

Dear Reader:

I have been asked to write a column about how to be hopeful in the age of AIDS, and I think it's about time that I put it down on paper. I have been thinking about this subject ever since I myself was tested. I nearly started to write about the benefits of being positive following a surprise birthday party my other half threw for me over a year ago, but that's not exactly the same as the notion of being hopeful. Let me tell you first about a discussion we had of the benefits of being positive.

I was just finishing my second year in this job as Director of the AIDS control program for the Department of Public Health, had just suddenly lost a physician friend to AIDS, and had had to attend a meeting back east. With piles of work undone I was supposed to give an AIDS lecture to a potentially hostile crowd in Spokane and then go on vacation for a week. It was just too much to handle to start out 1988, and I was quite close to burnout.

The party occurred the night before I left Seattle. After work, I went to a local motel to pick up a friend from Houston who, to make matters worse, informed me on the way home that his lover had just left the hospital following treatment for pneumocystis, AIDS, and now my friend in the car with me was crying that he too had been tested and was seropositive. "Happy Birthday" I thought to myself. We got home, and I introduced him to our other friends present -- all of whom happened to be HIV seropositive that evening. The subject of AIDS and HIV infection seemed to fill the air and dominate the evening.

But those of us with longer awareness of our serostatus seemed surprisingly full of energy and optimism as we tried to reassure our Houston friend that after a while you didn't necessarily see things as bad, and that we have learned to see some benefits in being positive.

For example, some of us described taking vacations that we might normally have put off -- for example, a fantasy trip sailing in Greece that might have been delayed until retirement age by many people, but could now be justifiably enjoyed immediately. Or, a week skiing followed by a week at the sea. There was little reason to delay giving in to the pleasures we could afford or to save large amounts for a rainy day. As we talked about our experiences, there was a uniform sense of living more in the present, taking each day as it goes, not getting too worked up about the distant future. Instead of feeling depressed that one may not have as much time as one would want, we expressed not being burdened too much about needs to plan way ahead. We could take charge of our lives and reduce petty concerns.

In addition to a sense of living more in the present, we seemed to have more of a sense of control about our present and future. We were aware that disease could happen, but were facing the future with a clearer sense of the possibilities. Our future was more predictable perhaps than for most people.

Those are some of the benefits of being positive: living more in the present, permitting ourselves to be more hedonistic, being in more control, having more predictability, etc. What about being hopeful?

I think there are good scientific reasons to be hopeful. For one, many studies suggest that people who are hopeful appear to live longer and happier. Anecdotaly, in my experience, patients do well with all sorts of diseases (including AIDS) so long as they are hopeful, by which I mean optimistic about the future. Once they give in and let go of hope, they pass to another plane easily and quickly. (A lesson: when you're ready to let go, focus your hope only on the present, and let loose of the future.)

For those who want to be hopeful about the future, there is also solid evidence that the future is becoming longer for persons with HIV infection and AIDS. For example, in the early 80s the average life expectancy for someone with AIDS was about 8.3 months; in the later 80s this period is at least twice as long, and there is an ever widening range of length of survival. Several months ago, the Advocate wrote a story about long-term survivors of AIDS, some now alive 6 or more years from diagnosis. Thus, it's clear that the face of AIDS is changing as we learn how to recognise AIDS earlier, to treat it better and to prevent many of its component diseases.

People with HIV infection may also be living longer, since the incubation period from time of infection to the diagnosis of AIDS has been gradually lengthening, even before the recent study developments about AZT were revealed. Now it is very clear that HIV infection can be slowed, and the immune system protected by AZT, and it seems very likely that better drugs will not be far behind.

I could write on and on, but isn't that enough? Being seropositive is not all that bad, it can have very good effects if people develop the right attitudes. It is possible to be hopeful about the future in the face of HIV infection and increasingly in the face of actual AIDS as well.

Sincerely, Dr. Bob