Editor’s Letter

Not Our Bad

December 1, 2009 By Regan Hofmann

I want to believe that AIDS stigma is dissipating. I want to think we have successfully educated people about how HIV is—and isn’t—transmitted so that they no longer fear, avoid or condemn people with the virus. I want to feel that we are getting to the point where HIV is seen as it should be—just another disease. But reality proves otherwise.

I have battled stigma for 13 years. And though I’ve been talking publicly about having HIV for nearly four years, it’s still incredibly hard to watch people’s reactions. Jaws drop, mouths gape then clamp self-consciously closed. Eyes widen, then look quickly at the floor. People go away. Some never come back.

Stigma affects, even ruins, the lives of people living with and affected by HIV. It stands in the way of people getting tested, getting care and treatment and getting emotional support. It also makes it harder for people to disclose. Stigma keeps people living with HIV from their dignity, their self-esteem and the resources that can save their lives. As a result, stigma kills just as surely as the virus itself.

But don’t take my word for it. We posted a survey about HIV stigma on poz.com and received almost 1,000 responses. In some cases, your words could have been mine. I, too, have had nurses put on three pairs of gloves before touching me. I’ve had dental hygienists leave the room, all a-flustered. I’ve had potential dates flee a dinner table or never return a call once they discovered I had HIV. Before I publicly disclosed, I worried about losing my friends, family, job—and the roof over my head.

I think the reason people are so determined to stigmatize those of us with HIV is because making us “other” allows people to believe that AIDS can’t happen to them. “If only gay/black/promiscuous/drug-using/[fill in the blank] people get HIV, and I’m not any of those things, then I can’t get HIV, right?” That thinking is exactly why we are failing to stop the spread of this preventable disease. Stigmatizing people with HIV is a way for people to easily dismiss their fears that they may have been, or may be, exposed to HIV. It gives them an excuse not to take responsibility for their sexual health, or the sexual health of their partners. And it gives them license to continue their current unsafe sexual behavior. And in this way, stigma is killing us too.

A factor that propels stigma is that not enough people ever see someone living with HIV. Which is why POZ is proud to support Infected & Affected, a special project aimed at busting stigma through sharing the stories of people living with and those affected by HIV (infectedandaffected.com). Education helps bust myths, correct misperceptions and reduce fear around HIV. But, ultimately, the faces and stories of people who stand proudly, publicly and positively are what will convince the world that HIV is not our bad.

It’s a two-way street. People living with HIV need to embrace the notion that we have done nothing wrong to contract this disease and that we deserve the same human rights as people fighting all diseases.

And when the world finally understands that every type of person can and does contract HIV, it will be that much harder for people to unilaterally dismiss those of us living with HIV as part of society’s underbelly.

Only then can we undo the deadly stigma around HIV and get on with our work of saving lives.

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