

FINDING OUR WAY

Living with Dying in America

Community Action Guide

Summer 2001

Supported by
The Robert Wood Johnson Foundation
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Finding Our Way: Living with Dying in America
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CONTENTS

About <i>Finding Our Way</i> _____	1
Synopsis of National Press Campaign _____	2
Recruit Your Newspaper _____	3
Hold a Community-Hospital Summit _____	4
Organize a Public Forum _____	5
Develop a Radio Campaign _____	8
Organize a Spirituality-in-Dying Event _____	11
Work with Bookstores and Libraries _____	13
Introduce Discussions into Schools _____	14

ABOUT FINDING OUR WAY

Finding Our Way: Living with Dying in America, a fifteen-week newspaper series, begins September 10th and continues through December 17th. The series is being distributed throughout the country *at no cost to any newspaper* by Knight Ridder/Tribune Information Services. The *Finding Our Way* national public education initiative is focused on bringing practical information to the American public regarding end of life and its surrounding issues.

Each article in the newspaper series explores a subject that faces seriously ill Americans, their caregivers, families, and communities. The newspaper series is written by experts in the field of medicine, sociology, theology or culture and explores issues that face seriously ill Americans, their caregivers, families, and communities. The series offers compelling personal stories and up-to-the-minute pro-active information and resources so that individuals, families and communities can find the help they need.

Hundreds of newspapers throughout the United States are expected to carry the series; national television and radio shows will discuss the issues covered in the articles, and there will be promotional tie-ins to National Hospice Month and National Family Caregivers Month in November.

The *Finding Our Way* series offers opportunities for community groups to partner with their local newspapers, sponsor community-hospital summits, organize radio campaigns, host public forums or creatively develop other ways to engage their communities.

In September 2002, *Finding Our Way: Living with Dying in America* will offer a web-based, noncredit course on the issues presented in the newspaper series. A study guide, as well as additional community activities will be organized. The overall effort is designed to provide practical information and user-friendly resources on end-of-life for individuals and organizations. We hope that it will also create a demand for change among American consumers. A critical element to the success of the effort is the cumulative energy being generated across the country by community and state end-of-life coalitions.

A number of national organizations are participating in the campaign to promote *Finding Our Way: Living with Dying in America* in communities around the country. Partnership for Caring, *Last Acts*®, The Center for Advanced Illness Coordinated Care/VA HealthCare Network, Upstate New York at Albany and the Center for Death Education and Bioethics at the University of Wisconsin provide leadership for the effort. The Robert Wood Johnson Foundation, FanFox and Leslie R. Samuels Foundation and Charitable Leadership Foundation provide funding.

Without discussion and preparation for the end of our lives, we run the risk of denying ourselves dignity and comfort. America is ready to talk.

*Schedules may vary in individual newspapers.

SYNOPSIS OF NATIONAL PRESS CAMPAIGN

The *Finding Our Way* outreach effort will be supported by three major news releases announcing the news of the series. These news releases will highlight the series, the local and national resources and how communities all over the country are contributing their own efforts to support this initiative. The news releases will:

- Give an overview of the newspaper series and talk generally about community activities
- Review what has already been covered in *Finding Our Way* articles and announce what's coming up

You can download each of three national news releases at www.findingourway.net on the following dates:

- August 15—First news release will be available
- September 12—Second news release will be available
- October 10—Third news release will be available

HOW TO USE THE COMMUNITY ACTION GUIDE

This guide provides specific action steps that community coalitions, healthcare organizations and individuals can engage in to improve end-of-life care locally. The guide can be used in conjunction with the Fall 2001 release of *Finding Our Way: Living with Dying in America*. The suggested activities are in addition to the many local and national efforts already under way in the movement to improve end-of-life care.

