

■ PWA Contingent, 1984.



The following is a memoir of sorts. Some names and identifying details have been changed to protect confidentiality.

“Can I help you?” asks a puzzled male voice.

“Yes, I’m interested in the AIDS Action hospice group.”

“Oh, my secretary said AGE Action!” We laugh at the absurdity. It is 1983 and AIDS is not yet a household word.

I am walking down a snowy street in Brookline. Three men and I converge at a front door, introduce ourselves, and shake hands. Leo, the man my friend Laurel had suggested I phone about the hospice group, opens the door. We ascend the stairs to his apartment. Almost immediately, I hear my name called and Peter and Randy run over and hug me.

It is my introduction to the AIDS Action Committee (AAC) formed as a support group in 1982 at Boston’s Fenway Community Health Center (FCHC), a local gay and lesbian health clinic. Peter, Randy, Laurel and I had trained together for ten weeks beginning in December of that year at OMEGA, the Somerville, Mass. hospice organization. Like other hospice groups, OMEGA provides support to people facing life-threatening illnesses. It turned out that more than half of our class was gay and lesbian. Though I don’t recall Peter or Randy mentioning they planned to work with people with AIDS (PWAs), I remember Peter coming out to the group as a gay man.

So much has happened since then. Randy was one of the green shirted men on the cover of the Boston *Globe Magazine* when it featured “The Social Impact of AIDS” in July, 1983. I saved it, not only because it was a “gay piece,” but also because that month I had come out to my mother.

This night, six months later, it is heart-warming to be welcomed by men who know something about me. I am the only woman at this meeting and it feels strange. “Why is she here?” registers on some of the faces around me as we sit in a small circle and talk about why we want to do hospice work with men with AIDS.

Larry Kessler, the only paid staff member of the AAC, asks me about my experience with OMEGA. Randy and Peter jump in, and both talk about our training together. I mention that, given my own experience with a dying loved one and no one to talk to about it, I feel compelled to work with others who may be as isolated or alienated as I had felt. I also say the stigmatizing around AIDS deeply disturbs me. This seems to strike a cord with the men who have spoken of friends dying and of their own fears.

Writing this four years later, I don’t remember who else was there except for Steven. I remember his excitement that I, a woman, was interested in AIDS work. On the subway trip back into town I waited to see if he would ask, but I don’t recall if he did. I know I said that as a lesbian and a hospice volunteer, AIDS work seemed to come naturally. We talked about being outsiders in some contexts — he, a white gay man singing in a Black church choir and I, a white lesbian, the only woman at a meeting about what was then thought to be a predominantly gay male affliction. Shrugging, I said I supposed I’d get used to it. Besides, Laurel was already involved and there had to be other like-minded women.

Finding the address on the dark South End street, I shiver in the January wind. A young intense-looking man — Kevin — greets me inside. He and another handsome man are eating dinner. I am early as usual and nervous, but I manage to introduce myself. I decline Kevin’s offer to join them and settle stiffly on a couch to await my first AIDS hospice meeting. Several men come in. A friendly woman, Gail, sits next to me.

Another, Katie, who appears around my age and a middle-aged woman, Joyce, enter. Joyce comes over and offers her hand so I figure she’s a dyke. I’m not sure about the other two. The meeting starts and, red-faced, I shyly introduce myself. It turns out Katie, too went through the OMEGA training before joining the Committee.

There are about twenty of us, seven women. Meeting every two weeks, we function as a support group, especially for those of us who are assigned to a PWA. It is the only place many of us have to talk about AIDS, to apprise each other of any press coverage, to vent. Rhonda and Jim, the two therapists who called the original meeting at Fenway to form AAC, come to some meetings and Larry comes to most. Peter becomes the second paid staffer and later Gail is hired as the Committee administrative assistant, all housed in a basement office at Fenway Health Center.

After an interview with Peter and Leo, I am officially open for assignment in February 1984. Katie and I become pals, usually going to meetings together and sharing an interest of going into social work some time in the future. Of the other women, Kathy, Bev, Joyce and Laurel are health providers and Gail (the only straight woman) became involved when a dear friend became ill. Kevin was the buddy to Gail’s friend. I feel a particular affinity for him, perhaps because he is young, Irish and gay. And angry.

