handle life and HIV." Jones first turned to a women's HIV support group, then to her church. "I was raised in church," she says, "so I went back to what I knew."

### **HIV Is Only A Part Of Life's Journey**

To help other people with HIV get services and support, Jones encourages them to build their self-esteem. "You can't let AIDS define you," she says. "It's just one part of the journey. I advocate for what I need because I am supposed to have it. I deserve it."

Also, know your rights. For instance, you deserve protection from violence or discrimination based on having HIV. You deserve help if you want to disclose your HIV status to family, friends or an employer. You deserve good health care and access to medications.

What if people with HIV are afraid to ask for the services they need? "I tell them, 'You have to be able to stand up for yourself. Maybe someone told you once that you'd never be anything. Get past that hurt and pain. It's a process, and it may take therapy. Once you feel good about yourself, you won't let people take advantage of you.'"

### **Take A Chance On Trust**

Working with a case manager isn't all that different from working with your health care provider. In order to get the most out of the relationship, trust and honesty are necessary, and that process needs to go both ways.

Jones found her first case manager cold and unsympathetic, so she asked for (and got) a different one. If one of her clients encounters the same problem, she says, "I would tell them to ask for another case manager. They are there to serve you. That's their job. If they're not making you feel like a person, you can fire them. They work for you."

And you have to do your part to build the relationship. At first, Jones says, "I felt, 'You don't know me. I have to explain things to you, and then you are going to judge me. Forget that—just sign what I need so I can go ahead.' But it didn't work. They wanted to know about my kids, how I got HIV." As it turned out, Jones being honest with the case manager was just as important as her being honest with her doctor. Case managers can help a lot more if you tell them about your life, the things you find hard and the burdens you carry.

People coming out of jail or prison, Jones says, face a particularly high hurdle: "In jail, the case manager's job is to control you. They didn't even call you by your name, but by a number."

When you get out, things are different. "Now you have choices. People do care about you." You

have to try, though, which may mean taking a chance. Jones says you can develop a good relationship with a case manager “just by stepping out on some trust. Give the case manager the benefit of the doubt so that he or she will look at you as a person—not as an ex-con or a drug addict, but as a person in need.” And deserving of help.

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