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TOWARDS CREATION OF AN AIDS HOSPICE IN METROPOLITAN BALTIMORE

A REPORT PREPARED BY THE
HOSPICE COMMITTEE OF THE
AIDS INTERFAITH NETWORK OF BALTIMORE

APRIL, 1986

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ACKNOWLEDGMENTS

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FOR IMMEDIATE RELEASE

TOWARDS CREATION OF AN AIDS HOSPICE IN METROPOLITAN BALTIMORE ...... A REPORT

AN INTERFAITH ASSOCIATION HAS CALLED FOR THE CREATION OF A BALTIMORE AREA HOSPICE WHERE PEOPLE WITH AIDS MAY DIE WITH DIGNITY.

THAT RECOMMENDATION IS BASED ON A STUDY OF EXISTING HOSPICE PROGRAMS BY THE AIDS INTERFAITH NETWORK OF BALTIMORE, AN ORGANIZATION FORMED IN 1985 TO MINISTER TO AIDS PATIENTS, THEIR LOVED ONES, AND THE COMMUNITY AT LARGE. RESULTS OF THE INTERFAITH NETWORK'S STUDY WERE RELEASED APRIL 30.

THE STUDY NOTES THAT THE TERM HOSPICE, AS USED TODAY, DESCRIBES NOT A PLACE BUT A CONCEPT OF CARE FOR PEOPLE IN THE LAST STAGES OF A TERMINAL ILLNESS. THE GOALS OF THE HOSPICE CONCEPT ARE TO PROVIDE FOR THE DYING PATIENT THE GREATEST POSSIBLE DIGNITY, SELF-CONTROL, AND FREEDOM FROM PAIN.

THESE GOALS MAY BE CARRIED OUT EITHER IN THE PATIENT'S HOME OR IN A HOME-LIKE FACILITY, OFTEN ATTACHED TO A HOSPITAL OR NURSING INSTITUTION.

THE HOSPICE ENVISIONED BY THE INTERFAITH NETWORK WOULD BE A SEPARATE FACILITY, SPECIFICALLY FOR PEOPLE DIAGNOSED AS HAVING AIDS. THE GROUP CITED THE WIDESPREAD FEAR OF AIDS IN THE GENERAL POPULATION AND THE RELATIVELY YOUNG AGE OF MOST AIDS PATIENTS AS COMPELLING REASONS FOR A SEPARATE AIDS HOSPICE. IN ADDITION, IT WOULD BE A FOCUS FOR COMMUNITY RESOURCES, VOLUNTEERS, AND PASTORAL CARE--A FACILITATOR FOR SPIRITUAL SUPPORT OF THESE DYING PEOPLE AND A MEANS FOR PROVIDING ADEQUATE CARE.

SARAH BUR, A CO-CHAIR OF THE INTERFAITH HOSPICE COMMITTE AND A NURSE AT THE VISITING NURSE ASSOCIATION SAID: "CAREGIVERS ARE OFTEN OVERLY STRESSED BY THE AROUND-THE-CLOCK CARE REQUIRED FOR AN AIDS PATIENT IN THE FINAL WEEKS OF LIFE."

ACCORDING TO DON MILLER, A PERSON WITH AIDS AND A CO-CHAIR OF THE INTERFAITH HOSPICE COMMITTEE, SAID: "THE NURSING HOME PLACEMENT IS UNDESIRABLE." MILLER FURTHER STATED: "AN INPATIENT HOSPICE FACILITY WOULD GIVE THE PERSON WITH AIDS THE OPTION TO DIE WITH THE SPECIAL SUPPORT CHARACTERIZED BY HOSPICE IN AN ENVIRONMENT THAT IS MORE HOME-LIKE THAN A NURSING HOME OR HOSPITAL.

IN MARCH, 1986, MEMBERS OF THE INTERFAITH HOSPICE COMMITTEE SURVEYED NINE ESTABLISHED HOSPICE PROGRAMS IN THE BALTIMORE AREA. FIVE PROGRAMS OFFERED THEIR SERVICES TO PEOPLE WITH AIDS, WHILE FOUR DID NOT.

BY FAR THE LARGEST NUMBER OF AIDS PATIENTS--APPROXIMATELY 35 TO-DATE--HAVE BEEN SERVED BY THE VISITING NURSE ASSOCIATION OF BALTIMORE'S HOSPICE PROGRAM, WHICH PROVIDES HOME CARE FOR THE TERMINALLY ILL. THE HOME CARE HSOPICE PROGRAM AT ST. AGNES HOSPITAL REPORTED CARING FOR 2 AIDS PATIENTS.

