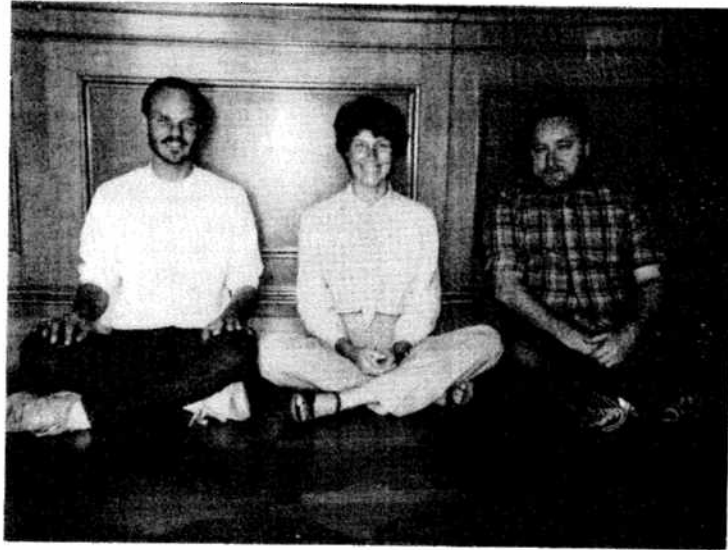




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The Shanti Project Newsletter

SUMMER 1984



AIDS Residence Manager Bill Barksdale, Director Helen Schietinger, and Secretary Michael Fiorentino

RESIDENCE PROGRAM ENTERS SECOND YEAR

by Helen Schietinger, M.A., R.N.

In March 1983, Shanti's Executive Director Jim Geary submitted a funding proposal to the City for Shanti to provide permanent, low-cost housing to displaced persons with AIDS. I came to work at Shanti in May to put the program together.

In July, four persons with AIDS met with me in a hospital room for their first house meeting, prior to their moving into Shanti's first residence. Today, Shanti has leased three houses, each with four to six bedrooms, allowing us to provide housing for 14 persons with AIDS at any one time. (We are now in the process of looking for a fourth house). In the last year, more than 30 people have lived in these houses. For many, the Shanti Residence Program has provided the stability and security which enables them to continue living their lives focused on what is important to them, rather than worrying about whether they have a roof over their heads. For some, the Program also has provided a haven in which they could live their last days with the familiar surroundings of their own belongings, in the company of familiar faces.

When I first interviewed Ted for the Program, he was living in his truck on the streets of San Francisco. He

was humiliated by his financial condition, having had a good job and a nice apartment before he got sick. It was hard enough for him to cope with his physical deterioration from AIDS and the visible lesions on his body. Moving into the first house gave him a foothold to begin piecing his life back together.

Brad moved in at the same time Ted did. He had spent the last year undergoing treatment for his KS and was living in a residential hotel through the Mayor's Emergency Housing Program. Prior to getting AIDS he had been a professional entertainer and felt as though his life as a performer was over. He had his strength back and had no visible lesions, but still his entire life was changed by having AIDS. Moving into the Residence was a financial relief and a first step in establishing a stable living situation.

Each person who is accepted into the Program must have a diagnosis of AIDS according to the Center for Disease Control definition, be a resident of San Francisco, and be willing and able to live cooperatively with his roommates according to the Program guidelines. There are weekly house meetings to encourage communication and to iron out difficulties among the roommates, who were strangers before and who may have only AIDS in common.

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The Shanti Project Newsletter

Published by Shanti Project for the friends, volunteers and staff of Shanti Project, 390 Hayes Street, San Francisco, CA 94117; 415/558-9644. Shanti Project is a contract agency of the San Francisco Department of Public Health.

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SUMMER 1984 NEWSLETTER

Managing Editors:

Jim Geary, Andrew Lewallen

Contributing Writers:

Daniel Barnes, Linda Maxey,
Helen Schietinger

Photography:

Chris Couzens, Bev Flynn

Graphics and Layout:

Kevyn Lutton

Word Processing:

Andrew Lewallen

Distribution:

Shanti Project Volunteers

Special Thanks:

BIZ Resources, for technical assistance.

PRINTING BY: Women's Press



Shanti is a Sanskrit word meaning "inner peace."

The Shanti Project logo is an eclipse, a circle within a square. The circle portrays the inner world of the mind. The square conveys the solid reality of earth and body. United, they indicate the wholeness of the human being.

