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Choosing Our Battles (Four Oral Histories Look Back at the First Generation of an Unwanted Disease).
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"It's very frustrating because here I am at the pinnacle of my career. I could do literally anything I wanted in the world of journalism, and you're left with the strange feeling that your life is somehow finished without being completed," Randy Shilts, author of the magnum opus of the AIDS pandemic, *And the Band Played On*, said months before he died, himself, of AIDS last year (Bravshaw 1994). Activists, city officials, old friends and colleagues converged in droves at Glide Memorial United Methodist Church in San Francisco's decaying Tenderloin District the morning of February 22, 1994 to pay homage.

"Can an aging faggot get a seat around here?" John Cailleau, a Shilts acquaintance from the decadent '70s heyday asked a guard.

"We don't use that word here," the guard responded.

"A lot has changed," Cailleau said. Earlier in the week the Rev. Fred Phelps had announced he was bringing members of his Topeka, Kansas congregation to picket "the faggot writer(s)" funeral. Fears of violence lingered as the crowd of two thousand waited for the service to begin. Two men held signs, "OUR RIGHT TO LOVE" and "OUR RIGHT TO GRIEVE." In the end, the Phelps group was pelted with eggs and ran. Phelps tried to take refuge in a police van but the cops kicked him out (Raine and Flinn P 4). The spectacle around his funeral encapsulated many things Shilts had fought for. He had aspired all his life for gays and lesbians to live and die with dignity and respect. Perhaps the most disturbing aspect of Shilts' death was the books he did not get to write, the memories lost. He was planning on writing his memoirs of the '70s, '80s, and '90s in San Francisco. This story, like those of so many others, is gone. His death leaves a huge void.

Across the city, the morning of Shilts' funeral, George hobbled with his stroller out of an elevator at the AIDS housing facility where he lives and I work. He had wasted to a point where his emaciated bicep could be held between a thumb and forefinger. His once black mustache was now gray. His Creole accent was still thick.

"Hi Ben," he said as he sat on a couch in the lobby.

"How was the movie last night, George?" I asked.

"Pure camp," George smiled, "but I couldn't enjoy it too much because the seat was so uncomfortable. My rumps gotten so small, it's all bone. I don't get padding," George confessed. He died a month later. His old lover, Rick, came by the building to pack his things.

"After 3 days on the respirator, he said forget it and told the doctor to pull the plug. He died within the night. The man never hurt a soul," Rick recalled.

"Except for the homophobes who came to the Stud in the '70's looking for fights. George told me he would prance around until one of them would start something then he'd beat the tar out of the guy."

"Yeah, he used to call home and tell me, 'I did it again. Now everyone in the bar is buying me drinks.' When he was done with one of those guys he would tell him, 'Go home and tell your friends you got beat up by a fag!'"

Many of the PWA's (People with AIDS) where I work have told me they intended someday to write down everything they have learned. Melvin, a black man who served in the army in the Czech Sudetenland, told me stories about his years romping around Europe. He regretted not having written his story down. "I wanted the world to know that as gay black man with AIDS, I have been able to make it." Sigmeund, a painter who walked with a limp, used to hobble through the building clad in dirty sweat pants, dress shoes, wire rimmed glasses and long blond hair. He tried to hunt and peck his way through his memoirs before he became too suicidal to work. I found him odd looking until I saw one of his works at a local gallery. I saw in the brush strokes in his self portrait the motion of his limp. It occurred to me that in the portrait as in his life, Sigmeund's limp obfuscated the dignity of his face. Opportunistic infections eventually caught up with him and he died while seizing.

These men lived through a litany of failures as doctors developed treatments with the sophistication of blood letting; the President shook his fist at "the Evil Empire" while failing to mutter the word AIDS for six years and the plague raged unchecked (Shilts P.595). Having felt the consequences of our culture's awkward and frequently Byzantine means of grappling with death and disease, their time ran out; their experiences, for the most part, are lost.

The day Melvin died, I went to buy a tape machine to use for taping the recollections of other PWA's so as to never watch another story like

his vanish. I made a flyer with the headlines, "Calling All Stories: Living Long Term with HIV? Remember Reagan and GRID?" and placed it all over the city. Although few women or people of color responded, gay men responded in force. I have sought to allow those who have watched the plague from the very beginning to share their stories. Others must bear witness to the lost family members, the dementia, the young left as widows, the budget cuts, the women dead who were never diagnosed, the condescending doctors, the foot dragging, the wasting syndrome, the weekly obits, the emotionally shell-shocked, those who died by themselves in hospital beds, those who have watched 60 or 70 friends die, those we loved who lost their minds to the tragedy and the humanity of AIDS.

