St. Francis Center

Let's send a thank you & then give back to me just in case we can visit. File

St. Francis Center

Providing guidance, information and support for individuals and communities living with loss, illness and grief.

5135 MacArthur Boulevard, N.W. Washington, D.C. 20016
(202) 363-8500 TTY (202) 362-7119 Fax (202) 363-4989

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St. Francis Center

a nondenominational resource center . . .
providing guidance, training, information and support for individuals and communities living with loss, illness and grief

About The St. Francis Center

Children & Adolescents Program

Counseling / Support Group Program

Training & Education

HIV/ AIDS Program

Friend Volunteer Program / Membership

St. Francis Community

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Winter 1993
XVII 4 ISSN 0733-8775

SPECIAL HIV/AIDS ISSUE

- From the Executive Director
- Living HIV Positive
- The HUG CLUB
- My Best Friend
- On the Road with a Therapist
- Living in the Open
- A Caregiver's Memorial
- *featuring* Poetry and Articles from Center Friends

CENTER NEWS

- St. Francis Center Highlights
- Benefit 1993 Wrap-up
- Upcoming Events

Centering

St. Francis Center
nondenominational

5135 MacArthur Blvd., N.W.
Washington, D.C. 20016
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Summer 1994
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FRIENDS

dedicated to the St. Francis Center Friends Volunteer Program
featuring articles from Center Friends

- From the Executive Director
- Getting to Know Our Friends
  —*interviews with Friends Volunteers*
- Friends Volunteer Training: The Experience
- Food for Thought

CENTER NEWS

- Ninth Annual St. Francis Center Benefit
- 1994 St. Francis Center Conference Review

Centering

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THE CHILDREN'S PROGRAM

Children grieve, each in their own way. They mourn all kinds of losses; friends or familiar surroundings when they move or "graduate" to a new school, their way of family life if separation, divorce or long term illness occurs and the ultimate loss, the death of someone or something cherished.

No matter the circumstances, grief becomes their journey toward healing. Our job is to walk with them. We listen, comfort and teach as they move from a place of confusion and heartache to a place of remembering and going on.

Shielding children from loss denies them the opportunity to learn how to grieve. Compassionate honesty gives the clear message, "You can get through this. I know it's hard but I'll be here to help you." It can allow children to feel respected and competent and it strengthens the bonds of trust between them and those they rely on.

Our Children's Program at the St. Francis Center offers comfort, support and guidance for children, adolescents and their families through:

COUNSELING ... individual, group and family counseling, as well as play therapy.

EDUCATION ... formal programs and workshops offered at the Center and in schools and agencies on topics including the dying and/or grieving child, coping with divorce and other transitions, chronic illness including AIDS and caring for the caregivers.

OUTREACH
... to D.C. and surrounding school districts, as well as hospitals, churches, agencies and organizations;
... Friends volunteers work with children and families in their homes;
... staff is available during usual work hours to provide information, support and referral by phone.

If you would like more information, or could benefit from any of our services, please call us at .....(202) 363-8500

A non-denominational, non-profit organization offering professional counseling, training and volunteer support to people facing illness loss and bereavement.

St. Francis Center

5135 MacArthur Boulevard, NW
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(202) 363-8500
Fax (202) 363-4989

Why We Play at the St. Francis Center

Children express themselves through play. Toys, games and drawings offer children a way to explore feelings and life situations. Fantasy is a very safe place where youngsters can look at all kinds of issues.

Talking is often not the most effective way for children to communicate their feelings. They are not mature enough to understand the complex way emotions effect their lives; nor have they learned the vocabulary. For instance, what is the difference between "mad", "angry", "frustrated", "scared", guilty", "ashamed", and "anxious"? Very few children could explain the differences among these terms or understand how the feelings influence their thoughts and behavior. Yet almost any child could play out the feelings with puppets, dolls, paints or even just some game of imagination. In the presence of a trained therapist, the play becomes the doorway to understanding even when the experience is not discussed in concrete terms.

That's why play therapy is almost always an important part of our work with children, either in groups or individually. Sometimes it gets quite active, sometimes it's silent. Sessions last about 50 minutes and therapy takes several months or longer. It may be a continuous process or intermittent because it is always responding to each child's needs.

It is also important to realize that the child will probably not return from a session able or willing to talk about what he or she learned. How many times have you asked your child, "What did you do in school today?", only to be told, "Nothing"? Yet, when report cards come out, it's clear they were doing something. Play therapy is like that. Parents frequently wonder what throwing a ball or acting out "Beauty and the Beast" could possibly have to do with grief. But for a child either could have important meaning.

We must also remember that confidentiality is as essential to children as it is to adults. Our conversations with the family always respect the child's privacy (unless, of course, there is a question of safety to the child or someone else).

Working with families to serve children in the most gentle and appropriate way is our primary concern. Please feel free to talk with our staff if you have any questions.

St. Francis Center
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KID'S GRIEF GROUP
for Children and Adolescents

Grieving can be hard work. It may be confusing and, at times, difficult for children because they are only beginning to develop the coping skills needed to carry them through the experience. Often, they feel alone as they struggle with these new feelings.

Support groups can offer a way for youngsters to discover they are not alone and that other kids may share many of their feelings. They can talk, in their own way, about what happened and how they feel without upsetting the adults around them. (For example, children often feel responsible for "making Mom cry" if they mention Dad's name.)

Each youngster grieves at his or her own pace. Our Kid's Group, therefore, will be open ended and on-going. Children are welcome to come for as many sessions as each one needs. The format will include activities as well as discussion.

——— *Kid's Grief Group Guidelines* ———

The Group meets at the St. Francis Center at 6:00 p.m. on the 2nd and 4th Wednesday of each month, beginning September 22nd, and lasts for an hour. There is no fee. But, there are a few "rules."

- ★ Each participant must meet with one of the group leaders for a get acquainted interview before joining the group.
- ★ Confidentiality is respected, so group leaders will not tell parents specifically what their child said during a session unless there is a safety issue. The children, of course may share whatever they like.
- ★ Goodbyes are very important. The youngster must let the group know when they won't be coming to meetings.
- ★ Whoever brings the child may either wait at the Center or must be there promptly at 7:00 to pick him or her up.

Here's a suggestion for the grown-ups. If you are grieving too, please take care of yourself. Children don't grieve in a vacuum and how you journey through your grief, reaching out, respecting and caring for yourself, gives them permission to do the same.

Please call the St. Francis Center at (202) 363-8500 if you have any questions or would like to have a youngster join the Group.

About the St. Francis Center

Since 1975, the St. Francis Center (nondenominational) has served as a unique resource for people living with loss, illness and grief. The Center counsels and supports adults, children and families; trains professional and volunteer caregivers, clergy and mental health workers; offers guidance to schools, religious institutions and workplaces; and helps the community respond compassionately to those affected by loss.

Support groups and all other St. Francis Center programs are guided by a philosophy of respect for individuals and their experiences, awareness and acknowledgement of the pain of loss, and loyalty to people in times of illness and death.

Donations are always appreciated.

St. Francis Center

nondenominational

Kid's Grief Group

A Support Group for Children and Adolescents

Beginning September 22nd

St. Francis Center
nondenominational

ANNOUNCING:
Kid's Grief Group
for Children and Adolescents

PLEASE POST

5135 MacArthur Boulevard, N.W.
Washington, D.C. 20016
(202) 363-8500 fax (202) 363-4989

St. Francis Center
1994 Grief & Illness Related Support Groups

● ***Life-Threatened***
This is a group in which individuals diagnosed and living with a life-threatening illness can explore, with others, the physical, emotional or spiritual challenges they may be facing.

Eight Monday afternoons, 4:00 - 5:30 pm
Facilitator: Sharon Lerner, MS, MFCC

● ***Bereaved Gay Men and Lesbians***
Lesbians and gay men are grieving both as individuals and as a community. This group provides an opportunity to sort out feelings, share experiences, and explore issues that affect our lives after the death of a loved one.

Eight Monday evenings, 6:00 - 7:30 pm
Facilitators chosen from: Paul Tschudi, MA, Robert Washington, PhD, Kevin O'Brien, MA, and Carol Farthing, PhD

● ***Professional Caregivers***
This is a group where mental health professionals, health care providers, clergy and others working with life-threatening illness and separation and loss issues can explore the impact of the work on their lives.

Eight Monday evenings, 6:30 - 8:00 pm
Facilitator: Sharon Lerner, MS, MFCC

● ***Bereaved Adults***
A group for adults who have experienced a loss by death of anyone who is significant to them: parents, friends, partners, spouses, siblings, children or others.

Eight Monday evenings, 7:00 - 8:30 pm
Facilitators: Cay Hartley, LICSW, and Susan Eig, MA, LGSW

● ***Volunteer Caregivers of HIV***
In the midst of the HIV and AIDS epidemic, volunteer caregivers provide crucial physical, emotional and spiritual support to people living with HIV, their loved ones and their professional caregivers. This group is designed to help volunteers find support for themselves.

Eight Monday evenings, 8:00 - 9:30 pm
Facilitators: Gayle Sherman, MA and Kevin O'Brien, MA

● ***Suicide Survivors***
The loss due to the death by suicide of a friend, family member or other significant person in our lives often leaves us with feelings that can be confusing and misunderstood. This group will focus on the grief of suicide survivors.

Twelve Tuesday afternoons, 12:00 - 1:30 pm
Facilitator: Susan Eig, MA, LGSW

● ***Adolescent Bereavement***
This group provides an opportunity for teenagers to talk with others going through grief in a supportive atmosphere. The adolescent years involve many changes and the death of a loved person at this time can be tremendously challenging.

