



ECLIPSE™

The Shanti Project Newsletter

Winter, 1985

The Unfolding of a Day on Ward 5B

By Ed Brophy

[Editor's Note: Ed Brophy is one of seven Shanti staff counselors who works with persons with AIDS and their loved ones at San Francisco General Hospital. Opening himself to pain, grief and joy is an everyday occurrence for Ed. In the following article, Ed gives us an idea of what his days are like on 5B, the special ward for persons with AIDS at General.]

11:00 a.m.

I arrive on Ward 5B after being off for several days. I joke briefly with the nurses on duty and seek out the charge nurse for a report. Steve gives me an update on each patient's medical and emotional status. I go to the Shanti office and read the notes written by my fellow Shanti co-workers. This clarifies what issues have arisen and have been addressed since I was last here.

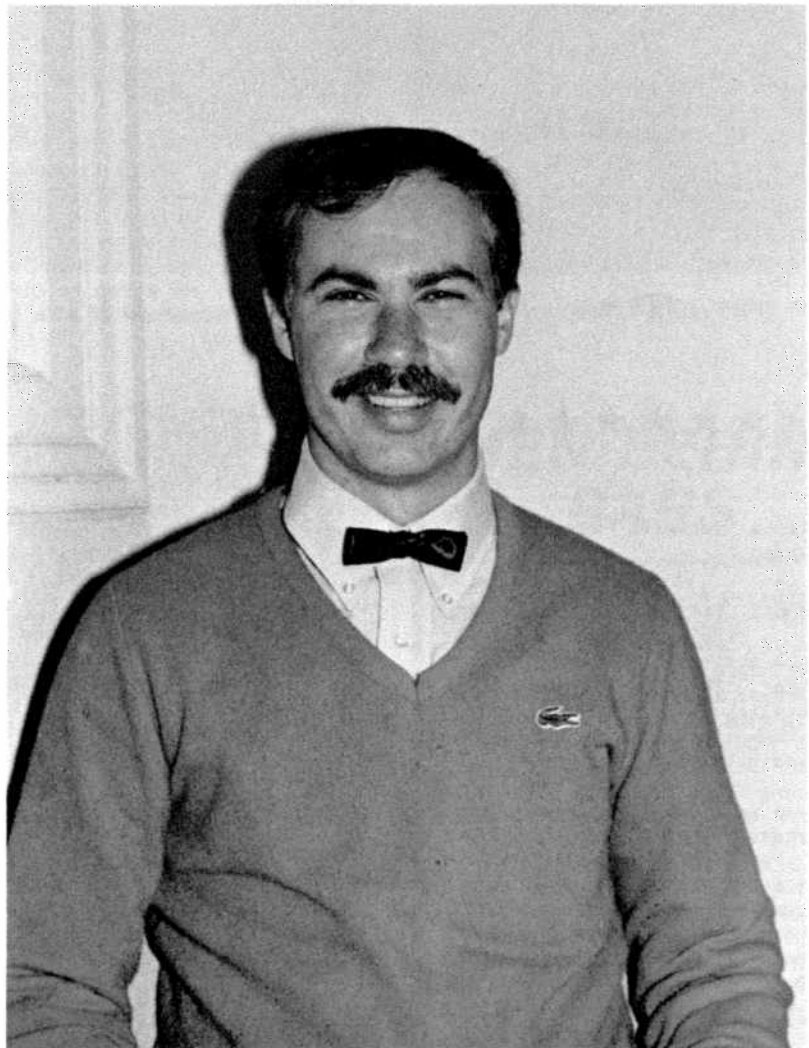
There are 12 beds on 5B and they are all filled. There are 10 additional AIDS patients to be seen on other floors.

11:30 a.m.

I decide to check in first with Fred. He is being treated for Pneumocystis Carinni Pneumonia (PCP), a protozoan infection that affects the lungs. Fred is a bright and gentle 24 year old who experienced serious medical symptoms for 18 months prior to being diagnosed with AIDS. Fred complains of his lack of appetite and stomach problems. Nausea is often a common side-effect to the medications used

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HOUR BY HOUR



Ed Brophy, Shanti Staff Counselor at San Francisco General Hospital.



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WINTER 1985 NEWSLETTER

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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.

