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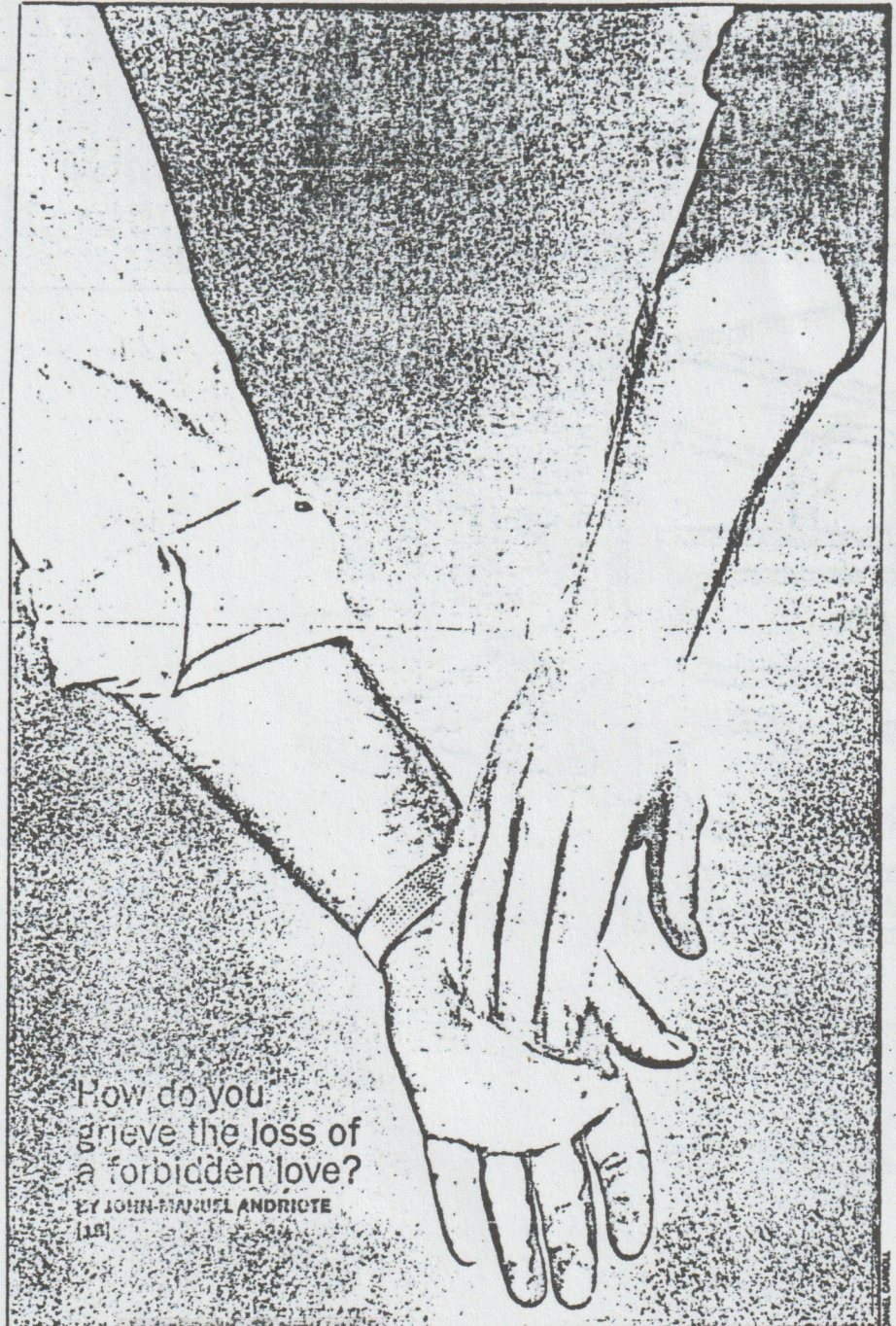
SEPT. 19 - SEPT. 25, 1986

*Will the new prison be built atop a  
potter's field?* THE DISTRICT LINE [4]

*Sally Quinn is haunted by her two  
dimensional characters in*  
3D NEWS [16]

*Good Golly, Mr. Dali! Joel E. Siegel  
on David Lynch's Blue Velvet'*  
FILM [26]

# THE SURVIVORS



How do you  
grieve the loss of  
a forbidden love?