An eclipse is the passage from light to darkness and the return to light. For Shanti Project, it represents the changes brought about by illness and death, the darkness that can fall upon people experiencing these events, and the light that can follow in the wake of helpers who bring love and caring.

Denny Thompson, Coming Attractions Communication Service, created the logo.

Residence Program, cont'd.

The predominant theme is one of support and caring among housemates. The other day one hospitalized person called home to say that he needed his walker for physical therapy. His room was locked, but his roommate climbed through the window of his room to get his walker and bring it to him. One of my major concerns has been that the residents not have to take care of each other, because they need to focus on their own individual needs and healing. But in a pinch, they usually come through for each other. The bonds they develop are strong.

Every person who has moved into one of the houses has been pleased with his physical surroundings. The apartments are all in very good condition and comfortable, each with relatively new kitchen facilities and appliances, including washers and dryers. Each resident has his own bedroom and shares the kitchen and living room and bathrooms with his roommates. Individuals pay 25% of their income for rent. (Rents usually range from \$50 to \$120 per month.)

Each household develops its own character based on the residents living there at the time, and the personality of the house changes with residents. In one house, roommates may buy groceries together and share meals. People in another household prefer to maintain individual control, buying food separately and labelling it. Some individuals are very social and develop their own support systems, which may include their roommates, friends, Shanti counselors, Practical Support volunteers, etc. Other individuals enjoy more privacy, using the common areas as necessary but spending the majority of time in their rooms.

A major commitment of the Program is to enable people to have as much control as possible over their lives, despite the tremendous changes which having AIDS has forced upon them. However, over the year, we've instituted systems and policies which make the Residence Program houses different from private housing. For example, to promote good hygiene, we collect \$5 a month from each person which goes toward the purchase of bulk paper towels, toilet paper and cleaning supplies. The Practical Support Program has provided weekly house-cleaning services in each of the houses to assure that a basic level of good hygiene is maintained.

There are no direct services such as meals or personal care provided to people in the houses by the Residence Program. However, the Residence Program staff has grown to three people and provides many indirect services. Bill Barksdale,

the Residence Manager, oversees the physical condition and safety of the buildings themselves. He spends a great deal of his time in tasks such as repairing appliances or organizing the moving of furniture when a new resident moves in or when a resident has died. He has and needs a great deal of help from Practical Support volunteers. Bill also is in charge of looking for new units when we need them and negotiating the leases with landlords. He is finding that even gay landlords often won't rent to us for fear of jeopardizing their relationships with future tenants. We're in our third month of looking for House #4.

Michael Fiorentino, the Program Secretary, usually has his ear glued to the phone from 9 to 5. His unofficial tasks include such things as arranging haircuts for the residents. His varied official tasks include collecting rent and managing the office phone while Bill and I are "out in the field," as we say in social services.

As Residence Director, I spend a great deal of time at the houses, hospitals, social service agencies and the Public Health Department. (If I'm not in one of those places, I'm usually on the phone to someone at one of those places!) My primary function besides administering the Program is to assure that the households are functioning smoothly and that the residents are getting along and getting their needs met. I am available to deal with the situations which arise when a resident has difficulty functioning in the cooperative living situation. Some people are not appropriate for living with a group of people, particularly if they have drug or alcohol problems which interfere with the lives of their roommates (we have a no-illegal-drug policy). Much of my time in the past year has been spent developing home care services for people with AIDS and providing residents with assistance in obtaining home care. This is obviously important because we as a program only provide the housing itself.

Many of the people with AIDS living in the houses have remained able to care for themselves, doing their own shopping and cooking for themselves. Many, however, have become too sick to manage on their own. Over the past year I have found and used several avenues to assure that people were adequately cared for. These are avenues available to any person with AIDS, not just to people living in the residences. Shanti's Practical Support Program, directed by Randy Chelsey, was our first mainstay when some residents became ill. Last fall in the first house, a team of Practical Support

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1983 Finance Report

VAN KEULEN & LUMER

AN ACCOUNTANCY CORPORATION
803 MARKET STREET - SUITE 1213
SAN FRANCISCO, CALIFORNIA 94103

415.384.0700

EDMUND H. COLEMAN
5715 MONROE AVENUE
MILPITAS, CALIFORNIA 95035

SHANTI PROJECT

STATEMENT OF SUPPORT, REVENUE AND EXPENSES AND
CHANGES IN FUND BALANCES

For the Year Ended December 31, 1983

To the Board of Directors
Shanti Project
San Francisco, California

We have reviewed the accompanying balance sheet of Shanti Project as of December 31, 1983 and the related statement of support, revenue and expenses and changes in fund balances and changes in financial position for the year then ended in accordance with standards established by the American Institute of Certified Public Accountants. All information included in these financial statements is the representation of the management of Shanti Project.

