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# Assessing Community Needs and Capabilities: A Community Survey

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**“Organizing begins at home. . . . Ask the questions that are at the center of your own lives. Ask them yourselves. . . . Think together and you will find the wisdom to go forward. It’s not as complicated as it seems.”**

— *Cesar Chavez*, 1966

Exploring how your community cares for dying people and their families is an effective step toward determining where change is needed. Because the process reveals strengths and resources as well as gaps and weaknesses, a community survey of end-of-life care can help the steering committee prioritize tasks and focus its efforts. In addition, coalition progress can be measured against this initial review.

## Survey Methods and Cost

The coalition must determine both design and budget for a community survey. Complexity and cost run the gamut from simple, small-scale telephone surveys conducted by volunteers, to more elaborate questionnaires and medical-chart reviews performed by marketing professionals and healthcare providers. The coalition may decide to focus on a particular area of concern to the community rather than undertaking a full-scale survey.

Some valuable statistical information may be available free-of-charge from local health departments and/or state offices or agencies on aging. Local hospices and hospitals are also good sources of information. Members of your coalition may also be knowledgeable about services and resources in the community through their own involvement with end-of-life care.

## How to Use Survey Results

Results of the survey may be framed as a “report card” and used as a communication tool to inform citizens about the state of end-of-life care in their community. If you choose, the local newspaper might incorporate parts of this report card in a series showcasing strengths and highlighting shortfalls in end-

of-life care. Optimum timing would be to place this media coverage the week of the broadcast premiere.

In addition, resources uncovered by the survey can form the basis of a community resource directory of support services for the seriously ill and their families. (See “Action Idea: Local Resource Directory”). The survey also may be shared with legislators or other policymakers to demonstrate community needs associated with end-of-life care.

## Issues to Consider

We have provided a list of topics to consider when looking at end-of-life care in your community. This list can be adapted and reframed as survey questions. The information gathered from a survey can help you learn more about where and how care is currently provided and whether people in your community are informed about their options. Your coalition may decide to expand on these topics or narrow them down even further to address areas of special concern to your community. The National Outreach Coordinators are available to provide technical assistance in designing a survey. See the “Contacts” section for information on reaching the Coordinators.

## Resources

While there is no one, comprehensive instrument available to fully measure end-of-life care in the community, there are various individual instruments that can be used separately or jointly to gather data in specific areas. Here are some instruments and resources that can provide more information:

### *Missoula Demonstration Project: The Quality of Life's End, Community Survey*

A tool to study community members' knowledge, attitudes and experience regarding the end of life.

#### **Contact**

[www.missoulademonstration.org/research.htm](http://www.missoulademonstration.org/research.htm)  
406-728-1613

### *Missoula Demonstration Project: The Quality of Life's End, Faith Community Leader Survey*

A tool to study strengths and needs of faith community leaders in providing end-of-life spiritual care.

#### **Contact**

[www.missoulademonstration.org/research.htm](http://www.missoulademonstration.org/research.htm)  
406-728-1613

### *Missoula Demonstration Project: The Quality of Life's End, Network and Systems Analysis*

A tool to study community-wide end-of-life resources.

#### **Contact**

[www.missoulademonstration.org/research.htm](http://www.missoulademonstration.org/research.htm)  
406-728-1613

### *Toolkit of Instruments to Measure End of Life*

Brown University

A comprehensive, annotated bibliography of instruments to measure the quality of care received at the end of life, including instruments that incorporate the voices of the dying and their loved ones in measuring quality of care. Categories include: quality of life, advance care planning, pain/depression/ other symptom assessment, functional status, survival time and aggressiveness of care, continuity of care, spirituality, grief, caregiver and family experience, and patient/family satisfaction with quality of care.

#### **Contact**

Joan Teno, M.D.  
401-863-1560  
[www.chcr.brown.edu/pcoc/toolkit.htm](http://www.chcr.brown.edu/pcoc/toolkit.htm)

## Checklists

### *The Agitator's Guide: Twelve Steps to Get Your Community to Talk about Dying*

Americans for Better Care of the Dying (ABCD)

#### **Contact**

202-467-2222  
[www.abcd-caring.org](http://www.abcd-caring.org)

### *Danger Signs: Indications That Care of the Dying May Be Inadequate*

Alicia Super and Lawrence A. Plutko, Health Progress. 1996; 77 (2)(1996):50-54.

A checklist of insufficient care possibilities that are helpful to consider when determining indicators in the community.

