



HIV & AIDS: The Grief Process

The phone call comes from a regional medical hospital, the news comes from out of the blue: Three sisters are told that their father has been hospitalized because of serious respiratory problems. The three women hurry to the hospital and are met there by a physician who, with their father's permission, gives them the devastating news: Their father has AIDS (Acquired Immunodeficiency Syndrome).



A young man returns home to renew relationships with his mother, father, siblings and boyhood friends. It is time to tie up loose ends, to resolve life stories. In the process, or perhaps to begin the process, he must find courage enough to share his news: He is HIV positive (Human Immunodeficiency Virus, a precursor to AIDS).



The teenager who dabbled in drugs and sex has grown into a woman with two lovely children, a caring spouse and an eye on the future. But a trip to the doctor for a recurring yeast infection yields unexpected results: a diagnosis of HIV/AIDS.



When a person first finds out he or she has HIV/AIDS, it can be a living nightmare. Shock, disbelief, numbness, anger, guilt, fear, depression—these and other emotions crowd in as the person struggles with worries about rejection, isolation and the anguish of a slow death.

Friends and relatives of those who have been diagnosed with HIV/AIDS or who have died of complications from the disease face their own

complex tangle of emotions: premature grief, fear borne of a lack of understanding, embarrassment and alienation in the face of social stigma or religious judgment, and discomfort in confronting issues of sexuality and chemical abuse.

The specter of untimely death is only part of what makes AIDS so difficult on everyone involved. Friendships can be strained, marriages embittered, religious faith tested. One mother captured the



sense of unresolved feelings with these questions: “Where is my support system when I need it most?” and “What might my son have accomplished had he lived?”

REACH OUT WITH CARING AND SUPPORT

Our emotions and attitudes can hinder our ability to care for and support persons with HIV/AIDS and their loved ones, thus deepening the pervasive sense of isolation and rejection common in such cases. As it is, our society is uncomfortable with death and the open expression of grief. Add the issue of AIDS, and we find that often those who desperately need our unconditional support are left feeling isolated, confused and shamed.

We must not let this happen. We must open our eyes and hearts and realize that we are all in this together, that with a few changes in circumstances any of us could be dying with AIDS. Both as individuals and as a society, we must find the courage to grow beyond our prejudices and fears. And we must each do what we can to offer understanding, practical help, and love.

THE GRIEF UNIQUE TO HIV/AIDS

People living with AIDS and those friends and family members affected by their plight often grieve in a way that is unique. Along with the more usual adjustments associated with loss and grief, they are also more likely to experience anticipatory grief, acute grief, and chronic grief.

Anticipatory Grief. Anticipatory grief generates overwhelming anxiety, with feelings of hopelessness soon after discovery. The hopelessness, in turn, may lead to suicidal thoughts and actions. Thoughts of sickness, suffering and medical expenses, as well as anxiety over the public perception of the diagnosis, can become overpowering. Fear of isolation and rejection by family and friends can be almost unbearable. During this stage, the person with AIDS often neglects his or her own physical and mental health.

Acute Grief. Acute grief occurs each time someone experiences an intense medical or social

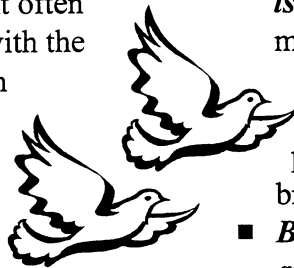
crisis. The specter of death is a constant companion for those with AIDS. The stress of waiting is exhausting. Acute grief generates thoughts driven by fear and fatigue. *Why can't I just die and end my family's misery?* The HIV-infected person and her loved ones need a wealth of reassurance, love and support during these times.

Chronic Grief. Chronic grief occurs because the AIDS patient generally lives for a considerable time after the diagnosis and, subsequently, may exhaust his or her positive outlook. AIDS patients who reach this stage may no longer feel able to maintain an acceptance of death or to prepare adequately for it. The long journey, with all its physical and emotional ups and downs, has become a roller-coaster ride. Weary of confronting social stigma and rejection, some AIDS patients become withdrawn and isolated, angry, lonely and bitter.

