Navigating Through the Grit: Conversational GPS for Mixed HIV Status Couples*

Relationships need grit. Sure, it may be the woo hoo, dancing on air and burst your heart open with joy sorts of fabulous feelings that get relationships off the ground, but it's the grit, the inevitable crunchy times, the fear of rejection and vulnerability and the desire to hide behind anger or numbness to avoid facing this fear, and the painful reflections we see of ourselves in our partners, that gives all those woo hoo feelings substance. Or, more specifically, it's honestly and compassionately facing the grit that makes love work.

It's this grit, the risk, the connection relating to the power of disclosure, the "us against the world" or "us against the disease" and the connection that comes out of it that can make a magnetic* relationship so compelling.

But let's face it, in the game of love, sometimes honesty is hard. Honesty requires us to show our warts, our fears and our vulnerable sides. It pushes us to risk rejection by saying something the other person doesn't want to hear. And it's not always easy to hear someone else's truth, especially if that truth involves us in some way. Given the added doses of shame, guilt, fear and anger that partners in magnetic relationships often feel, the kind of compassionate honesty required to make a relationship work can feel overwhelming.

The easy way around this is to simply not share the truth. Unfortunately, this is a setup for relationship meltdowns. First of all, if you don't show yourself, people invent you. They make you into who they want you to be or fear you to be. It's probably no surprise that at the beginning of an intimate relationship, the you they invent is usually who they want you to be, someone wonderful, but impossible to match up to. As the relationship slogs on, the you they invent is usually a lot less flattering. Second, we make shit up all the time. If we're feeling insecure or cranky, we may see a wave of crossness flash across our partner's face and think, "She's pissed off that I haven't washed the dishes yet." If we're in a particularly defensive or foul mood, we may finish it with, "Well screw her. It's not my fault she is such a neat freak. I'm sick of her nagging me all the time. Her standards are impossible. Besides, *she* still hasn't called the cable company about sending the DVR." And before you know it, there's a fight. If however, you were to ask her about the look, she might laugh and say, "Oh no, I just remembered that I left the report on my desk that I was supposed to get to my boss. Sorry if I looked cross."

Add to this, a lot of people involved in mixed HIV status relationships, deep down inside, think that they are either totally alone in their feelings, or that their partners will not understand. The truth is, if you've felt something or worried about something, it's likely that thousands of other people have also felt or worried about the same thing or at least something close. If your fear really is unique, I think you should write it down and get it published. Look how much money that's made for Stephen King. In the meantime, I put together a composite of some of the common but uncomfortable thoughts and feelings HIV positive and HIV negative partners in

mixed status relationships have that are challenging to share. Breathe as you read through this list. Remember that if what you're reading echoes what you've thought or felt, that that fear or issue is common. If you're reading what some HIV positive or HIV negative partners have felt, it's not about you, it's about the disease and the relationship dynamics that living with a life threatening disease can create.

(+) I'm terrified that if I have sex with him/her I'll infect him/her.

(-) Every time we have sex, I keep thinking, "Oh Crap! What if I get infected?"

(+) It's like I'm constantly seeing statistics in my head and coming up with rules to beat the odds. Like, for oral sex, if we want to have oral sex without a condom, we gotta make sure there are no open cuts or sores in the mouth, we can't swallow, we gotta wait two hours after brushing our teeth, and we gotta rinse w/ Listerine before and after oral sex. Sometimes it feels more like we're gonna do surgery than have sex.

(-) I only allow him to perform oral sex on me. Even though I know the risk for transmission this way is really low, I can't seem to totally relax when he performs fellatio. Forget about anal sex, even as a top. I'm just too nervous.

(+) I really love my boyfriend, but the only way I can have passionate sex is to have sex with someone else who's positive, someone I'm not worried about infecting.

(-) I tried to bottom once, with protection, but the whole time, I kept thinking, "Oh shit, is this gonna be the time!?" So it stopped. My boyfriend seems to take me not willing to go there as me not caring for him. It's like a wall between us.

