

On Our Own Terms

Moyers on Dying in America

LEADERSHIP GUIDE

A production of Public Affairs Television, Inc.
presented by



**THE LEADERSHIP GUIDE IS AVAILABLE ONLINE AT WWW.THIRTEEN.ORG/ONOUROWNTERMS OR
WWW.PBS.ORG/ONOUROWNTERMS**

Funding for the series, the outreach campaign, and the communications campaign is provided by The Robert Wood Johnson Foundation, The Fetzer Institute, The Nathan Cummings Foundation, The Kohlberg Foundation, Inc., The Laurance S. Rockefeller Fund, and Mutual of America Life Insurance Company.

Public Affairs Television, Inc.

Bill Moyers
Judith Davidson Moyers

Dear Community Leaders:

My colleagues in public television and I want to invite you to participate in the nationwide outreach for our forthcoming PBS series about dying in America, *On Our Own Terms*, which airs in the fall of 2000.

The series reports on the movement to improve care at the end of life. As I'm sure you know, modern advances in medicine and profound social changes have prolonged life but also transformed the experience of dying. While most Americans say they want to die at home, the majority die in hospitals. People die in pain who do not need to do so, and because the dying process takes longer, it exacts a greater toll on individuals, families, caregivers and communities.

As a result, surveys show that Americans – including baby boomers who are becoming aware of their own mortality while caring for their elderly parents – are exploring issues of death and dying with new openness. Awareness is growing that we can and must improve care at the end of life.

Our series will introduce viewers to men and women who have allowed us into their experience, including patients, doctors and nurses, hospital teams, hospice volunteers, palliative-care specialists and others. Their stories, we believe, stimulate an important public dialogue and help communities create coalitions that can lead to improving end-of-life care all across the country.

I am grateful to the Robert Wood Johnson Foundation, the Fetzer Institute, the Nathan Cummings Foundation, the Kohlberg Foundation, Inc., The Laurance S. Rockefeller Fund and Mutual of America for making this broadcast and the accompanying outreach possible.

Many professional, service, religious and advocacy organizations are participating in the series outreach with an experienced team that includes Thirteen/WNET, Barksdale Ballard and Company and Stewart Communications Ltd. We hope that after reading the enclosed material you will decide to join the endeavor, too.

Please let me hear from you if you need more.

Sincerely,



On Our Own Terms: Moyers on Dying in America

Leadership Guide

TABLE OF CONTENTS

Series Description	1	Community Awards for Public Television Stations	67
Project Overview	3	Request For Proposal for Community Awards	69
VISION		Keeping in Touch: Electronic Outreach Newsletter	71
The Power of Outreach	5	ON OUR OWN TERMS Online	73
The Context for Outreach	7	Discussion Guide for Individuals, Families, and Groups	75
PLANNING AHEAD		Discussion Guide Advance Request Form	76
Building Coalitions to Affect Change	11	Camera-ready Logo Art	77
Identifying Partners	15	Sample Letters of Invitation	79
Outreach Associates	17	Resources for Further Learning and Training	81
TAKING ACTION		Fact Sheet	99
Assessing Community Needs and Capabilities: A Community Survey	29	Project Evaluation	101
Creating Conversations That Matter	33	CONTACTS	
Action Ideas	37	Contacts	103
TOOLS		Funders	107
Leadership Training Seminar Videoconference	63	Planning Calendar	109
Steps for Hosting a Videoconference Site	65	Leadership Guide Credits	123

On Our Own Terms: Moyers On Dying in America

A 4-part PBS series from Bill Moyers will premiere in Fall 2000

Modern advances in medicine and profound social changes have prolonged life, but also transformed the experience of dying. While most Americans say they want to die at home, the majority die in hospitals. People die in pain who do not need to do so, and the dying process, which now takes longer, exacts a toll on individuals, families, caregivers, and communities. Based on two years of research and production, ON OUR OWN TERMS goes to the front lines of this growing movement to improve end-of-life care. From interviews across the country, Moyers reports remarkable human stories of the dying, their families, and their caregivers, as they struggle to balance medical intervention with comfort and humanity at the end of life.

