My Search for Support

January 27, 2011 By Anonymous

As promised, I spent the first few weeks of this New Year searching for the right HIV support group. For someone like me, who doesn't quite "fit" the HIV "mold," this was a harder, more time consuming process than I thought it would be. The first organization I went to blatantly told me I didn't belong. Although they agreed to meet with me, and completed the first step of the intake process, they told me (repeatedly), that the participants at their program were not my peers. They told me that the women in their support groups had a variety of complicated issues, were much older than me, and "different" than me. While I did believe the intake coordinator was trying to be honest, and help me find a support group of my peers, I think she failed to acknowledge an important notion that HIV helps remind us of: we are all human. HIV, as my therapist once said, is the "great equalizer."

Although I recognized that the intake coordinator's unwelcoming advice to seek support elsewhere was unfounded, and I probably could have received emotional support from the other participants of the program, I decided to keep looking for a place where I felt more welcomed by the staff. (Also, the program was right around the corner from my ex-boyfriend's apartment. *The* ex-boyfriend who's infidelities exposed me to this disease, and who I haven't spoken to in months. An unplanned rendezvous with my ex on my way to or from a support group would be the furthest thing from support I could think of!)

Fortunately, I live in New York City, where the stores are open all night, anything can be delivered to your front door, and the variety of non-profit organizations providing support to the HIV community is bountiful, (when compared to other areas of our country.) So, with hope that I could find a place with a more welcoming atmosphere, and with knowledge that I could always go back to the first location if my efforts failed, I decided to move on.

The second stop on my support group "hunt" was at an organization that was founded in the early 90's to provide emotional and spiritual support services to those affected by HIV and cancer. As soon as I opened the door to support group#2, I could feel their welcoming arms wrapping around me. Rather than being told I didn't belong because of my background, race, class, etc., I was being welcomed by staff who were empathetic, warm, and caring.

My first experience participating in the support group, however, was not as emotionally satisfying as I had hoped. Because groups were open to anyone dealing with a range of life-changing events, such as death, caregiving, and cancer, a great deal of the group time was spent dealing with issues surrounding grief, loss, and mourning. While I could see the value in the way that the facilitator helped lift up the spirits of the participants around me, I couldn't help but feel like this group too, wasn't quite 'for me.' I tried to keep an open mind, take what I could from the

facilitators' wise and comforting words, and see if the dynamic would change. When I went back for a second time, however, the same topics were discussed; death, loss, grief. While emotionally, I empathized with those dealing with the death of a loved one, and felt bonded to my fellow participants by the same overwhelming emotions we shared, another part of me just wanting to scream, STOP TALKING ABOUT DEATH - I'M NOT DYING!!

This time, however, instead of walking away, I decided to speak up. I formulated an honest, yet professional letter to the staff, explaining how I felt that the groups were not servicing the HIV population in the way that their founders set out to. I told them that I didn't want to always speak about death - but instead, I wanted to speak about life; life with HIV that is. I wanted to receive peer support and guidance around issues such as dating with HIV and dealing with stigma and disclosure, for example. In my letter, I suggested that at least one group (once a week, or even once a month) should focus on these unique issues that those of us living with HIV struggle with everyday.

So, I returned to support group #2, and walked to the front desk, with my letter tucked away in my bag. I asked if they had ever considered separating the groups, or providing HIV-only support groups, and they said that its "always on the table." So, with that encouraging response, I submitted my letter. They thanked me, told me it would be photocopied, distributed to the staff, and discussed at the next staff meeting.

About 4 days later, I checked my email, and opened a letter I received from the organization's director. He thanked me for my letter and informed me that it sparked quite the debate at their weekly staff meeting. He told me that after 20 years of combined group sessions, that were open to any one facing a life-threatening disease, they were going to begin having "focus" groups; one day a week would be dedicated to an HIV focus group; another day would be a cancer focus group; another day would be for caregivers, and so on. They emphasized the word "focus" and decided to still keep their open-door policy. Whoever needs help and support, can come in any day, and attend any group.

I felt as if I had just moved mountains! With one letter, one small voice, I encouraged an amazing organization to restructure its' services to better accommodate the needs of the HIV community.

Although support group #2 has yet to implement its' new schedule of support groups, just knowing that in the near future, I will be able to go to an HIV focus group, and get the emotional support I need at a place I felt so welcomed, is encouraging.

Based on my very limited experience so far with support groups, I put together a few words of advice I would recommend to anyone looking for peer support:

Don't allow yourself to be turned away by others' small-mindedness. Be willing to explore support groups where you may look, act, or even speak differently than those around you. (I don't mean to be hypocritical. I recognize that I walked away from this type of experience, but as mentioned above, I had other reasons that kept me away, and other resources available. And I still have a continuing internal debate about whether or not to return).

Speak up! If you don't like the types of services that are being provided, let someone know. Explain why you feel things need to change, and try to express yourself in as kind and professional

a way as possible.

Don’t give up. We all live busy lives, with plenty of distractions. Its easier, and arguably more efficient, to just get tired of the search, and continue with everyday life. But I have a feeling the emotional rewards will outweigh the difficulties involved in the process.

As my journey continues, I will try to take my own advice, and keep searching until I find the support group I need. Its hard not to let the paperwork, the time commitment, or an unfriendly staff member keep you away, but I believe peer support is an essential part of my ’medicine,’ and I’m not going to stop until I find the right prescription.

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