

AIDS

WHAT
DOES IT
MEAN
TO YOU?

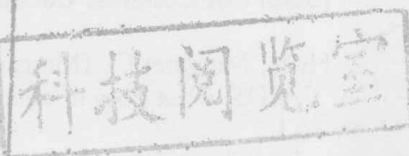
REVISED AND EXPANDED

**Margaret O. Hyde
and
Elizabeth H. Forsyth, M.D.**

AIDS

WHAT DOES IT MEAN TO YOU?

Margaret O. Hyde
and
Elizabeth H. Forsyth, M.D.



Y2001434



Walker and Company
New York

Copyright © 1987 by Margaret O. Hyde & Elizabeth H. Forsyth

All rights reserved. No part of this book may be reproduced or transmitted in any form or by any means, electronic or mechanical, including photocopying, recording, or by an information storage and retrieval system, without permission in writing from the Publisher

First published in the United States of America
in 1987 by the Walker Publishing Company, Inc.

Published simultaneously in Canada by John Wiley & Sons,
Canada, Limited, Rexdale, Ontario.

Library of Congress Cataloging-in-Publication Data

Hyde, Margaret O. (Margaret Oldroyd), 1917–
AIDS: what does it mean to you? Revised.

Includes index.

1. AIDS (Disease)—Juvenile literature.

I. Forsyth, Elizabeth Held. II. Title. [DNLM:

1. Acquired Immunodeficiency Syndrome—popular
works. WD 308 H994a]

RC607.A26H93 1987 616.97'92 87-2031

ISBN 0-8027-6699-4

ISBN 0-8027-6705-2 (lib. bdg.)

ISBN 0-8027-6747-8 (paperback)

Book Design by Teresa M. Carboni

Printed in the United States of America

10 9 8 7 6 5

AIDS

Acquired Immune Deficiency Syndrome

Recent books by Margaret O. Hyde

Missing Children
Cancer in the Young: A Sense of Hope
Sexual Abuse: Let's Talk About It (revised edition)
Mind Drugs (fifth revised edition)
Cry Softly, The Story of Child Abuse (revised edition)
Know About Smoking
and many others

Books by Elizabeth H. Forsyth
with Margaret O. Hyde

Terrorism: A Special Kind of Violence
Suicide: The Hidden Epidemic
What Have You Been Eating?
Know Your Feelings
Coming From Walker 1987.
Horror, Fright and Panic

Acknowledgments

The authors wish to thank the many health care workers, medical experts, educators, and AIDS patients who have contributed to the research for this book. Special thanks go to Ben Forsyth, M.D., Senior Vice President of the University of Vermont and Professor of Internal Medicine; to Alan C. Lusch, Chairperson, Department of Physical Education and Health, Abington Township Junior High School, Pennsylvania; and to Michael J. Callen for permission to use "A Personal Report."

Groups that supplied information include: Centers for Disease Control; U.S. Public Health Service; AIDS Action Council; American Association of Physicians for Human Rights; and the National Gay Task Force. Current information came from the Journal of the American Medical Association and other scientific journals.

AIDS
Acquired Immune
Deficiency Syndrome

Contents

Acknowledgments	vi
1. AIDS: What Does It Mean to You?	1
2. Living with AIDS	12
3. Michael Callen: A Personal Report	20
4. Avoiding AIDS	27
5. Plagues in Other Times	37
6. AIDS International	46
7. An Epidemic of Fear	55
8. Medical Progress	64
9. AIDS: A Challenge for the Future	74
The Surgeon General's Report	82
Groups Offering AIDS Information and Support	104
Glossary	106
Index	113

1

AIDS: What Does It Mean to You?

AIDS has been called the health threat of the century, the world's greatest public health problem, and the most misunderstood disease of all time.

Many people who talk about AIDS know very little about it. They may not even know that its full name is acquired immune deficiency syndrome. The A in AIDS stands for *acquired*, which means that it is not hereditary or introduced by medication. The I stands for *immune* and indicates that it is related to the body's system that fights disease. The D stands for *deficiency* and represents the lack of certain kinds of cells that are normally found in the body. The S stands for *syndrome*, which means a group of symptoms and signs of disordered function that signal the diagnosis. Although the full name may not mean much to you, it is likely that you have some ideas about AIDS. It is also very likely that you will continue to hear about AIDS for a long time, especially as it spreads more widely beyond the specific populations it first attacked. What does the headline DEADLY VIRUS HEADING TOWARD MAIN STREET mean to you?

