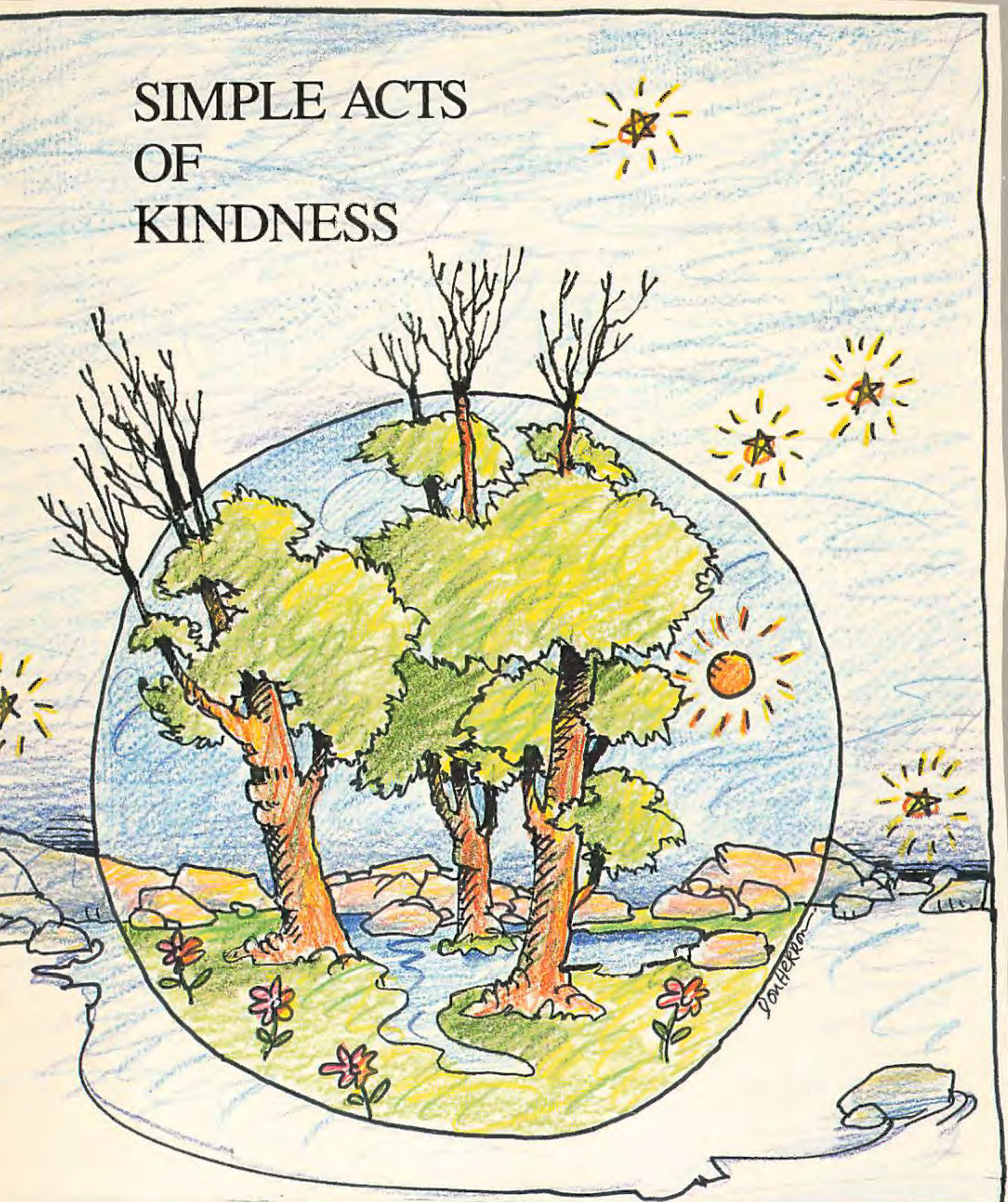
SIMPLE ACTS OF KINDNESS



VOLUNTEERING IN THE AGE OF AIDS

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"In the depth of winter, I finally
learned that within me there lay
an invincible summer."

—Albert Camus

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IN THE AGE
OF AIDS

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UNITED HOSPITAL FUND OF NEW YORK

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Preface

Volunteers have been important to and, in many cases, a vital driving force behind society's response to the growing healthcare and social challenges of the AIDS epidemic in the United States. The contribution of community-based, largely volunteer organizations in the epidemic of acquired immune deficiency syndrome (AIDS) and other illnesses related to infection with human immunodeficiency virus (HIV) cannot be overestimated. Indeed, in the early years of the epidemic, when governments and social agencies in the United States responded slowly or not at all to the growing health crisis, it was organizations of volunteers that took the lead in providing advocacy, counseling, education, and support networks.

In the beginning, as Carol Levine points out in her introduction to this book, these AIDS volunteers came mostly from the gay community, the group that was initially the most heavily affected by the epidemic and that provided much of the impetus for the creation of new community organizations to assist people with AIDS (PWAs) and people at risk. Organizations like the Gay Men's Health Crisis, in New York, and the San Francisco AIDS Foundation, in that city, were created to provide education and services where little or none existed. As the dimensions of the epidemic have continued to reveal themselves and a widening spectrum of people see themselves affected by AIDS, volunteers increasingly come from all groups and all walks of life. The number of organizations has grown in step with the epidemic, and, according to health economist Peter S. Arno, by 1988 there were more than 300 AIDS-related groups around the country, most relying extensively on volunteers, providing hundreds of thousands of hours of volunteer labor annually. The economic contribution of these volunteers may be calculable in some fairly simple arithmetic terms. The human contribution is quite simply incalculable, but no less tangible, in terms of comfort, compassion, and support to PWAs and volunteers alike. Mere numbers cannot tell all.

In recognition of the contributions of AIDS volunteers, and in keeping with that part of its mission that involves promoting health care voluntarism, the United Hospital Fund sponsored a conference, "AIDS and Volunteers," in New York City, on April 30, 1988. The purpose of the conference was to provide a forum for volunteers to discuss their responses to the epidemic and share their experiences. A number of the presentations at the conference were recorded, transcribed, and expanded, and became the basis for this book.

In Part I, several AIDS volunteers talk about what motivated them to become involved in volunteering and what their voluntarism has meant to them.

Phyllis Townley, in Chapter 1, describes a series of relationships formed with PWAs in the course of her work as a chaplain's aide volunteer in a major municipal hospital center. In Chapter 2, James H. Sugarman, discusses both the motivation behind his AIDS voluntarism and his experience as a "Friendly Visitor" at a large voluntary hospital. He also shares a list of volunteer *do*'s and *don't*'s he has compiled over many years as a volunteer in a variety of settings. In Chapter 3, Kenny Taub, a PWA himself, talks about coming to terms with an AIDS diagnosis, learning to live and work within that context, and finding both empowerment and hope.

The plight of hospitalized, often abandoned infants with AIDS and the powerful effect of simple, loving human contact are the focus of Charles Goggan's work in a pediatric service, described in Chapter 4. And Mildred Pearson's account, in Chapter 5, of how she and her family cared for her AIDS-afflicted son during the last months of his life is a moving story of courage, determination, and love.

In Part II, five model AIDS volunteer programs are described in terms of their development and how they recruit, train, and support their volunteers. In Chapter 6, Yannick Durrand relates how the Brooklyn AIDS Task Force managed a significant breakthrough in community AIDS education by using the talents of young people in its outreach efforts. Michael Bertish describes, in Chapter 7, how volunteers are employed, cultivated, and managed by God's Love We Deliver, a community-based program that delivers home-cooked meals to homebound PWAs. Volunteer teamwork in a municipal hospital's AIDS chronic care unit is Bob Sinnaeve's subject in Chapter 8, and the development of a volunteer program as a joint effort of voluntary and municipal hospitals, focusing on methadone clinic clients, is described by Bridget Poust in Chapter 9. In Chapter 10, Virginia Crosby relates what developing an AIDS-related "Friendly Visitor" program entails for a hospital volunteer director, including both the pitfalls and the rewards.

Next, readers who are interested in AIDS volunteer opportunities or wish further information about these programs will find guidance in Part III, Volunteer Opportunities.

Although the title of this book refers to "simple" acts of kindness, in that the commitment of these individuals and other volunteers springs from the simple human emotion of caring about others, the activities described in the following pages are anything but simple, and the experiences related here represent but a small sample of what is taking place as a variety of citizens respond to their fellow human beings in time of need. While these examples of voluntarism are unique in the individual sense, the contributions they describe have been replicated thousands of times in many other settings and situations.

The unfolding story of the AIDS epidemic continues to be a grim one indeed, and certainly not all of the social responses AIDS has elicited have been compassionate, honorable, and humane. But the accumulating examples of individual and group altruism, such as those recorded here, constitute moving testaments to the best instincts of humankind. In themselves, they give us hope.

JOHN GRIGGS

Acknowledgments

Several members of the United Hospital Fund staff deserve recognition for being instrumental in the genesis of this project and in bringing it to fruition. They include Deborah E. Halper, Director of the Division of Education and Community Services, and Ellen F. Fralick, Director of Voluntary Initiatives, who, assisted by conference coordinator Brenda Lamb and staff associate Debra Brown, organized the conference, "AIDS and Volunteers," on which the book is based.

Appreciation is also expressed to David A. Gould and Sally J. Rogers, respectively vice presidents for Program and Communications, for their invaluable editorial comments and guidance at various stages along the way.

In addition, thanks are due to editorial consultant Carol Ewig, whose keen sense of style and editorial expertise were indispensable in bringing this volume to its final form.

Finally, but not least, appreciation is also expressed to the American Foundation for AIDS Research, which provided grant assistance to make this publication possible, and to volunteers everywhere.

Introduction

CAROL LEVINE

Carol Levine is executive director of the Citizens Commission on AIDS for New York City and Northern New Jersey, a private citizens' group established in 1987, with funding by a consortium of 15 foundations, to explore the complex range of non-medical issues facing society in the bistate region as a result of the AIDS epidemic. Before joining the Commission, Ms. Levine was on the staff of the Hastings Center, a nonprofit research and education institute in the field of medical ethics, where she was co-director of the Center's AIDS projects and editor of the Hastings Center Report.

Even before AIDS had a name, there were volunteers to respond to it. As soon as it became apparent that a new disease was taking a fearsome toll in the gay communities of New York City and San Francisco, volunteers from those communities organized to provide care, education, emotional support, and political action. In New York, the Gay Men's Health Crisis, now one of the largest social service agencies in the city, began in 1981 as a small group of committed volunteers.

For several years, however, the volunteers in the gay community stood almost alone. In the recent past, that situation has changed. There is a growing sense of mobilization within agencies and on the part of individuals who have come to realize that AIDS and HIV infection are not going to go away.

New organizations are forming; older, more established organizations are exploring ways to respond that incorporate both their original mission and these new challenges. In this new spirit of mobilization, volunteers have a special role to play. The contributions to this book describe some of the many ways in which volunteers are making a difference in the lives of persons with AIDS (PWAs) and persons with HIV infection.

VOLUNTEER ACTIVITIES

These personal accounts document in concrete yet moving ways the enormous importance of simple acts of kindness. When someone is ill, the little setbacks in life—things that one ordinarily can shrug off as minor irritations—become overwhelming. And the small things that people do to help become even more important. A courtesy, a kind word, a thoughtful act—all these assume a significance to the person who is ill that may far outweigh the meaning to the actor.

The book also portrays the wide range of volunteer activities—from preparing meals to acting as advocates to fund-raising for organizations, and more. Many activities involve direct contact with clients; others, equally important, involve assistance to the organizations so that they can better provide client services.

The activities described by these participants illustrate what volunteers can do but do not exhaust the possibilities. For example, as executive director of the Citizens Commission on AIDS for New York City and Northern New Jersey, I work with a committed group of volunteers. The Commissioners, prominent citizens in the fields of business, law, education, journalism, and social service, are working together to stimulate private sector leadership in responding to AIDS. And I, too, am a volunteer—as a member of the Institutional Review Board of the Community Research Initiative in New York City and as a member of the Scientific Advisory Committee of the American Foundation for AIDS Research. The possibilities for volunteering are broad indeed.

VOLUNTEER NEEDS

Another theme of this book is the needs of individual volunteers. They clearly need to be well trained, and some of the accounts describe good training programs. Volunteers also need to confront their own attitudes about sexuality. And there is a growing need for volunteers to confront their attitudes about drug use and to learn about the methods of drug treatment and the coping mechanisms that drug users develop.

Volunteers need to feel competent. They need to understand the boundaries between volunteers and professionals and between volunteers and clients. They need to be given appropriate roles and clear definitions of their place within the organization. They need assignments that are within their capabilities, with training provided as needed.

Volunteers need to be rewarded. Organizations should create ways to acknowledge the contributions of their volunteers, whether it is in terms of formal recognition or just an informal thank you for a job well done. The simple acts of kindness that mean so much to clients also mean a great deal to volunteers.

Volunteers need to share their experiences. They can benefit from sharing within their own organizations and with others who perform similar tasks and also in forums with volunteers who do very different kinds of jobs.

ORGANIZATIONAL NEEDS

Organizations that use volunteers also have many needs. Clearly, they need more funding. But they also need support in building the administrative structures that will enable them to use that funding well, to develop sound fiscal policies, skillful public relations capabilities, and creative fund-raising programs.

Volunteers can help in these areas as well as in direct client contact. They can help build organizations that can serve clients better and also attract more volunteers. Nothing turns away volunteers more quickly than an organization that is managed haphazardly. People who give their most precious gifts—their time and their energy—want to feel that these gifts are not being wasted.

RECRUITMENT

Although there are many success stories in this book about volunteer recruitment, more innovative techniques are needed. Volunteers should be matched with appropriate organizations and assignments. There may be a role for a volunteer clearinghouse, so that a person who is not comfortable with a particular setting may find a more congenial organization. More volunteers should be recruited from low-income and minority communities, and from groups such as senior citizens and adolescents. Grandparents whose own grandchildren live far away may find working with young children particularly rewarding; teenagers may be able to give a special kind of emotional support to people their own age.

Although volunteers by definition are unpaid, a special category of "volunteer," one who is paid or at least reimbursed for expenses, may make it possible for additional people to enter the system without asking them to make considerable financial sacrifices.

CIVIC CONCERNS

Volunteers can become political and fund-raising advocates for their organizations so that the organizations have the resources to hire professional staff and provide expanded services. Volunteers can become educators to their families, friends, colleagues, and communities. They can help create the kind of informed citizenry that will finally draw the attention of political leaders to the enormous gaps in resources.

When Alexis de Tocqueville visited America in the eighteenth century, he was struck by the difference between American and European approaches to meeting social needs. In the Old World, either the government or the aristocracy was expected to solve problems; in the New World, where there was no institutional authority that everyone could turn to for sustenance, people, often ordinary citizens, organized in democratic associations to help themselves. Today, in a more complicated world, all of us, in both our professional and volunteer capacities, need to pay greater attention to the political process, to see that government does its share and does not abrogate its problem-solving responsibilities to the private sector.

And while volunteering should be encouraged, we should be cautious about the risk of creating a system in which public responsibility is not fulfilled because volunteer labor is presumed to be available to meet social needs.

Nevertheless, the volunteers whose stories are captured in this volume have drawn on a great American tradition. They should inspire others to join them in meeting one of the greatest social challenges of our time. ❑

Part I

VOLUNTEERS TALK ABOUT VOLUNTEERING

Volunteering is really about relationships. . . .
I brought a Jackson and Perkins rose catalog, and we chose some new plants Peter would never see.

Chapter 1

Let Me Tell You about Rubens

PHYLLIS TOWNLEY

Phyllis Townley is a chaplain's aide at Bellevue Hospital Center, a facility of the New York City Health and Hospitals Corporation. Ms. Townley has been a volunteer at Bellevue for 15 years and has worked in a number of departments there. She began working with people with AIDS in 1982.

Volunteering with persons with AIDS is really about relationships, and what I do as a volunteer at Bellevue Hospital basically reflects that reality. People meet as strangers and become friends at a time when at least one of them is most vulnerable and in a space that can dehumanize and devalue any individual, diminishing an often already fragile sense of self-esteem and fostering or reinforcing feelings of rejection and helplessness.

My role in the hospital as a Chaplain's Aide is to affirm life, to assure people that they are loved and valued, and that they are not alone. My own greatest assets that I can give are my time and my presence, especially in a large city hospital where severe staff shortages and overwhelming workloads are stretching resources, particularly human resources, to their limits. Why am I doing this? Let me tell you about Rubens.

RUBENS

Rubens ("as in the painter," he always reminded me, "be sure and put the 's' on the end") had more than his share of suffering. He came to New York City from Brazil when he was a teenager, after his parents separated, and he was soon drawn into the drug scene here, supported by rich friends who were attracted by his wit and charm. But when Rubens became ill with AIDS, they were sorry but they had other concerns. So, without resources or friends, Rubens came to Bellevue as a last resort.

When I met Rubens, he was filled with shame and self-disgust, feeling that he had wasted his life and misused his extraordinary talents and intelligence. In Bellevue, he was isolated in a room far from the nursing station and without visitors. Even his contact with hospital staff was limited to the bare essentials, and, at that time, around 1985, it was not unusual for dietary staff, fearful of entering the room, to leave food trays outside the door. Housekeeping staff, too, minimized their contact with Rubens and, as a result, his room was filthy. But he tried to clean it as best he could while he had the strength. He struggled every day to maintain some dignity in the midst of all his deprivation.

I visited Rubens often and we shared both laughter and tears. As the disease slowly progressed, he felt humiliated when he began to lose control of his bodily functions and his mental faculties, too. He talked of his fears, but he never lost his sense of humor.

One day, I arrived to find Rubens dazed and with a huge bruise on his forehead. He saw my look of obvious distress and laughed, explaining that he had become dizzy and fainted in the bathroom, hitting his head as he fell.

"Well," he said, smiling, "what a way to go. Can you imagine? After 'cause of death,' they would have to write 'head trauma resulting from violent contact with toilet seat.'"

What could I say? I just hugged him and said, "Rubens, you are marvelous." He never lost that vital spark, and I thanked him often for sharing it with me.

Once, during the time I visited Rubens at Bellevue, it was arranged for his mother to come from Brazil to visit him, after 15 years. Rubens's reunion with his mother was unforgettable. In his perfect English, he blushingly acted as interpreter as I told his mother what a wonderful son she had and how she should be proud of him. And I tried to reassure her that he was being looked after and cared for. She thanked me in Portuguese, and we all embraced.

Not long after that reunion, Rubens died. The nurses told me he just drifted off.

In all the time I knew him, despite his illness, I felt that Rubens was the strong one. On one occasion, when he was briefly discharged from Bellevue to a sleazy fleabag single-room-occupancy facility called the Terminal Hotel, it was Rubens who could articulate the irony of it all. I was shocked and speechless, but, "after all," he said, "aren't we all terminal?"

Of course, he was right. We are all in this life together and that is why we help each other out.