The series includes four programs that provide an intimate window into the daily experience of patients and their caregivers, including the decisions they face and the changes they undergo. Along with this deeply personal perspective, medical, legal, and public-policy experts in the end-of-life field discuss the cultural constructs that have shaped how we die and what can be done to rethink and redefine this approach.

- Program 1: The first program in the series will explore America's search for new ways of thinking about death. It will focus on people—patients and caregivers—who are finding ways to overcome the fear and denial that dominate mainstream American culture and open conversations that help us live with dying.
- Program 2: The series will continue with a report on the evolution of a different kind of care—commonly referred to as “palliative care.” Leaders in this movement emphasize a full spectrum of pain management and symptom relief and support—including physical, psychological, and spiritual care.

- Program 3: Dying well, to many, means a degree of control over how and where we die. We fear dying in pain; we fear that too much will be done to keep us alive, or we fear that not enough will be done. The third program will look at the issues surrounding efforts to control how we die and the implications for families, institutions, and communities.
- Program 4: In the final program, we will follow crusading individuals who are working to change public policy to improve care of the dying. They are creating models for change that deal with issues including insurance coverage, the training of doctors, and building communities of volunteer caregivers to relieve the burden on families of the dying.

During his 25 years as a broadcast journalist, Bill Moyers has explored a broad spectrum of issues and ideas and won over 30 Emmys. The official journal of the National Academy of Television Arts and Sciences placed Moyers among the top 10 journalists who have had the most significant influence on television news.

ON OUR OWN TERMS is produced by Public Affairs Television, Inc. and presented on PBS by Thirteen/WNET in New York. Funding was provided by The Robert Wood Johnson Foundation, The Fetzer Institute, The Nathan Cummings Foundation, The Kohlberg Foundation, Inc., The Laurance S. Rockefeller Fund, and Mutual of America Life Insurance Company.

Project Overview

The national outreach for ON OUR OWN TERMS will connect public television stations, healthcare professionals and institutions, civic organizations, community-based groups, and individuals on the national and local levels and encourage them to use this series as a catalyst for dialogue and community action on end-of-life issues.

Goals of ON OUR OWN TERMS Outreach

- Expand broadcast viewership for ON OUR OWN TERMS
- Encourage the development of sustainable coalitions in cities and towns across the country to address community concerns around end-of-life care
- Generate dialogue and community action on end-of-life issues among the general public, healthcare professionals and institutions, organizations, and small groups
- Promote in-depth conversation that will enable individuals and families to address dying on a personal level
- Encourage public-policy makers to participate in public discussions of what constitutes appropriate end-of-life care and policies that may need to be addressed

Strategies for Implementation

- Training of public television outreach staff and their community partners in the movement to improve end-of-life care
- Creation of sustainable coalitions representing key stakeholders in communities across the country to address local concerns about the care of the dying and their families
- Assessment of community strengths, resources, and service gaps in end-of-life care

- Development of outreach plans to stimulate dialogue and community action about end-of-life care

Tools

- ON OUR OWN TERMS: MOYERS ON DYING IN AMERICA series
- Leadership Guide
- Community Awards for public television stations' community outreach
- Leadership Training Seminar Videoconference on April 18, 2000
- Discussion Guide for Individuals, Families, and Groups
- Web Companion Piece
- Electronic Outreach Newsletter
- Professional Support from the National Outreach Coordinators

Thirteen/WNET, Barksdale Ballard and Co., and Stewart Communications Ltd. are the National Outreach Coordinators for ON OUR OWN TERMS. Contact them for information on other groups or individuals in your area interested in being part of this outreach, news about the activities of other local coalitions and ideas for outreach. Refer to the "Contacts" section of this guide for information on reaching the coordinators.