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for PCP but Fred's doctors are concerned that there may be another problem, such as an ulcer or lesion. They have scheduled Fred for an endoscopy (insertion of tube into the intestines for observation). Fred is quite anxious about undergoing this diagnostic procedure. I ask Fred what he would find helpful and I offer to do a neck massage or a visualization. He accepts the offer of a neck massage.

Fred also talks about the arrival of his parents yesterday. He had been anxious about their reaction but he found their presence reassuring. Fred expects his parents to return later this afternoon. I tell Fred I would be very happy to meet them and help address their questions and concerns. Fred wishes to rest for awhile so I agree to return later before he leaves for his endoscopy.

12:00 Noon

I visit Barry next. He's had two previous stays on 5B, once for treatment for PCP and once for a transfusion. We grew close during his first month-long admission and Barry feels like an old friend. He's been having headaches and he's worried about what's causing them. He's concerned that it may be cryptococcal meningitis. I sit by his bed, and he talks about his fears. He cries briefly and then quickly reverts to joking. He asks me for a back massage and he tells me about his trip to New Orleans last month. We agree to go up on the sunroof tomorrow if it's warm.

12:30 p.m.

The lunch trays have arrived. I decide to visit Gary, who's being treated for toxoplasmosis, a neurological infection which can affect mental capacities. Gary has been having trouble verbalizing. Gary greets me with his eyes and nods "yes" when I ask him if he wants help with his lunch. I wonder to myself if he's depressed. His lack of mobility must be a blow to such an active man. He acknowledges his sadness and frustration at losing some of his ability to care for himself. I let him know he's still a worthwhile person no matter what his capability of taking care of himself. He shows me some of his photography work. I help him with more of his lunch and then head for the cafeteria.

1:30 p.m.

After lunch I return a call from Laura, who is the first year medical resident taking care of Fred who I saw earlier. She has agreed to meet with Fred's parents later this afternoon and she would like me

to join her in that meeting. We agree to meet ahead of time to coordinate our approach to the family. The pain of family members, friends and lovers is very real and their needs for support and information can sometimes go unmet.

1:45 p.m.

I walk into Allen's room and touch his foot in greeting. He talks about his struggle with daily fevers and night sweats. His doctors have been unable to determine the source of his infection. He stayed on the cooling blanket most of the night and had a blood sample taken at 2:00 a.m. when his fever reached 103. He's exhausted, yet wants me to stay awhile. He talks about his anger and frustration and about his medical situation.

Allen has been using relaxation tapes every day and finds them helpful. I support him in his pursuit of stress-reduction methods. I do a 20 minute guided visualization with Allen and incorporate an image of cooling blue light. At the end of the session Allen sighs and looks at me with his big blue eyes. Allen talks about his feeling of being responsible for his fevers and illness. He relays how his friends "keep telling me if I change my attitude, I'll get better." He adds, "But I guess there is only so much I can do." I encourage him to let himself off the hook on feeling so responsible for his present situation. I feel I'm challenging Allen's views on the role of a positive attitude, but Allen responds well to this idea.

2:30 p.m.

I knock softly on Bob's closed door. I hadn't met him yet and I take in a slow breath as I wonder how he's reacting to being in the hospital. I find him to be friendly, scared and nervous, though eager to talk. Bob was admitted last night with shortness of breath and fevers. The bronscopy this morning confirmed the diagnosis of pneumocystis. Bob's first words were that he was more concerned for his mother than for himself. It was clear that he was in shock, yet becoming aware of how the diagnosis was going to change his life. We talked for a long time about how to tell his friends and family. Bob said he feared he might die but wanted to make the best of every moment he had. When I gave him a good-bye hug, he clung to me for a long time and thanked me for listening. I tell Bob how awed I am by his strength and ability to face what is happening.

I feel a lump in my throat as I leave and I feel sad that this

(Cont. Page 4)

TO FLO WITH LOVE

[EDITOR'S NOTE: Flo Elyon began her involvement with the Shanti Project in January of 1981 as a client. In attempts to give back to the Project the support she was given, she became a volunteer counselor. In March of 1982 she was elected by the volunteer body as Chair of the Board of Directors on which she served for over a year. In June of 1983 she became a member of the staff serving as Volunteer Coordinator.