A review consists principally of inquiries of project personnel and analytical procedures applied to financial data. It is substantially less in scope than an examination in accordance with generally accepted auditing standards, the objective of which is the expression of an opinion regarding the financial statements taken as a whole. Accordingly, we do not express such an opinion.

Based on our review, we are not aware of any material modifications that should be made to the accompanying financial statements in order for them to be in conformity with generally accepted accounting principles.


Van Keulen & Lumer

San Francisco, California
May 7, 1984

PUBLIC SUPPORT AND REVENUE	UNRESTRICTED FUNDS	RESTRICTED FUNDS	TOTAL ALL FUNDS
Contract cost reimbursement (Note 4)	\$ -	\$194,735	\$194,735
Sweepstakes sales	152,611	-	152,611
Donations	67,452	200	67,652
Concessions	12,876	-	12,876
Training and honoraria	12,405	-	12,405
Residential rent	4,644	-	4,644
Interest	2,133	-	2,133
TOTAL PUBLIC SUPPORT AND REVENUE	252,121	194,935	447,056
EXPENSES			
Personnel	5,821	131,340	137,161
Residence expenses	10,594	19,100	29,694
PWA recreation	-	872	872
Concessions	8,198	-	8,198
Consultants	8,986	-	8,986
Postage and printing	24,512	-	24,512
Advertising	2,686	-	2,686
Travel	1,769	-	1,769
Other operating expenses	-	28,185	28,185
Grants	7,233	-	7,233
Sweepstakes expenses	114,541	-	114,541
Video project	-	15,438	15,438
TOTAL EXPENSES	184,340	194,935	379,275
EXCESS OF PUBLIC SUPPORT AND REVENUE OVER EXPENSES	67,781	-	67,781
FUND BALANCES, beginning of year	(152)	-	(152)
FUND BALANCES, end of year	\$ 67,629	\$ -	\$ 67,629

SHANTI PROJECT

NOTES TO FINANCIAL STATEMENTS

For the Year Ended December 31, 1983

SHANTI PROJECT

BALANCE SHEET

December 31, 1983

(1) The Program

Shanti Project offers free counseling and emotional support for individuals and their loved ones facing life-threatening illness and bereavement.

Through its Community Volunteer Program Shanti provides non-counseling services such as transportation, shopping, and housekeeping to persons with AIDS. Shanti Residence Program provides long-term low-cost housing to persons with AIDS who are displaced because of financial difficulty and/or household rejection.

San Francisco General Hospital has contracted with Shanti to staff the Inpatient Unit, 5B, and the Outpatient Clinic, Ward 86, with counselors. They are available to friends and family for emotional support and information. Ongoing support groups are available on both 5B and Ward 86.

(2) Summary of significant accounting policies

The significant accounting policies followed by the Project are summarized below:

Basis of accounting - The financial statements reflect the accrual basis of accounting in which revenue is recognized when earned and expenses are recognized when incurred.

Property and equipment - The fair value of contributed assets to Shanti Project are not determinable within reasonable limits and, therefore, are not recorded on these financial statements. Otherwise equipment is carried at cost. Depreciation is calculated on the straight-line basis over useful lives of five years.

(3) Income tax status

Shanti Project qualified for tax exempt status under the Internal Revenue Code and the laws of the State of California and has been designated as a "publicly supported" organization. Contributions qualify as charitable contributions.

(4) Restricted Funds

The Project has entered into cost reimbursement contracts with the City and County of San Francisco and the State of California. The contracts cover various periods ending June 30, 1984.