HEALTHY GRIEVING

The path of grief and acceptance of death is distinctive for each person with AIDS and for each survivor. Here are four key guidelines for healthy grieving:

- **Remember that the only way out of your grief is through it.** Don't fight your feelings, no matter how painful or inappropriate they may seem. Whatever emotions come up, let yourself experience them. Grief is a natural process. Allow it; trust it. It's nature's way of bringing us to acceptance, healing and peace.
- **Be appropriately sensitive and discreet, but stay away from secrets and half-truths.** Talk openly; be true to yourself.
- **Give your grief words; share your pain and hopes with others who understand.** Find at least one person you respect and trust, and pour out your heart and soul. Do this as often as you feel the need. Consider seeking counseling from a qualified professional. It can help so much.
- **Complete "unfinished business."** Listen to the whispers of your heart and soul. Do whatever it is that you feel is important. It may be finding the courage to hug and say "I love you" to a special person. It might be giving closure to a



project that's close to your heart. Or it may be offering heartfelt forgiveness to yourself or others.

HONOR SPECIAL RELATIONSHIPS

If the AIDS patient has a partner, respect the importance of that relationship. Bereavement expert Dr. Alan Wolfelt, in his leaflet *Helping AIDS Survivors Heal*, notes: "Many lovers of AIDS victims have enjoyed lengthy, enriching, monogamous relationships with the person who died. Family members, however, sometimes deny the significance of that relationship. As a helper, acknowledge the impact . . . on the bereaved lover. Let the survivor 'teach you' about the meaningfulness of the relationship. Be nonjudgmental as you reach out with open ears and a loving heart."

SUGGESTIONS FOR FRIENDS AND CAREGIVERS

■ **Reach out and touch the person with AIDS.**

Shake hands, give a heartfelt hug, or ask if he or she would like a gentle shoulder rub or back massage. Such gestures of caring and affection establish a connection that allows each of you to open your hearts, share, and give to the other.

■ **Listen—with wholehearted attention, an open mind, and genuine caring.**

Trust your own sense as to whether the person or family members want to talk. The need to talk will ebb and flow. Remember that caring silence and sharing one another's presence are also powerful, healing forms of communication.

■ **Keep confidences.**

When a person with AIDS or his or her loved ones share matters of a personal nature, keep the information to yourself. Do not violate their trust or your own integrity. If you abide by these principles, people will sense that it is "safe" to open up to you if and as they are ready.

■ **Be prepared for a range of emotions.**

More so than in some other types of deaths, people with AIDS and their loved ones usually struggle with intense, explosive levels of emotions like anger, fear and guilt. If they seem to lash out at you,

don't take it personally; it's part of the grieving process. Though it may be hard, try to be patient and understanding. In the process, you also may experience a range of difficult emotions. If so, you might find it helpful to talk with a friend or counselor.

- **Focus on living in the present.** Do your best to be here now. Live fully in the present moment, accepting what is—be it pain, a sweet smile, a moment of gratitude, or a lively discussion of current events. Live each moment fully until it's time for the final goodbyes.
- **Offer practical assistance in meeting day-to-day needs.** The demands associated with AIDS may exhaust a person's resources. As appropriate, tactfully provide for basic needs such as food, clothing and transportation. Do a load of wash, clean the kitchen, contact a distant friend or relative. Encourage your friend to attend to his medical needs early rather than giving in to anxiety and postponement.
- **Link with community resources.** Don't let the patient and her loved ones become isolated. Do some exploring. Find out what resources are available in local and neighboring communities, such as AIDS volunteer groups and agency support systems. Your regional hospice and community mental health center are good sources of information. *We highly recommend participation in an AIDS support group as a potentially invaluable source of understanding and assistance.*
- **Provide respite care for family and friends.** Regularly caring for a family member or close friend who has AIDS is both a privilege and an enormously draining task. Taking a caregiver's place for an afternoon or day, called respite care, is one of the most practical ways you can help. It allows you private time with the dying person, and it provides the caregiver a chance to rest and attend to personal needs and responsibilities.
- **Encourage important decisions.** The person facing death will feel much better if he or she prepares for death and draws together loose ends. Talk about important end-of-life decisions he or she might want to make. Be sure your friend

knows about advance directives such as living wills, healthcare surrogates and durable power of attorney. For information on advance directives contact your regional hospice or an attorney.

