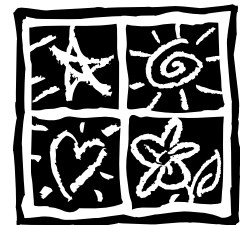
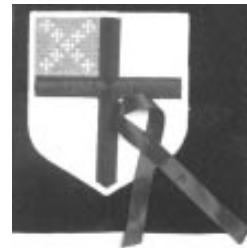


NATIONAL EPISCOPAL AIDS COALITION PARISH QUILT PROJECT

Bringing Our Names Home

HOSTING THE QUILT: A PARISH RESPONSE



THE NAMES
PROJECT

AIDS Memorial Quilt

“The Quilts have brought into focus the nature and impact of this epidemic... while we knew about AIDS, the Quilt makes it personal for each and every one of us.”

The Reverend James Fetterman
Danville, PA

INTRODUCTION

As the HIV/AIDS pandemic proceeds into its second decade, it has become apparent that some social institutions' public health practices have been insufficient in addressing the many facets of HIV/AIDS. Communities of faith, regardless of denomination, may play an important role in reaching people who have been missed by the media and who have not yet been touched by HIV/AIDS. The NAMES Project AIDS Memorial Quilt may help bring a human face to the epidemic and bring home the reality that AIDS affects us all. The Quilt can cultivate a readiness to hear the prevention message. The message that the millions touched by AIDS are individuals who are loved, mourned, and celebrated is a part of the AIDS Memorial Quilt. Its names bring messages, and the Parish Quilt Project is designed to bring those names home.

It is a widely held perception that religion has had little to do with the HIV/AIDS pandemic. The Episcopal Church, however, has been involved since 1983, when a pastoral letter calling for prayer for people living with AIDS was issued by the Presiding Bishop. Early in the epidemic, and even today, some individuals have proclaimed that AIDS is a form of divine punishment and are using HIV/AIDS as an excuse to condemn the lives of others. This type of thinking has hindered public health prevention efforts, stressed congregational unity, and most of all, hurt those affected by the disease.

Churches have a history of caring for the sick and watching out for the welfare of their congregations and communities, but many churches are still not addressing HIV/AIDS. Ignorance is a frail protection against a disease, and indifference is a poor Christian response to an epidemic. The Church is called to work toward the wellness of its congregations and communities. In hosting the Quilt, you will be taking an important step toward repairing hurt relationships and going about the traditional callings of

comforting the afflicted, instructing the uninformed, and praying for the living and the dead.

The National Episcopal AIDS Coalition (NEAC) Parish Quilt Project is a part of The NAMES Project Foundation's Interfaith Quilt Program. It is designed to help churches host one or more *twelve by twelve blocks* of The NAMES Project AIDS Memorial Quilt. Widespread awareness of HIV/AIDS, knowledge of the risks of transmission, and ways to prevent transmission are all essential to halting the spread of AIDS. Moreover, people affected by and infected with HIV need support and caring. For those who are religious it is especially important that they receive support from their church and are embraced by the love of God. In developing this project, it is hoped that churches will move beyond the stigmas and prejudices of the pandemic; *bring home the names* of the thousands dead and dying from AIDS; and move toward developing a compassionate and prophetic HIV/AIDS ministry.

This handbook is designed to help groups make the most of hosting the Quilt. It may be used as a reference to help each congregation or group decide what type of event they wish to hold, how big an event, and whom they wish to invite. Some churches may wish to host a small event, designed primarily for their congregation, but others will want to hold a community-wide event with many different groups participating. This handbook will help you make some of these decisions and suggest ways in which you can maximize your Quilt experience. Each section of this handbook addresses different aspects of hosting a display of the AIDS Memorial Quilt.

Note: one person does not, and should not, have to do it all. Different people can take different sections of this handbook as their part of the Quilt event. Keep in mind that the ideas herein are by no means exhaustive; you may choose to do a lot or a little, use suggested ideas or novel ones, all as you see fit for your church and community.

Bringing Our Names Home

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We would like to recognize the many parishes, schools and cathedrals that have participated thus far in the Parish Quilt Project. They are listed below. Special recognition is given to the many pilot project coordinators who arranged to bring the Quilt to their communities. The NAMES Project Foundation and the National Episcopal AIDS Coalition thank you for your time and efforts in both hosting the Quilt and in the construction of this handbook.

We also recognize the long-term support of the Center for HIV/STD/TB, Division of HIV/AIDS Prevention, Centers for Disease Control and Prevention, and the CDC National AIDS Clearinghouse.

Quotes throughout this manual are from project coordinators and others who have viewed The NAMES Project Memorial Quilt.

PARISH QUILT PROJECT PARTICIPANTS

Susquehanna Convocation, Diocese of Pennsylvania	St. Luke's Episcopal Church, Birmingham, AL
Christ Memorial Episcopal Church, Danville, PA	Church of the Holy Apostles, New York, NY
Christ Episcopal Church, Berwick, PA	Holy Trinity Episcopal Church, Gainesville, FL
St. Paul's Episcopal Church, Bloomsburg, PA	Church of the Holy Apostles, Wynnewood, PA
St. Thomas Church, Bath, NY	St. Luke's Episcopal Church, Gladstone, NJ
St. Andrew's Episcopal Church, Lewisburg, PA	St. John's Episcopal Church, Mankato, MN
St. Paul's Episcopal Church, The Dalles, OR	Christ Church Cathedral, Lexington, KY
Cathedral of St. Paul, Erie, PA	St. Mark's Episcopal Church, Mendham, NJ
All Saints Episcopal Church, Pontiac, MI	Trinity Cathedral, Miami, FL
Grace Episcopal Church, Anniston, AL	All Saints Parish, Concord, NC
Christ Episcopal Church, Ansonia, CT	St. James the Fisherman Episcopal Church, Shalotte, NC
St. Matthew's Cathedral, Dallas, TX	St. Matthias Episcopal Church, East Aurora, NY
Episcopal Church of the Transfiguration, Dallas, TX	St. Mark's Episcopal Church, Berkeley, CA
St. Paul's Episcopal Church, Port Townsend, WA	
Groton School, Groton, MA	
St. John's Episcopal Church, Royal Oak, MI	

GETTING THE QUILT

Your first step in getting a *twelve by twelve block* of the Quilt is to form a Quilt Host Committee and deciding what dates you may want to host the Quilt. It has been displayed during Thanksgiving, Advent and Christmas, and through Lent and Easter. Other times you may want to consider are during the All Saints and All Souls feast days, on December 1st - World AIDS Day, or when the Quilt can be experienced during First Communion or Confirmation. Hosting the Quilt for several weeks, especially during special occasions or seasons, makes it harder for people to ignore the Quilt and the reason it came into existence.

After you have formed a committee, send a letter to NEAC describing (1) your congregation and community, (2) its experience with HIV/AIDS, (3) any experience you or your faith community has had with HIV/AIDS work or ministry, and (4) and why you wish to display the Quilt. Include what you have planned and what you hope to gain by having the Quilt. Your letter should be signed by you, the rector or vicar, and a member of the vestry.