- OVER -

HOSPICE PROGRAMS AT SINAI, ST. JOSEPH AND CHURCH HOSPITALS REPORTED THAT THEY WERE WILLING TO ACCEPT AIDS PATIENTS, BUT HAD NOT ACTUALLY CARED FOR ANY WHEN THE SURVEY WAS TAKEN.

THE PROGRAMS UNWILLING TO CARE FOR AIDS PATIENTS WERE THOSE AT UNION MEMORIAL HOSPITAL, JOHN L. DEATON MEDICAL CENTER, LEVINDALE GERIATRIC CENTER AND STELLA MARIS HOSPICE.

THE REPORT NOTED THAT PEOPLE WITH AIDS MAY ALSO BE SERVED BY H.E.R.O. (HEALTH EDUCATION RESOURCES ORGANIZATION) AND BY THE STATE SOCIAL SERVICES ADMINISTRATION'S PROJECT HOME, BUT THESE SERVICES ARE NOT HOSPICE CARE.

THE SURVEY FOUND THAT IN PRACTICE, THE ONLY HOSPICE CARE NOW AVAILABLE TO PEOPLE WITH AIDS IS HOME CARE. BECAUSE THE NUMBER OF AIDS CASES IS INCREASING, AND MANY PATIENTS IN THE LAST STAGES OF ILLNESS CANNOT BE CARED FOR AT HOME, THE INTERFAITH NETWORK CONCLUDED THAT A SEPARATE INPATIENT HOSPICE IS NEEDED IN THE BALTIMORE METROPOLITAN AREA FOR PEOPLE WITH AIDS.

IN SUPPORT OF THE HOSPICE RECOMMENDATION, THE REV. EDWIN G. BENNETT, WHO CHAIRS THE AIDS INTERFAITH NETWORK OF BALTIMORE COMMENTED: "SO OFTEN REJECTED BY THEIR FAMILIES, FRIENDS AND LOVED ONES, PEOPLE WITH AIDS, PERHAPS MORE THAN MOST, NEED A PLACE WHERE THEY CAN FACE DEATH WITH DIGNITY, KNOWING THAT THEY ARE LOVED, CARED FOR AND PROTECTED FROM AS MUCH PAIN AND LONELINESS AS POSSIBLE."

THE INTERFAITH NETWORK ALSO RECOMMENDED THAT THE FAITH COMMUNITY PROVIDE BEREAVEMENT SERVICES FOR FAMILIES, LOVED ONES AND FRIENDS OF PEOPLE WITH AIDS.

A TOTAL OF 294 CASES OF AIDS HAD BEEN REPORTED IN MARYLAND IN MARCH OF 1986, WHEN THE HOSPICE SURVEY WAS MADE. OF THESE, 178 AIDS PATIENTS HAD DIED.

AIDS, WHICH STANDS FOR ACQUIRED IMMUNE DEFICIENCY SYNDROME, IS CAUSED BY A VIRUS THAT DESTROYS THE BODY'S ABILITY TO FIGHT OFF INFECTIONS AND DISEASES. PEOPLE WHO CONTRACT AIDS ARE PARTICULARLY SUSCEPTIBLE TO RARE FORMS OF CANCER AND PNEUMONIA, AS WELL AS TO OTHER OPPORTUNISTIC INFECTIONS.

THE AIDS INTERFAITH NETWORK OF BALTIMORE WAS FORMED IN AUGUST, 1985, BY A GROUP OF LAITY AND CLERGY IN THE BALTIMORE AREA. THE GROUP'S STATED GOALS ARE TO INSURE PASTORAL CARE FOR AIDS PATIENTS, THEIR LOVED ONES, AND FAMILIES, TO DISPEL FEARS AND MISCONCEPTIONS ABOUT AIDS, TO ADVOCATE FOR JUSTICE IN SUCH AREAS AS HEALTH CARE AND JOB SECURITY, AND TO PROMOTE THE DEVELOPMENT OF AN AIDS HOSPICE.

THE GROUP ALSO ENCOURAGES PRAYERS FOR THOSE WHO HAVE AIDS, FOR THEIR FAMILIES, LOVED ONES AND FOR THE COMMUNITY.