Kelly & Salerno Communications is coordinating a national media campaign for ON OUR OWN TERMS. They are generating press attention in print, television, radio, and Web media for both the television broadcast and the national outreach project. Media coverage not only draws viewers to the television series and promotes participation in the outreach initiatives, it also provides another effective vehicle to increase public awareness and understanding about end-of-life issues. They will also be preparing press materials that help local outreach coalitions promote their activities. Refer to the "Contacts" section of this guide for information on reaching Kelly & Salerno Communications.

The Power of Outreach

The following is an example of how this outreach may develop in a community.

September 1999

The Anytown public television station sends its outreach coordinator to the one-day Leadership Training Conference for ON OUR OWN TERMS hosted by Thirteen/WNET and the National Friends of Public Broadcasting. At the conference are representatives from the national offices of major healthcare organizations as well national consumer and community-based groups. All pledge to collaborate in a national drive to improve end-of-life care. They are there to learn how their local chapters, members, and stations can become involved in community outreach around the broadcast.

Judith Moyers describes ON OUR OWN TERMS for the group. In the break-out sessions, attendees share ideas about encouraging discussion of dying and involving the community in action to improve end-of-life care. The Leadership Guide, used as a working textbook during the session, contains models of both discussion and community action that outreach coordinators and professional and consumer groups can adapt on the community level. The outreach coordinator leaves the conference with a vision, armed with practical tools and a valuable set of contacts.

October 1999

When she returns to Anytown, the outreach coordinator contacts the local chapters of the national outreach associates. Some contact her as well, at the instigation of their national offices. These interested folks and other targeted leaders form a core group—the steering committee. The Leadership Guide provides them with a menu of activities from which to choose. Their goals are to build viewership for the series and to develop local programs around the series that promote discussion and improvement of end-of-life care at a variety of levels.

January 2000

The steering committee conducts a community assessment using the template and resources in the Leadership Guide. They survey key people and groups in their community and learn more about gaps in services for the dying and their families and the types of care currently provided. The information from the assessment helps the steering committee prioritize needs and discover other groups and people that want to be a part of the outreach.

April 2000

The public television station serves as the host site for the national Training Seminar Videoconference. Anytown's steering committee invites an audience of community leaders, clergy, healthcare professionals, and local policymakers to view the live program and participate in a follow-up discussion. This event helps recruit these groups to a larger coalition that will plan and implement Anytown's outreach efforts. The follow-up discussion focuses on the results of the community assessment and how it informs the outreach plans. The group decides on which Action Ideas described in the Leadership Guide to implement and plans the next steps. Each attendee leaves the event with a set of tasks and a date for the next coalition meeting.

Spring 2000–Summer 2000

The coalition finds that people are eager to talk about end-of-life issues, as they begin to plan outreach activities to coincide with the broadcast of the series in Fall 2000. They refer to the ON OUR OWN TERMS Web site for information about the action ideas and post questions for other coalitions planning similar activities. Coalition members call the national outreach coordinators to find out about other local organizations that have expressed interest in joining the effort. The monthly Electronic Outreach Newsletter notifies them of tools such as graphic materials and the feed of the highlight reel to public television stations. The station outreach coordinator contacts

Thirteen/WNET as needed to discuss strategies for outreach planning and for information about the project elements.

Fall 2000

In the weeks before and after the broadcast of ON OUR OWN TERMS, the coalition implements the action ideas. They engage diverse groups of people in dialogue and community action. Examples of outreach activities include:

