AIDS

PERSONAL STORIES IN PASTORAL PERSPECTIVE

Earl E. Shelp, Ronald H. Sunderland &
Peter W.A. Mansell, M.D.

This descriptive and suggestive book provides information about a devastating disease, its effect on people (patients and non-patients), the response of society, and the obligation of the church. The stories in it are true.

This book calls the church to meet its obligation to provide redemptive and compassionate ministries in the crises generated by AIDS. Stories of people with AIDS or ARC, family members, lovers, nurses, social workers, and physicians are told as a means to illustrate the suffering associated with AIDS. The authors see the people with AIDS and others in their circle as contemporary examples of the "poor," "alien," and "oppressed" for whom the people of God have a special obligation, following the example of Jesus, to befriend and defend. The authors hypothesize that the response to AIDS by the church and society reflects the varied fears that the disease evokes and a disregard for the populations associated with it. The fact that people with AIDS tend to be abandoned and ostracized in society underscores their claim upon the church for compassion. The stories illustrate the need for ministry, and a pastoral commentary suggests ways in which these needs might be met by pastors and congregations. In short, AIDS is seen by the authors to challenge the church to reflect on its identity and mission. It provides a unique opportunity for the church to be the church, to be a servant people serving a servant Lord.

One chapter tells in understandable language the medical facts about AIDS.

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The Pilgrim Press
New York

$8.95

ISBN 0-8298-0739-X

Cover design by Patricia Kellis

3d printing, 1988

Library of Congress Cataloging-in-Publication Data

AIDS, personal stories in pastoral perspective.

Bibliography: p. 201.
1. AIDS (Disease)—Religious aspects. 2. AIDS (Disease)—Case studies. 3. Pastoral medicine.
I. Shelp, Earl E., 1947– . II. Sunderland, Ronald, 1929– . III. Mansell, Peter W. A.
[DNLM: 1. Acquired Immunodeficiency Syndrome—personal narratives. 2. Acquired Immunodeficiency Syndrome—psychology—personal narratives. WD 308 A28838]
RC607.A26A3486 1986 362.1'9697'92 86-21209
ISBN 0-8298-0739-X (pbk.)

The Pilgrim Press, 132 West 31 Street, New York, New York 10001

To all who have suffered
or will suffer as a
consequence of AIDS

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Preface

The stories in this book are true. Names and minor details have been changed to obscure identities. The sequence of events and features of particular experiences have not been altered. We have endeavored to tell each person's story faithfully, using his or her language where appropriate and possible. We have refrained from interpreting or commenting about each story or class of subjects until the final chapter. Even in the last chapter we have intentionally refrained from psychoanalyzing stories or any aspect of the AIDS crisis. Rather, the stories and other information provided are an effort to make known to a wider audience the pain, suffering, satisfaction, and peace that people involved with AIDS have experienced and are experiencing. As such, this book is a descriptive and suggestive piece that provides information about a devastating disease, its effect on people (patients and non-patients), the response of society, and the obligation of the church.

The people whose stories are told were carefully selected. We admit a bias in the selection process. Quite intentionally we turned to people whose histories we considered interesting and instructive. Not every category of person with AIDS is represented. For example,

adjusting to the latter prospect but is terrified by the former.

AIDS has revolutionized Bryan's life. Intimacy with his siblings has become more important. Similarly, intimacy, not necessarily sexual, with another man is a need once again. Finally, his faith in God and confidence in God's people has been affirmed. Bryan is a member of a Protestant denomination that does not condemn homosexual people or homosexual contact. He has no doubt that God loves him. AIDS is not God's punishment on him. As far as Bryan is concerned, he has AIDS because he was unlucky. God, in his mind, accepts him as he is—gay. Bryan is certain that God provides for his current needs. His faith in God and God's love for him, in Bryan's words, "will allow me to die a peaceful and serene death, soon if no cure for AIDS is found, or at a more distant time if there is a cure."

The pastor of the congregation where Bryan worships knows that he has AIDS. They talk frequently. A few people in the congregation are aware that he is ill. They treat him now as they did before. Their affirmation and courage not to withdraw have given Bryan strength to continue participating in worship services when he can. These sorts of pastoral and emotional supports are vital to Bryan's hope. These evidences of their concern for him have been reinforced by periodic monetary gifts from the congregation's benevolence fund. Unlike many people with AIDS, Bryan believes that he has not been abandoned by God or the church. These loyalties have enabled Bryan to retain some hope and sense of security. His spiritual family has helped to fill the void left by the withdrawal of his natural family.