If you have any questions, or need further information, please contact:

Catherine Smith
Director of Outreach
Barksdale Ballard & Company
1951 Kidwell Drive #205
Vienna, VA 22182
Bus: (703) 827-8771
Fax: (703) 827-0783
csmith@bballard.com

Garey Eakes
Community Liaison Coordinator
Partnership for Caring
1620 Eye Street NW, Suite 202
Washington, DC 20005
Bus: (202) 296-8071
Fax: (202) 296-8352
Eakes@partnershipforcaring.org

Sherri Roff
Project Coordinator
The Center for Advanced Illness
Coordinated Care
VA Healthcare Upstate NY
113 Holland Avenue (111T)
Albany, NY 12208
Bus: (518) 634-7203
Fax: (518) 626-6094
Roffsl@aol.com



Recruit Your Newspaper

Goal To encourage local newspaper to run the *Finding Our Way* newspaper series.

Suggested Timing Start now and continue throughout the series

Suggested Action Steps Your local newspaper can obtain this series free of charge from Knight Ridder/Tribune Information Services in two formats: text and paginated. They can run the articles as part of their regular news section or as a separate supplement. Your community coalition can strengthen the impact of the series with local stories and resources.

- Meet with your newspaper's managing editor to encourage the newspaper to run the series. A small, diverse delegation from your coalition might be most persuasive
- Meet with your newspaper's editorial board to encourage supportive editorials throughout the series
- Offer to help develop directories of *local resources* on issues covered by the series. Your newspaper can print these as "sidebars" along with the national resources that will appear as part of the series
- Provide ideas to your newspaper for local stories and people—including patients and families—to whom reporters can talk on specific topics, for example, spirituality, grief, or hospice.
- Offer to help reporters develop their own stories
- Offer to collaborate with the newspaper in hosting one or two high-profile community events (e.g., a Community-Hospital Summit, Public Forum)
- Meet separately with the newspaper's advertising department to suggest potential advertisers related to specific topics covered by the series. This should be done after your newspaper has expressed interest in carrying the series.
- If your newspaper has a relationship with a particular local radio or television station, talk to the news directors there about developing related coverage
- Talk with the outreach directors of your local public broadcasters about coordinated coverage. Remind them of the success of *On Our Own Terms* last fall and invite them to participate in the outreach campaign for *Finding Our Way: Living with Dying in America*.

Instructions for Newspapers

- The articles will move to KRT (Knight Ridder/Tribune) subscribers via AP DataFeature
- The articles, the accompanying photos, the series log, author photos and short bios of each writer will be available to any newspaper at no cost on KRT Direct at www.krtdirect.com/dying after August 6th.
- KRT will produce a set of paginated pages for this series. The pages will begin posting after August 30th and are also free to any newspaper. For questions about the paginated pages, contact KRT OnePages at (202) 383-6151 or krt-onepages@krtinfo.com



Hold a Community-Hospital Summit

Goal Sponsor a Community-Hospital Summit to discuss how to get a palliative care program and an effective pain management focus in your local hospital. It is likely to have a more positive impact if this meeting is organized as a constructive, rather than a confrontational, discussion.

Suggested Timing During the Week of 10/1 (release of Palliative Care article)

Title Finding Our Way: How to Manage Pain and Symptoms Near the End-of-Life

Invite For the panel, invite well-spoken representatives from the hospital, hospice and local policy makers, and possibly a law enforcement representative. For the audience (if not on the panel), be sure to include the Chief of Medicine, Chief of Nursing, Chief of Anesthesiology, Chief of Surgery, Hospital Director, Hospital Board of Directors, local palliative care experts, local foundation leaders, local policy makers, law enforcement (if law enforcement is involved in pain medication issues in your community), local radio and TV shows, and the public.

Discussion Facilitators First, find a good facilitator! Next, look for experience. Choose a well-respected and well-spoken physician with palliative care experience or community leader in hospice palliative care. The same is true for other panel members. Often, a local radio or TV show host can capably facilitate discussion.

Set up A panel discussion with rows of chairs available for the audience; lectern for moderator with microphone; several microphones at the head table; standing microphones in each of the aisles; print-outs of *Finding Our Way* articles that have run so far; print multiple copies of the Palliative Care article and place copies on each chair or hand out to each attendee. Put an easel-backed *Finding Our Way* poster next to the lectern. These will be available after August 15, by e-mailing your request to findingourway123@aol.com.