Early in 95, Frank Rich wrote of the influence AIDS has had on our culture: "History may show that the epidemic has changed our culture in much the way that the cataclysmic carnage of World War I transformed English literature. However it turns out, this is the story of our time (A15)." AIDS has produced a generation of HIV positive writers devoted to Sartre's idea of engagement, telling this story with their last gasps. Paul Monette and David Feinberg, who both wrote books on AIDS themes, died this year. Writer Larry Kramer, who first sounded the alarm recognizing the impending disaster with the foundation of GMHC and ACT-UP is positive. Through her organization, *WORLD* (Women Organized to Respond to Life Threatening Diseases), Rebecca Denison does more for HIV positive women than many San Francisco agencies combined. She is positive. Many of the most effective AIDS activists who have fought the pandemic the longest, are positive. They are lions in winter. The attrition rate is phenomenal. Their deaths leave a huge void.

I entered the interviews believing that PWA's, having had the most at stake, have a unique perspective with which to reassess and offer fresh insights into the strengths and weaknesses of the First Generation. PWA's often know more about the disease or how their bodies are functioning than their doctors. Like the ever mutating nature of the virus itself, I found a range of strategies for battling both the disease and the industry surrounding it, nicknamed "AIDS Inc." Some interviewees such as G'dali Braverman choose to become activists. Others such as Art choose to look inward. G'dali, Darnell, and Bob challenged themselves to be the best possible people they could be in taking care of those closest to themselves. Darnell Davis chose battles around a world of institutional discrimination. When every cough could be the beginning of a bad day, possibly a trip to the hospital, maybe a month long stay or a taxi ride leading to a final destination of a hospital bed the arena of choice becomes critical. These are personal accounts of choices made with information in constant flux, telling a fundamentally American story of the last 15 years, as HIV slowly became a fixture and failure on the American historical, political landscape.

The Early Years

"Early on, we believed it was something that would only hit leathermen, then we thought it only hit men in SF and New York, then it hit my lover—that's how we learned about the disease," one long-term survivor remarked. Four interviewees recalled initial thoughts as HIV first crossed the paths of their lives:

Bob Lee, a middle-aged Alabama native, recalls: Those first years of the disease, the conversations over dinner and at the bars were basically denial. You know, "So and so I know has got the Gay Cancer but he was a slut." It was that kind of a reaction, "He deserves it." It just reinforced what we had been told.

G'dali Braverman of ACT-UP Golden Gate recalls: In 1981, it was still just a 'hmm, that was weird, that's sort of weird,' 'huh, what do you think?' 'I don't know, what do you think?' 'It just sounds like something isolated,' that's sort of the general response. But by mid-1982 it was clearly different. People were starting to shake in their pants; it was clear that it was more than isolated incidents. You heard about it very directly but peripherally in terms of those personally afflicted. Someone you know who had tricked with someone was sick and you didn't even know what sick meant because it was still something that was peripheral.

Art explained: I never have tested. I got diagnosed in '82 before there was a test. There was no HIV; there was no AIDS. It was - there is, something was wrong. Basically the picture that came across was that you will probably die soon.

Darnell Davis, an African-American from Las Angeles, explained: I remember a friend coming out to visit in LA and saying to me, "Are you positive or negative?" I had no idea what the fuck he was talking about. We, here on the West Coast, didn't know. It took us a long time to even understand what the boys on the East Coast were going through. It first hit me when my friend went to New York. He went to the hospital with the flu and he was dead. That's absurd. There's got to be more to it than that. When it did come to us on the West Coast, we didn't know what the hell was going on. It was something that we didn't think about; it was total ignorance, put it that way. I was too busy working and having a

good time, and never once thought about it. Then all of a sudden, slowly, people you knew were gone. I guess we were all going through a certain amount of denial. Nobody wanted to get tested—let's just pretend like it doesn't exist. I guess all of us who didn't get tested right away probably already knew that we were already infected. Dealing with it on that level, it was pretty hard to finally wake up and realize that this is real.

G'dali explained his approach to the first few years: By mid-1982 I had gotten involved with Gay Men's Health Crisis when it was all of literally 20 people. The year before, I had met a man in our office and we got friendly. He was gay and an older man. I ran into him in the Village, by that time it was 1982 and everything was happening. He said, "Are you interested in giving some of your time to do some volunteer work?" And I said, "For what?" And he told me and I said, "Yea, I am."

I was 22 years old. I always felt that community service on some level was important. I wasn't wholly out. I felt that there was a basic urgency here. I couldn't identify why it was and I completely did not feel that I was at risk because I neither lead a promiscuous life as an adult nor had I ever used any drugs. Even though, in those early days, we didn't identify that those were the things that transmitted the virus. It seemed on one level or another that those would probably be connected to whatever was going on. So it was just something that I felt in my gut was important. You know, in a corny way maybe there was some higher power there.