BY JOHN MANUEL ANDRIOTE

[15]

# THE SURVIVORS



How do you grieve the loss of a forbidden love?

BY JOHN-MANUEL ANDRIOTE

DAVID CARROLL

JOHN HAD PASSED IN AND OUT OF lucidity since being admitted to George Washington University Hospital the day before. Pain shook his frail body one moment, morphine assuaged it the next. His mother, father, and brother were down from Baltimore and would stay to the end—which would come in a matter of hours, the nurse said.

Manny waited with John. For three years he knew this moment would come. This was it. Goodbye. Nine years of togetherness ending in this hospital room. John, his 39-year-old lover, was dying of AIDS.

John was never a "patient," Manny says. He demanded nothing. In fact, Manny worried that one morning he would wake up to find that John had died in bed next to him, not wanting to disturb his sleep.

But on John's last morning, the morning after Gay Pride Day, he called Manny's name over and over again. Manny had left the hospital at 2 am, seeking much-needed rest. "Manny will be here soon," John's mother assured him. Manny returned at 7 am. The nurse gave John another shot of morphine to soothe the now-incessant pain. They called in a priest from nearby St. Stephen Martyr. John's mother sat at the foot of her son's bed, quietly saying her rosary. Manny held John's hand.

A final gasp and he was gone. It was over now for John. And just beginning for Manny.

Manny was single again. And not just a single man, but a man whose lover had died. Of AIDS.

Manny would still attend Dignity, the weekly gay Catholic masses where he and John had met and sung in the folk group. This next Sunday Dignity would offer a memorial service for John, the one John had planned for himself in such detail. John's parents would come. His friends would turn out in number to pay their last respects to the former seminarian, the man who had led them as their president, who in loyalty to his church had taken a lesser job with the

National Catholic Conference rather than leave completely when they learned he was gay and wanted him out.

The service was simple, a folk mass. John's favorite homilist spoke, his favorite songs were sung. "That made it easier," Manny says, "it wrapped up the whole week."

Manny hasn't cried in the three months since the memorial service, although there have been teary moments. Mostly he wonders what grieving is. Is it being sad? Crying? Being helpless? Is it anger? "I've read a book on coping. But I don't even know what I'm supposed to be coping with," he says.

Manny's uncertainty about how grief is supposed to feel isn't unusual. Judy Pollatssek is a grief therapist whose work in Washington revolves largely around people with AIDS, their lovers, and friends. "Gay or straight, people know so little about grief," she says.

"If you want to grieve well you need to wallow in it, to really feel it." After three months "you're just beginning to hurt," she says.

Dace Stone, a D.C. therapist who co-leads a couples group for people with AIDS and their partners, says that grief varies with the kind of death. She says there are two kinds of death, good and bad. "Good" death comes when peace has been made, in which death is a resolution. A "bad" death comes when the survivor is overwhelmed with "what ifs."

But whichever kind of death, Stone says that with a terminal illness such as AIDS, grief "begins at diagnosis." From that point, the sick person and his lover, friends, and relatives all move through what psychiatrist and thanatologist Elisabeth Kubler-Ross has described as the five "stages" of death and dying.

While her 1969 book *On Death and Dying* is considered an important work in its field, Kubler-Ross has since modified her explanation of the death and bereavement process, noting that the five stages vary in length and intensity, that someone may get "stuck" in one stage. As Pollatssek explains, "the stages aren't set in concrete."