At December 31, 1983 the status of the contracts was as follows:

CONTRACTOR	Costs Incurred	Unreimbursed Costs	Remaining On Contract	Total Contract
City and County of San Francisco	\$178,711	\$25,474	\$255,834	\$434,545
State of California	16,167	16,167	4,299	20,466
Total	\$194,878	\$41,641	\$260,133	\$455,011

ASSETS

	UNRESTRICTED FUNDS	RESTRICTED FUND	TOTAL
CURRENT ASSETS			
Cash	\$40,328	\$ -	\$40,328
Receivables (Note 4)	1,000	41,641	42,641
Interfund advances	30,063	(30,063)	-
TOTAL CURRENT ASSETS	71,391	11,578	82,969
OFFICE EQUIPMENT, net of \$3,998 in accumulated depreciation (Note 2)	2,046	-	2,046
DEPOSITS AND PREPAID EXPENSES	9,912	-	9,912
TOTAL ASSETS	\$83,349	\$ 11,578	\$94,927

LIABILITIES AND
FUND BALANCES

CURRENT LIABILITIES			
Accounts payable	\$ 6,600	\$ 11,578	\$18,178
Accrued wages	1,242	-	1,242
Payroll taxes payable	7,878	-	7,878
TOTAL CURRENT LIABILITIES	15,720	11,578	27,298
FUND BALANCES	67,629	-	67,629
TOTAL LIABILITIES AND FUND BALANCES	\$83,349	\$ 11,578	\$94,927

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Counseling Program At S.F.G.H.

by Linda Maxey, R.N.

Shanti's involvement at San Francisco General Hospital began with a request from a person with AIDS, Shanti Project Board Member Bobby Reynolds. On Mondays, Bobby would go to the outpatient clinic on Ward 86 to receive his chemotherapy. During the long hours in the waiting room he saw so many people like himself sitting there alone and terrified, waiting to find out the results of their biopsy, dazed and wondering what the doctor had just said, and watching others whose treatment had failed and whose lesions continued to spread. In response, Shanti provided a counselor to be present during the three-hour Monday clinic. At the request of the physicians and nurses, the three-hour position quickly expanded to the current 20 hours a week in order to provide for the patients in the other expanding AIDS and AIDS-related clinics.

In July 1983, SFGH opened its 12-bed Special Care Unit, 5B, to improve the quality of care for people hospitalized with AIDS. In planning the unit, Cliff Morrison, the Clinical Coordinator and a former Shanti volunteer, recognized the immense amount of emotional support that would be needed for these patients, their families, friends and lovers, as well as the nursing staff. He felt that staffing 5B daily with Shanti counselors was the best way to meet these needs. Through a City contract providing for one full-time Counseling Coordinator and three half-time counselor positions, Shanti counselors joined the team caring for people with AIDS on 5B.

For all of us working at SFGH, this past year has touched our lives deeply. The reality of the devastating effects that AIDS has had on those with the disease and their families, friends and lovers is inescapable here. We have seen young, previously healthy and independent people rapidly become financially destitute and physically dependent on others. We have supported them through the roller-coaster changes and the loss of many of the things that make us feel important: our jobs, our ability to be productive and contributing members of society, our physical appearance, our talents, etc. In the face of all this, what we see are the incredibly loving and courageous qualities of those we serve. I am reminded that it is the darkness of the night that allows the brilliance of starlight to be seen most clearly.



SFGH Counselors

We have talked to families and friends who live great distances away, struggling with the decision of when to visit. We have comforted them in their pain of arriving to find someone who appears vastly different from the son or friend they last saw. We have supported them through the agony of having to leave and say good-bye, wondering if it is forever. We have sat with patients during that painful phone call, "Mom, I have something to tell you. Is Dad there with you? . . .". We have spent many hours with parents who have just been told that their son is gay, that he has AIDS and that he is dying. Though being confronted with overwhelming issues and decisions in an all too limited amount of time, we continuously see people meet the challenge with amazing inner strength and compassion. We have seen some patients who do not have the support of parents or brothers and sisters but who have a loving family of friends. We are always saddened when for others the staff of 5B may become the closest semblance of a family that they have.

The word "epidemic" has taken on new meaning over the past year. We opened the unit with six patients. Primarily we saw people with *Pneumocystis carinii* pneumonia. They often responded well to treatment and went home in fairly good condition. During their stay they were often well enough to attend our patient support groups and visit staff and other patients in the conference room. We would joke about the "country club" atmosphere, the elaborate ways people would decorate their rooms and the gourmet meals friends would bring in to offset SFGH cooking.