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# Topics to Consider When Developing A Community Survey

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Information gathered from a local survey can provide a snapshot of end-of-life care in the community. Areas to consider include:

## Quality and Range of End-of-Life Care Currently Available in the Community

Where people in the community die

\_\_\_% hospital    \_\_\_% nursing home  
\_\_\_% home    \_\_\_% hospice    \_\_\_% elsewhere

### HOSPITALS

- Number of palliative care units/services/consults
- Number of patients served by palliative care units/services/consults
- Protocols and/or guidelines in place to support the delivery of quality palliative care (pain and symptom management and psychological, emotional, and spiritual support)
- Arrangements (formal or informal) between hospital and local hospice(s) for coordinating care of terminally ill patients
- Emergency-room protocols for seriously ill patients who have a Do Not Resuscitate (DNR) order in place
- Protocols for portable/transferable DNRs between healthcare facilities
- Coordination among hospitals, nursing homes, and home-health agencies regarding portable DNRs
- Local emergency medical service protocols to honor DNRs and Do Not Hospitalize (DNH) orders

### NURSING HOME

- Formal or informal relationships between nursing homes and hospices or other palliative care providers
- Procedures for regularly assessing and treating pain and other symptoms in nursing homes
- Provision of pastoral care services for residents and families
- Support services for families to help them cope with loss and bereavement

### HOSPICE

- Number of hospices in the community
- Community awareness of hospice
- Referral rate for hospice care
- Average length of stay for patients in hospice care
- Extended services that allow palliative-care services to be provided prior to a six-month diagnosis

### HEALTHCARE PROFESSIONALS

- Number of physicians in community certified in hospice/palliative care (eg, pain and physical symptom management, effective communication, identifying and treating depression and anxiety, spiritual history taking, etc.)
- Number of physicians in community trained through the American Medical Association EPEC program
- Number of nurses in community certified in hospice/palliative care (pain and physical symptom management, effective communication, identifying depression and anxiety, spiritual-history taking, etc.)

## **FAITH COMMUNITY**

- Visitation services for homebound and nursing home residents
- Number of parish nurses in the community
- Bereavement-support services for congregants and other people in the community coping with a recent loss

## **VOLUNTEER SERVICES**

- Range of community volunteer services for the terminally ill and their families (respite care, household assistance, etc.)
- Source of volunteer services
  - religious groups
  - service/civic clubs
  - hospice- and hospital-affiliated groups
  - community service organizations
  - individual volunteers
  - other
- Availability of volunteer services to public

## **FAMILY SUPPORT**

- Availability of family support services in the community
- Support groups for caregivers
- Support services provided by local employers to employees who are caregivers or in bereavement

## **Preparedness of Citizens to Make Informed End-of-Life Decisions**

Of the people in the community surveyed:

- Number of people acknowledging having at least a periodic conversation with a loved one or friend regarding end-of-life treatment preferences
- Number of people entering the hospital or nursing home who have completed an advance directive or designated a healthcare proxy
- Educational programs through churches and schools that deal with end-of-life issues
- Recent coverage of end-of-life issues by local media
- Sources of information on:
  - pain management
  - hospice
  - support groups for bereavement
  - support groups for caregivers
  - advance directives

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# Creating Conversations That Matter

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**Conversation comes from the Latin *conversatio*, which means “state or act of living with others: an abiding...”**

— *Webster’s New International Dictionary*, 1926

ON OUR OWN TERMS creates an opportunity for stimulating conversations rich with meaning. By entering into creative and honest exchanges with others, we can embrace the reality of death more fully and experience how living with dying can inform our lives. These conversations can take place in small groups, such as support, bereavement, or study circles, or larger community-wide discussions.

Meaningful conversation is more than getting the right people together in a room and talking. The atmosphere of the place, the attitudes of participants, and the process that creates shared meaning are critical components of conversations that matter.

The following guidelines are for organizers and facilitators. For organizers, understanding these practices will help you determine the size, make-up, focus, and intent of the gatherings. For facilitators, these guidelines will help you envision how to create a safe environment for talking about the difficult subject of dying. Practices such as “speaking from the heart” will naturally begin to emerge when participants feel safe and supported. While the guidelines are particularly suited for small groups, they can be adapted for larger groups.

## **General Guidelines for Conversations: Practices That Cultivate Meaning and Understanding**

■ **Creating a Circle:** When seated in a circle, people see and greet one another, get comfortable and settle in. The circle supports the equality of all members. To provide a center focus, you may want to place a low table with a single flower, small bouquet or candle at the center of the circle. For a large group, you may want to have flowers or a candle at the front of the room to give a focus for the group.

■ **Incorporating Ritual:** Ritual helps a group coalesce and calls attention to its purpose for being together. You can honor a gathering as a special time in a special space by performing simple rituals that mark the beginning and end. Through ritual, we can create a sacred space in which to engage each other more openly and with greater vulnerability. The power of a simple ritual comes not only from the care and attention you give to the moment and the details but also by its repetition. Take care that the rituals you choose do not conflict with participants’ religious beliefs or customs.

Possible opening rituals include: Lighting a candle; taking a moment or two to breathe deeply; observing a few moments of silence; listening to a selection of music; or beginning with a song, a prayer, or a reading from a source of inspiration.

Closing rituals might include: Extinguishing the candle and sharing a moment of silence; offering thanks for the time spent together in a single word or a brief phrase spoken by some or all of the participants; or sharing a song or an inspirational reading or even a dance.

■ **Beginning the Conversation:** A brief story, a reading, or a poem can help open the conversation. You might begin with a question designed to help participants to get to know each other better, such as: What is your interest in being here? What do you want to get out of our time together? What in us gets in the way of talking about death? Or you might begin by asking each person to bring a treasured object to share with the group that connects him or her to the topic.