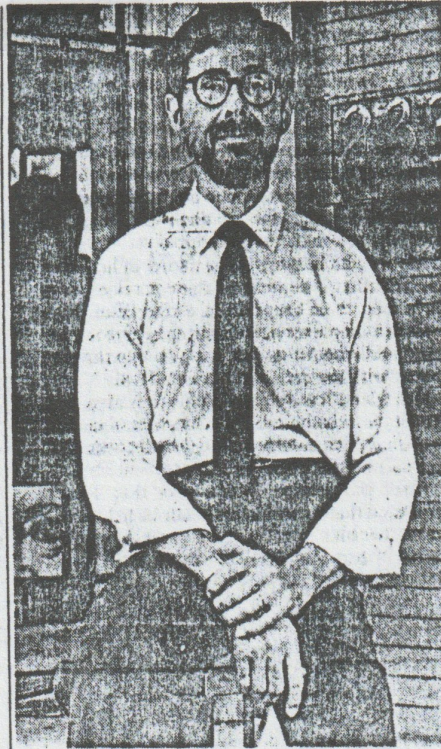
Nevertheless Kubler-Ross' five stages stand as one of the most cogent explanations of the bereavement process to date.

First comes denial and isolation. *This can't be happening to me—or to the person I love.* The unwillingness to face the reality of impending death. And with no known cure, death is the unavoidable, implacable effect of AIDS. Kubler-Ross writes that "denial functions as a buffer after unexpected shocking news, allows the patient time to collect himself, and, with time, mobilize other, less radical defenses."

When denial is finally untenable, it is replaced by feelings of anger, rage, envy, and resentment, Kubler-Ross writes. "The logical next question becomes 'Why me?'" She says that this is the stage when the patient wants to blame something or somebody to the point that his anger "is displaced in all directions and projected onto the environment, at times almost at random."

Kubler-Ross says the third stage is bargaining, trying to "enter some sort of agreement which may postpone the inevitable from happening." The patient wants to buy time, to delay the inevitable.

Fourth is depression. Leaving—or losing—his job, medical bills piling up, death imminent, the dying person's denial and anger and blame melt into a pool of depression. The overriding sense is one of great loss. Kubler-Ross describes a "preparatory depression" in which the terminally ill patient "prepares himself for his final separation from the world." During this stage she says the most worthless advice is "don't be sad."



**Paul Van Ness leads a gay bereavement group.**

Finally comes the stage of acceptance, in which Kubler-Ross says the patient "will have mourned the impending loss of so many meaningful people and places and he will contemplate his coming end with a certain degree of quiet expectation." The patient is at peace.

While Kubler-Ross has been a pioneer in the study of death and dying, AIDS has added unexplored dimensions to what is known about the ways people grieve. Before the AIDS crisis, "gay grief" was not a subject of study.

Most men dying of AIDS, and their partners, are between 20 and 40 years old. Typically they're "people who usually haven't thought about their own death because it's not a developmental issue for their age," says Gerald Soucy, mental health consultant at Chicago's Howard Brown Memorial Clinic. That has changed. "I feel as if I'm in my grandmother's generation, talking about funerals, who's sick, who's about to die," says a volunteer at Whitman-Walkér, the D.C. clinic that specializes in AIDS cases. "I'm in my mid-30s. This is stuff I didn't think I was going to have to think about for a long, long time."

Dr. John Martin, a psychologist and epidemiologist at Columbia University's School of Public Health, describes the grief of gay lovers and friends in the AIDS crisis as an "off-time life event." He says that while bereavement is a "normal" experience, it is particularly stressful and sad for young people. We generally expect death and bereavement in old age, he says, not in life's prime.

Since May 1984 Martin has been following

800 gay men in New York City in a study designed to assess the psychosocial effects of AIDS on the gay community. The study as yet is inconclusive, but Martin says the men he's observed have reported the "classic symptoms of bereavement"—nightmares about AIDS, an inability to be comforted by friends, problems in their daily lives because of worries about AIDS.

Classic symptoms notwithstanding, one pair of therapists describe what they call the "uniqueness of gay grief." Writing in this month's *Journal of Psychosocial Oncology*, Sandra Jacoby Klein and William Fletcher of Los Angeles describe their own work as leaders of a grief recovery group under the auspices of the Los Angeles AIDS Project.

In the article, which will be expanded in the forthcoming book *Gay Grief: A Guide to Mourning the Death of Someone Gay*, Klein and Fletcher say that therapeutic support for persons with AIDS, their families, friends, "and ultimately their survivors" is very new. In their 12 years of specializing in the emotional effects of illness, death, and bereavement upon patients and their "significant others," Klein and Fletcher say they've found a "paucity of available literature on gay grief."