We used to set up a folding table around the city, usually Saturday and Sundays. There were like six or seven of us. The little information that was available was printed up into brochures and we'd stand at the table with a bucket asking for donations and all the pamphlets at 77th and Columbus or down at Sheridan Square. It was really interesting to start getting a feel for the dynamic and the response on a very interactive level of the city on whole. Most gay men would pass by the table or would cross the street to avoid the table, sort of the way that you avoid someone honking at you or the perfume salesperson at Bloomingdale's. So you'd find yourself just disgusted with the community. But women with babies with strollers would stop, younger heterosexuals seemed to be interested or accessible on some level that most gay men weren't. Literally you could spend entire Saturdays and Sundays with maybe three or four gay men ever stopping to talk or donate money. Of course, as the incidents rose, more people knew someone who knew someone who knew someone, then more people knew someone who knew someone who knew someone. And then more people were dead.

I can remember we had a placard. It was handmade. Everything was really very primitive. We mounted it behind the table and on the top it said: "New York Cases" and then below it said: "U.S. Cases" and I can remember when there were 300 or 400. I can remember when we hit 1,000 in New York and we switched the numbers. It was 83....

GMHC was extremely disorganized. It was extremely difficult to do the work we were committed to do. One of the guys in our group had in 1981 lost his lover, Robert. By 1983, people that I had worked with or volunteered with had become sick. People who came up to the table would come up with concerns regarding their friends or lovers. None of my friends died until 1985.

I did the work from 82 to 83, and then I took a hiatus from 83 to 88. I stepped out of the world. I think a lot of people just took to hiding in hopes that. It was like the Jews in Egypt putting lambs' blood on their door so that god would pass over their doors and not smite their first born type thing. I think there was that attitude. If I don't go out and I don't interact then it won't happen.

G'dali' was one of a small group of Americans actually confronting the little known affliction, but he wasn't yet facing his own mortality. Art, on the other hand, had been diagnosed in 82. Unlike G'dali who reacted to HIV by looking at the macro level, Art chose to turn inward. In the days after he was first diagnosed with KS: I didn't have a script. This was a mystery and I was/am a lot better dealing with a mystery than I was dealing with a script everybody agrees to: "This is how its going to happen and this is how its going to happen." So I think I was pretty lucky in that way.

I went to SF General when I was first diagnosed. There was a list of tests that we were expected to go through, a whole page and everyone said, "Your appointment is here, here, here and here." Once I was with the doctor I said, "Lets look at this list," and only one or two of them would do me any good and some of them were dangerous and painful. Nobody questioned it. I know people who have had their lungs collapse from bronchoscopies that weren't necessary. Blood gas tests they were doing... were a very painful process. You have to open an artery. Anything not to have fear, to pretend you've got something in control. If people believe there is nothing then they'll take what comes and there is money. And doctors are scared, another thing they often won't cop to. If a doctor is scared, bases will be covered even if it's something he knows nothing about. Present it with some semblance of certainty, "This is good for you" when they don't know, and patients will listen 'cause they don't know. "I'll do what my doctor tells me."

Early on I set to looking at the alternative treatments. It was really quite a wonderful proving ground. This was one area in which the

doctors had to admit that they knew absolutely nothing and were having no success. So, where else to prove the holistic methods? I took a lot of time and effort into exploring how the body deals with cancer, how it can deal with it naturally and how there are things that get in the way—from stress and alcohol and drugs and often the treatments that you are given for it...even from spiritual lack. It turned out being that an illness is not an isolated thing as we would have it. Dealing with it involves a different movement of art.

Somewhere there is a virus that either comes along for the ride or is caused. I don't know which and I don't care. That's about it. I have strong experiences and belief about ways our consciousness can affect our bodies. At some point early in this process, I sat down and wrote up a list of things that I was going to do if I was going to die and what I was going to do if I was going to live. I worked on that, meditating and really analyzed those two ways and found that the more that I thought about it, meditated on it, the more they became the same list, and that the illusion that they were two different lists represented a split in me and living in a place that wasn't now. All those "what ifs" were sucking the life out of me. Those lists just started to merge. What I was feeling at that point should have been just what I wanted to and should do. What was going to happen in another 10 years all depended on what I was going to do right now.

Bearing Witness to the Dying.....

