

# Resurrecting the Body Politic by John Hannah

I thought I'd be focusing this month on the Lark Lands treatment workshop sponsored by the Vermont People with AIDS Coalition on December 12th. But I was kept home from Montpelier last Thursday by a nasty stomach ailment, so I missed the jamboree. I thought a good way to find out what happened, not only for myself, but for any other interested absentees, would be to invite those who attended to report their take on the event in the space of this column. I will surely ferret out some opinions in the course of things, but I warmly encourage anyone with something to say about the workshop to write, e-mail or phone OITM with your bead on this hotly debated movement in HIV/AIDS treatment management. By reflecting on the broadest possible range of opinions, it seems to me, we can find the best path of positive change. It is lack of discussion that has created a rift between consumers and providers of HIV and AIDS treatment in this state, and I hope that you will help to move us all forward by speaking up.

Besides, it's the holiday season, and I don't feel like being scrappy. So I thought I'd regale you with a lighter tale of space. Space, that is, as it relates to HIV.

Since testing positive for HIV a year and a half ago, my life has undergone a phenomenal cycle of shrinkage and growth. Not only practically and psychologically, but spatially as well.

By practical and psychological shrinkage, I mean an implosion of my attention and concern to the state of my health, to the immediate future of medications and potential treatments and, not least, the scoping down of my ambitions and plans to allow for a possibly shorter and certainly much more complicated life. None of this surprised me particularly, though an HIV positive diagnosis is obviously a bitter pill to swallow.

The thing for which I was

wholly unprepared, however, was the spatial effect of the news. My lifestyle was already fairly lean, having just moved to Manhattan from San Francisco, I was provisionally staying with a friend in a tiny apartment. I was looking for (and not finding) work in an unfamiliar city and I was totally broke. The physical territory over which I felt some sense of ownership and control had boiled down to a couple of suitcases and my immediate person. I was already making radical adjustments psychologically to deal with my new situation, to feel in control of my life, when the shit really hit the fan.

Suddenly, the well-meaning friends and family to whom I had naturally disclosed my diagnosis laid siege to my mind. Any boundaries of privacy which I had hitherto taken for granted, and indeed depended on for peace of mind in my tentative situation, were suddenly nullified. My sexual behavior, my emotional well-being, my physical health were opened up for scrutiny, criticism and, worst of all, prescriptive advice. I found myself shrinking from those who knew me and whom I loved. Not because I was ashamed of being HIV positive, but because I couldn't afford the constant infiltration and intrusion into my psyche.

As human beings, we all need some space of our own, whether it be a physical place or just some compartment of our minds, to which we can retreat in times of crisis to take stock, to figure out for ourselves what we must do, what we *want* to do. This was the space that I desperately needed when I got my diagnosis, and this was the space that knowledge of my diagnosis amongst my friends threatened to annihilate.

Privacy and autonomy are the first casualties of HIV, and their loss is grievous, representing a collapse of one's sphere of control, a loss of personal space. Any attempts I made to assert my right

to personal privacy after my diagnosis were branded by my friends as secretive and indicative of "denial." It is typical of a Western medical sensibility, I suppose, to focus on disease as a purely scientific phenomenon, to ignore the individual, to dismiss the soul.

It was only when I retreated to Vermont, nine months later, bereft of nearly all possessions and relationships, that I began to find some space in which to think for myself, to decide how, or whether, I wanted to live. For some of us, we must lose everything to see what we need.

Finding this space was a slow process. It began with a bed in the psychiatric ward at Fletcher Allen, where I was mercifully left alone for two weeks. On checking out, I moved into a small room at the Wilson Hotel, where I stayed for two months, nursing a fragile sense of independence and cautiously investigating treatment of my HIV. I was then able to secure a small apartment in the old North End with a HOPWA (Housing Opportunities for People with AIDS) Certificate.

As my living quarters expanded, so did my ability to deal with my condition. I am deeply indebted to my case-workers at Vermont CARES and COTS (the Committee on Temporary Shelter) not only for facilitating my reentry into "normal" life, but for having the profound sensitivity not to pressure me to take any particular course of action. They recognized that HIV, or for that matter, any serious illness, afflicts the soul as well as the body.

The last chapter in my story of space is being played out at the Vermont CARES House at Fort Ethan Allen. With my lover, whom I met in an HIV positive support group, I've moved into one of the building's two-bedroom apartments. At first, because the setting is so beautiful, I almost felt guilty for being here. But then I realized what Tim Palmer, the Executive Director of Vermont CARES whose vision created this house, already knew: that space is medicine.

Living with HIV is truly a full-time job. Particularly as new medications and strategies of treatment are being developed, those affected must constantly take stock of a tremendously complex world of scientific data and make highly individualized decisions as to how to proceed.

Now I sit on my couch and look out on the fields of Fort Ethan Allen, watching the clouds move across the sky and the cars slide quietly by in the distance, and I chart a new course for my life. There is room here to lay a great many things out, and I need every square inch of it.

I'd like to wish everyone in the HIV/AIDS community all the best for the coming year, and to thank you, from the bottom of my heart, for the space and light and life that I've found in Vermont.

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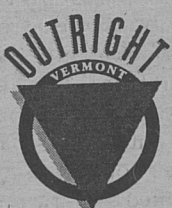
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