- Study groups watch the series together and discuss it afterwards, using the Discussion Guide's models for promoting deeper dialogue.
- The coalition compiles a Local Resource Guide listing services and options for care in Anytown and distributes it at all outreach activities as well as through libraries, religious organizations, and health and social-service providers.
- A group of local physicians and other healthcare providers form a committee to begin planning for a palliative-care hotline.
- Clergy representatives contact religious leaders in the area, distributing suggested sermon topics and urging them to take advantage of this unique opportunity to address the end-of-life concerns of their congregations.
- The coalition brings together policymakers at the municipal, county, and state level for a screening of ON OUR OWN TERMS and presentation about the current state of end-of-life care in Anytown. They review the results of the coalition's Community Assessment and use it to assess areas of need.
- A support group for chronically and terminally ill people posts information about advance directives and how to use them on its Web site for patients and their caregivers.
- The medical society partners with members of a hospital staff to organize a speaker's bureau and coordinate their participation at local forums.
- In conjunction with the broadcast, a radio talk show features psychologists and bereavement counselors. Another has a panel discussion about policy issues related to end-of-life.

- Through the collaborative efforts of area employee-assistance professionals, many employers include flyers in pay envelopes that promote the series and local activities.
- Employee-assistance professionals host discussion groups with representatives of local businesses, employees, and union leaders to probe the needs of caregivers in the work force.
- Community associations, working in conjunction with local churches and the local hospice, register volunteers to visit the sick and dying in their neighborhood.
- A series of in-studio town meetings is broadcast by Anytown's public television station, allowing participants and viewers to share concerns and discuss steps for creating a greater sensitivity to the needs of the seriously ill and dying as well as their caregivers. The Discussion Guide is distributed to attendees to encourage them to initiate conversations with their families and friends about their own wishes for their final days.

Post-broadcast

The coalition meets to assess the impact of the outreach on Anytown and decides to continue working together on this issue. A representative of the local clergy and the medical society director are chosen to co-chair the coalition, which will continue to build partnerships. They meet initially at the public television station, which commits to host two follow-up meetings to track progress toward improving access to and delivery of end-of-life care.

There are signs that the outreach has had a major impact in Anytown. The hospice is experiencing "growth pains" as the medical community begins to refer more patients to them. The hospital's task force has invited the regional Veteran's Administration hospital pain management director to help adapt a program similar to the VA model throughout the community. The local chapter of the American Cancer Society reports that the number of visits to the advance directives page on their Web site has increased dramatically. Discussion groups continue to meet and shape a constantly evolving plan for the future.

The Context for Outreach

“Help me to know the shortness of life that I may gain wisdom of the heart.”

— Psalm 90

“Death destroys a man: the idea of Death saves him.”

— E.M. Forster, *Howard's End*

“When it's over, I don't want to wonder if I have made of my life something particular and real. I don't want to find myself sighing and frightened or full of argument.”

— Mary Oliver, *When Death Comes*

“As a culture, we need to reintegrate dying within living.”

— Ira Byock, M.D., *Dying Well: The Prospect for Growth at the End of Life*

“I have sensed the birth of a new grassroots movement for change, which in some ways has the excitement of the early days of the women's movement.”

— Marilyn Webb, *The Good Death*

What Do We Want? What Do We Experience?

Facing death, whether it be a loved one's or the possibility of our own, can open us more fully to a deeper experience of life. Through caring conversations with our family and friends, among healthcare providers, clergy, and fellow citizens, we can begin to envision a more humane, compassionate, and trustworthy process for dying.

A 1997 Gallup Poll on Spiritual Beliefs and the Dying Process reveals how most of us want to die. We want dying to be pain-free. We want to be surrounded by family and cared for by a competent physician who knows us well and listens to our concerns. We also want to protect family finances and preserve personal dignity.¹

Living with dying is not only about the physical and emotional issues that dying people and their family face. First and foremost, living with dying is about spiritual and existential issues. From the moment of birth until the moment of death, everyone searches for meaning and purpose in life. Consideration of dying often triggers profound questions such as:

■ Who am I really?

- Why am I suffering?
- What gives meaning to what I am going through?
- How will I die?
- What will happen to me after I die?
- Did I live a good life? Did I do my best?
- Can I make peace with others? With myself?

