

Reclaiming A Lost Future: The Challenges of HIV At Midlife

By Paul Heidt

What can you expect to hear about life goals from middle-aged gay men living with HIV/AIDS? We're not going to recapture the glory of our youth nor, for many, even the vigor or stamina we once imagined could be ours in our middle age. High blown notions of fame or fortune or lofty status we may have carried from childhood into our invincible twenties are largely irrelevant now. The compromises of life and vagaries of luck have pretty much set the parameters of our personalities. Not the least of those twists of fate, of course, being to have lived the majority of our adulthood at one of the epicenters of the HIV epidemic – knowing we carried the dreaded infection in our own bodies. We saw scores of young men in their twenties, thirties and forties sicken and die, all the while wondering when our number would be up. We got in the habit of reining in the horizons of our futures, taking care of the basics – medical care, income, housing – looking forward to the next trip if we were feeling well, to the next advance in treatment if we weren't. Discounting our future, we strove frantically to empty our todays of stress and fill them with value.

As our survival wore on, we came to realize that we are among the living until we are dead. We came to experience the isolation that can come from taking ourselves, by degrees, out of the futures of the

people in our lives. That isolation could be felt most acutely when friends and family would slip and let on that they, too, were silently writing us out of their futures.

We learned not to live like aspiring ghosts, and we looked for objective evidence for how far our arc has traveled. One recent study found that people who attain and maintain a CD4 count above 500 cells live as long as people without HIV. That's the optimistic side for those in that category who may want to shift again to longer term goals, like the dream of home ownership, for instance. On the more somber side, seven men I knew have died in the past year and a half, all but one in his forties or fifties. I have also seen the struggles some have shared about their hip replacements or creeping neuropathy.

When is it safe to reclaim a stake in the future? The thought patterns and behaviors some of us have developed over two decades of hearing the faint tolling of the bells are somehow, now, hard to shake off. And even if we're successful, we're still twenty years farther along that arc the end of which we've glimpsed too closely.

These are not comfy and cozy thoughts we want to go around voicing every day. But they intrude on our consciousness daily. Some difficult feelings associated with these

thoughts are the immense gratitude for the support we've gotten from the gay community, government, social service agencies, and individuals, and the feeling of a need to give something back for all that caring.

For me, knowing how to meaningfully give back requires figuring out where I fit in the fabric of community as a 51-year-old man nearly 20 years out of the labor force, feeling more optimistic about living a normal life span, but still with limited energy left over from dealing daily with the maintenance of a body slowed down not only from HIV and its drugs, but now, also slowed by aging. Having confounded the actuaries by surviving so long with AIDS, I wonder where I pick up in the game of life and how I start preparing for a middle age I figured would never come – a preparation that involves not only financial issues like retirement savings, but also the harder emotional issues that come with the realization that HIV or not I now, most probably, have less years ahead of me than behind.

I've come to realize that that preparation inescapably requires interaction with other men in middle age. Who are the models who demonstrate by example how it's done? The obvious next step was to go out and find some friends my own age and older. There is where I found my door to a renewed involvement with

community. There are actually many doors that can lead one out of isolation and back into a social world. There are many who can show you the doors, but only you can walk through one.

I was extremely lucky to have been shown the door by a remarkable mature man, 10 years my senior and a genius at encouraging others to challenge themselves. He invited me to participate in meaningful activities to “break patterns” and enrich my mind, body, and spirit by joining the group Thriving in San Francisco. One of the patterns I needed to break was hanging back when presented an opportunity to jump in with others to find something meaningful and fun to do. I was, as I’ve heard many others say at the invitation to participate, not a joiner. Whatever you’ve been in the past, you may find a lot of satisfaction by trying out the role of joiner once in a while.

Thriving in San Francisco was started by guys with HIV looking for a way to live openly with HIV/AIDS and to get the most from our present, no matter how long that may be, by playing and talking together. Mostly we’re middle aged now having lived through the period of massive deaths and not much medical hope to the dawn of HIV/AIDS as a chronic illness. We are the rear guard of the first wave of HIV/AIDS in the gay community who somehow struggled across the milestone of drug regimens more effective in halting the destruction of our immune systems. As a result of having grasped each new anti-HIV drug as it came along, many of us, including myself, have virus that has grown resistant to one or more classes of these drugs and immune systems that refuse to recover fully, still doling out T-cells at less than 100/uL. We are said to be on salvage therapy, struggling

to hang in there until some new breakthrough yields a new class of drugs to attack the virus. Occasionally we meet to talk about what we would like to do with the reprieve time we’ve gained, how we have revised our life goals, and how to engage in meaningful activities.

What are these meaningful activities? They’re really rather ordinary things like going on a hike, arranging a potluck, or sitting around in a circle commiserating over afflictions or celebrating living through another year. A secret I’ve learned is that the meaningfulness of the activity emerges largely from the mere act of participation. And I have found that if I challenge myself and am willing to be comfortable with being a little uncomfortable I will find the level of participation appropriate for me, and if I have patience with myself and the group that I spontaneously begin to build confidence for deeper levels of involvement. For me, the appropriate first level of participation was just listening and observing in the group – shy one that I’ve been most of my life – and joining in the hikes. Before long, however, I found myself helping to plan for the group, sharing tasks and responsibilities with others going through their own paces in resocializing and learning from them in the process. Besides making new friends and acquaintances, I found that my relations with old friends were more fulfilling as I had enriching experiences to bring to our time together.

Of course, there are many circumstances other than having HIV that can lead to social isolation, and mid life adjustment is a challenge for nearly everyone. There are, however, lots of opportunities out there in San Francisco to participate in community activities for anyone of any health status

or age. Being in a community doesn’t just denote living in a certain geographic area. Community is an emergent reality arising from the web of personal connections and shared activities we partake of. You will encounter this web almost anywhere – sports leagues and churches, political clubs and hobby groups, and book clubs and Billy Clubs.

We all must take care of our economic needs, but we all must also find other things to live for. The next time you take stock of where you are along the life curve and are calculating how to increase your net worth, remember to take measure of the uncountable. Be aware that investment in community activities has its own invaluable payoff.



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