Paul-David, a newcomer of late from the Bay Area, tells us about Shanti and New York’s Gay Men’s Health Crisis in his soft southern drawl. I enjoy hearing about San Francisco, the gay mecca. Only recently have I braved a woman’s bar alone and, in March, had my first affair with a woman now living in SF. P-D talks about feminism, too, and acknowledges racism in the gay community. It’s like a breath of fresh air. He’s the only one younger than I in the group. We become closer, sharing an appreciation for Audre Lorde.

Kevin is furious. The Eagle, a men’s leather bar in the South End, continues to show Eddie Murphy videos and play Donna Summer music. Murphy features homophobic and AIDSphobic jokes while Boston-born Summer, a favorite in gay discos, has been quoted as saying people with AIDS “deserve what they get.” We picket the bar on a warm night after individual pressure doesn’t work. Cops, Larry, and Boston’s mayoral liaison to the community Ann Maguire, show up as we walk in a circle outside the entryway. Our protest lasts less than an hour but one enraged patron begins to pick on Katie because she is the smallest of us and because she is a woman. He calls her a “dyke commie.” The scene might be laughable but for the tension, pain and misogyny of the moment.

“Why don’t you pick on someone your own size?” I say angrily as he tries to push her out of line.

In April, U.S. Department of Health and Human Services Secretary, Margaret Heckler, a one-time Congresswoman from Mass., calls a press conference and predicts a preventive vaccine for AIDS will be “ready for testing in approximately two years.” (Already, Gallo’s HTLV-III has been hailed as “the virus” causing AIDS, a contention that will be hotly disputed.) Heckler later retracts the statement, warning AIDS must be stopped before it reaches “the general population.” She never addresses the lack of federal impetus for AIDS funding, but continues to call the disease the nation’s “number one public health problem.” Nor does she discuss what policymakers intend to do with those already infected or showing symptoms when the hailed vaccine ever appears. Meanwhile

in 1984, San Francisco spends \$7.6 million in AIDS-related programs and Boston’s Mayor Raymond Flynn funnels \$150,000 in Community Development Block Grants (federal funds distributed by cities) to AIDS Action.

Kevin is diagnosed in May. Louie, another man in the group, is also ill. They are the first buddies in Boston to live with AIDS.

And that is how we refer to it; “hospice” is losing favor. The group is hit hard. Several men talk about guilt and confusion. “Why not me?” Peter asks one night. The women face other sorts of alienation and Laurel speaks eloquently one night about how defensive she feels when lesbians ask why she is putting energy into AIDS. I listen curiously. No one has asked the question of me, but then I know few lesbians.

“They’re asking what are they doing for us?” she says ironically, looking around the room. “AIDS is a gay mens’ disease.”

It is Gay Pride Day in Boston. Katie and I run into the Boston Public Library to change into the verdant green “To Life” shirts of the AAC. It is the first March for both of us and we are flushed with pleasure. Lining up behind the banners, we carry some of the signs stenciled with the dates of each person whose official cause of death is AIDS. We’ve been instructed to stay dignified: no cheering.

Chills run through me in the brilliant June sunshine as we lead off the March. There is scattered applause but also a stillness as we march in our green, bearing witness. The bells toll from the Arlington Street Church sending us forth and welcoming us at the same moment. I feel strong reflecting on the battles I have waged with my family, with myself, to be here today. Most striking, perhaps, I feel like a soldier, as if I am part of a battalion marching off to war. I am uneasy about that.

A man with a camera is taking so many pictures as we march down from the State House summit that we joke he’s from the FBI. He approaches those of us holding the “How Many More Must Die?” banner and asks what the signs are for. “All the people who’ve already died,” someone says.

“In the U.S.?”

Stunned, we exchange glances and say “in Massachusetts.” He looks shocked, turns and walks away without a word.

“Jesus!” says the exasperated man next to me. Several others will ask the same thing before the day is over.

At the gate to the Common, we split to line the entry route and watch the rest of the parade march in. Spotting a woman from high school, I call her name.

“What are you doing here?” she asks.

“What do you think?!” I smile and tell her I’m in the book. The man next to me chuckles as she walks away still gaping.

One night Peter asks how I’m feeling, still unassigned. It’s been several months.

“Pretty useless,” I say quietly, meeting the men’s eyes around the circle. They are all assigned and, again, I am the only woman at the meeting. Joyce, Kathy and Bev are all working in paired buddy situations and Katie has begun work with a Haitian family whose children are infected. I hope the upcoming AIDS training weekend will help me to feel more included.