Both as a board and staff member Flo has deeply touched the lives of those with whom she worked. She is deeply loved by us and we will miss her. However, we are happy that she has made the decision to further her growth by moving to Sri Lanka to continue studying meditation at a Buddhist monastery. We look forward to her return.

When asked to write about her involvement in Shanti, Flo submitted the following words of gratitude.]

As I lie awake in the most quiet hour of the night, searching through my treasure box of Shanti memories and experiences for something to share with you, what is most heartfelt in this moment is my deep gratitude. A gratitude that will last through the years. For the whole fabric of my being has been profoundly affected, and you will all remain as important threads among the many threads of a lifetime.

I honor and express my deep appreciation:

--to my parents Sidney and Phyllis and my sister Joyce for bringing me into this world with love and caring; whose deaths first brought me to the Shanti Project;

--to the many friends who helped me live through and heal from that period of intense grief, and who have become my new family;

--to Stephen and Andrea Levine who taught me about keeping my heart open in hell, and finding a path to my inner being;

--to Jim Geary for his continuous encouragement and faith in me, and for his joy and laughter;



Flo Elyon, retired. All of us at Shanti wish you well and look forward to your return.

--to Bobby Reynolds for his unconditional love and unparalleled contribution to people with AIDS;

--to the many clients I've worked with, learned from and been inspired by, for trusting me with their innermost feelings and sharing their journey with me;

--to the volunteers, staff and board of the Shanti Project for their remarkable work and their love, friendship and support.

--to all of you for your courage and commitment to go beyond your fears, to expand your personal boundaries, and bring such love into the hearts of so many people.

May you be filled with and surrounded by love and peace.

Flo



MEN BEHIND BARS

Men Behind Bars, a variety show and musical revue featuring San Francisco bartenders will be a benefit for Shanti Project and the San Francisco Band Foundation this year on President's holiday weekend. Three shows are scheduled; Sunday February 17th at 8:00 p.m., Monday, February 18th at 2:00 p.m. and Monday February 18th at 8:00 p.m. Tickets are \$12 and can be purchased at Headlines on Polk or Castro Streets in San Francisco. Men Behind Bars will be performed at the Victoria Theater at 2961 16th Street (between Mission and South Van Ness) and promises to be as entertaining and well received as last year's show.

A special Shanti thanks to Jim Cvitanich and Mark Abramson, producers of the benefit.

(Hour by Hour, Cont. from Page 2)

disease has stricken another vibrant man just beginning to settle into a career, home and relationship. As I wash my hands, I try to let go of these feelings. I consciously relax my body and take some deep breaths.

3:20 p.m.

I decide to see Don briefly. He's recovering well from his PCP and will be discharged soon. I was with him when he was first diagnosed and helped him deal with his intense anxiety. He now likes to regale me with stories of his days in Hollywood as a costume designer. He's an older man, with a sharp mind and a campy sense of humor. This has endeared him to all the staff. Being with him certainly lifts my spirits. He pokes fun at the hospital routine and complains about the uncomfortableness of his bed.

3:45 p.m.

It is time for my meeting with Fred's parents, Harry and Eloise. They are fundamentalist Christians from Arkansas, who clearly love their son but express some strong feelings around Fred's lifestyle. They are angry that Fred won't see a minister and are trying to cover up their anger to Fred. Laura and I encourage them to share their feelings with Fred as he probably is picking up their anger and wonders what it's about. Harry and Eloise do not want to share their feelings with Fred out of fear of upsetting him. They vent their anger and frustration to Laura and me. We empathize with and validate their pain and anger. We then focus on his present medical situation. Laura feels that Fred will recover from the PCP, and expresses her puzzlement over what is causing his stomach problem.

4:30 p.m.

I decide to return to Fred's room as he's due to leave for his test. He has decided to refuse the endoscopy. I support his right to make those choices around these diagnostic and treatment procedures. Laura joins the discussion and Fred explains his decision to her. Laura seems somewhat surprised but accepts Fred's decision.

4:45 p.m.

As I walk down the hallway thinking about the past hour, I see Tom being wheeled on a gurney to his room. He is just returning from U.C. Hospital where he is undergoing radiation treatment. I help his nurse get him back in bed. He complains about the bumpy ride in the ambulance and the wait in a chilly corridor for his treatment. He's angry, yet is still hopeful

that the radiation will help reduce his Kaposi's sarcoma (KS) lesions. I validate his anger and his hope. He's tired and wants some icewater and a foot massage. As I massage his feet, he talks about his career as a gourmet chef. Even through his tiredness, Tom manages to joke about the hospital food.