The struggle to find answers to these questions offers an opportunity for tremendous growth. Often, however, people do not face these questions until they are diagnosed with a serious illness and experience a sense of missed opportunities and conflict about dying. Anxiety created by these feelings may prevent a dying person from discussing what he or she wants at the end of life and may lead to unwanted procedures and therapies. By talking about spiritual issues earlier in life, people may be able to explore how they want to live and how they want to die.

We also worry about the specifics surrounding our deaths. Although most people say they would prefer to die at home, as many as 80% of us will die in a healthcare facility.² Exact percentages vary by geographic region. We worry about becoming “vegetable-like” and about not being able to say good-bye to

someone who is important to us. Most of us say we would choose a plan of care that relieves pain but shortens life, versus lengthening life and allowing pain.¹

The Complications We Face Today

A century of progress in sanitation, nutrition, medical science, and technology has prolonged life dramatically. But along with this progress has come some unintended consequences. Now, the longer we live, the sicker we get, until we die not from one illness, but from a complex interplay of diseases, far removed from what used to be called “natural causes.” Meanwhile, friends and family must shoulder often overwhelming burdens of care, feelings of ambivalence and guilt, and financial stress. And to complicate the picture even more, decision-making around end-of-life issues has evolved into an often confusing process that can be fraught with pain, emotion, and moral as well as legal dilemmas.

Technology has served us well and continues to extend and save lives, and science has also transformed the experience of death into a biomedical event in which the dying and their families sometimes have little say or for those difficult decisions they are often unprepared to deal with. And yet, of all of life’s passages, death is one in which it is so important for people to have their wishes known and respected.

Talking about Death

For our families to know our wishes, however, means we must tell them. In any given year, nearly half the US population is touched by the death of a relative or close friend. Though we can’t change the fact of death, we can alter the way we experience it and the way we feel about it. Talking with each other is how we start—as individuals with family and friends, as healthcare professionals with patients and their families, and as citizens in our communities. By encountering and talking about death, we transform the way we experience life.

For most people, talking about death is a new experience—and an uncomfortable one. In an April 1999 survey sponsored by the National Hospice Foundation, about 50% of respondents said they would rely on family or friends to make end-of-life decisions for

them. Yet fewer than 25% have put their wishes in writing.³

A third of respondents in the Hospice Foundation survey also say that they are unsure about whom to contact with questions about end-of-life care. The logical choices — healthcare providers—are sometimes uncomfortable talking about death and dying, and often have little training in this area. Medical care at the end of life has been focused more on prolonging life than it has on care of the whole person including his or her physical, psychological, and spiritual well-being and the comfort and peace of mind of the family.

Yet clearly it is comfort and peace of mind that we are seeking. People who are dying have very real human concerns, including spiritual needs. Research indicates that 50% of Americans consider prayer important at the end of life, and nearly as many as 44% would like to receive counseling to reach spiritual peace. But when asked who could be most comforting to them in their dying days, only 36% of survey respondents said a member of the clergy. Family and friends were the most trusted sources of solace.¹

Ira Byock, M.D., author of *Dying Well: The Prospect for Growth at the End of Life* (Riverhead Books, 1998), sums up our need for compassionate end-of-life care when he says, “We need to be assured of relative comfort while we die. We need to be assured that our wishes for care are accepted, and that our families will have effective support in their caregiving and in their grieving. Beyond this, as a culture, we need to reintegrate dying within living.”⁴

Goals of ON OUR OWN TERMS

Outreach

- Expand broadcast viewership for ON OUR OWN TERMS
- Encourage the development of sustainable coalitions in cities and towns across the country to address community concerns around end-of-life care
- Generate dialogue and community action on end-of-life issues among the general public, healthcare professionals and institutions, organizations, and small groups

- Promote in-depth conversation that will enable individuals and families to address dying on a personal level
- Encourage public-policy makers to participate in public discussions of what constitutes appropriate end-of-life care and policies that may need to be addressed

Leveraging ON OUR OWN TERMS and Using the Leadership Guide

As a leader in the ON OUR OWN TERMS outreach program, you are tapping into a growing social movement to improve care at the end of life. When people in your community are encouraged to think, speak, and act on their own experiences with and feelings about death—some perhaps for the first time—they may recognize how large the gap is between what many of us want and what we actually receive at the end of our lives.