They explain that the literature specifically about gay couples focuses on the lack of societal support for the grief that ensues upon one member's death. This, they say, is because "it is difficult for most people to conceptualize the affectional bond that can exist between two men,

## ◀ SURVIVORS

and in many states, the sexual expression of this love is prohibited by law."

The problem, they find, is that there is "no tradition for gay mourning." A surviving lover isn't called a widow or widower. Rarely do financial benefits accrue to him upon his partner's death. Typically he can't take time off from work. If he does, and if he wasn't "out" with co-workers, they'll wonder about the intensity of feeling for someone who was "just" a friend, or "just" a roommate. This leads to a "stronger sense of deprivation," says Paul Van Ness, a psychologist who leads a bereavement group for AIDS survivors through Whitman-Walker. "At the moment that you need the most support," he says, "you have to hide and demean the nature of the relationship to the dead man and of the [AIDS] death."

For the surviving gay man, there's not even a wedding ring to symbolize the union that was—"at least none is supplied by the church or society," says Jim Graham, Whitman-Walker's administrator. "But christenings, weddings, and funerals—rituals—surround our important life events."

Back home in the Philippines, Manny says there are traditions surrounding a spouse's death. There is the novena, the nine days of prayer. On the ninth day, there's a big party to celebrate the

dead person's passing. Then there's a whole year of formal mourning to be observed. But he's not sure how this applies to his mourning John's passing.

From his point of view, Richard Rapp says that "everything you do after death is for the living, not the dead." Rapp is a D.C. undertaker who specializes in "alternative" funeral services, such as cremation, the choice of many people with AIDS. He says that he has seen a number of instances where a man's family "came swooping in at the last minute," spurned their son's lover and friends—his family of choice—and spirited the corpse away for a private family service back home.

It's *still* not unusual, Whitman-Walker's Graham says, for gay men to be so deprived of the rituals and final arrangements associated with death, arrangements which are "terribly important to the grieving process." Not only are there no formalities or traditions, but because so many Washingtonians were born and raised elsewhere, their deaths may leave their lovers and friends feeling alienated, without a chance for a proper goodbye.

Klein and Fletcher observe the same thing in Los Angeles. "Surviving partners are frequently excluded from participating in funeral plans," they say. "The deceased is sometimes buried 'straight,' with no acknowledgement of his ties to his gay life."

One response of surviving lovers and friends—and often the dying man himself—has been the kind of memorial service that John planned. "Memorial services are becoming more common," notes the Rev. Harry Stock, associate pastor of the Church of the Disciple, a church which ministers specifically to the gay community and through which a number of the services have been conducted. Stock says he's seen people with AIDS plan their own memorial services "right down to the last detail."

Stock says the memorial service is of utmost importance to the surviving lover and friends. "It acts as a final opportunity to say goodbye." He notes that survivors who don't go through a memorial service, or a similar ritual, "are the ones who grieve the longest."

Stone, who because of the nature of her work has attended a number of these services, says she's seen them range from a traditional high mass to a simple service of sharing, where friends stand and recount stories, happy moments they shared with the deceased before AIDS.

Her friend Randy planned his own memorial service, which included a 10-minute recorded "goodbye," an enlarged photograph of himself, and pots he had made for his ashes.

After the service, Stone says that Randy requested that a party in his honor be held at her house because it's "such a great house for parties," and that everyone drink B & B and

champagne and eat chopped liver.

Christmas 1985. Richard and Louis were comfortably settled into their new four-bedroom home in Virginia. It was a relief to be away from New York's hurlyburly. Richard's new business was taking off. Louis had found a new job in Washington. In February they'd celebrate their 24th anniversary together.

Middle age was feeling good indeed.

But Richard was having high fevers lately, swollen lymph glands, and he had discovered a spot on his back. Both of them thought they knew what it was, but neither talked about it.

"You know this will be our last Christmas together, don't you?" Richard asked.

"Yes," Louis knew.

Richard died New Year's Eve. Of AIDS.

Both families were supportive, as they always had been. Richard's estate was in order; they'd each drawn up wills in 1968 and had kept them updated since. Twenty-four years' worth of friends told Louis to call anytime he needed help.