■ **Ensuring Confidentiality:** Confidentiality allows people to take risks, to experiment with ideas, and to change their minds as their understanding grows. At the first meeting of an ongoing

group, or at the beginning of a one-time conversation, talk about the importance of keeping what is shared within the group.

- **Listening in the Circle:** People will differ in their degree of openness, and each person must feel free to participate at his or her own comfort level. Some participants simply want to listen. To really meet others in the circle, we must listen with openness to what they say and who they are. Listening openly in this way is simply receiving another person with full attention and presence.

It is equally important to listen to ourselves. A range of emotions may emerge—fear, anger, grief, confusion, joy, empathy, and compassion—all of which offer insights if we listen and honor them.

- **Speaking from the Heart:** Sharing our inner feelings invites others to listen more deeply and enriches our conversation and connection with one another. Speaking from the heart, we share our personal stories and reveal who we are and not just what we know. When we speak with reverence and true connection with our experience, such as when we remember the death of a loved one, it is as if we are having the experience at that very moment, and in many ways we are. Sharing ourselves in this way helps others remember similar experiences in their own lives and feel the connection between our joy or suffering and their own.
- **Practicing Discernment, Rather than Judgment:** Discernment is the ability to listen, sort, and speak without having to be “right” or in total agreement with another. Engage in friendly disagreements when appropriate, and strive to fully understand the positions of those who disagree with you. Listening respectfully, with care and without judgment, opens us up to the possibility of learning from others and being changed by what we hear. Make an effort to build on what has been said, and be mindful of how often you are speaking. When you want to jump in and make a statement, ask yourself if what you have to say contributes to the conversation. As facilitator, you may want to share these ideas and others with the group to create agreement and comfort with the group’s boundaries and procedures.

- **Making Room for Silence:** When the conversation moves too quickly, with many people queued up to speak, it may be wise to take a moment or two of silence. Periods of silence allow us to develop more clarity, objectivity, and discernment—the qualities inherent in wisdom. Anyone in the circle may call for silence, time out, or a ritual to reestablish the focus of the group. You may want to ring a small bell or chime to signal a time for silence, so the group can reflect upon what has been said. The bell also can be used to help keep time, move the conversation along, and ensure that everyone has time to be heard.

- **Caring for the Body:** During long meetings, participants might enjoy a break for movement, stretching, yoga, etc.

## Guidelines for the Organizer of the Groups

- Groups can be structured in many ways. You may create a group composed of nursing personnel or of family members who have had a loved one die. A mixed group of family, clergy, professional caregivers and others working or living with the dying can create a rich conversation. A manageable group size is between eight to twelve participants. With a group of 20 or more, it is helpful to break into small groups for more intimate conversation and come back together to share insights and experiences.
- Try to assemble a diverse group. Most of us tend to talk to people like ourselves, but diversity in age, race, culture, religion, etc., adds depth and texture to the conversation.
- Select a person with good group-process skills to serve as facilitator. Ideally, the facilitator will be comfortable with his or her own issues concerning death, or, at a minimum, will be aware of personal areas of discomfort. Your local hospice, hospital, or bereavement center are possible resources for facilitators in your area.
- Decide when, how often, and where you will meet. Select a site that is reasonably quiet and free of distractions. You may want to distribute a copy of the ON OUR OWN TERMS Discussion Guide to participants before your first meeting.

## Guidelines for the Facilitator

- The facilitator should have a clear purpose for the meeting yet remain open and flexible to the needs and direction of the group. Thinking through the questions ahead of time will help to suspend judgment during the conversation.
- The facilitator encourages all members to participate and also may contribute to the conversation.
- The subject of death and dying may trigger some intense feelings. Participants uncomfortable with emotion may attempt to divert the attention of the group. The facilitator can refocus participants by gently returning to the emotions. If distractions occur repeatedly, it may be best to acknowledge that the group tends to pull away from intense feelings and to confirm how painful it is to deal with such emotion. This approach keeps the group focused on the most important issues while honoring the courage required to face these issues

## Stimulating Conversations

The following questions and others you may bring will help open the conversation. The questions you choose depend upon the specific needs of your group. Because the topic is not an easy one, you might begin with the following questions: What is your interest in being here? What do you want to get out of our time together? What in us gets in the way of talking about death?

- **Exploring Life in the Context of Death** — What would help you live well at the end of your life? What do you want to accomplish before you die? How will you prepare for your own death? What would your eulogy say about your life? What aspects of you do you hope to remain alive among those you leave behind? How might considering these issues help you live more fully? What would help you cope with facing your own death or the death of a loved one? What would be your community of support? Do you have any relationships that need attention, care and/or reconciliation?