As the plague earned a formal name, AIDS, and began taking thousands of victims, LA, New York and San Francisco became the disease epicenters. For many the close association with friends and lovers as they died became a call to arms. "It's where we learn about love, where we discover new values and qualities in ourselves. Death joins sex as a community sublime," Robert Gluck wrote (P. 86). However, this didn't happen overnight. Many turned away from community life. Men like Bob Lee took on seeing many left behind in the hospitals. As he took care of his dying lover, Darnel found a new approach to his own life. For G'dali, taking care of his spouse as he died served as a call to political action. Allan Troxler put AIDS and its relationship to the American political landscape into a proper context. "I see now why Whitman embraced the chance to nurse Civil War soldiers. Surely the democracy of death confirmed all the egalitarian effusion of Leaves of Grass," (P.43).

Bob Lee's lover died in their home in '87. He shared his recollections of the loneliness he felt in a community that had gone into hiding. "For a long time I would not go and visit anybody in the hospital after the experience. I really resented all his friends who never came by the house, who never called. Now I'm starting to have compassion for them but I didn't for a long time. I couldn't do it. It's so hard. I can do it now. God did this.

One of my very best friends going back to back when I was in Atlanta, Bob got very sick. I was able to visit Bobby. Every Monday I would go see him over to Davies Medical Center. Sunday night at MCC (a gay friendly San Francisco Church), it just so happened that the rector from St John's was doing the visitation that night. One of Bob's chief caregivers was there. He was saying, "You know, he's dying. He's not going to make it through the night." And the rector says, "Bob would you come with me?"

So I went to the hospital with them. It was obvious that Bob was near death. He was not able to talk. He had tubes down his throat and all. Bob's eyes were very very much alive. And I knew that Bobby could hear what we were talking to him about. And Warren, our rector at the time, starts a caring, loving meditation and was touching him, a letting go kind of meditation. And he had to go.

So while I was still there, I took over when he was done. He did all the rites and that kind of stuff. I sat on Bobby's bed and he had TB so I had to wear the mask and all that stuff. There was so little of his body that I could touch physically, just sort of rubbed his arm with my left hand like I was petting my cat, just a loving touch. I had my hand right on his heart where I could feel his heart beating. I just started talking to Bobby 'cause I knew he could hear me. And I started talking about this past life together, how many wonderful experiences we had. For a letting go type of meditation I said, "It's OK Bobby. Die. That's what you have to do. It's OK. You know, we'll miss you. Our love will go with you. That doesn't die. Your daughter is going to hurt. She's going to miss you but you'll still be there for her. It's OK Bobby."

This, I don't know if you want it on the tape or not. Part of Bobby's and my experiences over the years were in fist-fucking and speed and whatever. My inner voice just brought this out when I realized what a struggle Bobby was having fighting death. He was really fighting it. Actually I say, "Bobby, remember the first time a man ever put his fist up your butt? How much it hurt when he started and how wonderful it was when you just relaxed and let it in and how marvelous that felt." I could see the smile in his eyes. "Just think how wonderful it will be when you just open your body and let God come in and let him take you home with him to where you belong." And very shortly after that Bobby's breathing was very shallow and very rapid. He took one deep breath. My hand was still on his chest. I could feel his heart breathing. He took one deep breath and he held it in for a second. And he let it out and I could feel his heart slowing down. He took a second deep breath and he just went

"hhhhh," so beautiful and so peaceful. And I felt the last beat of his heart. It was so beautiful and so peaceful sharing the death with this man, seeing him make that transition. And I sat there just holding him and sending him my love for at least five minutes before I went out and got the nurse. The nurses at Davies are so wonderful. If I had know I would have been the person in there when Bob died I would have run so far in the other direction. I would have flown to Arizona if I had had to.

It was almost exactly 1:20 in the morning when he took his last heartbeat. I walked up to the nurses' desk and all of a sudden this rage just came after me. It must have been almost 2 in the morning and screamed at the top of my lungs and just pounded the nurses station, "GODDAMN THIS FUCKING DISEASE!" And a nurse got up from her station, puts her arms around me and says, "Rob, let's just take you back here. You can rest." She took me back to the head nurse's private office, sat me down, said, "There's the phone. Make any calls you need to make. If they are long distance, don't worry about it. The hospital can afford it." I don't even know where she went but she brought a cup of coffee and sat it down beside me.

Darnel found a man who showed him how to live on in this world with AIDS: I was always single, independent. I knew he was also HIV positive. He had just lost a lover a couple years prior. We met on a Friday night when I didn't want to go out but I was dragged out anyway, and we were together from that day forth. He taught me that it was okay. He taught me that it was important to care about oneself. At that point I still didn't go to a doctor. This was a couple years even later. I just would not go. He tricked me. I had an earache, so we went to the doctor. He says, "Tell the doctor your HIV positive." So I did. And he was sittin in the waiting room laughing cuz I was back there for three, four fuckin hours. And I came out and said, "You little fucker, you knew they were going to do this to me" which was good because he used to be a registered nurse. I thank him to this day for doing that for me, that just showing how much he cared; and he made me start caring too. That's when I started educating myself.

