

# TANGLED MEMORIES

*The Vietnam War, the AIDS Epidemic,  
and the Politics of Remembering*

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Chapter 6:  
AIDS Quiet

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acknowledging AIDS as an "American" epidemic. If those who have AIDS or HIV can be defined as marginal and outside the mainstream, then the funding of the services that fight the epidemic can be seen as outside the national interest. The battles of AIDS representation have been precisely about access to the mainstream national culture, be it the culture of commodity exchange or the nation as represented by its institutions of funding. In the AIDS epidemic, the marginal and the mainstream, the commercial and the home-made, the sentimental and the cynical all converge in producing meaning. The complexity of this tangled set of meanings keeps closure at bay; simple narratives cannot take hold.

## *Chapter Six*

### Conversations with the Dead

#### Bearing Witness in the AIDS Memorial Quilt

Events of tragic consequences demand memorials, yet the complexity and urgency of the AIDS epidemic have placed unique demands on the process of memory. Though it has produced many forms of cultural memory, the epidemic's largest and most national memorial is the NAMES Project AIDS Memorial Quilt.

The AIDS Quilt, like the AIDS epidemic, evokes immensity. It consists of an ever-growing number of three-by-six-foot panels, each of which memorializes an individual who died from AIDS (see Figure 18). The quilt has been exhibited throughout the world and includes more than 40,000 panels from twenty-nine countries, yet it represents a mere fraction of those who have died from AIDS.<sup>1</sup> Over 5 million people have viewed the quilt. In its epic size, it attempts to create a visual image of the enormous proportions of the AIDS epidemic, its potential to kill millions of people worldwide.

AIDS Quilt panels are created by friends, lovers, and families of the dead and by concerned strangers. Panels incorporate diverse materials: cloth, leather, photographs, stuffed animals, clothing, wedding rings, credit cards, dolls, flags, champagne glasses, condoms, cowboy boots, feather boas, human hair, old quilts, and cremation ashes, among other things. Panels are consistent, however, in their desire to name the individual and to present artifacts of their lives: pictures, memorabilia, symbols, colors, messages.<sup>2</sup>

Parts of the quilt have toured the country several times, and

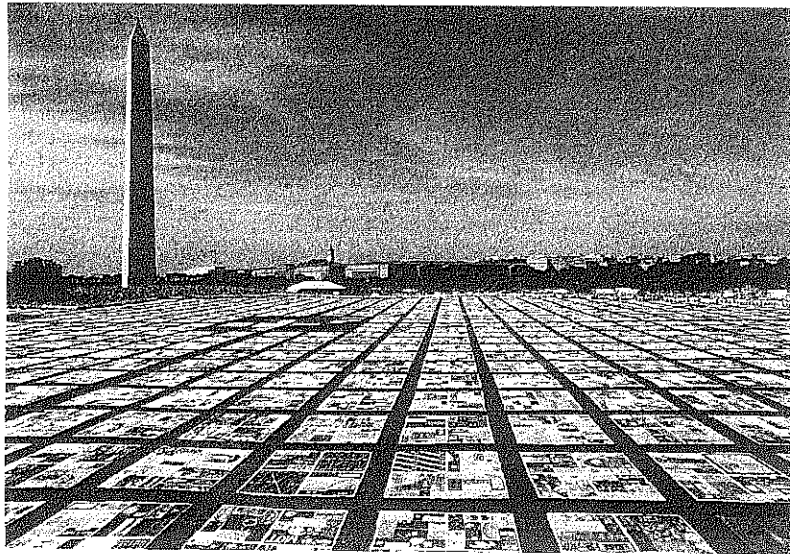


Figure 18. NAMES Project AIDS Memorial Quilt, with 20,064 panels on display in 1992. Photo by Mark Theissen. NAMES Project Foundation.

sections are constantly on display at any given time. Thus, every showing of the quilt is unique, with different panels presented in different configurations. The quilt has been shown in its entirety on the Mall in Washington, D.C., four times—in 1987, 1988, 1989, and 1992, when it consisted of over 20,000 panels. It returns in 1996 with an estimated 45,000.

Both the AIDS Memorial Quilt and the Vietnam Veterans Memorial stand as, and invite, testimonials of and to specific individuals, and both attempt to create a community of shared loss. Both have been packaged and popularized in the media. The AIDS Memorial Quilt, however, radically distinguishes itself from the Vietnam Veterans Memorial and from most public memorials through its phenomenology and authorship: the tactile, foldable quality of the cloth, the uniqueness of each panel, and the variation that speaks of the different hands that crafted it. The quilt has created a particular kind of community in which loss and memory are actively shared, even among the highly fractured and divided groups—the gay population,

black and Latino inner-city populations—that are dealing with the AIDS epidemic. It has facilitated and inspired the production of cultural memory, the sharing of personal memories to establish a collectivity; it has also brought the politics of identity, gender, race, and sexuality to the surface and spurred debate over contested notions of morality and responsibility. The quilt's therapeutic role often conflicts with what many see as its political role in the debate over AIDS funding. In addition, the quilt exposes the rift in gay politics between speaking defiantly from the margins of society and demanding inclusion within the mainstream. In this chapter, I examine how the AIDS Quilt functions as a memorial constructed in the midst of a war of rhetoric, identity, the politics of disease, and the struggle for life.

### Origin Stories

Like the Vietnam Veterans Memorial, the AIDS Memorial Quilt has an origin story, one with elements of spontaneity and innocence about the impact of the project to come. Fittingly, the origin story of the AIDS Quilt is set in the Castro, the gay district in San Francisco that serves as an icon for gay communities throughout the United States. The siting of the quilt's origin in San Francisco is significant because of the devastating loss from AIDS in that community.<sup>3</sup> The story begins at a candlelight march in memory of an earlier crisis in San Francisco, one that preceded the AIDS crisis: the assassinations of Mayor George Moscone and Supervisor Harvey Milk, an openly gay politician:

The idea for the Project originated the night of November 27, 1985, when San Francisco activist Cleve Jones joined several thousand others in the annual candlelight march commemorating the murders of Mayor George Moscone and Harvey Milk, San Francisco's first gay supervisor. As the mourners passed by, they covered the walls of San Francisco's old Federal Building with placards bearing the names of people who had died of AIDS. "It was such a startling image," remembers Cleve. "The wind and rain tore some of the cardboard names loose, but people stood there for hours reading names. I knew then that we needed a monument, a memorial."<sup>4</sup>

The patchwork effect of the placards reminded Jones of a quilt, and a year later, using spray paint, he made the first panel—for his best

friend, Marvin Feldman, who had died in October 1986. In May 1987, Jones and Michael Smith began organizing the NAMES Project, the organization that raises funds for and maintains the quilt. In October of that year, when the quilt was first displayed in Washington, D.C., it consisted of 1,920 panels.

Jones originally envisioned the AIDS Quilt as a message that would call upon the conscience of the nation. He expected it to produce a huge impact: "I truly believed that when we went to Washington in 1987, it would be like Jericho, that what we had built was so beautiful, so exquisite. I thought, they are going to see the evidence of our labor and they will be moved."<sup>5</sup> Jones conceived the quilt on two levels: a national memorial of epic proportions and a grassroots memorial produced by "quilting bees in little communities with all different kinds of people coming together." The tension between these two levels—the quilt as a massive project versus the quilt as a product of intimate, local communities—is a major part of its complex effect.

### Naming the Dead

All memorials participate in the act of naming, from the engraving of individual headstones to the pointed non-naming of the Tomb of the Unknown Soldier. By naming the dead, the quilt produces a collective body count (Figure 19). At Quilt displays, this takes the form of a roll call of the names of the dead, in which community and civic leaders, lovers, family members, friends, and AIDS volunteers read the names out loud, each marking those who were close to them.

Naming has particular significance in the context of the AIDS epidemic. Communities affected by AIDS have struggled with battles over language, metaphor, and representation. In the context of the quilt, naming is often seen as equivalent to coming out, in particular for the families of gay men; a fear of or refusal to name in the quilt often reflects families' fear of acquiring by association the stigma of homosexuality. Panels cannot be altered by anyone but their makers once they have arrived at the NAMES Project and been catalogued. Hence, battles over naming in the quilt take place at the time of panelmaking, often as conflicts between families and lovers. These



Figure 19. Twelve-by-twelve-foot section of the AIDS Memorial Quilt. Photo by David Alosi and Ron Vak. NAMES Project Foundation.

conflicts all seem to imply homophobia—the fear that inclusion in the quilt will reveal a gay identity (whether true or not) to the world. One panel reads:

—I have decorated this banner to honor my brother. Our parents did not want his name used publicly. The omission of his name represents the fear of oppression that AIDS victims and their families feel.

Many disputes over naming have been resolved by the NAMES Project; however, in the first years of the quilt approximately 10 percent of the names were fully or partially withheld. Since the early 1990s, most names have been given in full, testifying, according to NAMES

Project director Anthony Turney, to the increasing destigmatization of AIDS, a process in which the AIDS Quilt has played a primary role.<sup>6</sup>

The AIDS Quilt does not present the singular, uniform cataloguing of names that the Vietnam Veterans Memorial does. The NAMES Project does not restrict the number of panels that can be made for a specific individual; some are honored in several panels made by different people. No relationship between the panelmaker and the panel subject is privileged over another: Panels are made by strangers, families, lovers, friends, and distant admirers. Some people with AIDS even have made their own panels before they died. The process of panelmaking can produce a community of concern, in which strangers reflect on the lives of others and lovers and families meet for the first time.

At the Vietnam Veterans Memorial, people leave personal artifacts in order to individualize the names inscribed uniformly on the wall. In the AIDS Quilt, by contrast, the names are already personalized and distinct. Whereas the Vietnam Veterans Memorial emphasizes lives lost, the AIDS Memorial Quilt emphasizes lives lived. NAMES Project staff member Scott Lago said, "It is a celebration of a person's life. Not a comment on death. Hell, we know he's dead. But she was a scream when she was alive!"<sup>7</sup>

Each panel responds to the question: How can this person be remembered? What elements will conjure up their presence? Individuals are often symbolized in a literal way by their images and artifacts of their lives, their favorite activities or places: a baby's blanket for an infant, a leather jacket for a biker, a pair of scissors for a hairdresser, a blue scrub tunic for a doctor. Often they are commemorated in letters addressed to them (one panel is a large fabric letter, addressed to "Mark Richard, A Better Place").

