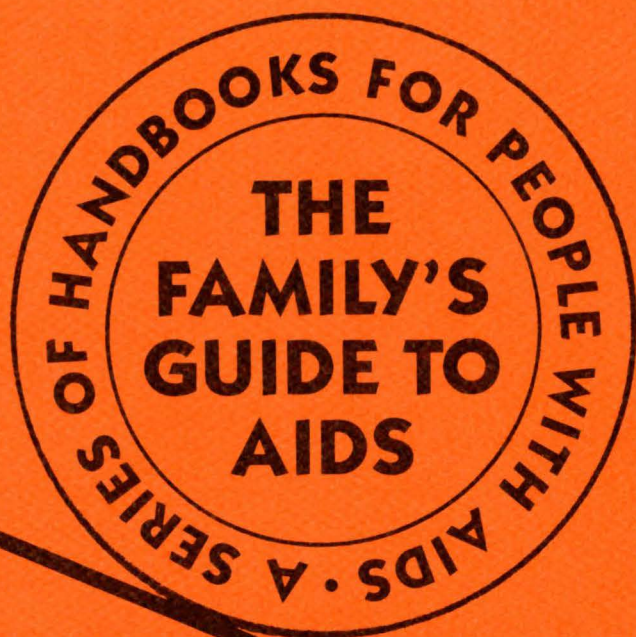




THE FAMILY'S GUIDE TO AIDS: Responding With Your Heart

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Why This Brochure May Be For You

If someone in your family has contracted AIDS, you may feel that your life suddenly resembles a roller-coaster ride. Not only will you have a great number of questions related to medicine and illness, but you will most likely experience intense feelings of fear, anger, and sadness as well as confusion and frustration. It is a very difficult experience to care for someone who has a life-threatening illness.

This brochure has been developed for relatives of people who have been diagnosed with AIDS. Included are suggestions about how to take care of both your loved one and yourself during this difficult period. Some basic medical information about AIDS and a list of community resources that may prove helpful to you have also been included.

Your first concern will probably focus on the condition — both physical and emotional — of your loved one. People with AIDS usually experience overwhelming changes when they are diagnosed with this life-threatening illness. Often their life changes radically. Health, social life, and expectations for the future are altered. Some must also adjust to the loss of their jobs, their independence, their homes, to reduced personal finances, to lengthy hospital stays, and to tiring treatment programs. Not understanding what is happening to their bodies now and not knowing what will happen next may cause severe emotional strain. Additionally, they must confront feelings of isolation from friends, loss of independence, and fear of dying. Parents, brothers and sisters, other relatives, lovers and friends become perhaps *more* important than ever before for someone with AIDS.

The Family of the Person with AIDS

In San Francisco the majority of individuals who have AIDS are gay men. The parents and other relatives of many of these men do not live in the Bay Area. Perhaps your situation is similar. Many gay people have developed an "extended family" comprised of a number of close relationships with other men and women friends. This network of relationships frequently becomes a valuable source of support, especially during difficult times. You may find these close friends to be a source of comfort and help for yourself as well.

One mother who traveled from her home on the East Coast to visit her son in San Francisco found the presence of his friends very reassuring. In her words:

parents. To undertake such discussions now, while coping with the diagnosis of a serious disease, can be very difficult. You may feel shocked, embarrassed, hurt, and angry. You may not know what to tell friends and neighbors. You will perhaps want to confide in a trusted friend or perhaps in a pastor, minister, or rabbi. You may also feel proud of your son's decision to live his life in a manner that is true to his own feelings. For many parents what becomes most important at this time is the love they share with their son. With those feelings expressed and confirmed, other considerations can fall into some perspective.

Some people diagnosed with AIDS develop more serious medical consequences than others. When tests, treatments, and hospitalizations become frequent, the life of the person with AIDS and the lives of loved ones lose their normal daily patterns and often become very difficult. If you find yourself in this position, the following ideas may be helpful.

- **Patient Advocacy** Confronting the medical establishment can be overwhelming for a person in good health. The unknowns about AIDS often mean that there are numerous tests, reports, and opinions. It can be very helpful to have one or two others who are close to your loved one to listen to the doctor's reports, ask questions, and take notes. Information can help reduce fear.

You can also help establish a rapport with the medical staff in the clinic, doctor's office, or hospital. Let the staff know you are interested, and that you will politely, but firmly, follow through to fulfill the needs of the patient. Become a partner in the medical care, and ask questions when you need to.

There is reason for assertiveness in the hospital. All institutions have their own daily routines that seem to work best for that facility. Sometimes the routine may not be the best for the patient. For example, a patient's room does not have to be cleaned at a given moment; the staff can be requested to wait 20 minutes. Your loved one can also ask for maximum privacy — not only from visitors, but also from staff.

- **The Hospital Room** In the hospital room, you may want to make the surroundings as pleasant as possible. Flowers, music, balloons, food that you have prepared, and whatever else might be pleasing to your loved one are all appropriate.

Sometimes it may be more comforting to the patient to have silence in the room, and some visitors may have to learn to be comfortable with this. Quiet background music, perhaps a light

massage, or just quietly holding hands can be very soothing for your loved one. If the room is being shared with another patient, be considerate of that person's needs as well.

