

AIDS

THE ULTIMATE CHALLENGE

“Incredible bedside compassion.... Kübler-Ross has been considered the world’s foremost expert on death and dying.” —Pat Holt,
San Francisco Chronicle

ELISABETH
KÜBLER-ROSS

Author of *On Death and Dying*

ELISABETH
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AIDS

The Ultimate
Challenge

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AIDS: The Ultimate Challenge is available in a hardcover edition from Macmillan Publishing Company.

This book is dedicated to G., who lived only nine months but whose life was not in vain. And to Larry. And to all our AIDS patients—the men, women, and children—who, through their suffering, became our teachers in *love*, understanding, and compassion.

—*Elisabeth*

“Today, something is happening to the whole structure of human consciousness. A fresh kind of life is starting.”

—Teilhard de Chardin

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Thank you Mwalimu Imara, you have stuck it out with me for twenty years, starting as one of my theology students two decades ago and going over my first book, *On Death and Dying*, and again you are the first person to read the complete manuscript of this, my fourteenth book.

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—*Elisabeth*

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Introduction

It may be necessary to give those readers who are unfamiliar with what I do a brief summary of my life's work so they will understand why working with AIDS patients was a natural outgrowth of my everyday work and concern.

For over twenty years I have been involved in caring for terminally ill patients, both adults and children. My goal has been, and still is, to educate health-care professionals as well as clergy to become more familiar with the needs, concerns, fears, and anxieties of individuals (and their families) who face the end of their lives.

As a result of my work with medical and theological students at the University of Chicago, and hundreds of terminally ill patients who volunteered to be interviewed by me for their "enlightenment," my first book, *On Death and Dying*, was published in 1969. It was in that book that I explain the "stages of dying"—*denial and isolation*,

anger, bargaining, depression, and acceptance—simply outlining the major emotional reactions patients, family, and sometimes even hospital staff undergo from the beginning of the diagnosis of a potentially fatal illness up to the death of the patient. Those five stages have been found again and again (not necessarily in the same chronological order) in many different forms of loss besides critical illness: in couples who go through divorce or separation; in a family whose house burns down; a farmer who loses his farm to bankruptcy; in parents whose child ends up in jail instead of college; mothers whose sons are found to be drug addicts or pushers.

Depending on the personality of the individual and/or the suddenness of the occurring drama, the stages of dying, as we used to call them two decades ago, can surface dramatically and quickly. In the sudden death of a child, however, many a parent stays in a state of shock, numbness, and denial for weeks. It can even last for years if in the emergency room or trauma unit the parents are sedated and tranquilized when the news is given, if they are stuffed with Valium to block emotional reactions and are sent home without the chance to view the body. As I've said elsewhere, health-care givers have to become more honest; we have to admit that we use far too many tranquilizers, that we send families home only half aware of the reality of their loss. The result is a prolonged and painful mourning period that is easily preventable.

We have, in many of our workshops, strongly advocated that soundproof "screaming rooms" be established adjacent to emergency rooms, and that they be staffed by members of the Compassionate Friends, who have worked through their own grief over the death of a child and can thereby help newly bereaved families exter-

nalize their pain, disbelief, anger, and rage before returning home. In this way they will have already begun to deal with their loss and be better able to inform the rest of the family and friends, share the death of a child with a sibling, and prepare for the funeral.

Life was tough in the early days. There was so much resistance, so much fear and reluctance. Many thought it “odd,” or at least unworthy of a physician, that one would spend so much time with dying patients. It was very difficult to obtain permission from primary physicians for medical and theology students to interview their dying patients. The doctors were afraid they might become “famous” for their dying patients—their “failures”—rather than for their successes. Cancer was a word that few mentioned openly in those days, and substitute labels such as “tumor” and “growth” were used when a patient inquired about the results of tests and examinations.

More often than not the family was informed but not the patient whose life was threatened by the diagnosis of a malignancy. Two decades later, laws and attitudes have changed. Thousands of books and papers written on the topic of terminal illness have led to yet another subspecialty, thanatology. Patients and families now talk more about an impending death, and thousands are preparing their own funerals. By accepting their deaths, patients are more willing to finalize their Last Will and Testament to ensure that their wishes are known and the family taken care of. There is rarely a medical or nursing school, a seminary, or social work institution where courses are not given on the needs of terminally ill patients. The clergy have also come a long way in their counseling.