> WE HUMBLY BEG OF YOU, O GOD, MERCIFULLY TO LOOK UPON YOUR PEOPLE AS WE SUFFER FROM THIS DREAD DISEASE; PROTECT THE HEALTHY, CALM THE FRIGHTENED, GIVE COURAGE TO THOSE IN PAIN, COMFORT THE DYING. GRANT TO THE DEAD EVERLASTING LIFE; CONSOLE THE BEREAVED, BLESS THOSE WHO CARE FOR THE SICK, AND HASTEN THE DISCOVERY OF A CURE. AND GRANT THAT IN THIS AND ALL OUR TROUBLES WE MAY PUT OUR WHOLE TRUST AND CONFIDENCE IN YOUR STEADFAST LOVE. AMEN.

# # # # # # #

TOWARDS CREATION OF AN AIDS HOSPICE

IN METROPOLITAN BALTIMORE

This report is dedicated to persons with AIDS, special people in life from whom we have learned so much, including how to live and die with dignity.

"You matter because you are you. You matter to the last moment of your life, and we will do all we can not only to help you die peacefully, but also to live until you die."

.... Cicely Saunders

TABLE OF CONTENTS

Introduction . . . . Page 1

Position of the AIDS Interfaith Network of Baltimore 1

The Hospice Concept: Philosophy and Evolution. 2

Baltimore Hospice Survey 6

Summary 8

Recommendations 9

References 10

APPENDICES:

A. National Hospice Organization (NHO) Statement . . . . . . Yellow

B. Hospice Resource Assessment Questionnaire . . . . Gray

C. Bibliography . . . . Green

D. Maryland AIDS Statistics . . . . Pink

TOWARDS CREATION OF AN AIDS HOSPICE

IN METROPOLITAN BALTIMORE

April, 1986

INTRODUCTION

AIDS is an epidemic. The national figures for reported cases continue to grow. To date, nearly 9,988 persons in the United States have died of AIDS and another 8,919 cases have been diagnosed. The projections are that the number of diagnosed cases will double every six months. In cities such as New York, AIDS is identified as the leading cause of death among males between twenty-five and forty-four years of age. The Maryland Department of Health and Mental Hygiene reports that as of March 27, 1986 there have been 178 deaths and another 116 cases diagnosed in Maryland. There are few of our houses of worship that have not been touched by AIDS in some way, either by persons dealing with diagnosed cases or by persons with strong fears of contagion.

The AIDS Interfaith Network of Baltimore was formed in August of 1985 as a positive religious response to the AIDS epidemic. It is an association of laity and clergy representing many denominations who share a ministry of healing for persons with AIDS and healing for a community confused by fear. Goals of the Network include assuring adequate pastoral care for AIDS patients and their loved ones, providing education and training to the larger religious community about AIDS and promoting availability of hospice care for AIDS patients.

POSITION OF THE AIDS INTERFAITH NETWORK OF BALTIMORE

The AIDS Interfaith Network of Baltimore supports the development of a separate hospice facility for persons dying of AIDS in the Baltimore Metropolitan area. AIDS is a terminal illness with uniquely catastrophic physical, psycho-social and

spiritual implications (1). Dying is an active process in which people continue to live and grow. This time is precious and important and is often a period of tremendous spiritual growth for persons with AIDS and their loved ones. Hospice allows the dying person to spend his or her final days in a nurturing, supportive environment, one that is attentive to the unique needs of each individual. Hospice enables persons to die with dignity. Traditional hospital and nursing home settings cannot provide the comprehensive care embodied by the hospice concept. *The AIDS Interfaith Network of Baltimore* believes that persons with AIDS should have the option of in-patient hospice care when care at home is not feasible. As people of faith we are called to minister to the special needs of this ever growing number of dying people.

The Network endorses the idea of a hospice specifically for AIDS patients for the following reasons. *FIRST*, fear of the disease is widespread and those who contract AIDS are often socially stigmatized. The life-styles of persons with AIDS are often non-traditional and require special understanding on the part of staff to adequately support patients and their loved ones. A hospice specifically for AIDS patients would insure that fear and prejudice not influence the care AIDS patients receive. *SECOND,* AIDS is a disease of relatively young people. Because institutions such as nursing homes serve an older population, many persons with AIDS are reluctant to enter them. Moreover, peer support can be encouraged in a hospice unit, helping the person with AIDS to cope with the disease and dying. *THIRD,* an AIDS hospice will be a focus for community resources--funds, volunteers, and pastoral care--for terminally ill AIDS patients, a facilitator for spiritual support of these dying people and a means for providing adequate care.