But Louis wanted to be strong. He didn't want to be a third wheel to couples. Rather than call, he'd lie in bed crying. Or thinking about suicide. Now that Richard was gone there was nothing—no one—to live for. Probably there would never again be someone to live for, someone like Richard.

Besides, he was testing positive for the AIDS antibody. He might get the disease himself.

Louis knew he had to do something. Finally he called a friend who works with AIDS patients through the Whitman-Walker Clinic. His friend put him in touch with Paul Van Ness. Louis has been in the Monday night bereavement group since April.

Louis doesn't blame Richard for his exposure to the virus that causes AIDS. After all, there were those "nights out." "Living in New York, in the gay world, you cannot be monogamous," Louis says. Quite possibly it wasn't Richard who exposed him.

Whether it's a tacit or verbal agreement, Stone asserts that most gay relationships aren't monogamous. She says that although she would have assumed that one man might be angry that his partner "infected the relationship," she hasn't seen people angry about who infected whom.

Dr. Michael Pistole, a D.C. physician described by some as a "doctor in the trenches" of the AIDS epidemic, agrees that there's little blaming being done. But he observes that the most unusual thing about the grief surrounding AIDS is that, while there is grief with all terminal illnesses, such as leukemia, AIDS grief is a "combination of grieving for the loved one and fear for oneself—a double whammy."

"Am I the next to go?" is a typical question. Rev. Stock says he's seen two responses. He's

seen cases where the healthy lover is utterly devoted to the man with AIDS. "I've had them break down and cry and tell me they're scared to death—even as they're hugging and holding and going through all the agony their spouse is going through."

The other response, he says, is to "run from the relationship." Afraid of the disease and of the stigma attached to it, the healthy man abandons his dying partner. The stigma of AIDS is real. As therapist Stone says, "We're dealing with two taboo subjects here—death and sex." Pollatsek says AIDS is treated "very much like leprosy, something shameful."

The shame for heterosexuals and homosexuals alike lies not in AIDS being a sexually transmitted disease. AIDS is seen as shameful, she says, "because it's associated with being gay." To put an even finer point on it, it's because, despite all we know about epidemiology, AIDS is seen as a disease of "faggots and drug addicts who don't really deserve any better," says a Whitman-Walker volunteer.

The stigma of having AIDS and the stigma of loving someone who has it, is as present in the gay community as in society at large. Klein and Fletcher say that the fear of AIDS in the gay community has a tremendous impact on the survivor's reentry into a social environment and on his ability to meet new partners. Van Ness describes it as a "feeling that they're marked and

aren't eligible for new relationships."

Louis' friends seem to be exceptional. Pollatsek, and others in the Washington area who work with bereaved gay men, say that the gay community itself provides little support for its bereaved members. As Pollatsek puts it, gay men "don't give each other permission to grieve." She says that when a heterosexual spouse dies, three months of "rallying around and bringing casseroles" is typical.

In the gay community, *one week* is stretching it.

Ours is a "death-denying society," Kubler-Ross writes. Even so, grief therapists, such as Pollatsek and Stone, say the root of the problem in gay grieving goes deeper than that. Stone says that in the gay male community, because there is so much emphasis on sex and looks, relationships are formed much later. But even then, she says, there is a defeatist expectation that gay relationships don't work anyway.

Klein and Fletcher say the problem is that society doesn't recognize these relationships as legitimate. But Stone takes it one step further. She says that gay men themselves don't validate their own relationships. "You give yourself permission to grieve when you validate your relationship," she says.

But gay men often are unsure of *how* to grieve, because there's "no history of how to grieve over a lover," Stone says. They may wonder how

much grief is appropriate given the fact that theirs wasn't a socially, legally, or religiously recognized marriage relationship, and the partner wasn't a husband or wife.

A typical response to the death of a gay partner is to avoid dealing with grief altogether. "In order to avoid dealing with grieving, the hole, the emptiness left by death, you minimize to yourself the amount of intimacy that was in the relationship," Chicago's Soucy says. "You try to minimize the size of the gap in your life by telling yourself that 'men don't feel so intensely for one another.'"