MY INTRODUCTION TO AIDS

It was a great privilege to have been trained as an Interfaith Chaplaincy volunteer at Bellevue by the Reverend Mead Bailey, who was my supervisor until he died, and also a dear friend. He was a Bellevue chaplain and one of the founders of the AIDS Resource Center. Bailey House, a health-related facility for persons with AIDS in New York City, is named in his memory.

In the fall of 1982, Reverend Bailey asked me if I would represent the chaplaincy in the oncology clinic. And it was there that I first met people with AIDS, when they came to receive treatment for Kaposi's sarcoma. So, in meeting them when they were relatively well, helping them cope with the complicated clinic system, checking on their immediate needs, and making referrals or just chatting to fill in the long hours of waiting, I made early contacts. Naturally, I followed their progress as inpatients, and it was usually later, in the hospital, that there was time for relationships to grow.

PETER

When Peter came to the oncology clinic, it was clear that he did not welcome opportunities to socialize. He sat apart, buried his head in the *New York Times* crossword puzzle, went through the necessary medical procedures, and left.

But Peter's lover, Charlie, who also came to the clinic, was more outgoing. And he was the one who told me about their turbulent relationship, which was deteriorating rapidly under the stress of their common illness.

Gradually, Peter began to talk to me about "safe" subjects. He told me that he came from Massachusetts, and it happened to be not far from where I myself live. Then I could understand better his need to be independent, his laconic, almost black, sense of humor, and his Yankee self-reliance. We shared our love of classical music, cats, and the New England seacoast, but feelings were carefully avoided.

"Don't," Peter cautioned me, "try to talk religion—if you plan to."

I assured him that I didn't and I wouldn't.

Predictably, Peter accepted AIDS with a kind of stoic resignation. When he was admitted as an inpatient, I went to visit. All he wanted was a coffee milkshake made the special way they make them in New England.

Peter loved to play cards. I was terrible at cards, and he teased me unmercifully. He also delighted in telling me I was growing my roses all wrong. He and Charlie had a small roof garden over a laundry in Chelsea [the West Manhattan neighborhood just north of Greenwich Village] and, from the pictures he showed me, their plants *were* spectacular. But I insisted that it was all only because of the steam from the laundry, so comparisons weren't fair.

Thus, Peter and I became friends, and he began to share some painful feelings. But he still allowed very few to surface. At times, he could be bitterly sarcastic and seemed to need to hurt me. He also seemed to trust that I would understand and not reject him.

After Peter's discharge from Bellevue, he and I kept in touch by telephone. Meanwhile, I saw Charlie in the oncology clinic, and he told me things were horrible for them both, and there were quarrels and threats to leave.

Then, one day, Peter was taken by ambulance to St. Vincent's Hospital, in Greenwich Village, and he asked me to come and visit. There, I sensed a change immediately. Peter's characteristic reserve and defenses were breaking down. He told me that he had contacted his family in Massachusetts and wanted to go home, but he knew it was impossible. He also gave me messages for Charlie, things he couldn't say for himself.

One night, Peter telephoned and said abruptly, "Well, I suppose you'll be pleased, I saw a priest today. Don't ask me why. But it will make my mother happy anyway." And then, more quietly, he said, "The strange thing is I feel much more peaceful with myself, now." Then, "See you tomorrow."

The next day, Peter was in great pain, but he never complained and tried to reassure me that he was all right. He had a milkshake, as usual, but playing cards was too much effort. We looked through a Jackson and Perkins rose catalog and Peter chose some new plants he would never see. I helped his nurse change his dressing and rubbed his back. Peter was exhausted, and said so. And then I left.

When I returned, as promised, several days later, Peter's room was empty. But that summer I met his sisters in Massachusetts. It was very healing for us all—and it helped to tie up some loose ends.

COPING WITH DEATH

In the hospital death is the enemy. But we must all come to terms with it in our own way, and, meanwhile, live life as fully as we can.

The search for meaning—Who am I? Why am I here?—is universal, yet unique for each person. I feel my responsibility to myself and to my friends with AIDS is to be sensitive to my own feelings and fears about death, loss, and suffering, so I can be open to others.

My first encounter with the death of someone I cared for deeply at Bellevue was a disaster. I refused to deal with it.

I even challenged Reverend Bailey. "I know you expect me to talk about Michael's death. Well, I can't and I won't."

With his infinite patience and wisdom, Reverend Bailey told me, very gently, that it was okay.

For a few days, I was hyperactive. Doing anything, so I wouldn't think or feel. I was no good to myself or to anyone else.

Then I met a social worker who was also close to Michael. And we recognized our common need. I went to her office and we talked and cried together, and comforted each other. I was finally able to let go and allow my grief to be expressed.

Every single death is painful, but since that first experience, I've learned a lot about what clinicians call "coping mechanisms." Coping mechanisms are very personal and cannot be taught, only learned by experience. I learned that, finally, I must rely on my own spiritual resources. And, in realizing this, I respect the same personal process in others.

My role is to be open and supportive, all the time affirming the patients' dignity, their integrity, and their freedom to make choices about how to live with AIDS, of which death is a part.

Twice, I have been called to be with a dying person because, for different reasons, their loved ones could not be there. This was a tremendously moving experience for me—and a great gift.

HERMAN

One of the hardest things to learn is how to deal with helplessness. Herman and I taught each other.

In the clinic, there is always something to do, someone to talk to, some help that someone needs. As an outpatient, Herman was a favorite of everyone. He had a gentle, disarming smile and was always "up," so that seeing him was always nice for us.

Then, Herman became very ill with *pneumocystis carinii* pneumonia and was admitted to Bellevue. I visited him often and, when he became too weak to eat alone, I timed my visits to coincide with lunch hour, so I could feed him.

But from a lively and outgoing person, Herman became fearful and withdrawn. However, he could express his anxieties to me, anxieties which were more directed to the process of dying than to death itself. And I have found this to be the case very often when people talk to me about death.

When Herman told me that he felt "so useless," I understood, because that's the way I felt sometimes myself. But, "no," I said, "you are never that, never useless. Every time you say 'thank you' to your nurse and give her your wonderful smile, believe me, you make her day."

When Herman could no longer even eat, he liked me just to sit by his bed, say a prayer, and hold his hand until he could go to sleep. There was nothing else I could do or say anymore. However, Herman knew he was not alone.

At times I feel it is important to share my own sense of helplessness with the patient, and we are both freed by this honesty.

Certainly, there are a lot of things that can be done. One patient claimed he was kept alive by quantities of lime Jello, which I brought regularly. But even small acts of service like these are not a substitute for just listening or for simply being there.

SUPPORT FOR VOLUNTEERS

Sooner or later, everyone involved in volunteering seems to experience a sense of burnout to some degree or other. Symptoms of burnout—emotional fatigue, feelings of futility, or a numbing depression—signal me that I need to do some work on myself. Perhaps the physical demands of volunteering have been too great, and some rest and recreation is in order.

At Bellevue, we have a volunteers' support group, comprised of volunteers and chaplaincy staff, that is essential for me. The support group gives us a chance to relieve emotional stress, share our joys and our griefs, and reflect on what we do.

Once, I found myself at a patient's door, paralyzed and unable to face anymore of his suffering—or anyone else's. I was embarrassed and ashamed about this, but I was able to talk it out through the support group.

Guilt after the suicides, anger at injustice and indifference, conflicting obligations and responsibilities—all these, the usual stresses and some unusual ones, can be dealt with in a trusting atmosphere encouraged by mutual support. Fortunately, for me, there is always someone at Bellevue who is ready to listen. And most important, I do not neglect my daily quiet time, time to become spiritually centered and to learn how to listen and hear what others are telling me.

My other involvements, the AIDS Committee of the Community Board at Bellevue and the United Hospital Fund's City Hospital Visiting Committee, provide opportunities to address issues of patient care, which are very important to me. I stay informed about the politics of AIDS and clinical developments, as well as outside services in the community. Conferences on care giving, intensive training weekends, in-service education, and personal study offer ways to focus on helping skills. And, finally, I have a husband who understands my commitment.

Every volunteer will identify their own needs and should find a support system to meet them. Basically, I think burnout concerns the recognition and acceptance of our human limitations—and AIDS is a relentless reminder that we can never do too much. But, at the same time, I think every small act of service is enough, if it is all that we can do. Somehow, there seems to be an awareness that we are part of something larger than our own lives and efforts.

REWARDS

David was in Bellevue for many months. His family seldom visited and he had few friends. So David's life revolved around his care givers, both staff and volunteers, who gave him encouragement and support.

Not long ago, David was discharged. Before leaving, he said to me, "I had to get AIDS to find out that people could love me just for myself." ❑

WE, AS VOLUNTEERS, HAVE TO REMAIN VISIBLE, HAVE TO STAND OUT FRONT.

Chapter 2

Reaching Out

JAMES H. SUGARMAN

James Sugarman is director of the Retired Senior Volunteer Program (RSVP) of New York City, an organization with 10,000 volunteers over the age of 60. An AIDS volunteer for several years, he also has worked as a volunteer in public schools, hospitals, and nursing homes, as well as assisting new refugees, the homeless, and the homebound elderly. Mr. Sugarman is currently a volunteer with the Friendly Visitor program for AIDS patients at St. Luke's-Roosevelt Hospital in Manhattan.

Recently, on television, I saw an old movie that took place in the Caribbean during World War II. It was a terrific movie, *To Have and Have Not,* with Lauren Bacall and Humphrey Bogart. In the movie, Bogart, as "doctor," enters a room to perform surgery, to remove a bullet, and save someone's life. It's a very exciting scene because the person whose life he is going to save is a heroic member of the French resistance.

All of a sudden, Bacall walks into the room behind Bogie, and the girlfriend of the man Bogie is trying to save looks at Bacall and says, "Well, who are you?"

And Bacall answers, "I'm just a volunteer."

Well, I was outraged when I heard that statement. It is often interesting to hear people's attitudes and ideas about community service, but the concept, "I'm *just* a volunteer," is one with which I have a lot of trouble. It reminds me of hearing women say, a few years ago, "I'm just a housewife." Being a volunteer—or, for that matter, being a housewife—involves, as any volunteer can tell you, quite a bit more than that simple phrase suggests, particularly during this time of AIDS.

I returned from a vacation not long ago and found, on my answering machine, a message telling me that another friend had died. After about 25 deaths of friends, and having faced as well the death of a close relative last summer, who died as the result of AIDS from a blood transfusion, this message was like receiving a telegram during a war. A telegram reading, "This is to inform you . . .," and telling me very clearly that a loved one had passed away. And it was a significant message, telling me that family, neighbors, friends, members of my extended family, people I knew and cared about, were suffering with AIDS and were passing away. It reminded me why I became a volunteer.

BECOMING A VOLUNTEER

About five years ago, when the scope of the AIDS epidemic was just beginning to make itself known, I decided that I had to do something. I knew that I did not have the funds to carry out great philanthropic work or the medical knowledge to go out and do research, so I decided to become an active volunteer.

However, I felt that I needed to acquire a knowledge base before I could begin volunteer work. I felt that that knowledge would be very important for me as a volunteer. I went to the Gay Men's Health Crisis (GMHC) and became involved in their community education outreach program.

On the whole, it was a very positive experience. GMHC provided excellent volunteer orientation and training. I had a very good supervisor, and I learned a great deal about AIDS and community education. But there were other, less positive, dynamics that need to be mentioned as well.

Volunteers in GMHC must go through an interview process. After I made my desire to become a volunteer known during the preliminary interview, I was told that someone would get back to me about it. But no one ever did. From my professional work, I know that that sort of thing is a cardinal sin in managing a volunteer organization. But I do not think, in GMHC's case, that it was necessarily reflective of the organization's attitude toward volunteers but more reflective of the fact that, at the time, GMHC was being overwhelmed by prospective volunteers and still getting the kinks out of its volunteer intake and placement processes.

As I believed in my mission—and GMHC's—I decided to persevere. That was and will probably always remain important for volunteers. If you are going to become a volunteer or motivate other people to volunteer, you must underscore the word *perseverance*. This is particularly true in an area such as AIDS volunteering.

COMMUNITY EDUCATION

After orientation and training, I began serving as a volunteer handing out literature and talking to people about AIDS on the streets of Greenwich Village and East Harlem. I worked with a team of one or two other volunteers at a folding table, where we distributed information and spoke to people who were interested. Each Saturday, we spent anywhere from five to six hours in this education and awareness effort.

As well as interest in the issue, we were confronted with anger, with bigotry, with outrage, with ignorance, and with illiteracy from passersby. While we had a particular problem in East Harlem because we did not have any literature in Spanish, illiteracy was a problem in both places, in East Harlem and in the Village, in Spanish and in English. Nevertheless, we understood that it was important that we communicate with people when they were angry or hostile, interested or illiterate, did not understand what we were talking about, or had heard all kinds of misinformation about AIDS that we needed to begin to correct.

The confrontations could be difficult, but they really helped me understand the need for what I was doing and how important it was that I perform this volunteer work. This experience underscored for me the value of training, education, and supervision as essential components of the volunteer service I had undertaken.

I also realized that it was important for volunteers to acknowledge just what the limitations of their service are. For instance, as cold weather began to set in, I simply could not continue to stand outside and hand out literature.

THE FRIENDLY VISITOR PROGRAM

Fortunately, around that time, I was working with the United Hospital Fund on a study to find out which New York City hospitals were developing AIDS-related volunteer programs. That was in 1985 and, as it turned out, there were only two such hospitals: One was Bellevue, and the other was St. Luke's-Roosevelt. The director of volunteers at St. Luke's-Roosevelt asked me to become involved, and that was all I needed to hear. I decided to renew my commitment to the epidemic through hospital volunteer service. *Commitment* is another word that should be underscored when talking about volunteering.

Every Saturday, since January 1986, I have gone to St. Luke's-Roosevelt as a volunteer "friendly visitor." Actually, I have always had some trouble with that term: It seems a bit redundant. So I've turned it into a joke when I visit patients for the first time. I say, "I'm a 'friendly visitor'—and be sure to watch out for the other group! You had better beware of them."

Using my sense of humor up front has been one way of beginning to interact with hospitalized people. I never know what I am going to encounter when I walk into a patient's room, and I try to start off on the most positive note possible.

Friendly visitors serve as a "friend" to the person who is hospitalized, and, like other visiting friends, they do not enter patients' rooms entirely unprepared. The "friends" are supplied in advance with a log which provides some information about the patients and whatever issues are pertinent. It also provides the visitors with information about what others have observed. After each of us have visited the patients, we note our observations and interaction with the patients in the log. But even with this background information, a visitor walking into a patient's room might be in for several surprises, including anything from psychological and physical changes since the last visit to issues related to supporting family and/or other care givers.

I often try not to start my conversation with "How are you doing, today?" even though that is the most common way we greet people we encounter. But a person who is lying in a hospital bed has been asked "How are you?" by every hospital professional and every other friend who walks into the room.

If you are able to make small talk, to pick up on anything—like "beautiful flowers" or "beautiful day"—if you're good at cocktail parties, you will probably be very good at this sort of volunteer service.

During my visits in the hospital, I meet with five to 15 individuals for a few minutes to an hour at a time. The amount of time varies because I never know how much time individual patients will want or need or how many patients I may have to see. The entire time spent, on Saturdays, is from two-and-a-half to five hours.

When I get to the hospital, there is a roster of people that I am asked to visit, but I also like to do my own little bit of "case-finding" along the way, seeking out patients who might have come into the hospital the night before or who are not yet on the roster. It is very important to reach out to those who have yet to become familiar with the volunteer department and the services we offer.

Like other volunteers in the program, I have also provided support to families, shopped for patients, assisted with the preparation of parties, and carried out any other request that has been made of me.

For AIDS patients, the hospital is a revolving door. Most people with AIDS will have several hospital admissions during the course of their illness. Thus, I often see the same patients again and again. Sometimes, they come in looking as healthy as any of the rest of us, and sometimes they look as if they are definitely making their last visit. The volunteers have had to prepare for that possibility and learn to cope with it.

VOLUNTEER NEEDS

When I began at the Roosevelt Hospital, we had four or five AIDS patients at a time. Now, we have 20, 30, sometimes 40 or more patients in the hospital on a given day. Some have family and friends who visit regularly. Some have none, no family, no social supports whatsoever. Some do not want to develop support systems outside of the hospital because they do not want people to know they have been in the hospital with AIDS. Some have rejected support that has been offered to them. Some feel rejected because of their illness, so it has become important for me to promote the sense that they are not a rejected group. But it is also important for me to be aware of the patients' own psychosocial needs and of the need to respect their own "space."

As a volunteer, I have learned a great deal from this type of work. I have personally learned a lot about caring and compassion, and a lot about reaching out to people who are quite ill, or frightened, or feeling alone. I have learned the importance of knowing about resources that are available for persons with AIDS and how and when to present such information. I have grown tremendously from the experience.

This past Christmas, I played Santa Claus for the patients. It was a great joy, and I had a wonderful time. And I also felt that I was being given some sort of promotion, after playing Santa, because the following Easter the volunteer department asked me to play the Easter Bunny! And the idea that I was being recognized and valued for my volunteer service, that people were also reaching out to me, made me feel quite special. It underscored something else that I have realized is important in AIDS volunteering: Volunteers need a great deal of support, and they need to reach out to one another. The former must be provided by the paid professionals, and the latter must be done through structured and spontaneous support systems.

OUTSIDE THE HOSPITAL

I have also realized that there are other things I can do beyond being a friendly visitor just in the hospital. So I have taken my role of hospital volunteer outside the hospital, on my own, visiting some patients in their homes for "after-care" support.

One of them, a man in his mid-forties, lives in a fourth-floor walk-up and is having a very difficult time. For his studio apartment, a 9x12-foot room, he pays over $300 a month in rent. His medications cost over $150 each week. Before the onset of his illness, he was earning a salary of $18,000 a year. He felt he was moving ahead in his career and thought that he was doing quite well. He felt very successful. His illness has literally wiped him out. He is living with financial constraints that the average person would have great difficulty living with.

Periodically, friends, volunteers, and social service agency personnel have pooled their resources to help him with money, clothing, and personal care, as well as provide other support. None involved has ever felt that it has been enough to keep him going or to improve the quality of his life as well as they would like. On the corner near his apartment building, ironically, is a health food store with a sign that says "Health is Wealth." How true that is.

WHAT I HAVE LEARNED

As a volunteer, I have worked not only with gay men and straight women but with intravenous drug users of both sexes and, recently, I have taken an interest in working with children, in pediatrics. All of it has given me a great deal of satisfaction, and I believe that all of us, as volunteers, have made a significant contribution.

Each patient I have encountered has taught me something. I have learned that touching and hugging are essential for AIDS patients, if they are receptive. And I underline that part—if they are receptive. For the person with AIDS who has become frail, consideration must be given to all of their personal and psychological needs and concerns.

I have learned that I must continue to have hope for all of our patients and encourage them to have hope for themselves. Some patients have a great deal of hope, and some have little or none at all. But most patients I have met have given me greater hope than I usually had when I first walked through their doors—hope that they will be the one to make it, hope that this disease is not invariably fatal. As long as I keep realizing the importance of hope for these patients and that there are people who are surviving and thriving, I have something positive to hold on to.