(-) She doesn't seem to want to touch me, even though the risk of me getting AIDS from her is really low. I feel like I'm toxic, like there's something wrong with me. It's hard and it really hurts.

(+) I've been out for years, but now, because of AIDS, I feel like I'm living in the closet and have to live in secret or come out all over again. It's exhausting.

(-) Sometimes I think the disease gives him a license to be self-centered. I can't reach out for support without outing him and he doesn't want anyone to know.

(+) "Did you take your meds?" "Are you eating enough?" "I smell cigarette smoke on your jacket? You know that weakens your immune system." All this worry about my health, it makes me so crazy sometimes I just want to scream. I want to eat chocolate ice cream and Twinkies for breakfast and smoke cigarettes and throw my medicine out the window just to spite him.

(-) When he gets sick from HIV related complications, I feel powerless because I can't do anything to help him.

(-) I'm scared that someday he's gonna get really, really sick. It's like hearing the ticking of a time bomb and always wondering when it's going off for real.

(+) If I hear one more time that it's "a manageable disease like diabetes" I think I'm gonna scream.

(-) Part of me doesn't want to be his crutch, his caretaker and to baby him, but part of me likes taking care of him, or at least thinking in some way that I am.

(+) Every time he gets sick, catches a little sore throat or a cold, he freaks out. I feel guilty because somehow I think it's all my fault that he goes through all of this because I'm positive.

(-) I feel guilty because he got sick and I didn't. Like there was some sort of lottery and I escaped.

(-) Every time I come home and the house is a wreck, I get so angry I can't see straight, not at him, at the disease, because it's left him so weak.

Think of this list as kindling, as something to get an honest conversation going. If it's helpful you can base your conversation around the list. "You know, a lot of HIV positive (or negative) people worry about bla bla, and I worry about it too."

This might be a challenging conversation because it involves sharing things that are difficult to say or difficult to hear. For this reason, it's important to establish some basic ground rules.

Rule 1: No name calling.

Rule 2: No using broad sweeping generalizations or interpretations. (I.e. "You never want to have sex with me because you think I'm disgusting.)

Rule 3: Use "I" statements, be specific and objective as possible and focus on your own thoughts and feelings. (I.e. "When your dick went limp last night when I mentioned the box of condoms, I rejected and it hurt.")

Rule 4: Listen with an open heart so that you can empathize with your partner rather than with a lawyer's mind focused on tearing their statements to shreds. No one wins in battles of the heart. But if both of you open your hearts in love, everyone wins.

Rule 5: Strike when the iron is cold. Bringing up sensitive topics in the heat of the moment can bring up shame. Sometimes it's better to wait until everyone has their clothes on the morning after and chat about things at the kitchen table over a cup of coffee or herbal tea.

Finally, if it feels too overwhelming to navigate this on your own, you don't have to. It's ok to get help from a friend or professional counselor. It's even ok to discuss these issues with the help of a counselor.

The beauty of having this conversation is that the truth will be out in the open. That truth can guide you to the next step, be it seeking more information on safer sex from reliable sources such as the Columbus AIDS Task Force (<u>www.CATF.net</u>) or The Body (<u>www.thebody.com</u>), talking to a medical doctor about a Postexposure Prophylaxis prescription, buying out the latex supply at the local CVS, going into individual therapy to deal with your feelings, or accepting that you just aren't willing to do the work to stay together. If you do stay together, having compassionate, honest conversations about your fears and pain as well as your hopes and dreams will help you feel the full power of deep, deep love.

*Mixed HIV status relationships, also called serodiscordant couples or magnetic couples are relationships in which one partner is HIV positive and the other is HIV negative.

*There's no such thing as "safe sex." Even if you masturbate with rubber gloves, you can wrench your back out of whack or pull a groin muscle. Still, the research is pretty clear that HIV cannot permeate latex condoms when they are used properly. It might be a good idea to have a PEP **Postexposure Prophylaxis** prescription on hand just in case something goes awry

Originally appeared in Outlook: Everything is Political