HOSPICE CONCEPT, PHILOSOPHY AND EVOLUTION

Hospice, an old word meaning inn or resting place for travelers, has been revived in recent years to describe a special type of care for dying people. Hospice is a *concept* and not a place. Models of hospice care range from hospice home care programs to free-standing hospice facilities. A goal of hospice care is to make the dying person's final voyage as comfortable and free from pain as possible, allowing the person to die with dignity. Hospice strives to enable the dying person to maintain as much self-control as possible. Cicely Saunders, the founder of the first

modern hospice, states the unique focus of hospice succinctly: *"You matter because you are you. You matter to the last moment of your life, and we will do all we can not only to help you die peacefully, but also to live until you die"* (2).

The key to success of the hospice concept is adaptability and empathy. A hospice program must be able to bend with the infinitely varied and important demands made upon it. Hospice staff carefully assess the possibilities and constraints of the patient's situation and creatively develop plans which are mutually satisfactory to patient and loved ones.

The admission criteria for hospice programs vary, but generally patients are considered who have a prognosis of six months or less. Many programs require a diagnosis of cancer. Most require that the patient have a full-time caregiver at home. In choosing hospice, a patient chooses to forego any life-sustaining measures. Medical intervention is geared toward palliative care, making a person comfortable. For example a hospice patient might receive radiation therapy, but only for the relief of pain, not for a cure.

Hospice programs have several essential components. A team approach is used to meet the medical, social, emotional and spiritual needs in a coordinated manner. A typical team includes physicians, nurses, social workers, physical therapists, occupational therapists, volunteers and chaplains. Nurses coordinate the care provided by various members of the hospice team. The team ministers to the needs of both patient and family. An important facet of a hospice program is ministry to the bereaved (3).

The hospice concept is achieved via home care and/or inpatient services. Hospice home care includes regular visits by nurses to teach families about care for the terminally ill. The nurse assesses the patient's status and contacts the physician for adjustments in the treatment regimen to best manage symptoms. Home Health Aides are available to assist the family with personal care. However, most programs are unable to provide twenty-four hour care. Rarely do insurance policies provide for twenty-four hour coverage. Only in instances of exceptional insurance benefits or the family's ability to pay can twenty-four hour Home Health Aide services be secured. Thus family members or friends provide most of the care. Social workers provide emotional support for patients and families and assist with financial adjustments that occur as the result of terminal illness. Volunteers fill the gaps that professional staff and families can not fill. Home care nurses are on call

twenty-four hours a day, but generally visit during day-time hours. Frequently patients are enabled to die at home. Sometimes, however, caregivers are unable to physically or emotionally cope with caring for a person dying of AIDS. Additionally, medical complications of AIDS may necessitate round-the-clock care. At that point some form of inpatient care must be obtained.

Inpatient hospice care is an important part of the hospice concept. Inpatient hospices are less institutional, more home-like, more able to minister to personal needs than traditional inpatient settings. No aggressive therapy is pursued and there are no visiting restrictions. "The spirit of the hospice environment is created as much by the staff as by the furnishings...an atmosphere of acceptance of terminal illness and death" (4). Patients are treated in an unhurried manner. They are known and greeted by name, not treated impersonally. Inpatient hospices become important when:

- patients can no longer be successfully managed at home;
- patients' symptoms can be better managed with round-the-clock care;
- care-givers are exhausted and need a respite from nursing responsibilities (5).

The history of hospice development in England is marked by an institutional focus different from the home care emphasis in the United States. The first modern hospice, St. Christopher's Hospice in London, opened in 1967. It revolutionized care for the dying, developing sophisticated approaches to pain and symptom control and providing a wholistic approach to care. Since then, numerous hospices have been created. The majority of hospice programs in England provide special institutional care, either in a free-standing hospice facility or in a special unit in a hospital. The socialized nature of Great Britain's medical system has allowed inpatient hospices to flourish. Home care of the dying has been developed but not as extensively as in the United States (6).

The organization of hospice administration in the United States is complex. Hospice services can be provided in home care and/or inpatient settings. Additionally this care may be administered from community or institution based organizations. Nationally more than half of the hospice programs in the United States are home care based. The evolution of a stronger focus on hospice home care versus inpatient care is probably due to the lower cost of home care (7).