Eight Tuesday afternoons, 4:30 - 6:00 pm
Facilitator: Barbara Rubin, LICSW

● ***Young Widows and Widowers***
Young widows and widowers often feel they have special needs which are not addressed in other groups. In this group, participants will receive support while dealing with their grief and other losses.

Eight Tuesday evenings, 6:30 - 8:00 pm
Facilitator: Barbara Rubin, LICSW

● ***Past Abortion***
An abortion may raise unexpected and confusing feelings. This group will provide a safe and supportive place for women to share their feelings, perhaps for the first time.

Eight Tuesdays
Facilitator: Lynn Bonde, LGSW

● ***Children's Grief (Drop-In Group)***
Children use play as a means of working through many difficult emotions. This group for children ages 6-12 uses play therapy techniques and the creative arts to facilitate the grief process. Although this is an on-going, drop-in group, all participants must be interviewed before joining.

Wednesday evenings, 6:00 - 7:00 pm
Facilitator: Dottie Ward-Wimmer, RN, MA

● ***Family and Friends of Life-Threatened***
This group is for family members and friends of people diagnosed with a life-threatening illness who may be experiencing concerns on how to support and accept the condition of the person they love.

Eight Wednesday evenings, 7:00 - 8:30 pm
Facilitator: Judy Bowes, LICSW

● ***Bereaved Adult Siblings***
The death of a brother or sister can have a profound and often unacknowledged impact on the surviving siblings. This group offers support on issues specific to sibling loss.

Eight Thursday evenings, 7:15 - 8:45 pm
Facilitator: Elizabeth Haase, PhD

To register for a St. Francis Center support group, please call the group facilitator at (202)363-8500. All participants are interviewed by the facilitator before joining the group.

The St. Francis Center is located at 5135 MacArthur Blvd., NW Washington, D.C. 20016. For more information on support groups and other St. Francis Center services, call the Center at (202)363-8500.

ALL INQUIRES ARE KEPT CONFIDENTIAL.

St. Francis Center
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5135 MacArthur Blvd., N.W.
Washington, D.C 20016

Providing guidance, information and support for individuals and communities living with loss, illness and grief.

St. Francis Center

1994 Grief & Illness Related Support Groups

Providing guidance, information and support for individuals and communities living with loss, illness and grief.

Grief & Illness Related Support Groups

The death of a family member, friend or other important person can often result in feelings of being alone in a world that seems out of control. When we are grieving, we may have trouble talking about our losses and believe that no one can understand the many emotions we are feeling.

We also may feel alone when we face a life-threatening illness or that of a friend. Each new emotion, each new symptom, each new fear can become overwhelming as we struggle to understand and gain some control of our lives.

Support groups provide an atmosphere in which we can face some of these feelings in a supportive and caring environment, with people who are having similar experiences. St. Francis Center facilitators are specially trained and experienced in working with grief, loss and life-threatening illness. They help provide guidance and information as group members share experiences and insights. While no group can "cure" grief, joining a support group can be one way to find understanding, hope and companionship through this experience.

HIV/AIDS Counseling Services...

funded through the Ryan White CARE Act

The St. Francis Center provides professional counseling services to persons with HIV/AIDS through the Ryan White CARE Act (Title I) in the District of Columbia, Northern Virginia and Suburban Maryland.

The St. Francis Center counselors assist people living with HIV disease to learn ways of coping with physical and social changes; to evaluate possible anxiety or depression; identify sources of hope; and enhance quality of life.

Philosophy...

Center services embody a philosophy of respect for individuals and their experiences; an awareness and acknowledgement of the emotional pain accompanying significant life changes; and of loyalty to people in times of illness and bereavement.

St. Francis Center Counselors are trained and experienced in helping individuals, couples and groups face the unique challenges of HIV/AIDS. Our work is based on a non-judgmental and accepting attitude toward all people, honoring the rights and privacies of individuals.

Unique Opportunity for Care...

This is an opportunity for some individuals to receive psychotherapy by a qualified mental health professional **at no charge.** Family members, significant others and friends may be included. Counseling sessions may occur at the Center, the individual's home, hospital room, or hospice, or other agreed upon location.

Eligibility Requirements...

To meet the requirements of Title I funding, individuals requesting the service must:

- ✓ be HIV+ or diagnosed with AIDS
- ✓ be a resident of the District of Columbia, Northern Virginia or Suburban Maryland
- ✓ lack insurance coverage or funds for in home mental health services

St. Francis Center...

Since 1975, the St. Francis Center has served as a unique resource for people living with loss, illness and grief. In addition to HIV/AIDS Counseling, the Center counsels and supports adults, children and families; provides guidance, training and support to schools, religious institutions and workplaces; and helps the community respond compassionately to those affected by loss.

Referrals for Services...

This program provides **free counseling** for a population which would not otherwise have access to mental health services. We encourage you to refer individuals to this service.

To refer a resident of the District of Columbia for individual or family counseling, contact **Robert Washington, PhD** at the St. Francis Center (202) 363-8500.

To refer a resident of Northern Virginia for individual or family counseling, contact **Judy Bowes, LICSW** at the St. Francis Center (202) 363-8500.

To refer a resident of Suburban Maryland for individual or family counseling, contact **Barbara Rubin, LCSWC** at the St. Francis Center (202) 363-8500.

For more information about other St. Francis Center services and our HIV/AIDS programs, contact:

St. Francis Center
5135 MacArthur Blvd., N.W.
Washington, D.C. 20016

or call us at (202) 363-8500.

St. Francis Center

The St. Francis Center is a non-sectarian, non-profit organization, founded as a source of guidance, information and support for people living with illness, loss and bereavement. For twelve years, the Center has been supporting persons living with HIV/AIDS through individual and group counseling, education, training and volunteer programs.

We believe that mental health counseling can help people living with HIV/AIDS explore their feelings and learn better coping skills as they face the challenges that may occur.

The St. Francis Center currently offers professional counseling for adults, children and families of origin and choice affected by HIV disease; training and support for professional and non-professional caregivers involved with HIV; volunteer support for those living with HIV/AIDS and others affected; and ongoing support and consultation to agencies.

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St. Francis Center

HIV/AIDS Counseling and Services

Providing guidance, information and support for individuals and communities living with loss, illness and grief.

St. Francis
Center

nondenominational

Providing guidance, information and support for individuals and communities living with loss, illness and grief.

THE FRIEND

who can be silent with us in a moment of despair or confusion, who can stay with us in an hour of grief and bereavement, who can tolerate not-knowing, not-curing, not-healing and face with us the reality of our powerlessness, that is the friend who cares.

Henri Nouwen
Out of Solitude

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St. Francis Center - Thanatology for Professionals Education Program - Fall 1994 - Spring 1995

St. Francis Center

Thanatology for Professionals Education Programs

Fall 1994 - Spring 1995

*SFC P 77

■ CHILDREN

When AIDS Strikes Parents

Who will care for a new generation of orphans—and the youngsters soon to become orphans?

By CHRISTINE GORMAN

TWELVE-YEAR-OLD NICOLE KNOWS more about AIDS than most children her age. She doesn't have the disease or carry the virus, but she has felt its deadly sting just the same. AIDS has taken both her parents. "I was nine years old when my mother died," Nicole (not her real name) calmly begins her story. "She told me that my father did drugs and died of AIDS, and that she got it from him." Nicole's grownup demeanor disappears, however, when she starts to read aloud a letter she wrote in the year after her mother died: "Dear Mom . . . I miss you so much. That day at the funeral I just looked at you, and I saw someone else in the coffin. I was saying to myself, 'That can't be my mother.' She is still in the hospital . . . I knew people had to die. But I never thought about you dying."

Nicole's story is becoming an all too common one in the age of AIDS. At least 30,000 children in the U.S. have lost one or both parents to the scourge, and over the next seven years that number is expected to at least triple. Within this group, Nicole is relatively lucky. She lives with her aunt on Manhattan's Lower East Side, does well in school and dreams of becoming a pediatrician. But perhaps half the AIDS orphans could wind up living in the streets or falling into an overloaded foster-care system. "We're seeing some 3,000 children in the Chicago area who will need placement very soon," says Cathy Blanford of the Lutheran Social Services of Illinois. "I expect the numbers will grow way beyond what anyone can imagine."