- **Beliefs about Death**—Drawing from your religious or spiritual background, what are your images of death? What happens to the body after death? What remains of us after we die?
- **Personal or Family Preparedness for Death**—Have you considered creating a will or power of attorney? Have you made plans for disposition of your body, memorial service, or for other aspects involved in preparing for death? Is it difficult for you to make plans like these? Why? What would it be like to discuss your wishes with family, friends, and healthcare providers?
- **How to Be with Someone Who Is Dying** — What can I do for a loved one who is dying to show that I care? How can I help someone explore how he or she wants to live? How can I prepare to be fully present with a dying person? How do I take care of myself? What have I experienced with someone as they were dying? What changed in my life?
- **Resources for Dying Persons and Their Families** — Where is help available in our community? What sources of help fit specific needs? What do you consider a spiritual resource? What are the policies in our city, state, or country that affect resources available to us and the actions we may take? If you have been through the death of a loved one, did you experience needing help? What resources were available to you?
- **Advanced Directives** — Advanced directives are often quite specific and technical yet may not give direction for the many nuances of a person's dying. How do I know what a dying person's wishes are, and how do I help to carry them out? What are the values and beliefs behind advanced directives or other instructions? Do you know what quality of life means to you, your parent/child/spouse? How would you communicate this concept to your family, your doctor?
- **Wisdom of the Heart** — What have you learned about yourself in facing your own death or the death of another? How has this experience affected your life and your relationships with others? What gives your life meaning?

## REFERENCES

Baldwin, Christina. *Calling the Circle*. New York: Bantam Books, 1998.

Jones, Bill T. *STILL/HERE: An Experiential Learning Guide*. Institute of Noetic Sciences, 1997. Contact: 415-331-5630

Ellinor, Linda and Glenna Gerard. *Dialogue: Creating and Sustaining Collaborative Partnerships at Work*. New York: John Wiley and Sons, Inc., 1998.

Wisdom Circles, 3756 Grand Avenue, Suite 405, Oakland, CA 94610, 510-272-9540.

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# Action Ideas

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The following are ideas for activities and events that you can implement in your community prior to the premiere of the series and as follow-up activities after it airs. Activities have been designed to meet the overall goals of the campaign — to increase the viewership for ON OUR OWN TERMS; to promote personal introspection and family discussions; to improve communications among healthcare providers, dying patients, and their families; to foster community dialogue; and to encourage community-wide engagement in a campaign to improve end-of-life care. Activities in this guide are geared to the following groups:

- Healthcare providers
- Policymakers
- Journalists
- Clergy and members of faith-based communities
- Volunteers
- Community leaders
- Librarians, school personnel

In short, we want to encompass the entire community.

How you shape your local outreach will, of course, depend on your coalition's priorities and the resources, needs, and size of your community. Use the preceding Community Assessment to help prioritize the needs of your region. Think creatively about ways to bring various groups together in the outreach events. Also consider partnering with other groups engaged in this issue. Suggest that medical centers, religious organizations, and other organizations already addressing end-of-life issues use ON OUR OWN TERMS to spotlight their efforts. Try to bring together representatives of the entire team that surrounds a dying person — the family, spiritual counselors, medical and mental-health professionals — and encourage them to work more closely with one another.

The National Outreach Coordinators welcome your ideas and suggestions. The bulletin board on the “Outreach” section of the Web site for ON OUR OWN TERMS will launch in April 2000 at [www.thirteen.org/onourown/terms](http://www.thirteen.org/onourown/terms) or [www.pbs.org/onourown/terms](http://www.pbs.org/onourown/terms). You can post your ideas and share resources with other community groups across the country taking part in this effort. Until then, subscribe to our e-mail list-service to become a part of the ongoing educational campaign. Send e-mail to [moyersoutreach@bballard.com](mailto:moyersoutreach@bballard.com).

We have compiled a list of detailed action ideas and additional outreach suggestions to spark your thinking. These ideas are not mandates or prescriptions. They are meant to inspire creative thought about what can be done in your community. All these can work best, of course, if everyone in your coalition — public television staff, community activists, clergy, healthcare professionals, etc. — work together. As suggested in the “Building Coalitions to Effect Change” section, you may wish to form a separate team or task force to accomplish different activities.

## Raising Visibility

Be sure to develop a promotion plan to attract publicity and attendance for your outreach projects. Contact Kelly & Salerno Communications for publicity materials that will inform the local media about the national context for your events. Kelly & Salerno will also be looking for opportunities to incorporate outreach activities into regional and national stories about ON OUR OWN TERMS and end-of-life issues that will appear at the time of the program premiere. See the “Contacts” section of this guide for information on reaching Kelly & Salerno.

## **Action Ideas**

- Local Resource Directory
- Screening Event at Community or State Level
- Town Meeting
- Community Action Campaign
- Small Group Discussions
- Working with Faith Communities
- Workplace Outreach
- Palliative-care Hotline for Physicians
- Supporting Bereavement Services in the Community
- Healthcare Providers Training
- Taking a Spiritual History
- More Outreach Suggestions

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# Local Resource Directory

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## Why

To provide a directory of organizations and individuals whose services support seriously ill patients and their families as well as those in bereavement.

One of the greatest challenges faced by seriously or terminally ill patients and their families is finding information on the services and care options available in the community. For example, volunteer services, which can provide assistance ranging from respite care to massage, are not always well publicized. Healthcare professionals also may find a resource directory useful as a referral source.