5:15 p.m.

I decide to go into the conference room for a short break. Five minutes later, Sam, a former patient, arrives. He looks great and has gained 25 pounds since he was treated for PCP six months ago. He's here to see Peter, who is a newly diagnosed patient and who wants to meet another PWA who is doing well. I introduce Sam to Peter and leave the two of them to talk.

5:30 p.m.

I return to the Shanti office to write up notes on my interactions with people I have seen so far. I look over my list of patients and decide to see Bill.

6:00 p.m.

Bill is sitting up drawing when I enter his room. Just yesterday he was experiencing some strong

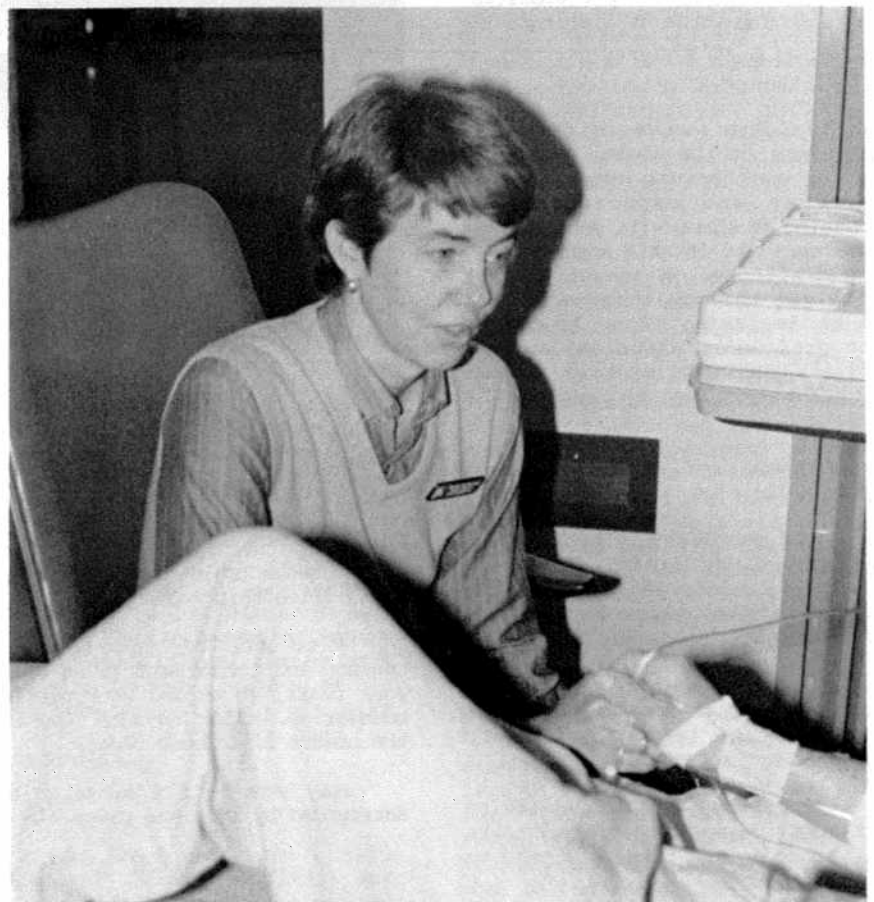
reactions to the chemotherapy he received for his lymphatic cancer. Bill is a tall, handsome, and confident man. He's struggling with allowing himself to shed tears over the incredible outpouring of love he's been receiving from his friends, lover and the staff of 5B. He is very proud of his identity as a man and he is making some changes in his image of what it means to be a man. He cries as he tells me about his lover's support and then apologizes. I tell him there is no need to apologize.

6:50 p.m.

I complete my remaining paperwork and decide to poke my head into Eric and David's room to say goodbye. I promise to see them tomorrow. They're doing well and are due to be discharged soon.

There is never any typical day on 5B. In the midst of our day we try to stay open to what Shanti has taught us, the communication of love which is often beyond words. It has been a privilege to share in the lives of everyone I have met today and I feel a mixture of sadness and joy as I leave the doors of the hospital.