I have learned that volunteers need to advocate on the patients' behalf, alongside them or alone, when they can no longer advocate for themselves. I have learned that volunteers need to be visible. Even though some patients with AIDS want to remain invisible, volunteers have to remain visible. They have to stand out front. Volunteers have to be educated and, in turn, must educate others. Volunteers have to be in the front lines of AIDS education.

DO'S AND DON'T'S FOR VOLUNTEERS

In the course of volunteering, I've compiled a brief list of *do*'s and *don't*'s for AIDS volunteers, a list of points I think are important to keep in mind.

First, the *do*'s:

- *Do* know the basics about AIDS. Educate yourself, if the volunteer agency fails to educate you, and know as much as you possibly can. Keep aware of new medications, treatments, and protocols.
- *Do* know the agency. Invest a fair amount of time so that you are familiar with the agency's policies and programs.
- *Do* know the needs of those you are going to serve.
- *Do* know your role as a volunteer, what is expected of you, and the role of the agency staff, what you can expect from them.
- *Do* know both the freedoms and the limitations of your role as a volunteer.
- *Do* know how to listen and be careful to do it. If you are not

a good listener, then this type of volunteering is not for you. But you also must understand and reinforce the importance of confidentiality—and you'll pick up a lot of information from people.

- *Do* know what resources are available for persons with AIDS, for children with AIDS, for mothers of children with AIDS, for families.
- *Do* know the myths about AIDS and work very hard, every day, at shattering them.
- *Do* know where to expect support for your role and how to accept it.
- *Do* know how to provide support for your fellow volunteers.
- *Do* know about burnout, what your limits are, and when to take a break, when to try something different.

The list of *don't*'s is shorter:

- *Don't* feel that you have to volunteer at a place where you are put through a very difficult, time-consuming process without being given a good explanation.
- *Don't* invest an unlimited amount of time in your volunteer service.
- *Don't* use the word "AIDS" with the person with AIDS until the person with AIDS has used it first. Then, use it sparingly.
- *Don't* consider yourself an expert on AIDS or assume you know it all because you've had friends with the disease.
- *Don't* go in and start talking to a patient about what you know, about some new drug or medication. It is better to listen.
- *Don't* do more than you can handle—but don't underestimate what you can do. I've seen volunteers overcome a variety of complex and serious problems. And I've seen volunteers help just by being there.
- Finally, *don't* play doctor, social worker, or health care professional. Your role as a volunteer is very important unto itself. ❑

I HAVE BECOME VERY POWERFUL IN MY OWN THINKING — AND I GO WHERE THERE IS LOVE, WHERE THERE IS SUPPORT.

Chapter 3

Living (and Working) with AIDS

KENNY TAUB

Kenny Taub was a volunteer with Gay Men's Health Crisis and was both volunteer coordinator for the People With AIDS Coalition (PWAC) and coordinator of PWAC's Speakers' Bureau. He discusses some of his own experiences as a PWA helping to manage a volunteer organization and shares some of his feelings about living with AIDS. Mr. Taub died on December 15, 1988.

I have been with the PWA Coalition for about a year and have been living with AIDS for almost three years. I stress that part, *living with AIDS,* because I do not consider myself an AIDS *patient* or a *victim* of the disease, terms that you hear and read a lot. I am a very productive human being, not a victim, and I'm a patient only when I'm hospitalized. I consider myself alive and well and healthy.

Over the past three years I have had *pneumocystis carinii* pneumonia five times, and tuberculosis once. But I'm recovering and able to be here to share this with you and others.

LEARNING TO LIVE WITH AIDS

Over the past three years I have also reached out and learned how to deal with living with AIDS. In the beginning, I didn't know many people with AIDS, and confronting the disease took a lot of courage and strength, on my part, and some support from my family.

It wasn't easy. In fact, it took me about a year and a half just to relax, just to understand that there is life with AIDS, and that I could achieve certain goals, and to learn not to give in to the thought that I was probably going to die very soon, so what's the use. But I did learn, and now I have a hard time dealing with other people's self-pity and have no patience for people who whine or complain a lot.

Perhaps that attitude is one I learned over the years from my mother, who has a rare blood disease, has had three major strokes, and, at this point, is totally physically challenged and needs constant assistance. It's sad and depressing to me, of course, but my mother was told 35 years ago that she would soon be dead. And she's still here today. So I look at her, and her strength, and say, "Well, if she can do it, I can do it." And I get my strength from that, and from other people who have done it.

Although I have still seen other family members become ill, deteriorate, and pass away, and felt helpless and powerless over their ailments and illnesses, I have become very powerful in my own thinking—and I go where there is love, where there is support. I have given up some old friends of the past because they cannot accept the fact that I am gay and the fact that I have AIDS, and they are afraid for their children. That is *their* problem. Naturally, there is pain in that, but you learn from it. So I go where I am loved and supported and stay very close to my support systems and family and friends.

I also reached out and was a volunteer for a while at Gay Men's Health Crisis, working both in education and in their recreation department, preparing food and serving people in different capacities. Then I became ill again with pneumonia and went on a sabbatical to recover. I'm also—and I am proud of saying—a recovering drug addict for the last three years, and I get a lot of strength from that support system. It is like dealing with dual diseases and dual recoveries, and it takes a little more energy, but I've found the strength to go on.

I got over the pneumonia, and after a while I realized that there has to be more to life than just lying around, talking on the phone, chatting with people, and going to therapy. And how much television can you watch? It is all very nice to sit back and wait for the Social Security checks, and feel like you're retired and ready for basket-weaving, but it didn't fit my lifestyle. So I got up and said, "I need a job."

THE PWA COALITION

I applied for a job with the People With AIDS Coalition (PWAC), a grassroots organization in New York City and one that is growing, unfortunately, by leaps and bounds. I say "unfortunately" because its growth also signifies that AIDS is spreading much more in the community. The organization was created by people with AIDS and people with AIDS-related conditions (ARC) to develop support services and provide opportunities for us to share experiences and strengths.

PWAC is best known for its publication, *PWA Coalition Newsline*, a monthly newsletter that is distributed to many people and different organizations and hospitals worldwide, and is in all the New York City public libraries. We also publish a book about living with AIDS, *Surviving and Thriving with AIDS*, which is full of information and hints for the newly diagnosed. It's like a bible and is available free to PWAs.

At PWAC, we run support groups and have a meal program, serving hot meals to people with AIDS and people with ARC three times a week. We are involved in education, empowerment, and outreach, and we have a lot of medical information about almost every AIDS treatment available. Everything is free to people with AIDS or ARC.

There are a lot of people who are willing to volunteer and help. But the growing need for volunteers is almost unbelievable, and I commend anybody who does volunteer work. I know it is not easy.

WORKING WITH VOLUNTEERS

I really knew nothing about being coordinator of volunteers when I assumed this position at PWAC, but, since the beginning, I have been learning every day—and learning and learning—about working with volunteers. I interview people who are potential volunteers and ask them how they heard about our organization, how much they know about AIDS, and how they would deal with a person with AIDS. I explain the fundamentals of our organization and what we do, so they know what they're getting into.

I have been through some training myself, and now I give classes for PWAC's volunteers. There is a lot of training involved, a lot of information and a lot of issues about AIDS that a person off the street will not know until they are experienced in this work.

Recently, I started something new with our volunteers: I take them out to dinner. And I have had them over for an evening at my house. Through PWAC, we have also been able to get free theater and movie tickets for the volunteers, and they deserve it all. They put in a lot of time and energy, even on days when some of them are not feeling well, if they have AIDS. We have a lot of people who are volunteers who don't have AIDS, but they burn out, too.

PERSONAL OUTREACH

Through the drug recovery program, I have also done what is called "Twelve-Step" work, and I go to hospitals and talk to people who are in bed, recovering or trying to recover from drug addiction or alcoholism. I try to get them to see the light, that there's no life with drinking and drugging. And there may be life with AIDS if you *do not* drink and *do not* use drugs.

I also go out and talk with pharmacists about why the hell their prices are so high for the drugs people with AIDS need. And I've helped the *Village Voice* put together an article about the price of AZT, a controversial drug that I have chosen to stay on for over two years. Now, I'm fighting with pharmacies over the price of pentamidine [a drug used to prevent and treat *pneumocystis carinii* pneumonia], which is a horror. I try every angle I can think of.

I've been in the newspapers and on television here and in Europe. I've also run support groups at St. Vincent's Hospital and Bailey House, in New York City, and in Miami, Florida, because I feel at this point that I have a message to carry.

I have experience. I have strength. I have hope. ❑

WHAT I fEAR MOST IS THAT THESE BABIES WILL NOT BE TOUCHED AND LOVED.

Chapter 4

Giving the Performance of My Life

CHARLES GOGGANS

In June 1987, Charles Goggans became a volunteer working with the boarder baby program at Harlem Hospital Center, a municipal facility in New York City. While at Harlem Hospital, he began to work with babies with AIDS. A native of Birmingham, Alabama, Mr. Goggans returned there in late 1988 and is involved in community AIDS education, with an emphasis on pediatric AIDS.

A little over a year ago, I turned on a television news program late one night and saw a CBS correspondent talking about a new phenomenon in this country: the phenomenon of boarder babies. He talked of hundreds of children who were being abandoned in hospitals all over the United States, with no family, no foster care, no one to care for them, and nowhere to go. They literally live in the hospital.

This, of course, is not a new problem. There have always been orphans and abandoned chidren, but suddenly, largely because of the problem of "crack" abuse, the numbers began to increase dramatically. But the part that got to me the most, that just grabbed me and wouldn't let go, was that because of the nursing shortage around the country, nurses were so overworked that they were not able to do much more than feed and diaper the children. So that if a child cried out for whatever else he or she needed—a drink of water or attention to diaper rash, or simply to be held—there often were not enough nurses to respond. And what was happening as a result was that huge numbers of children were learning not to cry, because they learned that if they cried, no one came to them anyway.

Like St. Paul on the road to Damascus, I felt struck by God and knew that I must do something about this problem. So, the next morning, I began to call hospitals to try to find a place where I could go and just hold these children. Last June, I began working with the infants at Harlem Hospital, under the guidance of Nettie Richards, the hospital's director of volunteers.

At first, I was working just with newborn infants, babies born with addictions to crack or other drugs. If you have never seen a two-day old infant going through drug withdrawal symptoms, you can't imagine what a horrible thing it is. Later, I began to work with AIDS babies.

BABIES WITH AIDS

When I started my volunteer work, I began to keep a diary about each night that I went to see these children. What follows is from my diary about the first two days I spent with the AIDS babies at Harlem Hospital.

THE FIRST DAY

Nettie called me a few days ago and we talked about what we needed for the volunteer program. She said that a brochure of some kind would be nice. I told her that I had been thinking about that for some time and asked if she would like for me to put one together. "Oh yes," she said, "that would be wonderful. I love delegating jobs to other people." We laughed together, and I immediately began writing.

I take what I had written to Nettie during the early afternoon. I want to stay and visit my usual infants but decide that what I really want to do is to go to the 17th floor. I keep hearing people talk about 17 with such great mystery. The 17th floor is where the AIDS babies are kept.

Nettie accompanies me upstairs. After checking in at the nursing station, we are directed to the end of the hall in the north corridor. Five babies are in what look more like cages than cribs; "cribs" is too civil a word. There is one infant, Nelson, and four one-to-two-year-old boys, Derrick, Walter, Jamie, and Kenneth.

Derrick is in the first "cage." The bars go up above his head and there is a clear plastic covering over that. He stands up, looks at me and says, "Da?" I go over to him. He places his hands on the plastic and says, "Da?" I touch his hand through the plastic. He laughs a funny little laugh, like Woody Woodpecker, but he never really smiles. He just keeps saying "Da" and giving me high-fives through the plastic. He has caked-on snot all over his face and in his nose and he has soiled his diaper.

Nettie is talking to the nurse who is feeding Nelson. I ask the nurse if she wants me to change Derrick. Nettie shoots me a look as if to say, "These babies have AIDS, let the professionals do it."

The nurse says, "If you want to, go ahead. Just put on some rubber gloves."

And I say to Nettie, "It's okay. I can do it."

I put on a yellow sanitary gown, slip on the rubber gloves, and begin to change Derrick. Nettie leaves at this point. I can see the concern on her face. I *am* afraid, but what I fear most is that these babies will not be touched and loved.

Jamie is in the cage next to Derrick. Jamie lies on his back with his arms over his head, his eyes closed, rocking his head back and forth. A radio sits on the stand beside his cage. I think he is either keeping time to the music or he is brain-damaged.

Kenneth is in an adjacent cage. Kenneth and Jamie are two of the most beautiful children I have ever seen. Kenneth smiles at me. I go over to him, reach through the cage and touch his hand. Kenneth laughs. He is such a good-natured baby.

Walter is obviously the sickest of the five children. He has huge brown eyes, beautiful lashes. There is a rash on his face. He can't hold his head up. AIDS has taken away all of his motor functions. His head, his hands, and feet are functionless. Yet, there is intelligence in his eyes. And when you hold up his hand to give him a high-five, he smiles.

There is a playpen in the room. I ask the nurse if I can take Derrick and Jamie out of their cages and put them in it.

She says, "Yes, but they'll fight."

I place both children in the playpen. They do not fight. The three of us play with toys while Kenneth and Walter look on. I stay with them for about three hours. We play and laugh. We act silly. I realize that Jamie is neither brain-damaged nor keeping time to music; Jamie is simply bored.

THE SECOND DAY

Wednesday. I go first to the fourth floor to visit and help feed the infants there. When everyone has been fed and all is quiet, I decide to go to the 17th floor again.

When I get there the children are alone.

Derrick says, "Da?" And I give him a high-five. Jamie has a tube in his nose and is asleep. Walter, too, has a tube in his nose. He is lying on his stomach. All of the children have soiled themselves and the room stinks.

I think that I will change them all but I suddenly feel overwhelmed. I go into the hall, find a nurse, and tell her that all of the children need changing. She says that as soon as someone is free, someone will come and help.

I go back into the room. Kenneth smiles at me. Derrick says "Da?" Jamie wakes up crying.

Nelson wakes up crying. I go to Nelson and pick him up and he stops crying immediately.

The radio next to Jamie's cage is blaring rap music. I go over and turn it off. And Jamie stops crying.

I walk around the room holding Nelson and I begin to sing to him. I make up a melody and words, something very simple:

"Little baby Nelson needs to be loved. I love you, baby Nelson, and so does God."

I sing these words to him over and over and he becomes very calm. I hold him out from my body, look into his eyes and sing to him. He seems mesmerized. Has no one ever sung to Nelson before?

When I look up from Nelson all eyes are on me. All the children are quiet and listening and I sing to them all:

"Little baby Walter needs to be loved. I love you, baby Walter, and so does God."

"Little baby Derrick. . .

"Little baby Jamie. . .

"Little baby Kenneth. . . ."

When I stop singing, it is so quiet in the room that one could hear a pin drop. I suddenly realize the unfathomable and all-powerful impact of music and words on us all. I dance around the room in my yellow sanitary gown holding baby Nelson. And I sing and I sing and I sing. My little audience gives me undivided attention.

I feel for a moment that I am on a very unique stage, giving the performance of my life. And, in a sense, that is exactly what I'm doing—giving hope, giving life, giving love.

SUBSEQUENT DEVELOPMENTS

These were my first experiences, my first two days with these children. And since that time many things have happened.

Derrick and Kenneth were placed in a group foster home, run by the Catholic archdiocese, in Albany. From the description, it sounds like a fabulous place. There are seven children there now, a staff of 13, and about 50 volunteers. We're planning to take a busload of people to Albany to see these kids. At the moment, it is the only such facility for children with AIDS in New York State. A planned residence for boarder babies in New York City was firebombed in April 1987. This is absolutely appalling.

Jamie celebrated his third birthday on Christmas morning, 1987. In early December, Derrick passed away.

Now we have a whole slew of new babies at Harlem Hospital, and they are so beautiful. There's a little girl named Erica who has eyelashes about a mile long and who can just charm the pants off you.

One recent morning I had a dream that disturbed me a great deal. I dreamt that I went to visit the babies and, when I got there, there were none, only two empty cribs in the ward where I had been. And a nurse came in and I asked, "Where are the babies? Where's Jamie?"

She just shook her head and said, "Please come with me."

So we went into a room and all of Jamie's things, his little toys and his little clothes, were there. The nurse said to me that if I wanted any of these things to remember Jamie by, I should take them. So I did. And it turned out, in this dream, that all of the babies had died.

When I woke up, I went to the hospital immediately. When I went into the room, it was exactly as it had been in the dream. There were only two empty cribs there. I was completely freaked-out, but it turned out that the children had become sick and had to be put into the intensive care unit. But they are alive and doing well.

PEOPLE LIKE US

We hear a lot of statistics about the numbers of people with AIDS and the numbers of children being born with AIDS. But what I want to stress is that these people and these children with AIDS are not statistics, they are people just like you and me. They have faces and emotions, and they are lovely and wonderful people. ❑

AND I ASKED HIM, "BRUCIE, WHAT'S THE MATTER?"

"I DON'T KNOW, MA," HE SAID. "I DON'T KNOW."

Chapter 5

I Tell Them to Hang in There

MILDRED PEARSON

In the fall of 1986, Mildred Pearson's son, Bruce, became ill with an AIDS-related condition. When doctors decided that Bruce had progressed beyond treatment, she took him from a Manhattan hospital back to her family's home in the Williamsburg section of Brooklyn. In a community where there has been both a great deal of denial about AIDS and rejection of persons suffering with AIDS, the Pearsons's experience stands as a powerful example of courage and compassion—and of the power of love. After Bruce's death, Mrs. Pearson became a volunteer at the Brooklyn AIDS Task Force, where she is active in AIDS education.

I lost my son on October 22, 1987. He was 31 years old, a beautiful son, a son who gave me love. And we gave him love in return.

Bruce was a vital young man. He was gay. I didn't like that, but I went along with it because that was his acceptance of life, and I'm his mother. I loved him dearly because he was the sort of son who was devoted to his mother; everything was for mamma. He would call me at 12:30 every afternoon from his job and ask, "How are you doing? What are you doing?" I waited for those calls.

PERSONALITY CHANGES AND A SEARCH FOR HELP

In 1986, Bruce began going through some very changeable moods and attitudes. He was a very intelligent young man, with a good job in publishing, but he began having difficulties with his work. He would come home and say to me, "They are getting on my nerves. I can't function. I'm making mistakes." He stayed later at the job to do over things he felt he had done wrong.

At home, we began to notice changes, too. Bruce became forgetful. Sometimes, at night, he would get up and walk through the house. He would sit, staring into space. Finally, he said, "I can't cope. I think I'm going to take a leave of absence."

"Well," I said, "take a leave of absence and get yourself together."

Instead of taking a leave of absence, Bruce resigned. He said he couldn't function anymore, so, in October 1986, he left his job.

The next thing that happened was that one night I got up and saw him walking through the house with a shopping bag full of papers. He also had a teddy bear in the bag. And I asked him, "Brucie, what's the matter?"