Five years after the discovery of AIDS, new information alerted the public to the need for drastic steps in order to prevent a grim scenario for the future. Feelings of hope for bringing the epidemic under control were mixed with feelings of fear. Some fears were realistic, other fears were based on misinformation, on prejudice, and on the fact that much remains to be learned about this new and deadly disease.

Many people sympathized with the twenty-five telephone repairmen who walked off their jobs rather than work with a man who had AIDS. A brilliant psychiatric social worker asked if she might have picked up the virus that causes the AIDS when she swam in a pool with a colleague who later developed it. A homosexual who had been promiscuous felt that he would never develop AIDS because he lived in the country; he believed that AIDS was prevalent only in big cities. One man who had only an occasional homosexual experience did not consider himself at risk. All of these people were misinformed.

In November, 1986, a major newspaper carried an article by a responsible reporter expressing the viewpoint that predictions about the spread of AIDS were exaggerated. The problem of AIDS was far less serious he said, than many people were being led to believe. About the same time, Dr. Halfden Mahler, head of the World Health Organization, announced a global program to combat the AIDS disaster, which he described as a pandemic. Dr. Mahler admitted that he had not taken the disease seriously enough at first, but now he said he was "running scared" and could not imagine a greater health problem in this century.

Doubts, fears, apprehensions, and ignorance about AIDS continue to abound. Myths and superstitions die hard, especially when many questions remain unanswered. But even though many people cannot bring themselves to believe it, there is no evidence that AIDS is spread by casual contact. The hysteria associated with fears of acquiring AIDS from swimming pools, restaurants, social kissing, sneezes, bathrooms, and any other form of casual contact appears unfounded.

The struggle between hope and fear is quite understandable. AIDS threatens millions of sexually active men and women, and it reaches around the globe. AIDS raises social, legal, ethical, political, and financial as well as medical problems. AIDS may be a national catastrophe in the making. Not everyone is pessimistic, but, even in the best scenario, AIDS will have an increasingly large impact on the world of tomorrow. In spite of phenomenal progress, AIDS is still considered one of the most difficult challenges ever faced by modern medicine. There is no cure on the horizon, and widespread prevention by vaccine is years away. Reports of new AIDS viruses add to the problem.

The virus that is responsible for almost all cases of AIDS today has been labeled with several names—HTLV-III, LAV-1, ARV—but is now commonly referred to as HIV (human immunodeficiency virus). Newly discovered viruses are called SBL, LAV-2, and HTLV-IV, but only the first two are known to cause AIDS.

Although a diagnosis of AIDS is not an automatic and immediate death sentence, as many as 75 percent of those diagnosed as having full-blown AIDS die within three years. They suffer from many diseases, and although it was once thought that AIDS did not kill directly, new information indicates that the AIDS virus can kill by attacking the nervous system. Also, since the virus destroys the immune system, people with AIDS are vulnerable to cancer and a variety of lethal infections.

Not everyone who is exposed to the virus will develop full-blown AIDS, with the malignancies, infection, and brain damage that can accompany it. The great majority of people who are exposed to the virus appear not to be susceptible to it, or they develop such mild symptoms that they do not appear sick. Evidently some people are more resistant to the virus than others. Genetic factors may be involved. Some medical experts suspect a “cofactor” such as another virus or drug use. Recent laboratory studies indicate that a person’s general health may be

an important factor, and that immune systems that have been weakened by various diseases may be more vulnerable.

Some individuals develop ARC (AIDS-related complex), and while no one knows how many of them will develop full-blown AIDS, estimates range from 6 to 20 percent. The distinction between the two is blurred; it is unclear whether a person has AIDS or ARC. In both diseases, people lose weight, lack energy, and develop fevers and swollen lymph glands. By some definitions, people with ARC do not develop life-threatening illnesses, but many people who have been diagnosed as having ARC have died.

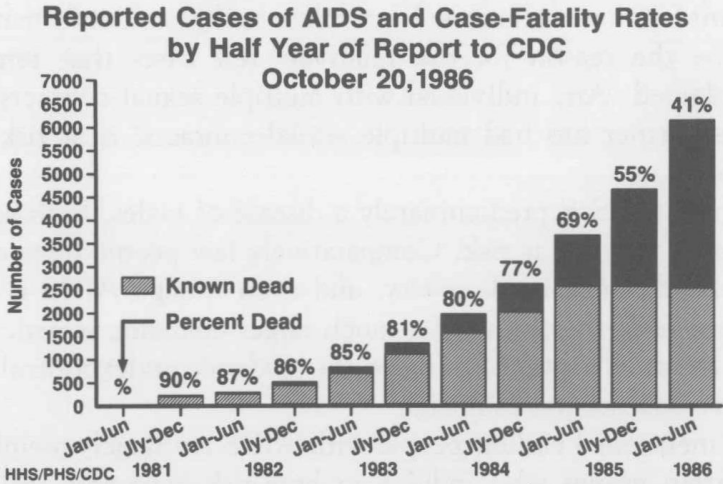
According to one definition, only people who have depressed immune systems together with one specific major illness tied to the syndrome have AIDS. Under other definitions, the total number of people who have AIDS would increase by 14 percent.

