

JANAC Editorial

HIV and Pregnancy: Tough Choices...And the Right to Choose

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An HIV diagnosis is devastating and debilitating for a variety of reasons – the shame and stigma, the fear of death, and the loss of a full-life, to name a few. The fear of death and the loss of a full-life are not the same to me. In my mind, a loss of a full life refers to the experiences, milestones, accomplishments, and adventures that so many people take for granted. The very same events that an abbreviated or complicated life (this is not specific to HIV, of course) can compromise. For me, an HIV diagnosis at 19 years old meant many things – most importantly that I would most likely never have the opportunity to give birth and raise a child of my own. In 1988, pregnancy seemed out of the question. I was told that there was a 70-100% chance of infecting an infant if I became pregnant. For the first several years, I cautiously brought up the subject to health care providers to see if there had been any advances or breakthroughs. Each time I was greeted with comments like, “only if you’re a homicidal maniac” or “what are you trying to do, give me an ulcer?” And each time I felt irresponsible, selfish, and judged.

Fortunately, in the early 90’s I broke out of the shroud of silence in which I was enveloped with HIV. After 5 years of protecting my secret – my HIV status – I began to emerge from my silenced, hidden cocoon. First, by becoming involved in a grassroots AIDS service organization and later, by becoming a very public national AIDS treatment advocate and founder of an organization called WISE that focused specifically on treatment information and advocacy for women living with HIV and AIDS. I am

extraordinarily fortunate because I was *able* to be liberated. I had a wonderfully supportive family, an army of loving friends, and no other responsibility that prohibited me from becoming a public spokesperson. And I believe this emergence – this liberation – is largely responsible for my good health, my strength, and even for my survival.

Unfortunately, most people with HIV do not have this luxury.

Almost 2 years ago, I finished a nearly yearlong hike of the Appalachian Trail (AT) – a childhood dream that I completed with my youngest brother, with my (now) husband, and my dog. We reached the summit of the last mountain in a 2,167 mile journey on the 12th anniversary of my HIV diagnosis in the presence of family, friends, and the media. It was an incredible day, an incredible experience, and the beginning of a new chapter in my life.

This past year I married that wonderful man who trudged through the endless miles of the AT with me – my best friend and soul mate. Thankfully, he's HIV negative. Over the years we have struggled through the challenges of being a sero-discordant couple – safer sex, emotional responsibility, shame, fear, and sadness. But we have emerged a stronger, more confident team each time. And for this, I am grateful. In fact, on many occasions it was me, not him, pulling away because I could not bear the thought of putting him through this frequently stressful and trying, day-in and day-out battle that I wage for my life. And each time it was his strength, his certainty and his love that pulled me through.

Among the many wonderful things we share, we both want children and feel the need to be parents. The reality of this is both exciting and daunting. It is not a decision to be taken lightly. What if we had a positive child? What if the drugs caused some awful birth defect? What if I got sick and couldn't care for the child? Or what if I died and left him alone with a child (or children) to raise on his own?

We are both intimately aware of the myriad issues that we must face if we are to venture down this path. Choosing method of conception, possible risks of transmission, whether or not to use antiretroviral therapy during pregnancy, vaginal or caesarean delivery, my health, the baby's health and development, and long range planning – these are just some of the many considerations I have pondered endlessly.

Fortunately, there is a wealth of information – including newly revised pregnancy guidelines released this month – to help us in our planning. There are few certainties, but living with HIV has taught me that life rarely deals you absolutes, just likelihoods. We know that the risks to me are few (other than those risks all women encounter), that the use of antiretroviral therapy seems to yield no greater risk of birth defects than that observed in the general population, and that the risk of transmission with aggressive prenatal care and treatment is as low as 1% in some places.

I have given serious thought over the years to the realm of possibilities – perinatal transmission, adoption, or even the chance that I may not survive long enough to see my

child reach adulthood. I've considered the potential burdens. The burden I could place unwittingly on my child, my husband, my family and friends – and myself.

Pregnancy and motherhood have never been issues that I take lightly. I know the risks. I know the possibilities – in a way that most people never consider. And I know how important this is to me. In the core of my being I know I was supposed to be a mother. There has been a child inside of me waiting to come into this world for as long as I can remember. She has shown up in my dreams and been a part of my psyche. Have you ever wanted something so deeply that you could feel it coursing through your veins and permeating every fiber of your being? If you have, then you know.

Although many women experience cultural, societal, or familial pressure to become mothers, one should never assume that an HIV-positive woman who chooses to conceive or carry a child is irresponsible, naïve, or a victim of circumstance. It's true that some are, just as there are in the population at large. But the assumption is dangerous. It carries with it a variety of attitudinal demeanors that can be demoralizing and defeatist in a care setting. Instead, listen to what a woman says and doesn't say. Share information in a supportive, caring, and positive manner. If we want people to take responsibility for themselves, we have to let them.

I have watched, read, studied, and waited for nearly 14 years to be comfortable with the decision to conceive. It is a deeply personal choice and unique process for each woman who considers it. Fortunately, my health is good, the treatments are effective, the

chances of transmission are exceptionally low, and there seems to be no detrimental effect caused by pregnancy on HIV progression.

Last Fall, my husband and I decided that we were ready to make space in this world for a child. And we have been blessed with the opportunity to do so. Sometime in July (or June if she rushes things like her mother always has...) we're going to welcome a baby girl. We are ecstatic. I feel great. We have successfully passed all screening tests thus far and an ultrasound showing all the things you hope for – good skeleton, arms and legs, fingers and toes, and a strong heartbeat, among other things. The only guarantee we have right now is that this child will be loved madly and raised by a caring village comprised of family and friends.

I don't need to tell you that nurses are the backbone of healthcare in this country. You are the trusted voice, the friendly face, the cheerleader and the counselor. You are, for many patients, a surrogate parent or sibling, the family that replaces their blood family who doesn't know what they're going through. You have more power than you realize. A disapproving glance, a judgmental question, a condescending tone – can shut someone down, send him or her out of care, or into isolation once again.

I hope that by sharing my story with you, you will recognize your immense power and be able to embrace the women who are fortunate enough to cross your path. HIV is a part of our lives now, but its many challenges should not prevent us from living.