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Sarah McPherson, one of seven Shanti staff counselors at San Francisco General Hospital offers emotional support to a person with AIDS on Ward 5B.

BROTHERLY LOVE

By Joe Bender and Kevin Conduff

As Shanti volunteers in the Practical Support Program, we are often awed at the expression of love between a person with AIDS and their loved ones. This is the story of two brothers. One, Mark, who had AIDS; the other, Don, who did everything he could to save his brother's life. To see Don go beyond his own sense of limits and do the extraordinary things that Mark needed and wanted during his illness filled us with wonder and admiration.

When Mark was diagnosed with AIDS, he immediately began a thorough, sometimes frantic quest to find out everything he could about what he might do to improve his health. After much research and consultation with his physician, he decided to go to Mexico to find out more about a dietary treatment that had been used to treat cancer patients. Mark spent 30 days in Mexico learning the theory and practical application of the special diet, which was designed to cleanse, and thus heal the body.

When Mark returned, he was steadily becoming weaker. His physician, while not wildly enthusiastic about the special diet, gave his blessing to its trial.

Although Mark was ready to begin the diet, he was not physically capable of the incredibly demanding regimen required to prepare the food called for. After a week, Mark realized he could not manage and called his brother Don who lived on the East Coast. Don, who was settled into a good job and comfortable home, quit his job, flew to San Francisco and "took over."

Don had known for some time that Mark was gay. He didn't, however, know anything about AIDS. Immediately, Don immersed himself in learning everything he could about AIDS so that he could help his brother regain his health.

For a couple of months Don tried to manage Mark's diet on his own. While the diet sounds simple (an 8 oz. glass of juice every hour on the hour from 8:00 a.m. to 8:00 p.m.), the preparation of the juice took extraordinary measures.

There were three kinds of juice; apple/carrot, green vegetable and raw baby calves liver. All vegetables and fruits had to be

organically grown and the calves liver fresh within three days. The shopping alone was a nightmare for Don.

Vegetables had to be purchased, washed in tap water, washed a second time in distilled water, put in a blender, wrapped in gauze and put in a press to extract the few precious drops of liquid for juice. It took literally pounds of Romaine lettuce to make eight liquid ounces and three refrigerators to hold a weeks supply of fresh organic produce. Three pounds of calves liver were required to make one glass of juice. Don was overwhelmed by the tasks. On top of laundry, cleaning and taking care of Mark's other needs, Don simply couldn't shop, wash, blend and squeeze fast enough. At the suggestion of some of Mark's friends who had been assisting Don as they could, Don called Shanti for help.



Randy, a Shanti Practical Support Program coordinator, put us in touch with Don who immediately put us to work. We began helping out twice a week for several hours at a time. Don continued to do the shopping and a significant amount of the food preparation. We were his helpers. We would wash, rinse, blend, wrap, press and squeeze for hours.

Don had everything superbly organized. The system he had worked out in the kitchen was a science. Each utensil had a certain spot and there was a specific way each task needed to be performed in order to conform to the specifications of the diet. Mark believed that each of these steps he had learned in Mexico were crucial and Don accepted Mark's beliefs without questioning. We accepted them too, and remember thinking more than once, "God forbid that this man should relapse because we didn't rinse something".

Don was so loving and protective of Mark. We were there three times before we were invited to take Mark's tray into his room. His bedroom was the inner sanctum, the holy of holies. You had to remove your shoes before going in because Don was afraid dust would aggravate Mark's lungs, which were weakened by pneumonia.

It wasn't long before Don's trust in us grew and we began to spend more time with Mark. We would bring Mark his favorite weekly papers and he would question us about where we had gone that weekend. He wanted to know what restaurants we had eaten at, what movies were playing and what was happening in the community. This time spent with him helped to ease his sense of isolation.