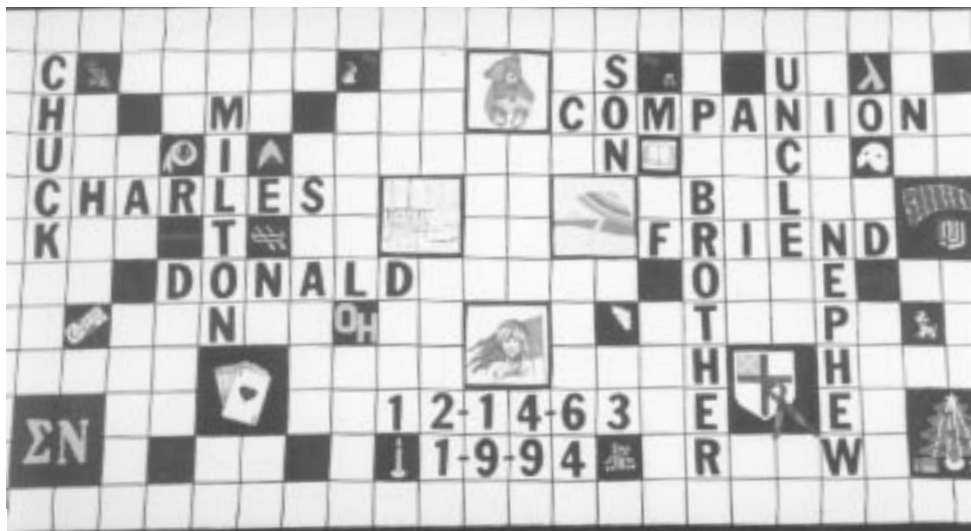
After the National Episcopal AIDS Coalition has received your letter and

verified any information necessary, you will be sent a pre-approved NAMES Interfaith Quilt Display Application. Note: this is an approved application for participation in NEAC's Parish Quilt Project (it still needs to be approved by The NAMES Project in order for you to get the Quilt). Complete this application and send it to The NAMES Project, along with a check (payable to The NAMES Project) to cover the fee for hosting the Quilt. The cost is \$200 for each *twelve by twelve block* you wish to host. This should all be accomplished at least four months prior to the dates you would like to host the Quilt. You should receive confirmation from The NAMES Project within three weeks after their receipt of your application. At this point, you may want to write NEAC and NAMES to confirm your dates and ask for any materials or resources that you may want to have while you are hosting the Quilt.

- Form A Committee & Decide Dates
- Initial Planning/Goal Setting
- Letter to NEAC
- Check for NAMES
- Application to NAMES
- Confirm Dates & Request Materials

"I read the information on the panels, but more important, I felt the love and loss they represented. Those names belonged to real people, and they became real to me. I cared about them, and I mourned their loss. I cared about the panelmakers, and I shared their sorrow."

Panelmaker
Alexandria, Virginia



"[The Quilt] is full of love and caring, but there is room for more."

Jonathan Bradley
Colorado Springs, Colorado

BUILDING A HOST COMMITTEE

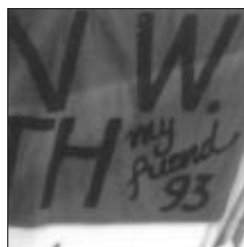
The committee or Quilt Display Team you will have to create must include the rector or vicar, a member of the vestry, and anyone else who may be interested. It may be helpful to ask people already active in the church to work on those Quilt projects similar to their existing roles.

If your church has an HIV/AIDS task force, its members will probably be good resources. Altar Guild members may make exceptional caretakers of the Quilt. Christian education leaders may be great workshop or seminar organizers and facilitators. People involved in youth or teen ministries, or parochial schools, may organize Quilt activities designed for their special populations. Also, teens who want to be involved may be able to help design or organize an activity. Others, such as the Junior Warden, may be able to better handle the logistics of a display, open house, or other activity.

Other committee members may come from anywhere, including people outside your church. When looking for your volunteers, persons directly affected by HIV/AIDS may be especially inclined to help bring the Quilt to your church. Someone who has lost a co-worker, family member, or partner to AIDS may have a very different perspective on the pandemic than those people who volunteer

for every church event. Having different people planning your event assures the program sponsors of your good intent and indicates widespread support for hosting the Quilt. Moreover, getting many different partners, groups, or individuals involved may solve problems of cooperation, information, or territory before they arise. Ideally, your committee will be formed in the planning process four to six months before completing and submitting your application to participate. Both the National Episcopal AIDS Coalition and The NAMES Project will send general information on request to help you in your planning.

Whether you need extra volunteers or not, it is important to involve those who have been directly affected by HIV/AIDS, especially persons with AIDS (PWAs). Try asking their advice, not merely getting them to help with the ideas you have in mind. They may be able to personalize your event and steer you clear of some potential pitfalls. In addition, their advice and perspectives may give you a clearer vision about what the Quilt and pandemic are about. Including congregation and community members on your Quilt Host Committee may help break down the barriers of unfamiliarity and be the first step toward a successful Quilt event and building an effective HIV/AIDS ministry.



PLANNING ACTIVITIES

The Quilt display team that you form to organize your Quilt event must make several decisions about what to do while you are hosting the Quilt. The size of your congregation and community, its needs and desires, must be taken into consideration. Your financial and human resources must also be reviewed and, if necessary, sources of additional money and labor found. To be effective your Quilt Host Committee members should come to a consensus on the following:

- What are the larger goals of the church in relation to HIV/AIDS:
—as applied to your congregation?
—as applied to your community?
- What dates you want to host the Quilt?
- What activities will be held while you are hosting the Quilt?
- Who will be invited to your activities?
- What people coming to your activities are expected to learn or experience?
- Who will work on what activity?
- Have the goals you set for yourself been accomplished?

Your main goal, most probably having to do with awareness and prevention, should be why you are hosting the Quilt. A clearly defined and widely agreed upon goal is vital to a successful event. While your objectives, activities, and dates may change, your goals should remain the same. Your objectives are the mile posts, the numbers of people and changes in attitude that you will work towards and measure. Your activities will help you reach your objectives and your objectives will help you reach your goal.

Once the Quilt committee/display team has set its goals, you may want to consider holding some of the different types of services of worship listed here. Each service can address one or more of your objectives or may be part of a larger objective such as community participation. They include:

Healing Service
Ecumenical Service
Interfaith Service
Stations or Way of the Cross
Youth Service
Memorial Service
Evensong or Vespers
Service of Light
Prayer Meetings
Meditation
Quiet Days/Evenings
Sunday Service

In holding your religious services you may want to recall the history of the Church and HIV/AIDS. There are people on all sides of the epidemic that feel that the Church should not be involved with the Quilt or HIV/AIDS. You must be ready to point out reasons for the Church's involvement and the potential benefits that may come about (or have already come about) because of your hosting the Quilt. One teen who learns the facts about HIV/AIDS, or one family that is comforted, should be all the justification you need. As well, you may want to point out the happiness and/or irony those represented on the block(s) may have enjoyed at being welcomed by the Church. In planning your religious activity you should review the NAMES Project Guidelines for using the Quilt in Religious Services.

While religious activities are encouraged and appropriate given the nature of the Parish Quilt Project, you may want to consider some other, more secular activities such as the following:

- Making a panel
- Having a parishioner affected by HIV/AIDS speak before the congregation
- Conducting silent or directed meditation
- Hosting a recital or concert
- Holding workshops or seminars
- Holding an open house several times a week
- Inviting schools to have field trips
- Supplying a meal to PWAs or those attending your activities

"You don't have to make a point, [the Quilt] speaks for itself."

Quilt Visitor
St. Louis, Missouri

“An unexpected reaction was, for me, the quiet, contemplative manner in which visitors view the Quilt. There are tears, some small talk among folks at panels, but for the most part it is a quiet observance. I compare it to the reaction of visitors to the Vietnam War Memorial.”