Actually, in the exact sense, there are no symptoms specific to AIDS, but similar symptoms of infection are common in people with AIDS because of their defective immune systems. In its most severe form, AIDS is a collapse of the body's ability to combat diseases that a healthy immune system fights without difficulty, and these diseases usually cause the death of the average person with full-blown AIDS within eighteen months after diagnosis.

The incubation period of AIDS ranges from a few months to at least five or six years. There may be no telltale signs during this period. As symptoms become apparent, people with AIDS may notice persistent swelling of lymph glands in the neck, underarm, or groin area, recurrent fever with night sweats, rapid weight loss, constant fatigue, diarrhea and diminished appetite, and/or white spots or unusual blemishes in the mouth. In the later stages, the immune system of a person with AIDS becomes severely weakened. At this point, diseases that are normally mild and harmless can be potentially fatal.

People with full-blown AIDS are subject to a host of illnesses,

particularly Kaposi's sarcoma (a form of skin cancer) and *Pneumocystis carinii* pneumonia (a parasitic infection of the lungs). These are normally rare diseases in the United States, but they are common and often fatal in people with AIDS. When the AIDS virus invades the brain, as it does in many cases, dementia is commonplace.



Experts predict that by 1991 there will be a tenfold increase in AIDS-related deaths. This prediction is based on careful studies, but many scientists believe that it is low, since AIDS is probably underreported by as much as 20 percent. By some estimates there are ten times as many cases of ARC, and no one knows how many of these people will develop AIDS or how many people they will infect. Suppose one adds these people to the one to three million already infected today. Dr. Robert Redfield of the Walter Reed Medical Center in Washington, D.C., suggests that the virus is likely to be present in the blood of from five to ten million Americans in 1991. Perhaps new drugs will be able to keep people reasonably healthy, or perhaps a vaccine will be available by that time. No one really knows, but the prediction

of a tenfold increase is based on the number of people who are already infected.

People contract AIDS not because of their age, their sex, their race, or their job, but because of their behavior. High-risk behaviors are well known. Sexual contact, especially anal intercourse with an infected person, blood contact through injections or transfusions or by accident, transmission from mother to child account for almost all cases. Incomplete background information may be the reason for the relatively few cases that remain unexplained. Any individual with multiple sexual contacts, or whose partner has had multiple sexual contacts, is at risk for AIDS.

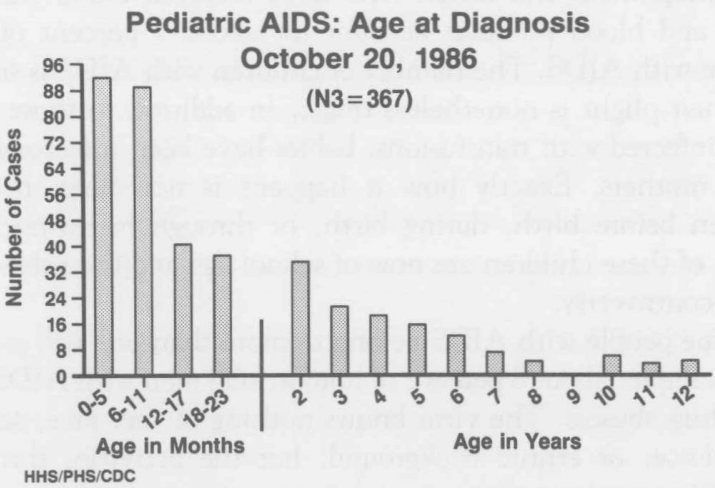
While AIDS is predominately a disease of males, both sexes now appear to be at risk. Comparatively few people have died from AIDS since its discovery, and even though AIDS is not easily spread, the threat of a much larger epidemic is real. For now, the only answer to bringing the epidemic under control is a massive educational campaign.

As mentioned earlier, people with AIDS are largely members of certain groups who indulge in high-risk behaviors. In the United States, roughly 70 percent of people with AIDS are male homosexuals or bisexuals (men who may be married, but indulge in homosexual as well as heterosexual activities). The disease is most frequently found among men who have had a large number of sexual partners.