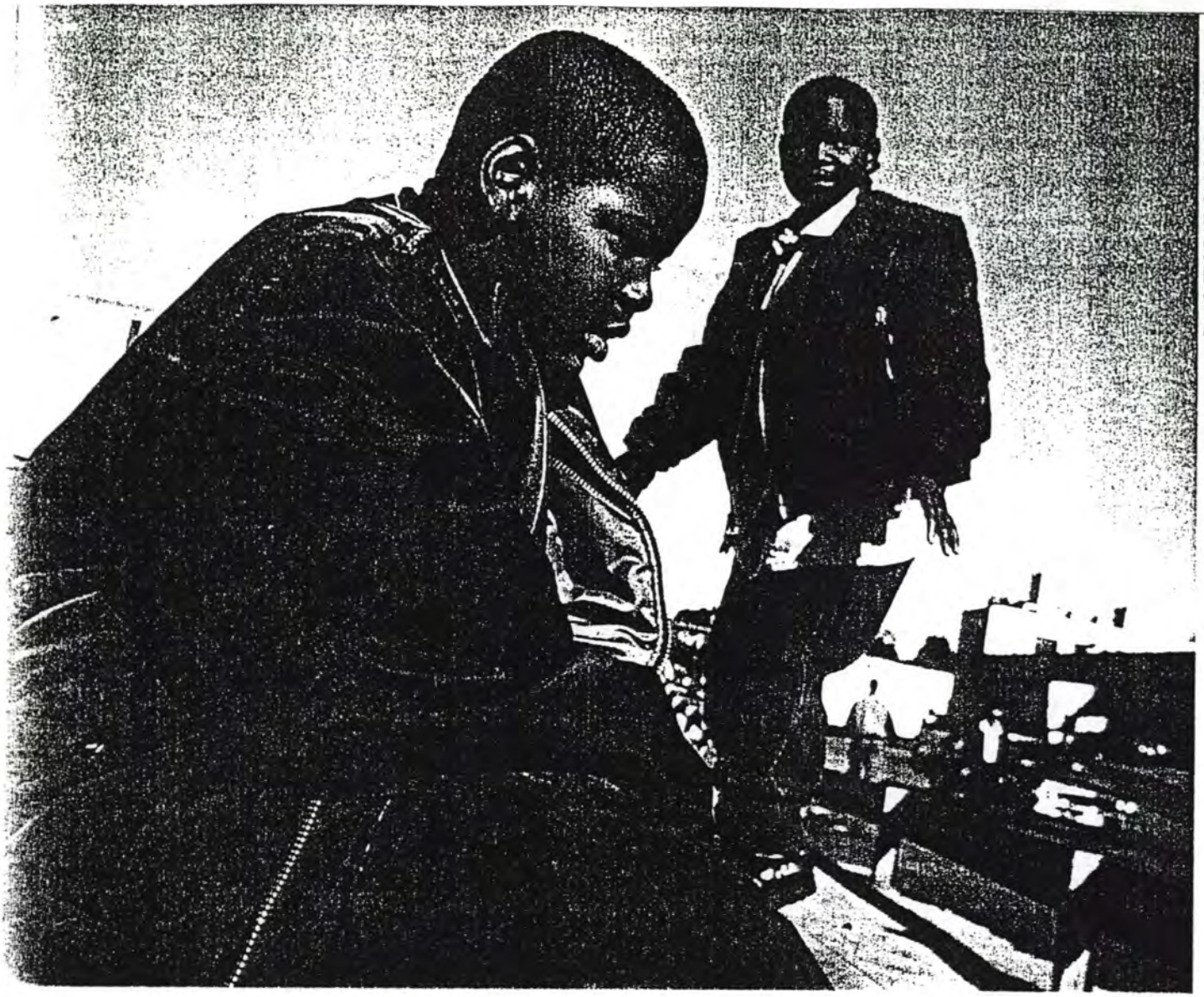
No one thought much about this dilemma back when AIDS was considered a disease of unmarried homosexual men. Now women are the fastest-growing segment of the AIDS population. From 1991 to 1992 the number of new cases among women jumped 10%, compared with 2.5% for men. Some of these women have husbands or boyfriends who are bisexual; others pick up the virus because they or their lovers are drug addicts who use contaminated needles. The majority have children.

A nine-year-old boy who lost both parents to AIDS drew his mother in heaven, hovering over his new family on earth

Although the toll is highest in drug-ridden ghettos, this is not just a big-city phenomenon. Rural Lancaster County, Pennsylvania, best known for Amish festivals and shoofly pie, has seen its drug problems increase as people have moved in from poor neighborhoods in New York City and Philadelphia. Some of the newcomers already harbor the AIDS virus; at least 400 children in the county have either lost or are about to lose a parent to the disease. Often, infected mothers leave large cities and return to places where they grew up, where aunts and grandmothers can take in the children. "Perhaps half the women we see have come home to die," says Jacquelyn Clymore of the AIDS Service Agency in Raleigh, North Carolina.

It is hard enough for a child to lose a parent. But when AIDS is the killer, the pain is all the more profound. Since most of the infected mothers are single parents, no father is around to fill the void. If the mother's drug use had caused her family to spurn her, relatives may be unwilling to care for her kids. Moreover, the stigma of AIDS causes many families to keep the cause of death quiet. The surviving children are isolated in their shame. "If they know, they usually don't tell anybody," Clymore notes. "Not their best friend, not their teachers, not anybody."

The silence takes its toll. With no acceptable outlet for their rage or grief, children often cause trouble in school. Boys, especially, may run afoul of the police.



LILIANA NIETO DEL RIO—JB PICTURES FOR TIME

In the Bronx, Michael, 11, and José, 9, learned from their mother that she is infected with the deadly virus

Some teenagers turn to indiscriminate sex or shooting drugs—as though they are daring the AIDS virus to do to them what it did to their parents.

But the cycle does not have to repeat itself. A growing number of community organizations are trying to prevent further tragedy by starting support groups for children orphaned or about to be orphaned by AIDS. Over the past three years, counselors at the St. Francis Center in Washington have helped the kids cope with depression, fear of abandonment, and the lifelike visions some have of their dead parents. "The teenagers, in particular, are caught in a squeeze," says Dottie Ward-Wimmer, a nurse at St. Francis who specializes in grief counseling. "They're older. They're smarter. They know that if their mother had cancer, people would feel sorry for them rather than shun them." Professionals at the Henry Street Settlement in New York City have found that if youngsters talk with one another about what they are going through, they are less likely to fall into self-destructive behavior. They also have an easier time adjusting to their new family.

Social and health agencies are trying to reach more AIDS sufferers before they pass away so that their children can be better prepared. That's not easy. Denial and shame are sometimes so strong that some parents never admit, to officials or anyone else, that they have AIDS. Marina Alvarez is not one of them. She founded a support group in the Bronx, New York, for mothers like herself who are HIV positive. "Information dispels fear," she says. "I can't say that my sons are absolutely O.K. with my illness. I don't think anybody's ever O.K. with a life-threatening illness. But they don't live in shame."

About half the ailing parents die before they designate anyone to take custody of their children. To improve that statistic, both Illinois and New York have enacted laws in the past year that allow parents to name a standby guardian to care for their children on a temporary basis. That way parents with AIDS do not have to give up permanent custody every time they go into the hospital, and they can know who will take in their children after death comes. "We try to match people up while the birth parents are still healthy enough to make good decisions," says Blanford of her Chicago program. "It helps the children make the transition because they have a sense from their parents that this is O.K."

After the guardians take over comes the hard part. The orphans need counseling, and their new families, which may have doubled in size, often require temporary financial and housing support. "For many families a little help at a critical time can make a big difference," says Carol Levine of the AIDS Orphans Project in New York. Otherwise, the newly blended families can break apart under the strain, and the orphans end up in foster care.

Some social workers believe communities may have to open orphanages. But they envision institutions that are smaller and more homelike than the cheerless warehouses of old. Whatever the strategy, society will need to pay more attention to AIDS orphans. "In the next 10 years a lot of the families who are presently coping will not be able to do it any longer," Levine predicts. "There are not enough grandmothers to raise these children." ■

When a teacher dies, her pupils face the hardest lesson alone

In the nation's capital, a city numbed by daily violence and death, a traffic accident that took the life of a young schoolteacher was barely noticed. But in the microcosm of Lafayette Elementary School, it was a tragedy.

By Carole Feldman
ASSOCIATED PRESS

Washington — Her name was Stephanie Hill, and she had 21 children — a devoted class of second-graders at Lafayette Elementary School. In an instant she was gone, killed in a car crash. The children had to learn their hardest lesson without her.

Their sense of security was smashed, like the car that Hill was driving. She wasn't sick, she wasn't old. But still she died.

Stephanie Hill died Sept. 25.

"Why?" sobbed my 7-year-old daughter, Rebecca. "Why couldn't somebody mean die instead? It's not fair."

"It's not fair," I agreed. I tried to comfort her, unable to hold back my own tears.

The new school year had held such promise. After nurturing Rebecca and her classmates in first grade, Hill had moved with them to second. She was as excited as they were. Now their dreams — and hers — were gone.

It was a Sunday, the day after the Sept. 25 accident, when Principal Sandra Bond notified teachers and began the sad task of telephoning parents.

Her task was enormous. Everywhere in the school, people were crying. Teachers. Parents. Children.

Hill, 26, had come of age at Lafayette, a public school in an upper-middle class section of Washington. She student-taught there and, after graduating from Howard University, was given her first class in 1989.

Her last lesson

With her cheerleading and cartwheels down the hall, soft shoulder and warm smile, she touched everyone. And when children fell in love with her, they fell in love with learning. Now they had to learn about death.

Rebecca recalled the last thing Hill told the class the Friday afternoon before she died: "Have a good weekend, children. Be safe."

The children wanted assurances that she had taken her own advice. They asked how the crash happened and whether she was wearing a seat belt.

Dr. Elizabeth Haase, a grief counselor who worked with the Lafayette community, said it is critical that adults be honest with youngsters right from the start.

The response to the seat belt question was, "I don't know."

Interspersed with the children's sadness were anger and apprehension. Who would be their new teacher? Would he — or she — be as nice?

We were told not to be alarmed — that all the reactions were part of the natural grieving process.

There are three main stages of grief: shock and denial; anger and depression; and reconciliation.

Children should be told what kind of emotions to expect when someone close dies "so they can understand what is normal," said Bari Ross, a counselor who worked with children and teachers when a special-education teacher at Sunrise Drive Elementary School in Tucson, Ariz., died of cancer.

Associated Press Photos

IN THEIR HEARTS: This artwork, done by one of Stephanie Hill's second-graders after her fatal accident, shows that she still holds a central place in their lives.

Learning to cope

"You've got to have your anger, you've got to recall your memories and learn to live in the world without forgetting the person who died," said Dr. Martha Oates, a counselor at William Howard Taft High School in San Antonio, Texas, and author of *Death in the School Community: A Handbook for Counselors, Teachers and Administrators.*

When a popular young teacher at her school died suddenly in her sleep, students were urged to write a goodbye letter. "I found a lot of them did write about things they wished they hadn't said . . . It was a very cathartic opportunity to say to her, 'I wish I had been kinder.' "

At Lafayette, grief counselors asked Hill's students to draw pictures of her, or of a memory they had. Every picture showed her smiling; most had her dressed in purple, her favorite color.