KEVIN

AIDS is a personal and gay cultural experience for Kevin. The "cloud" hanging over gay men and other

people about whom Kevin had been writing became his own in January 1985. An ominous purple spot appeared on his arm. Having known about AIDS since it was described in 1981, Kevin suspected the spot to be Kaposi's sarcoma. He was afraid. And as more lesions slowly have appeared on his skin, his worries about his health and future have grown.

Kevin, thirty-six, is reflective, educated, and articulate. He holds a bachelor degree in journalism and a master's degree in counseling. Further, he completed half the requirements for a doctorate in counseling and psychology. All his higher education has been at a prestigious northeastern university. He accepted his homosexuality in his early twenties, while at university. His talent as a writer and his interest in gay issues earned him the respect of publishers of predominantly gay-audience magazines and newspapers across the nation. As a result, Kevin has an extensive national network of politically active and issue-sensitive friends. Kevin tends to interpret AIDS in existential and sociopolitical terms.

Kevin is angry about AIDS. He is angry that he has it. His anger is a complex mixture of grief over a lost future, impatience with interruptions related to his medical care, frustration about contradictory medical opinions regarding treatment, and anxiety about not knowing what will happen to him next. At times his anger subsides. At other times it erupts, and he expresses it by pounding his fists on a wall or table in his apartment. In more reflective moments Kevin concludes: "Having AIDS is bad luck. Whatever the ingredients are that make certain people vulnerable to the virus, I happen to have them."

His mother and father have known about Kevin's sexuality for years. His father seems more able than his mother to accept Kevin the way he is. They were told that Kevin has AIDS. His mother's response is indicative

of how difficult it is for her to accept that Kevin is gay. Two comments reflect her ambivalence: "I thought only homosexuals got that." "You mean they let you walk around the streets with it?" She avoids the subject of AIDS in conversations with Kevin. She asks how he feels, but he senses that she really doesn't want to hear a detailed reply. Kevin thinks that her frequent assurance, "I think you'll be OK," comes because that is the way she wants it. A recovery would help her to deny the "awful truth" that she seems unable to hear.

Kevin's father seems better able to deal with Kevin's illness. He has responded to the fact of Kevin's illness in ways that convey a genuine concern. Despite what Kevin takes to be his evident concern, he feels that his dad has an overpowering sense of helplessness in the face of his son's tragic circumstances. Nevertheless, Kevin and his father are able to talk in detail about what is happening. These conversations have become important sources of support for Kevin. They speak by phone every two or three months and visit in person about every eight months. Kevin has not told his three younger siblings about his illness. He doubts that they know.

Kevin's life-style has changed some since he developed AIDS. He thinks that the changes he has made reflect the changes taking place among gay men in general. Prior to being diagnosed, Kevin had a large number of acquaintances, but it was with his small group of close friends that he spent most of his time. They would visit together at home, go to movies, eat out, or see a play. There were also outings to a bar or elsewhere to meet sex partners. Conversations focused on gay or non-gay political issues, gossip, the arts, bar-based events, or other topics of mutual interest. Kevin's diagnosis has caused him to cease his sexual activity, to engage in more private socializing, to be more attentive

to his body and health, and to talk more about depression, fear, isolation, discrimination, and death. Kevin's close friends have become even more important to him. They were told one by one over time what is happening to him. Without exception, the response was supportive and caring. This heartening response, however, paradoxically is painful to Kevin. He is aware of their mutual commitments and the meaning that their friendship gives to his life. His fear of losing them by his death is painful to him.

Equally painful, if not more so, is Kevin's inability to communicate with his mother about what he is experiencing. He is sorry that she is ashamed of him for being gay and having AIDS. But not talking about it burdens both of them even more, in Kevin's opinion. He recalls that she cried when he told her about his homosexuality. She never suspected it. Kevin jokingly remarks: "She must have thought that I was too masculine to be gay. Obviously she never found out that I was trying on her clothes when she was out of the house." Her wish that he had never told her about being gay was a preliminary response consistent with her desire now to avoid more knowledge about her son that is too distressing for her to manage.