Community-based hospices operate from either a free-standing hospice facility or out of offices that serve the hospice team. A free-standing hospice has the advantage of being an independent organization with a primary focus on hospice care. There is no free-standing hospice in Baltimore. Joseph Richey House will fall into this category when it opens. Other community-based hospices have a primary emphasis on home care. Inpatient admissions are to the hospital with which the attending physician is associated. Hospice patients who require long-term care are admitted to a nursing home or chronic care facility. An example of this type model in Baltimore is the Visiting Nurse Association Hospice Program. This is the primary model through which AIDS patients are receiving hospice care in Baltimore.

Institution-based hospices can be located in either hospitals or nursing homes. They are frequently operated from home care offices of hospitals. When the patient can no longer be cared for at home, the patient is admitted to the hospital. Usually the care provided is typical of any hospital inpatient care. Occasionally an institution will offer a separate hospice unit for the terminally ill. Patients are more likely to benefit from the services of a hospice unit than from a typical hospital setting. Plans of care are especially geared to the needs of each terminally ill patient. The only example of a distinct hospice unit in Baltimore is the Stella Maris Hospice located in a wing of the Cardinal Shehan Center for the Aging, a nursing home.

In review, there is great variety in the manifestations of the hospice concept in the United States. Its development has varied from the British experience where most models are institution-based. The emphasis on home care in the United States has created a large number of skilled professionals who specialize in home care of the dying. With the help of these professionals many people have been enabled to die at home. Unfortunately, those patients who can not be managed at home often end up dying in an impersonal institutional setting. In contrast, hospice units or facilities, relatively uncommon in the United States, offer a less institutional, more comfortable atmosphere with greater attention to individual needs. The goal of hospice, to die with dignity, with adequate pain and symptom control, is more likely to be achieved in an environment with a nurturing ambience and professionals skilled in meeting the special needs of the dying.

BALTIMORE HOSPICE SURVEY

In an attempt to assess the resources available to persons dying of AIDS in the Baltimore Metropolitan area and to evaluate the potential need for hospice services locally, the *Hospice Committee* of the *AIDS Interfaith Network of Baltimore* mailed a questionnaire on March 5, 1986 (see Appendix B) to nine hospice organizations listed in the Maryland State Hospice Network 1985 Directory of Hospice Programs. These nine programs were chosen because they operate in the Baltimore Metropolitan area.

Of the nine hospice programs surveyed, five offered hospice services to persons with AIDS. Of these five, four are hospital-based programs and one is community-based. All five programs offer primarily hospice home care services. The four hospital-based programs indicated that they can admit AIDS hospice patients to the hospital, if necessary. It is important to note that of these four hospice programs, none offered inpatient hospice care.

Four of the nine hospices indicated that their services were not available to people dying of AIDS. They either stated refusal to accept AIDS patients or their program required a primary diagnosis of terminal malignancy as an admission criterion.

The following Baltimore area hospice programs surveyed are willing to provide hospice home care services to AIDS patients as of March, 1986:

- The Visiting Nurse Association Hospice Program, a part of the Visiting Nurse Association of Baltimore, has provided hospice home care for approximately 35 terminally ill AIDS patients since 1984. They do not require a primary caregiver at home. They have some city and county grant monies available to care for indigent AIDS patients. Of those patients who have died, 78% were enabled to die at home.

- The St. Agnes Hospital Home Care/Hospice Program, has cared for a total of 2 AIDS patients. A patient who requires inpatient care can be

admitted to an available bed in the hospital. They do require a primary caregiver at home and do not have financial resources for those patients who are unable to pay.

- The Hospice Program of Sinai Hospital is willing to care for AIDS patients but at the time of the survey had not accepted any patients into their program. They require a primary caregiver and have minimal financial resources for thos AIDS patients who are unable to pay.

- The St. Joseph Hospital Home Care/Hospice Program has expressed willingness to accept AIDS patients but at the time of the survey had not cared for any. They do require a primary caregiver and do not have financial resources for those AIDS patients who are unable to pay.

- The Church Hospital Hospice has expressed willingness to accept AIDS patients but at the time of the survey had not accepted any patients into their program. They require a primary caregiver at home, must live within a twenty-five to thirty minute drive from the hospital hospice, and be diagnosed as having a malignancy with a life expectancy from five days to six months. A patient who requires inpatient care can be admitted to an available bed.

The following Baltimore area hospice programs surveyed are not presently willing to provide hospice services to AIDS patients:

- John L. Deaton Medical Center
- Levindale Geriatric Center and Hospital Hospice Program
- Stella Maris Hospice Care Program
- Union Memorial Hospital Hospice Program

It should be noted that at the time of the survey the Joseph Richey House, an inpatient hospice due to open in September, 1986, has not yet firmly established criteria for admission to their program. Admission criteria will be based on their basic philosophy which is to provide care for those terminally ill patients who are victims of a malignant disease in which further anti-tumor therapy does not provide a reasonable possibility of cure. The Joseph Richey House will operate solely for the benefit of those who do not qualify for existing hospice programs and have a short time to live.