Along with its communications tools and activities, ON OUR OWN TERMS can empower us to initiate a community-wide conversation and take action on end-of-life issues—a conversation that will bridge the gap between our personal visions of the care we want at the end of our lives and the realities of today. This outreach is a call to action for communities across the country to examine the care that is provided to the dying and to reflect on how it can be improved. In the coming year, caregivers, citizens, patients, clergy and lay leaders, healthcare providers, and institutions in your community can use this series and its outreach activities as a platform for establishing sustainable coalitions and developing a vision of how we should care for dying people and their families. To achieve that vision, your coalition can resolve that no one in your community should die alone in an institution, in unnecessary pain, or without their wishes for care being heard and attended to.

From Introspection to Dialogue to Action

This Leadership Guide presents a simple but powerful model for creating momentum and effecting change in your community:

“Although community is not an aim of dialogue, it seems to emerge organically. Dialogue seems to be the natural language of community.”

—Sarita Chawla, “Dialogue: The Language of Community,” *Vision Action*, Winter 1994.

- Create a coalition that represents the key stakeholders in your community. Identify organizations that can help you launch a successful outreach program. Key players include not only medical institutions but also local affiliates of national health and aging organizations; schools; schools of medicine, nursing, and social work; libraries; civic groups and faith communities and seminaries; governmental agencies; professional organizations; and ethics and policy centers.
- Assess the needs of your community. Identify strengths and resources in the community, as well as weaknesses and service gaps that need to be addressed. Establishing a consensus for action will result in a sustainable coalition—a powerful agent for change that can address needs, make recommendations, and build community support for end-of-life policies, regulations, and guidelines.
- Draft an action plan. Design outreach activities that bring together people from many different sections of your community to address the needs of individuals, families, and institutions and to identify barriers to care. Examples of activities include:
 - A town meeting
 - A series of small group discussions or study circles
 - A screening for policy makers
 - A palliative-care hotline
 - A campaign to improve the use of advance directives
 - A bereavement program
 - A local end-of-life resources directory
 - A campaign to promote discussion of advance care planning

Full descriptions of these steps can be found elsewhere in this guide, along with information about print, Internet, and many other resources.

Meeting the Challenge

As Donald Berwick, M.D., of the Institute of Healthcare Improvement observed in an April 1999 keynote address to the American College of Physicians and American Society of Internal Medicine: “We have some great examples of world-class end-of-life care in this nation—best practices based on best science—but these are not the prevailing practices, they are not even the common practices, they are rare practices.”

The ON OUR OWN TERMS outreach program is premised on the fact that each of us has a role to play in changing the culture surrounding death in this country. Working together, we can help raise the visibility of end-of-life issues, create a safe environment

for discussion, and develop more and better palliative-care services that are available to everyone. Simply put, it is a matter of life and death for all of us and for those we love.

REFERENCES

1. *Spiritual Beliefs and the Dying Process*. The George H. Gallup International Institute, October 1997.
2. Pritchard, RS et al. “Influence of Patient Preferences and Local Health System Characteristics on the Place of Death.” *Journal of the American Geriatric Society* 46:1242-1250.
3. *Baby Boomers Fear Talking to Parents about Death*. Press release. National Hospice Foundation. June 8, 1999. www.nho.org/foundati.htm.
4. Byock, I. “Dying Well in America: What Would Success Look Like?” *Last Acts Leverage Points: A Report Based on the Second Last Acts National Leadership Conference* Washington, DC: October 29-30, 1997.

Building Coalitions to Effect Change

“When people are engaged in an issue at a deep personal level, they are likely to feel a sense of responsibility for what happens in their own lives as well as in the life of the community in which they live.”

