

*Building
Community
Support
for*

Families of People with AIDS

J. Hare

*Home is the place where, when you have to go there, they
have to take you in. — Robert Frost*

AIDS attacks more than the immune system of HIV-infected people. AIDS also attacks the well-being of families by draining their relationships as well as their economic, emotional, spiritual, and social resources.

As of summer 1990, 31 of the 36 Oregon counties reported cases of AIDS. Considering that the proportion of Americans who know someone with AIDS has increased from 4 percent in 1986 to 6 percent in 1987 and to 7 percent in 1988, it can be assumed that in every county there are likely to be family members and friends of people with AIDS.

Many of these families and loved ones feel that they are stigmatized by their closeness to someone with the disease. Families may be afraid to identify themselves and their need for help, fearing they will be rejected or discriminated against in their own communities. Many of them suffer in silence.

How do we make our communities supportive environments for families of people with AIDS?

First of all, we need a broad definition of "family." There are many types of families:

- families of origin (the families we are born into)
- families of procreation (the families we marry into)
- unmarried couples in committed relationships
- friendship networks
- a close-knit group of caregivers which often evolves after an AIDS diagnosis. (This group may include a partner, spouse, friends, relatives, and health care professionals.)

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What would your community do in these situations?

Joe and Irene live in a very small town. They have five children, all of whom are grown and living away from home. Their youngest son John has been diagnosed with AIDS. He is currently struggling through his third episode of *Pneumocystis pneumonia*, a life-threatening complication of AIDS. Joe and Irene, accompanied by one of their daughters, are again traveling to Portland to help John. Since John's diagnosis nearly two years ago, Joe and Irene have told their friends and relatives that their son has an incurable cancer. Today John tells Joe and Irene that he no longer feels he has reason to stay in Portland. He would like to come home to his parents' house to die.

Joe and Irene, who love their son, are painfully torn. They believe that if John comes home, people in the community will learn his true diagnosis. Irene serves on the school board; Joe and Irene are both prominent professionals in the community. They feel certain their personal and professional lives in this community will be irreparably damaged. While they very much would like to care for John at home, they decide that it will not be possible. Three of John's siblings are very angry with their parents' decision. One of them leaves college and goes to Portland to care for her brother until his death. The family is now riddled with conflict.

Eleanor lives in a small coastal town in Oregon. She recently has become a grandmother for the third time. Her 28-year-old daughter, Jenni, is a single parent of two school-age boys and a newborn daughter. Late in her pregnancy Jenni learned that she is HIV infected. Her baby is showing symptoms meeting the definition of AIDS. Eleanor grieves for her daughter and worries about Jenni's capacity to care for her young sons and an ill baby. Eleanor considers moving to Jenni's town or bringing Jenni and the children to her own home. Where can she turn in this small coastal community for information and helpful advice?

If Joe and Irene lived in your town, could they have brought their son home without feeling rejected by their community?

If Eleanor lived in your town, could she have told her friends, her co-workers, and her church members of her troubles? How would they have responded?

Challenges of AIDS

Families of people with AIDS generally must confront many of the following challenges:

- Adjusting to the life-threatening diagnosis of someone they love.
- Dealing with their fears of contracting AIDS.

- Accepting the disclosure of a family member's gay identity.
- Accepting the disclosure of a family member's drug use.
- Accepting that their child was sexually active.
- Managing conflict inside the family.
- Confronting a time-limited need for emotional reconciliation with the ill family member.
- Beginning to grieve many impending losses.
- Shifting family roles.
- Providing emotional support and physical care to the ill member.
- Managing the multiple difficulties of the health care system.

Some ways you can help

Don't ask the family how the disease was contracted. Such a question is posed out of curiosity rather than to a desire to provide support. The central feature of the situation is that the family has a life-threatened member.

If the ill person is a gay man, you can provide a safe atmosphere for that disclosure by expressing compassion and withholding judgment. In such a case there also may be a loving partner who is part of the family. Extending your concern and support to all significant people in the life of the person with AIDS may help them join together in their sadness.

What Is AIDS?