But that has changed. The unit is now consistently full and there have been as many as 13 patients with AIDS on other units scattered throughout the hospital. We are looking at needing to double the counseling staff to be able to meet the rising needs of patients both on 5B and the other units. When we began we had hoped that by now the epidemic would have peaked and we would not be needed much longer. We no longer try to figure out if this is the beginning of the end of AIDS. We just stay in the present and try to meet the crisis as best we can. The picture of AIDS has changed. In addition to *Pneumocystis*, we are now seeing patients with what were previously rare neurological diseases, such as toxoplasmosis (a brain infection) and cryptococcal meningitis. These diseases often leave them bedridden and unable to speak or think clearly.

Since last August, over 70 of the people we have worked with have died. We have grappled with ways to manage the unrelenting and pervasive grief. On 5B there is a big red scrapbook that is dedicated to those we serve. In it are put pictures, poems, newspaper clippings, cards and drawings of our patients. One day recently we took the scrapbook and went to the beach for the day. We talked individually about the people we had worked with who had died and then tossed a flower into the ocean for each of them. It was really healing. It was nice to remember them as unique and special individuals.

The support and caring that we have for each other makes it possible to continue doing this work. In our weekly staff support groups we cry together and laugh together. We

Cont'd P. 7

A SHANTI 'Family' Experience

by Daniel Barnes

(Ed. Note: The names of clients in the following article have been changed to preserve confidentiality.)

I met Rick last fall on Ward 5B at San Francisco General Hospital. He was being released after having been treated for Pneumocystis pneumonia. We made one of those problem-focused connections, discussing treatment options and how to beat AIDS in spite of the long odds against it. Rick and I also connected on another more intimate level, which revolved around his needs for space, to handle his illness in his own way and in his own time.

Through the rest of the fall, the winter and into the spring, Rick and I connected in a way that left me questioning my own relationship to others. Rick never called me in crisis. He handled it alone. Then he would call me (or wait for me to call) to share his feelings about why he had been overwhelmed and how he had dealt with it. During our visits in those months we shared more about our lives--our childhood dreams, adolescent nightmares, adult fears, hopes and loves--than issues around his worsening health. I guess we were laying the groundwork for the trust, friendship and love that was to come.

The turning point came in April when Rick's Kaposi's sarcoma lesions had begun to line his mouth and lungs. Our conversations began to turn first to his family and then to death and dying. His coughing kept him awake at night, the lesions kept him from eating; and for the first time pain began to become an issue for him along with the loneliness that comes in the middle of the night when the rest of the world seems to be at peace. We talked about having his mother, Carol, come out for a visit and his relationships with his brothers, David and Jack, and his sister, Susan.

Rick had completed a course of treatment to remove the lesions in his mouth when he was admitted to the hospital again. Alan, Rick's best friend and support, called me to tell me Rick was in bad shape. Rick and I talked about calling his mom. She had known for a long time he was ill with AIDS, and he asked her to fly out that week.

I met Carol at the University of California San Francisco's oncology service a few days later. I'll never forget that first hug and those first few tears. She had not

known how sick Rick was, and it came as a shock to see her son covered with KS lesions. In response to his mother coming out to stay with him, Rick moved from his one bedroom apartment to a two bedroom Victorian. This required some significant adjustments for me in that I am wheel-chair bound and Rick's new place had thirty-nine steps. The solution to this logistical problem proved to be one of the most wonderful facets of our relationship with Rick. I say "our" because my Shanti group (Stu, Jeff, John, Mickey, and Michael) took turns helping me up and down the steps each time I visited Rick, and they became intimately acquainted with Rick's life and family.

Rick was unable to get out of his house for most of his last seven weeks. I tried to be with him each time he went to the clinic to support him as his breathing worsened and his physical pain increased. His optimism changed slowly to acquiescence that his situation was terminal.

It was a great relief to him when his friend Alan asked me for a Shanti counselor. The Shanti Clinical Coordinator, Bea Tracy, arranged to have one of my group members (Jeff) work with Alan. By working together, we were able to provide more understanding and support. Later, Bea volunteered to work with Carol. Again, Rick was visibly relieved to see another of the people he loved find support.

Rick's brothers came out from the East coast on separate weekends. I had the opportunity to talk extensively with them on several occasions, and I watched the family become more open with each other. I felt increasingly close to Rick and his family as we shared more and more during those weeks.

In early June, Rick began needing oxygen constantly as his breathing worsened. The KS had continued to spread internally, and the subsequent swelling made it painful for him to move from a sitting position.

During this time Rick's sister, Susan, came out to support both Rick and Carol. I spent a lot of time with Susan, with her gently moving from, "He's not going to die," to tentative acceptance of his condition, and finally to accepting and sharing the love and pain she felt for him--feelings so often difficult to express in words.