Kevin feels as if his life "may be fading away." These feelings are strongest when he is tired, has a headache, or an elevated temperature. He wonders: "Will I get over it; will I be able to do the things that I want before I die; will I ever feel desirable and have an intimate, romantic relationship again; should I make long-term plans; are any but my most immediate plans a waste of precious time; are my frequent, time-consuming trips to the doctors of any value?" Kevin believes that the purple lesions on his skin, although not visible when he is dressed, mark him, that people intuitively know that he has AIDS, and they withdraw. He feels, at times, as if he

and his life no longer count. If the data are correct, he will die soon. Why waste time, emotion, and energy on a dead man?

At other times, Kevin has hope. Defiantly he refuses to accept the description of AIDS as an "always fatal" and "terminal" disease. From reading the medical literature about AIDS he is aware that more is being learned all the time. He knows that the life expectancy for people recently diagnosed is better than it is for people diagnosed early in the epidemic. He thinks that the doom-and-gloom terms used in regard to AIDS perpetuate a negativism in patients that becomes a self-fulfilling prophecy. Kevin tries and prefers to think positively. This is why he has not appointed a legal surrogate for himself or made his last will and testament. He has a will to live. He is hopeful that medical science will develop effective treatments or a cure before it is too late for him. Nevertheless, he refuses to be passive about his illness. He presently takes antiviral and immune-boosting drugs that are not approved for nonexperimental use in the United States. He seems to be doing better than some other people he knows with AIDS. Kevin thinks that this may be due to his self-medicating, but he isn't sure. Nevertheless, he feels good about taking an active part in fighting and coping with his disease.

One way in which Kevin copes is through a support group composed of other people with AIDS that he gathered together. They meet regularly to share information, feelings, and concerns. Some of the group's members have become his friends. They met because of AIDS, he explains, but their friendship goes beyond this common trait. AIDS has created some new problems for gay men. But it also has enabled some gay men to let certain qualities or character traits surface. He thinks

that many gay men now, with or without AIDS, are becoming more genuine individuals, not merely conformists to expected gay roles and gay behaviors. The aspirations to be a "clone," an indistinguishable part of the crowd, seem to be disappearing. People are realizing that there is precious little time for posturing and playing games. The clock is ticking. Gay men now are doing things together out of compassion and mutual need, rather than out of pity and self-gratification. AIDS has given gay men a reason to grow up, to mature as individuals and as a community.

Another effect of AIDS has been less positive in Kevin's mind. Fear of the disease has become a facade for the expression of latent hatred for and oppression of homosexual people. Fear of AIDS and fear of homosexuality have joined forces to effect an even more powerful, concerted blatant effort to discriminate against and disenfranchise gay and lesbian people. The potentially limiting impact of repressive actions on employment, housing, and insurance options, for example, is frightening to Kevin. His concern is less for himself, since he works as a free-lance writer. He is concerned, nevertheless, for his homosexual brothers and sisters, who fight for their rights, respect, and decent treatment in a hostile environment.

MARY

Mary saw her dream come true only to have it destroyed by the AIDS virus. She is an attractive, soft-spoken, charming, intelligent young woman. She describes herself as an old-fashioned girl who wanted a husband who would be the man of the house and father of her children. Marriage, family, and home took on an

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To Craig,
In appreciation for making
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Earl E. Shelp

Ron Sunderland

Peter

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New York

but but there a few errors and things that have changed since I was interviewed almost a year ago. I'm told I'm one of two of the ten still alive since all included were interviewed.

What's different than the story suggests:

-My mother's attitude has improved some;

-I have two siblings, not three, and they both know now;

-I'm 38 almost, not 36 (as of December 11);

-I never tried on her clothes -- it was her makeup;

-I have made out a will;

-I don't think people "intuitively" know I have AIDS. I have returned to sexual activity, but not with the masses as before;

-I'm not nearly as altruistic as the last paragraph suggests;

-Most of my conversations are centered around gossip. That's much more interesting than the other stuff listed.

Anyway, I thought you might be interested in seeing this. This is your Christmas present so don't expect anything else. Ho Ho Ho.

Craig

aka Kevin