Suggested Format Discussion should be focused on the current status of local palliative care and pain management services. The following is a general guideline only. Be sure to address issues that identify next steps to secure palliative care and pain management for your community.

Facilitator Talking Points

- The recent NCI report and the SUPPORT study illustrated that a significant number of Americans, nearly half, die in significant pain
- The medical community is taking steps to implement educational programs to integrate palliative care into U.S. health care
- There is a national effort under way to improve pain management and palliative care and create consumer tools for improving care near the end-of-life

- Those of us who will face advanced illness—either with our loved ones or ourselves—have unanswered questions about what kind of care to expect; we don't know to whom to talk, we hardly know the questions to ask
- Introduce hospital and community representatives (who should be prepared to give brief summaries of their work—no more than 5 minutes each—to help stimulate questions from the audience).

Open the floor to questions. You might want to encourage the audience to ask the panelists:

- What is palliative care and where is it available in our area?
- What are your concerns about pain management?
- What is oxycontin and is there an oxycontin “issue” in our community?
- How can I get my doctor to answer my questions that include . . . ?
- How is our hospital currently addressing pain management near the end-of-life?
- What steps can be taken to improve how pain is managed in our local hospital?
- What are the next steps for getting pain management and palliative care services in our community?

If the discussion is slow to begin, the facilitator should be prepared to open with a real life circumstance, preferably one he or she knows personally, as an example that raises questions and topics for discussion.

Related Media Activities

- Write a news release announcing the public meeting(s) for your local newspapers and broadcasters
- Write a public service announcement with the time and place of the public meeting(s) for your local radio stations
- Contact your local TV and radio shows about interviews with the moderator and other facilitators, either announcing the public meeting or summarizing what happened afterward.



Organize a Public Forum

Goal To organize a local Public Forum to improve end-of-life care in your community.

Suggested Timing October or November

Title *Finding Our Way: Living with Dying in _____* (Cleveland, Tucson, Atlanta, etc.). It's time to confront the issues of pain, loss of dignity, and a sense of helplessness near the end-of life. Let's discuss needs and plan resources in order to help our citizens.

Invite For the panel, invite a prominent community physician, palliative and hospice care community leaders, a social worker, a member of the clergy (non-denominational, or a different faith for each meeting), and your Congressman or another local legislator. For the audience, invite local legislators, representatives from the Area Office on Aging and/or Human Services, elder law attorneys, business leaders, other community leaders, hospice representatives, physicians, social workers, local foundations, reporters from newspapers, radio and TV shows and the public.

Discussion Facilitator First, find a good facilitator! Next, look for experience. A well-respected and well-spoken physician with palliative care experience or community leader in hospice palliative care is a good choice. The same is true for other panel members. Often, a local radio or TV show host can capably facilitate discussion.

Set Up Panel members seated in the front of the room and rows of chairs available for the audience; lectern for moderator with microphone; several microphones at the head table; standing microphones in each of the aisles; print-outs of *Finding Our Way* articles that have run so far; print multiple copies of the Palliative Care article and place copies on each chair or hand out to each attendee. Put an easel-backed *Finding Our Way* poster next to the lectern. These will be available after August 15, by e-mailing your request to findinourway123@aol.com.

Suggested Format Discussion should be tailored to the needs and questions of your community. The following is a general guideline only. Be sure to address issues that require local action.

Facilitator Talking Points

- When facing advanced illness, far too many of us encounter unrelenting pain; too many of us suffer the indignity of restraints in hospital or nursing home beds; we have unanswered questions about what is happening to our bodies; we don't know to whom to talk, we hardly know the questions to ask
- Introduce palliative care practitioners, social worker, clergy (each should be prepared to give a brief—no more than 5 minutes—talk to help stimulate questions from the audience)

- We are here to help begin the conversation
- Without talking, without planning, we will not have a peaceful death; we will not have a “good ending” to our lives
- What specific action steps can we take in our community to improve end-of-life care?