The quilt panels reflect a diversity of relationships, roles, and audiences. Some speak to the audience in a tone of admonishment, others in direct political anger:

—They gave me a medal for killing two men, and a discharge for loving one—Sgt. Leonard Matlovich.

One of Roger Lyons's panels quotes his testimony before a congressional panel about AIDS:

—I came here to ask that this nation with all its resources and compassion not let my epitaph read "He died of red tape."

Some panels are pointedly dedicated to "those who died alone," "those in prison," "the forgotten," and others not specifically named in the quilt. The quilt thus serves as a sounding board for issues about AIDS; some panelmakers use it to speak to specific audiences, both those who already understand and those who need to be taught.

Some panelmakers use irreverence as a means to celebrate the lives or sense of humor of those they are commemorating, reflecting a desire to make the dead laugh:

—Stardate 10-9-87: Beam me up Scotty.

—Is This Art? No! It's Fred Abrams!

The most noticeable aspect of many panels is their function as testimony, stating quite simply: This person was here. Many panels tell biographies to provide a witnessing to the details of a life that may be known only by a few:

—David R. from Alaska, loved flowers and wanted to open a flower shop but he managed a bank instead (you know how life can be) well he was positive (?HIV?) and full of love, then his health slipped and he met a blond. They robbed the bank of \$60,000 and went to LA, the blond lost all the money in Las Vegas, David visited Hawaii, where he was very happy, then his health got worse, he went to NYC, was in tremendous pain, the first two nights he attempted suicide with pills but failed, then succeeded with a plastic bag. 1987.

This witnessing of a life and a death is presented as both biography and admonition: He lived and loved, he was foolish, but he killed himself because of great pain. This disease causes pain and desperation.

Many voices speak in the different panels and even within a single panel, sliding from testimony about the subject to testimony about the relationship between panelmaker and subject to testimony solely about the panelmaker. In fact, many of the quilt panels speak more of the maker than of the subject:

—Ricky—You probably don't remember me. We went to high school together, and you played the organ at my Southern Baptist church. We should

have talked but I guess we were afraid. I still am sometimes . . . Silly, huh? Watch over me.

—Randy Clarke—My Boy.

Some panels ask for forgiveness and are tinged with overtones of regret and guilt:

—I couldn't accept the love you offered. I know better now.

—You meant so much to me, I wish I had told you.

—I didn't get a chance to say goodbye.

Through the simple act of testifying or confessing to these feelings of regret, the speaker achieves a kind of cleansing of guilt. Panelmakers assign meaning to the AIDS deaths through the redemptive transformations those deaths caused.

Significantly, most of these panels are unsigned. Hence, they are not about authorship or individual production. Those that speak to the dead need no identification, and for others signing may seem simply inappropriate. Panels made by families are often signed with a relationship: Mom, Dad, your brother. The objects in quilt panels are less cryptic than many of the articles that have been left at the Vietnam wall, perhaps because their purpose is often intended to be pedagogical as much as memorial.

Thus, these panels represent a multiplicity of testimonies and tones, some irreverent, many sad, some regretful. All reflect with irony on life's finitude. In a panel for James Meade, a scrawl of text is written around the quilted image of a man lying under a quilt next to a window:

—Dawn at the window—Birds singing—The cats crying to be fed—Linger-  
ing dreams—The light in the tree limbs—Shaving—Putting on a bath-  
robe—The smell of the coffee—Ironing a shirt—Picking out a tie—Waking  
up Harry—Feeding the cats—The warmth of the toaster—Oatmeal with  
raisins—Cleaning the sink—Making the bed—Packing a lunch—Remem-  
bering a song—Riding the bus—The weight of a pocketwatch—Telling a  
joke—Listening to Mozart—Coworkers complaining and laughing—The  
breeze in the grass . . . Bringing flowers to Harry—Chow-mein and fortune  
cookies—Brushing the cats—Fourhanded Mozart—Folding the wash—  
Watching an old movie on TV—The moon and the fog—Drowsing in the

armchair—The kimono hanging on the wall—The cleanness of clean  
sheets—Fingernail clippings—Reading in bed—Evening prayer—Stars and  
sleeping—Dreaming.

This is a middle-class life disrupted. The evocation of the daily life of  
this gay couple takes on a kind of compelling ordinariness, and small  
details become charged with loss.

### Quilting and Folk Art

*Quilts combine old use—tatters—with new use. All parts of  
them are pregnated with memory. They are always records of  
accomplishment, solo and mutual, and promises of continuity.*

Jeff Weinstein, "A Map of Pre-  
ventable Death," *Village Voice*,  
October 1988

Technically, the AIDS Quilt comprises not only quilting but also ap-  
pliqué, spray paint, embroidery, and other crafts. It is not quilted  
with a backing or used, as are most quilts, as a blanket to provide  
warmth. Yet the connotations of warmth and comfort associated with  
traditional quilts are central to its commemorative role. Visitors touch  
and stroke the AIDS Quilt. A quilt also connotes nostalgia, family  
heritage, folk art, Americana, and women's collective work. Jones has  
said: "I said to myself we need a memorial. Then when the word *quilt*  
went into my brain, what I remembered was my grandmother tuck-  
ing me in with this quilt that was made by my great-great-  
grandmother and has been repaired by various grandmothers and  
great aunts over the years. I immediately had a very comforting,  
warm memory and that was the key."<sup>8</sup>

Quilting has multicultural roots in Africa, Europe, India, China,  
and other places throughout the world.<sup>9</sup> Though Jones and the  
NAMES Project staff emphasize the international status of the quilt  
and its place in many traditions of folk art, Jones's description reflects  
his own midwestern background. His language is steeped in Ameri-  
cana: "I think of it as a strong durable fabric that is made by collabo-  
rations of prairie women who have marched with their Conestoga  
wagons across the plains; it is something that is given as a gift, passed

down through generations, that speaks of family loyalty." This image is particularly important when the quilt is shown at the Washington Mall, where it represents an attempt to incorporate those symbolically cast out of America—homosexuals, drug users, the poor—back into the nation. This evocation of American tradition is not without its critics. Daniel Harris has written, "It evokes nostalgia for a simpler, more innocent time, a pastoral world of buggies and butter churns—an America that never existed."<sup>10</sup>

Indeed, the quilt's relationship to nostalgia is contradictory. The quilt implies a sense of personal and familial continuity, moving through the years from generation to generation. Yet the AIDS epidemic has struck primarily young men, young women, and children, disrupting the life cycle. Many parents have buried their children, many young children have been orphaned, and the sense of generations and "families" within the gay community has been devastated. In addition, many young men have returned to their families from the urban centers where they lived in order to be cared for and die at home, a reversal of the expected movement of children outward from home.<sup>11</sup> Letters to the NAMES Project testify to this unexpected interruption in the life cycle:

—We lost our son. It is hard to believe that one in the prime of life is physically gone from us. Is it not supposed to be the older who depart from the living first? . . . We really didn't begin to know him until he came home in his manhood to spend his waning months with us. . . . He was a teacher, probably our best.

—We were supposed to grow old together.

The family quilt connotes continuity; AIDS creates disruption and broken lineage. In its evocation of the past, a quilt promises a future to which it will be handed down. Moreover, many quilts evoke the presence of previous generations by incorporating scraps of clothing literally worn out by family members. Hence, fabric changes its status in a quilt: A functional article of clothing becomes an element in a design. In keeping with this tradition, many panels in the AIDS Quilt include articles of clothing. But unlike the scraps used in a traditional quilt, these are not clothes that were worn out or outgrown. They are vacated, poignantly empty, echoing the body that once filled them.

Traditionally, quilting has been the handiwork of women. It has been a means by which women, who were excluded from recorded history, created forms of cultural memory. In the United States, quilts were made by women for warmth, friendship, and political expression. The AIDS Quilt draws on several traditions of quilting, including the crazy quilt, the friendship quilt, the fire quilt, and the memory quilt. Like a friendship quilt, the AIDS Quilt incorporates signature panels from quilt displays; like a fire quilt, which was made from scraps for emergencies, it conveys comfort in the context of urgency.<sup>12</sup>

Cleve Jones consciously borrowed from a historical connection between cloth and mourning. In Greek mythology, the fates were said to spin the "thread of life," which was measured and cut to determine the length of a life. In the Jewish tradition, mourners wear a torn piece of cloth to symbolize the torn fabric of life, and during the plague in Europe churches hung banners with the names of the victims.<sup>13</sup> In the westward migration of Euro-Americans, a quilt often stood in for a coffin when someone died on the treeless Great Plains.

As folk art, the AIDS Quilt straddles the realms of art and craft. Produced collectively by thousands of mostly unskilled people, the quilt bears a tenuous relationship to the discourse of art. It has only rarely been shown in art venues such as museums, more commonly being seen in civic centers, churches, schools, and community centers. It has not been subjected to the aesthetic debates of, for instance, the Vietnam Veterans Memorial precisely because it is not being produced by one artist and is perceived as a craft as opposed to a work of art. Hence, although certain panels are aesthetically more ambitious than others, the quilt affords equal status to all panels regardless of elaboration, style, or uniqueness. Many refer to its "democratizing" effect and its "relentless understatement."<sup>14</sup> Some commentators have reflected, seemingly with relief, on the lack of pretension in most panels: "There is extraordinary artistry here, and also a carnival of tackiness. Perhaps that is the most moving and at the same time most politically suggestive thing about the quilt: the lived tackiness, the refusal of so many thousands of quilters to solemnize their losses under the aesthetics of mourning."<sup>15</sup> The AIDS Quilt, in fact, appears to be a kind of reaction to a traditional "aesthetics of

mourning." In their bright colors, playfulness, and humor, many of the panels seem to reject the notion of a somber meditation on death.

In the interviews he has given about the quilt, Jones has cited several artistic influences on his original idea, including Maya Lin's memorial, Judy Chicago's *Dinner Party*, and Christo's *Running Fence*.<sup>16</sup> In these projects, the artists dictated their vision to a large number of workers and collaborators. Chicago's project, completed in 1978, is a "feminist last supper," a table setting of hand-crafted ceramic plates and needlework honoring historical women.<sup>17</sup> Christo's *Running Fence*, an immense nylon curtain that wound through the northern California coast, was, like all of his projects, executed by a huge group of people. Unlike the quilt, however, both of these projects have authorship attributed to an individual artist. Jones's relationship to the quilt is considerably different than, for instance, Maya Lin's relationship to the Vietnam Veterans Memorial or Christo's to *Running Fence*, because he has no aesthetic control over the quilt. However, at least initially he saw himself as the quilt's author and as "the only person who knew how it would look" when it was to be first exhibited on the Washington Mall, the "space it was originally designed for."