The Reverend Deacon Ciritta Park
Columbus, Ohio

- Having an arts or crafts show with homemade quilts
- Inviting guest speakers or lecturers
- Producing a dramatic production that deals with AIDS
- Screening a movie or video (Appendix D)
- Receptions after services or activities
- Creating special activities for youth/teens
- Creating special activities for children
- Four part series on experiencing the Quilt with congregations (Appendix E)

In designing your activities you may want to get advice from community members who regularly work or organize similar activities. An elementary school teacher may have a good HIV/AIDS coloring book, a drama teacher a good one-act play, and a college professor may know of a colleague who would make a great guest speaker. Likewise, a lawyer may know someone who knows all the ins-and-outs of AIDS legal issues, and a doctor may know someone who gives a good AIDS talk. It is important to get qualified, well-versed speakers for your activities. It is also important that they be clear and nonjudgmental in their presentation. If you think a doctor will get too technical about transmission and prevention, or a priest too uncomfortable talking about condoms, they do not have to speak. The Red Cross, local health department, or another individual or organization can do it instead. You may want to contact local AIDS organizations, especially those with Speakers' Bureaus. Use your connections and community resources to put together the best program to meet your goals.

It will be important for you to have current information about HIV/AIDS, locally pertinent statistics, and information about HIV/AIDS service organizations in your area. A good place to start finding information is by contacting your local health department (see Resource Appendix C) and calling the Centers for Disease Control's National AIDS Hotline at 1-800-342-AIDS (1-800-342-2437) and the National AIDS

Clearinghouse at 1-800-458-5231. The Hotline will have current national statistics and will be able to answer many of your questions regarding HIV/AIDS transmission and prevention. Although no one group has all the answers, the Hotline tries to keep the most current information, guidelines, and news stories available to its workers. The Clearinghouse has lists of HIV/AIDS service organizations and a variety of resources for religious organizations. Depending on the information you desire, you may find it more helpful to look for information by subject rather than by denomination. Remember that the pandemic has and continues to change rapidly, because of this you may want to check the information you find against current recommendations.

Due to the multifaceted nature of the HIV/AIDS pandemic, many of your activities will cover a variety of subjects. Depending on your audience and its needs and desires, you may want to make a special effort to cover some of the following subjects.

CAREGIVING ISSUES

Caring for the sick
Care Teams and Buddy Systems
Home health care
Hospice or nursing care
Medical concerns

SPIRITUAL ISSUES

Relationship with God
Theological basis for caring
What the Church can or should do
Spiritual growth

DEATH AND DYING

Losing family members to AIDS
Funeral Planning
Process of grieving
Memorials and their meaning

EDUCATION AND PREVENTION ISSUES

HIV/AIDS awareness
Local and national HIV/AIDS statistics
HIV/AIDS transmission and prevention
International effects of HIV/AIDS

AIDS RELATED ISSUES

Multicultural/Minority AIDS

Ethical situations

Legal concerns

Unity of purpose among affected groups

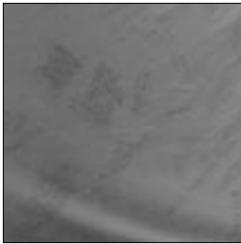
Youth/Teens

Sexual orientation

Value judgments

Because no one person will be an expert on all of the subjects you wish to

address, you may need to recruit volunteers from your community. Before you ask for help be sure you know what subjects you want your volunteers to address and when approximately they will be needed. Inviting experts from your community will create an excellent learning opportunity for you and those attending your activities to learn about HIV/AIDS and the groups involved in fighting the disease.



"I have seen Quilt panels gently and quietly crack the veneer of people who once turned stone hearts to the AIDS crisis."

Bruce Garner
Atlanta, Georgia

"[The Quilt] is very overwhelming...A powerful experience of understanding AIDS."

Eric Scharf
Washington, DC

DISPLAYING THE QUILT

The most important equipment you will need is that used to display your *twelve by twelve block(s)* of the Quilt. Because every building is a little different, this handbook cannot address the specific equipment necessary for each Quilt display. However, an *Installation Guide* will be provided by The NAMES Project (see "Caring for the Quilt") and some local NAMES Project chapters or the national headquarters of The NAMES Project Foundation will have instructions for building a stand or have a stand that can be loaned to you. Stands have been built of plastic pipe, wood, and even metal. Churches have had stands donated, or had labor and supplies to build a stand donated. Others have hired carpenters to build stands, some of which have been donated to The NAMES Project.

Some groups have hung the Quilt from rafters or stage battens, others from wall hooks or scaffolding. Displays may or may not have special lighting, such as spotlights, flood lights, and or lights that can be dimmed to create a special mood. You might want to refer to the Caring for the Quilt section for additional guidelines on displaying the Quilt.

Tissues, votive candles, red ribbons, and information about the Quilt are all

additional things you may wish to have on hand. A schedule of activities and/or brochures from your ministry or from other organizations might also be good to have. These should not be placed on a table that blocks the view of the Quilt, but rather to the side or in the back of the display area. Evaluation sheets, should you choose to evaluate with a survey, can be placed on your information table, but should be somewhere where people can fill out the form in private and leave it without being unduly scrutinized.

Quilt caretakers or attendants might need name tags, and if they are in an area where it would be hard to contact someone on the Quilt display team, a portable phone in case of an emergency. You might also have a guest book where people can write down their thoughts or ask for special prayers of healing or remembrance. You might consider making a signature panel—a special panel for those visiting the display to write on, whether a message in remembrance of a specific individual or simply to denote one's presence. After the display, this panel can be given to The Names Project for inclusion in the Quilt. Instructions for making a signature panel are available from The NAMES Project.



CARING FOR THE QUILT

One of the things that make The NAMES Project AIDS Memorial Quilt so special is the one-of-a-kind nature of the individual panels. Each panel is irreplaceable and has great meaning for those touched by the life the panel represents. You will probably want to have an orientation meeting with your different groups of volunteers so they know what their responsibilities are and how to care for the Quilt. The *Installation Guide* that The NAMES Project will send to you details how to display your block(s), but for now keep the following in mind:

- You are responsible for the Quilt—do not entrust it to those you cannot trust

- The display must be indoors in an area that can be either continually monitored or locked
- A respectful atmosphere must be maintained
- There should be no eating, drinking, open fires, or smoking near the Quilt
- The Quilt should be accessible, located so that it can be seen up close
- There should be both seating and adequate lighting
- The Quilt should not be bunched, tied, or draped
- The Quilt is never cleaned, so please keep it from getting dirty
- Avoid using holy water or incense on or near the Quilt
- Do not place the Quilt over air vents or where it may move in the breeze
- Do not lend or unnecessarily move the Quilt once it is in place.



“The Quilt is created as an icon of healing and remembrance.”

The Very Reverend James L. Burns,
Lexington, KY

"The project was a stunning success, and it was much larger than what we expected. We have since found ourselves organizing our community to do exciting and important new ministries. The impact of this Quilt is being felt and lived out well past the time of our display."

Sue Kuebler
Erie, PA

INVOLVING OTHERS

Think of hosting the Quilt as planning a special event. Everyone likes to be invited to something special. There are always people who will come even if not directly invited. Similarly there may be others you can beg to attend, but who will ignore your best efforts. In planning your Quilt event and/or activities, it is probably better to invite everyone whom you might like to attend rather than merely hoping they hear about your activities and show up.