Until then I tried to pretend it wasn't really a big thing when in turn, deep down in my soul, it was tearing me apart. At age 20, a friend said to me, "Why are you so self-destructive?" I went to therapy and I realized that I was angry with my mom, 16 years later. A four year old going to his mother's funeral and not being told a damn thing knows a hell of a lot more than people give him credit for. I knew I was never going to see my Mom again. I lost my dad when I was 17; I lost a sister. It's been hard.

No one wants to wake up one day and know that your time is limited. I had planned on being 60 or 70, a dirty old man, but I don't think that's going to happen. And then again it may. You know? It was something I had not planned on. To me, my lover was something that was brought to me for a reason. It's funny, we met and we talked about our HIV status the first night. When we went into this relationship, we knew this. We also knew that we were going to be together regardless. We didn't know how much time either of us had; we didn't know if I was going to get sick or if he was going to get sick or what. It just happened that he got sick first, out of the blue.

For a year and a half after that I did nothing but take care of him. I quit work; he was the most important thing to me. People respected me for that. My family respects me for that, and it made me grow up a lot. I thought I was an adult but, after this, I think I've covered all bases: I've dealt with the doctors; I've dealt with the volunteers; I've dealt with the social workers; I've dealt with the programs, etc. I've been pissed off; I've been lied to; we've been lied to; we've been misled; we've been denied. While I was going through this with him, I was also educating myself, because I also have to realize that one day I'm going to be in the same predicament and I want to know what the hell they're talking about. He was the best thing that came into my life. God gave me the strength to stay there and do what a lot of other people would have walked away from.

But, you tune it out and do what comes naturally—you do it without thinking. You don't realize what you're doing until it's all over; and you sit and you think, "My God, I can't believe I did that, that I had that in me." You realize after that, that, you know, Phew! that was heavy. I miss him very much. He is the one that gives me the strength to sit here and be honest and speak up. I understand what's in myself. If it takes me another ten years, which I plan on, I'm going to keep on talking, because it needs to be heard.

His friends, his family weren't here. I was the only family he had here. They said he should have been dead six months ago. But he didn't want to be alone or to be stuck in some hospice. He said, "Darnell, I want to stay at home." I says, "Don't worry about it." I won't do that to another individual. It's a lot to ask and not everyone can. The last month he really tried to push me away. I was there for him, but I was also running a hundred miles an hour and going nowhere. I was hurting very deeply because I was losing something that was very important to me. In between accepting the fact and denial, I realized that we were going to get through this, but I was going to come out alone. But I didn't come out alone.

Activism

The two most famous quotes in activist folklore are Joe Hill's "Don't mourn, organize" and Mother Jones's "Pray for the dead, but fight like hell for the living," (Bronski P.138). G'dali watched friends and his lover die: The critical personal point was that my spouse, who I met in '83, became ill and died very quickly. That really changed my perspective on the epidemic and of the gay community. Most of our friends disappeared. Once he was hospitalized, I was literally living at the hospital. I had a bed there and I would go to work from the hospital in the morning and come back directly after five o'clock and live there. He was on a wing where there were probably eight or nine AIDS patients, all of whom were going to die in short succession. Nobody was ever released. Once you were in the hospital that was it, that was your last stop. People who were released for a few days would inevitably end up back in the hospital with complications. So, I came to know all these other people who died, before he expired, during their time and their families, you know, started getting familiar with the whole disease on a whole other level.

We were kids and we didn't expect that this was going to be part of our lives. We knew this was going to be part of our life but not our lives as young men. He was 22, so the future was ours, but that's the way the cards fell. It completely altered my life. I had never personally dealt with death. I had no idea what a dying person would be like, look like, sound like, you know, kiss like. And I had never grieved for that type of a loss or really ever lost. I removed myself from society because I was so devastated by this loss and by the lack of overall support. I really endured that with only one of his friends as a support.

I met a guy in '87. We were in a relationship for the better part of 87, 88. I was feeling that I was in this relationship with a generally vacuous person who didn't have any great concern for the world around him besides how good he looked and which club he was going to. When ACT-UP passed at Gay Pride in 1988, a year after its formation, I took one look and said, "I am going to go to the next meeting of that organization." There was a sense of power. There was a sense of action. It didn't appear to be about pity or shame or sadness or guilt. It seemed to be about anger and action. I think that as the individual that I am and as a Jew those were things that I could identify with. So I dumped him, picked up ACT-UP.