We were concerned about both Mark and Don. Everything that could be done for Mark was being done and yet he still was getting weaker and weaker. Don, at first, refused himself any time away from Mark and the herculean task of taking care of him. As time progressed, however, we were able to persuade Don to get out of the house a little. He treated us like family and we became equally fond of him. Occasionally, he would bring a girlfriend home for introductions and coffee. Most of these informal gatherings passed uneventfully, but one unfortunate woman walked into the kitchen just after we had ever so slightly overloaded the press with raw baby calves liver. The press had blown up under the pressure and just as Don and his date walked in, we were scraping little red bits and pieces of mangled calves liver from our hair as the rest dripped from the ceiling. It was not a pretty picture. Don quickly escorted her through the kitchen to the back porch to show her the three refrigerators full of organic veggies. She never seemed to recover from the whole thing. We didn't see her again.

After several months of the special diet, it became evident that Mark was not benefiting from it and he decided to abandon it. We felt a mixture of sadness and relief. Sadness that the diet had not done what Mark had hoped and apprehension that there were not any other viable alternatives. We also felt relieved that Don's load would be lessened. Don stayed on, looking after Mark and his needs. He would bathe him,

(Cont. on Page 6)

Honoring Another's Truth

By Jim Geary

Something I have always highly regarded in Shanti has been its views and approach in working with the spiritual beliefs of both its volunteers and clients. In essence, Shanti volunteers are taught to honor the religious beliefs of their clients and to work on client issues within the client's belief system. For example, if a client fears hell, yet the volunteer's belief system doesn't include a hell concept, our volunteer's counseling approach might include encouraging the client to express his or her fear of eternal damnation and feelings of guilt. Exploring how within the client's belief system he or she could seek forgiveness and attain peace may follow. Another example might involve a client who doesn't believe in an afterlife and a volunteer who has a strong belief in reincarnation. In this situation, the volunteer's goal does not become "saving" the client from a belief system but to accept the client's belief as chosen and true for the individual. If the client desires to explore any issues relevant to his or her beliefs, then the volunteer may help to provide that avenue.

In the last ten years there has been much written about death and dying. Much of it has centered around life after death and the "positive transformative" experience that dying offers us. I have observed how the dying process only recently hidden is now sought by those who feel that they will gain something from participating in it. I readily admit that my own self development is a principal motivation for my doing this work. I feel many volunteers enter this work to gain a fuller knowledge of themselves, to confront their own fear of death, and in hope of capturing the essence of life's purpose. This in itself is well and good. The problem results when volunteers' expectations of the experience deprive them of simply experiencing what is.

I have found that in my work with clients my own spiritual beliefs are immensely helpful. I feel my spiritual beliefs help prevent burnout while allowing me to open to suffering; it follows that if our beliefs give us balance, then our clients, benefit by how we manifest our truths. However, we need not share our beliefs verbally for our clients to be benefited.

Letting go of any agenda as to where our clients should be spiritually allows us to enter our client's world without expectations and judgment. From this place effective communication follows.

In regards to my own changing spiritual beliefs, I had a very painful yet growthful experience two years ago. At that time, I witnessed the physically painful and disfiguring death of a client. I had known Jerry for about six months and we had built a close friendship. I spent much of the last 48 hours of his life by his bedside and witnessed his immense physical deterioration and opened to his total lack of understanding as to why this was happening to him.

After his death I experienced much rage and aimed much of it at myself. I felt stupid for having believed in a compassionate God that could allow such incredible suffering. I ripped up my "holy pictures" and told my friends that I no longer believed in anything. Fortunately, although my friends were concerned, they didn't try to rescue me, or attempt to rebuild my shattered belief systems, or to argue philosophical and/or spiritual perspectives. Instead my friends heard my hurt, and validated that it was understandable that by opening to such suffering my beliefs would be challenged. They gave me permission to let go of my beliefs and begin anew. My friends still maintained their belief in a loving God but their belief did not prevent them from opening to and even learning from my experience.

The total acceptance that my friends gave me to feel this void was exactly what I needed. For, in retrospect, that experience has strengthened my belief -- not in a God outside of myself but of a power within. A power within me which can open to incredible suffering and not pull away. What I had wanted was a God outside of myself that would not allow suffering. Yet, what I found after painful months of soul searching was the extraordinary ability within us to look into the face of suffering, of what is, and despite God's seeming inaccessibility and lack of caring, for us to remain accessible, loving and willing to continue caring.