"I don't know, Ma," he said, "I don't know." He seemed confused.

I have a 24-year-old son and a 22-year-old daughter and two grandchildren who also live with us at home, and they said, "Bruce is not acting right."

Then he became very high strung, so high strung that you could see that he was flushed at all times. So, I said, "Well, let's just go over to Woodhull Hospital and see what's wrong."

So we took Bruce to Woodhull. In his state of mind, it was just like you were leading a child, because something was wrong.

At Woodhull, they gave him examinations and ran tests. We went back and forth. They began by saying something about stress and that he had had a nervous breakdown. So they gave him pills of some kind, and he became a sleeping monster. Sleeping so heavily that he wet himself.

This is not right, I thought. So I spoke to a friend who worked in the hospital. She said, "You know, Pearson, I'm going to tell you that it sounds to me like he has a form of AIDS."

Well, I didn't want to hear that. I pushed it back, pushed that idea away, but I said, "Tell me what to do." She gave me a hotline number.

In the meantime, I had started taking Bruce to different hospitals. People said take him there, take him here. I was literally leading him by the hand. Then he couldn't control his bowels, he wet himself and soiled himself. We had to buy diapers from the druggist. And everywhere, there were waiting lists, waiting lists, waiting lists. So I called the hotline number; it connected me with Stuyvesant Polyclinic in Manhattan.

When I decided to take Bruce there in December of 1986, he was very cooperative. At that time he was still able to dress himself and to put on the diapers he needed.

DIAGNOSIS AND HOSPITALIZATION

When we arrived at Stuyvesant, we met Dr. Richard Elion, who asked me what was the matter. I told him of the diagnosis we had from Woodhull and explained that I couldn't give Bruce the pills they had prescribed because he just wound up sitting in a stupor, wetting himself, and so forth. Dr. Elion looked at Bruce and decided to schedule him for some tests the following week at Cabrini Medical Center.

But, during the week, Bruce became so irrational that I called the doctor back and said I couldn't wait, and asked if I could bring him in. It was a Friday and there were no beds available at Cabrini, so we went to the emergency room. Bruce was talking incoherently, out of his head. In fact, he was talking in a language I couldn't even understand.

By Monday, they gave us a diagnosis. They said Bruce had parasites in the brain that had caused brain damage. So he was hospitalized in Cabrini. They never mentioned AIDS to me, they just said parasites on the brain. What is it coming from? They couldn't give me an answer. What will happen? They don't know.

They gave him some kind of serum for treatment, but his body rejected it, and he had to be put in restraints. After giving Bruce this medication for a week, they took him off it and said they didn't know what to do.

"Well," I asked again, "what is it? Is it AIDS?" They didn't know exactly how to categorize Bruce's illness but said, "We'll put it in the AIDS-related category." They ran all kinds of brain-wave tests and spinal taps, and all they could tell me was parasites in the brain.

Bruce stayed in the hospital for three months. Meanwhile, my blood pressure went up to 210 over 110 and my doctor forbade me to go to the hospital because, he said, I was stroke material. But my other children and my husband went. My daughter, who worked in Manhattan, took her lunch hour to visit Bruce in the hospital and feed him, because he couldn't feed himself. She also had to clean him up. My husband also went to the hospital to make sure Bruce was getting fed. They had him on a liquid diet, which he didn't like.

And he was just talking gibberish. I said, put him on the phone, let me say it's Ma. But he talked all out of his head.

COMING HOME

Bruce's doctors had reached the point where they said they couldn't do anymore for him. They said they were going to transfer him to Roosevelt Island [where there are chronic care facilities at the Coler Memorial and Goldwater Memorial Hospitals].

But I'm a believer, a true believer. I believe in God and I know he performs miracles. I started praying. And I woke my husband up at 4:00 one morning and said, "They're not taking Brucie to that place and forget about him."

He was too vital to me as a son. So I said, "I'm bringing him home."

So, on March 27, 1987, the day before his 31st birthday, we brought Brucie home. They gave me all the hospital equipment for my home.

And they brought me home a son in a wheelchair who just sat and stared. But, as God gave me grace, I was determined to hang in there with Bruce and see what the end was going to be.

My two grandchildren, aged 9 and 11, started rallying around their Uncle Brucie. I had told them that when Uncle Brucie comes home, he'll be different. You can't eat after Uncle Brucie anymore, I said, but love him. You can't kiss him on the lips, but you can kiss him on the jaw.* He's still your Uncle Brucie.

So Brucie came home in a stupor, and he just stared. At first, he had 24-hour nursing service. He had been transferred to the hospice service because there was nothing else the doctors could do. But the constant nursing shift changes became a pain for me. I couldn't stand all the people rotating back and forth. So I called the hospice program and asked them to cut back the nurses and told them that the family would take care of Brucie.

They asked if I could manage. They sent over a spiritual minister from the hospice who talked to me and prayed. "It's going to be a big job," they said.

"That's my son," I said. "When he was on his feet there was nothing he wouldn't do for us. Do you understand? So we're going to take him on our backs. We're going to take care of him." And we did.

Well, one afternoon my grandchild came to me and said, "Grandma. Uncle Bruce. He can talk."

I said, "Talk?"

So I went back into Brucie's room myself, and he looked at me and said, "How are you?"

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* Although HIV has been found in saliva, household studies have shown that neither HIV nor AIDS is transmitted by sharing food, plates, drinking glasses, eating utensils, or toothbrushes with AIDS patients, or by kissing them on the lips.—ED.

COMING BACK: PROGRESS AND IMPROVEMENT

We fed him the most nutritious foods. A nutritionist friend told us that, in addition to the vitamins the hospital was giving Bruce, we should also try liquid vitamin B complex and liquid vitamin C. We started giving him heavy doses. I did his cooking, and the home health aide who stayed from nine to five every day fed him.

Bruce went from the wheelchair to a walker. He came back. He came back and was able to walk with a cane. We began taking him out. His memory began to return. He started regrouping, not entirely but halfway. He began eating and wanted to try feeding himself. He also began asking questions.

My grandchildren taught Bruce how to write his name again. Then the hospice nurse, who now came once a week and took his vital signs, said, "I am going to recommend that he come into the clinic where they can do better tests." So we had the ambulance begin coming, and we would go to the hospital. At first, the nurse said, "You don't have to go." But I said, "He's mine. I'm going."

I had to give up going to church to take care of my son, but my minister would come to our home, and we had prayer once a week. In the beginning, Bruce rejected prayer, but we sort of forced him to come on in and join the circle.

On Saturdays, a male nurse would come and take Bruce out. He seemed to respond better to men, and the nurse saw the progress. Everybody saw the progress. But Bruce was still just sitting around, doing nothing. So someone recommended that I call Gay Men's Health Crisis, and they assigned Haden Boswell, a volunteer, to be Bruce's care buddy.

Haden would come out to visit and bring a flower and sit down and talk with Bruce. He was an older man, but they hit it off and Haden became our friend. After Bruce passed away, Haden was the one who recommended to me that I get involved in something like volunteering.

All of us in the house, me, my children, learned how to cope and how to give Bruce the tender loving care he needed. He became like my baby again, and I diapered him and cleaned him up when he needed it. When he developed a thing about juices, there wasn't a juice in the world that we didn't try to keep in the house for him.

One day, Bruce got up and said, "I'm coming to the table to sit." It was like he was saying he wanted to be part of things again, and we jumped for joy. He was really coming back. So he sat and ate with us. He still would get a little sick at times, and he had times of depression, very bad depression.

At Polyclinic, they started him on physical therapy, with leg movements to try to overcome muscle weakness, so he could walk up the stairs. There were times when the weakness would come and he couldn't do anything. But he was progressing nicely.

DYING WITH DIGNITY

Then, on the twenty-first of October, when I went into Bruce's room that morning, his breathing was very labored. I said, "What's the matter, kiddo?"

And he just said, "I don't know, Mom. I don't know."

Before the home health aide came, he had an uncontrollable bowel movement and messed himself up pretty badly. My son and I tried to clean him up before the aide got there, but it was uncontrollable, and we had to keep cleaning him up. When the aide came—her name was Mildred, too—she said, "I think you had better call the hospice program." We were in the home care part of the hospice program, and they had told us to keep them informed.

At noon, someone from the hospice called back and asked if they should send oxygen.

I had never seen anybody breathing like Brucie was, from his stomach up to his chest. It was so labored, but I didn't think about death. He didn't have any appetite, but he was talking to us. I just thought he was having a bad day. They had told us to expect them.

By the end of the day, they told us to bring Bruce back to the hospital because the oxygen wasn't doing him any good. So the ambulance came, and we took him back to Cabrini around 8:00 that night. On the way, he was in good spirits, talking and joking with me. I said, "Keep moving your legs, kiddo. Don't get stiff on me."

At Cabrini, when the doctors examined him, they said that parasites in Brucie's brain had come down into his chest cavity and caused pneumonia. I think he had had a feeling, because he had said to me, "I hope I don't have pneumonia."

We stayed with Bruce until 9:30, hugging and joking and laughing together. Then we left him.

By ten minutes to 2:00, on the morning of October 22, Bruce was gone.

As he was dying, Bruce asked the nurse to rub his back. She did and asked him what was the matter.

He said, "Oh, I don't know. I'm restless. I can't sleep. I'm tired." Then he put his head back on the pillow and said, "I'm going to dreamland."

And that's when my child died.

So I came to the Task Force to tell everybody that when your son has AIDS, he is still your loved one. You don't throw him away. You hang in there, especially when it's a good son who never gave you an ounce of trouble. You love him. You give him tender, loving care.

BRUCE'S STRENGTH

I found out along the way that when Bruce was released from Cabrini the first time, they thought he had only three days to live. Well, with loving care, and nuturing, and knowing God is there to help you and sustain every minute of the day, you can make a difference. You can do it. And if AIDS hits your home, remember Brucie and his family. We stood by him to the end, and my son was able to die with dignity.

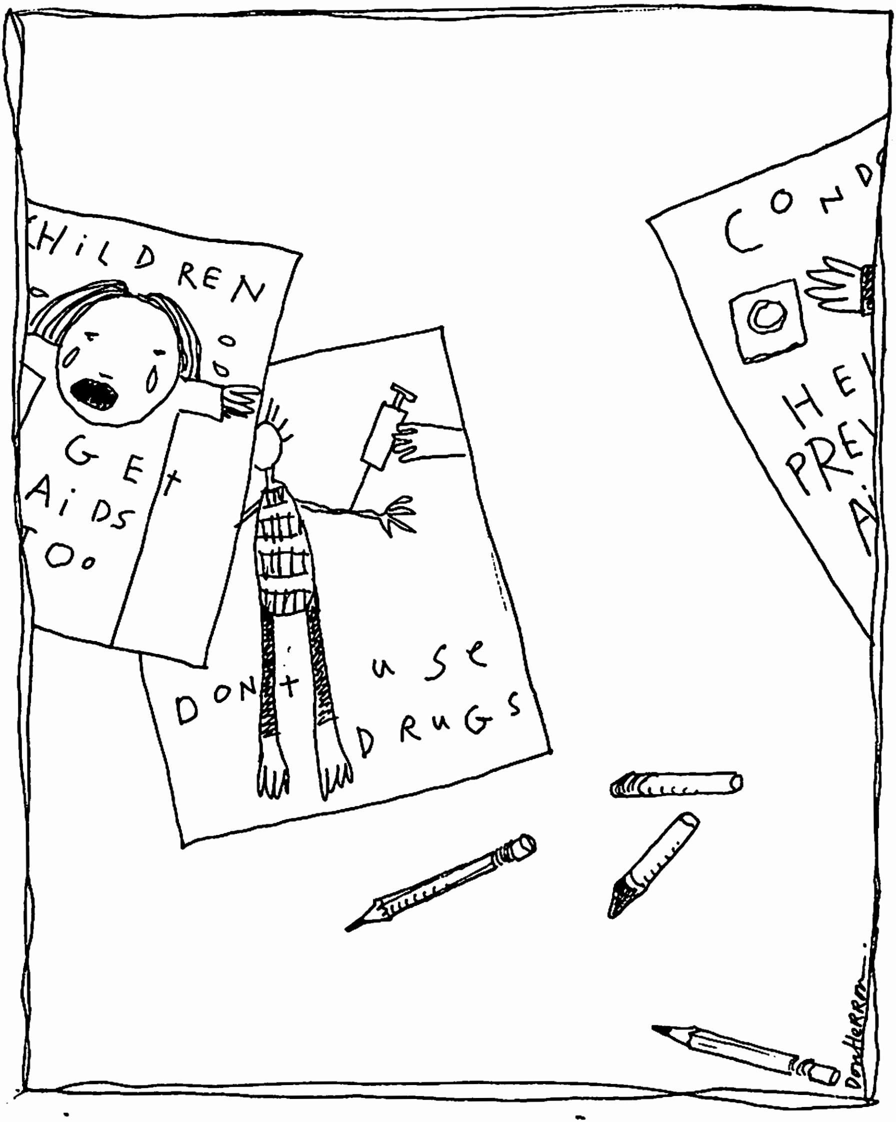
And I'm out here to show and to tell the world don't abandon your loved ones. Love them as you loved them when they were on their feet. Don't abandon them, because you will be a better person if you stand firm. You'll face rejection. Friends have rejected; half my family rejected. But we hung in there. And we couldn't cry when Bruce died, because when you live with yourself and know that you have done your best, you get the strength to march on.

Now, at the Brooklyn AIDS Task Force, when mothers call and need a little uplifting, I'm able to give it to them, even if it's no more than just a prayer on the phone. I tell them to hang on in there.

My Bruce didn't leave me any babies, and he didn't leave me any money. But he did leave me his strength. ❑

Part II

MODEL VOLUNTEER INITIATIVES



KIDS CREATED DRAWINGS TO SHOW people THAT THEY UNDERSTAND WHAT AIDS IS ABOUT AND HOW IT'S TRANSMITTED.

Chapter 6

Brooklyn AIDS Task Force: Outreach to a Resistant Community

YANNICK DURAND

Since 1987, Yannick Durand, Ph.D., education director of the Brooklyn AIDS Task Force, has been involved in community outreach and AIDS education in Brooklyn. She has experienced firsthand the important contribution of volunteers in helping to bring AIDS information to a difficult-to-reach population, where there is also a great deal of resistance to confronting the realities of the epidemic. As she also reports, Dr. Durand has found AIDS volunteers in unexpected neighborhood places.

At the Brooklyn AIDS Task Force (BATF), we are faced with a multicultural, multiethnic borough population. Brooklyn is also the borough with the second largest number of AIDS cases in New York City, following Manhattan.

When the Brooklyn AIDS Task Force got under way, it was difficult to reach many people in the borough because we were using existing AIDS educational materials that many people in our community just did not readily relate to. AIDS education literature that works for white, middle-class, educated Americans, for example, does not necessarily work for black Americans or for Haitians or for the Hispanic community. So we were getting nowhere in Brooklyn.

I was pulling my hair out with frustration. For instance, after I talked to a group of people about AIDS for an hour or so, they would still say, "Okay, can you get infected by touching hands with a person with AIDS?"

That was after an hour of explaining exactly how you get AIDS, how you do not get AIDS, and particularly that you do not get AIDS from touch or casual contact. The situation was frustrating, draining, and exhausting for me.

Finally, one day, my mother said, "You're too educated. You have to reach people where they are, on their terms. If you want to reach the black community, talk to the kids, talk to the women. They are the ones carrying on traditions. They are the ones on whose shoulders the whole community rests."

NEIGHBORHOOD OUTREACH

So, I started doing outreach on my own time, in my own neighborhood, including at the supermarket and the laundromat. One day, at the laundromat, a little girl approached me and asked why I was always walking around with heavy boxes of pamphlets. She really didn't associate this sort of thing with any type of existing profession; it was just very weird to her.

I explained that I was doing AIDS education. All of a sudden, she was interested, she was curious, and she was concerned. And she had a thousand questions. In fact, it seemed to me that I could not go out to my car in the morning without this child coming up and saying, "Hey, can I ask you something?"

That little girl is 11 years old. Her name is Kathy. As it turned out, Kathy's friends had questions, too. So I told them, "Get all your questions together, come to my office, and we'll talk."

Of course, they didn't make an appointment. They just walked in one day. They had note pads and a list of questions to ask. It was very serious stuff, and we spent the entire afternoon talking about and discussing AIDS.

Now, those children—there are five of them, black, white, and Hispanic—are our most active, most concerned, and most effective volunteers. They are workers; they are speakers. And when we go into the community, they talk to people in a very casual, familiar manner about things that people can relate to. And people relate to them and listen. This has been more effective than my just coming on with statistics or with any sort of story *I* might have.

MULTILINGUAL EDUCATION

This same group of kids draws a lot, and they created drawings to show people that they understand what AIDS is about and the ways in which it is transmitted. Sometimes, we adults are afraid to talk to children about topics like sexuality and condom use, but, in fact, I found that they knew more than I did. And, like many curious young people, they were very happy to be able to talk about sexuality. So they did drawings to explain to other people, including other children, what AIDS is, how people get infected with the virus, and how they can avoid getting infected.

We also produced a short videotape, entitled *Children Speak About AIDS*, with the same children telling people, in their own words, all about the disease. This videotape is available at the Brooklyn AIDS Task Force office, and it can be borrowed, viewed, and copied. Because Brooklyn is a multilingual borough, the video has been done in several different languages: English, Spanish, French, and Creole.

This video has been useful in helping us reach into parts of the community that have been hard to reach with AIDS information. It opens doors and provides a basis for us to initiate discussions about topics, such as sexuality and condoms, that people otherwise have trouble talking about. In this and other ways, we are adjusting our AIDS information and our approach to fit the different cultures of Brooklyn.

In addition to the video, we have had the children create an AIDS-related coloring book, because we work in the schools a lot. It is the first of a series that will explain the different processes of the infection, virus transmission, and so forth. Like the video, the coloring books also come in four languages.

The first comic, which conveys information about the human immunodeficiency virus, what it is, and what it does, is entitled *Mr. HIV*. It has been very useful, but we have gotten some criticism because of the title. People have been asking why we called it *Mr*. HIV. Frankly, I do not know; I guess we just assumed the virus is a male. However, in the next version, Mr. HIV will lose his gender.

VOLUNTEERS MAKE A DIFFERENCE

In organizing our AIDS education programs, we have to recognize the socioeconomic reality of the communities in Brooklyn, too. We are planning a community outreach "AIDS Information Day," when our young volunteers will speak, and we will provide entertainment, food, and gifts for those who come to the programs. We will have both a children's workshop and baby-sitting, so that mothers can attend without having to worry about who will take care of their kids. We will also have people with AIDS and people from the community who have dealt with AIDS or are dealing with AIDS in different ways themselves, because we find that other people will relate better to someone they can identify with.

For example, one very effective volunteer who has come to work with the Brooklyn AIDS Task Force is Mildred Pearson. Mrs. Pearson is the mother of a young man who died of AIDS in October 1987. She and other family members cared for her son in their Brooklyn home during the last months of his life [see Chapter 5].