In addition to the hospice services listed above that were surveyed, and the *AIDS Interfaith Network of Baltimore,* two service organizations exist in the Baltimore area for people with AIDS. These services are not hospices and therefore are not listed as members of the Maryland State Hospice Network. The two organizations, H.E.R.O. and Project Home, are discussed next.

H.E.R.O. (Health Education Resource Organization) is a group that provides information and education about AIDS as well as a support network for people with AIDS. Working through trained volunteers, HERO provides advocacy with social service agencies, referral for housing and funeral assistance. HERO provides the ancillary services numbered 1,2,3,4,7,8,9, and 10 listed in the Hospice Resource Assessment Questionnaire (see Appendix B).

Project Home. Working through the Department of Human Resources, the AIDS project of Project Home seeks to provide housing for people with AIDS. Financial support to home providers is supplied by this aspect of the State Social Services Administration. Eligibility for the program requires that the person present a diagnosis of Acquired Immune Deficiency Syndrome (AIDS) or AIDS Related Complex (ARC) and that he or she lack an appropriate housing situation due to the client's financial situation. Clients are certified according to the amount of assistance they require.

In summary of the hospice survey, nine hospice programs exist in the Baltimore Metropolitan area. Five of the nine hospice programs offer services to terminally ill AIDS patients. Hospice home care is the only option for hospice care currently available for persons dying of AIDS in Baltimore. Hospice type volunteers are available to AIDS patients through HERO. Homeless AIDS patients are recipients of services from Project Home, a program devoted to finding foster care for AIDS patients. *Presently, there is no inpatient hospice in the Baltimore area willing to accept AIDS patients.*

SUMMARY

As the number of AIDS cases increases, there will be a growing need for inpatient hospice care, which is presently not available in the Baltimore Metropolitan area. While many persons with AIDS can be maintained at home until they die, for a significant number this is impossible. The hospice concept is very specific. It embodies the belief that a person in the last stages of life deserves special, individualized and supportive care. It recognizes that the needs and desires of the patient and

loved ones matter and should be respected. The dying person's special needs can best be met in a flexible non-institutional environment. Baltimore needs an inpatient hospice for people who are dying from AIDS.

RECOMMENDATIONS

The religious community is called to be a healing force in the community, assuring the care of the sick and dying, ministering to the grief of family and friends. People of faith must move to ensure that persons with AIDS are enabled to die with dignity, that trained people are available to minister to the bereaved. To this end, the *AIDS Interfaith Network of Baltimore* recommends that the religious community move in an organized and effective manner to:

1. Ensure the establishment of a separate hospice facility for AIDS patients in the Baltimore Metropolitan area, one that remains in keeping with the ideals of the hospice movement.

2. Ensure that bereavement services are available for families and loved ones of persons who die from AIDS.

REFERENCES

1. National Hospice Organization Policy Statement on Acquired Immune Deficiency Syndrome, Adopted by NHO Board of Directors November 6, 1985.

2. Stoddard, Sandol. The Hospice Movement. New York: Stein and Day Publishers, 1978.

3. Lindstron, Bonnie. "Operating A Hospice Bereavement Program." Corr, C. and Corr, D. eds. Hospice Care Principles and Practice. New York: Springer Publishing Co., 1983.

4. Wentzel, Kenneth. To Those Who Need It Most Hospice Means Hope. Boston: Charles Rivers Books, 1981.

5. Buckingham, Robert. The Complete Hospice Guide. New York: Harper and Row, 1983.

6. Hillier, E. Richard. "Terminal Care in the United Kingdom." Corr, C. and Corr, D. eds. Hospice Care Principles and Practice. New York: Springer Publishing Co., 1983.

7. Corless, Inge B. "The Hospice Movement in North America." Corr, C. and Corr, D. eds. Hospice Care Principles and Practice. New York: Springer Publishing Co., 1983.

National Hospice Organization

NATIONAL HOSPICE ORGANIZATION

POLICY STATEMENT

ACQUIRED IMMUNE DEFICIENCY SYNDROME

Acquired Immune Deficiency Syndrome (AIDS) is a terminal illness with uniquely catastrophic physical and psychosocial implications for the patient and those who share the patient's life. The search for causes and cures for this disorder should rightly claim the attention, energy, and support of the public and the providers and payors of health care in the United States.