If your loved one is in the hospital for an extended stay, be sure to let others — friends and relatives — assist you with the visiting. Take a break from your visits; perhaps get some fresh air by going for a walk. You need your moments of relief and rest.

- **Getting Out Information** It might be helpful for one or two friends to serve as a contact for the larger group of friends and acquaintances who are concerned about medical developments. These contacts may want to make their phone numbers available for others to call them. There's a delicate balance between getting overwhelmed with questions and disseminating needed information. Some families find it helpful to have a telephone answering machine with a message that is updated on a regular basis.
- **Insurance Forms, etc.** It may not be possible or desirable for the person with AIDS to be responsible for completing all the insurance forms, disability forms, etc. One other person could relieve much pressure by assuming this role of "taking care of business." Perhaps someone could "monitor" non-medical mail for important bills, checks, and letters.
- **Medical Issues** You or someone else might keep track of the medications: which drugs are to be taken and when. Questions may arise: Is it alright to take another pain killer now? When was the last one taken? You should also know who to call in time of emergency.
- **Personal Affairs** Getting personal affairs in order is a good idea for the most healthy among us. Does your loved one have a current will? Do you know where it is kept? Is there a list of bank accounts, charge accounts, outstanding loans, etc.? The San Francisco AIDS Foundation can assist you with these matters.
- **Emotional Stress** The strain of serious illness can be very intense for everyone involved. Much of this experience can be shared with a spouse, other family members, or close friends. But much of it may be too personal to share. This can be very frustrating. You may find that these difficult events cause much strain for you with your other relationships. An awareness of this natural response and a willingness to communicate may prove helpful.

a healthy immune system combats without difficulty.

There are many diseases to which people with AIDS are susceptible. Collectively these diseases are called "opportunistic" since they rarely occur in individuals with normal immune functions. The two most frequently reported of these diseases continue to be an otherwise rare form of cancer called Kaposi's sarcoma (KS) and a more common protozoan infection of the lungs called pneumocystis carinii pneumonia (PCP) that is not ordinarily seen in healthy individuals.

What Causes AIDS?

Several theories are being investigated and many researchers believe that an infectious agent, probably a virus, is causing a breakdown of the immune system. It is further believed that this virus is carried in the blood or other body fluids (such as semen) and may be transmitted through intimate sexual contact, by the sharing of needles used for the injection of illicit drugs, or very rarely by receiving blood products. **AIDS IS NOT TRANSMITTED BY CASUAL SOCIAL CONTACT.**

Can AIDS Be Treated?

Medical treatment of AIDS varies with the diseases involved. These treatments include antibiotics, chemotherapy, radiation therapy, and experimental agents and techniques. As yet, there is no effective treatment to rebuild the immune system and to reverse the immune deficiency. The specific treatment modalities to be followed should be a joint decision making process between your loved one and the medical team.

Community Resources

San Francisco AIDS Foundation

54 10th Street
San Francisco, CA 94103

Information and medical referral hotlines:

(415) 863-AIDS in San Francisco

(800) FOR-AIDS in Northern California, outside San Francisco — TOLL FREE

(415) 864-6606 TTY line for the hearing impaired

The San Francisco AIDS Foundation provides primary information and referral services to residents of San Francisco as well as to others living in Northern California. The Foundation, in cooperation with other agencies and organizations, provides extensive community education through public forums, informational brochures, and a hotline telephone service. A special hotline service

personed by people with AIDS to deal specifically with the special concerns of other diagnosed persons as well as their family, friends and loved-ones, also exists at the Foundation. The Foundation provides assistance to people with AIDS in obtaining needed social services, such as emergency housing, emergency food and food stamps, social security and veterans benefits, medical benefits, legal consultation about wills, power of attorney, etc., by a specially trained group of on-site social workers. There is also a special food bank program at the Foundation for people with AIDS to supplement their food needs.

Shanti Project

890 Hayes Street, San Francisco, CA 94117 • (415) 558-9644

The Shanti Project provides individual volunteer counseling and support groups for persons in San Francisco with AIDS, their families, lovers, friends and the bereaved. Shanti also provides volunteer assistance with grocery shopping, transportation, meal preparation, and other direct services to people with AIDS.

The following books may be helpful and informative to you:

Getting Well Again

A Step-By-Step, Self-Help Guide to Overcoming Cancer for Patients and Their Families

OC Simonton, S Mathews-Simonton, JL Creighton
Bantam Books (paperback) New York. 1980.

Anatomy of an Illness

As Perceived by the Patient
Reflections on Healing and Regeneration
Norman Cousins
Bantam Books (paperback) New York. 1981.

Now appearing in bookstores are a number of books especially devoted to AIDS. Some of these are primarily oriented to medical and research issues; others offer a general overview of AIDS for the lay person. The San Francisco AIDS Foundation currently suggests two titles that may be helpful to you. These are:

AIDS Epidemic

Kevin M. Cahill, MD
St. Martin's Press 1983.

The AIDS Fact Book

Ken Mayer, MD and Hank Pizer
Bantam Books, 1983.

Informational brochures prepared by the S.F. AIDS Foundation office may be helpful, and these can be sent to you upon request.