—Janel Radtke, *Public Engagement*

What is a Coalition?

At the heart of a successful coalition are two critical dynamics: membership and collaboration. In recruiting members for an end-of-life coalition, remember that people and organizations join a coalition to accomplish a shared objective that they cannot achieve alone. Coalition partners share their resources because it is in their best interest to present a united front. Collaboration can create a powerful network to achieve common goals and enhance each partner’s own sphere of influence. It can also create a shared feeling among members that others share the goals of their organization. The process of building a coalition can rejuvenate many who have worked on these issues, as they discover new allies and colleagues.

How to Identify Potential Members?

The first step in building a coalition is to form a steering or planning committee. Identify key players or individuals who are already involved in the movement to improve care for the dying. For example, is there a hospice organization in your community? Who is on the board of directors? Is there a chaplain or a member of the clergy who is a mover in this arena? Is there a hospital ethicist, or a doctor or nurse who champions better management of pain or actively advocates for improved palliative care? Is there an interested leader in the retiree community? Other leaders may be found in bereavement groups or health organizations like the Alzheimer’s Association or American Cancer Society. The National Outreach Coordinators may also know about local efforts and may be able to direct you to others in your community.

The National Outreach Coordinators for ON OUR OWN TERMS are recruiting a wide variety of national organizations with networks of state and local chap-

ters to join this effort as Outreach Associates. The objective is to have these national organizations promote the value of ON OUR OWN TERMS as an educational tool to their members. The local chapters of these organizations should be prime candidates for your coalition-recruiting efforts. Basically, any group or organization that holds a stake in the health and wellbeing of the community is a potential coalition member. Examples include:

- Local affiliates/chapters of national organizations
- Health, health-advocacy, and aging-related agencies
- Healthcare professionals and institutions
- Social workers and other mental-health professionals
- Educational institutions
- Women’s groups
- Veterans’ groups
- Family-service community
- Libraries
- Community centers
- Faith-based communities
- Civic organizations
- Community leaders: political, social, religious
- Study groups
- Health plans
- Ethics-committee networks

- Employers
- Chambers of commerce
- Local chapters of disease-based support groups
- Caregiver groups

In particular, try to identify leaders in the healthcare community and in the religious community. Think about which organizations and individuals have the ability to attract others to the coalition; try to accommodate sensitivities among groups; and consider who might feel left out if not invited to join.

Barriers to Coalition-building

When any group of people joins together to accomplish a specific task, differences of opinion often emerge. This becomes increasingly likely when the focus of the work touches everyone in such a deep, personal way as death. The members of a coalition may have diverse opinions on controversial issues like pain management, healthcare reimbursement, or physician-assisted suicide. When these differences come forth, it is important not to allow them to derail the work of the coalition. Try focusing the conversation on areas of common ground rather than debating divisive issues. Topics such as compassion for the dying and their families and the coalition members' shared hopes for the success of this outreach in their community emphasize the connections between people rather than their differences.

“How does . . . a group of people become a community? And the answer is simple: it becomes a community when as persons the members enter into dialogue with one another and assume responsibility for their common life.”

— Reuel L. Howe,
The Miracle of Dialogue

The organization of a coalition for outreach planning involves some cost considerations. Coalitions may consider sources of funding such as the “Community Awards for Public Television Stations” described in

the “Tools” section of this guide or may approach other local businesses and agencies that have an interest in promoting dialogue and community action on end-of-life care. Guidelines for local fundraising are included in the “Community Awards for Public Television Stations” description. In-kind contributions of goods such as refreshments and office supplies or services such as duplication of materials and use of meeting space are an effective way to offset costs.

Assembling Task Forces

To coordinate the implementation of the Action Ideas suggested in the “Taking Action” section, the steering committee may find it helpful to organize a number of task forces. For example, one task force may focus on a screening for policymakers and another on outreach in the workplace.