The National Hospice Organization (NHO) believes that the care of AIDS patients is as important as the cure of the AIDS disease. Member hospices of NHO have been, since the discovery of AIDS in this country, providers of palliative care to AIDS victims. NHO affirms the pioneering work of our members in making hospice care accessible to AIDS sufferers and responsive to their needs. Those hospices which have pioneered palliative care for AIDS patients symbolize what hospices ought to do in fulfilling the standards and principles of the National Hospice Organization. NHO encourages all hospices to serve AIDS patients.

NHO understands that fear, stress, confusion, and lack of experience and resources may be obstacles to the care of AIDS patients in hospices just as in the rest of our society. The special needs of the AIDS patient and family should not be understated but should be understood.

The significant issues posed by AIDS and by the access of AIDS patients to hospice care must not result in avoidance, denial, or desertion by those to whom these patients have turned for help. The special needs of the AIDs patient call for the best in us as hospices and as hospice people.

The National Hospice Organization is committed to making hospice care accessible to AIDS patients throughout America and to making American hospices skillful in caring for AIDS patients.

Consistent with NHO's role and responsibility as the voice of the hospice movement and the advocate of the terminally ill patient and family, we are committed to finding the answers and finding the resources for competent and compassionate care for those suffering from AIDS.

Adopted by
NHO Board of Directors
November 6, 1985

1901 North Fort Myer Drive • Suite 902, Arlington, Virginia 22209 • (703) 243-5900

APPENDIX B

March 1986

AIDS INTERFAITH NETWORK HOSPICE RESOURCE ASSESSMENT QUESTIONNAIRE

(please respond to all questions)

NAME OF SERVICE:______________________________

CONTACT PERSON :______________________________

Part I--Medical Care

1 Is your service willing to provide services for people with AIDS? ________

2 How many people with AIDS have you serviced in the past? ________

3 What is the maximum number of people with AIDS you could serve? ________

4 Are there minimum requirements thet must be met to be elligible for your services? If yes, please list them.

5 Do you provide the following care? If yes, which ones? ________
inpatient hospital care ________
inpatient hospice care ________
inpatient nursing home ________

6 Do you provide home care for people with AIDS? If yes, ________
Is the person required to provide his/her own care giver? ________
Do you provide respite care so that care givers can get a break? ________

7 Will/can you provide a home care giver if necessary? ________

8 Do you accept the following insurance coverages for people with AIDS?
Medical Assistance ________
Medicare ________
Private insurance ________
Other ________ Please specify:

9 Do you have financial resources (grants etc) to assist people with AIDS who cannot pay for your services?

10 Do you have financial support for the services you give? ________
(ie. does your service cost the patient?) ________

11 Are there other sources of income that you can help us activate for people with AIDS to help pay for your services? If yes, please list:

12 Other comments:

AIDS INTERFAITH NETWORK HOSPICE RESOURCE ASSESSMENT QUESTIONNAIRE March 1986

Part II Ancillary Services
please answer all yes or no

Do you provide any of the following services to people with AIDS?

1 legal services/assistance

2 financial assistance

3 social work

4 pastoral counseling

5 physical therapy

6 occupational therapy

7 psychotherapy

8 hospice education/awareness

9 counseling/ assistance for family and friends of people eith AIDS

10 bereavement follow up

Please list any other services you offer to poeple with AIDS:
Please mail to us any printed information you have about your service.
Thank you very much.

BIBLIOGRAPHY

Buckingham, Robert. The Complete Hospice Guide. New York: Harper and Row Publishers, 1983.

Corr, Charles and Corr, Donna, eds. Hospice Care Principles and Practice. New York: Springer Publishing Co., 1983.

Davidson, Glen W. The Hospice: Development and Administration. Washington D.C.: Hemisphere Publishing Corp., 1978.

"Facing The AIDS Epidemic". American Journal of Hospice Care, Vol. 3, No. 2, March/April, 1986.

Hamilton, Michael and Reid, Helen. A Hospice Handbook: A New Way To Care For The Dying. Grand Rapids: William P. Ferdmans, 1980.

Kubler-Ross, Elisabeth. Death The Final Stage of Growth. Englewood: Prentice-Hall, 1975.

Kubler-Ross, Elisabeth. On Death and Dying. New York: MacMillan, 1969.