## Goals

- Identify and compile existing resources for seriously and terminally ill patients and their families in the community
- Distribute the guide to seriously or terminally ill patients and their families as well as to healthcare providers
- Share this information with the community at large
- Identify where the gaps and shortfalls are in providing services for dying patients and their families

## When

The resource guide can be introduced to the community when ON OUR OWN TERMS is broadcast. It can be offered at all outreach events and/or distributed by the public television station in conjunction with the broadcast.

## How to Compile a Local Resource Directory

- **Plan content.** Select categories for the directory. Think broadly and remember to include services for families, especially children. Use results from the community assessment to create a framework.

Check with the local health department for additional information. Determine the geographic area the directory will cover (e.g., metropolitan, county, region, or state). Consider including a glossary of terms.

- **Seek support for the project.** Determine costs associated with compiling and distributing the directory. If budget is an issue, use a photocopied, stapled format rather than a printed, bound format, or an electronic version that can be downloaded. Consider partnering with a group that will underwrite the effort, or put together a coalition of groups to support the project.
- **Gather and verify information.** Designate a person(s) to contact local providers (e.g., hospitals, hospices, nursing homes, cancer clinics, etc.) to ask about their resources and other services they may be aware of. Consider using an intern or student for this function. Speak to discharge planners, care managers, and others who assist patients after they are discharged from an institution. Check with the faith community about its support services, and ask for suggestions concerning services that are not included in the original directory plan. Verify the information on the organizations/ individuals that will be listed in the directory, so that entries are accurate and approved for inclusion.
- **Market the directory.** Develop a strategy for dissemination of the directory to patients, families and healthcare professionals. Develop a strategy for making information known to the community at large. Banks, medical centers, and religious institutions are viable distribution points. Also consider using Web links and listservs.

## Potential Directory Categories

- Hospice programs (including ancillary programs)
- Palliative-care programs (hospital-based, pain clinics)
- Home-health agencies

- Mental-health agencies
- Bereavement support (including programs for children)
- Caregiver and respite-support services
- Chaplaincy and spiritual support
- Senior and disabled services
- Volunteer services (e.g., linen, meals, companion services)
- Ethicists

- Care managers
- Advance-care planning services
- Visiting-nurse programs

### **Resources**

**(See “Resources for Further Learning and Training” for Details and Contacts)**

- *Colorado Resource Guide for End-of-Life Care*
- *The Final Months of Life: A Guide to Oregon Resources*

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# Screening Event at Community or State Level

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## Why

To give policymakers and community leaders an overview of the many faces of end-of-life care—from patients, caregivers, spiritual advisors, and healthcare professionals.

A screening of brief excerpts from ON OUR OWN TERMS may be followed by a presentation of information about end-of-life care and a Q&A.

## Goals

- Provide policymakers and community leaders with up-to-date information about the movement to improve end-of-life care, the importance of listening to the desires of patients and their families, and the need for greater continuity of care among everyone involved in the healthcare system
- Spotlight aspects of end-of-life care in the community that require change
- Focus community leaders' attention on barriers to good end-of-life care, such as pain management regulations and reimbursement questions
- Help policymakers and community leaders understand how to use the series, and provide them with information needed to respond to constituent concerns
- Help people understand what care at the end of life should be

## Who Should Attend

- Governors and state legislators
- County executives and commissioners
- Mayors and council members
- Civic leaders
- Health-department officials
- Staff from appropriate public agencies
- Hospital trustees

- Healthcare-system executives
- Prominent healthcare professionals
- Business leaders
- Insurance-company executives
- Educators
- Clergy

## When

Early to mid-September 2000

## Where

An “official” venue such as:

- State capitol
- City Hall
- Courthouse
- Civic center
- Government building
- Chamber of commerce office

## How to Organize a Screening Event

- Mobilize the end-of-life community coalition. Coalition members such as the local public television station outreach staff or Friends group, healthcare professionals, consumer and religious groups, local hospice, civic groups, state or county medical societies, and ON OUR OWN TERMS outreach associates such as the local chapter of the American Association for Retired Persons are among the kinds of coalition partners well positioned to contribute to this effort. (See the list of Outreach Associates.)
- Think creatively. For example, use a screening event to attract corporate leaders by convening a local or statewide group of employers, healthcare professionals, human-resources managers, and employee assistance professionals to explore how death and grief are handled in the workplace.

- Pay attention to details. Some of the organizational tasks involved in planning a screening event include determining the event format and reserving space, selecting a host and panel of local experts, and creating and mailing invitations. Plan on building a local email network or listserv via a sign-up sheet at the event, so you can follow up after the event.

## How to Format a Screening Event

- Establish some context for the event and give a brief description of ON OUR OWN TERMS.
- Screen excerpts from the program. (Highlight reels will be fed to public television stations several months prior to broadcast.)
- Consider following the screening with a presentation and Q&A about the current state of end-of-life care in the community — e.g., the percentage of people who use hospice services, the percentage of people who have established advance directives, the level of continuity of care among healthcare settings and among providers, and the availability of support programs for caregivers. The report card you create from your community assessment can be a useful tool. The screening event should not become a forum for advocating particular policies.
- Schedule an activity at the end of the program to propel attendees to take additional action after the event. Some possibilities are joining the local coalition, signing an advance directive, or obtaining a proclamation from the governor or mayor of “ON OUR (CITY OR STATE’S) TERMS” Day.