### The Quilt as a War Memorial

What happens when a "war" is memorialized while it is still being fought? The AIDS Quilt takes its place in the tradition of war memorials; but it does so in a radical way. This war is not being fought against a foreign state; in fact, the quilt initially sought to bring recognition of the AIDS epidemic as an American crisis (in response to the notion that AIDS originated in Africa). The quilt depicts many enemies, of which, ironically, the virus is represented as the least and the U.S. government as the most culpable.

AIDS activists have employed many war metaphors in their rhetoric, often comparing their movement to the protests against the Vietnam War. In proclaiming, "AIDS is our Vietnam," these activists equate the U.S. government's AIDS policies of the 1980s and 1990s with its Vietnam War policies of the 1960s and 1970s. The Vietnam War is often represented as a gauge of the country's pain; reiteration

at the Vietnam Veterans Memorial of the names of the 58,196 men and women who died establishes a standard of collective grief. Thus, in 1992, when the number of AIDS dead in the U.S. surpassed the 120,000 mark, many AIDS activists noted that twice as many Americans had died from AIDS as in the Vietnam War.

For many, the deaths of thousands of young men equates the AIDS epidemic with a war. One NAMES Project flyer bearing an image of needle and thread states, "Not All Battles Are Fought with a Sword." AIDS activist Vito Russo once said, "You know a lot of people who have lost all their friends, and that's an experience that I don't think a lot of [young] people have in their lifetime except during war."<sup>18</sup>

Like the Vietnam memorial, for which the veterans stipulated an "apolitical" design, the quilt is an overtly political work that has been declared nonpolitical by its creator. Jones has stated:

The Quilt quietly does advocate a certain stance in the fight against AIDS. We are not a political organization—we don't take stands on any of the political issues that surround the AIDS epidemic. But the quilt very eloquently says, "You're to love each other, you're to care for each other, these were real people whose lives were valued and whose memories are cherished." The political message is that human life is sacred.<sup>19</sup>

Yet the quilt, with its messages of loss, anger, and tribute, belies Jones's definition. In fact, Jones would appear to want it both ways: the quilt as a political tool that does not threaten or exclude through its politics. The quilt's educational purpose is clearly political. It is meant to change the average American's—and the average American politician's—relationship to AIDS. When displayed in Washington, the quilt has functioned at least initially to call the government to task. Says Jones, "It is very much an accusation, bringing evidence of the disaster to the doorstep of the people responsible for it. We have never depoliticized it to that extent. We want to move them to act." Thus, the quilt accuses more strongly than the Vietnam Veterans Memorial precisely because it is not as easily subsumed into the nationalist discourse of the Washington Mall.

Traditionally, war memorials are not built until the war is over; yet the quilt grows along with the epidemic. Declarations of the quilt's



size are deeply ironic—on one hand, they evoke an astonishment and pride at the collective output of grief, rage, and creativity; on the other hand, they serve as a painful reminder of how many have died. The quilt's immediacy derives from its intended purpose as an educational tool: to raise consciousness about AIDS in order to increase government funding, develop adequate treatment methods, and find a cure for AIDS—to stop the dying. Each display of the quilt raises money for local AIDS organizations that provide direct services and primary care for people with AIDS. Thus, the AIDS Quilt intends to end the "war" it memorializes. As such, the debate it produces is very different from that raised by the Vietnam Veterans Memorial: it is a debate not only about how to remember the dead but about how to effectively end the dying.

#### Locating the Dead: The Presence of Bodies

The AIDS Quilt provides evidence of the human loss of the AIDS epidemic. Jones says: "When I thought of the quilt I was thinking in terms of evidence. It was in a conversation on Castro Street with my friend Joseph, who is now dead, when the story came out that there were one thousand dead in San Francisco in 1985. I said to Joseph, 'If this were a meadow and there were one thousand corpses lying out here and people could see it, they would have to respond on some level.'"

Each panel corresponds approximately to the size of a body or a coffin; thus, the quilt laid out on the mall in Washington evokes for many an image of war dead strewn across a now quiet battlefield. To many panelmakers and viewers of the quilt, it remains the sole location of the dead. There, the dead are spoken to; there, the dead are perceived to hear and respond. Visitors to quilt displays write messages on signature panels, permitting them to maintain an active relationship with the dead. The quilt evokes conversations with the dead.

—Hey . . . Wait a minute . . . Where did you go? We're not done talking yet. Can you hear me? I really miss you, Jon Stangland.

—Is that you, Clyde?

—Marvin, your grandson has your smiles. We miss you.

—Call collect.

Families and friends often come to the quilt bearing flowers and talismans as one would at a cemetery. Thus, the quilt operates as a surrogate for the bodies of the AIDS dead, placing it within the tradition in this country of memorializing the dead in the absence of their bodies, in which the naming of the individual serves to establish their location. Where are the bodies of the AIDS dead? According to Jones, the majority of gay men who have died of AIDS have been cremated, their ashes scattered. They leave no headstone or physical trace. The AIDS Quilt is the sole testament to their names and their existence. Several panels actually have cremation ashes sewn into pockets. One of the first panels made in Japan was created by an artist with AIDS, who painted calligraphy using red paint mixed with his own blood, literally fixing his body and the virus within the quilt.

The location of bodies symbolically (and literally) within the quilt evokes the larger discourse of bodies in the context of AIDS. One of its distinguishing features is the aging effect of the opportunistic infections that ultimately cause death. These diseases, such as Kaposi's sarcoma, pneumocystis pneumonia, and cytomegalovirus, waste away once strong and healthy bodies to skeletal frames, making those in the advanced stages of AIDS appear to be decades older than they are. In the beginning of the epidemic, when the transmission mechanisms of the virus were not yet known, these were bodies isolated from human touch. One panel in the AIDS Quilt reads: "Steven, hug me." Panelmaker Vicki Hudson explains:

Steven had AIDS when I met him in 1981. We were all frightened about his sickness. He had been deserted by his lover and family. He was a very lonely man. . . . Once, he and I were dancing and when a slow song began to play, he begged for me to hold him and dance with him. To hug him. He was drenched in sweat, and he saw the fear in my face at coming into such close contact with him. It's 1987 now and I know that holding an AIDS victim is not going to give me the virus.<sup>20</sup>

These bodies of people with AIDS, coded as frightening, untouchable, and contaminating, are transformed through the quilt into fabric and cloth, embraceable and tactile forms that evoke warmth and

attraction. Many of the dead are remembered at their healthiest, represented by images of youthfulness and vigor, or as children.<sup>21</sup> Panels of figures defined by empty clothing conjure the shape and space of the absent body, uncontaminated and devoid of disease. Thus, the quilt represents a restoration of these bodies to their pre-AIDS status, and reinscribes them as touchable, healthy, and dignified.

### The Mourning Process: For the Dead or the Living?

The quilt foregrounds the needs of the panelmakers. It is a means for lovers, friends, and families to grieve publicly, to share their loss, and to partake in a ritual of paying tribute to the dead.

Creating a panel is a cathartic means of expressing grief and loss. That the act requires considerable effort, time, and work contributes to this catharsis. Letters sent to the NAMES Project testify to the extended and elaborate process involved in making many of the panels. Other letters reveal that the time spent making a panel is itself a memorial, a contemplation of the departed. For this reason, many panelmakers find it difficult to finish, and some make duplicate panels in order to keep one. One individual wrote to the NAMES Project: "I'm glad the panel took so long to make because many people saw me working on it, and I got a chance to talk to them. We talked about Esperanto. . . . We talked about AIDS. . . . We talked about friends who died because of the AIDS virus. . . . We talked about love and compassion. . . . And that is important."

The creation of an object in the face of death is an act of connection. Elaine Scarry writes, "The making of an artifact is a social act, for the object (whether an art work or instead an object of everyday use) is intended as something that will both enter into and itself elicit human responsiveness."<sup>22</sup> All objects carry the implication of human contact; the quilt, in its materiality, conveys the message of human connection and community to counteract the isolation and loneliness of AIDS.

Panelmaking is both cathartic and painful, an intense confrontation with grief that will help the panelmaker to heal. Thus, the AIDS

Quilt raises the question of the purpose of mourning. For whom do we mourn when we mourn? The foregrounding of the needs of the living and the creation of a community through the quilt point to mourning not simply as a process of remembering the dead and marking the meaning and value of their lives but also as an attempt to create something out of that loss. The discourse around the quilt is focused on the "good" that can come out of the epidemic—the human resources that were discovered, the strength people found within themselves and within others in the face of tragedy. We mourn not only for the dead but for ourselves.

The outpouring of sentiment toward the AIDS Quilt resembles the embrace of the Vietnam Veterans Memorial as an expression of loss and grief that previously had not been sanctioned. Like the memorial, the quilt mollifies the incommunicability of the experience of loss and isolation, of families who kept silent for fear of the AIDS stigma, of the immense sorrow of losing all of one's friends, and of the prospect of one's own death.

The quilt also enacts specific rituals for grieving. Displays of the quilt, all of which are overseen and organized by the NAMES Project, are systematically set up to allow viewers to take a journey of grief through the quilt. Unlike the journey past the walls of the Vietnam Veterans Memorial, the journey through the quilt is an ever changing one. No display is ever the same; no starting or end point exists.