"No permission is given oneself to honor the relationship," Pollatsek adds. She attributes this to "internalized homophobia," hatred and fear of homosexuality, turning society's disdain of gays in upon oneself and one's relationship.

But not just homophobia inhibits gay men's grief. Like most American men, they "don't escape the macho thing," says Van Ness. Men aren't supposed to cry. Rather they're expected to be in control, to express emotions privately, be "strong," and not lean on others.

Still, many gay men aren't as wrapped up in the delusions of American machismo as their heterosexual counterparts and express their feelings openly. Sister Patrice Murphy, a Catholic nun who directs a bereavement group at St. Vincent's Hospital in New York, says that gay men

## ◀ SURVIVORS

in her group are "much less inhibited in showing their feelings." She says the men sometimes cry during group meetings or talk about crying. "They don't seem to have a problem at all in talking about this in the way a heterosexual man wouldn't even acknowledge it."

"I was at my desk in my office," Bob says, and I saw something dripping on my work. I was writing with a fountain pen, and it made the ink

run on the paper and pissed me off.

"I looked up—I'm on the seventh floor of a 12-story building—and I thought, what the hell can be leaking?"

"I looked down and it dropped again. Suddenly I realized I was crying.

"Fortunately I'd brought my raincoat that day. I closed the door, balled up the raincoat, and buried my face in it for 20 to 30 minutes."

Bob was spending the bulk of his free time doing volunteer work as a "buddy" to two men with AIDS through the Whitman-Walker Clinic.

In addition to the usual dinners and get-

togethers, the social-support role all buddies in the AIDS program are expected to play, Bob developed close friendships with both men.

His first buddy, 37-year-old Ray, died in August 1985. His second, 52-year-old Don, died February 1.

"Being an AIDS caregiver is one of the most difficult tasks in the caregiving system today," Columbia University's Martin says. To assist its volunteers, the Whitman-Walker Clinic offers a thanatology program in which Judy Pollatsek encourages them to experience their own death, to imagine how they'd feel and how their loved

ones would feel if it was known they were dying.

"Everybody has different ideas about how they want to die," Pollatsek says. "There's no one way to die—or to grieve. My theory is that you can't help someone who is grieving without getting through your own shit about death first."

With AIDS, that's a tall order. As one volunteer puts it, "For everyone who's gay, it's all on a personal level. It's looking the demon right in the eye and realizing that there but for the grace of God go I—and tomorrow it could be me."

As with Bob and the men he worked with, Pollatsek says "there's always that special person who tears you apart, who falls into your heart. When you get that one you almost want to quit."

Or at least take a break. Since Don died, Bob hasn't taken on another buddy. Instead he's worked as team leader overseeing 26 volunteers who work with 23 AIDS patients.

After the leaky ceiling incident in February, Bob also joined Van Ness' bereavement group—together with Manny, Louis, and seven others. Since forming in May 1985, the group serves as a

forum in which bereaved survivors "compare notes" with others who have also lost a lover or close friend to AIDS.

Van Ness says the group is unique because it is "catalyzed by a desire to get over [the grief] as soon as possible." In this sense it's not at all like typical group therapy where "garden variety neurotics" bring all and sundry problems.

Bob explains how his personal grief has made him more conscious of his own and others' feelings and less tolerant of things like unkindness. "You know what things mean," he says, "you have a real understanding of love, of things that

will discourage and hurt you, of goodness and kindness—and the antitheses of those things. You don't tolerate people who say things like, 'oh, get over it.'"

Martin suggests that the gay community as a whole may be developing a new seriousness, a new consciousness. "Being confronted with one's own mortality," he says, "leads to a deeper appreciation of the world in which we live."

Each week the community is reminded of its loss in the obituaries of the *Washington Blade*, a steady tolling of the bell for the fallen and their survivors. Thee. Me. Us.

Van Ness says that confronting one's own mortality, knowing one is going to die, coping with the death of a loved one, is a turning point that makes one better or worse. He adds that communal grief probably makes confronting mortality especially unavoidable, because you see it at every turn. And you can't just go on the same as before, he says.

"Gay men who are bereaved get through it and go on with life," Martin says. "It's important to keep in mind that throughout this epidemic, people are coping."

And going on.

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