Rick saw the changes too, not just in Susan but in the quality of his relationships with other people. Most notably, Alan. When Rick's family moved into his life during those final weeks, Alan did not have the same central role he had had for nine months earlier. He faced dealing with feelings of resentment and pain that many experience when they feel displaced.

So many of Rick's and my conversations during those last two weeks began with tears and the words, "How much is enough, Daniel--how much?" I remember the depths of sadness in his eyes and the pain that flashed across his face when we always reached the same non-conclusion. I wanted to save him; I wanted so badly to reach inside him and release him from his helplessness and his pain. He was tired of it all. He had lost any purpose to his life. Life had become so painful that death had become a friend in those last days.

7:00 a.m. Carol called: Rick's condition had worsened greatly, and he felt the time of death was near. She asked me to get there as soon as I could. I called Michael and Jeff (Alan's counselor) and they said they would meet me at Rick's.

When I entered Rick's room he looked up slowly--I knew it before he said it, "How much is enough?" Carol cried on the bed next to him. I held her and asked her for some time alone with Rick. She understood and hugged us both before she left. Rick and I talked and cried, listened and cried, for several hours--we talked about knowing that today had been the "enough" we had discussed so often. Before the pain came flooding back as the medication began to wear off we talked about death and what it meant to him and what it meant to me. We did several visualizations. Then he turned to me and asked me to get his doctor on the phone. We talked about what he really wanted. He wanted out of his pain. He wanted to die on his own terms, pain-free, with the people he loved (and for some strange reason he wanted to be eating orange jello!).

After Rick talked to his doctor, I called his brothers to let them know Rick's desire (more tears, more love, more support). Jeff and Michael of my support group, who had

Cont'd P.6

"Family" Experience, cont'd.
and Susan and Alan, left so that Carol, Susan and I could be alone with Rick. We knew without reservation that we were in the right place in the universe, and we felt the inner peace of "shanti."

Rick wanted us to drink with him so we cracked open a bottle of white wine. We toasted each other, the future, the past, and even the painful present for its part in his release. Rick chose two tapes to listen to as we celebrated--one was of my friends and me when I still could play guitar and the other was George Winston. The music was a healing background as we held each other, laughed, cried, and drank. Rick had us open up champagne after the white wine had been drunk. Alan arrived just as Rick was saying he'd like to have him there.

We had about an hour with Rick before his eyes and his touch began to be his only way to communicate-- words would have only been in the way then. As he put his head down to rest, his goodbyes said, we told him through the tears that we loved him, that we would miss him, but that it was time to go. His eyes answered back that he knew--he knew it all at that point. His breathing became more labored and it seemed to be the oxygen that kept him going--it kept him here. He shut down the oxygen and he continued to breath on his own.

I stayed with Rick. I kept repeating a "move towards the light" message for several hours. Jeff and Michael had returned and Carol and Susan came in many times during that period. I was frightened Rick was not going to die. I felt emotionally and physically drained, so I had the team (Carol, Susan, Jeff, Michael, and Alan) help me to bed for a while at about 11:00 and told them to wake me up if there should be a change.

At 1:00 in the morning Susan and Carol came in to tell me Rick had died. I felt a tremendous sense of release--of freedom. I hope Rick could see me as I stared up at the ceiling lights, feeling wonderful in spite of the tears that came like a stream.

I knew he was all right now, that everything had been done as well as it could possibly be done in those circumstances.

Carol, Susan and I found different places in the flat while Jeff and Michael washed Rick's swollen, body and wrapped it in a sheet. I didn't see Carol much the rest of those morning hours. It was as if I couldn't leave Rick's body alone just in case he might not have made it away safely. Susan and I sat together--holding and talking in the room where Rick had died. I think we needed that time with Rick's body

to feel that he was really gone. The incense, the music, the light, and our exhaustion freed us from feeling that this empty cocoon was somehow still Rick. I called Lambda (the gay funeral guild) and they were over about 20 minutes later to take Rick's body; and after they left we went into the kitchen for coffee and more hugs. It's strangely reassuring to be touched so much after experiencing someone's death.

We made a list of things to do, people to call, etc., and we began taking care of it. By 10:00 a.m. we had the room back in shape and everything but the rented wheelchair and bedside table out of the house. It was a relief that all the preparations had been made in advance, and we were free to take care of the business of supporting each other.