The rest of the school was invited to leave messages for her — and her family — on a huge roll of paper spread out in the school's Great Hall. "If I were a kite, I would fly to Ms. Hill," wrote one first-grader.

Some children were in such shock that they were unable to draw or write, and counselors moved around the school to help.

Haase said that young children are only able to cope with small bits of feelings at a time. "They may miss their teacher strongly one moment. Then 20 minutes later, they're off playing and really enjoying themselves."

It's important to give children the opportunity to talk about the person who died, and to answer their questions, she said.

Counselors worked, too, with Hill's devastated colleagues. Many wanted to spend time with Hill's parents, and Bond drove them to the family home. Parents stayed with those classes then and on the day of the funeral.

Bond delivered the eulogy: "She walked the earth to teach, and she did it the old-fashioned way, by setting a good example." But she also spoke of another side of Hill: "Who else could dress like Raggedy Ann at Halloween . . . do a perfect cartwheel in front of 500 children, a host of parents, and all her peers . . . ?

"Who could support and nurture you without any need for recognition except love, and understand you without any regard for age, gender, color or status, and strengthen herself with qualities she found in others and the experiences she shared with them? Stephanie could."

The children seemed to yearn for a sense of routine. When they were brought back to their classroom after counseling, several immediately started working in their math and phonics books.

Parents assisted the substitute teacher at virtually every hour. Another mother and I worked with the children on a poem, *We Remember Ms. Hill.* Others taught the children how to make glow-in-the-dark slime.

The class also raised money from the Lafayette community to plant a red maple tree in memory of Hill.

"We're really sad she died," the children said in their poem. "But we know she's teaching school up there."

FEATURE

Frontliners Talk About How They Prevent AIDS-Related Burnout

AIDS-related burnout (ARB) among professional and nonprofessional caregivers is one of the primary causes of staff absenteeism and turnover in AIDS agencies, according to Kairos Support for Caregivers, a nonprofit San Francisco-based organization that provides programs and resources to AIDS caregivers.

"In many instances, people aren't aware they are 'burned out' because it slowly catches up with them," said John McGrann, a Catholic priest who founded the Kairos organization in 1988.

For professionals counseling patients with HIV/AIDS, the emotional strain can be overwhelming. And year after year, such work can take its toll, causing caregivers to feel anxious, numb, or angry enough to abandon their undertaking.

McGrann maintains that ARB is quite preventable. But in order to manage stress, caregivers need to be aware of the issues that come up in AIDS care, he said. For example, Kairos advises professional caregivers to adopt the following four-step intervention process: recognize the symptoms of stress; identify the major sources of stress; determine where stress reduction is possible; and take care of yourself. "We ask people to take care of themselves so they can be there for clients in a supportive way," said McGann.

Caregivers may experience nightmares, anxiety, fatigue, palpitations, insomnia, aches and pains.

What are the symptoms of severe stress or burnout among those who counsel individuals with HIV/AIDS? Peter Kassel, Ph.D., director of inpatient psychology and associate director of HIV psychiatric service at Beth Israel Hospital in Boston has begun investigating the phenomenon among health care workers (including mental health professionals) providing frontline care to AIDS patients.

"There appears to be a syndrome that mimics post-traumatic stress syndrome," observed Kassel. These caregivers may experience several of the following physiological symptoms: nightmares; increased anxiety; chronic fatigue; palpitations; insomnia; and bodily aches and pains. In the workplace, he said, ARB can manifest itself through substance abuse; reduced productivity; impaired performance; a feeling of numbness; hypervigilance; increased opposition to change; decreased interest in interacting with co-workers, clients and their families; dislike of the work environment; and expressed dislike for the recipients of services.

Professional caregivers who have experienced symptoms of ARB and have managed to decrease their stress can offer some valuable coping strategies. After only eight months of counseling HIV-infected patients at the Whitman-Walker Clinic in Washington, D.C., Mardi Fritz, described feeling "an overwhelming sense of numbness, isolation and separation because death had become a constant companion."

To help herself stay the course, Fritz developed a method of exploring multiple loss and grief which she now includes in individual counseling, support groups and weekend workshops for professioinal caregivers.

Fritz currently practices social work in New York City and consults with eight AIDS organizations across the U.S. "The average person experiences a grievous loss every nine to twelve years. Yet, for the caregiver working in HIV, the cycle of loss can occur every few months, weeks, or even days," she explained.

Fritz said she tries to "create a space that is safe enough and open enough for therapists to talk about their issues and pain." According to Fritz, many therapists turn to this type of work after having lost family members and close friends to AIDS. "So with every new patient, they are at risk of emotionally revisiting their first traumatic loss." She encourages mental health professionals to recognize their past grief and connect it to their current reactions to a client's distress or even death. "Ironically, it is the professional training of many therapists that often gets in the way of their handling multiple loss," said Fritz. "Mental health professionals have a great deal of trouble getting beyond intellectualizing and psychoanalyzing to being honest about their emotional reactions to HIV patients."

When Gail Sherman, a psychotherapist and director of HIV training at the St. Francis Center in Washington, D.C. feels burnout approaching, she said, "it's because I'm not taking care of myself and honoring my feelings. The last thing I want to do is take time out to feel bad."

Once Sherman recognized the toll her work was taking on her own psyche, she figured out some methods of coping.

First, she attended staff meetings where people talked about patients who had died. "It's important to create rituals that help memorialize people. As therapists, we often can't attend funerals." Then, Sherman redefined what her role was with her clients. "I realized that I couldn't cure or fix their lives but I could help them be a person who lives with HIV. We don't have as much control as we think we do. And there is a certain amount of serenity that comes with that understanding."

Sherman said she also shifted her responsibilities. She decided to combine counseling and training so that she would have a healthier mix of responsibilities. "I try to build in breaks and flexibility so that I am not swamped with clients."

Sandra Lewis agreed that maintaining balance in her life is her best defense against burnout. "When working with children with HIV, you've got to have other things in your life," said Lewis, a psychotherapist and psychologist educator at the National Pediatric HIV Resource Center in Newark, New Jersey. "You can't live, sleep, and eat HIV, because there are so many ups and downs to treating people with the disease." Lewis avoids burnout by reaching out to colleagues. For her, participating in courses and conferences helps alleviate intense stress.

She also joined a support group at work. "Those of us who do education have to tell administrators to provide support for staff," said Lewis. She recalled the tension in her office before the group met. "People would pick on little things like whose turn it was to clean the coffee pot."

In his studies of caregivers, Kassel has found that long-term support groups can provide an effective way for professional caregivers to "integrate and share their experiences working with the HIV-infected population."

But many mental health professionals don't participate, he added. "We are very verbal and used to talking about emotions—so consequently we think we can handle this."

Tom Eversole recalled feeling overstressed while working as a psychotherapist at Johns Hopkins Hospital in Baltimore. "I felt I was falling down with my clients." He said his stress stemmed from confusion about his professional role. "Many of us were trained by standards that were never meant for AIDS," said Eversole, who is currently program development officer for the AIDS Training Project at the American Psychological Association, in Washington, D.C. "We need to let go of what doesn't work. For example, when someone's sick with AIDS and too weak to put in an air conditioner, they need help and care, not psychotherapy. Sometimes you just have to help install the air conditioner."

Many caregivers report feeling stress and embarrassment when they cross professional boundaries, according to Kassel, who counsels mental health professionals in his private practice. He reported that clients have expressed such worries as: "I did an unprofessional thing. I gave James a ride to the hospital because it was snowing." Kassel said working with HIV patients calls for greater flexibility on the part of the mental health professional.

Another source of stress and shame for caregivers, especially for those working in rural areas, is the stigma still associated with HIV disease. "In an agency where only one person is working with HIV clients, they may feel isolated and in some cases ostracized by the rest of the staff," reported Kassel.

Increasingly, rural and suburban areas are developing network support groups that enable caregivers in different offices to communicate with each other. For example, Karen Laquidara-Dickinson and John Hartigan, both social workers in Albany, organized the Professionals Working with PWAS Support Network. "We felt there was a lot of isolation among caregivers here. In rural parts of upstate New York, there's still a lack of knowledge about HIV transmission and caregivers often have to bear the brunt of this ignorance," said Laquidara-Dickinson. Their group, which has close to 50 members, meets every two months.

Some mental health professionals, like Jerry Gelfner, a San Francisco social worker, point out that stress and burnout can be related to how an organization is run. Gelfner surveyed 43 social

Continued on page 6

RESOURCE MATERIAL FOR PROFESSIONAL CAREGIVERS

The Kairos Support for Caregivers offers various services to help professional caregivers handle stress and burnout. They provide on-site presentations, seminars and retreats as well as resources and information for individuals and groups outside the San Francisco area. For example, Kairos has produced a caregiver's booklet that addresses common caregiving challenges and concerns and a start-up packet with guidelines for developing local support groups.

For more information, contact:

Kairos Support for Caregivers
114 Douglas St.
San Francisco, Calif. 94114
(415) 861-0877

In addition, the AIDS Information Network, a library of AIDS information, maintains a collection of articles on stress and burnout. For a small fee, they will conduct a literature search and also send out original material.

To find out about their services, contact:

AIDS Information Network
32 North 3rd Street
Philadelphia, PA 19106
(215) 922-5120

Avoiding Burnout

Continued from page 5

workers in San Francisco and found that stress was related more to poor working conditions than to intense emotional issues related to AIDS. "Rapidly expanding caseloads, changing organizational structures, unclear role definitions, and lack of support were cited," he said.

According to Gelfner, the majority of respondents said they had no power to affect change in the workplace.

