

NO END TO THE GRIEVING

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More than "grief overload" or "bereavement burnout"

AIDS-Related Multiple Loss Syndrome defines the condition formerly categorized by the terms "grief overload" and "bereavement burnout," which were used to describe mourners who have insufficient time to complete the normal bereavement process leading to recovery before other deaths compound the situation. Klein found that never before in modern history has such a young group been forced to endure so much ongoing death and loss of their peers. An average person goes into a three- to six-month depression after the loss of someone close to them, but in the modern lesbian and gay community many experience repeated losses before coming to closure for the initial losses. This results in a constant depression, feelings of hopelessness, lack of planning for the future, reckless living and apathy.

Discrimination and homophobia conspire against the survivors of AIDS

It is not uncommon for a gay male in Los Angeles, for example, to have lost more than 50 friends and acquaintances over the last several years. The people with AIDS and their survivors are generally under 40. Klein reported that "The ever present possibility of early death leads to a sense of fatalism, with a lack of enthusiasm for long-term goal planning. There is simply no equivalent to this experience in the nongay community. While a pandemic might be compared to natural disasters in which a large proportion of a particular community is wiped out, there are important differences.... [Ordinarily when a] disaster occurs, broad emotional and financial support for the survivors becomes available. For the survivors of AIDS, however, discrimination and homophobia conspire to keep them socially isolated and stigmatized."

Klein warns that such multiple losses often lead survivors to turn inward, with long-term and sometimes irreparable consequences including emotional numbing, depression, inability to emote, and pervasive expressions of pessimism, cynicism, fatalism and insecurity.

"And now, to deal with so many people dying..."

Dan Bjierke, M.A., M.F.C.C., has his private practice in San Diego and works 20 hours per week at CIACCIO Memorial, a long-standing HIV clinic. When asked if he agreed with Klein's findings, Bjierke replied, "I absolutely agree. Gay people in their 30s are dealing with developmental issues that previously only elders dealt with. It is a loss of their mid-life phase, where people should be thriving. Many people lost their adolescence when they were gay, and now, to deal with so many people dying, it's a loss of focusing on thriving. I think it could affect [them] for the rest of their lives." When asked if he meant the syndrome could put a survivor into a negative rut for the rest of his or her life, Bjierke continued, "Sure, in fact the rut itself can lead to risky sexual behavior."

Klein has interpreted multiple loss in a broader sense to reflect the many other types of AIDS-related losses that interact and reinforce one another, such as loss of sense of community, loss of sexual freedom, loss of hope for the future, loss of employment stability due to the stigma attached to HIV and AIDS, loss of privacy and personal power resulting from the "outing" of sexual orientation when HIV status becomes known, and loss due to disease-related personality changes of people still alive.

"Gay survivors face a number of unique issues related to their multiple losses throughout the AIDS pandemic," Klein says. "The grieving process for gay survivors of individuals who have died from AIDS is quite different from the



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traditional model of grief and mourning, with numerous obstacles to effective resolution." She has documented that compounding the loss of friends and loved ones are the difficulties of often having to hide the importance of friendships that were often homosexual affairs, or hiding the circumstances of death from co-workers and others that ordinarily would be the source of some support during the difficult times.

Syndrome attacks the root of gay power—its spirit

AIDS' devastation of the surviving gay community is more far-reaching and deadly than most have realized. Many HIV-negative people have had their lives permanently damaged, and the pandemic has been sapping the entire gay community of its energy, determination, optimism, spirit and political clout.

Bjierke has regularly observed the damage to gay activism, and states, "There is just a cloud of grief that has truly affected our ability to work collectively towards life-promoting issues. I know that it has bound people together in very specific causes, but overall, I feel there is a lack of collective energy, because of the number of people that are dealing with AIDS themselves as well as the people who are suffering individual losses. The collective power is decreased. I don't know anyone who hasn't been affected by these losses."

Asked if she thinks that current lack of interest in activism relates to the syndrome, Klein replies, "Yes, I do, because the survivors get numbed out. Even more than the loss is the sense that people

don't care, or that people aren't doing anything about it, or even the erroneous assumption that things aren't as bad as they used to be."

Klein explains, "When you're involved in grief and you feel like a lone survivor, you just don't have energy the way you used to. I think that the syndrome is debilitating in ways that people are not even aware. It can often lead to things like apathy and cynicism and just an inability to get involved or continue to be involved in trying to change things."

Klein also feels that it is important to understand that the prolonged emotional numbing commonly noticed in victims of multiple loss should be seen as a natural result of an individual who

repeatedly watches his or her friends die after prolonged illness. She says, "Most disasters have an ending, with clearly defined phases of recovery and rebirth. For the survivors of multiple losses due to AIDS, there has been no post-trauma. Individuals who face loss after loss realistically cannot be expected to bounce back, as each grieving

process is compounded by the one before it and is complicated by the anticipation of more to come. There is insufficient time between traumas to work through the complex grief process."

—Dan Bjierke

Sandra Jacoby Klein M.A., M.F.T., has 20 years of experience in grief therapy and has had her research findings regarding AIDS-Related Multiple Loss Syndrome repeatedly published in professional journals for the therapeutic community. She began working with AIDS survivors in 1982 at The AIDS Project-Los Angeles.

Sandra Jacoby Klein offers these coping strategies for survivors of multiple losses:

1. Become actively involved with friends and social support systems and use those networks as forums to discuss feelings and stresses.

2. Take occasional HIV or AIDS "vacations" to avoid being constantly reminded of the disease. This might involve short trips out of town or even just refraining from taking all the usual medications for a brief period of time.

3. Engage in symbolic rituals and ceremonies, both personal and shared. At the personal level, a big fat candle can represent "Loss." It can be lit each time a deceased friend comes to mind. Candles also can be lit to symbolize those living with HIV and their significant others. Find a new place in your life for those who have died, a place in which their specialness can enrich your life. Welcome them when they walk through your dreams, and realize that they still play an important part in your life.

4. At the community level, become involved in efforts such as the NAMES Project Quilt, which symbolizes a continuing reinvestment in life and hope. Engage in volunteer activities to help those less fortunate. Ideally, active participation connects to personal empowerment, contributing to an enhanced ability to cope with the situation.

5. Learn to focus anger, harnessing and using the emotional energy to positive effect. Acknowledge the anger within and rechannel it into helpful modes—dance, draw or paint, or learn a musical instrument. Use the emotional energies released by anger to explore your underlying and previously neglected emotions.

6. Pay special attention to your own self-care, including grooming, exercise, nutrition, fluid intake and adequate rest.

7. Understand that you always have choices, and learn how to choose the best alternatives given your current situation, knowledge and resources. Create a sense of being in control by identifying those areas in which you can still "take charge." While you cannot change the inevitability of death, you can change your attitude.

8. Always hold on to your sense of humor and appreciate the lighter side of even the darkest situations. As George Bernard Shaw said, "Life does not cease to be funny when people die, any more than it ceases to be serious when people laugh."

We're interested in hearing about the ways that Just Out readers deal with the profound loss we've all experienced. How do you cope? We'd like to publish your ideas in a future issue. Maybe your strategy would come as a welcome gift for someone else who's having a tough time. Send us your recipes for healing; let's share the wisdom we've gained. Send your coping strategies to Just Out, PO Box 14400, Portland, OR 97214-0400; e-mail to JustOut2@aol.com; or fax to 236-1257. Please include a way for us to contact you during the day.