Kubler-Ross, Elisabeth. Questions and Answers on Death and Dying. New York: MacMillan, 1974.

Little, Deborah Whiting. Home Care for the Dying. New York: Doubleday and Co, Inc., 1985.

"The National Hospice Study". Journal of Chronic Diseases, Vol. 39, No. 1, 1986.

Rossman, Parker. Hospice. New York: Fawcett Book Group, 1979.

Sandol, Stoddard. The Hospice Movement. New York: Stein and Day Publishers, 1978.

Wentzel, Kenneth. To Those Who Need It Most Hospice Means Hope. Boston: Charles River Books, 1981.

AIDS CASES REPORTED TO MARYLAND D.H.M.H FROM 1979 THROUGH 03 / 27 /86

PLACE OF RESIDENCE	CASES	DEATHS
BALTIMORE CITY	111	66
SUBURBAN BALTIMORE Anne Arundel Co. Baltimore Co. Carroll Co. Harford Co. Howard Co.	36	22
METRO-BALTIMORE (SUB-TOTAL)	147	88
SUBURBAN WASHINGTON, D.C. Calvert Co. Charles Co Frederick Co. Montgomery Co. Pr. Georges Co. St. Mary's Co.	128	76
EASTERN SHORE	14	11
WESTERN, MD.	5	3
MARYLAND STATE TOTAL	294	178

MARYLAND AIDS CASES BY YEAR

	CASES	DEATHS	STATUS UNKNOWN
1979 - 82	11	11	
1983	32	28	2
1984	75	55	
1985	157	80	
1986 YTD	19	5	
TOTAL ------	294	178	

CENTERS FOR DISEASE CONTROL NATIONAL STATISTICS AS OF 03/ 27/ 86

REPORTED CASES 18,576 DEATHS 9,865

(as of 4/10/86 18,907 9,988)

SCOTT H. STAMFORD
AIDS PROGRAM COORDINATOR
OFFICE OF DISEASE CONTROL AND EPIDEMIOLOGY
PHONE: (301) 225-6711

GENDER	CASES	PERCENT
MALE	268	91 %
FEMALE	26	9 %

ETHNIC/ RACE BKG.		
WHITE	136	46 %
BLACK	148	50 %
HISPANIC	8	3 %
OTHER	2	1 %
TOTAL	294	100 %

AGE GROUP		
0-12	3	1 %
13-19	3	1 %
20-29	51	17 %
30-39	131	45 %
40-49	63	21 %
Over 50	43	15 %
TOTAL	294	100 %

METRO-D.C. STATISTICS

RESIDENCE	CASES	DEATHS
Wash. D.C.	342	189
VA. SUBURBS	126	57
MD. SUBURBS	128	76
METRO-D.C.	596	322

*THROUGH 03-16-86

AIDS INFORMATION AND REFERRAL LINE (BALTIMORE HERO) 301-945 AIDS
STATE WIDE TOLL FREE IS 1-800-638-6252

MARYLAND AIDS CASES BY ADULT-ADOLESCENT POPULATION GROUPS MOST AFFECTED

	Male	Female	Total	Percent
HOMOSEXUAL MEN*	146	N/A	146	50%
BISEXUAL MEN	48	N/A	48	16%
HOMOSEXUAL/BISEXUAL I.V. DRUG ABUSER	7	N/A	7	2%
HETEROSEXUAL**	2	4	6	2%
HETEROSEXUAL I.V. DRUG ABUSER	27	10	37	13%
HETEROSEXUAL*** OTHER COUNTRIES	5	1	6	2%
HETEROSEXUAL HEMOPHILIAC	3	0	3	1%
HETEROSEXUAL TRANSFUSION RECIPIENT	10	5	15	5%
OTHER / UNKNOWN***	20	3	23	8%
TOTAL ADULT/ADOLESCENT	268	23	291	99%
MARYLAND PEDIATRIC AIDS CASES				
BORN TO MOTHER WITH AIDS OR "AT RISK" FOR AIDS		2	2	1%
HEMOPHILIAC				
TRANSFUSION RECIPIENT		1	1	
OTHER /UNKNOWN				
TOTAL PEDIATRIC		3		1%
GRAND TOTAL	268	26	294	100%

* Includes 1 person from other countries

** Sexual partner either diagnosed with AIDS or identified as person "at risk" for AIDS.

*** Denotes individuals who have immigrated to the United States from countries where AIDS is endemic.

**** Includes 3 cases who died prior to interview, cases with unknown risk factor and cases currently under investigation