Each display is a highly structured event. The opening rituals of folding and unfolding the panels, reading the names, signing signature panels, and walking through the display are tightly orchestrated, almost theatrical (see Figure 20). Every display is monitored by local volunteers, each holding a box of tissues, who are instructed when to comfort visitors, when to leave them alone, when and when not to offer them tissues, and never to touch anyone without their permission. This protocol encourages the expression of loss and sorrow—crying is considered the most appropriate response and is properly attended to (with the tissues)—and facilitates both personal and collective grief.<sup>23</sup>

For those living with AIDS, however, a visit to the quilt is not an

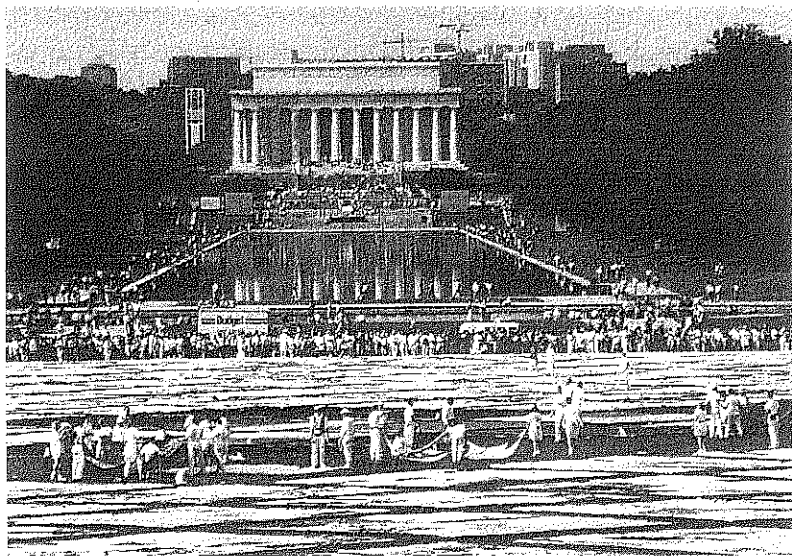


Figure 20. Volunteers unfolding the AIDS Quilt, Washington, D.C., 1992. Photo by Mark Theissen. NAMES Project Foundation.

occasion for remembering as much for facing death and seeing past it. The late Vito Russo used to say at rallies, "I am here today because I don't want a quilt with my name on it to be in front of the White House next year"; there are now several panels that bear his name. Thus, for many people with AIDS, the image of the quilt is one of relentless death.<sup>24</sup>

A quilt display can be seen as defining the range of emotions that constitute mourning, including sadness, regret, fear, and pride. However, the quilt's relationship to anger, and the relationship of mourning to anger, has been contested within the AIDS movement. In the activist gay community, there are factions that see mourning and memorializing as opposed to organizing and protesting. Hence, the quilt is sometimes read as taking attention away from the anger of living; one activist wonders, "Why is grief getting all the press, and not the living and the fighting back?"<sup>25</sup>

At issue here is the relationship of collective mourning to anger.

In "Mourning and Melancholia," Sigmund Freud defined mourning as a solitary experience:

Profound mourning, the reaction to the loss of someone who is loved, contains the same painful frame of mind, the same loss of interest in the outside world . . . and the same turning away from any activity that is not connected with thoughts of [the dead]. It is easy to see that this inhibition and circumscription in the ego is the expression of an exclusive devotion to mourning, which leaves nothing over for other purposes or other interests.<sup>26</sup>

Freud's definition leaves no room for the role of collective mourning. Yet for many people living daily with the AIDS crisis, there is no time to indulge in individual grief or to mourn properly the passing of each individual. Many gay men living amidst the epidemic say they no longer attend memorial services because they have been to so many that the memorials have lost their meaning. For many, anger has replaced grief. Is anger a form of mourning? Although Jones foresaw the display of the quilt in Washington as a bringing of evidence before the nation, he defined it as a statement primarily of loss and hope rather than of anger:

The quilt has been used to try and appeal to a high authority. We don't use anger. Anger is released at the quilt, it is expressed in the quilt, but we don't cut people off. And this has been the greatest source of conflict between me and my colleagues in the movement is that they want the quilt to be angrier—let's take it up and use it to surround Bush's summer house. . . . But I think in some quarters anger and the expression thereof are highly over-rated. I know when I feel that rage in my stomach and my chest, I am losing T-cells.

For many AIDS activists, mourning is transformed into action through collectivity. Douglas Crimp has written, "For many of us, mourning becomes militancy."<sup>27</sup> Thus, the act of protest has, for many, replaced rituals of mourning. However, for others, mourning in the face of AIDS takes different forms: For those in inner-city communities, mourning may more often be tinged with the rage of despair rather than the anger of a middle-class sense of entitlement; for many families, mourning is a processing of feelings of shame and guilt. In the quilt, mourning is both angry and hopeful but above all something that must be shared.

### Women's Work and Men's Grief: The Gender Politics of the Quilt

Like the Vietnam Veterans Memorial, the AIDS Quilt is the site of contested notions of femininity and masculinity. Much of the quilt's power is derived from its evocation of the tradition of women's collective handiwork. In addition, like the Vietnam Veterans Memorial, it is the site of the construction of notions of manhood, albeit very different ones; it shares the metaphoric language of war as well as of the aftermath of the Vietnam War. Cindy Patton notes: "The generation of men first hit by AIDS was roughly that of Vietnam veterans (there were of course many Vietnam veterans among the early diagnosed cases of AIDS); thus both AIDS and the war are cast as masculine experiences in highly eroticized male-only zones."<sup>28</sup>

Because AIDS was initially seen as a disease of men, many doctors misdiagnosed women and children and failed to warn them about the risk of acquiring the virus.<sup>29</sup> The Centers for Disease Control (CDC) did not change its definition of AIDS to include women's symptomatology until 1986. As a result, many women were misinformed. Women with AIDS have consistently died sooner than men. Although AIDS groups have increasingly attempted to focus on the concerns of women with AIDS, the association of AIDS with gay men, and the consequent emphasis on prevention and treatment among gay men, is still prevalent.

The gender politics of AIDS in the United States thus began with the erasure of women at risk; the gay man operated as a substitute for the female subject. Says Paula Treichler, "There is no need for female representation in the AIDS saga because gay men are already substituting for them as the Contaminated Other."<sup>30</sup> Yet because of gay men's marginal status in the general society, AIDS is not read as a male or masculine disease. Michael Kimmel and Martin Levine write:

No other disease that was not biologically sex-linked (like hemophilia) has ever been so associated with one gender. And yet virtually no one talks about AIDS as a men's disease. . . . In our society, the capacity for high-risk behavior is a prominent measure of masculinity. . . . To men, you see, "safe sex" is an oxymoron: That which is sexy is not safe; that which is safe is not

sexy. Sex is about danger, risk, excitement; safety is about comfort, softness, security. . . . [Men with AIDS] are not "perverts" or "deviants" who have strayed from the norms of masculinity. They are, if anything, over-conformists to destructive norms of male behavior.<sup>31</sup>

The coding of AIDS as a gay male disease in the United States has given it an ambiguous and shifting gender status, both male and not male.

In its appropriation of a women's craft, the AIDS Quilt represents a further complication of gender status. Although the quilt's demographics are gradually changing, the majority of the panels in the quilt are memorials to gay men. This means that at a display of the AIDS Quilt the expression of men loving men is not condemned but taken for granted, and celebrated. Men embrace each other, speak of male love, and fathers mourn the loss of their sons, creating a new kind of masculine relationship to the public display of emotion and sorrow. Stoic responses to grief have no place at an AIDS Quilt display.

Often the voices that speak to male love in the quilt are direct, compassionate, and erotic. One well-known panel consists of the image of a silhouetted figure standing against a wall. Around the edges of the figure, drawn by David Kemmeries of his Native American lover, Jac Wall, when Wall was barely able to stand, a handwritten text reads:

—Jac Wall is my lover. Jac Wall had AIDS. Jac Wall died. I love Jac Wall. Jac Wall is a good guy. Jac Wall made me a better person. Jac Wall could beat me in wrestling. Jac Wall loves me. Jac Wall is thoughtful. Jac Wall is great in bed. Jac Wall is intelligent. I love Jac Wall. Jac Wall is with me. Jac Wall turns me on. I miss Jac Wall. Jac Wall is faithful. Jac Wall is a natural Indian. Jac Wall is young at heart. Jac Wall looks good naked. I love Jac Wall. I will be with you soon.

Kemmeries states, "From a distance you can see that it's a person, but you have to get up close to read what he's really about."<sup>32</sup> Here the verb tense reflects the presence of the dead and the complex process of letting go. Jac Wall still is. Though Kemmeries does not sign this panel, his presence marks this text, testifying to the viewers, speaking finally directly to Jac.

The declaration of gay male love is mixed with the unspeakable disruption of what were supposed to be narratives of pleasure and liberation:

—This is the way I felt about Paul in the beginning (April '81)—What is it I like about Paul? His devastating smile, for one thing. Also, his smooth, tight body. Beyond all that, he is intelligent (which somehow surprises me) and supremely confident (which excites and perhaps intimidates me.) At 30, he is a marvel. I think I'm in love. . . . And this is how I felt at the end (March 1987): This is a man I once loved above all others, remember. This is a man I once would gladly have spent my life with. Now he is dead, and I never counted on this. Mike, August '87.

The powerful presence in the quilt of gay male love reveals the marked absence of the voices of heterosexual men. Though fathers make appearances as shadowy figures, they often appear on the sidelines, writing messages that say their wives brought them in order to change their minds about their gay sons, or signing on after their wife has made a panel.<sup>33</sup> Remarkably few panels have been made by straight men as fathers, brothers, or friends. Moreover, involvement in AIDS service organizations has been almost exclusively the work of gay men and of women, both lesbian and straight (although scientific research has been dominated by men). This disproportionate level of women's participation can be attributed to their traditional involvement in health movements and to male homophobia. In the case of the quilt, however, this dynamic is further complicated by associations with quilting and sewing.

The comforting softness of fabric is a primary element in the quilt's gender politics. Some commentators have noted the quilt's "sheer sentiment," whereas others have seen it as "almost embarrassing in its vulnerability."<sup>34</sup> For some activists it is too soft, too passive, too much about loss and not enough about anger. Here, the malleability of the cloth is interpreted, or one could say misinterpreted, as vulnerability.

Yet there is nothing inherently vulnerable about cloth; in fact, the history of flags and political banners attests to cloth's tradition as a powerful symbolic tool. This association of cloth with vulnerability would seem, rather, to be a gendered reading of quilting as women's work. Jones has stated:

I was very conscious that quilting is a women's craft. I remember thinking in the early days before I knew it was going to work that, if nothing else, there are enough angry men with sewing machines out there to put together something for the National March on Washington for Lesbian and Gay Rights. The first panels were made entirely by gay men for gay men, but even that is not exactly true. There have been women involved from the very beginning—lesbian and straight women.<sup>35</sup>

Jones conceived the quilt project specifically in terms of women's work to offset stereotypes of masculinity: "We picked a feminine art to try and get people to look beyond this aggressive male sexuality component." The connotations of the quilt as nurturing, comforting, and protective are thus aligned with the gay community's taking care of its sick and responding with compassion to the dying. Yet this move to appropriate women's work conveys shifting meanings. The domesticating qualities of the quilt are read as both nurturing and potentially sanitizing.