In that there are still many stigmas surrounding HIV/AIDS, and that invitations tend to reduce barriers to attendance, it is especially important to invite everyone you want to attend. You might want to consider direct invitations to some of the following groups:

- Other faith communities, their clergy and organizations
- Public Health authorities, especially their care providers
- Your local AIDS community, including people infected with HIV and those that provide services to people living with AIDS
- Local gay/lesbian/bisexual organizations
- Neighborhood groups or associations
- Organizations serving people of color
- The business community
- Local, state, or national governments
- Educational institutions (public, private, preschool, elementary school, middle school, high school, college, trade, boarding, military, disabled, and special education)
- Women's organizations
- Local service clubs such as the Rotary Club
- Youth organizations like the Boy Scouts and Girl Scouts
- Your parish and any special organizations in it
- Clergy, religious orders, and other parishes



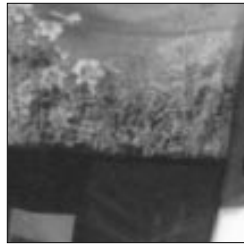
Each of the groups you invite to your activities can contribute to your event. You may find supporters in the most unlikely of places and receive little help from what would seem like a logical place to find it. The people you invite may provide, especially if you ask for their assistance, any number of the following:

- Time, as a caretaker of the Quilt or in assisting with your activities
- Their services as a guest speaker or workshop leader
- Attendance at your event and activities
- Money to obtain the Quilt for your activities, or for your ministry
- Equipment, such as a Quilt stand, lights, or tables
- Food for PWAs, for shelter or home meal programs, or for receptions after your activities
- Advertising for your Quilt event
- Information about HIV/AIDS and how it affects your community
- Mental or moral support in letting you know your efforts are worthwhile and appreciated

- Expertise about organizing activities, contacting the media, or building a Quilt stand

Be sure to give people enough lead time to plan to attend your event. School calendars and those of politicians and clergy are often made out well in advance. Depending on whom you are inviting, you may need to write several months in advance with a tentative schedule of activities. Most groups, however, will need no more than two weeks to a month advance notice before your event.

It may be helpful to have prominent supporters of your event send your invitations for you. For instance, an invitation from a supportive bishop (who may be officiating at one of your services) may bring a greater response than an invitation from an unknown individual. Avoid coercion of any sort. If someone truly does not want to be at your event and activities, his/her presence will probably bring more harm than good.



"I think the chapel the most appropriate place to memorialize...and to draw the community to reflection and responsibility."

The Rev. John F. Smith
Groton, MA

"To me, there is a spiritual sense brought by the personalized reminders of those who have died of AIDS...it's about grieving."

William Kalb
Port Townsend, WA

PUBLICIZING YOUR EVENT

Publicity should probably start up around one month to six weeks prior to your Quilt event. Some organizations and publications, however, may need to know earlier so the publicity will come out on time. For instance, unlike a feature article in a newspaper that may require two to four weeks of lead time, an article in a monthly art/events publication might require a month or more of lead time. You may have to contact representatives from each of the different publicity channels and determine what kind of time frames they work under. You should do this information gathering well before your Quilt announcements need to be sent out.

When actually writing your advertisements or press releases be sure to include general knowledge about the Quilt, why you are doing what you are doing, and why it is important. You will also want to include at least some of the following:

- What:** What services or activities you have organized or plan on organizing
- When:** What date(s) you have chosen for your event and activities
- When:** What time your activities will be held
- Where:** Where the event is going to be held (provide directions if necessary)
- Who:** Who will be speaking, presiding, or officiating at your activities
- Why:** Why this event is being held at this time in this community
- Contact:** Who can be contacted for more information
- Other:** What, if any, requirements or restrictions are there for

attending your event? For instance:

- is registration required?
- does it cost to attend?
- who is welcome to attend?
- do individuals need to bring anything?
- do large groups need to set up separate appointments?
- can pictures be taken of the Quilt and any visitors?

In answering these questions, you will help clarify both how your activities will be run and what about them may need to be publicized.

After deciding what you need to publicize, you need to decide how you plan to get your message out. Church bulletins and word-of-mouth may be sufficient for small displays, but for larger events you may want to consider some of the following publicity channels:

- Local PWA/AIDS-HIV organizations
- locally published newspapers
- arts/events publications
- brochures for waiting rooms or information tables
- letters to organizations and prominent individuals
- locally produced television programs
- billboards or bus signs
- gay/lesbian/bisexual publications
- a prominent sign in front of the display building
- public access cable television
- posters around the neighborhood and in stores
- locally broadcast radio programs
- flyers to be handed out at related or unrelated events
- electronic mail, bulletin boards, or web sites

EVALUATING YOUR EFFORTS

An evaluation of your congregation or community may be helpful not only in determining what events may be most useful, but also, when it is over, in determining what information may have been gained or how attitudes may have changed. Evaluations help find the strengths and weaknesses of your project and will hopefully point to ways to improve future events. You may find gaps of knowledge indicating that some follow-up may be needed, or a surplus of knowledge to let you know that future efforts can concentrate on other facets of the epidemic.

In smaller, close-knit communities, a simple discussion may be all the evaluation you need, but you may also want to consider surveys, interviews, and focus groups. A numerical value of some sort combined with individual instances of change is often the best way to justify the time and expense you have put forth.

- **Written Surveys:** Closed response, written surveys where you only allow respondents to choose one of the answers you have provided tend to be easier to analyze than open-ended questions. Open-ended questions, however, may reveal more of the scope and breadth of your community's knowledge. You may want to hand out surveys as people enter or leave an activity or service—depending on whether you are trying to determine knowledge, attitudes, and beliefs about AIDS before the Quilt display or after the Quilt display. Surveys are great for getting numbers and percentages, but heavily rely on the quality of the questionnaire and the number of people surveyed. One of the drawbacks of surveys is the cost of producing them.
- **Personal Interviews:** Personal interviews are surveys that are conducted face-to-face or by telephone. Like all information-gathering, the quality of the results depends on how well the questions are designed, how much

trust is inspired, and how good the skills of the interviewer are. How open and truthful is the person being interviewed will also change your evaluation results. Interviews can be both open- and closed-response, and the information received can be very enlightening. Depending on the length of the average interview and how many of them you plan to conduct, personal interviews can be very time-consuming and possibly more subject to error than a written survey.

- **Focus Groups:** A focus group is not a group interview. It is a group of people brought together to discuss a given subject. Direct questions regarding the subjects of interest may not reveal all of the issues and opinions of the members, but discussion among the members may show some of the depth for which you may be looking. A moderator leads the discussion and guides focus group members into talking about the subject of interest; moderators, however, do not actively participate in the discussion. Focus groups are often recorded for later analysis or an assistant is present and taking notes as the discussion progresses. The quality of information obtained relies on how well different groups in the community or congregation are represented, the skills of the moderator, and how free and open the participants feel they can discuss the subject at hand. How open a discussion will be often depends on the people chosen for the focus group. The equal footing of group members is important in facilitating easy discussion. An individual's community status, whether high- or low-standing, and individual character traits will often alter the dynamics of a discussion. Focus group information can not be measured in numbers, but may prove very useful in understanding the reasons behind actions and attitudes of others. Focus groups are not recommended unless a skilled moderator is available.

"It was a very moving experience to visit the Quilt display which was in a location where we could pray and reflect as well as see it."

The Right Reverend
Charlie F. McNutt, Jr.
Diocese of Central Pennsylvania

"A Sunday was devoted to programs of local AIDS service providers."