I am committed to maintaining the integrity of honoring our clients' beliefs at Shanti. I have

observed how other projects serving persons with life-threatening illness struggle with these issues sometimes erring by attempting to present death in a particular light. I feel this not only narrows the clientele they are able to serve but also narrows those serving. Imposing our own beliefs prevents us from entering an experience in which essence and gifts are borne by laying aside any preconceived ideas and opening unconditionally to another's truth.

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Love, Cont. from Page 5

feed him, read to him and talk to him by the hour. As Mark worsened, it became more difficult for all of us to see his pain.

Our role as Shanti Practical Support volunteers changed also. Instead of helping in the kitchen, we visited weekly to see Mark and Don and to clean the two story Victorian house that was their home.

Mark died on Labor Day, 10 months after Don arrived to care for him. At the funeral, we were treated like family -- hugged appreciatively and lovingly. Mark had lived long enough for his father to arrive and say goodbye. His Aunt Edna and Uncle Carl were there to share their grief and to be with Don.

Don told us that he was going to miss Mark but was relieved that he wasn't going to hurt anymore. As he was talking to us, we were both thinking of how much he had left back East to be there for Mark and how very much Mark had loved him.

Mark is at rest now and Don has the peace that comes from knowing you were there for someone. Their brotherly bond inspired us and we feel privileged to have been part of this remarkable family and to have shared in their love.



The Shanti Staff provides support to 250 Shanti emotional and practical support volunteers as well as direct services to persons with AIDS and their loved ones. Pictured above: (L.toR., standing) Stan Roberts, Residence Manager; Charles Herrington, Office Manager; Bev Flynn, Asst. Finance Manager; Jim Rulon, Public Affairs Officer; Rik Isensee, Clinical Consultant; Daniel Brewer, Van Driver; Bea Tracy, Clinical Coordinator; Steve Lessure, Practical Support Coordinator; Michael Fiorentino, Residence Program Secretary; Linda Maxey, Counseling Coordinator (SFGH); Helen Schietinger, Director AIDS Residence Program; Paul Shearer, Counselor (SFGH); (L.to R. center) Jim Geary, Executive Director; Jan Boddie, Counselor (SFGH); Andrew Lewallen, Volunteer Coordinator; Robin Johnson, Volunteer Coordinator; Randy Chelsey, Practical Support Coordinator; (L.to R. front) Ed Brophy, Counselor (SFGH); Andy Bowlds, Information and Referral Receptionist; Flo Elyon, Volunteer Coordinator; Jess Randall, Finance Manager; Christopher Couzens, Office Operations Assistant. Staff members not pictured are Daniel Barnes and Sarah McPherson, staff counselors at San Francisco General Hospital.

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 _____
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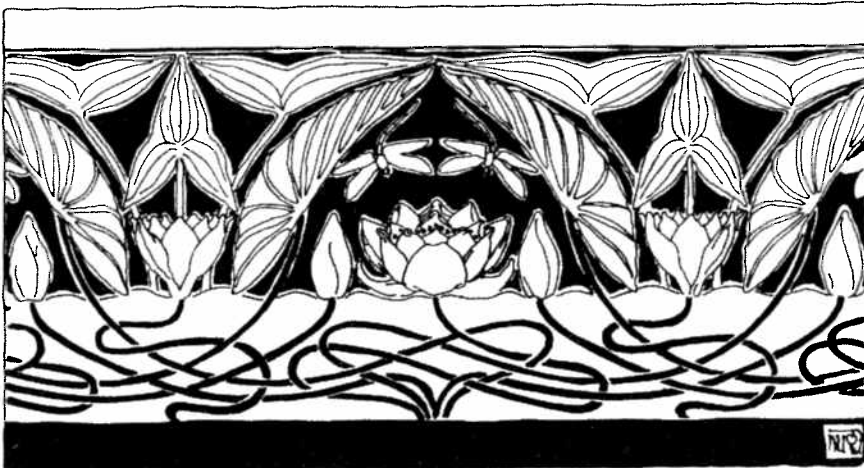
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SHANTI VIDEOTAPES

The Shanti Project is proud to announce the availability of our complete volunteer training program on videotape. Videotapes of the training program can be used by any group wishing to start an organization to provide volunteer counseling to people with AIDS, their loved ones and friends. These training materials are designed to be used both as a resource by the organizers of a new group and in the training of volunteer counselors.

For more information about the Shanti training videotapes, call the Shanti Project office at 415/558-9644.