Descriptions of the quilt as passive sound suspiciously like criticisms of the design of the Vietnam Veterans Memorial. Like it, the quilt has an antiphallic intent. In most exhibits the quilt is laid out on the floor, with some sections hung on the walls. Like the memorial, the quilt has a relationship to the ground; visitors interact with it mostly by looking down at it, kneeling by it, and touching it. It does not impose its presence as a solid piece of sculpture but lies flat, much as the Vietnam Veterans Memorial is set within the earth.

Yet the massive size of the AIDS Quilt counters the notion of passivity and softness. Indeed, the most publicized image of the quilt is an image of spectacle, tens of thousands of panels spread out on the Mall in Washington, D.C. This is an image not of intimacy or yielding space but of impressive size and stature. As one writer notes, "The quilt weighs tons. . . . It has the capacity to crush."<sup>36</sup> In its antiphallic and antiaggressive presence, the quilt is not a "feminine" or passive form but an object whose massive size conflicts with its "tuck-me-in" qualities.

Though disdain of quilting has limited the numbers of straight men working on the AIDS Quilt, quilting has acted as a bridge for many women. Stories of the women involved in the quilt, in particular mothers, infuse the letters and panels at the NAMES Project. Many young, white, middle-class, straight women have become

involved, as have many older, more conservative women, and there are increasing numbers of panels for women who have died of AIDS. Frequently, these panelmakers are women who have been politicized by the death of their children or husbands. They write of their pain and loss and of finding a new community among their dead son's or husband's gay friends. One woman, a suburban housewife whose husband died from AIDS while denying his bisexuality, states: "I went to strangers—people I thought that I'd never rub shoulders with—for support. . . . I had a driving need to stay with people with AIDS and people who are gay. The men in my support group helped me get acquainted with a side of John I didn't know—the giving, caring side of the gay personality. I'm lucky there are men who have been willing to open themselves to me."<sup>37</sup>

For women such as this, the quilt form itself has acted as a radicalizing force. Many of the quilting bees throughout the country are staffed by women, whose self-perception as quilters is integral to their involvement. These women, who had had no previous contact with AIDS or the gay community, were exactly the type of people Jones had in mind when he conceived the project, which he often describes as one he wants his grandmother to feel she can participate in.

Like the Vietnam Veterans Memorial, the AIDS Quilt disrupts and reconstitutes standard definitions of masculinity and femininity. It is neither a masculine nor a feminine object; rather, it is the site of a refiguring of men's relationship to grief and loss and of women's relationship to memory and masculinity. The quilt makes a statement about how men should grieve, often couched explicitly in terms of what gay men can teach straight men. Whereas the Vietnam War has been represented as the site where American masculinity was lost, the gay movement is a much more radical threat to traditional concepts of heterosexual manhood. Through both of these memorials, new paradigms for a masculine relationship to grief are emerging.

### Belonging and Ownership

At the core of debates about the quilt is the question: To whom does the quilt "belong"? Debates about how "gay" the quilt is, and its relationship to the gay community, have taken place in the gay press.

Though inclusion in the quilt still carries the marker of being gay, increasing numbers of women, children, and heterosexual men are represented in a kind of lag effect as the demographics of the epidemic continue to change.

The AIDS Quilt carries particular meaning in the gay community's redefinition of itself. It symbolizes a shift in the gay community's image from one of pleasure to one of caring. This shift has been constructed by both mainstream media and some members of the gay community. In the mainstream media, characterizations of this shift imply that responsibility is incompatible with pleasure-seeking; in the gay press, discussions of "rehabilitation" emphasize that caring and community are aspects of the gay community that were simply invisible to mainstream culture prior to the epidemic. One resident of the Castro states:

During the seventies the gay movement here created an almost totalitarian society in the name of promoting sexual freedom. It evolved without any conscious decision, but there was so much peer pressure to conform that it allowed no self-criticism or self-examination. . . . But AIDS forced a reexamination in the way that few issues do. What we're seeing now is a revolution. We're seeing a reevaluation of life and relationships and what being gay is all about.<sup>38</sup>

In this new image, which is not without its cynical observers ("It's just like the fifties again: people getting married for all the wrong reasons"),<sup>39</sup> the quilt is a marker of the "good" that has come out of the AIDS epidemic: the love and caring generated to comfort those who were dying and those who are suffering loss. An editorial in a gay newspaper, the *San Francisco Sentinel*, states:

The quilt will also help in the long, long struggle for gay emancipation. Whether it is scientifically true or not, AIDS is viewed as a gay disease. The staggering number of lives which the project memorializes will be viewed by America as gay lives. Former priest John McNeill recently observed that while Stonewall brought gay sex out of the closet, the AIDS crisis has brought gay love out of the closet. Indeed, only a heart truly sclerotic from bigotry could look at those panels and not sense the love of their makers.<sup>40</sup>

However, in 1988, Cleve Jones announced that "we are not a gay organization." Jones said that to call the NAMES Project "gay" would be a disservice to the increasing numbers of heterosexual people with

AIDS. Critics countered that the quilt—"born" in, nurtured, and supported by the gay community—was being removed from that community by an organization that was forgetting its roots in the Castro. The NAMES Project was accused of "de-gay-ing" the quilt, a term that has been used to describe a tactical change in the representation of the epidemic. In discussing the "litany of de-gay-ed organizations," Robin Hardy wrote in the *Village Voice*: "The most notorious is the NAMES Project—the quilt memorial—which has siphoned hundreds of thousands of dollars out of gay pockets, but omits the word 'gay' in its literature and puts a photograph of a mother and children on the cover of its commemorative booklet."<sup>41</sup>

On one hand, some people see the quilt as too gay, coding all named within it as gay; on the other hand, the NAMES Project is said to be not gay enough. This conflict is the result of the NAMES Project's outreach efforts. Jones states: "We very deliberately adopted a symbol and a vocabulary that would not be threatening to nongay people. We have resisted being labeled as a gay organization. . . . I really believe that if you look at the responses that have sprung up because of the epidemic, ours is really the most inclusive. We mobilize heterosexuals; we mobilize the families that have been afflicted." In his vision of the potential audiences of the quilt, Jones speaks specifically of reaching the unconverted and conceptualizing the quilt as a tool to educate nongay people. He continues:

Over the last five or ten years, I and everyone in my position has found themselves saying something like "it's not just a gay disease." I feel diminished every time I say that, because I don't want to minimize what has happened to me and my world. . . . I have lived in this neighborhood for almost twenty years, and I cannot begin to even count how many people I know that have died; every week there are more people. But I also believe that when the final history of this is written, that HIV will be seen as a disease of poverty and ignorance that destroyed the developing world. It will be remembered as the disease that depopulated one third of Africa, and the disease that wiped out a generation of Brazilians, and that what happened to hemophiliacs and homosexuals in the industrialized world will be seen as really a fluke of nature and society.

Questions of ownership of the AIDS epidemic have been at the core of the epidemic. The initial battle over the United States's re-

fusal to own the epidemic, its insistence that Africa was the source, has now been replaced by a debate over the perceived ownership by the gay community and a perceived refusal by black and Latino communities to own the epidemic. The two-tiered aspects of the AIDS-affected community have become increasingly clear, and the NAMES Project is often implicated in that schism. With ad copy like, "The Laughter. The Love. The Life. In the midst of crisis comes something beautiful, something magical, something that guarantees our friends will always be . . . more than names," it seems apparent that much of the rhetoric is geared specifically at middle-class communities, gay and straight, rather than at inner-city Latino, black, and other poor communities affected by AIDS. The rhetoric of healing and redemption may, in fact, be one of privilege. Is the AIDS Quilt the product of only one part of the community of AIDS in the United States—that is, the people that have the time and resources for "spiritual growth" and mourning?

The quilt has helped both to foster new communities and to reiterate the significant divisions in American society, which have only been exacerbated by the epidemic. The quilt has produced numerous stories about the coming together of strangers: strangers working together to put on a quilt display; people making panels for someone they didn't know; lovers and families working together; mothers and wives finding a community with gay men. For all of the stories, of which there are many, of alienation, rejection, and discrimination that are revealed through the panels of the quilt, there are innumerable stories of the construction of an AIDS-affected community unified in loss. The community-building that takes place around the quilt extends to quilt displays, where people have met and discovered that they had made separate panels for the same person. The complex web of a person's life thus continues to weave after death.

The stories told in the letters sent to the NAMES Project often testify to new alliances within traditional families:

My mom wanted to know if I had ever made a panel for Dennis. I explained that I had tried but it just brought back all of the pain and loss. . . . I returned home last December for Christmas. After dinner we unwrapped our packages. Opening my last gift, I found the most beautiful panel that my family had made for Dennis. My mom, sisters, aunt and grandfather worked

together on the quilt. . . . I feel that the NAMES Project provided them a way to let me know they shared my loss. I thank you for giving them a way to let me know they care.

These stories belie the stereotype of gay men as inevitably estranged from their families.<sup>42</sup> In addition, popular accounts of the epidemic rarely consider the kinds of extended "families" that are constructed within the gay community and outside of nuclear family structures. Letters sent to the NAMES Project describe how strangers have chosen to make panels for people who died of AIDS:

—I did not know David Thompson or his lover. I had no photograph to part with or any fond memories of his experiences. We were strangers. But when he died I felt a loneliness that scared me beyond belief. On October 23, 1986, I came upon his death notice in the paper. It read "On Sunday evening, October 12, my lover and best friend David R. Thompson, died of AIDS. It was a wonderful ten years. I will miss him very much." This letter is to David's lover in the hopes that he will realize that his love for David reached out and touched my heart so tenderly.<sup>43</sup>

—We want you to know how much we gained as a family from working on this quilt. Through our work and discussion we have come to love Rodney. Although we know virtually nothing about him, we have all come to think of him after with a very special fondness. I assure you that in thought and prayer, Rodney will remain a part of our family for years to come.

These panels address the question of what it means to remember any life cut short, of how one can be touched by the death of a stranger. They are often produced in local quilting bees, where volunteer panelmakers have only the barest of details: dates of birth and death, occupations, sometimes the knowledge that someone was a drug addict. For these panelmakers, all AIDS deaths are tragic, untimely, unjustified, and lonely.