Open the floor to questions. Please tell us your story and let’s talk about it. You might encourage the audience to ask the panelists about:

- When is the right time to start talking about end-of-life issues?
- What local and statewide legislative agendas can be developed?
- What is palliative care and where can I get it here?
- How can I be sure my concerns about pain management are addressed?
- How I can get the doctor to answer my questions such as . . . ?
- What should/can I tell young children about dying?
- How can we handle suicide, car accidents that result in death, other violent death in our community?
- How can I bring up the subject with my family?

If the discussion is slow to begin, one of the facilitators can open with the story of a real life circumstance, preferably one they know personally, and use it as an example that raises questions and topics for discussion.

Possible action steps include:

- Ask your local hospitals about their pain management practices—are they committed to helping their dying patients be pain-free?
- Make a list of the hospitals in your area that offer palliative care services. What does each include?
- How can they be improved?
- Find out who is—or could be—organizing training programs for family caregivers. How would such a program be funded? Promoted?
- Create “support” groups to help people learn to discuss the issues with their families.

Related Media Activities

- Write a news release announcing the public meeting(s) for your local newspapers and broadcasters
- Write a public service announcement with the time and place of the public meeting(s) for your local radio stations
- Contact your local TV and radio shows about interviews with the moderator and other facilitators, either announcing the public meeting or summarizing what happened afterward.



Develop a Radio Campaign

Goal For community groups to schedule local radio interviews that tie in with the *Finding Our Way* newspaper series themes.

Suggested Timing and Steps Early August

Suggested Action Steps Locate and designate three local experts, each of whom is:

- comfortable doing radio interviews
 - knowledgeable about local EOL resources
 - credentialed and articulate on the topics specified below
 - available for radio interview in the month specified below
1. For the first radio interview, recruit a palliative care doctor, social worker, hospice representative, or other qualified person who is comfortable talking about end-of-life issues and can help lead conversations about the end of life. Discussion points might include how to talk to doctors, how to begin planning, and how to make choices. The expert should be able to address physical, emotional, and spiritual concerns. *This expert needs to be available for radio interviews during the month of September.*
 2. For the second radio interview, recruit a doctor whose expertise is in the area of pain management and is able to discuss cutting-edge pain treatments as well as answer questions from people who call in to the radio show. *This expert needs to be available for radio interviews during the month of October.*
 3. For the third radio interview, recruit one or two people who can talk on radio about the emotional and spiritual issues that arise near the end of life. Consider having a clergy-person and/or a social worker who can offer inspirational stories of people “finding their way” near the end of life, who can answer questions and guide callers with questions.

Diversity is particularly important for this topic: be sure your expert(s) can talk about the ways people from various cultures and heritages deal with emotional and spiritual issues near the end of life. *These experts need to be available for radio interviews during the month of November.*

On August 15, you will be able to download at www.findingourway.net the first of the three radio “pitch” materials that tie in with the topics outlined above. The radio pitch materials that you’ll use to obtain September interviews will include:

- A two-page news release that announces the *Finding Our Way* national campaign
- A one-page “Radio Interview Suggestion” release suggesting a radio interview dealing with the topic, *How to Talk about the End of Life*. There will be suggested points of discussion, including how to talk to doctors, how to talk to family members, how to talk to the person who is dying, how to make choices, etc.
- A one-page “Radio Interview Request Form.” The first half of this sheet will have one area for you to fill in:

1. a space for you to write a brief bio about your local expert on holding conversations about the end of life
2. a space for you to fill in your name or the name of the local contact person, i.e., the person who will work with the radio show and the expert to arrange a date and time for the interview(s).

The second half of the Radio Interview Request Form will be a note to the radio shows from Diane Glynn Publicity. The note will tell the shows that they have the option of also interviewing a national expert *during their interview with your local expert. If the radio show chooses this option*, the following will occur:

1. The radio show will work with your local community contact person to confirm a date and time for an interview with your local expert. The local expert will most likely go to the radio station to do the interview. In some cases, the radio show and the local expert may prefer to do the interview by telephone.
2. The radio show will then work with Diane Glynn Publicity in New York City to arrange an interview with a national expert on the same topic. The radio show will telephone the national expert at some point during the interview with the local expert, and the radio show host, the local expert, and the national expert will all talk about what is happening both locally and nationally.