It begins on a sweltering July day in Leo’s large living room. Gazing around me at the new men, I marvel at all the varieties of people so often lumped into “a lifestyle” — as if gayness is monolithic. Gail, Katie, and I are part of AAC’s first in-house education and team-building workshop. We pair off for introductory exercises and I meet Richard, a blond man with a Celtic accent.

Katie’s partner is Mil, a sharp-featured redhead who appears very serious. We are told to look closely and decide whether our partner is single or coupled, gay, straight, or of “indeterminate sexuality,” in short, what he or she is like and our own assumptions about that.

Richard shoots Peter a glance when I guess that he’s single and thirtyish — wrong on both counts. He is in his mid-twenties and formerly a volunteer with the Terence Higgins Trust, London’s version of AAC, named for the first Englishman to die with AIDS. Mostly I like what he says about me though I’m annoyed when he guesses “indeterminate sexuality.” (We will kid each other about that one for years!) Mil gives Katie the benefit of the doubt: single with as many girlfriends as she wants! (She elbows me and I snicker about it.)

A flamboyant man asks us to fill out a questionnaire on the subject of AIDS in our lives. I take issue with one true/false item: “AIDS has taken all the fun out of being gay.” It presumes “the gay community” is only men, or that the effect is the same for lesbians. On one of our balcony breaks, Bob, cute and bubbly in his coveralls outfit, tells me he’s never known any lesbians. To him “the gay community” has always meant “parties, men, lots of shopping, men —.” We joke about all the lesbian stereotypes.

Kevin and Louie, Fernando (a Puerto Rican man with Kaposi’s Sarcoma) and Brian, a former nurse, are scheduled to join us for the Persons with AIDS segment. Each very different and articulate, they speak about the isolation, homophobia and patronization they’ve encountered. It is the first time many of the trainees have encountered a man with AIDS. Kevin is angry and confrontative. Gaunt, more so than in May, he tells us PWAs are not victims and how disempowering it is to refer to them as such.

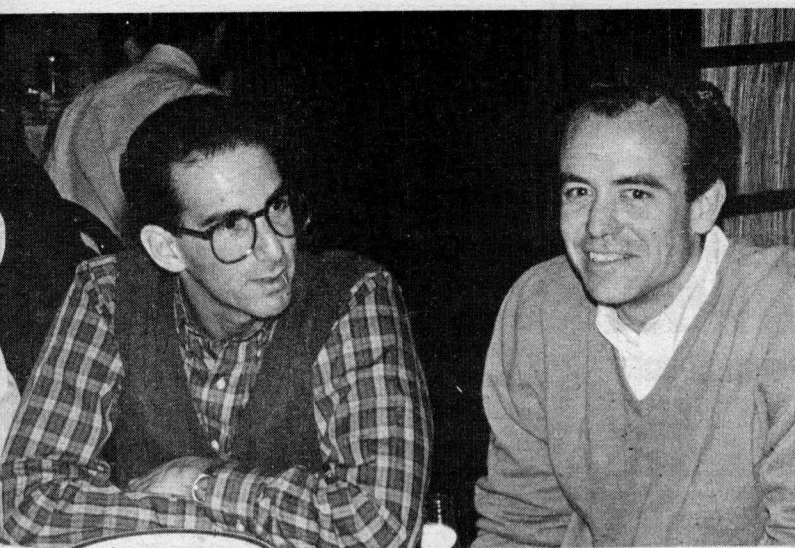
In August I go to San Francisco for the first time. I feel strangely at home. Sexuality is palpable in the streets. There are also AIDS billboards in the subway stations, information tables in the Castro and brochures in the openly gay businesses.

Returning to Boston in September I am more frustrated with the wait at AAC. Maybe there’s a reason they’re not telling me; otherwise why haven’t I been assigned yet? I jot a note posing the questions to Peter. Why are there no lesbian primary buddies? And what about the Dynasty Ball poster? It is of a man; and several women have asked me if this, the first big AIDS Action fundraiser, is a men-only affair.