Yet with all these stories of community-building and redemption, and while the demographics of the quilt are changing as it becomes increasingly diverse, it still remains a project that is primarily white and middle-class. If the quilt is a compelling means to confront and diffuse homophobia, it has only begun to be used as tool to bridge issues of race and class. Difficult divisions exist between the gay community and inner-city black and Latino communities in all facets of the epidemic. Though outreach to communities of color has in-

creased, the quilt is still seen as a white, gay project. Do the quilt's origins in the Castro cause these communities to reject it?

Questions of privilege are directly related to the very nature of the AIDS Quilt. Most organizations that are struggling to deal with AIDS in inner-city black and Latino communities do not have the energy or resources for quilting. Is it a privilege to be able to mourn in the middle of an epidemic? Initially, the quilt only went to those communities that raised the money to sponsor it. Since 1992, the NAMES Project has used some of the funds raised in selling merchandise to display the quilt in high schools and communities that could not otherwise afford it.<sup>44</sup>

Concerns with the quilt's purpose as it continues to grow prompted what Turney calls "an attitudinal shift" in the early 1990s to redefine the quilt's educational role, emphasizing its potential role in communities of color. Turney states: "Our attitude used to be that those who wanted to have the quilt needed to prove to us that we should let this thing go. That has changed dramatically. In a sense, we are knocking on the door and saying 'take this thing.' It is part of seeing the quilt as something to be used; there is no value in having it neatly folded on shelves. . . . People want their memory to be energized."

Cleve Jones conceived the quilt as a project that would "mobilize heterosexuals," bridge the gap between the gay and straight communities, and involve families. In conceiving it as a project in which his grandmother could participate, evoking his own family history, Jones in fact created a very American image of quilting. Yet the quilt means different things in different communities. The quilt represents something quite different to the gay and lesbian community versus heterosexuals, whites versus communities of color. The tensions between these communities about the quilt are in fact central to its meaning.

### The Marketing of the Quilt

The AIDS Memorial Quilt has become extraordinarily popular and, despite the debates in the gay community, has generated surprisingly little controversy in the mainstream media. The quilt was featured on the television show *Nightline* in 1988; it was the subject of a storyline in the comic strip *Doonesbury* and has been featured in an



episode of the soap opera *All My Children*. The documentary film *Common Threads: Stories From the Quilt* (1989) has been shown widely on public television and won an Academy Award. In 1989 the quilt was nominated for the Nobel Peace Prize.

Hostility against the quilt has been rare. In a Miami display in 1990, a panel was vandalized and two teddy bears cut out;<sup>45</sup> the quilt has also been called a "v.d. blanket" and a "fag scam." At quilt displays, homophobic messages are sometimes written on signature panels; other messages usually respond with anger and dismissal. In general, the quilt is extremely effective in plugging into Middle America—reaching and perhaps transforming those who think the AIDS dead (with the exception of certain "innocent" victims) deserved their fate.<sup>46</sup>

However, there is a tension between the quilt's role in education and outreach and its role as a catharsis for panelmakers. Moreover, its function as a fundraising tool has generated controversy, particularly in the gay press, where some critics have alleged that mass marketing of the quilt betrays the intentions of the panelmakers and the community that has supported it and renders it "political." As the NAMES Project has grown from a grassroots volunteer group to a professional nonprofit organization with thirty employees and an annual budget of \$2.5 million, its marketing of the quilt has been perceived by some as a violation of grief.

The marketing of the quilt is, in fact, part of what keeps it funded. Thirty percent of the NAMES Project budget comes from the sale of quilt merchandise, such as T-shirts, videos, *Common Threads*, the coffee-table book *The Quilt*, buttons, and posters. Turney notes:

Merchandising for us has always been and remains (and I see no sentiment to change it) a rather narrowly defined phenomenon. Certainly the vehicles are the usual ones—T-shirts, books, and buttons—but the icons are always very narrow. The reality is that when you are attempting to do programs like the High School Quilt Program, that don't generate a nickel in revenues in themselves, you have to find a way of subsidizing them. Frankly, if that means us selling T-shirts, we will do it.

The commodification of the quilt and the press kits and public relations material generated by the NAMES Project have raised

money but also have been subject to debate. Some critics have joked about "the quilt the book, the quilt the movie." Steve Abbott has written:

Panels from the Quilt appeared in the display windows of Neiman Marcus and, later, were used to decorate a mass for the pope's visit. This went beyond—indeed, exploited and manipulated—the private intentions of at least some who were actually making the Quilt. In short, the Quilt no longer belonged to those who were making it—it had become a commodity to be used and controlled by the officers of a bureaucratic institution. Once the Quilt was "embraced" by the media, its "meaning" went beyond even the NAMES Project's control.<sup>47</sup>

The quilt is bright, colorful, easy to understand, and moving, a perfect human interest story on the evening news or in the local paper. Displays of the AIDS Quilt usually generate articles in the local press about AIDS and its effect within the community. However, the quilt's popularity raises the question: does it allow people to grieve for the dead yet ignore those living with AIDS? The NAMES Project tries to dispel such criticism by publicizing, for instance, a survey in which 71 percent of respondents said that "the experience of viewing the quilt inspired them to take positive action in their lives in response to AIDS." Despite the quilt's ability to raise money, the perception remains that it could be draining funds from other AIDS organizations.

Suspensions about the quilt's universal appeal are raised mostly by gay critics, who have good reason to wonder at the ease with which it can move previously homophobic people to cry over the AIDS dead. One writes, "There should be a warning sticker on it: 'Don't feel that by crying over this, you've really done something for AIDS.'"<sup>48</sup> This criticism implies that the quilt sanitizes the AIDS crisis and offers viewers the illusion of participation and concern. One critic states, "What we *don't need* is what the Quilt seems most efficient at raising: pity, guilt, sorrow, and tears."<sup>49</sup> Abbott goes further:

On one hand, the quilt's message is positive. It personalizes the plights of PWAs; it builds support for AIDS care and fundraising; it helps break down previous stereotypes of oppressed communities or subcultures; and it has

become a bridge between communities. On the other hand, one reason the quilt was so readily embraced by the media is because it can also be read as a memorial to a dying subculture (i.e., "We didn't like you fags and junkies when you were wild, sexy, kinky and having fun. We didn't like you when you were angry, marching and demanding rights. But now that you're dying and have joined 'nicely' like 'a family in a sewing circle,' we'll accept you").<sup>50</sup>

The NAMES Project has no rules excluding the use of any material in a quilt panel, so sanitization is at the discretion of the panelmaker. Yet the quilt form, its role as an outreach tool to nongays, and the form of a memorial in general are potentially restricting influences. Concerns over sanitization are expressed exclusively by the gay community. Richard Mohr writes:

Because the panels are not essentially tributes, in the sense of honors paid to the dead, their stories—the dead's—need not have been sanitized, as so many obviously have been. Lies of omission abound. A panel for an acquaintance of mine reported that he helped found a gay organization and that he liked Broadway musicals. That is true enough, but what he loved was to eat shit and get beaten up. No mention was made of these activities. His narrators, out of squeamishness, lost his center of gravity. Aside from scattered trinkets of leathersmen, sex is bleached right out of *The Quilt*, although sex was what was most distinctive of so many of the dead.<sup>51</sup>

Mohr's contention raises the question: How does one narratively memorialize a person, and does the phenomenology of the quilt make that process more or less inclusive? Certainly it is contestable that sex was what was most distinctive about most of the dead—a statement that assumes that everyone represented in the quilt was a gay man who would have claimed sexuality as his most distinctive characteristic. Would the dead have wanted to be remembered that way? Furthermore, there are panels that are genuinely unsentimental: a panel for Roy Cohn, a notoriously homophobic and unscrupulous lawyer, reads, "Bully. Coward. Victim." Other panels display black leather (a panel to Mark Metcalf, the heaviest in the quilt, is composed entirely of leather), sequined dresses worn by transvestites, and a shroud with ID tags for a corpse; at least one contains a needle for injecting drugs.

## The Quilt and the Nation

Issues of the quilt's potential to sanitize or sentimentalize are integral to debates about the quilt's relationship to the nation and its message when it is displayed on the Mall in Washington, D.C. Criticism of the marketing of the quilt can be read as concern that it is being removed from the realm of cultural memory—where personal memories are consciously shared in an attempt to create a collective memory—and turned into not only a public relations device but also a memorial or monument with nationalist, historical meaning. The implied patriotism and connotations of family heritage implicit in the quilt form threaten to rescript those memorialized in the AIDS Quilt into a narrative of Americana in a country that has systematically marked them as outsiders.

The popular image of the quilt spread out on the Washington Mall is an image of spectacle, operating in tension with the intimacy for which most quilt panels are designed. However, the quilt was conceived both as a site of personal grief and as a project that would make visible the numbers of dead; hence, its enormous size is integral to its message. Large displays of the quilt have a very different kind of effect from smaller displays. Whereas an individual panel carries a particular power by speaking to the dead and the viewer, that same panel carries the weight of the collective message of a community or communities—of a "nation"—when it is part of a large display of the entire quilt on the Washington Mall.

It has been noted that the quilt's "removability" is essential to its meaning in the gay community. Henry Abelow writes: "The project, like [the gay community], has no ongoing places of its own on American soil, no necessary connection anywhere to any major American institution. Nothing located or fixed could serve well as a memorial to our losses."<sup>52</sup> It could also be argued that the quilt's removability is essential to its relationship to the nation, a symbol that, on one hand, can travel to its center but, on the other hand, does not rest there and comes from somewhere else.