I left at about 11:00 and couldn't get to sleep, so spiritually and emotionally energized yet so physically exhausted. Later that night Carol and Susan came by my house to visit. They crawled into bed and we just held each other for a while, not wanting to let go. As I glance up even now at our "team" photo we took that night I can't help but feel that I've never seen a happier family portrait. And if I look just below it I see Rick's photo and know that somewhere he must be smiling too.

Please excuse me for feeling so inadequate now--faced with this article now written, now related, feeling like I've failed to capture the humor, the love, and many of the very painful and very healing connections between the seven of us who shared in the dying and death of Rick. Rick was one of those gifts in life that come all too infrequently--but that reaffirm your belief in your heart and in humanity, that enjoin you to believe in opening yourself wholly to the magic of other people. For myself, for Rick, for my new family, and for my group, thank you, Shanti.

Residence Program, cont'd.

volunteers developed a wonderful evening meal program which provided not only nourishment but companionship and socializing for the four residents living there at that time. Individuals who are weak or homebound have also been assisted with groceries and banking by Practical Support volunteers.

Another resource has been attendant care through home care agencies such as the Visiting Nurses Association. For example, one resident became too weak to do the large amount of laundry he had or to prepare meals for himself. There was no medical reason for him to be hospitalized,

but he certainly couldn't meet his needs alone. An attendant came daily for eight hours to assure that he had clean linens, was bathed, and was well nourished. Many people with AIDS in the City, not simply those in the Residence Program, have benefited from home care and attendant care services.

The other avenue for help which has been available to persons with AIDS with a clearly limited time to live is Hospice of San Francisco. They have provided attendant care and the skilled nurses and social workers to supervise attendants.

I asked roommates at a house meeting in November how they felt about Ted remaining at home with Hospice care and if they felt comfortable with the possibility of his dying at home. Their response was clear. They didn't want him to have to return to the hospital if he preferred to stay at home. Their only concern was that he have other people to care for him so that they were not responsible for him. With Hospice, this was possible. His roommates' Shanti counselors were kept informed of Ted's situation so that they could be of support to their clients as Ted became sicker and died.

For Ted, the Residence Program became the safe place in which he struggled valiantly to face himself and his disease. He was at peace

when he died, both with himself and with those whom he loved.

We are very fortunate to be living in San Francisco, where the City has responded to the need for additional services for people with AIDS. Shanti is providing three major components of service which are needed (counseling, practical assistance, and housing). In the next two months, the home care component will be consolidated into an AIDS Home and Hospice Care Unit, administered by S.F. VNA and Hospice. The Residence Program depends on good home care services to enable some of the residents to remain at home without being a burden on their roommates.

Brad is alive and well, living in the Residence. He is now becoming involved with theater again. His disease is stable, and he feels that maintaining humor in his life is an important part of his healing. He has seen many of his roommates become sicker and die of AIDS. But he is well, and many of his brothers have remained stable.

The Shanti AIDS Residence Program is the only program of its kind in the country. Somehow, the fact that we provide housing is only part of the story. The Residence Program is an intense program, and the work has stretched all of us.

SFGH Counseling, cont'd.

disappointments. We give and get lots of hugs. We confront our fears and find new strengths. We learn and grow. We are very fortunate to be part of the supportive team working on 5B and Ward 86. It is truly inspiring to work with such dedicated and caring people as the nurses, the clinic physicians, the social workers, the psychiatrists and others. We have also received an unprecedented amount of support from the San Francisco community at large. People have given selflessly of their time and money to make life more pleasant for our patients. There is a lot of love here for these people who often experience rejection elsewhere. It feels good to be a part of making this possible.

We are often asked about our work and what we have learned and how it has affected us. Here are some of our replies:

Jan: "I can't imagine not being involved and doing this work. AIDS is a human issue, not a gay issue. My ego interferes less in my work now. The pace is so fast and there is so much happening there is no time for it. That makes it easier to walk into patients' rooms. It is our acceptance of people where they are, wherever that is, that allows them to move through it. We are not doing therapy. Mostly we are allowing ourselves to be vulnerable to another's pain. Our availability is important."

Paul: "I have learned to let go of a lot of my prejudices and stereotypes of relationships or lifestyles that are different from mine. It has really been more like 'unlearning.' I am inspired by the amount of altruism and humanitarianism I have seen from the San Francisco community. This work grounds me. These are my peers. They are no different than I am, and I have no idea that I will be excluded. There has been a shift in the way I look at people. I try to see beyond their physical appearance into their hearts and minds."