## Sample Agenda

- Greet participants as they arrive.
- Ask participants to sign in with name, address, phone and email address.
- Distribute handouts.
- Introduce program.
- Screen excerpts from ON OUR OWN TERMS.
- Presentation and optional Q&A.

- Make a motivational call to action to improve end-of-life care in the community.
- Say, “Thank you.”

## Handout Materials

- ON OUR OWN TERMS Discussion Guide (See “Discussion Guide Advance Request Form”)
- Local Resource Directory
- Executive summary of community survey (see “Assessing Community Needs and Capabilities: A Community Survey”)
- *Vision for Better Care at the End of Life* document
- *20 Improvements in End-of-Life Care — Changes Internists Could Do Next Week*

## Resources

### (See “Resources for Further Learning and Training” for Details and Contacts)

- *Death with Dignity and Caring in Nevada*
- *The End of Life: Exploring Death in America*. National Public Radio (NPR)
- *The Final Months of Life: A Guide to Oregon Resources*. Task Force to Improve Care of Terminally Ill Oregonians
- *Missoula Demonstration Project, The Quality of Life’s End, Community Survey*
- *A Vision for Better Care at the End of Life*
- *20 Improvements in End-of-Life Care — Changes Internists Could Do Next Week*
- *Last Acts*

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# Town Meeting

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## Why

To reflect upon and discuss how the community cares for dying people and their families and how they can establish a new vision for the end of life.

The town meeting is a public forum in which end-of-life coalition members gather with interested citizens to discuss the need for change in the way their community cares for dying people and their families.

Meeting participants can use results of the community assessment (See *Assessing Community Needs and Capabilities: A Community Survey*) to examine how services for the dying are currently delivered, to discuss how they can be improved, to set goals for specific improvements and to develop a structure for follow-up.

## Goal

Facilitate a solution-oriented community discussion concerning gaps in services for the dying and their families and how the community as a whole can address these issues.

## Who Should Attend

All interested citizens of the community, including :

- Senior citizens
- Citizens
- Elected officials
- Civic leaders
- Business leaders
- Educators
- Hospital trustees
- Healthcare-system executives
- Healthcare professionals
- Insurance providers
- Clergy
- Members of faith communities

- Social workers
- Employers
- Family caretakers
- Community colleges

## When

Within one month before or after broadcast of ON OUR OWN TERMS. The town meeting could be held in conjunction with a screening event.

## Where

- School auditorium
- Public library
- City Hall
- Civic center
- Government building
- Place of worship

## How to Organize a Town Meeting

- **Meet on “neutral” territory.** Hold the town meeting in a public space such as a library rather than in a particular healthcare setting.
- **Have experienced helpers on hand.** Select an experienced moderator who can keep things moving, and have a trained counselor present to deal with emotional situations that may arise.
- **Promote the event.** Market the event by issuing a news release and sending flyers to local organizations to attract participants with varied perspectives.
- **Push the boundaries.** Include speakers outside of healthcare. To enrich the discussion of living with death and dying, think about spirituality, racial and cultural diversity, even visual and performance art.

## How to Format a Town Meeting

- Start with a panel of three to five citizens who have had a variety of experiences with “living with dying” — whether as patients or as caregivers.
- Seed the audience with citizens, healthcare professionals, clergy, insurance providers, and employers who can offer their perspectives. It is important to have a trained counselor on site to deal with any particularly difficult situations.
- Use a moderator to pose important questions to the audience and to lead a discussion based on the community assessment and community resources.

## How to Handle Controversy

Conflict may erupt between participants with diverse opinions on topics such as pain management, physician-assisted suicide, or the use of life-sustaining medical technology. Although juxtaposing divergent positions can stimulate discussion, that discussion is ultimately irrelevant to the vast majority of people. Focus on issues that are of concern to everyone such as access to palliative care, adequate insurance reimbursement, overcoming the cultural fear of talking about planning for end-of-life, and simply facing the reality of death.

## Handout Materials

- ON OUR OWN TERMS Discussion Guide (See “Discussion Guide Advance Request Form”)
- Local Resource Directory
- Executive summary of community assessment (See “Assessing Community Needs and Capabilities: A Community Survey”)
- *A Vision for Better Care at the End of Life*

## Resources

### (See “Resources for Further Learning and Training for Details” and Contacts)

- The Good Death Initiative, Inc.
- *Baby Boomers Fear Talking to Parents About Death*. National Hospice Foundation Survey, 1999.
- The Study Circles Resource Center (See “Outreach Associates” list for contacts)
- *A Vision for Better Care at the End of Life*

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# Community Action Campaign

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## Why

Advance directives are documents that encourage people to think and talk about the care they want at the end of life. They can be a living will, healthcare proxy, or power of attorney for health care. Only 15% to 25% of Americans report having completed an advance directive. Even fewer patients have an advance directive in their medical record, a necessary first step in assuring that one's wishes for care are known, understood, and followed. Advance directives are most effective when used as a tool to promote discussion among patient, family, and physician.