Intravenous drug users who become infected by needles contaminated with infected blood make up the next largest group, at this writing about 25 percent nationwide, and this group includes both men and women. The percentage of incidence among these people is much higher in cities such as New York, where there are comparatively large numbers of drug abusers. There is growing concern about the spread of disease to the heterosexual population by drug abusers.

Some experts warn that teenagers and young adults in urban

areas are “ripe for a heterosexually spread epidemic of AIDS.” Others warn that a balance must be found between panic and realistic fears. Many people are frightened for the wrong reasons. It is next to impossible for someone in your family, one of your friends, or you to get AIDS if the guidelines for prevention are followed. Knowing the facts about how AIDS is transmitted and avoiding dangerous behaviors are the keys to controlling this disease.



Although the incidence of AIDS is still quite small among heterosexuals in the United States as compared with homosexuals and drug abusers, it has been increasing. By 1986, the number of cases traced to heterosexual contact in the United States had risen to 2 percent, a percentage point above that of the earliest years of the epidemic, and 80 percent of this group are women. Some cases of heterosexual transmission may be included among the unexplained cases. A total of about 7 percent of all cases may actually be the result of heterosexual transmission.

New evidence that the virus passes from women to men has

highlighted the risk of unprotected intercourse with someone who may be infected. The fact that prostitutes have been added to the list of unsafe blood donors, along with homosexuals and intravenous drug users, is indicative of the concern about the increase in heterosexual cases. Although the number of AIDS cases in this population will still be small, the Public Health Service predicts that the percentage will rise to 9 percent of the total cases.

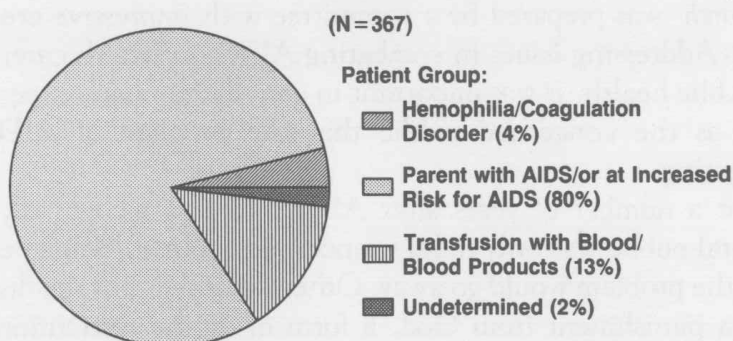
Hemophiliacs and others who have received blood transfusions and blood products account for about 3 percent of the people with AIDS. The number of children with AIDS is small, but their plight is nonetheless tragic. In addition to those who were infected with transfusions, babies have been infected from their mothers. Exactly how it happens is not clear; it may happen before birth, during birth, or through breast-feeding. Some of these children are now of school age and the subject of great controversy.

Some people with AIDS belong to more than one risk group. For example, about 8 percent of homosexual men with AIDS are also drug abusers. The virus knows nothing of age, race, sexual preference, or ethnic background, but the activities through which it spreads are more common among certain groups.

Even though the percentage of people in each risk group varies somewhat from year to year, the relative proportion of cases in the highest risk groups has remained remarkably stable and is expected to continue to do so.

It is frightening to consider that an estimated one to three million people in the United States and ten million worldwide are now infected with the AIDS virus. It is more frightening to consider that these people can spread the disease even though they have no symptoms. Many of them will do so quite innocently. No wonder people are asking what they can do to protect themselves. No wonder they are asking, "Can AIDS be stopped?"

Pediatric AIDS: Distribution by Patient Group October 20, 1986



HHS/PHS/CDC

No one knows all the answers to all of the questions that are being asked, but two reports that appeared in the fall of 1986 played a major role in alerting the public to the necessity of immediate action. In these reports, health officials announced their growing concern about the threat of AIDS for the future. Both reports pointed out that increased educational efforts were needed immediately.

In 1986, the Surgeon General, C. Everett Koop, released a 36-page report that startled many educators and parents. He proposed teaching young children about AIDS, both in schools and at home, so that they would know about the risks of dangerous behaviors before they were tempted to participate in them.

Adolescents were among those targeted for a continuing campaign of awareness and of education in avoiding the spread of AIDS. For many teenagers, experimentation extends to sex and illicit drugs. AIDS has been called a young people's disease, so it is for this age group that education is especially important.

Another report, published at about the same time as the Surgeon General's, came from the prestigious Institute of Medi-