Here's how to use these radio pitch materials:

1. Fill in information about the local expert in the space provided.
2. Make copies of all three pieces—the news release, the radio pitch, and the request form for each potential station.
3. Collate and paperclip them in this order:
On top: the radio pitch
In the middle: the news release
Last: the request form.
4. Mail or hand-deliver them to radio shows: morning drive shows, public radio, library radio shows, general talk shows.
5. Call the shows 5 days after you mailed the materials or 3 days after you dropped off the materials, and ask if the shows are interested in interviewing the local expert. If you leave voice mail messages, we suggest calling every other day. If you do not get a call back, leave no more than 3–4 messages.
6. When the show is ready to schedule an interview, check with the show on whether the interview will be in the studio (verify the date, time and exact location) or by telephone. Coordinate with the station and your local expert as necessary.
7. Ask the show if it is interested in the *option* of also interviewing a national expert by telephone during the interview with the local expert. If yes, remind the show to contact Diane Glynn Publicity. (If the show has lost the Radio Interview Request Form, fax them a copy. The show must contact Diane Glynn Publicity to get a *Finding Our Way* national expert.)
8. Try to schedule these interviews for the month of September; if a show wants to do the interview in October, that's fine, too, but we'll have a new pitch and new press materials coming to them for October and November as well.

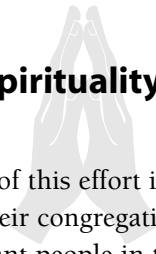
On September 12, you will be able to download the second set of radio pitch materials from www.findingourway.net. The topic for discussion will be *How to Manage Pain and Symptoms Near the End of Life*.

Follow the same procedures as outlined above; try to schedule the interviews for the month of October.

On October 10, you will be able to download the third set of radio pitch materials from www.findingourway.net. The topic for discussion will be *How to Find Positive Opportunities Near the End-of-Life* (this is the psychosocial and spirituality-themed topic). Try to schedule the interviews for November and early December.

Contact Info

Diane Glynn Publicity & Public Relations, Inc.
274 Madison Avenue, Suite 1103
New York, NY 10016
Bus: (212) 689-0002
Fax: (212) 689-4540
E-mail: dglynnpublicity@aol.com



Organize a Spirituality-in-Dying Event

Goal The focus of this effort is to encourage the clergy to hold a special event at which they encourage their congregations to explore spiritual issues near the end of life and honor the important people in their lives who have died.

Suggested Timing During the Week of 10/22—it could be either a *special* event or an *emphasis at services* to coincide with the release of the Spirituality and Faith article. Although the Spirituality-in-Dying Event does not need to be done on the same date in all congregations, the greater the participation on the same day, the more newsworthy the event.

Title *Finding Our Way: Spiritual Growth Near The End of Life*

Key Participants Local religious leaders, hospice and community members working with faith congregations

Suggested Action Steps Have religious leaders, select a date for a Spirituality-in-Dying event or sermon and announce it to their congregation. Offer to help leaders of faith communities organize and promote the event.

Gather information from your hospice and other appropriate community members and provide it to local faith organizations as inserts for bulletins. Offer suggested talking points for an event or sermon. Have this information available four weeks before Spirituality-in-Dying Event.

Materials You Need

- Draft a letter to send to the leaders of the faith community and invite them to attend a planning meeting for a Spirituality-in-Dying Event. At this meeting, work with them to select the date and time for the event.
- An overview of the Spirituality-in-Dying Event or sermon and include suggested talking points that can be integrated into a discussion and worship service.
- The *Finding Our Way: Living with Dying in America* article that addresses Spirituality and Faith, as well as other local materials dealing with end-of-life issues, can be offered to faith communities at any time.
- Prepare a Conversation Starter (based more-or-less loosely on the suggestions below) that faith leaders can use or give to their members.

Conversation Starter Topics

- What do you want your personal legacy to be?
- If you had one month left to your life, what kinds of things would you do?
- How do you find the spiritual support that you need?
- What was the most spiritual moment in your life?
- Do you have any relationships that need attention, care and/or reconciliation?