He concluded that rather than emphasizing how caregivers should handle stress, organizations needed to provide better management and peer support. "To keep people in the field, the mental health profession must develop strategies to improve conditions and make structural changes in the work environment." ■

Death and Grief in the Workplace

Hard to Discuss, Worse to Ignore

JANE TOLD HER SUPERVISORS HER illness was terminal. She did not ask them to hide her condition, but senior management treated her sudden absence with a business-as-usual attitude and gave staff no hint of her prognosis. When she died, co-workers felt guilty about calls and visits they had not made and were furious at management's callous attitude. "Is this how the company really feels about its employees?" they asked.

Terminal illness and death affect every workplace. Aside from the human toll, these losses also cost businesses millions of dollars in diminished productivity, increased absences and grief-related health-care costs. Managers and staff need to recognize the emotional and practical problems death and grief cause in order to minimize their impact. According to Sharon Lerner of the St. Francis Center in Washington, flexibility and communication are the keys to successfully balancing managerial responsibilities with the desire to show compassion.

DEATH OF AN EMPLOYEE When a co-worker becomes terminally ill or dies, the company's attitude and the example the manager sets are important in determining how the office reacts. If the illness is a prolonged one, as is often the case with AIDS or cancer, how well management handles the period before the death can be as important as what is does afterward. Lerner and other professionals say that supporting the sick person should be a priority, but not at the expense of office morale and productivity. Your first responsibility as a manager is to take steps to keep the workplace functioning. Here are some ideas:

■ **Encourage your staff to discuss the situation privately with you.** People may have questions and may want to help their co-worker. They may also feel overwhelmed or angered by added responsibilities and extra hours. These conversations will give you insights into how well your group is functioning.

■ **Be sure to acknowledge extra staff effort.** For example, when Cathy Wright's economic-forecasting team at her previous workplace had to work overtime to cover for a member who took time off due to illness, Wright not only thanked them but also informally acknowledged their efforts by letting them go to personal appointments without taking official leave.

■ **Tell your own manager.** This should be part of your agreement with the sick employee. You are not in this alone, and anything that affects your group's performance has the potential to affect your career. Your boss can help share the burden, offer additional resources and be supportive if you have to shift or hire personnel.

■ **Take action before the problem becomes critical.** An employee's illness may progress to the point where, in your judgment, she can no longer handle her responsibilities. Try to find a humane solution that somehow maintains a link between the employee and the office. (A dying person's connection to her work life can be vitally important. Even if the person is absent, keep her aware of work progress and office news.) Some options are to bring in additional staff, transfer the person to a less stressful area, reduce her

Working Woman

responsibilities or offer part-time non-supervisory work or a specific project. Ultimately, disability, retirement or medical leave may be the only recourse.

■ **Make a point of visiting the employee and encouraging staff members to visit as well.** A staffer or co-worker's illness reminds us of our own mortality. The instinct is to shy away, as though the condition were contagious. It will mean a lot if you visit and call while the person is ill, and your staff will take note.

DEALING WITH CO-WORKERS' GRIEF Give your employees the opportunity to grieve. When the co-worker dies, inform the staff immediately, individually if possible. Allow them time to attend the funeral. Grief does not end with the funeral, so you'll need to find ways to help employees channel both their immediate and their ongoing grief. Some things that you can do include:

■ **Holding or participating in an event to raise money for the family of the deceased or for the employee's favorite charity.**

■ **Creating a book of memories to give to the family.** Many people are not familiar with the work life of those they loved. The book will offer unique memories for the family and a way for staff to privately express their feelings and memories.

■ **Conducting an office-only event.** Washington, Inc., an event-planning company, held an employee luncheon that gave the staff an opportunity to talk openly about a co-worker's recent death.

Be aware that the death may affect employee productivity and motivation. And pay attention to co-workers' reactions to the person's replacement, who may face resentment, anger and a lack of cooperation having nothing to do with his or her abilities—and a lot to do with grief for the deceased staff member. Acknowledging that this is the case can help alleviate the stress these emotions cause.

WHEN AN EMPLOYEE SUFFERS A LOSS More common than the loss of a co-worker is the death of an employee's parent, spouse or even his or her child. In these cases the manager's task is slightly different. Our society gives little formal time for grief; typical work policies allow up to three days off, or a week for the death of a spouse or a child. As Mary Jo Lawrence of Holy Cross Home Care Hospice has noted, "We give people leave of four to six weeks for heart surgery, but a broken heart can be equally hard to heal."

The initial reaction to death is shock and denial. Lack of motivation, mistakes, confusion and an inability to concentrate are all symptoms of grief. Ask the employee what you can do to help relieve some of the work stress. You can help the situation by setting an example. Many people are concerned that they will say the wrong thing, or they are so fearful of death that they shy away from someone who has suffered a loss.

EMPLOYEE DANGER SIGNS Although you can't put a timetable on grief, a manager should be alert to some signals that the person is not progressing through the grieving process. As the manager you have the right—and the obligation—to

raise your concerns with the bereaved person. According to Janice Miller-Thiel of Children's Hospice Services, who works with many bereaved parents, the danger signs include increased absence, indications that the person is not sleeping or eating, changes in personal habits (e.g., clothing, hygiene) and inability to work (distraction, continued mistakes, attitude problems). Note that an employee who has suffered a major loss and shows no signs of grief may be more at risk than the one who does show signs.

If you suspect a problem, be prepared to offer counseling resources. If your office has an employee-assistance program (EAP), refer the person to it or obtain information from the EAP office. Hospice staff and other professionals are available to come in and talk with management or employees about grief, and what they and the bereaved employee may be experiencing [see Resources, this page].

Remember, death is hard to discuss. But facing it and the grief it causes will help you—and your staff—survive, stronger and wiser. —Karen Lubieniecki

RESOURCES

MANY ORGANIZATIONS IN THE WASHington metropolitan area offer bereavement support services. Below are a few of the organizations to contact.

■ **Hospice Council of Metropolitan Washington** Its members have professionals and trained volunteers who can speak on grief and loss during and after an illness, and provide bereavement information and support groups. Members are located in the District of Columbia, Prince Georges and Montgomery counties and in northern Virginia. For assistance and information, contact the Hospice Council at 202-828-0777.

■ **St. Francis Center** A nonprofit, nonsectarian organization, St. Francis Center provides services to people living with illness, loss or bereavement. It offers publications and programs, including professional counseling for adults and education and training for organizations. Call 202-363-8500.

■ **The Center for Loss and Grief** The center offers psychotherapy and counseling for individuals of all ages and families coping with life-threatening illness, death, divorce and other losses. Call 202-466-3557.

RECOMMENDED READING

■ "Nothing Prepared Me to Manage AIDS," by Gary E. Banas, *Harvard Business Review*, July–August 1992, pp. 26–33. Moving article that addresses some difficult choices the author had to make when AIDS touched his workplace.

■ "Monday Mourning: Managing Employee Grief," by Alexis Jay Stein and Howard Robin Winokuer, *Disenfranchised Grief: Recognizing Hidden Sorrow*, Kenneth J. Doka, ed., Lexington Books, Lexington, Mass., 1989. pp. 91–102.

■ "Grief in the Workplace," *Work & Family Coalition Quarterly*, Metropolitan Washington Council of Governments, Vol. 2, Spring 1991. Article on dealing with grief. —K.L.

Support group for those affected by AIDS in the family

Judith Gregory Bowes, MSW
Joan F. Dickson, MSW, MA

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Introduction

The St. Francis Center of Washington, DC has been for 15 years a source of guidance, information and insight for people living with life-threatening illness and bereavement. At the same time that the Hospice Movement was coming to the United States, the Reverend William A. Wendt founded the Center to help those confronting the realities of serious illness and bereavement in a death denying society. The Center is a non-medical model emobodying the Hospice philosophy and offers counseling, support groups, education and training to anyone affected by loss, illness or death.

Judith Gregory Bowes, MSW, is Director of Volunteers at St. Francis Center, Washington, DC .

Since 1983 the Center has been available to those for whom AIDS (Acquired Immune Deficiency Syndrome) is a major concern. Because AIDS is a medical and psychosocial crisis for everyone involved, and there are always family members and loved ones needing care and support as well as people living with AIDS (PLAs). In Washington there was no group specifically for families where their concerns and experiences could be shared and support found. Consequently, in March 1989 the authors, both members of the Center staff, started a support group for those affected by AIDS in the family, drawing on the Center's expertise and Dickson's experience co-facilitating a similar group in London.

Joan F. Dickson, MSW, MA, is AIDS Training Coordinator at St. Francis Center, Washington, DC.

In the first year 55 persons representing 52 families attended. This paper includes a literature review and relates how the group functioned.

Literature review

Only recently has professional literature appeared on the subject of family issues and the AIDS crisis. Rinella and Dubin assert that "While tragically, the AIDS victim will ultimately die, the family will continue living and failure to consider their needs may lead to dissolution, prolonged psychological morbidity, and unresolved grief."[1] Likewise, Macklin stresses that the family must be seen as a unit of care in treatment, realizing that the impact on the family continues beyond the illness and death of the infected member.[2] Studies of other illnesses such as cancer reveal that the trauma which affects the patient also affects significant others.[3]

There is evidence that a diagnosis of AIDS causes other complicating factors for relatives. For example, many family members learn that their loved one is homosexual at the same time that the AIDS diagnosis is disclosed. This is true for wives of bisexual men as well as the families of origin of gay men. Studies of parents who know that their children are gay reveal uninformed attitudes about homosexuality involving superstition and stigma as well as feelings of shame, guilt, secrecy and ambivalence.[4,3] Parents find it difficult to

accept a child's homosexuality for several reasons: They must adjust to the knowledge that their child is not part of the majority; dreams that their child will have a traditional family life with grandchildren must die; a different kind of identity, behavior and lifestyle for their child must be faced; changed relationships within the family occur; and finally, AIDS and death are a real possibility for male homosexuals. These studies were based on samples of parents from the organization Parents and Friends of Lesbians and Gays who tend to be more supportive of their homosexual children, as indicated by their membership in the organization. Persistence of a bond between parent and child was evident in their responses. However, other reports indicate that over 70 percent of PLAs live alone and over 60 percent have little or no contact with families of origin. A study by McMillan reveals that of 30 men interviewed, 17 were not in contact with their biological families, some for as many as 18 years.[5] This estrangement limits potential sources of support and prevents or seriously interferes with completion of "unfinished business" which could benefit the patient and family before his death and help the family in their grief.