Spread out on the Washington Mall, a traditional American handicraft in its most symbolic place, the quilt demands that the nation take notice. A 1989 ad for the quilt presented the sewing needle as

"the most important tool in the building of a national monument." This type of rhetoric was a tactic to get the American public to pay attention, but it was also initially a way of defusing the notion that AIDS invaded the United States from foreign territory. Jones has said: "In the first brochure we wrote, we deliberately used the word 'American' in every paragraph. We wanted to apply a uniquely American concept to this disease that everyone wanted to see as foreign."<sup>53</sup>

The AIDS epidemic brings forward the tensions of the "imagined community" of the nation. The hyperindividualization of each panel can be contrasted with the generic identity of the body in the Tomb of the Unknown Soldier, pointing to the impossibility of a singular imagined community. Yet it is much too simple to say that the quilt is oppositional to the nation. The tradition of nationalism in which Jones wanted to situate the quilt is not the nationalist context of stone monuments on the Mall but rather the context of the Mall as a site of protest, a place to "call attention to the nation's conscience" and make "an accusation, bringing the evidence of the disaster to the doorstep of the people responsible for it." Turney calls the quilt a "national guilt trip." However, each time the quilt returns to Washington, its status as an oppositional symbol wanes. In the mid-1990s it can no longer be perceived as a protest to the nation; it has come rather to symbolize national grief. The image of the quilt laid out in Washington can also mean, Peter Hawkins writes, "America has AIDS."<sup>54</sup> One of the quilt's fundamental paradoxes, then, is that by claiming inclusion in the nation for those who have died of AIDS, it also tends to negate their difference.<sup>55</sup>

Has the popularity of the quilt backfired? The quilt may indeed be appropriated into public discourse as a symbol of America's dealing with AIDS. Like the healing represented by the Vietnam Veterans Memorial, the healing represented by the AIDS Quilt is very different when it is attributed to a nation rather than to an individual. The quilt can be a powerful tool in absolving guilt, easing regret, and facilitating redemption for those who make quilt panels. When this absolution of guilt is applied to a nation, it can act as false redemption.

Yet Jones originally saw the quilt as a subversive tool, one that would appear nonthreatening but impart a radical message. The ac-

cusatory aspects of the quilt work in tension with its sentimentality. By marking deleted names, anonymous tributes, and gay male love, the quilt refuses to a certain extent to sanitize the epidemic. Though displays are emotional events filled with expressions of sorrow and pain, they are also charged with a fervent air of the determination to live, making it difficult to conceive the quilt as a tribute to a "dying subculture." Because the quilt remains, in Jones's words, "a very powerful symbol of the love and solidarity of the gay and lesbian community," its message will always carry the accusation of homophobia. The AIDS Quilt, like the Vietnam Veterans Memorial, shifts between national and counternational narratives.

### The Archive and the Construction of a History

Those working on the AIDS Memorial Quilt began with a vision of the day when the quilt would be finished, when adequate treatments and cures would be found and the dying would stop. They were inspired by the image of a finished quilt, stored for posterity in a museum or archive. Yet the AIDS epidemic shows no signs of ending, and the concept of an ever-expanding memorial poses questions.<sup>56</sup>

The NAMES Project is a self-conscious effort to intervene in history. Letters addressed to the organization show that panelmakers share this sense of the quilt as history. All explicitly bear witness:

—One of his fears was that he would be soon forgotten after his death. I assured him that would not be the case. I am grateful for the opportunity to present this quilt panel as a permanent memorial to F., and one which will help keep his memory alive.

One panel contains a letter written by the panel subject before he died:

—By the time this letter is read to you, I will have gone on to my new life. . . . In the future, when you look at the history books that will be written about AIDS, you will find that one of the highlights of the book will be a chapter on one of the good results of the disease—that is—humanity became more compassionate. From that compassion the world became a better place. And you, my friends, will be the history makers.

Historically, however, quilts are not easily preserved as archival objects of history, and preservation of the AIDS quilt is difficult and costly. For this reason, in 1994 the NAMES Project began the Archive Project, which involves photographing every quilt panel and creating a CD-ROM of the quilt. This record is intended as a management and archive tool, a fundraising mechanism (panelmakers are offered a photograph of their panel or a CD-ROM including it in exchange for a contribution), and an educational resource that can reach a wider audience than the panels themselves. Though it may resolve certain issues of preservation and management, the Archive Project also raises issues of phenomenology and meaning. Can looking at a quilt panel on a computer screen have the same meaning as seeing it and touching it? How important are its physical qualities to experiencing the quilt?

The Archive Project addresses the issue of preservation to a certain degree, but the question of the quilt's future role is always present. Will it and the epidemic ever end? What if the quilt continues to grow—how will it be housed? What if it becomes a burden? The issue of what role the quilt should play in a long-term epidemic, as it approaches its tenth anniversary, is one that, Turney notes, "is constantly asked and constantly side-stepped." He adds, "Human beings love to bring things into being, but they are not so good at identifying the appropriate time to shut things down. The NAMES Project could be an organization to eventually address that issue. Then you would have to ask the question, what are you going to do with this thing?" In the early 1990s, as the quilt continued to grow and the NAMES Project became less centralized, the organization shifted its emphasis to the quilt's potential to promote HIV prevention. This shift in emphasis, from mourning to direct outreach, also came in response to the debates about the quilt's purpose—one originally conceived amid hopes for a short-term epidemic. As the epidemic drags on, the quilt's meaning and purpose change.

The AIDS Quilt is both a new kind of war memorial and a memorial to a "new" kind of epidemic. It constructs a collective, cultural memory that is fractured, multifarious, and diverse. It is a central site of healing in the context of the AIDS epidemic, reaffirming a dignity for many who died of opportunistic diseases that reduced them to a

weakened, humiliating state. The quilt has catalyzed a rich discourse about what it means to live, to remember a life, and to pay tribute to the dead. Its message is that memory has purpose. As a site of cultural memory, the quilt creates a community united by sorrow and anger, yet always in tension with itself. It raises fundamental and difficult questions about the conflict between the therapeutic and the political. It is asked, in a certain sense, to represent AIDS and thereby becomes the subject of struggle around who is visible and invisible in the AIDS crisis in the United States and worldwide.

The AIDS epidemic could not have been memorialized in a traditional way because it is not over and because it encompasses highly contested notions of what constitutes normality, moral behavior, and responsibility. The quilt's power lies in how it retrieves this discourse of morality and responsibility and turns it back on itself: To be moral, say the quilt panels, is to state a name in the face of discrimination; to be responsible, they say, is to care for the dying. Yet the success of the quilt is a bitter one. As NAMES Project staff person Scott Lago, who died in July 1991, once said, "This is a very successful project, but it's only resting on a pyramid of bones."

ment: Camcorder Activism and the Making of *HIV TV*," *Camera Obscura* 28 (1992), pp. 135-54; *AIDS TV* (Durham: Duke University Press, 1995); Lorraine Kenny, "Testing the Limits: An Interview," *Afterimage* (October 1989), pp. 4-7; and Paula Treichler, "Beyond *Cosmo*: AIDS, Identity, and Inscriptions of Gender," *Camera Obscura* 28 (1992), pp. 21-78.

### Chapter Six

1. The NAMES Project now has independent affiliates in twenty-nine countries. In these countries, the quilt is housed centrally, just as the panels of the quilt that are not traveling in the United States are housed in San Francisco. Panels from foreign affiliates are sometimes displayed within the United States, as in the quilt display in Washington, D.C., in October 1992. The vast majority of quilt panels are American.

2. AIDS Quilt panels made in the United States are sent by their makers to the NAMES Project in San Francisco, where they are sewn together in groups of eight according to what region of the country they are from, their pattern and color, and community relevance to form twelve-by-twelve-foot sections. Chapters of the NAMES Project keep twelve twelve-by-twelves and organize displays in their local regions.

3. By 1995, more than 14,000 people had died of AIDS in San Francisco.

4. Cindy Ruskin, *The Quilt* (New York: Pocket Books, 1988), p. 9.

5. From an interview with author in San Francisco, October 22, 1991. "It may be an origin story," Jones told me, "but it's true!" Unless noted otherwise, all quotes from Jones are from this interview. Jones is no longer director of the NAMES Project but still works with the organization as a spokesperson for the quilt.

6. From an interview with author in San Francisco, May 18, 1995. All quotes from Turney are from this interview.

7. Quoted in Joe Brown, "The Quilt," *Washington Post*, October 2, 1988.

8. Quoted in Gary Abrams, "AIDS Quilt Comforting U.S. Grief," *Los Angeles Times*, March 22, 1988.

9. See Patricia Mainardi, *Quilts: The Great American Art* (San Pedro, CA: Miles and Weir, 1978).

10. Harris, "Making Kitsch from AIDS," p. 60.

11. A quilt also evokes a rural context in contrast to the associations of epidemics with cities (see Gilman, *Disease and Representation*). It has been noted that the AIDS Quilt charts, in effect, the migration of gay men to cities throughout the United States, in particular New York, San Francisco, Houston, and Los Angeles (see Lawrence Howe, "The Moving Text," paper delivered at the California American Studies Association, April 1991). Thus,

the rural implication of the quilt form acts to domesticate the image of the disease-ridden urban environment.

12. The women of the Boise Peace Quilt Project carried on the tradition of political quilts. This collective, which was begun in 1981, has made numerous quilts to promote the idea of nonviolence and peace throughout the world, including several collaborative USSR friendship quilts, a Hiroshima quilt, a Sanctuary quilt for political refugees from Central America, and a quilt for Nicaragua. To make the National Peace Quilt in 1984, the women asked fifty children, one from each state, to draw their vision of peace and used their drawings to create the quilt. They then asked every U.S. senator to spend one night sleeping under the quilt and to describe his/her feelings in a Peace Log. This gesture is an extraordinary testament to a belief in the phenomenological capacity of the quilt—that its effect as a comforter can change states of mind. See the brochures of the Boise Peace Quilt Project and the videotape *A Stitch For Time* (1987) by Nigel Noble. Cleve Jones knowingly borrowed from the tradition carried on by the Boise Peace Quilt Project when he conceived the AIDS Quilt.

13. Jonathan Pearlman, "Remembering the Innocent," unpublished paper, 1990.

14. Larry Rinder, "The AIDS Quilt," *Artpaper Minneapolis* (May 1988), p. 9.

15. Elinor Fuchs, "The AIDS Quilt," *The Nation* (October 31, 1988), p. 409.

16. The arpilleras created by Chilean women have also been cited as influences on the AIDS Quilt, and as the quilt expands beyond its initial creation by Jones in the Castro, they are an appropriate analogy. Small embroidered or patchwork wall hangings that depict the daily struggles of these women, the arpilleras were condemnations of the repression under the Chilean military of General Pinochet in which thousands "disappeared." Created anonymously for political purposes, the arpilleras were smuggled out of Chile to call attention to the political oppression there. They share with the AIDS Quilt an immediate political urgency. See Marjorie Agosin, *Scraps of Life: Chilean Arpilleras*, trans. Cola Franzen (Trenton: Red Sea Press, 1987).