After her son's death, Mildred came to the Task Force one day because she was in grief and wanted to do something for others. Now she is involved in community education. Through her willingness to go out into the community to share her experience with AIDS and her experience of loving and caring for someone with AIDS, she is helping our community to come to terms with this disease and to understand what AIDS means to those who are sick and to their families and others who love them.

Volunteers such as Kathy and the other children and Mildred Pearson are making an enormous difference in our ability to reach into the various communities of Brooklyn, to present our AIDS information, and to be heard. ☐

WITHIN A few HOURS, A VOLUNTEER would come KNOCKING AT THE DOOR WITH A BEAUTIFUL MEAL THAT DAY.

Chapter 7

God's Love We Deliver: Volunteers are Vital

MICHAEL BERTISH

Michael Bertish is business manager of God's Love We Deliver (GLWD), a not-for-profit, nonsectarian organization that delivers home-cooked meals to homebound persons with AIDS. Mr. Bertish began as a volunteer at GLWD in June 1986, delivering meals and working on donation cannister routes. He was one of the first volunteers to become a regular staff member, working in a variety of capacities, including volunteer coordinator, office manager, and accountant. He begins each day by helping volunteers prepare the delicious meals that are the hallmark of GLWD's service.

Five days a week, Monday through Friday, God's Love We Deliver prepares and delivers hot, five-course meals, free of charge, to clients who are homebound with AIDS. There are a variety of activities in this endeavor that provide opportunities for volunteers—in the kitchen, in the delivery vans, and in the business office. Without volunteers, our work could not be done.

In thinking about what sort of information might be useful for others who are involved in or thinking about establishing AIDS-related volunteer efforts, I came up with a list of questions that need to be asked and answered, and some examples of what service organizations might expect. While the examples may be specific to God's Love We Deliver, they are also sufficiently generic to be broadly applicable to a variety of other AIDS-oriented volunteer projects, and to give us all some things to think about. Through these questions and examples, I hope to present a basic philosophy behind a successful, positive volunteer program.

What makes a successful volunteer program? This question boils down to one simple answer: How well the organization is able to fulfill the desires of the volunteer.

VOLUNTEER MOTIVATION

Keeping your volunteers satisfied begins with understanding what motivates volunteers in the first place. Why does a volunteer come to an organization to offer his or her services? Motivation may be simple or complex. Sometimes an unusual event or chance encounter may prod a prospective volunteer into getting involved, or the individual may do so purely out of compassion and love for humanity.

For example, Susan, one of our new volunteers, was shopping at Zabar's food shop on Manhattan's Upper West Side. While there, she happened to see one of our donation cannisters sitting on a counter near the cash register. "I might want to check into that," she thought. So she made a mental note of our phone number.

This happened to be on a cold January day and outside, as Susan left Zabar's, she saw a man slip on some ice and fall, putting a gash in his head when it hit the sidewalk. He was bleeding. As Susan rushed up to help him, he cried out immediately, "Don't touch me, I have AIDS!"

Ignoring his warning, Susan helped the man up, covered him with her coat, and got him into a taxi and to a hospital. Then she went home and called us right away, saying, "I want to volunteer."

Volunteers could also be simply curious. They may be seeking information or answers about AIDS because of fears about contracting AIDS themselves. Or the volunteer could possibly have recently lost someone, a friend or loved one, to AIDS and is going through a grieving process.

PLACEMENT REQUIRES A PERSONAL APPROACH

To place volunteers in a task that would best benefit them and the organization, a very special personal approach is required to figure out their motivation and how it might affect what job they can do.

If you find out, for instance, that the prospective volunteer's lover has just been diagnosed with AIDS, and the volunteer is shaking with nervous tension during the interview—this is a regular case scenario for us—you need to know that you can't possibly send this person to deliver a meal to a client whose face is riddled with Kaposi's sarcoma lesions and who suffers from projectile vomiting. This volunteer would be much happier chopping carrots in the kitchen, while listening to soft music, or helping to get letters out of the office.

Once the shock and horror of the diagnosis and the anxiety, the anger, and the fear have worn off, and the volunteer has been with you for a while and sees how the organization operates, then he might be able to handle delivering a meal, and you can send him out.

If, however, you send out a volunteer who is vulnerable, you risk upsetting both volunteer and clients. Persons with AIDS are often very, very self-conscious. They may be nervous, embarrassed, weak, and are often apologetic. They may often worry more about how you perceive them than about the suffering they are going through. To have a brand new volunteer passing out cold on a client's bedroom floor because he's overwhelmed, and taking out the client's IV tube on the way down, could prove disasterous.

TREAT YOUR VOLUNTEERS WELL

A good organization treats its volunteers in the same way in which it treats its clients, making sure that everyone's needs are met. This is not as easily done as said. The issue is not one of having enough bodies to do the job; it is about having the right person to do the right job, to ensure that love and sustenance are given to those who need it.

At God's Love We Deliver, we regard volunteers as pure gold. Without them we could not guarantee that every time the phone rings with an emergency call for help, a PWA would receive a beautiful meal that same day, that within a few hours a volunteer with a big smile would come knocking at the door with raspberry-poached salmon and fresh strawberries with whipped cream. If you don't have happy, willing, dependable volunteers who are eager to help, then this sort of job just cannot be done.

BE PREPARED FOR RECRUITMENT

How do you get volunteers to join your organization? Simply put, if the service is worthy of having volunteers, then the volunteers will be there. But to ask for volunteers, you must first have everything in place. In order to use the volunteers' time efficiently and effectively, you must have your service already organized and running. Otherwise, how are you going to be able to explain to volunteers what you need from them?

Word of mouth is an organization's ultimate advertising and recruiting tool. You need to have volunteers already working who will be able—and want—to tell their families and their friends what a wonderful opportunity has been created for them to help provide services. Volunteers who are committed and punctual and eager will always have friends who are the same. As the Chinese proverb says, "behind every able person there are many other able people." If your organization is just starting out, your first volunteers will probably be recruited from among your best friends.

PAY ATTENTION TO PUBLIC RELATIONS

A second source of volunteers is newspapers and the media, and if your organization is running well, word will get out and you will find reporters knocking on your door. News reports are a powerful tool for attracting volunteers to an organization because the readers or viewers see that something concrete is being done by powerful people, and that people are being helped. Naturally, they will want to jump aboard your bandwagon. So you need to treat your reporters like pure gold, too. Even if they are freshmen in journalism school and afraid to ask you questions, they still represent a student body of several thousand people who are potential volunteers.

In dealing with reporters, be sure you are well versed on the AIDS crisis and your role in it. Know your organization's history and its goals. If you do not know where you have come from and where you are going, how can you expect to be able to communicate your needs to someone who is asking these questions? If you communicate effectively, you will be able to inspire other people. Several of the reporters who have come to us to do stories are now working with us as volunteers.

Approach church communities. Churches are always one of the first groups to initiate service provisions and they are the best sources for networking. By trying for over two years we have been able to create a relationship with the Catholic Archdiocese of New York in which the church will open hospice centers and God's Love We Deliver will be responsible for providing food for their clients. And the archdiocese will be providing volunteers so the service can be in place. This is a tremendous step forward.

Treat your vendors, your officials, your bureaucrats as you would treat your clients. You will be surprised how many people are motivated by the work you do and the example you set, as long as your reputation for the service you provide is a sterling one.

God's Love We Deliver had a fish purveyor who stopped making deliveries when they found out we were an AIDS kitchen, because they were afraid their delivery boys would contract AIDS. After we provided some AIDS education, and they learned the truth about HIV transmission, a few people from the company wanted to volunteer.

Bureaucrats and public officials have the capacity to draw attention to you in a way that also is beneficial. Within a short time after New

York City's Mayor Edward I. Koch visited us, we received a new delivery van.

Public service announcements are another very powerful volunteer-getting tool, if you have a budget that can afford them or you can get someone to underwrite them.

NETWORK AT EVERY OPPORTUNITY

It is important to remember that every person you meet may be a potential volunteer. So you should take the time to greet that person, to know that person, to explain your organization to that person. Network with every social service agency, hospital, health worker service, church, school, university, and every other service-providing organization. Get your name in their literature and resource guides, too; cross-referencing is very important.

There are organizations that specialize in referring people who want to volunteer, such as the Retired Senior Volunteer Program, the American Association of Retired People, and New York Cares, all of whom have provided volunteers to staff our kitchen.

AIDS service organizations naturally need to find pools of volunteers, but we need to do so in ways in which we are not competing with one another. There are enough people and enough money out there to accomplish every service we want to perform, without having to feel as if we must fight for bodies or beat someone else to the bank. The power we must constantly exercise is the power of creative thinking.

Go to every street fair and every community meeting and take along your press packages, your newsletters, your brochures, your business cards, and, most important, your volunteer applications.

Become affiliated with foreign exchange student programs that have community service as a general requirement. But stay away from juvenile court offenders, traffic violators, and high school seniors working off detention hours because you simply end up baby-sitting without getting anything done.

It is also very important, particularly in terms of representing your organization, to avoid bad-mouthing anybody. It's like poisoning your own well. Moreover, a service organization that gets mixed up in politics gets labeled by the policies it espouses, and being opinionated only serves to attract people who are as opinionated as you are. This is very difficult to avoid because AIDS is so full of emotionally charged issues, but it's worth remembering that HIV is not at all opinionated or biased against anyone; it is a very non-discriminating virus.

SCHEDULE AROUND VOLUNTEERS' AVAILABILITY

Once you are successful in attracting volunteers, once the phones start ringing off the hook with people who want to help, what are you going to do?

First, make sure that every message gets taken, recorded, and responded to. Invest in lots of carbon-copy message pads, use a Rolodex, or, even better, enter the caller's information in a computer, if you have one. Be sure to return all calls, and don't try to explain everything to people when they first call; that's counterproductive. A volunteer is only going to be useful if he or she can take the time to come and find out in person what the organization is all about.

Schedule regular interviewing hours on a daily basis so that access to your organization is very easy.

We had many volunteers come to us but we had no place for them because they work from nine to five and we work from nine to five. At one time, we worked seven days a week, 24-hours a day, but ran into the burnout factor. So we cut back to five days a week, Monday through Friday, during the day only. And, as a result, we had a lot of people who were willing to work but we had no time to offer. Rather than lose these people, we added a Wednesday evening program, we call it "Yuppie Night," so that nine-to-fivers can come straight from their jobs, have some pizza, and bake cookies or paint Easter eggs and so forth. It solved the schedule-conflict problem wonderfully.

Who *can* you find to volunteer between the daylight hours of nine to five? Retired people, actors and actresses between engagements, the self-employed, the unemployed, and those wealthy enough not to need to have a full-time job. Basically, at God's Love We Deliver, these are our volunteers.

TAILOR JOBS TO VOLUNTEERS' ABILITIES

You must interview volunteers very carefully and become best friends with them. To do this successfully requires a full-time volunteer coordinator. We finally have one. Until a few months ago, I was performing that task while running the organization's business affairs at the same time. It was very difficult.

When a volunteer approaches you and offers his or her services, ask for a commitment up front. Tell them you want to see them in the kitchen for six months, for at least three hours once a week. Tell them it's great if they can do more, but not to take on too much because they will burn out. With this approach, you will scare off the lazy people right away.

Find out what aspect of the organization's operation best suits the abilities and talents of the volunteer. Do they have computer skills? Can you use them in the office? Do they have a valid driver's license? Can they pinch-hit for you if your delivery van driver is ill? Have they been chefs in a past life or have they always been waiters?

The best attitude a volunteer can have is: Whatever you need me to do I will be most happy to do. If someone comes to you with a personal agenda of his or her own—such as, I want to be a counselor and I want to deliver your meal and give therapy while I'm delivering it—that's very dangerous. Volunteers should know that you expect them to stick to the service you are already providing. If someone comes to you with a preformed personal agenda, you need to try to refer them to some other organization whose services more closely match the type of volunteer work they want to be involved in.

Once a woman came to us from the Red Cross, where she had worked for 25 years. And she said, "I've been working for the Red Cross for 25 years. I don't sharpen pencils. I won't talk to anyone on the phone. I don't type but I can do numbers very well."

This woman was obviously willing to work or she would not have come. But we can't use someone like that. I would have to spend my entire day trying to figure out something that she could do.

On the other hand, people who are HIV-positive can—and have every right to—work for you 100 percent of the time unless they are really visibly ill, such as with a persistent cough, runny nose, or runny eyes. They can cook; they can deliver. And they can hug anybody.

PROVIDE VOLUNTEER GUIDELINES

It is important to create a written set of volunteer guidelines so that your volunteers know what their job is when they come to you, and they know how to dress, what to expect, who their supervisor is, and that they are going to be trained by that person. Supervisors and trainers should be appropriate to the trainees' jobs. And the trainer needs to be thoroughly familiar with and understand the volunteer's job. In other words, a person who is going to be making deliveries should not be trained by your computer expert.

If you have a volunteer who is going to be particularly involved in direct client contact, you need to explain thoroughly the worst possible case scenario to that person, so that he or she will be able to operate in an emergency mode. You can't subject someone to the shock of being thrown unprepared into a difficult situation or of having to face unprepared the ravages of AIDS or the anxiety of seeing someone pass out on the floor upon their arrival.

For example, one of our volunteers arrived at a client's building to deliver a meal. As he was approaching the door, there was an ambulance out front. And there was the client being carried out against his will, with four health workers, each wearing white, the white masks, the white gloves, strapping him to a stretcher. The client was crying and screaming, horribly embarrassed. And, of course, the whole neighborhood was there, gawking. In a case like this, our volunteer is then responsible for going with that person and checking on him to see that he gets the care and the love and the comfort he deserves and that is really not being given at that point in time.

KEEP COMMUNICATIONS CHANNELS OPEN

It is very, very important to always keep the channels of communication open between yourself, the people who are working for you, and your clients. Problems, when they arise, should be solved as quickly as possible. In this regard, staff meetings are particularly important.

You also must be sensitive to your volunteers' attitudes and their individuality. We had a problem recently when we decided it might be a good idea, in the course of our work, to stop, take a deep breath, and have a moment of silence in memory of our clients, similar to the sort of remembrance that has been done in parades held recently in New York. And suddenly we found ourselves confronted with a "separation-of-church-and-state" issue, with some people very upset that we were bringing "religion" into the kitchen. So we immediately cut that out.

The growth of every organization is dependent on the attitudes and ideas that are presented by its volunteers. If you are not open to your volunteers' suggestions—actually, the moment of silence was a volunteer idea—then you will never be able to know what may be a good idea and what may be a bad one.

You must also remember that volunteers are not peons. You cannot say to a volunteer, "Go clean that stove, because I don't have time." You need to be able to put on your apron and gloves, grab the Easy Off, get down on your hands and knees, and scrub the oven right along with the volunteers.

Volunteers need to be privy to every piece of information about the organization. After all, they have applied for a position with your group because they are interested in what you are doing, and they deserve respect for giving you their time. Interestingly, and perhaps not coincidentally, more than 50 percent of the staff of God's Love We Deliver began working with the organization as volunteers.

Recently, we were holding a staff meeting and really getting hot and bothered about some particular issue when a new volunteer came in from Long Island. It was her first day and she really wanted to get to work, but she sat down in the staff meeting and we just carried on with our discussion. As a result, because we had aired all our ideas in front of her and treated her as an equal, she offered to help us connect with some Long Island foundations as sources of funding.

Not only should you always treat your volunteers well, you should also always keep them well-informed. Volunteers are your best press representatives and should be able to speak for you as clearly as you can speak for your own organization. Send them all of your press clippings and your newsletters. Throw parties for them and send them flowers on their birthdays. Tell them how much you love them and they will be very happy and very grateful.

Finally, in managing volunteers, it is important to remember that we are not in a them-and-us situation. I will close with a simple analogy: Working in an organization as a volunteer is similar to performing in an orchestra. And the performance is not about the conductor, nor about the first violinist; it is not about the symphony, nor even about the composer. Close you eyes and listen to the music as it is played. That is the message: It is the ensemble effort. ❑

WE HOLD. WE HUG. WE CRY.

Chapter 8

Goldwater Memorial Hospital: Teamwork in a Chronic Care Unit

BOB SINNAEVE

Bob Sinnaeve, the retired president of a vocational school, is a volunteer on the AIDS long-term care unit at Goldwater Memorial Hospital, a municipal chronic care facility located on Roosevelt Island, in New York City's East River. Mr. Sinnaeve has been at Goldwater since the inception of the volunteer program there in August 1987. In addition to his work at Goldwater, Mr. Sinnaeve was also, until recently, director of volunteers for the Community Research Initiative, an organization involved in sponsoring and organizing clinical trials of new drugs for the treatment of persons with AIDS and HIV-related illnesses.

Goldwater Memorial Hospital is a 912-bed long-term care and rehabilitation hospital for the chronically ill and physically disabled. It is a facility belonging to the New York City Health and Hospitals Corporation, the city's municipal hospital system. At Goldwater, there is a separate 32-bed unit for AIDS patients who need chronic care. The program is expected to expand to 64 beds by early 1989, so the need for volunteers is quite obvious.

Our AIDS patients at Goldwater are sent to us only by referral from other New York City municipal and voluntary hospitals, and some come to us from Rikers Island, the city prison. Our patient population ranges from the very frail, who may need a great deal of care and are not very responsive, to those who are stronger, respond well, and need relatively little help caring for themselves. Thus, the care needs of our patients range from minimal to intense as their conditions fluctuate.

A VOLUNTEER TEAM APPROACH

Volunteer recruitment at Goldwater is a continuous process conducted by the hospital's volunteer director, Tammy Carlisle. The volunteer program at Goldwater is set up on a team concept, usually with two or more members per team. Volunteers are asked to make a commitment of at least three hours per week to the program.

Training is provided before volunteer service begins, and a very extensive training manual has been developed for the volunteers. Other informational and training resources also are provided frequently to volunteers, updating the AIDS situation and keeping them informed about newer approaches to patient care that volunteers may provide. In addition, volunteers receive public transportation fare and are offered lunch. Not all volunteers take advantage of these perks, but they are offered to everyone.

Since all of our patients are together in a discrete unit, our volunteers can provide a full range of services to address most of the patients' needs. We feed patients, make coffee, and provide recreation programs on and off the unit. Clothing is available for those patients who need essential items. Volunteers act as advocates for family problems and for complaints with Social Security, Medicare, and Medicaid benefits and entitlements. We assist with dietary problems. We paint. We write. We sing. We hold special holiday events. We hold. We hug. We cry.

We provide any special services that may be needed, for example, for the blind or the deaf. Recently, at the patients' request, we arranged and held a memorial service for all those from the unit who have died.

There is also a marvelous interlocking relationship support system among the patients themselves. Since they are all in the same unit, they visit each other and support and help each other. Patients are not confined to the AIDS unit at Goldwater but are able to travel throughout the hospital, to attend any hospital function, and to take advantage of any service that the hospital provides. They are not isolated and are completely free and encouraged to visit other parts of the hospital. Since the patients are all in one unit, however, special functions can be held very quickly and very conveniently for them. They don't have to be moved all over the place for a special group function.