My first meeting was right after Gay Pride. It was on the first floor and it was packed. People flooded out the doors. There was no ventilation. But there was the sense that this was the place to be, that all the energy, all the focus around HIV was happening in that room. And I just listened. For the greater part. The populace of the early meetings was characterized by their intelligence. If I'm like doing a physical overview of the room, it was probably young gay men mostly, 23-35, physically fit, many attractive, energetic, articulate people. Probably 30 to 40 percent of the organization were Jews. Jews have always been at the center of leftist movements which has always ended up fucking them over in the end. All ages, 16-60, the whole gamut. Men, women, boys, girls, parents, but mostly gay men, and you didn't know who was HIV positive or not.

Even from that early time, there were only a few of us who identified as positive. I was one of those people. I found out in early 87. I don't remember it definitely. By that time I had accepted the fact that chances were that everybody I knew was going to die and that I was going to die and it was just a question of time. It just seemed the logical conclusion. In retrospect it *was*.

I would have to say that one of the most successful demonstrations in New York proper would have been in 1989, the anniversary action where we shut down part of downtown and had a march to city hall. I recall well over 2,500 people with a massive picket and incredible posters and propaganda. The group that I was with decided to take over the street and block all traffic. It was one of the major streets near city hall, downtown, I think? So we waited for the appropriate moment and chained ourselves together and went into the street and lay down. Then the police went through the crowd of people who were risking arrest. It was rush hour. The last of us probably weren't arrested until around lunch time. Then we were carted off in paddy wagons and held. There were probably a couple of hundred that were arrested at that demonstration. They weren't able to move us through the system rapidly enough and they didn't have enough jail space. That was a massive demonstration.

Those local actions really brought people in masses. The following week you would suddenly have 800 people at the meeting instead of 400. It also began drawing media attention and the attention of other AIDS organizations to better identifying the real issues and what was truly going on in the system. City bureaucracies were starting to unravel the kind of corruption within the administrations—that programs like shelters weren't working or that hospitals were overcrowded or that health care was insufficient. Those things that seemed like such highbrow intellectual garble when we first started talking about them became commonplace ideas among the mass media.

There's a point when there's a demonstration where my mother will call me from New York, and if I pick up the phone she will say, "I can't believe you are out of jail already. I thought, you know, I'd leave a message on your voice-mail just saying, 'Call me when you get home later.'" I'm not blasé about the importance of civil disobedience and the importance of risking arrest to get your message across. It's just part of my

responsibility as an activist.

I can honestly say that I didn't become an AIDS activist to save my life. I became an AIDS activist because I felt that the whole system was corrupt and that our government was at fault for the spread of this disease and that we needed to wake up. It really was about the world and about our world as a gay people, which I still recognize and believe will be annihilated because of this epidemic. As our community becomes more passive, more reticent, I can see those who are left, as AIDS activists, saying that old adage, Help yourself first so you can help others. Many of us are at a mid to late stage of disease where if we don't survive and there aren't any new people coming into it, then we can't do anything to help future generations. Ultimately that hasn't been my objective. My philosophy is that this epidemic will be with us for at least another generation and that therefore we should do everything in our power to keep the urgency of AIDS focused in the public eye.

You're really jostling my memory now and all sorts of fun things are coming out, and the horrible things. When you're in jail, you know, waiting to be released or sighted out, it's a weird feeling because you've suddenly gone from this energy of a crowd and a demonstration and your action that you planned down to the final detail to being a hostage. You can feel very trapped and it can be a very unpleasant, hot, unsanitary, disease-ridden environment to be in. You feel very disempowered. They seek to make you feel that way for the most part. Although I have been in situations where I felt that the police were more than compliant, that they were actually aiding and abetting us in ways which I really respected.

I was arrested in Albany three times. The first time was that time that I interrupted Mario Cuomo at the State of the State. And the officer that arrested me, he pulled me out and then headed me over to this big burly officer, 250 pounds. And I turned to him and I said something like, "Just don't mess my hair up." And he looked at me and I winked at him. We both started laughing and we became buddies. And when I came back in my Marie Antionette outfit, he actually sought me out. This is an upstate New York middle-aged married guy, you know, and we developed this connection. And that wasn't the last time that that happened to me with a police officer. And I never hid that from my co-activists, even the ones that are the most dire cop-haters. The third time that I came back he asked some other activists that he had arrested, "So where's Braverman?" Someone else arrested me and, of course, he came over and said, "Sorry I didn't get you this time, you know." I think several of us have had that kind of a rapport because we didn't... turn as we were getting arrested and say, "Fuck You! You Goddamned Pig!" and spit on the guy. If you can just turn and say, "Hey look, I know you are doing your job. Do me a favor, don't put the cuffs on too tight, I've got bad circulation. I'm a person living with AIDS." Or "Do you know anyone who's died?" I can't tell you how many times an officer has turned to me and said, "My brother died. My brother's sick. Do you have some information?" One time we got arrested here in San Francisco shortly after ACT-UP Golden Gate was formed and we were brought into the North Station, I think it's at North Beach, and the lieutenant said, "What phase of clinical studies is this drug in?" If you are always going to assume that the cops are ignorant or that they are politically on a different side then you are wrong. You shouldn't and you can't make that assumption. The last time I got arrested, which was just a month and a half ago, the cop said, "You know, my wife has been battling cancer and I'll tell you, the system just fucks people." I don't believe that they're my enemy. I'm not an activist because I have a disrespect for human life. I'm an activist because I respect human life and the need for a quality of life.