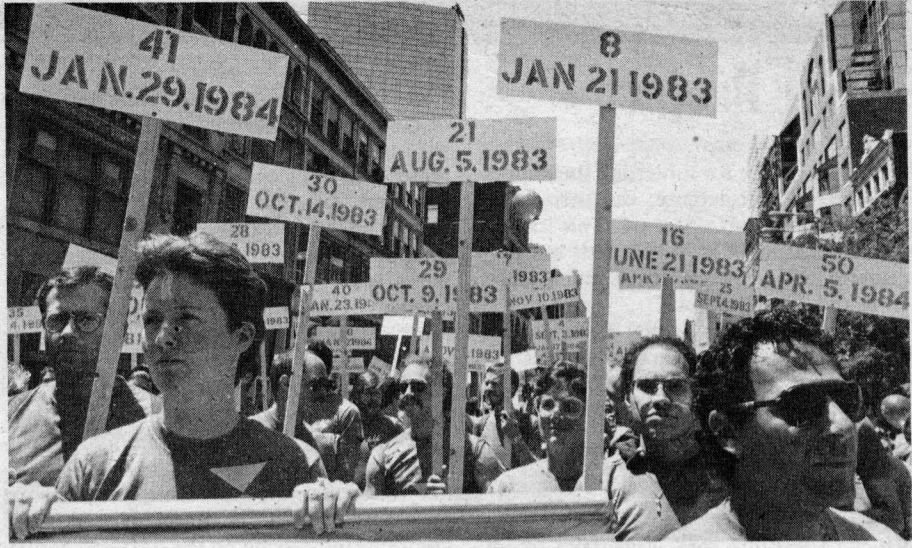
Peter calls and teases me about reading him the riot act. He presents two options: I can work with Lee who is having a difficult time with the guy to whom he’s assigned or help Katie with the kids. Irritated, I ask him how he’d feel assigning a woman to a man.

“I’ve never thought of it.” He’s assumed a gay man wouldn’t want a woman. Has he ever asked? He turns sheepish and says “no.” I elect to work with Lee. I’m not a kid person.

Meanwhile, I’m getting an education from and about gay men. (In training, I’ve become versed in more gay sex practices than I’d ever imagined.) I realize I cannot touch the fear and loss they voice. Sometimes, too, these men look through me and there is awkwardness when we hug. The peer group, affectional feelings (or fear and arousal) I’d feel in a room full of lesbians or women is elusive. There is drama and affection between the women but it is less visible and our small numbers add to feelings of isolation. Gay men work with gay men; women it seems, are a group that may work in tandem with men or (as in Katie’s case) with children. Lesbians are subsumed in



■ Paul-David, the author, Jay and Randy at the November 1984 BLGPA dinner honoring AAC buddies among others.



Susan D. Fleischmann

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BATTLES JOINED ODYSSEY OF A LESBIAN AIDS ACTIVIST PART 1 OF 5 BY MAREA MURRAY

"the other."
 I go with Lee a couple of times to visit his buddy, a man living with a woman Lee tells me is bisexual. We don't click at all; Lee and I both dislike the man. We're a taxi service for him because Lee, unlike most of the rest of the team, has access to a car.

With nearly 40 people, the team is getting too large to meet in anyone's apartment for support meetings. With difficulty we break into small groups meeting on different nights. Later called "pods," these groups of eight to ten people are facilitated by two convenors. I join the group with Gail and Leo.

AIDS articles are appearing with greater frequency and sensationalism, if not informed analysis, in the mainstream press.

My friend Susan and I are eating lunch at work. I've been on the job some months. My boss, Fred, is gay and Susan is an old friend. Another man I work closely with comes into the conference room announcing he's got a great joke for us about AIDS. I tell him I'd rather not hear it. He exhorts me to humor him because it really is funny. I'm getting very angry and Susan is visibly tense, waiting to see what I will do. I say, again, "I don't want to hear it." He goes on. It is about Haitians. Furious, I stand and tell him I don't think his racist joke is funny and go to my office, shutting the door after me. I will come out to him later about myself and my AIDS work. He is apologetic....

One of the Haitian children goes into the hospital a few blocks from where I live. I begin to visit her every few days while Katie continues with her ill sibling and her parents in the home. No home health aides would go in so AAC was called.