VOLUNTEER ASSIGNMENTS AND SUPPORT

AIDS volunteers at Goldwater are expected to address the full range of needs for the entire unit, not just for one individual. They are assigned not to one, single patient but to everyone on the unit. That is a heroic task and a challenge for our volunteers, but they meet this challenge, and it is amazing that they can offer their services to so many people.

Progress notes on each patient are written up and maintained by the volunteers as a working tool to assist both other volunteers who will interact with the patient and the hospital professional staff, who review the notes and follow up, if appropriate.

Of course, we do have problems. Who doesn't? For example, we have a shortage of nurses. In some cases we don't have any TV sets for the patients. And we need more volunteers.

Perhaps our greatest problem currently is how to bridge the cultural and social gap that sometimes exists between volunteers and patients who are admitted with histories of social problems or troubled backgrounds. While the volunteers are rightly advised of any potentially violent situations, it can be intimidating for some of them to handle.

This is where our volunteer support system and our team concept come into critical play. Volunteers call each other at home. They go in on extra days to be with each other, to talk, and to resolve problems as they arise. Names, addresses, and telephone numbers are provided by the volunteer office so that easy communication between volunteers is encouraged. The volunteer director also calls volunteers from time to time to discuss current situations and to identify any problem areas.

A volunteer bulletin is published by the director to keep everyone informed regarding pending changes in the wards. Future social activities and functions are publicized so volunteers can participate fully. In order to keep volunteers informed regarding a death on the ward, a note is sent to alert the volunteers whenever we lose a patient. In addition, when a death is expected, the volunteers are alerted if a particular patient is experiencing difficulty and may need special support. This assists in preventing burnout and sudden bereavement when the loss occurs.

Our AIDS unit volunteers are permitted access to the hospital, day or night; if they want to go in at three in the morning, they have access. They have their own identification cards and keys to their own supply facilities. They have a refrigerator and a coffee maker and constant access to refreshments. No other unit in the hospital has these amenities or this degree of autonomy, and we are able to provide unique services for our particular patients.

THE REALITY OF AIDS

Because most of our patients are in the end stages of disease, we also have in our volunteer training at Goldwater a special emphasis on preparing for death and dying. It is very rare that we ever discharge a patient from the AIDS long-term care unit; sadly, I know of only one who has been discharged since I have been at Goldwater. Some weeks, we have been devastated, losing five or six patients, but, recently we haven't lost one.

However, even if our patients' condition improves enough to make discharge to the community a possibility, where do we send them? We have a couple of patients now who are well enough and could be discharged but they have no place to go. They are homeless, abandoned by family and friends. We observe few or no visitors for most of our patients, thus the volunteers become their only contact with the outside world and their only friends—beyond the doctors, nurses, and patient advocates—on the unit.

Our volunteers at Goldwater are very dedicated and loyal people, and our director, Tammy Carlisle, has given me a quote that she likes to use to encourage all of us. It's from Erma Brombeck. She wrote that "volunteers are like yachts. They could stay moored where it's safe and still and still justify their being. But they choose to cut through the rough waters, ride out storms, and take chances. They have style and they are fiercely independent." ❑

During Volunteer Training sessions, we have a person with AIDS speak about living with AIDS.

Chapter 9

Project BRAVO: A Boroughwide Effort in the Bronx

BRIDGET POUST

Originally a volunteer with the Bronx AIDS Volunteer Organization, Bridget Poust became the project coordinator for Project BRAVO, as this volunteer program is called for short. Headquartered at Montefiore Medical Center, the BRAVO program began in order to serve and support persons with AIDS at Montefiore and at North Central Bronx Hospital, a municipal facility affiliated with Montefiore, using a diverse group of volunteers, including recovering intravenous drug users from methadone maintenance clinics as well as HIV-positive persons and persons with AIDS. BRAVO has since expanded to also serve PWAs at Bronx-Lebanon Hospital Center, Bronx Municipal Hospital Center, and St. Barnabas Hospital.

The Bronx is the northern borough of the City of New York. It has a population of about 1.1 million people, with a variety of ethnic communities and peoples. The South Bronx, with about 50 percent of the borough's total population, is notorious for its poverty and its massive housing destruction. Demographically, the South Bronx is predominantly black and Hispanic and has a high prevalence of HIV-positive persons and persons with AIDS-related conditions and AIDS itself.

Project BRAVO, originally called the Bronx AIDS Volunteer Enterprise (Project BRAVE), was created in 1986 to establish support networks for Bronx AIDS patients, many of whom come from impoverished and isolated home situations, or may, in fact, be homeless. While similar efforts have been organized and undertaken in Manhattan by the Gay Men's Health Crisis, for a predominantly gay population, until Project BRAVO, the Bronx had no such support system for persons with AIDS (PWAs).

At Montefiore Medical Center, our patients are predominantly intravenous drug abusers and/or their sexual partners, a group that has little or nothing in the way of advocacy skills or political clout.

In 1985 at Montefiore, the Division of Community Health, in the Department of Epidemiology and Social Medicine, launched an intensive AIDS education and research project at the hospital's three methadone maintenance clinics, serving about 1,000 patients. This population had become increasingly alarmed and demoralized by the threat of AIDS, and, in response, both clinic staff and patients wanted to do something to prevent the future spread of the epidemic and to help those persons already stricken.

In addition, the Department of Epidemiology and Social Medicine wanted to find a way to nurture and mobilize the altruistic feelings of some of our population to be of service to AIDS patients. It was hoped that in the process volunteers would find ways to empower themselves and become more confident. It was also evident that the most natural and effective way to help our PWAs in the Bronx was to recruit and utilize volunteers who matched them in terms of ethnic background, shared values, and economic class.

To pursue these objectives, Project BRAVO got under way in February 1986, initially with the training and supervision of four methadone maintenance clients as buddies for AIDS patients. The "buddies" would visit PWAs, run errands for them, baby-sit for those with children, act as patient advocates, and perform other services. In

September 1986, the program was expanded to admit people from all walks of life and all backgrounds, anyone with the willingness to serve as a volunteer.

This cooperative Montefiore Medical Center-North Central Bronx Hospital project is a collaboration of four departments within the medical center: the Department of Epidemiology and Social Medicine, which operates the methadone program and conceived the original project plan; the Department of Medicine, which provides care for the PWAs; the Department of Social Services, which provides support and supervision to the volunteers; and the Department of Volunteer Services, which processes volunteer applicants, maintains activity records for administration, and participates in training new volunteers.

Today, the project, though still small, has grown to involve more than 12 active volunteers who have direct contact with patients both in the hospital and in their homes. We also have a much larger number of people who are "on call," who have telephone contact with patients and who help with recreational projects, at parties, in community outreach and volunteer recruitment, but who may not directly visit patients on a regular basis. Their activities include serving as "friendly visitors," escorting PWAs to support groups, assisting with arts and crafts and recreation groups, and bringing home-cooked meals. Through the telephone contacts, assessments of current living situations and physical health can be made and companionship offered.

Our volunteers make up a diverse community group, including methadone maintenance clients, gay men and lesbians, working people, and people on public assistance. We have black, Hispanic, and white members. Our volunteers generally reflect the population that we serve in the Bronx.

The BRAVO program contains several components: recruitment, screening, training, support and supervision, referral, and assignment.

RECRUITMENT

Recruitment is a continuing process at Project BRAVO, as it is in other volunteer organizations. As volunteers leave the program, for a variety of reasons such as burnout or changes in their personal lives, it becomes imperative to look for new sources of help.

Volunteers are recruited in many different ways. Some have lost family or friends to AIDS. Some are PWAs themselves. Some hear about us in their churches. Some are students from area colleges. Some are from the local methadone maintenance clinics. Our criteria for selection of methadone users as volunteers is that they be free from any other drugs and be responsible in honoring their commitment to patients and the project.

Quite a few of the volunteers who come to us do so out of a deep spiritual commitment to help in this crisis.

This diversity of origins and motivations results in an interesting mix of people who, in more ordinary times, might never have met to work together in such an intimate and poignant way.

We have come to recognize that if we want to enlist other people's help, we must take the initial step to educate them about AIDS, the medical facts and psychosocial effects, as well as to publicize our project. This fulfills the needs of both the community and the project. Obviously, people will not think of lending a helping hand if they are afraid themselves of catching AIDS. Community outreach is done at churches and other community groups and agencies. In our outreach programs, we present the medical facts about AIDS and the epidemiology of AIDS in the Bronx. We also have active volunteers speak about their work.

SCREENING

Our individual screening of new volunteers includes an assessment of their motivation and readiness to do the project's AIDS volunteer work as well as of the degree of involvement they are willing to undertake personally in the program. Project BRAVO differs somewhat from the more traditional volunteer programs in that we are eager to take a chance on almost anyone as long as they show a seemingly sincere desire to help, are reasonably free from bias toward patients, are off all drugs except methadone—if they are in the methadone program—and demonstrate a determination to follow through on their commitments.

This lack of restrictions has led us to accept provisionally some volunteers with marked personal problems and some people with strong religious beliefs. In such cases, we try to closely supervise their initial contacts with patients to make sure neither the volunteer nor the patient is overwhelmed by the contact. Of course, we are also bound to comply with hospital policy, which requires pre-service medical screening—that is, physical exams—for the protection of both volunteers and the persons with AIDS whom they serve.

TRAINING

In our initial orientation program, volunteers are exposed to the medical, psychosocial, and epidemiological aspects of AIDS as well as to the implications of working with terminally ill persons. Part of the process involves an open dialogue among new volunteers, AIDS patients, and volunteers who have prior experience working in the hospital with PWAs. This is in keeping with our philosophy that this project should start to remove hierarchical barriers wherever possible and help its participants to grow as persons and leaders.

On the first day of training, we introduce a staff person from hospital infection control. Infection control procedures are explained: the different blood and body fluid precautions, the labels and stickers, the concepts of airborne isolation versus contact isolation, and the many different things one may encounter working in the hospital.

Next, an epidemiologist discusses the pattern of the epidemic in the Bronx. This is a very important piece of the training program. Many people do not volunteer to do AIDS work because they think that AIDS has nothing to do with them; they don't know anyone with the disease. But after someone hears our epidemiologist, they can't go home and still feel the same way. It is projected that soon 20 percent of the male population in the Bronx will be HIV–positive. And a growing percentage of young Bronx women is also infected with HIV. So, eventually, everyone is going to know someone who has AIDS.

Our first day of training also includes seasoned volunteers who share their experiences working with PWAs and the different situations they have encountered. For example, a volunteer has shared the experience of bringing into the emergency room, in the middle of the night, a patient who would not have come in alone. Another volunteer might relate how a patient repeatedly kept sending him to the store and each time kept saying, "You didn't get the right thing!" Finally, in anger and despair, the volunteer gave up. In another incident that trainees may hear about, a volunteer, in a sincere desire to be helpful, violated our prime directive of no personal medical care, by helping to remove mucus that was obstructing a patient's air passages.

On our second day of training, we have a medical doctor or a physician's assistant from our hospital AIDS team. They talk about HIV transmission, HIV-disease symptoms, the different opportunistic infections associated with HIV and AIDS, and other medical matters that volunteers need to know about, and answer volunteers' questions.

We have someone who speaks on death and dying. Very often it is our director of volunteer services or one of the AIDS chaplains. We find that people cannot be effective working with a terminally ill population if they have not come to terms with their own feelings regarding death and dying. This is usually a very moving piece of our volunteer training.

We also have a person with AIDS and his or her family members speak about living with AIDS and engage in dialogue with the group of volunteers in training. No number of professionals can have the impact on a group of new volunteers that a person with AIDS and his or her family members can have. No one can sensitize volunteers quicker to the needs and feelings of someone with AIDS than those who are living with the experience themselves.

SUPPORT AND SUPERVISION

Continual help to volunteers is provided by support and supervision meetings, which are currently held every other week and where experiences, difficult-to-face feelings, problems, and dilemmas are shared and a safe climate for self-exploration and growth is fostered. These meetings provide a setting, a home base, where all types of experiences can be safely shared and problems frequently solved. Problems often are related to hospital operations and procedures with which a volunteer may not be acquainted.

REFERRAL AND ASSIGNMENT

Since Project BRAVO is affiliated with a medical institution with an AIDS service unit, patient referrals come to us through any member of the hospital's AIDS team. Referrals could come from the doctor, the nurse, the pharmacist, the chaplain, or from anyone who has met the patient, such as myself, other volunteers, or other patients themselves. Based on the compendium of their knowledge of the patient, along with ours and what we have learned about the volunteers, we endeavor to match patient and volunteer.

VOLUNTEER ROLES

Educational and recreational projects are jointly undertaken by persons with AIDS, their families, and the volunteers. For example, volunteers have helped to set up a meeting for PWAs with a speaker on nutrition and to organize a summer picnic in the Bronx Botanical Gardens, where transportation and refreshments were provided for patients, their families, and their friends.

Project BRAVO allows for a wide range of volunteer involvement, from the most minimal to the most extensive, both in direct patient contact and in planning and development. For instance, some of our volunteers may prefer to organize activities that include contact with local schools and churches or recreational and educational forums for patients. Some volunteers may want to shop for patients, collect needed furniture, or be a buddy to a particular patient and do whatever is necessary. They may help patients fight for their different entitlements and benefits, or argue with their landlord or with the telephone company that wants to cut off service.

Volunteers have been instrumental in having locks repaired on apartment doors when, prior to the volunteer's involvement, the PWA's landlord would not do the repairs. Volunteers have also managed to obtain the funds to send a patient home to St. Thomas for a last visit with the patient's children.

Other volunteers serve as community health educators, opening their homes once a month to people from their neighborhoods who are anxious to get the facts about AIDS but would never present themselves to an agency, would never read a brochure, but feel very safe in their neighbor's house, where they go all the time anyway. In this way, they are better able to hear and absorb what is being told to them because it is in a non-threatening, familiar, and safe environment.

COMMUNITY OUTREACH

We plan to continue developing strong ties to the black and Hispanic communities, especially through churches, which, in the Bronx, are probably the only social institutions that are still intact. We have, for example, made a valuable connection with a local church leader, a woman who has a large feeding program for the destitute that serves 1,000 people each week at Love Gospel Assembly. After participating in our initial orientation program, she pledged to help us in telephoning patients and providing us with food and cakes and beverages for different holiday parties that Project BRAVO staff and volunteers host for people with AIDS.

To counteract the stigmatizing and scapegoating of persons with AIDS, we continually look for opportunities to build bridges to the mainstream middle-class communities. We have had outstanding support from Trinity Baptist Church, which is a predominantly middle-class black church in the northeast section of the Bronx. They have become part of our "network" and now have a weekly Thursday lunch program where groceries and clothing are made available. We also want to recruit more volunteers from the methadone clinics.

As has been done in both Manhattan and San Francisco, we would also like to develop a community space in the Bronx where persons with AIDS can drop in, be served a free meal, socialize, get assistance, or develop their own programs.

The hospitalized person at Montefiore or North Central Bronx is quite often in the institution for long period of time because he or she has no place to go on discharge. And life in the hospital can be very boring. At North Central Bronx, a New York City Health and Hospitals Corporation municipal facility, for example, there are no telephones in the rooms, many of the patients cannot afford television rental, and there is only one AIDS social worker. Some sort of recreational project is definitely needed, and we hope to recruit more volunteers who have an interest in helping us develop these sorts of projects.

A Special Project Fund grant from the United Hospital Fund has allowed us to expand Project BRAVO and extend the volunteer program to Bronx-Lebanon Hospital Center, Bronx Municipal Hospital Center, and St. Barnabas Hospital. Through a Department of Health grant, we have been able to hire a community outreach worker who will organize AIDS education workshops in the communities around each BRAVO hospital.

PROBLEMS

What are some of our difficulties? Our number one difficulty, as it is probably everyone's, is funding. As is often the case with this sort of program, funding is precarious from year to year. Until recently, we did not have a clear line of fiscal responsibility for operating expenses and we have to continually justify our financial needs and finesse our way through the system. And operating a grant-supported program means that while we continue to make long-range plans, we understand that we must be aware of funding cycles and the need to satisfy funders' criteria.

Second is the recruitment problem. In marked contrast to other volunteer programs in the world of AIDS, which tend to draw recruits heavily from the gay population and from among straight middle-class women or well-educated minorities, we seem to attract more community college students and working-class people. Generally, these are people in difficult economic circumstances. Recruitment of persons in this situation has to take into account the limits on their availability and their own struggles in balancing the pressing demands of work, family, school, and their deeply felt commitment to help in this crisis.

Recruiting from methadone clinics is not easy. Our volunteers from these clinics are from groups severely stigmatized and disparaged by the outside world. Many internalize these attitudes and initially present themselves with self-doubts, fears, and ambivalence. Working out these dilemmas is a continuing issue for us, but, paradoxically, our volunteers from the methadone maintenance programs have proved to be some of our best. They have been compassionate, dedicated, and tireless in their willingness to give of themselves and, in the process, have emerged as self-assertive and self-actualizing, demonstrating that this work can have unforeseen beneficial consequences. Several of our methadone volunteers have obtained or are now actively seeking employment, a byproduct of their increased self-esteem and the higher aspirations gained, in part, from our program.

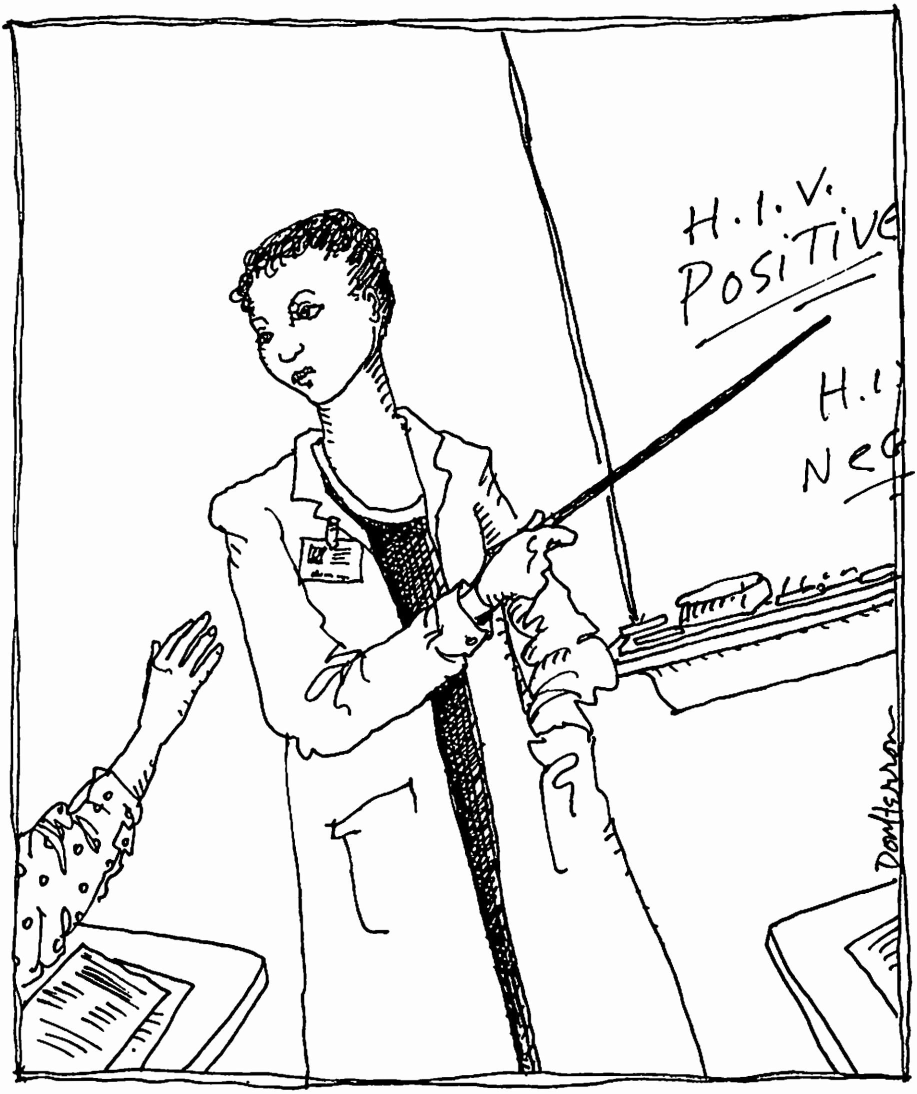
Program volunteer membership shifts continually because of burnout and other factors. Burnout is, of course, a consequence of the heavy emotional toll involvement in AIDS takes on the lives of the volunteers. As the volunteers' lives and needs change, we have to look constantly for new recruits and encourage new sources of volunteer involvement.