But afterwards, when we left a demonstration in the early days, we had this sort of unspoken understanding that we would gather, those of us that had been arrested. Or some of us would gather in groups, go get something to eat, or hang out at someone's house, or spend the rest of the day together because of the crash. The emotional crash that comes afterwards is intense because for those instances of the demonstration you forget that you're not living at the tail end of an epidemic. You forget that everything that you are demanding is not going to be achieved when the demonstration is over. You are so focused on the moment that you, somewhere in your mind, believe that the solution is here, in the action and clearly it isn't. This is just part of part of the process. So when you end up home alone afterwards, you wake up to the fact that death is still here, your friends are still dying, you're still sick, the system still exists as it was and that some changes may have come about but it's just the beginning. One of the difficult things of being an activist is maintaining that high level of energy and not letting the crashes destroy you. My crashes were always short lived cause I was always so busy organizing another project. I think in the earlier days, particularly in New York, there were so many people and there was such camaraderie that it was easy to stay focused and to feel a sense of support. With today's attrition, that doesn't exist.

I think that within the history of all political movements there are divisions and subdivisions. Movements become fortified and watered down as they grow. You can look at the history of political theory and what happens. History really does repeat itself. You see it over and over again, whether it's the Black Panthers or whether it's SDS or whether it's ACT-UP. People do not come into a movement that are essentially of like minds. People come into a movement because they have, essentially, the same interest in the same issue. But their origins are completely different. The key is how to, how do you use that diversity without letting it dissect the organization. I think there are inevitabilities of splits and I think that

they need to happen and they can be healthy. But I think also sometimes splits happen and conflicts within an organization are almost like a disease itself; it's almost that the body is fighting all these cancer cells and it's going through its own triage and the body begins fighting itself. And that happens within organizations. Friends turn enemies and people turn against each other and divisions become blurred. I think that AIDS activism as we know it is dangerously close to being on its deathbed. And I am not certain that it won't die as we know it. My prediction actually is that it will die as we know it and that several years will pass before it's resuscitated or reinvented.

AIDS Inc.

There's a perception that among research, health and service agencies—the so-called "helping professions"—a great deal of money and careers are being made off of people with AIDS. G'dali reflected: Part of what the evolution of this movement is based on is that some people can't live with the small changes, and they make choices to become part of what I call the AIDS industry because they think that being on the inside is going to make that change. People struggle to find ways to feel they are going to be more effective. But no one is sitting down to do an assessment and say, "You know what? Maybe it's better to sit down and start from scratch right now." I tend to have the attitude of "Why assume that anything worked?" We're still in this epidemic; people are still dying. People are clearly still becoming infected. There are no treatments that even come close to managing the disease as a chronic manageable infection.

The question that I would pose to every AIDS organization in this country is: If the cure was here tomorrow and it was not available for another year, or it would only be available on a limited basis and it was expensive, what would you do? Would you fire your entire staff and liquidate to have the funds to be able to buy that out now to provide it to the people who would have died between now and next year? What is the triage that you are willing to consider and why isn't that approach being taken with every advance that could move toward making this a chronic manageable disease? The answer that you'll get is, "We have limited discretionary funding and we have to put together a budget and allocations and we get government money and we get grants. We have to substantiate where that money is going so we wouldn't be able to direct the funds." So what have we got? Do we have a machine that's representing the needs of people? Or do we have a machine that's simply recognizing that people exist and is doing something that is amorphous around that? It's bullshit. If we feel we have the right and the ability to revise the FDA, the drug approval system and call on the White House to create an AIDS office, then what's our responsibility to our community to look at our organizations? This has been a financially efficacious disease for a lot of people.