... many family members learn that their loved one is homosexual at the same time that the AIDS diagnosis is disclosed.

Other authors discuss conflicts within the family caused by changing roles, difficulty in communication and emotional cut-offs.[5,1,6,7,8] Mothers may look on their grown sons alternately as partners in the AIDS struggle or as infants in need of care.[5] Communication, according to a study by Christ and Wiener is most open between the PLA and siblings and least open with fathers.[9] Experience with an AIDS support group reveals that even more complex situations occur between sexual partners, whether heterosexual or homosexual, when fear of infection invades not only daily living but the intimacy of sexual relationships.[10] Knowledge and practice of safer sex do not prevent fear, shame and anger from interfering with communication and intimacy. Newmark and Taylor suggest that these basic role and communication problems lead to "isolation within isolation."[11]

... a study of families of PLAs ... found that in 55 percent of the cases studied, the family conflicts did not end with death.

Kelly and Sykes cite a study of families of PLAs which found that in 55 percent of the cases studied, the family conflicts did not end with death. "The emotions that are stirred up by the AIDS diagnosis do not go away quietly but can continue to disrupt what many consider to have been a reasonably well-functioning family."[12]

Many of the above authors are concerned also with other complicating issues for those affected by AIDS in the family. For example, some families struggle with one or more of the following: fear and panic; stigma and the fear of social rejection; isolation and secrecy; anger; guilt; helplessness; hate; bewilderment; depression; economic hardship; and exhaustion.[1,2,3,4,6,7,8,9,10] All of these factors as discussed in the literature also involve the unexpected illness and death of a loved one, in itself a source of extreme emotional response.

Rando suggests that the loss of an adult child is the most distressing and long lasting of all griefs and the most severe for fathers.[13] As families mature, role reversals and dependency shifts occur. While this adds new depths to the parent-child relationship, it also adds new dimensions to the loss when this relationship is severed by the death of a child. All of the family's hopes for the child's future die with the child. Rando cites literature suggesting that the time course of grief work based on hopes and memories is different. Loss of hope for a loved one is confronted at the beginning of grief, whereas the course of grief over a relationship rich with memories may or may not be intense at first but it will last much longer. Another relevant factor with the loss of adult children is the psychosocial situation of the bereaved parents who are experiencing their own life transition losses and relinquishing those things that had previously helped to define them, such as work and health. Already feeling the loss of control that comes with the aging process, it is dramatically increased when a child dies. Rando likewise suggests that complicated grief may be experienced when the parental relationship is marked by a high level of ambivalence or a distortion of guilt (both of which are likely to be present with a homosexual child). She further points to a "curious phenomenon in which older individuals are expected to be less grieved by death."[14] Furthermore, social negation of the loss and social isolation from support are among primary social reasons for failure to resolve grief.

... social negation of the loss and social isolation from support are among primary social reasons for failure to resolve grief.

According to Marshall & Nieckarz and Colburn & Malena, traditional counseling models do not meet the need of AIDS related grief because of factors which complicate the AIDS grief process, including: social stigma; multiple deaths (common in gay community); complicated family and community dynamics (including homophobia); secrecy; fatigue from caregiving responsibilities; religious conflicts; and unacknowledged relationships.[15,16] In their experience with 75 participants, Marshall & Nieckarz found that denial of an AIDS related death is significant and the risk of related illness during the grieving period is high. Substance abuse, suicidal feelings and social isolation among survivors require monitoring and intervention. Marshall & Nieckarz, both Roman Catholic clergy, also contend that the religious beliefs of most people affected by the AIDS crisis have been of little help and have inherent tendencies to add guilt and conflict to the situation rather than comfort and pastoral care.[15]

Weinbach and Doka elaborate on problems faced by survivors of relationships that lack social approval and represent major obstacles in the grieving process.[17,18] Doka calls this "disenfranchised grief" i.e. "the grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported."[19] The nature of AIDS and its psychosocial meaning relegate both the patient and such survivors to a marginal place in society.

Parry believes all kinds of families are affected by a life-threatening illness like AIDS and describes four categories of families:

- Intact;
- Fragmented;
- Extended; and
- Made up of unrelated individuals.[20]

She considers groups to be a way for participants to gain control over the environment. In groups the helpless become the helpers, enabling them to move from a dependent role to a more interdependent role.[21] Stephens, in her article about support groups quotes on AIDS support group leader who believes people under the stress of AIDS need social support, the origin of the notion of support groups.[22]

The group is confidential and informal, and each session becomes a new group with different dynamics

The literature on the affect of AIDS on relatives and friends of PLAs confirms their need for support. Groups enable the AIDS families to share their pain and to give and receive support.

Goals and style of the St. Francis Center Group

The goals of this support group are to provide:

- A safe confidential setting in which participants can choose to remain anonymous;
- The opportunity for the common ground of shared experience and shared information; and
- Altruism.

The group's power lies in the possibility of regaining control through the emotional support and practical information given and received.

A drop-in format with meetings twice each month was selected to provide for people with differing needs. This drop-in style is suited for those requiring immediate support or those who want to try out a group without making a commitment to an ongoing closed group. It is a service too for those caught up in the uncertainties of AIDS who may not be physically or emotionally able to come to all meetings.

The group is confidential and informal, and each session becomes a new group with different dynamics connected by the common experience of having a relative or loved one with HIV infection. Newcomers are invited to participate at their own pace.

Many express relief at knowing that they are welcome, though not required, to return. A mother may be reassured to share in a familiar setting the circumstances of her visit to her son in another part of the country. She, in turn, can be helpful to another relative joining the group temporarily while visiting a hospitalized family member in Washington.

Participants

Family members are self-defined and are from both traditional and non-traditional families. Interactions between partners/friends and family of origin increase understanding and respect for each other's significant roles in the life of the person with HIV infection. Peabody, mother of a PLA, wrote about her need "to know another mother, someone with whom to share common pain and sorrow in the months to come."[23] She could have been describing this group when she wrote:

> We are seven people, all united by AIDS. None of us would have met without this common bond. We are from all walks of life, regions, religions, professions. Some are families of patients, some are lovers, some are just concerned friends. Some have already lost their loved ones, others are still fighting, at different stages. Judy, who nursed her brother for a year before he died five months ago, is telling Maria she must be sure to tell Peter all she feels for him now, before it's too late and she's left with regret for things not spoken.[24]

Seventeen men and 38 women attended in the first year. Thirty-nine were caucasian and 16 were people of color. Half of the men clearly identified themselves as gay partners or friends of persons living with AIDS.

Some members may have recently learned of a loved one's diagnosis while others are grieving a death from AIDS. Of the 52 families represented, two had already lost someone to AIDS and also presently included someone living with AIDS; 18 were concerned about someone who was HIV positive; 25 were concerned about someone with AIDS; and seven were bereaved from AIDS.

The route of transmission of HIV infection is not always shared in the group. We know that there was one instance of perinatal transmission, three via transfusions and five via drug use. In thirty-one persons the route of infection was stated to be sexual contact, either homosexual or heterosexual.

Most people heard about the group from clinics, hospitals, other AIDS service organizations, or through Center publicity in newspapers or magazines. The two hour sessions are held twice a month in the District of Columbia close to public transportation and in the early evening, enabling people to stop in after work. Some participants, however, travel for an hour from Maryland or Virginia to get to the meetings.

Why people come to the group

One person who had attended five times explained to a newcomer, "This is a safe place to say the w.-d AIDS." Frequently newcomers are bursting to share their situation. Their emotions seem unmanageable in isolation: they need someone else to hear their story and respond with understanding. As soon as an encouraging listener is available words and emotion are freely expressed. It may be the shock of a loved one's diagnosis along with the revelation of drug use or homosexuality which brings a sense of crisis to the family. It may be a feeling of betrayal through infidelity or shattered idealism when a child, parent, spouse, or partner reveals secrets or confirms suspicions. A daughter learns of her heterosexual father's infection by a female prostitute with the same sense of shock and betrayal as a daughter of a gay man infected by his lover. Both daughters are aware that their fathers' actions are perceived by society as unacceptable, so that their secrets cover up the diagnosis and also the methods of transmission. Parents of gay sons are often ashamed, confused, and angry about their sons' sexual orientation and devastated by their pending premature death from AIDS.

One person explained to a newcomer, "This is a safe place to say the word AIDS."

Most people come to the group because they are desperate to get out of their isolation. Often secrecy exists within the family, among friends, and at the work place. However, while some may be eager to talk, others sit silently and wait until they feel it is safe and appropriate to share. Occasionally a newcomer will linger at the end of a meeting for a quiet word with one of the facilitators or another member whose experience seems similar. It takes courage to come to a group. One woman carried the newspaper clipping in her pocketbook for months before attending.

Issues brought to the group

The issues for the family change during the unpredictable course of the disease. Reactions are diverse within the families, but some examples within this group's experience give a flavor of the commonalties which draw people to risk a group experience.

The stigma is so real that families may find themselves living in an emotional exile. Fearing ostracism they exist in isolation and secrecy. Many experienced relatives advise openness but most have some area of their lives in which they are uncomfortable sharing that a loved one has or had HIV or AIDS. It does not seem to matter whether one lives in Washington, a suburb, or is visiting from a small town or city. The fear of disclosure drives many families to complicated lies and evasions within the family and community.