A third set of problems is institutional in nature. We are a hospital-based project, yet we are a very nontraditional volunteer program with particular nontraditional needs. Our needs often conflict with the needs of the institution. For example, volunteers must get the necessary medical clearances on their own time and at their own expense; the hospital's employee health service does not provide the physical exam. Volunteers must have it, but we cannot provide it. Similarly, hospital identification badges are required, but the hospital security office, which provides the badges, is open only from 8 a.m. to 4 p.m., a time when most of our volunteers are at work or in school. These sorts of situations make it difficult and inconvenient for volunteers to obtain necessary items. And problems like these have caused us to lose potential volunteers, because if someone is working or going to school and they want to give their time, they do not need to spend their valuable time running around needlessly.

But volunteers are still the best. And whatever the obstacles and the problems, volunteers who work with persons with AIDS are the best of the best.

WHAT WE HAVE LEARNED

Project BRAVO has shown that the volunteers who participate in today's AIDS programs can be very different from yesterday's more traditional volunteers, and that they require different recruitment, different assessment, different training, and different kinds of volunteer support. This has far-reaching implications both for the AIDS volunteer programs themselves and for the institutions in which they are located. It also demands a new look at the rule book for volunteers and for the utilization of volunteers. ❑



IN OUR ORIENTATION FOR VOLUNTEERS
WE HAVE A NURSE / EPIDEMIOLOGIST
PRESENT TO ANSWER ANY QUESTIONS.

Chapter 10

St. Luke's-Roosevelt Hospital Center: A New Breed of Volunteers

VIRGINIA D. CROSBY

Virginia Crosby is Corporate Director of Volunteers at St. Luke's-Roosevelt Hospital Center, a voluntary institution in New York City. Formerly, Ms. Crosby was volunteer director at Calvary Hospital, a cancer care facility in the Bronx, where she developed programs that focused on the special needs of terminally ill patients and their families. St. Luke's-Roosevelt Hospital Center consists of two facilities on the west side of Manhattan: the Roosevelt Division site, located at 59th Street and Columbus Avenue, and St. Luke's Division, at Amsterdam Avenue and 114th Street. The AIDS program serves both sites.

The medical, social, and psychological crises precipitated by an AIDS diagnosis have become increasingly well known in the hospital. Because AIDS is by and large a sexually transmitted or drug-use-related disease with a high fatality rate and a high degree of stigmatization, it elicits in the patients—and often in those close to them—emotions of panic, guilt, shame, anxiety, depression, and isolation. Uncertainty about the prognosis, the threat of premature death, lifestyle changes, and physical degeneration make living with AIDS especially stressful.

Persons with AIDS (PWAs) lose control of their bodies and often feel desperate, their hospitalizations are frequently prolonged, and complications can cause much loneliness and depression. It is not unusual for patients to lose their income, homes, insurance benefits, family, friends, and their capacity for hope, and to feel extremely isolated.

Moreover, in the early days of the AIDS epidemic, PWAs needing institutional support services often encountered overt discrimination even among some hospital staff because of fear of contagion or disapproval of their lifestyle. Food trays were sometimes left outside patients' doors and housekeeping personnel were reluctant to clean their rooms, further increasing PWAs' sense of rejection and isolation.

Regular hospital volunteers also often expressed either no interest in offering support to PWAs or outright refusal to become involved with them. Many of the regular volunteers were terrified of the AIDS patients and quite a few made it known that they would not go into an AIDS patient's room. Even though they have had in-service AIDS education, the majority of regular volunteers remain quite squeamish about PWAs. And AIDS patients really do not need to have to deal with that sort of thing; for them, life is hard enough without having another person with a negative attitude come through the door.

In the fall of 1985, when St. Luke's-Roosevelt Hospital Center had an average daily census of 20 to 30 AIDS inpatients at its Roosevelt Division site, the need to develop special programs to meet the psychosocial needs of these patients and their friends and families, so different from those of the ordinary hospital inpatients, became apparent. The improvement of social support systems for PWAs while they are within the institution could, it was felt, reduce psychosocial distress and, to some degree, physical morbidity and mortality.

The AIDS "Friendly Visitor" program was subsequently conceived of and developed by the Department of Volunteers and the Department of Social Work to recruit, interview, train, and place appropriate volunteers to work with and support patients with AIDS, providing psychosocial support, entitlement information, advocacy routes, and friendship to PWAs in Roosevelt who might not otherwise have any. At the time the program was being developed, there was no designated AIDS unit and PWAs were distributed throughout the hospital's medical/surgical floors.

OVERCOMING RESISTANCE

Initially, there was some institutional resistance at Roosevelt to the idea of an AIDS-specific volunteer program, and volunteer directors in general can expect that there will be people in favor of such programs and those who are opposed, for a variety of reasons. One of the concerns raised initially was the question of maintaining confidentiality about the patient's diagnosis, a concern that is moot for patients in an AIDS-only unit but that is an important issue for an institution with PWAs scattered throughout its floors. Presence in the unit immediately identifies the patient as a PWA, so it is all right for an AIDS volunteer to go there and begin doing things. Otherwise, the project needs to begin small and be kept low-key while the institution finds its own way of assimilating these volunteers. At St. Luke's-Roosevelt, we decided that, despite the program's rationale, the term AIDS would not be used and that the volunteers would be called simply "Friendly Visitors," not "AIDS Friendly Visitors."

Public relations departments and others concerned about public opinion may express nervousness about an AIDS-related volunteer program or any project that draws attention to the fact that the hospital is caring for AIDS inpatients. Some administrators worry, for example, that if their institution becomes known as an AIDS hospital, other patients will stay away or the institution will be swamped by PWAs looking for treatment.

Volunteer directors planning an AIDS program need to be prepared to address and allay these sorts of fears, and it helps to identify allies and cultivate support from others in the administrative hierarchy.

Fortunately, at St. Luke's-Roosevelt, an institution that was already dealing quite well with PWAs, hospital administrators were supportive and approved the undertaking of a demonstration project. The vice president for social work services, for instance, was able to see that volunteers could support and supplement his social workers, who were overburdened and overstressed as a result of the increasing AIDS patient census.

It is important to touch base with all the department heads who might be affected by a new program, and to make sure that staff do not feel threatened in any way. Some staff may be more territorial than others when it comes to volunteers, but turf problems can usually be defused if the input of those concerned is sought and listened to. During the planning phase at St. Luke's-Roosevelt, the program was explained to the head of nursing and she was asked whether she had anything to add to it, or any objections to raise.

Of course, if the hospital administration is not interested in having this sort of program, it will be hard to carry out. But administrators' resistance might be overcome if they can be convinced that the program will be implemented with thoughtfulness and care, and that it can benefit the patients—and we know from experience that it does indeed benefit the patients in a tremendous way. It also benefits the staff and offers an opportunity to improve community relations.

After getting approval from the administration at St. Luke's-Roosevelt, an application for support of the AIDS Friendly Visitor project was made to the United Hospital Fund's Special Project Fund grant program. Once the grant was approved, the next step was to begin recruiting and screening potential volunteers.

RECRUITING AND SCREENING VOLUNTEERS

Volunteers were initially recruited through the newsletters of community organizations such as SAGE (Senior Action in a Gay Environment) and GMHC (Gay Men's Health Crisis), and through church bulletins and other volunteer and social agencies. By the fall of 1986, we ceased active recruitment; we found that prospective volunteers were learning about the program by word-of-mouth, and we had a waiting list.

In the beginning, we wanted a special core group of sensitive and intelligent volunteers and we looked for people who were relaxed, had a good sense of humor, and could be a good guest at the bedside of a patient.

AIDS volunteers for the most part are very different from the regular hospital volunteers that most volunteer directors are familiar with. They tend to be younger, very sophisticated, very highly educated, very stable people. They tend to be very sincere about what they are doing and they don't really want to be thanked for it. They come there committed to do a job and they are very responsible to that commitment. And they don't complain about the usual things volunteers complain about, such as the elevators, the temperature, or that the coffee is too strong or too weak.

When people come to us and say they want to be an AIDS volunteer, we interview them carefully. If they were not interested in working with PWAs, they would not be there in the first place, but in the screening process, we ask them to tell us exactly why they have come and why they want to work with AIDS patients.

We get a variety of reasons, such as, "I feel like I'm not doing anything [about the AIDS epidemic] and would like to do something," or, "I have friends who have died," or, simply, "I am just very concerned." A lot of the time in the interview, men will just say frankly that they are gay and want to help.

We are very careful about who comes in, because PWAs in the hospital are usually very sick and they really do not need any more aggravation in their lives. We look for a sense of humor because it is vital to this sort of volunteering. We make it clear to people when they come to volunteer that everyone they make friends with on the AIDS unit is going to die eventually. Some people take exception to that but it is important that prospective volunteers know that they must be able to deal with the realities of death and dying.

We stay on the lookout for the person who seems to have a personal agenda or appears to be manipulative or talks too much. The last thing a patient really wants is somebody hanging around and yattering away.

Finally, we rely on instinct, on gut reaction to the person, asking ourselves, "If I were a patient in the hospital, would I want this person in the room with me?" And if we do not like someone, we do not take that person. Of course, we may sometimes turn away someone who might be good, and that is too bad. But whenever we have taken someone we felt hesitant about, it has backfired and the person did not work out.

By and large, most of those who come to us to volunteer do well. But when we turn people down, we make it clear that while we think they are very nice people, we do not think that ours is the volunteer program for them. One has to be tactful and not hurt people's feelings. However, when someone comes in with a religious agenda—and we have had quite a few—we just tell them, "Well, you have an agenda and this is not the place for it."

Another issue that may need to be addressed is that of the HIV-positive volunteer or one who has had an episode of HIV-related illness. We do not, of course, discriminate against seropositive persons, but the hospital floor is not a very healthy environment for persons who have lowered resistance to infectious agents and pathogens. Working directly with AIDS patients who have opportunistic infections may put the immuno-compromised volunteer at risk for illness. It may also be a depressing experience for a seropositive volunteer or one who has been sick to be constantly confronted with patients who are very ill and with whom they can be expected to identify. We prefer having these volunteers in the office doing paperwork or making phone calls. Some may have strong feelings that they should be working on the floor, but when we talk to them about the realities of the situation, they realize that it is not a good idea.

ORIENTATION AND TRAINING

After the screening process, we schedule a volunteer orientation meeting just as soon as we have enough new people to make it worthwhile. Attendance at the orientation is mandatory.

Because most of our AIDS volunteers work at regular jobs during the week, orientation is held on a Saturday. I do not believe in long orientations and try to keep them short, to about two hours. I think over-orientation tends to make volunteers feel over-qualified or that they are a sort of "mini" social worker, while we want our volunteers there just to be a friend, as anyone else would be if they were visiting someone they knew in the hospital.

In the orientation process, we begin by having everyone come in, sit down, and talk to each other about who they are, why they came, why they are concerned about people with AIDS, about any fears they may have about volunteering, and any particular thing they would like to know about or discuss.

I provide a psychosocial overview of the AIDS patients' situation and talk about what it is like to be a patient in our hospital. I explain that the volunteers are basically there to be the patient's friend, a "guest" at the bedside, and that they should not feel over-qualified or read too much into things that transpire during their visits.

Orientation also includes a component on AIDS epidemiology, mythology, and infection control. We always try to have a nurse/epidemiologist present to talk about HIV infection and illness and to answer any questions that come up. As sophisticated as our volunteers tend to be, they still have questions such as, "If a patient spits in my face by accident and some of the spit gets in my eyes, will I get AIDS?" These concerns are understandable and need to be professionally addressed.

We discuss the basics of what being a Friendly Visitor is all about, institutional rules and regulations for volunteers, what is expected of volunteers in the program, and what they are *not* allowed to do—nail-cutting and bed pans, for example. We tell them never to mention AIDS by name, because it is never disclosed to the patients that the volunteer program is strictly for PWAs and some patients may be awaiting the results of a procedure to determine a diagnosis. Another reason not to mention AIDS is that some patients or their families may not be accepting of their illness, and the issue should not be forced.

Volunteers are assigned to see many patients, rather than form a single relationship with a particular patient, and they can expect to have close, even very deep and intense relationships with some patients and surface friendships with others. In orientation, we talk about how close volunteers can get and how careful they have to be not to become overburdened. We tell them that if staff feels they are burning out or getting overly involved, we will pull them back. We point out that we do not allow people to come in more than once a week; otherwise, they become too involved and then become a burden to the patient. We also emphasize that when *they* feel the need to pull back, they should let staff know, and not simply disappear.

We talk about manipulative patients, how volunteers can recognize when they are being manipulated, and how to avoid being manipulated. Patients, not only AIDS patients but all of us when we are sick, can become very manipulative. My experience at Calvary Hospital had shown me that this is particularly true of terminally ill patients. When they are in the hospital, they have very little or no control over what is happening to them. One of the only opportunities for control that they have left is to manipulate people, and it is easy for volunteers—by the very nature of what they are already doing—to be manipulated.

When a volunteer announces that he is leaving and the patient says, "Well, before you go, could you just..." or "Where are you going? Out to dinner? Well, have a good time [*while I am here in the hospital*]" and so forth, then the volunteer is being manipulated.

Thus, we tell volunteers to simply say, "I have to go now." Never lie to a patient, never make an excuse, such as "I have to go to the theater." Just say, "I have to go."

Volunteers are also told that if patients ask for their phone number they are to tell them that the volunteer director forbids exchanging numbers and the volunteers who do so will be "fired." In this situation, volunteers are instructed to tell the patient that the volunteer director will be glad to get in touch with the volunteer for the patient.

Sexuality is also discussed in orientation because what often surprises volunteers in the beginning is that some patients will make passes at them. It is important for volunteers to know that this may happen, to be alert to what is going on, and to be able to deal with this sort of event.

We know that some of our volunteers may keep up a relationship and visit some patients at home after they are discharged. We try to discourage this and tend to be very strict about it during orientation, but, practically speaking, it is going to occur. Volunteers are going to meet wonderful people and care about them and it might be normal to see them at home. But we worry about volunteers getting in over their heads and suddenly having someone calling them at 4:00 a.m. and saying, "Come over here right away," or "I need this," and "I need that."

Beyond our own training material, through the generosity of one of our volunteers, we have the complete video training manual from the Shanti Project, a San Francisco organization that provides support for PWAs. It is an excellent educational tool and volunteers can borrow any of its 22 videocassettes for their own viewing.

VOLUNTEER ASSIGNMENT AND ROLES

After orientation and training, volunteers begin visiting the patients. In setting hours, we try to be flexible and do not insist on a specific volunteer commitment to a set number of hours per week. Volunteers tell us what hours are good for them and we put them on the schedule for those hours. Even if it is 6:00 in the morning or 10:00 at night, we will find something for the volunteer to do.

Patient referrals come to the volunteer office from the nursing, social work, and religious services, through the patient representative's office or various clinical specialists, and through a confidential list provided by the nurse epidemiologists. Patients are interviewed to determine their desire for volunteer support, and we try to match volunteers and patients with similar or compatible interests.

On their regularly scheduled day and time, volunteers report to the Department of Volunteers and receive their assigned patients from the volunteer coordinator. While we tell volunteers that, as a rule, they may not report more than once a week, exceptions are made during holiday periods. On average, volunteers commit themselves to three to four hours visiting per week. The time volunteers spend with individual patients is not rigidly set but allowed to vary naturally according to the patient's ability to be visited and the volunteer's ability to visit. Volunteers are required to wear a smock or jacket and hospital identification badge at all times.

Although this is essentially a visiting program, the range of things that our AIDS volunteers do is really quite remarkable. In planning the program, we thought that these volunteers would probably just go up and sit and maybe hold the patient's hand, as volunteers had done in the palliative care center at Calvary. But as the program has grown—along with the number of AIDS patients—so has volunteer involvement with the patients. We did not realize, for instance, that beyond offering supportive friendship, helping with entitlements, and advocating for patients, volunteers would be running errands, filling special food requests or cooking meals, doing patients' laundry, showing movies on a VCR, bringing in newspapers, magazines, and other special items requested by patients, talking to relatives in other countries, providing support and reassurance to family, lovers, and friends of patients, arranging funerals and flying in family members, and so on. Overall, our AIDS volunteers have taken a very aggressive—and a very caringly aggressive—role in our patients' lives.

Volunteers document each patient visit in progress-note fashion in a log that is kept in the volunteer office. They record such information as day and length of visit, the patient's situation, their observations, and plans for the next visit. The log is available for other volunteers to consult when they are going to see a patient and need to be up-to-date on that patient's circumstances. Notes on discharged patients are removed and kept in confidential files in the volunteer department to be utilized if the patient is readmitted and volunteer visits begin again.

We are always aware in the office that volunteers tend to "isolate out" with patients they really like. So, when a patient is readmitted or is waiting in the emergency room, we call that volunteer and let them know. When a patient has had multiple admissions over a couple of years, the volunteer may have grown to care very much and the patient comes to depend on that particular volunteer in that particular climate. The volunteer becomes that friend in the hospital whom they do not expect to see anywhere else.

Some of the volunteers have extended their work with patients into the community and have served as transitional support people for some of our patients. After patients are discharged, we do follow-up phone calls to see how they are doing when they get back into the general community.