A Coalition Organizer’s Checklist: ACTION!

The following questions are designed to help your steering committee guide the coalition:

- **Awaken a desire to change.**
 - What is important to you personally about participating in this coalition?
 - Has the coalition performed an assessment to identify community values, norms of care, needs, gaps and barriers to change?
 - Has a core group(s) that will attract others to the coalition been identified?
 - Is there an outreach strategy for involving and orienting new coalition members?
- **Convert desire to organization.**
 - Has the coalition reached consensus on its goals and objectives?
 - Is there a structure in place to carry out the work of planning and implementing the outreach?
 - Does the outreach plan take advantage of all resources, including the ON OUR OWN TERMS series, outreach staff, Discussion Guide, and Web site?
 - Is the coalition tapping into all possible sources of information—local, regional, and national?

- Is there an action plan for developing community activities?
- Is there a method in place to track activity?

■ **Train effective leaders.**

- Is there a strategy for identifying, recruiting and training leaders?
- Are the roles and responsibilities for leaders and other coalition members clearly described?

■ **Involve citizens at the grassroots level.**

- Is there a strategy for generating grassroots involvement?
- Is information about the outreach accessible to all?
- Is the schedule of activities broad enough to engage a wide variety of individuals and groups?
- Is there a promotion plan in place to promote awareness of the coalition's activities?

■ **Open lines of communication.**

- Is the communication among coalition members open and authentic?
- Does your communication address a range of experience, including your own fears and reluctance to talk about death and dying?
- Is there a formal system for updating members about activities and progress?
- What are the lines of communication between the coalition and the community?
- Does the coalition reflect and respect the cultural diversity of the community?

■ **Now do something!**

- Is the coalition's outreach plan realistic, flexible, and responsive to the needs of the community?
- Is the outreach plan sequenced?
- Is the timeline realistic?
- Is the plan in writing, and is it distributed to coalition members?

ACKNOWLEDGMENTS

End of Life Coalitions: A Manual for Building Successful Coalitions Around End of Life. Coalition for Dialogue on Death and Dying funded by Project on Death in America, a project of the Open Society Institute, 1998.

Howe, Reuel L. *The Miracle of Dialogue.* Seabury Press Paperback, 1963.

Radtke, J. *Public Engagement: A Process to Increase Understanding and Build Community Action.* Community-State Partnerships to Improve End-of-Life Care, Midwest Bioethics Center, March 1999.

Identifying Partners

The following is a list of national organizations that have agreed to participate in the outreach for ON OUR OWN TERMS on both the local and national levels. These Outreach Associates share an interest in end-of-life issues and a concern about the way care is delivered to the dying and their families. Each organization has a unique perspective to offer on this subject and different means to address this issue, depending on their mission and constituency. Call or email the contact person listed to get information about local chapters or key members who may collaborate with you on developing local outreach.

The list of organizations is still growing. Check for updates in the Electronic Outreach Newsletter or the Outreach section of the Web site, at www.thirteen.org/onourownterms or www.pbs.org/onourownterms.

These Outreach Associates may act as:

- partners in the coalition-building process
- resources for information on community services
- advisors on end-of-life issues on the national, state, and local levels
- liaisons between the public television stations and key stakeholders in the community
- partners in planning of local events

As broadcasters of ON OUR OWN TERMS, public television stations are integral to the success of this outreach campaign. Call or email the Outreach Contacts at Thirteen/WNET listed in the “Contacts” section of this guide to find out the name of your local station’s outreach coordinator.

Coalition organizers should also take stock of their own communities to determine who are the key local stakeholders who can contribute to the assessment and planning process. These stakeholders will vary by community and will need to be assessed by each coalition. Ask yourself, which people or organizations have been successful in effecting change in our community? Which agencies or groups offer services unique to our community? Who are the leaders helping to shape the public agenda? Your coalition membership should also reflect the ethnic and religious diversity of your community.