The Reverend Michael Hartney
East Aurora, NY

FOLLOWING-UP

Follow-up activities are encouraged because they may increase the impact of your event. Positive perceptions or convictions can be reaffirmed, any misinformation can be corrected, and new planning can be initiated. It is important to remember that follow-up activities will be most effective when they fall in the range of time when more information is not overkill and the information already presented with the Quilt has not been forgotten. Novel information and activities, rather than repeating those previously performed, will also make a follow-up more effective. You may want to get an AIDS activity book or contact organizations such as the Red Cross that have HIV/AIDS exercises in their education programs.

Follow-ups may be a planned discussion, a guest speaker, or an interfaith prayer service. Almost all of the things listed in the handbook activities section can be used as a follow-up, including helping others host the Quilt. Follow-up activities are whatever you wish to make them. You can personalize these follow-ups with your own experiences or those that may have been related to you by people who came to your event. You can also invite people to tell their own stories and

relate how they felt when seeing the Quilt. This provides an opportunity for them to process the emotional impact that the event may have had on them.

In indicating an interest in your community and in inviting people living with HIV/AIDS, AIDS service organizations, the local health department, and other organizations such as the United Way, you will learn more about your community and they will learn more about you. Your follow-ups should be designed with just as much care, if not more, than your Quilt activities. There will not be a *twelve by twelve* to attract everyone's interest; you must gather people through the information you intend to provide and with the attitude of openness that you exhibit.

Good follow-up activities will let your community know that you "walk the walk and talk the talk" - that you truly care about those affected by HIV/AIDS, that your church welcomes everyone, and that you are serious about preventing the spread of the pandemic. Hosting the Quilt will get people to try your product, but the real sale occurs when the community sees what you do after it is gone. Consider evaluating your follow-up activities to see if there been changes in knowledge, attitude, beliefs or practice.



SUMMARY

The HIV/AIDS pandemic is still growing and we are all affected. The National Episcopal AIDS Coalition's Parish Quilt Project is a way for you to host The NAMES Project AIDS Memorial Quilt. The Quilt portrays the human face of AIDS. It brings home the names and stories of people who have died from AIDS. It brings home the human dimension that is often hidden behind statistics, fear, and indifference. The Quilt is a

memorial and can be used as a tool to create awareness and generate compassion. In hosting the Quilt, you will have the opportunity to reach out and embrace those affected in your congregation and community. You decide what you will do while hosting the Quilt, and just as important, what you will do once it is gone. The following chart outlines the basic steps in hosting a block of the Quilt. (Hosting the Quilt is meant to be the work of the entire faith community.)

"Let the presence of The NAMES Project AIDS Memorial Quilt speak to you."

The Reverend Paul Donnecker
Lewisburg, PA

Time	BEFORE DISPLAY								DISPLAY				AFTER DISPLAY		
	-6 mth	-5 mth	-4 mth	-3 mth	-2 mth	-1 mth	-2 wks	-1 wk	1st wk	2nd wk	3rd wk	4th wk	+1 wk	+2 wk	+? mth
Activity															
Forming A Committee															
Planning Your Event															
Letter to NEAC															
Check for NAMES															
Application to NAMES															
Confirmation & Materials															
Invitations & Publicity															
Getting Equipment															
Services & Activities															
Evaluation (pre-test)															
Evaluation (post-test)															
Follow-Up Activities															

RESOURCE APPENDIX A:

SERVICES AND ORGANIZATIONS

The following information on HIV/AIDS Services and Organizations is current as of August 1995.

Advocates for Youth

HIV/AIDS Department
1025 Vermont Avenue, NW, Suite 200
Washington, DC 20005
(202) 347-5700

AIDS Action Council

1875 Connecticut Avenue, NW
Suite 700
Washington, DC 20009
(202) 986-1300

AIDS National Interfaith Network (ANIN)

110 Maryland Avenue, NE, Suite 504
Washington, DC 20002
(202) 546-0807

American Civil Liberties Union

AIDS and Civil Liberties Project
132 West 43rd Street
Second Floor
New York, NY 10036
(215) 592-1513

American Foundation for AIDS Research (AmFAR)

733 3rd Avenue
12th Floor
New York, NY 10017
1-800-392-6327

American Red Cross*

Program Support
8111 Gatehouse Road
Falls Church, VA 22042
(703) 206-7120
*contact your local chapter first

Council of National Religious AIDS Networks

110 Maryland Avenue, NE, Suite 504
Washington, DC 20002
(202) 546-0807

Federation of Parents and Friends of Lesbians and Gays, Inc. (PFLAG)

P.O. Box 27605
Washington, DC 20038-7605
(202) 638-4200

The NAMES Project Foundation

310 Townsend Street, Suite 310
San Francisco, CA 94107
(415) 882-5500

CDC National AIDS Clearinghouse

P.O. Box 6003
Rockville, MD 20850
1-800-458-5231

National Association of People with AIDS (NAPWA)

1413 K Street, NW
7th Floor
Washington, DC 20005
(202) 898-0414

National AIDS Fund

1400 I Street, NW
12th Floor
Washington, DC 20005
(202) 408-4848

National Council of La Raza

Department of HIV/AIDS
1111 19th Street, NW, Suite 1000
Washington, DC 20036
(202) 785-1670

National Episcopal AIDS Coalition

2025 Pennsylvania Ave, NW
Suite 508
Washington, DC 20006
(202) 628-6628

National Gay and Lesbian Task Force

Public Policy Director
2320 17th Street, NW
Washington, DC 20009-2702
(202) 332-6483

National Hemophilia Foundation

110 Green Street, Suite 303
New York, NY 10012
1-800-424-2634

National Minority AIDS Council

1931 13th Street, NW
Washington, DC 20009
(202) 483-6622

Planned Parenthood Federation of America

810 7th Avenue
New York, NY 10019
(212) 541-7800

Sexuality Information and Education Council of the United States (SIECUS)

Research Library
130 West 42nd Street, Suite 350
New York, NY 10036-7802
(212) 819-9770

United Way

*Contact your local United Way for information about AIDS services in your community



RESOURCE APPENDIX B: HOTLINES

**Drug Abuse Treatment Information
Referral Line**
1-800-662-HELP (1-800-662-4357)

**HIV/AIDS Treatment Information
Service (ATIS)**
*Federally Approved Guidelines and
Information*
1-800-HIV-0440 (1-800-448-0440)
1-800-234-7012 TDD

CDC National HIV/AIDS Hotline
1-800-342-AIDS (1-800-342-2437)
English
1-800-AIDS-TTY (1-800-243-7889)
TTY/TDD
1-800-344-SIDA (1-800-344-7432)
Spanish

**Clinical Trials Information
National Institute of Allergy and
Infectious Diseases (NIAID)**
1-800-TRIALS-A (1-800-874-2572)

Project Inform
Treatments and Experimental Drugs
1-800-822-7422

AIDS HOTLINES BY STATE:

Alabama	.800-228-0469	Nebraska	.800-782-2437
Alaska	.800-478-2437	Nevada	.800-842-2437
Arizona	.800-334-1540	New Hampshire	.800-752-2437
Arkansas	.800-364-2437	New Jersey	.800-624-2377
California (N.)	.800-367-2437	New Mexico	.800-545-2437
California (S.)	.800-922-2437	New York	.800-541-2437
Colorado	.800-252-2437	North Carolina	.800-342-2437
Connecticut	.800-203-1234	North Dakota	.800-472-2180
Delaware	.800-422-0429	Ohio	.800-332-2437
Florida	.800-352-2437	Oklahoma	.800-342-2437
Georgia	.800-551-2728	Oregon	.800-777-2437
Hawaii	.800-321-1555	Pennsylvania	.800-662-6080
Idaho	.800-677-2437	Puerto Rico	.800-981-5721
Illinois	.800-234-2437	Rhode Island	.800-726-3010
Indiana	.800-848-2437	South Carolina	.800-322-2437
Iowa	.800-445-2437	South Dakota	.800-592-1861
Kansas	.800-342-2437	Tennessee	.800-525-2437
Kentucky	.800-342-2437	Texas	.800-299-2437
Louisiana	.800-992-4379	Utah	.800-366-2437
Maine	.800-851-2437	Vermont	.800-882-2437
Maryland	.800-638-6252	Virginia	.800-533-4148
Massachusetts	.800-235-2331	Virgin Islands	.809-773-2437
Michigan	.800-872-2437	Washington	.800-272-2437
Minnesota	.800-248-2437	Washington, D.C.	.202-332-2437
Mississippi	.800-826-2961	West Virginia	.800-642-8244
Missouri	.800-533-2437	Wisconsin	.800-334-2437
Montana	.800-233-6668	Wyoming	.800-327-3577

Note: Many of these numbers are available only to callers who are calling from within that state.

RESOURCE APPENDIX C: HEALTH DEPARTMENTS

STATE DEPARTMENTS OF HEALTH:

Alabama205-613-5362	New Jersey609-984-5874
Alaska907-561-4406	New Mexico505-827-0090
Arizona602-230-5819	New York518-473-7542
Arkansas501-661-2135	North Carolina919-733-7081
California916-323-7415	North Dakota701-328-2378
Colorado303-692-2719	Ohio614-466-0295
Connecticut203-240-9122	Oklahoma405-271-4636
Delaware302-739-3032	Oregon503-731-4029
Florida904-487-3684	Pennsylvania717-783-0479
Georgia404-657-2588	Rhode Island401-277-2320
Hawaii808-733-9010	South Carolina803-737-4110
Idaho208-334-6526	South Dakota605-773-3364
Illinois312-814-4846	Tennessee615-741-7500
Indiana317-633-0893	Texas512-458-7209
Iowa515-242-5838	Utah801-538-6096
Kansas913-296-6173	Vermont802-863-7245
Kentucky502-564-7243	Virginia804-786-6267
Louisiana504-568-7474	Washington206-586-8344
Maine207-287-3747	West Virginia304-558-5358
Maryland410-225-5013	Wisconsin608-267-5287
Massachusetts617-727-0368	Wyoming307-777-5932
Michigan517-335-8371	Washington, D.C.202-727-2500
Minnesota612-623-5363		
Mississippi601-960-7723	Puerto Rico809-721-2000
Missouri314-751-6141	American Samoa011-684-633-4071
Montana406-444-2457	Guam011-671-734-7142
Nebraska402-471-2937	Marshall Islands011-692-625-3355
Nevada702-687-4800	Micronesia011-691-320-2619
New Hampshire603-271-4576	N. Mariana Islands.011-670-234-8950

RESOURCE APPENDIX D: HIV/AIDS VIDEOS

There are a great number of videotapes having to do with HIV/AIDS. Unfortunately, many of the ones dealing with transmission and prevention no longer agree with current government recommendations. It would be wise to review the tape before showing it to your audience so you can find those errors and correct any misinformation after the presentation is over. Also, you may want to review the tape to make sure the presentation is appropriate for your audience. You can probably find videos about AIDS at a large video store or your local library. The CDC National HIV/AIDS Clearinghouse has a large list of some of the different videos available. Some of the videos you can order from the Clearinghouse, but the majority must be ordered directly from the organization that produced it. For instance, The NAMES Project will have videos you can order. The National Episcopal AIDS Coalition will lend out the videos *After Goodbye* and *Common Threads*.

After Goodbye: An AIDS Story—Award-winning actress Ruby Dee narrates this powerful documentary about the impact of AIDS on the families, friends, and members of Dallas' internationally acclaimed Turtle Creek Chorale. This chorus of 200 men has lost more than 60 of its members to AIDS in the past decade. Although grief is a constant presence, *After Goodbye: An AIDS Story* shows that the singers and their loved ones are also engaged in a continual process of healing. This ultimately uplift-

ing and inspirational video is a testament to the amazing strength of the human spirit. (producer's notes) Copyright 1993 North Texas Public Broadcasting Inc. (60 minutes)

Seldom have love, loss and courage been more candidly, and movingly, portrayed.

—Fort Worth Star-Telegram

Common Threads: Stories from the Quilt—Academy Award Winner 1989 Best Feature Documentary. From an Olympic athlete to an eleven year old suburban boy to an inner-city married man, *Common Threads* tells the story of five people who shared a common fate—they had AIDS. Their names are now commemorated in five panels of an ever-growing quilt that now covers 14 acres (now larger)—the NAMES Project AIDS Memorial Quilt. With compassion and quiet dignity, *Common Threads* tells of their lives and deaths—the support they found, the courage they summoned, and the love they shared. *Common Threads* tells the dramatic story of the first decade of AIDS in America. It shows the human face behind the cold statistics of the epidemic and provides an unforgettable testament to the strength and endurance of the human spirit. (producer's notes, comments in parentheses added) Copyright 1989 Telling Pictures, Inc. & The NAMES Project Foundation. (79 minutes)

As powerful and moving a documentary as you will ever see...This one stays with you.

—People

RESOURCE APPENDIX E: SAMPLE QUILT PROGRAMS

Four-part series related to the Quilt being present with a congregation

SESSION I: WHAT IS THE QUILT? (1-1/2 HOURS)

1. Welcome and statement of purpose.
2. Agenda for this session.
3. Story of the Quilt. How it was made, what it represents, and what is planned for the series.
4. Attention to how we will be caring for the priceless Quilt block we have the privilege of hosting.
5. History of Quilting—a short presentation by a local quilter on how quilts came to be made, by whom, and for what purposes (community, necessity). Hold dialogue with group on connections between the history of quilting and this particular Quilt.
6. Discuss the meaning of the word *memorial*. What are some rituals surrounding memorials? What are some symbols used in creating memorials? What does the process of creating memorials do for the person creating, the person viewing once finished, etc.?
7. Read stories from the Quilt from The NAMES Project *Book of Letters* included in the resource book.
8. Arrange for a time of quiet meditation, with the Quilt being the focal point for silent reflection. If time and circumstance appropriate, ask persons to talk in pairs about what their silence suggested to them, and then have a facilitator guide a brief large group dialogue.
9. Concluding Activity—Set the stage for designing a quilt panel for themselves or for a friend or family member. The panel should be on a sheet of 11"x17" paper. Have everyone sketch a preliminary design. Participants may want to take their papers home to work on them with more time and reflection.
10. What is coming? Preview of next three sessions.
11. Closing prayer.

SESSION II: WHAT DO THE STORIES SAY TO US? (1-1/2 HOURS)

1. Welcome and introductions.
2. Purpose.
3. Today's agenda.
4. Silent meditation with Quilt as focus.
5. Stories: Invite in caregivers (family members, Hospice staff or volunteers, friends, hospital staff, anyone who has been or is caring for someone with AIDS or other terminal illnesses) and listen to their stories. Or secure one or more of the impressive video stories available for telling a story about specific groups or individuals. (See number 4 on preliminary activities sheet).
6. Reflection: After hearing one or more relate their stories or seeing a film or video, facilitator guides a dialogue among those present. One possible focus question is: "Is our Church open to persons with AIDS, their families and friends?" If open, "How could we be more open?" If not open, "What can we put forward to be more open?"
7. Continue active involvement designing your own quilt. Share sketches or ideas generated during the week in small groups (6-8 persons). (Potential to create a dialogue and on issues from what is being presented by individuals.
8. Read stories from The NAMES Project *Book of Letters*.
9. Notes for preparing for next session.
10. Closing prayer.