Hospices have sprung up in every major area and palliative care units are available. Dying patients and

their families now have several alternatives to dying in a regular hospital. Thanks largely to the thousands of classes, workshops, and seminars given at medical and nursing schools, theological seminaries, and social work schools all over the country—many using *On Death and Dying* as their textbook—families are given the option of taking dying family members home for the final stage of their illness. When the science of medicine has done all it can, patients can either sign themselves into a palliative care unit or a hospice, where the quality of life is emphasized and not the prolongation of dying (at all costs!).

Hundreds of hospices are now available throughout the United States and overseas, and a couple of years ago we proudly started the Children's Hospice International, Inc., an umbrella organization to facilitate the inclusion of children in regular hospices as well as to establish hospices for children alone.

Little did we know when we first started that all this was subtle preparation for a far greater tragedy that was still on the horizon: the pandemic of AIDS. It took twenty years for the American people to feel more comfortable talking about death, openly discussing the possible use of a hospice and/or palliative care unit for elderly parents. Now, millions of young people are faced with premature death, and the number of hospice and hospital beds available to them is far too small to accommodate their needs.

Not only do people with AIDS have to go through the "stages of dying," they are faced with issues the world never has had to deal with to such an extent, in such massive numbers, and from every direction. AIDS has become our largest sociopolitical issue, a dividing line of

religious groups, a battleground for ambitious medical researchers, and the biggest demonstration of man's inhumanity to man—even far exceeding the treatment of leprosy patients in Damien's days.

When AIDS started to appear in the United States in the late seventies, no one in the government, or in the medical profession, had any idea the extent to which this soon-to-become epidemic disease would alter the life and life-expectancy of thousands (if not millions) of people the world over. Tragically, the "stages of dying" are experienced by millions in America today. Feelings of denial abound when it comes to facing the reality of a son's homosexuality; a child's contact and infection with the AIDS virus; a husband's bisexuality that led to an infected newborn baby. And when it comes to being more careful about any sexual encounter or the use of needles for illegal drugs, thousands more still live with the illusion that it cannot happen to them.

Denial is a difficult defense and it cannot be maintained over a long period of time unless parents totally avoid contact with their children and "keep their heads in the sand." Just as Americans have been known to be a death-denying people, so it has become quite obvious that we also attempt to deny AIDS, to pretend it is none of our business! We hear weekly, from thousands of pulpits, "love thy neighbor," but when it comes to putting that into practice we quickly add a few conditions. And it is those who preach the loudest who have shown the poorest records in their care and compassion.

When a mother discovers that the cause of her baby's AIDS is her husband of ten years, she desperately tries to deny the possibility that he has a history of bisexual behavior. Even if he eventually admits it, she still tries to find

another reason for the infection. One such woman even accused her pediatrician of having used unclean needles on her infant son despite the fact that her husband proved to be an AIDS carrier and admitted to having had a long-standing affair with one of his male co-workers.

Once families can no longer maintain denial, anger and rage set in. A German family was so upset and furious when the casket containing their son was shipped to their hometown marked in big letters "AIDS," that they left—never to return—the village where the family had lived for several generations.

Fury and anger is obvious in the "solutions" so many apparently well-meaning citizens present in their oratories and offer to "put all AIDS carriers on an island, or in some sort of camp where they can be watched and unable to spread the dreaded disease." Does that sound a bit like Molokai in the last century or the Nazi concentration camps, where they "isolated" the unwanted race or all those who did not agree with the Führer? We have indeed learned very little from history.

Does it remind you a bit of the war in Vietnam, where we were exposed daily to such statements as "Ten Vietcong were killed, but only one American." Yes, we still live in the illusion that it shall happen to thee and thee, but not to me. How many more wars, epidemics, famines, or other tragedies do we humans need before we open our minds, hearts, and ears and finally believe that whatever happens to our fellow man happens to us? We were taught that we are our brother's keeper, but we quickly add all sorts of conditions before we even consider such a possibility.