Anger is always present and varies in intensity and focus. It may start with anger toward the infected person and ricochet to society, the medical establishment, the government, other family members, one's self, or God. At times a parent, child, or partner may be so exhausted from the uncertainties and extreme fluctuations of the illness, along with the stress of constant care, that the anger may be directed to the ill person for continuing to live, suffer and need care.

HIV infection and AIDS carry a burden of fear for families. Spouses and partners seek about their irrational fear of contagion; fear of not being able to cope; fear of the stigma and of being found out; fear of disfigurement; fear of the dying and death of their loved one and possibly themselves; and fear of the unknown. Like anger, at times fear seems overwhelming and presages annihilation.

Such feelings as helplessness, frustration, hopelessness, revulsion, rejection, and homophobia may be the underlying causes of some of the fear and anger.

Guilt for not being a better or perfect parent, child, sibling, or lover drags down some family members. There is also guilt for having unacceptable feelings like anger, hate, blame or resent-

ment. Survivors may feel guilty that they are not infected. A widow who felt guilty over the circumstances of her husband's final illness and death has a particularly difficult time with her son's diagnosis of AIDS. She compensates, insisting that her relationship with her son is perfect and there will be no regrets or guilt when he dies.

Another reason for guilt among family members is the knowledge that an infected relative's irresponsible behavior may be infecting others, yet they are powerless to change that behavior. This is true for drug use as well as heterosexual & homosexual activities, including prostitution.

Some relatives have a strong sense of shame which is linked at times with the issue of class and status. One wife wept and raged that AIDS was happening in her middle class black family. The concept of AIDS as a disease of street people or of gay men is still strong and adds to her distress.

Almost everyone experiences some confusion during the unpredictable course of the illness because of the lack of unambiguous information. New developments in treatment and contradictory stories in the media are perplexing. Hopes are raised and dashed about medical break throughs, and the refocusing of hope is exhausting and depressing.

Sadness and grief are part of loving someone with a life-threatening illness. The grief may be anticipatory or focus on the loss of the potential of the ill person. The loss of the socially acceptable relative whose sexual orientation, infidelities or drug use are now overt leads to grief over the loss of the idealization of that person. Sadness may be expressed when families realize that limit of their influence, or conversely when the person with HIV or AIDS reveals a good, more loving side too late for the family to appreciate and enjoy it.

Financial concerns and the choice of caregiver are mentioned as stressful factors for the ill person and the family. The partner or spouse may become involved in a "kitchen war" with other relatives or friends trying to provide care. It is often pointed out in the group that ongoing extended family tensions are not submerged when decisions about financial obligations are caregiving are vital for the ill person.

Sometimes there is anguish that the person with AIDS has survived yet another illness ...

A difficulty some families bring to the group is the complicating factor of drug or alcohol use. It does not matter who in the family uses drugs or alcohol because addiction impacts the whole family system, creating yet another strain relating to concerns about unsafe sexual or needle sharing activities.

Faith is often tested for everyone involved with a person with AIDS. The meaning of life, death and spirituality get obscured by blame, fear, anger and panic. God may become the target of these volatile emotions. Or, in some belief systems, AIDS might be considered God's punishment for homosexual or drug addicted lifestyle. Sometimes a previous faith is strengthened; sometimes a faith is shattered; other times faith is discovered. One of the possible dysfunctions within a family system can occur because of different ideas about spirituality, which may change over the unpredictable course of the disease.

One particular situation, which is common in the group, occurs when the family member must balance his or her needs against the needs of the person with AIDS. Partners, parents, or friends, regardless of the type or degree of caregiving involved, are under enormous strain while trying to weigh their work, finances, other relationships and health in response to the ill person. Love and devotion can be so strained that the caregiver is shocked to experience flashes of anger and resentment. Sometimes there is anguish that the person with AIDS has survived yet another illness: how many times can the family prepare for the death? One partner described how awful it felt for him to watch the physical and mental disintegration of his lover and then to experience the relief of having him in the hospital for treatment. Other caregivers related a sense of relief mixed with guilt for recognizing their own needs at a time when someone they loved was dying.

Depression brought on by any or all of the above situations may be obvious in the group or acknowledged as uncomfortably close. Sleep and appetite disturbances are not unusual. Many people admit to the need for sleeping tablets, anti-depressants or tranquilizers to keep them functioning. Sometimes it is the beginning of depression that drives a person to try the group.

The importance of family history, dynamics, and traditions cannot be ignored. An additional stressor for some families occurs when there is a role shift within a family. For example, the previously domineering patriarch is so distraught over his son's illness he can no longer function as the leader of the family. People are vulnerable when the family is subject to the stresses of AIDS. Because of the stigma of AIDS and the isolation of some families there may be stifled communication within families. On the other hand, there is the possibility of positive transformation in the face of death from AIDS when relationships improve and quality time is valued and utilized.

What is gained from the group

People find the group a safe place in which to express their emotions and concerns. Because group members listen to each other, the understanding, sharing, and empathy are more meaningful. The commonalties of AIDS lead to an openness to the pain of others. A gay man talks about his fear of being infected by his lover with AIDS in spite of adhering to all the rules of safer sexual behavior. He elicits an immediate response from a man whose wife has AIDS and who shares the same fear. The two men, one homosexual and the other heterosexual, feel a bond with each other. The mother who fears the possibility that her son will die gains strength from meeting a bereaved mother who has survived. A discussion of difficulties and successful strategies for coping is more acutely heard when the information is shared as part of the process of helping each other. Participants gain from giving and receiving help from others. The group experience reduces their feelings of isolation, difference or abnormality. Through hearing the different situations in the group, tolerance is increased. The commonalty of pain can restore hope while validating the normality of the responses. For example, guilt is lessened when someone in a similar situation says, "If you don't take care of yourself, you can't take care of Bob." When group members can help each other, the empathy, understanding and suggestions seem more authentic. Attending as few as one or two sessions can improve coping skills. Additionally, participants are encouraged to exchange telephone numbers or to call the facilitators at the office between sessions so that everyone has the sense of being held by the group. In groups the helpless can become helpers so that their experiences can lead them towards others rather than into further isolation.

An important consideration for facilitators contemplating a drop-in support group is the ability to face a new group each session.

The facilitators

An important consideration for facilitators contemplating a drop-in support group is the ability to face a new group each session. There should be two facilitators who trust each other not only to help with the running of the group but to be available to each other in sharing the emotional stress of the group. For each session facilitators decide who is responsible for answering the door to greet the arrivals. The other remains in the group to maintain the flow and pay attention to the process. The task is to provide a psychologically safe environment in which all feelings and concerns can be freely expressed. Little direct intervention is made, so that group members have the chance to initiate discussion of issues and respond to each other. Sometimes it is helpful to point out similarities in situations and to encourage a newcomer to share. Usually there is someone in the session who takes it upon himself or herself to include a newcomer. The facilitators take every opportunity of stressing normalization while recognizing the crisis. Facts about the disease are available and misconceptions clarified. Resources and referrals are provided for individual situations. People need to know that they are not going crazy when they become forgetful or disoriented under pressure. It is important to validate the intensity and shifts of feelings as normal for the circumstances. Facilitators need to be alert for handling disagreements and misunderstandings, but thus far the group itself has dealt with differences of opinion.

In the midst of isolation and fear, bonding takes place, if even for one evening, providing a sense of community and support.

Conclusion

This group format provides a safe haven for relatives and friends of people with HIV or AIDS when and as needed while making no demands on their already complicated and overburdened lives. In the midst of isolation and fear, bonding takes place, if even for one evening, providing a sense of community and support. Accurate information is provided and appropriate resources made available. Individuals are strengthened and empowered to use their own inner resources in the face of this dreaded disease. It is also a reassurance for people with AIDS to know there is continuing support for their loved ones.

This informal, drop-in style would be suitable in a hospice where family members and friends are all recognized as significant to the welfare of the patient and to each other. A supportive community can be formed from among individuals who might otherwise be isolated in their pain. The hospice environment already incorporates the characteristics of safety and welcome which are so essential to a support group for those affected by AIDS in the family.

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Working With Grief

When Colleagues Are at a Loss for Words

By Barbara Mathias
Special to The Washington Post

For months, Stuart Shippereit had difficulty answering the phones in his office. The sound of the dull bell triggered an indescribable anxiety. There was no mystery about the origin of his phobia: A year ago, Shippereit routinely answered the office phone at 9 in the morning; it was the police informing him that his 18-year-old daughter, Caroline, a freshman at the University of Notre Dame, had been killed in an early morning car crash outside of Washington.

Now, Shippereit and his wife, Marianne, who live in Springfield, adjust to the emptiness of survival and the pain of bereavement both in their private lives and in their jobs. Like many couples who share a loss, they responded differently. Marianne preferred to get right back to her government office where she could "keep busy" and surround herself with friends. She took no time off and at home she put her energy into numerous projects from painting the entrance hall to writing personal letters to Caroline's many "compassionate friends who need to keep in touch."

A Navy man, 43-year-old Stuart Shippereit had been assigned to Operation Desert Storm, but after his daughter's death his orders immediately were canceled and he was given a new desk assignment. Relieved and grateful that he did not have to leave his family, Shippereit says that it still was difficult to enter a new job with new faces and new responsibilities. Initially, he chose to take two weeks off, and he later took individual days of leave. Admittedly, he "vegetated," wanting to do nothing.

"Those first few months I was in shell shock," explains Shippereit. It was fortunate, he says, that his superior was someone who "understands grief, somebody who understands that I was in a fog . . . that helped us both."