SESSION III: WHAT DOES GOD SAY TO US? (1-1/2 HOURS)

1. Welcome and introduction.
2. Purpose.
3. Today's agenda.
4. Silence with the Quilt.
5. Telling our own stories about terminal illness and mortality. Invite people with AIDS, family members, caregivers to return for this session, and all join in telling stories with the assignment to connect each story with a Biblical story. Conclude this part with up to three personal stories and Biblical connections shared with the whole group.
6. Invite someone to develop a brief meditation on dealing with two topics: "How do we deal with those of us who believe AIDS is a "sin against God's creation"?" and "How and where do we see GRACE at work in the current AIDS epidemic?"
7. Continue work and dialogue on the individual memorial quilt design by making the actual panels on 11" x 17" paper with cut outs and other craft materials as needed. This activity has potential to create multiple opportunities for agenda items, dialogue and follow-up work and service.
8. Read stories from The NAMES Project *Book of Letters*.
9. Next weeks concluding session
10. Closing prayer.

SESSION IV: WHAT DOES THE QUILT SAY TO US? (1-1/2 HOURS)

1. Welcome and introduction.
2. Purposes and today's agenda.
3. Silence in the presence of the Quilt.
4. Small group conversation, then shared with large group: "What have we learned?" and "What else do we need to learn?"
5. Group dialogue on major concerns and issues that have emerged in the previous three sessions. Facilitator can take cues from the Host Committee and structure this dialogue or activity. The focus could be: "What is God's call to us at this time and place?"**
6. Assemble the individual panels of your memorial quilt by connecting the 11"x17" papers on the wall or on the floor.
7. Share thoughts about seeing your panel assembled with others. "Imagine what life in this community would be like if we were not here?"
8. Assessment of series.
9. Ritual around packing the Quilt for return to the NAMES Project.
10. Closing prayer.

****Examples:**

- Learn about HIV/AIDS
- Choose to wear red ribbon signifying AIDS awareness
- Contact local health department for information about HIV/AIDS programs in your area
- Organize an AIDS healing service with the larger community
- Talk with friends in other congregations about HIV/AIDS and the Quilt experience
- Organize or support a local agency that provides transportation, meals, or other support services for PWAs and their families
- Join NEAC, ANIN, The NAMES Project Foundation, or another national organization
- Start a local chapter of The NAMES Project in your area
- Arrange fund-raising dinners in homes for AIDS-related services and support
- Design age-specific activities for children, teenagers, young adults, middle-age and older adults
- Organize network of safe places for people to be heard and paid attention to
- Establish continuing support group for caregivers, if situation suggests this is needed
- Encouraging or taking leadership in designing a program on AIDS in a local church and community

RESOURCE APPENDIX F: NAMES PROJECT GUIDELINES FOR RELIGIOUS CEREMONIES*

Well-planned, meaningful ceremonies greatly enhance the impact of the Quilt's visit. Merging spiritual activity, ritual, and ceremony into the many lives and traditions represented by the Quilt can be a moving experience for all communities.

Depending on the structure and breadth of your activities, ceremonies often deepen the spiritual, religious, and cultural dimensions of the Quilt.

It is important to remember, however, that the panelmakers and people represented on the Quilt panels come from many faiths. In order to respect this diversity, please adhere to the following guidelines:

- The NAMES Project Foundation asks that the audiences or congregations not bless Quilt panels or pray for people represented on the Quilt, or perform religious rituals with the Quilt.

- People submitting new panels may bless or include their panels in religious ceremonies if the panelmakers wish, since these panels are not yet part of the Quilt.
- Quilt blocks may be displayed in places of worship where religious prayers and rituals take place but ceremonies that include Quilt panels or are designed specifically to honor the Quilt's visit need to be inclusive of all faiths. The following are some ideas for incorporating the Quilt into interfaith services:
 - Use litanies, hymns, poems, and songs that are spiritually appropriate and inclusive of people of all faiths.
 - Encourage participation in your ceremony by integrating hand-holding, singing, or storytelling.
 - Invite audiences to reflect on the Quilt and its meanings through meditation or a moment of silence.

*The NAMES Project Foundation
11/02/94.

RESOURCE APPENDIX G: RESPONDING TO QUESTIONS ABOUT THE QUILT

Some people may ask questions about the Quilt that are especially difficult for you to answer. Here are some suggestions for how to respond.

IF SOMEONE ASKS...

YOU CAN RESPOND...

What makes AIDS so special that we need something like a Quilt?

The Quilt helps us remember the real people affected by AIDS, not just the numbers and statistics. Every panel is unique, like the person it represents, so it becomes a way to remember that person's individual qualities. The act of making a panel helps friends and relatives deal with losing someone they love. As the Quilt gets larger, it reminds us that more and more people are being directly affected by AIDS.

What makes AIDS so special that we need something like a Quilt?

It's sad when anyone dies, but there are a couple of important things to remember about AIDS. Although AIDS is a disease you can prevent, more and more people are dying from AIDS. The Quilt is a way to remind us how important it is to learn how to prevent it.

Why should I care about the Quilt: It's for gays and drug users. They deserve to get AIDS.

It's wrong for us to judge people we don't know. The 31,000 people on the Quilt include young and old people, men and women, gay and straight, of all races. The Quilt is also about the people who made the panels: parents and friends, children and partners—all who have lost loved ones to AIDS. AIDS has affected all kinds of people.

Why should I look at the Quilt? I won't get AIDS.

Even if you know how to prevent AIDS, more and more people of all ages are becoming infected with HIV. Chances are you will know someone in your lifetime who has AIDS. It is a problem that affects all of us.

Adapted from the National High School Quilt Program, "A Lesson Guide for Teachers." The NAMES Project Foundation, 1994.

RESOURCE APPENDIX H: NEAC MATERIALS

METAL BUTTONS

“Our Church has AIDS”
“AIDS Spoken Here”

NEAC Logo PINS

Enamel

EPISCOPAL SHIELD WITH RED RIBBON PINS

Enamel

PRAYER CARDS (BOOKMARKS)

3 styles: Cure, Healing, Remembering

ORDER BY PHONE

202-628-6628

ORDER BY FAX

202-628-1127

ORDER BY MAIL

NEAC

Suite 508

2025 Pennsylvania Ave. NW

Washington, DC 20006

GLOSSARY

In working with the National Episcopal AIDS Coalition, The NAMES Project Foundation, and in using this handbook, there are certain terms that you may want to have explained. The following sections cover many of the terms used in this handbook and terms you may need to use when doing HIV/AIDS education and prevention programs. Keep in mind that clear and specific information tends to have a greater effect than information couched in vague or ambiguous terms. For instance, the term “bodily fluids” tends to lead to more misunderstandings than the use of specific terms such as “blood, semen, vaginal fluids, and breast milk.” If you or your guest speakers are uncomfortable using certain words, you may want to get someone else to give basic AIDS education about transmission and prevention. For more assistance contact your local Public Health Department.