Anger comes in many forms with the AIDS epidemic. When I called the higher authorities of our penal system

years ago to offer a plan as to how to avoid the spreading of AIDS in our prisons, I was told, "This problem simply does not exist." They assured me that they had had only four such patients in the system, and three of them had already been released! The following day I visited a prison that had *seven* AIDS patients housed in one wing. No, denial will not work, and anger at the sick men and women will help neither those afflicted nor those who don't know how to cope with the ever-increasing reality that this is an illness that will continue to spread until we learn to change our ways!

I became very angry myself when one of the bedridden inmates I had visited asked for some oatmeal or anything that he still might be able to swallow—and they brought him tacos! This man was literally starving to death because he had a fulminating infection in his mouth and throat and was unable to receive adequate soft foods, which might have at least made him a little more comfortable. A transfer to a city hospital was out of the question because it would take too much time to handle the red tape. It is this disguised anger, this passive-aggressive hostility that was rampant in the early years of AIDS in the United States—not only in the penal system but everywhere in our communities.

With a sweet smile on his face, a minister informed one of my female AIDS patients that she was no longer able to attend Sunday services as her presence would empty the church rapidly and he did not like preaching to empty pews! The same thing happened to the unmarried mother of a dying three-year-old when she needed the support of her church more than ever.

How many children who had attended Sunday school for years were confused by the dichotomy between what

they were taught and what they witnessed when an infected hemophiliac was refused permission to attend school. The anger, frustration, and toll on energy parents feel is often insurmountable when it comes to standing up to the community or school board. And since this happens when the family is already suffering sleepless nights—from worries about the next ominous symptom of their child, from concerns over the ever-increasing cost of tests and available treatments—there is little if any energy left “to fight city hall.” They either give up or withdraw from the community to live out the last few weeks or months together in as peaceful an environment as they are able to muster. And again, it becomes evident that those who stick together will be strengthened, and those who have to struggle alone either fall apart or withdraw completely, abandoning a baby in the hospital in order to “disappear from society.” At least this way they know their child has good medical and nursing care and they can go someplace where no one knows them and quietly die in a rented apartment or room.

“Bargaining” is evident in older children and adults, as well as in the family, and often in the health-care providers: “If she only makes it to first grade, then her immune system will be stronger and she can lick this disease.” One prostitute said to me, “If my child gets well, I promise I will live like a nun thereafter.” It was not to be: both died within seven months of each other. Then there are the mothers who, upon hearing of their sons’ AIDS, move clear across the country, strongly believing that if they give up their homes and work to care for their “boys,” their sons will make it.

Naturally, depending on the course of the illness, this type of thinking does not stand up very long. It is gradu-

ally replaced with a mixture of anger, frustration, exhaustion, and *depression*. Different from patients with cancer, or other more “acceptable” illnesses, this depression cannot be shared with many. The man whose wife has cancer finds compassion, a listening ear, organizations: clergy, hospital personnel, relatives, and friends who will pitch in and listen to his grieving for hours. They can empathize with the man who has to hold down a job, then come home and cook dinner, who has to learn to do the shopping and laundry, and get the children to bed and to school early the next morning.

Yet if this man’s wife was suffering from AIDS, he’d see little of his neighbors, and if they occasionally did some shopping for him, they’d drop the groceries in front of the apartment door with the excuse, “I did not want to disturb you.”

Someone whose next of kin is dying of AIDS may desperately need to lean his head on a shoulder, but he will not even get as much as a handshake out of fear that the disease can be spread this way. The barbershop—often a place where people can pour out their hearts—may be closed to him with the explanation that the barber had to cut down his clientele and is no longer available to give him his regular haircuts. The same treatment may await him at the dentist’s office, or in the neighborhood bar, where his old buddy suddenly has an important appointment and leaves in a rush when he shows up. One formerly very uptight couple became so frustrated when a well-known Californian funeral chain refused to bury their son that they sought help in the gay community, which had buried hundreds of their own friends. Those men not only welcomed the couple warmheartedly, but arranged the whole funeral and attended in great num-