17. Judy Chicago, *The Dinner Party* (Garden City, NY: Anchor Press, 1979).

18. Quoted in *Common Threads* (1989), a film by Robert Epstein and Jeffrey Friedman.

19. Quoted in Brown, "The Quilt."

20. Quoted in Ruskin, *The Quilt*, p. 45.

21. I have been struck in both the AIDS Quilt and the Vietnam Veterans Memorial by the number of children's toys that are left for adults. There is

a preponderance of teddy bears left at the memorial, where they seem to connote a childlike innocence and a desire to remember the young soldier as a younger, unsuspecting child. There is also a tradition in the gay community of giving teddy bears to people with AIDS, and many quilt panels incorporate teddy bears.

22. Scarry, *The Body in Pain*, p. 175.

23. Mailings announce quilt displays so that people can request the presence of a certain panel at a display (the fact that panels are sewn together in groups of eight to form twelve-by-twelve-foot sections sometimes causes scheduling conflicts, although panels are grouped as much as possible by location). If all of the panels that are requested cannot fit, some are kept at the "truck stop" and can be brought out and unfolded upon request. An increasing number of displays are smaller and organized by local chapters.

24. There is debate about whether or not the public display of grief is truly therapeutic. While most people involved with the AIDS Quilt believe that it serves a therapeutic function (which many believe is also at odds with its political and fundraising functions), there are those who see that public expression of grief as only partially therapeutic. Russell Friedman, director of the Grief Recovery Institute in Los Angeles, states, "The publicizing of grief doesn't actually help at all. It creates the illusion that 'I'm doing something good,' and while quilts are wonderful, they're not therapeutic. I guess I find a little danger in the public expression of grief . . . it doesn't teach to complete our grief" (quoted in Ellen Uzelac, "The Public Eye of Mourning," *Common Boundary* [November/December 1994], p. 42).

25. Mike Signorile of ACT UP, quoted in Dan Bellm, "And Sew It Goes," *Mother Jones* (January 1989), p. 35.

26. Sigmund Freud, "Mourning and Melancholia," in *The Standard Edition of the Complete Psychological Works of Sigmund Freud*, Vol. 14, trans. James Strachey (London: Hogarth, 1917), p. 244.

27. Douglas Crimp, "Mourning and Militancy," *October* (Winter 1989), p. 9.

28. Patton, *Inventing AIDS*, p. 61.

29. See ACT UP/New York Women and AIDS Book Group, *Women, AIDS & Activism* (Boston: South End Press, 1990); Nancy Stoller Shaw, "Preventing AIDS Among Women," in *The AIDS Reader*, pp. 505-21; Paula Treichler, "AIDS, Gender, and Biomedical Discourse," in Elizabeth Fee and Daniel Fox, eds., *AIDS: Burdens of History* (Berkeley: University of California Press, 1988), pp. 190-266; and Cindy Patton, *Last Served? Gendering the HIV Pandemic* (London: Taylor and Francis, 1994).

30. Treichler, "AIDS, Gender, and Biomedical Discourse," p. 217.

31. Michael Kimmel and Martin Levine, "A Hidden Factor in AIDS," *Los Angeles Times*, June 3, 1990.

32. Quoted in Ruskin, *The Quilt*, p. 53.

33. Compared to those of the mothers, these inscriptions tend to be short on words. For instance, one typical letter at the NAMES Project contains a long section written by a mother, who ends, "A mother holds a child in her arms for a short time, but in her heart forever," and a brief, though moving message from the father: "He was my boy. I loved him and I miss him." Also common are stories told by men whose wives have acted as mediators between them and their gay sons. One man at a quilt display stated, "I haven't spoken to my son since the day he told me he was a homosexual. I told him that in my mind, I no longer had a son, and that if he got sick with AIDS, I didn't want to know about it. My wife forced me to come down here, so I did. I warned her that it wouldn't change my mind any . . . but I want to tell you that I'm going home to phone my son right now and try to talk to him if he'll let me . . . before it's too late" (quoted in Judy Weiser, "Stitched to the Beat of a Heart," *Art Therapy* [November 1989], p. 113). I do not want to imply that all of the parents associated with the AIDS Quilt fit this pattern, simply to indicate that these stories stand out because there are many of them.

34. Rinder, "The AIDS Quilt," p. 9.

35. Quoted in Paul-David Wadler, "Internal Strategies, Community Responses," *Boston Gay Community News*, December 4-10, 1988.

36. Whitney Otto, *How to Make an American Quilt* (New York: Villard Books, 1991), p. 110.

37. Quoted in Ruskin, *The Quilt*, p. 69.

38. Quoted in Frances Fitzgerald, *Cities on a Hill* (New York: Simon and Schuster, 1987), pp. 116-17.

39. Quoted in *ibid.*, p. 115.

40. "Sewing up Memories," *San Francisco Sentinel*, September 18, 1987.

41. Robin Hardy, "Die Harder," *Village Voice*, July 2, 1991, p. 33.

42. Jan Grover points out that the word "family" in the context of AIDS often connotes those who are HIV-negative, when, in fact, "families often contain and accept openly gay and lesbian children—and parents—as well as IV drug users" ("AIDS: Keywords," p. 23). Grover's example is a 1986 congressional bill on AIDS and the family, passed with virtually no opposition, that legalized the creation of designated-donor pools that would allow families to donate blood within the family to prevent transmission of HIV from anonymous donors. The bill thus defines the family as inherently HIV-negative and anyone who is HIV-positive as outside of the realm of the family. In 1992, a National Institutes of Health study found that blood donated by "loved ones" was no safer from infectious agents than the general supply, with the exception of HIV, which appeared in 4.6 donations of 100,000, compared with 10 in 100,000 in the general blood supply (Associ-

ated Press, "Blood of Loved Ones Is No Safer Than General Supply," *New York Times*, November 12, 1992, p. A9).

43. Quoted in Ruskin, *The Quilt*, p. 63.

44. The National High School Quilt Program was established by the NAMES Project in 1994 with the aim of using the quilt as a tool for education and HIV prevention in high schools throughout the country. The NAMES Project provides a high school with one twelve-by-twelve section of the quilt, which is then the focus for HIV prevention programs that are already approved for the school. Studies by the NAMES Project show that 85 to 90 percent of the students feel that having the quilt there makes a difference in how they perceive AIDS, their own risk, and their own understanding of what it means to die of AIDS. Turney states, "What the quilt does is put a human face on the statistics, and most HIV prevention programs are about statistics and threats." In these programs the students are put in charge of caring for the quilt panels so that, according to Turney, they become invested in them while they are there.

45. Associated Press, "AIDS Advocates Report Quilt Vandalized," *New York Times*, September 20, 1990, p. B5.

46. Indeed, the quilt has a fervent and dedicated following and actually has acquired a cult status in some circles. There are people who follow the quilt, traveling from display to display, who are called "threadheads" by the NAMES Project staff.

47. Steve Abbott, "Meaning Adrift," *San Francisco Sentinel*, October 14, 1988.

48. Michael Musto, "La Dolce Musto," *Village Voice*, October 25, 1988.

49. Quoted in Elizabeth Kastor, "Mending a Patchwork of Pain," *Washington Post*, October 8, 1992, p. C9.

50. Abbott, "Meaning Adrift."

51. Richard Mohr, "Text(ile)," in *Gay Ideas* (Boston: Beacon Press, 1992), p. 121.

52. Henry Abelow, "The Politics of the 'Gay Plague': AIDS as a U.S. Ideology," in Michael Ryan and Avery Gordon, *Body Politics: Disease, Desire, and the Family* (Boulder: Westview, 1994), p. 7.

53. Quoted in Wadler, "Internal Strategies, Community Responses."

54. Peter Hawkins, "Naming Names," *Critical Inquiry* (Summer 1993), p. 777.

55. In 1988, sections of the AIDS Quilt were acquired by the Smithsonian Institution as part of its Division of Medical Sciences and thus subsumed into the national discourse of that institution, but the "fit" was awkward. Smithsonian curator Ray Kondratas stated: "There is no question whether we should collect part of the quilt. But there is considerable sensitivity about

how it will be perceived and presented to the public. We're a national institution and we have to be very careful about how controversial subjects are treated" (quoted in Coimbra Sirica, "Smithsonian to Collect some AIDS Quilt Panels," *San Francisco Chronicle*, October 7, 1988). What is so controversial about memorializing an epidemic, one wants to ask?

56. The quilt also raises the question of the uniqueness of AIDS and the memorialization of epidemics in general. Arguments about the specialness of AIDS tend to work both ways. On one hand, AIDS activists and care professionals argue that AIDS is a special disease that requires priority funding and care; yet at the same time they argue against policies that mark AIDS as special for discriminatory reasons.

AIDS activism has raised the issue of how research and treatment of other diseases are funded, and the quilt has pointed up the fact that those who have died of other diseases have not been collectively memorialized. In fact, the AIDS Quilt has spawned the creation of many other quilts, including the Children's Quilt Project (for children with HIV), a cancer quilt, a quilt in Detroit for teenage victims of urban violence, and one for victims of the Oklahoma City bombing. Prior to this, with the exception of medieval plague memorials, there have not been other memorials to those who have died in an epidemic.

## Chapter Seven

1. Anne Marie Moulin, "The Immune System: A Key Concept for the History of Immunology," *History and Philosophy of the Life Sciences* (1989), pp. 221-36.

2. Nancy Leys Stepan, "Race and Gender: The Role of Analogy in Science," *ISIS* (1986), p. 267.

3. See, for instance, the popular book by Bernie Siegel, *Love, Medicine and Miracles* (New York: Harper & Row, 1986); and Howard Kaplan, "Social Psychology of the Immune System: A Conceptual Framework and Review of Literature," *Social Science and Medicine* (1991), pp. 909-23.

4. Patton, *Inventing AIDS*, p. 59.

5. T-cells are divided into subgroups. These include helper T-cells, which amplify the initial immune response; cytotoxic or killer T-cells, which neutralize cells that contain foreign antigens; and suppressor T-cells, which curtail the immune response when the "event" is over.

6. Mary Catherine Bateson and Richard Goldsby, *Thinking AIDS* (New York: Addison-Wesley, 1988), p. 30.

7. John Dwyer, *The Body at War* (New York: Mentor/Penguin, 1990), p. 39.