Block Number: A four-digit number for each *twelve by twelve block* of the Quilt that is written several times on its edging. The number helps locate specific blocks for displays.

CDC: Acronym for the Centers for Disease Control and Prevention. The part of the U.S. Department of Health and Human Services responsible for disease control and prevention; provides safety guidelines and statistical data on HIV/AIDS and other diseases.

HIV: Acronym for the Human Immunodeficiency Virus; the virus that causes AIDS.

List of Names: The list of each name that appears on the Quilt, in directory form.

NAMES Chapters: Partners with The NAMES Project Foundation, volunteer groups that organize local panelmaking, display, education, outreach, and fund-raising activities.

NEAC: Acronym for the National Episcopal AIDS Coalition.

Pandemic: A world-wide epidemic.

Panel: A three foot by six foot cloth memorial to at least one person who has died of AIDS.

Panelmaker: A person who creates a panel as a personal tribute to someone who has died of AIDS.

PWA: Acronym for Person With AIDS.

Quilt Display Committee/Team: A group of people who wish to display the Quilt and who coordinate the different activities held while hosting the Quilt.

Signature Square: A blank twelve foot by twelve foot piece of cloth for people who visit the Quilt to write memorials or their feelings about the Quilt.

Twelve by twelve: A block of the Quilt containing eight panels that are arranged to make a 12 foot square.

AIDS TERMINOLOGY

Abstinence: Refraining from all sexual intercourse—oral, anal, and vaginal.

AIDS: Acronym for the Acquired Immune Deficiency Syndrome; an advanced stage of HIV infection where the body's immune system is severely damaged.

Anonymous testing: Testing done without connection to a name or other identifying information.

Anal sex: Sexual intercourse where the penis is inserted in the anus of the sexual partner (anal intercourse).

Bisexual: Being romantically or sexually attracted to people of either sex. Also, having sexual partners of either sex.

Casual contact: Ordinary social contact, not a means of transmitting HIV—e.g. shaking hands, kissing on the cheek, using a telephone, toilet, etc.

Communicable disease: Any disease that is capable of being transmitted.

Condom: A thin sheath, made of latex or lamb intestine, that fits over the erect penis used for disease prevention and/or contraception. A latex condom, when used consistently and correctly, significantly reduces the chance of HIV transmission. (rubber)

Confidential testing: Testing which is linked to an individual and recorded in medical files.

Confidentiality: Keeping information private or secret.

Contact tracing: See partner notification.

Contaminated needles: Hypodermic needles that have been used and not cleaned properly.

Gay: See homosexual.

Gender-neutral terms: Terms that do not refer to a specific gender—e.g. partner rather than husband or wife.

Exposure (to HIV): The condition of being physically near and unprotected from contact with HIV; raises the possibility of HIV transmission.

Heterosexual: Being romantically or sexually attracted to people of the other sex. Also, having sexual partners of the other sex.

Homosexual: Being romantically or sexually attracted to people of the same sex. Also, having sexual partners of one's own sex.

Hospice: A program offering comfort care in the home or in a home-like setting to terminally ill people who are close to death.

Incubation: The period from the point of infection to the first appearance of symptoms.

Infection: Invasion of the body by a disease causing agent.

Infectious disease: A disease caused by or capable of being transmitted by an agent; not all are highly contagious or easily communicable to others—e.g. HIV is highly infectious, but is not easily or casually transmitted.

IV drug use: Intravenous drug use; injecting drugs into a vein. Considered a limited, outdated term; the current term being used is "Injection Drug Use" or IDU.

Lesbian: A woman whose sexual partners are women.

Mandatory testing: Required testing of a population or group of people; traditionally used only for diseases that have a cure and effective treatments available.

Nonjudgmental perspective: A point of view that recognizes the right of all people to their own values, attitudes, and beliefs.

Opportunistic infections: Infections that occur in people with impaired immune systems that would not occur in a person with a fully functioning immune system.

Oral sex: Contact of the mouth or tongue with a partner's penis, vagina, or anus during sexual activity.

Partner notification: The process of letting the sexual and/or needle-sharing partner of an infected person know that they have been exposed.

Prevalence: The total number of cases of a disease in a given population in a given period of time.

Respite Care: Care provided in someone's home so that the primary caregiver can rest.

Risk behavior: Any activity that puts a person at risk for contracting HIV. “Groups that practice risk behavior” is preferred to the term “risk group”.

Risk group: For statistical purposes, a collection of people thought to share a common feature that puts them at increased risk of contracting a disease.

Safe sex: Sexual activities that do not involve the exchange of blood, semen, or vaginal or other bodily fluids.

Sexual orientation: The attraction people feel for or the erotic relationship they develop with others of their own sex, of the opposite sex, or of both sexes.

STD: Acronym for Sexually Transmitted Disease.

Stigma: A mark, whether visible or not, that detracts from the character or reputation of a person or group.

Syndrome: A group of related problems or symptoms.

Vaccine: A substance that produces or increases the immunity to and protection against a particular disease; a vaccine is ineffective if someone is already infected with the disease.

Vaginal sex: Penetration of the vagina by the penis (intercourse).

Wasting syndrome: The extreme weight loss (more than ten percent of body weight) that often affects people living with AIDS.

Works: Needles, syringes, and other equipment used to “cook” or prepare and inject street drugs.

Adapted from the *National High School Quilt Program, “A Lesson Guide for Teachers.”* The NAMES Project Foundation, 1994, and the *American Red Cross HIV/AIDS Instructor’s Manual.* The American National Red Cross, 1990.

AIDS-RELATED EXPRESSIONS

Because AIDS is an emotionally charged subject, be careful in what you do and do not say and in what terms you use to convey your message. You should be clear and specific in your information; generalities only tend to perpetuate misinformation. Talk about latex condoms, dental dams, and other explicit information, do not just talk about “protection” and expect your audience to understand how to protect themselves. In communicating information accurately and nonjudgmentally you may want to take note of the following terms.

AVOID

AIDS Victim—This term implies powerlessness and defeat.

AIDS Patient—Should be used only when a person with AIDS is actually receiving medical treatment. Improper use implies passivity, helplessness, and dependence.

Condoms—There are many different types of condoms, those made of the intestinal lining of sheep are permeable to HIV.

Innocent Victim—Often used with infants and people who have become infected through blood transfusions. The term implies that some people with AIDS are “guilty perpetrators.”

Intravenous Drug Abuse(r)

Intravenous Drug Addict—This term has a derogatory moral connotation. Many drug users do not consider themselves to be addicted or drug abusers and may not see themselves as engaging in risky behavior.

Risk Group—This term implies that all people in certain groups are at increased risk for infection, which is not true. Only those engaging in risk behavior are truly at risk. Additionally, the term gives people not in that group a false sense of security.

General Population—This term tends to imply an “us” versus “them” situation. People often use this term to exclude minorities, homosexuals, IDUs, and others. These groups are just as much part of the “general population” as any other group.

PREFERRED

Person Living With AIDS or HIV

Person Living With AIDS

Latex Condoms

Person Living With AIDS or HIV

Intravenous Drug Use

Injection Drug User (IDU)

Risk Behaviors—This term put the emphasis on the behavior of the individual not what group they may be categorized into, includes unprotected sexual intercourse, needle sharing, and others.

All of Us

Adapted from *AIDS and Your Religious Community: A Hands-On Guide for Local Programs*, “AIDS-Related Expression.” Blumenfeld, Warren J., writer, and Alexander, The Reverend Scott W., project director, Copyright 1991 by the Unitarian Universalist Association.