- **Offer to assist in distributing possessions.** It may be appropriate for you to help in passing on meaningful possessions to family members and others who will appreciate them. While this can be done after death, often a dying person appreciates the opportunity to participate in giving away choice possessions. It allows him a measure of control and helps to prepare for a good death.
- **Respond to spiritual needs.** If spirituality is important to the person with AIDS or his family, gently encourage them to draw on this resource according to their beliefs. Would your friend with AIDS like you to invite in a member of his faith community? The love and acceptance felt in a warm relationship with God or a higher power can be profoundly comforting. Activities such as prayer, meditation, forgiveness, listening for inner guidance, and inspirational reading can bestow a welcome measure of understanding, acceptance and peace.
- **Maintain a sense of humor.** As appropriate, let your joy bubble up and shine through. Smile, tell a joke. When something strikes you as funny, let go with a full-bodied laugh. Send a humorous greeting card. Or clip a funny cartoon and take it with you the next time you visit. Humor refreshes, breaks down barriers, and helps to heal the human spirit.

YOU CAN MAKE A DIFFERENCE

Be an informed advocate for better understanding of AIDS and of those with this disease. Work to put an end to misconceptions and fear. Stick by those who are rejected. Learn about HIV/AIDS. Share your knowledge. Confront the stigma of AIDS at home, in school, in your neighborhood, at work, and in your spiritual community or place of worship.

Open your heart, so that when the opportunity presents itself, you can reach out in love to those with HIV/AIDS and their families. Transcend the

barriers of prejudice and loneliness by connecting in friendship, spirit to spirit, one human being to another. ☺

REFERENCES

- Oates, W. (1981). *Your Particular Grief*. Philadelphia: Westminster Press.
- Parkes, C. (1986). *Bereavement: Studies of Grief in Adult Life*, 2nd edition. Nashville: Abingdon Press.
- "Grief and Loss," *Dictionary of Pastoral Care and Counseling*. Rodney J. Hunter, ed. Nashville: Abingdon Press, 1990.
- Caring for Someone With AIDS*, Center for Disease Control and Prevention, Public Health Service. # 498, 10/93.
- Salerno, M., Brock, L. & Wrightsman, J. (1994). *Caring Commitment and Choices*. National Association of People With AIDS.
- Wolfelt, A. (1992). *Helping AIDS Survivors Heal*, Batesville Management Services.

Prepared by Mary Mophew, M.S., Grief Specialist in Private Practice; Cathy Kunkel-Mains, Supervisor, HIV/AIDS Prevention and Management, Northern Kentucky Independent District Health Department; and Sam Quick, Human Development & Family Relations Specialist; portions adapted with permission from HIV/AIDS and the Grief Process, written for the Cooperative Baptist Fellowship by James A. Hyde, Associate Professor in Psychiatry, University of Louisville. For his editorial assistance, we extend appreciation to Robert L. Kaiser, Jr., Journalist, Lexington, Kentucky. (# 19 of 33, 1996)

This GriefWork publication is one of 33 fact sheets on topics related to death and dying. For more information about the GriefWork Project, contact your local Cooperative Extension Office. Although this publication is copyrighted, you are free to reproduce it in its entirety for non-profit, educational purposes.

Educational programs of the Kentucky Cooperative Extension Service serve all people regardless of race, color, age, sex, religion, disability, or national origin.

NOTE: Research has produced several drugs that in certain cases appear to delay or otherwise control the effects of HIV/AIDS. Such discoveries give hope that further advances will be made.