Ken: "I have found that it is enough to be with someone, to talk to them, to care. To give yourself and listen is an incredible gift. I am amazed at the effect that it has. I have changed and grown in ways that I didn't know were possible. I have gone beyond what I thought were my emotional limits and now see that anything is possible. I no longer live in terms of the past or future but more in the moment. I have learned not to have expectations of my patients or myself about what is appropriate behavior in this situation. We are incredibly lucky to be able to do this work. It gives us the chance to be the very best we can possibly be."

Ed: "Working on 5B has been a bittersweet experience for me. I find that I have to stretch to meet the demands of the job. While it is very difficult to see my peers, young gay men, die of a painful and disfiguring disease, I feel it has been a lesson for me to stay open to what is. I feel that meditation has provided the power for me to get through many difficult days. In order to deal with the reality of so many young men dying, I find I need to drop my assumptions about many things but, most importantly, about when the 'right' time to die arrives."

This work has shown me that we are all brothers and sisters and that love given is always passed on. Like the ripples of a pebble tossed into a pond, it touches shores we may never see. This was very clear when on Christmas eve a young man came to 5B bringing a teddy bear with a big red bow around its neck and a card. He said he did not have a family or children or a lover and wanted to give a special gift to someone. Did we have a patient who might like it? We were amazed as we had just admitted someone who had no family or friends present and whose room was the only one without presents or decorations. We gave the teddy bear to Jeff and read the card. In essence it said:

'To my brother,

I was once a patient in a hospital like you. I was lonely and afraid. Someone I did not know gave me a teddy bear. It brought me much comfort and love, and I want to pass that on to you.'

The spirit of giving is present everyday on 5B and Ward 86.



Letter To SHANTI

Joe Zygielbaum died of AIDS on Sunday, June 17, 1984. Joe died at home, with friends and family at his side and attended by Shanti counselor John Ward and Joe's lover Sam Allen. Sam wrote the following note to the Shanti family.

"Shanti,

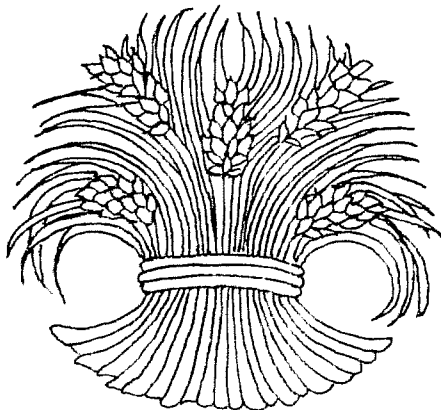
I want to thank you for all the help and love and support you have given me and my lover Joe these past two years. Joe fought his battle against AIDS courageously, and we both would have caved in long ago if it were not for "shanti." But what comes to mind most is the dignity, the consciousness and the courage Shanti and Joe's counselor John Ward inspired in Joe--to choose his death and to die in a state of clarity and grace.

What would all the hurting, suffering people caught up in this plague have done without you?

I have grown and profited so much for it--and can even find joy and consolation in all of this.

God bless you--and for everything, thank you. My memory of Joe will always be tied to my experience with Shanti and a larger circle of love than I have ever known.

---Sam Allen"



The Shanti Project, a volunteer-based organization, welcomes financial contributions from those who appreciate our efforts and want to help. Please send your tax-deductible donation to the Shanti Project, 890 Hayes St., San Francisco, CA 94117.

I would like to support the Shanti Project with a donation of
 \$15.00 \$25.00 \$50.00 \$100.00 Other \$_____

I am interested in becoming a volunteer

The enclosed is a Memorial Gift from _____

IN MEMORY OF _____

Please notify the family members at the address below:

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Street _____

City _____ State _____ Zip _____

I have moved; my new address is:


Name _____ Phone _____

Street _____

City _____ State _____ Zip _____

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- Residence Program - Practical Support Program
- SF General Hospital Counseling



Announcement

Shanti Project is pleased to announce the availability of a videotape series of the Shanti Project volunteer counselors' training.

These materials are designed to be used as a resource by organizers of counseling groups and in the training of volunteer counselors.

Contact Shanti Project for further information and prices.

Volunteers Needed

For details and application, phone Shanti Project, 558-9644

Shanti trainings are co-sponsored by the Pride Center.