AIDS, a medically diagnosed disease, is caused by the human immunodeficiency virus (HIV). The virus is harmful only if it gets into the blood stream. Once it is there, it attacks and slowly destroys the body's immune system, allowing other infections to invade the body. These infections cause serious illnesses, such as pneumonia and cancer. The HIV virus also can damage the brain. There is not yet a known cure for AIDS.

The virus that causes AIDS also produces illnesses called AIDS related complex (ARC). Typical symptoms are prolonged swelling of lymph nodes, chronic fatigue, fever, weight loss, night sweats, and abnormal blood counts. The ARC complex can be fatal.

How is AIDS spread?

AIDS is preventable by the choices you make. There are three main ways the AIDS virus is spread:

- By having unsafe sex with an infected person.
- By sharing needles and syringes with drug users.
- From mother to fetus during pregnancy, or to the baby during delivery or breast feeding if the mother is infected.

Fortunately, AIDS is hard to catch. There is no evidence that it is spread through casual contact such as shaking hands, social kissing, coughing, or sneezing. No one has ever caught AIDS by casual contact in the workplace, schools, swimming pools, stores, or the home.

In your own words, say to the family, "I recognize that you must be having many difficult feelings. I hope you know that I care about you and I am ready to listen if you would ever like to talk."

Remember that most people with AIDS are young. Their illness and death are out of step with the expected life cycle. Children die before parents; parents die leaving

young children, and several people in the same family network sometimes die in the same time period. Community support groups for survivors may help them go on with their lives.

Most important, be aware that families of people with AIDS are families in grief. Grief is a long and arduous process which generally begins long before the anticipated

death occurs. The single most helpful gesture you can make for someone in grief is to allow that person to express pain; try not to say or do anything that will close off such expression. It is almost always best simply to be present for the other person. Richard Kalish, a well-known author on grief-related topics, said it like this, "Don't just do something. Stand there!"

Where you can get more information about AIDS

Note: The AIDS Hotline for information and referrals is 1-800-777-2437.

Baker County Health Department 523-8211	Crook County Health Department 447-5165	Hood River County Health Department 386-1115	Lane County Health Department 687-4013 Shanti in Oregon, Inc, Eugene 342-5088 Willamette AIDS Council, Eugene 342-5088	Multnomah County Health Department 248-3406 Cascade AIDS Project, Portland 223-5907 Oregon Hispanic AIDS Project Portland 228-4131 Oregon Minority AIDS Coalition Portland 274-1305	Union County Health Department 963-1013 Eaglecap AIDS Support Team La Grande 962-3384
Benton County Health Department 757-6835	Curry County Health Department 247-7011, Ext. 265	Jackson County Health Department 776-7335 Rogue AIDS Project Medford 772-4380	Lincoln County Health Department 265-6611, Ext. 2379 or 265-4179	Polk County Health Department 623-8175	Wallowa County Health Department 426-3627
Clackamas County Health Department 655-8471, Ext. 7543	Deschutes County Health Department 388-6616 Central Oregon AIDS Support Team Bend 389-4330	Jefferson County Health Department 475-4456	Linn County Health Department 967-3888	Washington County Health Department 296-4636	
Clatsop County Health Department 325-8500	Douglas County Health Department 440-3500	Josephine County Health Department 474-5325	Malheur County Health Department 889-7279	Tillamook County Health Department 842-3900	Wasco-Sherman County Health Department 296-4636
Clatsop County AIDS Coalition Astoria 325-4321	Gilliam County Health Department 384-2061	Klamath County Health Department 882-8846 Klamath Co. HIV/ AIDS Support & Educational Council Klamath Falls 883-2437	Marion County Health Department 588-5342 Mid-Oregon AIDS Support Services, Inc., Salem 363-4963	Umatilla County Health Department 276-3211 Blue Mountain AIDS Task Force, Pendleton 278-1529	Wheeler County Health Department 763-2725
Columbia County Health Department 397-4651	Grant County Health Department 575-0429	Lake County Health Department 947-6045	Morrow County Health Department 676-5421		Yamhill County Health Department 472-9371, Ext. 525
Coos County Health Department 396-3121, Ext. 329 GALON, Coos Bay 269-4183	Harney County Health Department 573-2271				



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