## Goals

- Encourage people to express their end-of-life choices well before they become unable to do so. This will stimulate better communication among loved ones and may instill a greater sense of the meaning of life
- Engage people in dialogue concerning the care they want at the end of life
- Ensure that patients and their families know how to keep track of and use advance directives to convey their wishes for care at the end of life to healthcare professionals
- Increase the number of people in the community who complete advance directives
- Increase the number of people in the community who ask their physician to place their documents in their medical record and talk to their physicians and family members about their preferences

## Who Should Participate

All members of the community, especially:

- Outpatients
- Inpatients
- Caregivers
- Healthcare-system executives

- Healthcare professionals
- Emergency medical technicians
- Civic groups
- Clergy
- Members of faith communities
- Book groups and study circles
- Financial planners
- Legal community

## When

Fall 2000, before or after the premiere of ON OUR OWN TERMS

## Where

- Hospitals
- Medical centers and clinics
- Schools
- Public libraries
- Religious institutions
- Homes

## How to Organizing the Campaign

- **Collaborate.** Encourage local healthcare providers to partner in this educational effort.
- **Tap into existing resources.** Choose one of the nationally recognized advance-directive patient-education programs to distribute throughout the community. (See Resources below.)
- **Build a strong team.** Involve advance-directive educators and social workers at all healthcare organizations in the community. Work with local healthcare institutions to ensure that advance directives are documented in patient charts. Encourage physicians to discuss advance directives with their well patients. Also, engage groups

outside the healthcare community, for example civic or service organizations and libraries. Legal and financial planners may also be helpful in starting conversations.

- **Get on the same page.** Ask local healthcare systems to develop common policies and practices to maintain and use advance-directive documents. Encourage broad-based physician involvement. Check local protocols to see if systems are in place to ensure that advance directives “travel” with patients across care settings and are honored. If not, work with healthcare systems to institute proper protocols.

## Resources

### (See “Resources for Further Learning and Training” for Details and Contacts)

- *The Advance Directives Community Project*  
Midwest Bioethics Center
- *Choice in Dying* (CID)
- *Critical Conditions<sup>SM</sup> Critical Planning Guide* (designed for consumers)  
Georgia Health Decisions
- *Finding Your Way: A Guide for End-of-Life Medical Decisions*  
Sacramento Healthcare Decisions
- *Five Wishes (English and Spanish)*  
*Aging with Dignity*
- *POLST Program (Physician Orders for Life-Sustaining Treatment)* (Tool for Professionals)  
Center for Ethics in Health Care, Oregon Health Sciences University
- *Respecting Your Choices: An Advance Care Planning Program*  
Gundersen Lutheran Programs for Improving End-of-Life Care
- *A Good Death: Challenges, Choices and Care Options*

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# Small Group Discussions

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## Why

The end-of-life coalition can encourage the formation of small groups that will allow participants to share their visions of how life can be lived fully in the face of death. Participants talk about the care they want at the end of life and identify their needs to make choices about their own care. Another phase of the dialogue gives people an opportunity to tell their personal stories and explore life's deeper meaning as it is revealed by embracing death. These small group discussions can take place in community forums, at the kitchen table, at the workplace, in places of worship or a library.

They might include thoughts on:

- The importance of addressing the physical, emotional, and spiritual needs of the patient, families, and friends
- Perceptions of care
- Personal relationships with caregivers
- Where and how people wish to spend their final days
- How thinking about death affects our desires for our lives

During another phase of the dialogue, people might be encouraged to explore, recall, and tell their life stories, and to capture on paper the meaning of their lives.

## Goals

- Encourage participants to identify and discuss what they want at the end of life and how to live with the concept of dying in the foreseeable future
- Give participants an opportunity to reflect on especially meaningful experiences and to explore their feelings about their own mortality

## Who Should Participate

- Individuals interested in the topic

- Healthcare professionals
- Clergy
- Members of faith communities
- Study circles and book groups.
- Civic groups
- Educators
- Medical ethicists
- Senior centers

## When

Form conversation groups before ON OUR OWN TERMS airs. Have discussions once viewers have watched the series and reflected on it.

## Where

- Colleges/universities
- Hospitals
- Medical centers and clinics
- Hospices
- Places of worship
- Retreat centers
- Workplaces
- Public libraries
- Bookstores

## How to Organize a Conversation

- **Seek "buy in."** Invite sponsorship from as many of the following groups as possible: the state hospice association, the state medical society, the interfaith council, the association of hospitals and health systems, AARP, and/or the regional health-education center.
- **Be flexible.** Small group discussions can be held in a variety of venues. Conversations can center

on reactions to ON OUR OWN TERMS, to books or articles that explore end-of-life issues, or to personal experiences with the death of a friend or family member.

- **Find a group leader.** Discussions might be facilitated by a professional or volunteer skilled in dealing with grief and bereavement. Check with a local hospice, healthcare institution, social-service agency, or study group for names of potential discussion leaders.
- **Decide on a format.** There are many options for discussion groups. The program can be developed as a daylong or weekend retreat, or as a series of two-hour events over a period of weeks or months.