The girl is the first AIDS-related case at the hospital although she has technically not been diagnosed and carries only a CMV (cytomegalo-virus) and "opportunistic infection" label. Three years old, terrified and angry, she doesn't say much or seem interested when Katie introduces us. Years later I will learn that language is one of the first developmental areas to reflect regression in HIV-infected children. Katie tells me her family has enormous trouble going to visit — the hospital is across town, an obvious stronghold of Western medicine, and English-speaking. Seeing their daughter in a hospital, in addition to the helplessness, fear and guilt they endure, is overwhelming. One afternoon I arrive and find relatives visiting. They look curiously at this white woman who brings a coloring book for the baby. Uncertain of their understanding, I decline to stay or what my affiliation is.

The nurses sometimes chat with me about AIDS or CMV, a common infection of immune-suppressed people. Some don't ask me any questions and go about their business. Most are glad for a visitor to the little girl so set apart from the others and often in a great deal of pain, fed by a tube into her stomach. I am heartened several don't wear gloves when simply handling the child.

Feeling helpless, I ask myself what can I do with, for this child? I have heard stories about how gay men and PWAs have been treated in some settings and, while there is sympathy here, there is invisibility as well.

I bring her toys, chewing gum, whatever I can think of — but I *feel* woefully inadequate. I am used to working with adults who are living and dying, not with children. I don't know what to say to her, what she understands. As much as I bristle at the media's attention to kids as "the innocent victims of AIDS," I am unspeakably pained by the knowledge this child will never grow up and feel love as I have, that her fresh air is limited to how open her window is, that she can no longer really take food in, that she lives in chronic pain and she knows she is suffering, even dying. She asked her mother

about dying on entering the hospital.

One day I come in to find her bed empty. For a brief moment I think the worst, then find her out in the hall, amidst the hubbub of visiting hours. Wheeling her down the hall into the playroom, I hope she will feel the bright sunshine entering through the large windows.

She is scribbling furiously with black and red crayons when a woman approaches me, asking where I'm from. AAC, I reply in a low voice. (Do I look like a candy stripper?) She doesn't indicate any recognition of the acronym.

"I just wanted to make sure you knew about —" and she begins to list precautions. I cut her off.

"I've been trained, thank you," I smile to soften my words.

"She's a very angry little girl," she remarks, looking at the paper the child draws on.

"Yes," I nod. "I know."

Around Thanksgiving, Louie is the first of the buddies to die. Devastated, most of the group goes to his funeral on a frigid day in Dorchester. Though I didn't know him well, I go to support the others. The church is packed. He was an only son.

As a recovering Catholic, I find it strange to be in a church for the funeral of a gay man who has died of AIDS. But they say cancer. Over and over the priest says it and so does the obituary. We know why, and as the cases continue to mount in tandem with our invisibility, many of us grow angry. AAC haggles with obituary editors to allow lovers' mention and with hospital intensive care units to allow visits from "non-family" members.

Meanwhile, the first articles about health worker risks and female prostitutes in the U.S. appear in local and national papers.

Home on a weekend morning as Christmas 1984 kicks in, I'm trying to work myself up to go over to the hospital. It is a gloomy mission as the child I visit has been more lifeless and in greater pain of late. I decide to give myself another half hour. Gail calls from the AAC, telling me the girl is "in a bad way."

I make my way through the windy streets, up the slow elevator and to the familiar corridor. The room is empty, stripped bare. Must be in the ICU. I walk to the nurses' station and ask a crusty, unfamiliar nurse.

"She's gone away," she says gruffly as she puts a child into a strolling chair.

"Gone away?" I echo, unable to believe she'd use such euphemism. She ignores me. I look around for someone I recognize. A nurse near my age comes up and draws me aside. "She died about a half hour ago." I must have gone pale because she puts her hand on my arm and tells me she didn't know the girl but there are nurses around who did...her family is in another room. Thanking her, I decline and try to pull myself together. Going to the elevator, I will it to come soon so I won't have to stand raw, holding my body tight, not wanting to be alone mourning in a hospital corridor. Cold grayness comes down once I'm through the crowded lobby. Home, I put a favorite lullaby I associate with the little girl on the turntable and, later, play angrier music.

Katie and I go to the funeral together. She is anxious as she's never been to one. I play old hand. It is a Catholic service, entirely in Creole with plenty of moving songs. We are the only whites in the church and sit near the rear in low profile. It is a grueling ceremony. There is wailing grief and the child's mother must be helped from the hall. Her other symptomatic child will die within the year with AIDS-related illness.