Editor’s Letter

September 1, 2001 By Walter Armstrong

In 1993, when POZ was in the planning stage, the idea of a terminal disease going glossy was met with gallows of humor. “Just what we need, “ bitchy friends would say. “Feature like ‘What to Wear to Your Own Funeral,’ complete with an open-casket photo shoot.” Back then a swimsuit issue was more POZ’s style, and that, too scares the horses.) The truth is, through the years, POZ has had little truck with memorials, morphine drips, and other trappings of morality. If we haven’t treated death and dying as a piece of shit that the mainstream generally does, still we tend to cover it in pretty conventional, consoling ways—as, say, the “kick in the ass” a dialogue can deliver. And why not keep Mr. Jones on the margins? In your mission to survive HIV, don’t you want inspiration, education, and community, not a glossy reminder of your worst nightmare?

Yes, but…Death and loss are at the very heart of our experience of the epidemic, and however much we may not want to go there, we know deep down that health and hope demand it. This isn’t to say that many survivors aren’t on intimate terms with grief; the gradual withdrawal in the 90’s from both grass-roots and institutional promotion of treatment, prevention, and other AIDS issue hints at a kind of mass depression, if not grieving. But this sad, lonely personal process has, at a community level, been largely denied—and, as a result, only made more difficult. So with the issue of POZ, we begin to give death its due.

“Oh God! May I be alive when I die” is a prayer that the British psychoanalyst D.W. Winnicott wrote in his journal in 1970, the last year of his life. I share it because it expresses what seems to me the wisest way to face the inevitability of dying. There’s a lesson in the prayer’s humility and acceptance—no grandiose plea to be spared the common fate. But inside its simplicity hides the paradox—alive when dead—well worth unpacking. For Winnicott, a healer of souls, denial (not death or disease) is life’s destroyer. Denial, while protecting you from intolerable feelings for the moment, can have enduring evil consequences. You can wind up not only telling yourself a pack of lies about reality but killing your capacity to feel at all. And feelings are all we have to create meaningful, truthful lives. To “be alive when I die,” then, is to live full out, from love to hatred, anger and grief, and to accept the precarious, disappointing and yet precious nature of life. Even dying is not to be missed.

Now it looks like Mr. Bones is about to kick us in the ass again. As the mid-‘90’s “miracle” treatments reveal their all-too human side effects and failure, some Lazaruses are running out of options. Other HIVers are stopping meds—and risking resistance—to postpone that fate. But this crisis, if it comes, will likely be as much psychological as medical: After having your hopes repeatedly and cruelly raised and crushed, are you prepared to make the best of another series of
treatment setbacks? Or even organize to reform the research system? The evidence in favor is slim. A year ago, spurred by the death of Stephen Gendin, one of AIDS activism’s last leaders, a group called Wake Up gathered to agitate for better, safer HIV meds. While its presence at least briefly reaffirmed the possibility of a communal response to loss, its effect was a fizzle. Meantime, activism’s ancient regime is dedicated to developing-world initiatives that, however worthy, hold neither help nor hope for drug-failing HIVers here at home. Of course, we have few leaders left to lose.

But mourning, not militancy, may be what we need most. It’s worth asking whether the absence of a vital, visionary PWA movement is due, in part, to the the fact that anger grew rote and activism empty, while no new rituals have emerged to help us learn what we need to know and feel now. To state the obvious, anyone who has survived the AIDS catastrophe is indelibly imprinted with memories of fear, illness, death and loss; friends and lovers are gone, and so is any trust in a safe, just universe. Taking it all in is, at best, overwhelming; doing so while continuing to live it, with health perils and treatment problems crowding in, can seem unbearable. The alternative to undertaking the painful repair work of mourning is denial, and its symptoms—numbing fear and immobilizing depression—are all around. Especially troubling to me, for example, are the rising rates of HIV transmission among gay men. In flight from the virus on the wings of drugs and sex, guys who know better and mean well often seem to have no feelings at all about infecting others or getting infected themselves.

These infections are gestures of despair. If you have forgotten how to care, you will forget to take care. As a medical student, Winnicott was exempted from serving and dying in World War I—the fate of his generation. Spared, he felt a lifelong responsibility to live not only for himself but for those who died too soon. “My prayer had been answered,” he wrote after dreaming of his death. “But that makes me feel awful because so many of my friends died, and I have never been free of the feeling that my survival is a facet of some one thing of which their deaths are other facets: a huge crystal, a body with integrity and shape.” This is the voice of mourning. What I find most moving is that half a century later, the survivor still feels a living connection to the dead—a faith and commitment that can only be called love. This love outlives loss. It is a vision of solidarity that transcends our own small selves and yet drives us to reach for lives as rich and full as possible. I offer it as proof that even out of a holocaust, humanity can make a love more powerful than death.