VOLUNTEER SUPPORT AND RETENTION

The Friendly Visitor program is a large project that needs a lot of nurturing, constant surveillance, and increased volunteer support. Once regular volunteers are in place, they are fine; they just go and do their jobs. But the AIDS program is totally different. It is so emotionally draining that you have to stay on top of it. You have to be there for your volunteers at all times and you are constantly reading notes and often facing some pretty awful things. Several volunteers have left the program because of changes in their personal life, and a few because the nature of the program was simply too overwhelming for them.

Monthly support meetings for the volunteers are essential, although attendance is not mandatory. One hopes that volunteers will want to come to these meetings but they are allowed to determine their own needs. On the whole, the meetings are well attended; some volunteers come to every meeting and some come three or four times in a row and then skip the next few meetings. Although we have a lot of wonderful retired people in the AIDS program, most of our volunteers are employed and do their visits in the evening; therefore, we must have evening support available for them.

The support meetings offer an opportunity for the volunteers to network with others, to meet people they might not encounter otherwise, to put "faces" on the volunteer notes they read in the log, to exchange experiences, expertise, ideas, and observations, and, in effect, to support each other. If one or more of the patients a volunteer cares about have died, then getting into a meeting and sharing what it is like to lose patients is a great help. Every meeting ends with a list of the names of patients who have died, followed by a moment of silence. Additional bereavement support is available for those volunteers who feel they need it when a patient with whom they have been working dies.

Providing a place where these volunteers can meet and talk with others about their experiences and concerns is additionally important because some are not able to tell their employers, fellow workers, or families about what they are doing, because of the stigma that is attached to AIDS and which, unfortunately, sometimes attaches itself to people who work with AIDS patients. That is really too bad for the volunteers because here they are doing these wonderful things, making an important contribution, and often they have to keep it secret from people with whom they might otherwise share their experiences.

The support meetings also provide an opportunity for in-service education for volunteers on topics related to AIDS patients and the complicated concerns that surround their situation. Therefore, we periodically have outside speakers in the meeting and we solicit suggestions from volunteers about anything they would like to have included.

While the AIDS volunteers need to be commended, they do not really want rewards for what they are doing, nor do they seek praise. They make it clear that they are here to give and not to receive. However, we do have annual Christmas and spring parties just for the volunteers. These special events encourage a sense of comraderie, which is very important for these volunteers because the underlying reality of what they are doing is very sad.

But when I have the annual tea for my regular volunteers, I have to beg the AIDS volunteers to come to it, and they resist. And when I have tried to give them Christmas presents, the volunteers say "no," but then they themselves will bring in gifts for the entire unit. It really is astonishing.

UNEXPECTED PROBLEMS

Anyone considering starting an AIDS volunteer program needs to know that it poses difficulties and that it becomes more time-consuming than one realizes. Interviewing people, for example, takes a great deal of time. At St. Luke's-Roosevelt, I had to hire a volunteer coordinator as an assistant to do interviews and handle other program details.

One of the unexpected problems we encountered at the beginning of the program was that some of our AIDS volunteers who were completely comfortable visiting gay men did not want to visit intravenous drug users with AIDS. That attitude had to be addressed, and in orientation we build on the fact that there is a common denominator of illness and death in this epidemic and that it does not matter who is there, for what reason, or for whom: *Everybody* has to be there to care. Orientation is the place to head off these sorts of problems and similar issues so that they do not spill over into the unit or onto the floors.

Not only do most of our regular hospital volunteers have no interest in visiting AIDS patients, some of them do not like the AIDS Friendly Visitors, either. But not all of them have continued to refuse to visit our PWAs; the library cart ladies, for example, will now go to the unit. However, when one of them insisted on wearing a mask, I told her she could not go there. We are very firm about that sort of thing.

In time, as people become more accustomed to AIDS, these kinds of attitudes will probably break down and change. But right now, I see two separate communities of volunteers. Moreover, for the most part, the AIDS volunteers themselves are not interested in working in other areas of the hospital. They are there specifically to work with AIDS patients. But a few of them have begun to work with the boarder babies. One, a successful bank vice-president, works on the AIDS unit until 10 p.m., then goes to the nursery for the 10 o'clock feeding. I think it helps him make the transition from the AIDS floor back to the outside world.

MEASURING PROGRAM SUCCESS

It was hoped that the AIDS Friendly Visitors would be a source of friendship, conversation, and small acts of care and kindness for our

AIDS patients. The volunteers have accomplished not only that, but much more. This conclusion is supported by the acknowledgments and appreciation expressed by much of the staff and by the families and loved ones of the patients receiving visits.

Moreover, the hospital's trustees, administration, managers, and staff at all levels have responded positively to this unique project. In fact, the volunteer coordinator position, originally supported by a United Hospital Fund grant, is now funded by the institution, and the program has been expanded to encompass both hospital sites.

The relationship between the medical staff and the AIDS volunteers is a closer one than you would find with regular volunteers. The doctors and the nurses feel supported by the AIDS volunteers and have tremendous respect for them because the volunteers provide support to the patients that professional staff, with their existing duties, could never do. And the staff do not appear to feel threatened in any way by the presence of these volunteers.

It is interesting, for example, to see that physicians are very impressed with the AIDS Friendly Visitors; they seek them out and ask how they think a particular patient is doing, whether the volunteer has noticed anything, and so forth. One of our psychiatrists remarked that the volunteers seem to get more out of patients than psychiatric staff themselves. I think this is due, in part, to the extraordinary sense of trust that patients develop for volunteers and to the fact that the volunteers themselves are very nurturing to the patients and very giving of their time. Clearly, this new breed of volunteer is easing the workload of our staff, improving staff's ability to do its work, and making life—and hospital stays—better for our AIDS patients.

CHALLENGE AND REWARD

As the average daily census of PWAs in St. Luke's-Roosevelt has grown from 20 to 30 four years ago to about 80 to 100 currently, the AIDS Friendly Visitor program has kept pace. We began in November 1985 with 14 volunteers visiting seven patients at Roosevelt Hospital. With the expansion of the program to the St. Luke's site, there are now over a hundred volunteers; some are Friendly Visitors, some come for an AIDS Sunday brunch program, some for lunches on Thursdays, and some come in for special seasonal events. And they are by and large extremely dedicated to their commitment.

While the Friendly Visitor program for AIDS patients has been a challenge, it is one that has enriched my life as a director of volunteers by giving me a new sense of accomplishment and putting me in touch with a whole new group of wonderful, caring, and fascinating people: AIDS volunteers. ❑

Part III

VOLUNTEER OPPORTUNITIES

Volunteer Opportunities

In New York City and throughout the United States, there are many institutional programs and community-based organizations that provide opportunities for persons interested in becoming AIDS volunteers. The list below includes those organizations whose programs are discussed in this book. Persons interested in volunteering or who would like further information should get directly in touch with these organizations.

Bellevue Volunteer Visitors Program
Paul A. Zakrzewski
Bellevue Hospital Center
First Avenue and 27th Street
New York, N.Y. 10016
(212) 561-4858

St. Luke's-Roosevelt Hospital Center
Virginia D. Crosby, Director of Volunteers
428 West 59th Street
New York, N.Y. 10019
(212) 523-7155

People With AIDS Coalition (PWAC)
31 West 26th Street
New York, N.Y. 10010
(212) 532-0568

Harlem Hospital Boarder Baby Program
Nettie Richards, Director of Volunteers
Harlem Hospital Center
506 Lenox Avenue
New York, N.Y. 10037
(212) 491-1201

Brooklyn AIDS Task Force
Yannick Durand, Director of Education
Mildred Pearson, Women's Program
22 Chapel Street
Brooklyn, N.Y. 11201
(718) 638-2437

God's Love We Deliver
P. O. Box 1776, Old Chelsea Station
New York, N.Y. 10113
(212) 874-1193

Goldwater Memorial Hospital Volunteer Program
Tammy Carlisle, Volunteer Director
Goldwater Memorial Hospital
Roosevelt Island, N.Y. 10044
(212) 750-6755

Bronx AIDS Volunteer Organization (Project BRAVO)
Bridget Poust, Project Director
Montefiore Medical Center
3320 Rochambeau Avenue
Bronx, N.Y. 10467
(212) 920-4301

A wide range of other opportunities exist for AIDS voluntarism in New York City—and volunteers are needed. For information about additional volunteer programs, please write to the Director of Voluntary Initiatives, United Hospital Fund, 55 Fifth Avenue, New York, N.Y. 10003, or telephone (212) 645-2500.

Outside New York City, interested persons should get in touch with their local department of public health for referral to AIDS-related organizations in their vicinity.

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Current Publications

HEALTH POLICY

Poverty and Health in New York City

This six-chapter volume brings together several distinct studies that explore the link between economic circumstances and health in New York City. An invaluable resource for anyone concerned with the poor and their health, the book uses several methods to demonstrate that the poor are sicker and that they do not receive the same medical services as the affluent. Individual chapters present a wealth of information on general health status and disability, infant morbidity and mortality, the socioeconomic and diagnostic pattern of children's hospitalization, the hospital utilization patterns of the elderly residing in low-income areas, and avoidable disease and death among disadvantaged population groups.
224 pp. 1989 $40.00
ISBN:0-934459-52-5

Caring for Children with Chronic Illness: Issues and Strategies

This book takes a critical look at the current medical, social, and psychological framework for providing care to children with chronic illness. The 21 chapters, written by some of the leading health care professionals in the field of child health today, examine major public policy issues, the roles of professionals and institutions, the needs of chronically ill children and their families, new challenges in today's social and technological environments, models for service delivery, long-term effects of chronic illness for the individual, and the financing of care.
320 pp. 1989 $36.95 plus postage and handling
Available from Springer Publishing Company, 536 Broadway, New York, N.Y. 10012.

In Sickness and in Health: The Mission of Voluntary Health Care Institutions

This eight-chapter book, consisting of contributions from leading health policy scholars and practitioners, traces the evolution of voluntary health care institutions and the sociological, philosophical, and legal principles upon which they were founded. It provides a comprehensive analysis of the unique characteristics that distinguish the voluntary health care institution and form the basis of its mission of and commitment to community service.
256 pp. 1988 $32.95 plus postage and handling
Available from McGraw-Hill Book Company, Health Care Group, 4401 Connecticut Ave., N.W., Box 12, Washington, D.C. 20008, or call 1-202-686-7900. Prepayment not required.

AIDS Public Policy Dimensions

Based on the proceedings of a major national conference, cosponsored by the United Hospital Fund and the Institute for Health Policy Studies of the University of California, San Francisco, this book examines health policy and related socio-medical issues, including acute care, community services, and financial implications, raised by the epidemic of acquired immune deficiency syndrome.
304 pp. 1987 $30.00
ISBN: 0-934459-35-5

Medicare and Extended Care: Issues, Problems, and Prospects

This 17-chapter book, based on a national conference, presents a comprehensive examination of extended care and its place in the health care system. It identifies patients who would benefit from extended care, describes model extended care programs, and includes financial perspectives on providing such care as it was originally conceived.
180 pp. 1987 $34.00 plus postage and handling
Available from Rynd Communications, 99 Painters Mill Road, Owings Mills, Md. 21117, or call 1-800-446-2221.

Mission Matters: A Report on the Future of Voluntary Health Care Institutions

This 47-page report reinforces the essential role of voluntary hospitals and other voluntary health care institutions as indispensable parts of American health care and community life and, by the use of concrete examples, urges voluntary health care leaders to reemphasize—or in some cases recapture—a sense of their historical mission to their communities. It is the first chapter in *In Sickness and in Health* (see earlier listing).
47 pp. 1987 $5.00
ISBN: 0-934459-36-3

Health Care of Homeless People

Based on the proceedings of a national conference, this state-of-the-art guide identifies and discusses health and public policy issues in caring for the homeless and provides specific information on medical treatment, psychiatric intervention, and program planning. Barriers to successful model programs are also described.
349 pp. 1985 $29.95 plus postage and handling
Available from Springer Publishing Company, 536 Broadway, New York, N.Y. 10012.

INFORMATION SERVICES

New York City Health Facts: A Profile from the National Health Interview Survey

This chartbook takes a close look at the health status of New Yorkers and their use of health services, highlighting the significant variations that occur among different age groups and along racial, ethnic, and economic lines. The findings depict unsatisfactory health status as a common problem for poor New Yorkers, as well as for many of the city's children and elderly residents, and provide an important new perspective on how the health care system is meeting or failing to meet the population's health needs. This book will be useful to policymakers, planners, providers, researchers, consumers, and others interested in the health of New Yorkers, providing valuable information from a population-based perspective.
54 pp. 1989 $20.00
ISBN: 0-934459-54-1

Health and Health Care in New York City: Local, State, and National Perspectives

1988 Edition

An annual publication providing a graphic overview of health and health care in New York City, New York State, and the nation. Designed to provide a framework for decision making and planning, the chartbook depicts the most recent trends in population, health status, availability and use of health facilities, health employment, education, and finances. Data are preceded by a narrative overview.
96 pp. 1988 $30.00
ISBN: 0-934459-48-7

Health Facilities in Southern New York: A Guide to Inpatient, Outpatient, and Long-Term Care
1989 Edition

A directory of health care facilities in New York City, Long Island, and the Northern Metropolitan area containing information on location, ownership, and certified beds of all facilities as well as detailed information on the capacity and utilization of hospital inpatient, outpatient, and long-term care services. Hospital statistics reflect 1987 operation. Hospital addresses, phone numbers, and chief executive officers are listed.
88 pp. 1989 $20.00
ISBN: 0-934459-55-X
Previous editions are available at $15.00 each.

SPECIAL STUDIES

New York City's Hospital Occupancy Crisis: Caring for a Changing Patient Population

This report, prepared by the Fund and the Bigel Institute for Health Policy of Brandeis University, summarizes the findings of the first comprehensive analysis of New York City's hospital occupancy crisis. It focuses on changes in inpatient bed capacity and especially on the extraordinary growth in the number of patients being treated for AIDS, mental illness, neonatal problems, and substance abuse and the resulting backups in emergency rooms that have led to "medical gridlock" throughout the city. Forty-five charts and tables are included.
36 pp. 1988 $25.00
ISBN: 0-934459-50-9

Health Expenditures in New York City 1983
Paper Series 1

A United Hospital Fund paper providing an overview of health care spending patterns in New York City in 1983, by object of expenditure and source of funds. Selected trend analyses and national comparisons are included.
32 pp. 1985 $5.00
ISBN: 0-934459-09-6
1984, 1985, and 1987 updates are included free of charge.

The Financial Condition of New York City Voluntary Hospitals: The First Year of NYPHRM
Paper Series 2

A multi-dimensional approach is utilized in this important publication to describe the changes in the financial status of voluntary hospitals in New York State in 1983, including the first-year effects of the New York Prospective Hospital Reimbursement Methodology (NYPHRM). The hospitals' annual operating results, cash position, capital structure, and age of plant are examined and then compared to hospitals in the rest of New York State, the Northeast region, and the nation.
24 pp. 1985 $5.00
ISBN: 0-934459-10-X
A 1984 update is included free of charge.

Is Counting the Dead Enough? Strategies for Monitoring Health Care Needs and Health Status in New York City
Paper Series 3

The measurement of the health status and consequent health care needs of New Yorkers has traditionally relied on such indicators as mortality and gross morbidity. However, in an era of sophisticated survey and research tools, more accurate and sensitive measures are possible. In this paper, several promising approaches to measurement, sur-

veying, and information analysis are examined, and measures that detect problems earlier in the course of illness are called for.
36 pp. 1986 $5.00
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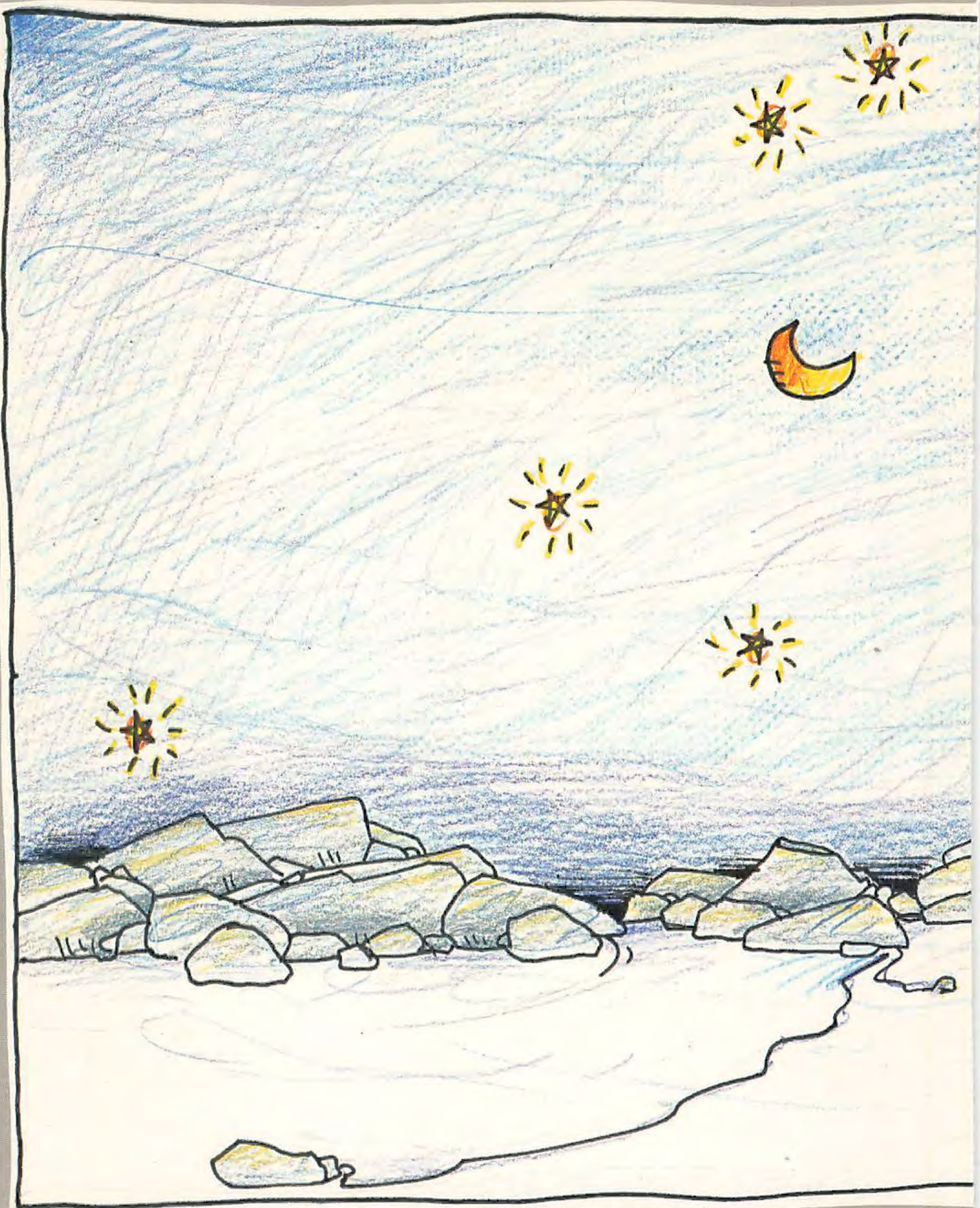

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