As Darnell observed: I moved twice in a two month period. Do you know how exhausted I am? That stress was brought on me unnecessarily by people. I went to the people running the building I just moved out of, I says, "Look, my life is wonderful; I've gotten everything on track. I have a one-room apartment, but my concern is maintaining my home. My home is very important to me." What did they do? The first thing they fucked with is my goddamned home. So I moved out. I'd rather sit and die by myself, in my own shit, than to allow some of these people to take care of me.

I was under the impression that I was moving into a building that was there for HIV people who needed help with low-income housing. I agreed to come in there and pay low rent. I did not agree to any other program. I didn't need a caseworker. I was not aware that I had people policing me everyday or that someone could come to my house at the age of 35 and say, "You can't have guests, you're on house restriction." I don't need that shit! When you take away the people that love you, deny them access to me, then you take away a lot from me. Then you make me totally dependent on you, and that means you can rub me anyway you want. So that means that I have to sit down and say, "Yes, yes, yes," when I say, "No, no, no." In other words: "Fuck you. You don't live here. I do. You go home and you entertain your guests and you have dinner. I can't. What? Because you've agreed to give me low-income housing." If that's the price to pay for low income housing, then it's no longer helping the people.

The false facade is that they are here to help people. When my T-cell drops, my stress level skyrockets; that's not helping. In a two month period, I lost more weight and sleep and gained more stress than I have over the whole fucking year that my lover died. That's pathetic. If they were able to do that to me, can you imagine what would happen to someone that isn't as strong as I am?

I was treated like I was brought in there off the street. In one meeting, I says, "Oh, I went to visit my nieces." She says, "It must be nice to finally have an address!" Excuse me? I had an address before I got here. That just showed me where her head was: disrespect, blatant disrespect. You think about these little things and wonder how deep does this attitude in the organization run? You're dealing with people's emotions at a point in their lives where their self-esteem is very low, their tolerance of pain is very low. And you have someone dishing out that much pain and hurt, it

goes deep.

I was able to move out. I'm going to die the same way I live, with pride and dignity, and you can't have that. And that's what they strip. You take that pride, dignity and self-respect away, we just have a hollow shell. We have people walking around scared; these are adults, they're having the roughest time of their lives. Faced with something that a lot of people have no perception of what these people are feeling, mentally and physically. And they're taking away the last little thing that they have left in their heart away from them. If they're just going to take that away, who the fuck wants to live?

My goal is to rock the fucking boat. There are things that need to be known and changes that need to be made. Health wise, stop using these fucking people as guinea pigs. If a person chooses to take trial-basis medication, fine. But tell them the whole story and not part of the story, that's deceiving, and it's lying. It's tricking people into taking shit which these people know are going to kill them. I've seen it, I've seen it done.

When my lover started the radiation treatments, I didn't want him to, but the decision was his. He says, "Oh, you just have a little hair fall out and that's it." That's what his doctor told him. He lived on the pride of his hair. All his hair fell out. Then he said they said it would clear up for the KS Lesions and it did not clear up. Finally, close to the end he says, "Baby, will you be mad at me if I stop?" I says "No. If you want to stop, you stop." I always wanted him to stop but the decision was his. A lot of people are taking things that are making them ill. I met a guy the other day that's taking Septra. And some people just can't take it. His doctor says, "Well, break it in quarters and take it." If your body don't want it, don't fucking put it in it. And if your body's rejecting it, the doctor should never have forced him or even convinced him to take it. Listen to your body.

Doctors take this thing too lightly. Too many do not educate themselves on what's going on. If you feel that you have a doctor that don't know what the fuck he's talking about, lose him; do not be afraid to change doctors. Those are your rights. When you walk into a doctor's office and he's looking through your god damned chart cuz he don't know what's wrong wit you, it's time to change doctors.

I have people run up to me, they want me to try this and I say, "No. Will you take it? Will you put that shit in your body? No. Then why the hell you think I should put it in mine? I'm healthy. What you all want me to take something that's going to make me sick for?" There's no logic in that. None. So, I choose not to and maybe, by not doing so, my body can fight this disease off itself.

As HIV settles into its place beside other such failures of the American political landscape as the Civil Rights Movement and the War on Poverty, it is easy to allow AIDS to become an abstract concept. As of '94, national priorities have shifted away from handling social problems, such as AIDS or poverty. In this second generation, combined strategies to stop the disease have to be more thoughtful and less hysterical, more organized. Early in the interview process, I talked to a man whose dementia intensified between interviews. At the end of the final interview he stopped, got up and vomited. When he sat back down he starred earnestly and told me, "Ben, if you can do anything, tell the world this isn't a joke." He died two months later. Art died earlier this year. As we witness them, these voices help illuminate the concept that behind each of the 270,000 registered deaths from the epidemic in the United States and millions worldwide, lived a human being with a story. Their deaths leave a huge void, a chasm.

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