But after the death, "There is a storm surge of concern, people to hug, all the food . . . ," says Shippereit, while proudly showing a large album of photos and touching commemoratives from relatives, friends and Caroline's classmates. "Then after a while it subsides. After you go back to work, you don't have the amount of people and support. You don't know if you are going insane."

During the precarious period of grieving, the feeling that one is going crazy is not uncommon. It may come in the middle of the night, at lunch with colleagues, or at the start of a staff meeting: Grieving is not an emotion that easily can be turned off when one dons business attire or steps onto the subway. The same is true for the symptoms of grief—the despair, anxiety, anger and confusion. The bereaved soon learns that these feelings may flare up at the most unexpectant and inappropriate moments, so he does everything he can to suppress them.

"We get very good at avoiding the grief, so good that we don't realize we are doing it," points out Ron Culberson, counseling manager with the Hospice of Northern Virginia. "If it hasn't been dealt with, it comes out in other ways, such as physically or emotionally—a short temper, exhaustion, burnout."

Culberson says he believes that our society is uncomfortable with grieving because there is "no quick fix." He often hears of cases where the bereaved return to work and nobody even asks how they are feeling. Or co-workers will say, "Haven't you gotten over it yet? It's been six weeks!" Or, "Well how old was your father?" implying that his age should make the death easier to accept.

"We have an unconscious scale of grief carried in the minds of a large segment of society," says Sharon Lerner, director of education and training at the St. Francis Center, a nonprofit organization in Washington that offers grief, illness and bereavement counseling and training to the community.

"But grief," says Lerner, "is unique to the life of the individual experiencing it. It is not tied to whether the [deceased] was a child or a parent or a spouse. Where we see the most evidence of the mythological scale is in terms of allotted time off in the workplace to different kinds of losses. If it was a friend, in some jobs there may be a day off even if that friend was more important than the parent. For the death of a child or a spouse, one may be given two weeks; for a parent, only one week. I frequently hear that from employees over and over again, though it is not true for all workplaces."

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>
> —counselor Ron Culberson

According to Lerner, people were better equipped to handle death in the preindustrial era, when communities were much closer and people died in their homes. Mourning periods were marked by rituals and tradition in dress and ceremony so that the grief was recognized by all who came in contact with the bereaved. "Death and illness was more a part of our visible lives," says Lerner. However, "As a result of technology, more people died in hospitals and funeral agencies handled the death."

Another significant societal change that affects bereavement and employment is that the family is more transient: Patsieann Misiti, 32, grew up in West Virginia and now lives and works in Alexandria. Three years ago her 57-year-old mother died of an inoperable brain tumor. Misiti vividly recalls the frustration and guilt she felt working full-time as a commercial interior designer and wanting to be with her ailing mother "as much as possible." Limited in the number of days she could take off, Misiti traveled home on long weekends for more than eight months, often returning to work physically and emotionally exhausted. When her mother died and Misiti returned to work, the silence was deadly and her exhaustion continued as she constantly tried to "appear happy."

"I wanted to wear a sign around my neck that said, 'Don't you know my mother has died? Please don't brush this under the rug!' " exclaims Misiti. "It would have been all right to talk about it, even for me to cry a little bit."

When Misiti met two other women who had similar experiences they formed the Parent Loss Support Group, an organization for young adults in the metropolitan area. "We've learned that the best thing that anyone can say is, 'I don't know what to say, but I'm here.' "

Few people know what to say to the bereaved or how to act, particularly in the workplace, where people are expected to perform at their optimum, and where the office politics and hierarchy keep people from reaching out. "In the past few years there has been a growing awareness of a need to address grief in the workplace," says Lerner "but there is still a tremendous amount of work to do.

"In any other situation you would look at a person who is grieving and tend to think they need some psychiatric treatment: They may lose their appetite, forget, not be able to perform, feel like they are going crazy. What people don't realize is that this is normal. If employers can know that, they can reduce their fear and anxiety of this being a very long-term situation. The more support that they can give, and the more space they can provide . . . and understanding, that will facilitate that grief process more than anything else."

A number of private and public industries are employing organizations like the Hospice of Northern Virginia and St. Francis Center to instruct them on how to support and communicate with their employees in times of loss. Depending on the size and make-up of the industry, the grief counselor may meet with a large number of employees, a handful of managers or one senior manager. Some businesses call for "crisis assistance" when an employee dies and there is concern as to how her colleagues will cope with the emotional loss.

Since 1987, the St. Francis Center has provided workshops on grief to the Association of Flight Attendants (AFA). Flight attendants selected as peer counselors from all the airlines learn how to recognize signs of problems among their ranks, for example when a colleague has a miscarriage, loses a parent, a spouse, or a friend.

"We learn what to say, what not to say, how to stick with the bereaved, and how to recognize the grief processes," says Barbara Feuer, director of the Employee Assistance Program for AFA in Washington. Whether the

BY BOB DAHM FOR THE WASHINGTON POST

loss is caused by AIDS, cancer or old age, Feuer notes that the most important thing they have learned is that the length and stages of the grief can vary and be unpredictable. The grieving may take as little as two months or more than two years, and the feelings of shock and acceptance may "bounce back and forth." The best adage for the peer counselors is to be prepared.

Ellen Nielsen, an accountant for a national travel agency, returned to work six months after a car crash in which her 12-year-old stepson was killed and she was critically injured. Her boss understood when she told him that she could "no longer handle" her staff and to appoint another in her place. "He was very kind and took that load off me," recalls Nielsen. "He gave me assigned projects, very easy ones. At first I thought 'I am working not as an accountant, but as a clerk.' But I had to realize my limitations."

"We've learned that the best thing that anyone can say is, 'I don't know what to say, but I'm here.'"

—Patsieann Misiti

Initially, others in Nielsen's Virginia office also reached out. She was moved by the fact that one of her superiors hugged her and told her she could not comprehend losing a child. "My former staff came to my [work] station and talked, giving me kind words, like, 'You look good; you've gained weight.' That was compassionate of them," says Nielsen, whose injuries had reduced her weight to less than 100 pounds. "None of them said any of the platitudes, like 'It is God's will, you have to accept it' or 'You have other children.' "

Gradually the words and the arm around the shoulders stopped and Nielsen was left with her relentless grief. With the aid of her siblings and family she realized that she had to go outside the workplace to find a "safe place" for grieving. In time she joined and became the leader of the Alexander chapter of Compassionate Friends, an international support group for parental loss. Like the Shippereits, who also are members, Nielsen found she could talk more easily to others who had been through the same type of loss. And, as Stuart Shippereit says appreciatively: "Through Compassionate Friends I learned that this is a hard, long process."

This May, two months after his 49-year-old wife, Jackie, died of breast cancer, Bernard Smith, the administrator of an Army agency with eight offices in the United States and overseas, attended a meeting with his regional directors. "They all knew about Jackie and had expressed their condolences after the death," says Smith, "but that week no one—men or women—mentioned it, nor did I.

"During the meeting I sat where there was a view of Virginia Beach; there was a storm raging outside. I would catch myself getting lost in thought. As the head I had to get myself moving. You have to get back to business." Despite his concentrated effort, which includes a healthy diet and daily exercise as recommended by his doctor, Smith allows: "When you go back to work, you wear a tie, the same suits, but the pain . . . " he shakes his head as if in amazement. "I don't think I can cut any slack for myself. People say things the first time they see you, then after that nobody says anything, except for the people who are close to me in work."

Because of his senior, global position, Smith frequently is in touch with people who are unaware of his wife's death. "I handle it like nothing has happened," Smith explains sadly. Opening up to his colleagues somehow seems inappropriate. "I may say nothing but I think about it."

Fortunately, Smith has found considerable relief through the support of his three grown children and by being in contact with a social worker at the Hospice of Northern Virginia. (When his two daughters had to return to their jobs in Chicago and Richmond, the hospice put them in touch with hospice condolence counselors in their area.)

In the past few weeks Smith's social worker has reassured him that his need to visit his wife's grave, to read her letters, and to plant a tree in her memory, is perfectly normal and a way of "leaning into the grief." He also has been counseled that going on trips and then returning to an empty house and a rush of memories, can be "very hard."

Just last week Smith finally went on a business trip to New Jersey that he had postponed several times because he dreaded reliving the memory of how he and Jackie had last taken the trip together and she had won his colleagues over with her warmth and enthusiasm. Once there, however, Smith soon realized that no one felt at ease to mention his wife or her death. "I mentioned her one time and there was total silence, so I changed the subject. Eventually everyone started talking again. My subordinates are especially reluctant to talk."

Smith emphasizes that with cancer and death there is no feeling of control, so it is important to him that he now has control, especially in his job. That's really what motivated him to go to New Jersey last week, Smith says: He wanted to master the fear of the memories. "You have to figure out how to bring up [his wife's death] naturally to make people comfortable. And you've got to keep moving ahead."

Resources

The number one need that people have during grieving is to talk about it. There are numerous facilities and opportunities in the Washington area for helping individuals and families through the mourning process. Among them:

- St. Francis Center: Grief and loss counseling services, training programs for professionals and care givers, Volunteer Friends program, 202-363-8500.
- Hospice of Northern Virginia: Support groups, individual and group counseling, public education on grieving, 703-534-7070.
- Compassionate Friends: A national, self-help support group for parents who have lost children. Call 202-244-1026 for a recorded message that will direct you to the chapter in your area.
- Parent Loss Support Group: Self-help for young adults who have lost parents, Patsieann Misiti, 703-549-1094, or Elisabeth Schuler, 703-836-3374.
- On Sept. 12 there will be an all-day workshop on grieving and loss, cosponsored by Compassionate Friends and Parent Loss Support Group. $10 fee. Location: Blessed Sacrament Catholic Community, 1427 West Braddock Rd., Alexandria. Call Ellen Nielsen, 703-528-7813, or Bob Rosenberger at 703-698-6898.