- How can you support your loved ones after loss?
- What do you think your loved ones will need to be able to come to terms with your death and their grief?
- What are the three most important contributions you have made to your world?
- How do you find meaning in loss?
- What kind of memories are you making with loved ones?
- How do you react during the holidays to the prior death of loved ones?
- How do you honor a life in death?
- How would you describe a “peaceful” death?
- Do you believe that pain is a natural and acceptable part of dying?
- How can dying be a spiritual act?
- Is your death the end of your spirituality?

Related Media Activities

Contact the religion writers for your local newspapers as well as hosts of any television or radio talk shows who might be interested in spirituality and let them know that this event is happening. Tell them that it’s in conjunction with *Finding Our Way: Living with Dying* in America and offer to provide them with the names of the clergy whose congregations are participating.



Work with Bookstores and Libraries

Goal To get local bookstores and libraries to establish topic-specific areas on end-of-life issues and create a quiet, comfortable space for reading and contemplation.

Suggested Timing Start now and work throughout the fall

Suggested Action Steps Contact your local Borders, Barnes & Noble, independent bookstores, and public libraries and ask for designated space throughout the fall, to coincide with the *Finding Our Way* newspaper campaign. Give them the schedule of topics for the series. Explain that since there are new topics every week, there are a wide variety of relevant books to highlight.

What the Bookstores or Libraries Can Do

- Highlight books and information on a broad range of end-of-life topics ranging from talking to parents, help for caregivers, books on bereavement, and books for children.
- Set aside an area for reading and contemplation with copies of topic-appropriate books and the *Finding Our Way* newspaper articles; these might be “housed” in a 3-ring binder. You may want to provide stores with brochures on local end-of-life services from them to have available. Prominently display the *Finding Our Way* easel-back poster (request it by e-mailing: findingourway123@aol.com).
- Create a “book club” discussion group of the *Finding Our Way* articles and related books.

Related Media Activities

Write a news release announcing the participation of the local stores and libraries in the *Finding Our Way* campaign. Point out that the stores and libraries are doing this to make it easier for local residents to access helpful information. Include the dates that they will be participating and send the release to the community newspapers and the news desks at your local radio and TV stations for use as news or public service announcements.



Introduce Discussions into Schools

Goal To introduce end-of-life issues to school age children through a variety of media.

Suggested Timing July, August and September

Suggested Action Steps Contact schools (principals and teachers) about taking advantage of the *Finding Our Way* newspaper series to help young people deal with end-of-life issues.

What Junior High (or Middle Schools) and High Schools Can Do Invite a palliative care physician, funeral director or hospice social worker who deals with end-of-life issues to speak to the class and answer questions. Topics they might cover include:

- How to talk to their parents about a grandparent's or other loved one's advanced illness and coming death
- Diversity in funeral rites within the United States and throughout the world
- The importance of grieving and communicating grief
- The impact of suicide, car accidents that result in death, or other violent death in the community
- What to do and say when a friend has lost a parent or grandparent
- How to be a good friend to someone who has lost a loved one
- What to expect when visiting someone who is seriously ill
- How to help younger siblings understand what's happening
- Conversations near the end of life—what young people might do to build and share memories with someone who is dying
- Why do we die

Point teachers to the *Finding Our Way* website at www.findingoutway.net to preview (not print) copies of the *Finding Our Way* newspaper articles and suggest that they use the articles as discussion topics. Ask your local librarian to put together a list of age-appropriate books that students can find at the library if and when they want to “read more about it.”

What Elementary School Teachers or Counselors Can Do

- Use *The Fall of Freddie the Leaf* by Leo F. Buscaglia or *Good-bye, Mousie* by Robie Harris (to be published in September 2001) to open a discussion about dying, funeral rites, and grieving.
- Encourage the students to talk about a grandparent who doesn't remember them (due to Alzheimer's disease) or is sick in the hospital.
- Have student's draw/color/paint their experiences and feelings about a pet that has died.
- Ask them if they would want to be told if someone they love was dying.
- Ask them to write a poem about what it means to be dead.