## Handout Materials

ON OUR OWN TERMS Discussion Guide (See “Discussion Guide Advance Request Form”)

## Resources

**(See “Resources for Further Learning and Training” for Details and Contacts)**

- *Caring Conversations*  
Midwest Bioethics Center
- “Creating Conversations That Matter” section
- *A Guide for Recalling and Telling Your Life Story*  
The Hospice Foundation of America
- *Journey’s End — A Self-Exploration*  
Vermont Voices on Care of the Dying
- *Finding Your Own Way: A Guide for End-of-Life Medical Decisions*  
Sacramento Health Decisions
- *Critical Conditions Planning Guide*  
Georgia Health Decisions

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# Working with Faith Communities

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## Why

To motivate faith-based organizations in the community adopting a mission of educating their members and ministering to them on end-of-life issues.

Potential activities include sermons, study groups and small group discussions within the faith communities as well as an ongoing ministry to the dying and those who care for them.

## Goals

- Engage a broad cross-section of religious groups in ongoing education, outreach and ministry around end-of-life issues.
- Lay the groundwork for developing caring communities that support the dying and their families.
- Help individual members of faith communities prepare for their own deaths and care for loved ones as they die.
- Create a support group for the dying and their caregivers.
- Create a supportive environment for grieving families.

## Who Are the Change Agents?

- Members of faith communities
- Spiritually minded people who are not part of specific religious organizations
- Clergy
- Ministerial associations
- Church councils
- Chaplains and pastoral counselors
- Lay leaders
- Parish nurses

## When

As part of regularly scheduled worship and study, before and after broadcast of ON OUR OWN TERMS

## Where

- Anywhere people come together to worship
- Community centers
- Private homes

## Suggested Outreach Activities

To congregations:

- **Open the door.** Invite religious congregations in the area to participate in the ON OUR OWN TERMS outreach effort, both before and after the broadcast. Help congregants assess the need for an end-of-life ministry in their faith community.
- **Establish a task force.** Select a group of coalition members (e.g., physicians, nurses, hospice workers, and clergy) to collaborate with lay leaders, volunteers, family members, and terminally ill patients in holding end-of-life discussions at religious gatherings (See “Small Group Discussions”).
- **Encourage volunteerism.** Ask congregations to make a commitment that “no one in our community” will die alone. Set up a volunteer network to accomplish this goal. Volunteers also can provide a “night off” for caregivers, establish regular visitation schedules, create a “buddy” program, and/or introduce pets to the lonely.
- **Host a Compassion Sabbath.** Compassion Sabbath is an interfaith initiative to equip clergy and religious educators to address the spiritual and emotional needs of dying people and improve end-of-life care. The initiative is directed to and by faith community leaders. There are four parts to the model program: Conference for Clergy to educate faith community leaders in end-of-life care issues; Train the Trainer Workshops for pastoral associates and educators from each faith

community; Compassion Sabbath Weekend during which all participating communities dedicate liturgy and services, sermons and homilies, education and other programs to engaging and educating the entire congregation about end-of-life issues and ways to improve care of the dying in their faith community; and Follow-up Evaluation and ongoing educational programs.

To clergy and pastoral counselors:

- **Encourage physician-clergy interaction.** Physicians and clergy can form small groups to talk about the challenges involved in working with dying people and to share techniques (See “Action Idea: Healthcare Providers Training”).
- **Coach and mentor.** Use trained facilitators to coach and mentor clergy and to lead small group discussions about attitudes toward death. Prepare leaders to address question such as: Why do bad things happen to good people? How does an experience with death change one’s perspective on God? Why plan for death? Who should plan and why? What does planning entail?
- **Don’t forget the details.** Give clergy and counselors state-specific information on living wills, advance directives, durable powers of attorney, memorial/funeral-service planning, etc.

- **Harness the power of the pulpit.** Encourage clergy to preach sermons on end-of-life issues before or after ON OUR OWN TERMS airs.
- **Help people confronting death find solace and wisdom.** Use the Spiritual History to converse with congregants on their beliefs, hopes, and fears about dying and the spiritual resources they can use to cope with suffering. (See “Action Idea: Taking a Spiritual History”).

## Resources

### (See “Resources for Further Learning and Training” for Details and Contacts)

- *Clergy-to-Clergy: Helping You Minister to Those Confronting Illness, Death and Grief*
- *Compassion Sabbath*  
Midwest Bioethics Center
- *Deciding About Life’s End*  
Foundation for Interfaith Ministry
- “Action Idea: Taking a Spiritual History”

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# Workplace Outreach

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## Why

To help employers recognize and respond to employees' needs related to the end of life.

Nearly one out of three workers is currently involved in caring for an aging parent or relative. That percentage is projected to grow to 54% by the year 2010. Nevertheless, only 6% of employers offer a comprehensive program for workers struggling with elder care or grief after a death.

In a 1999 survey conducted by the Last Acts Campaign, approximately two-thirds of employee-benefit managers at 170 small, medium, and large companies expressed interest in employee education concerning end-of-life issues, in preparing managers to cope with death and grieving, and in creating supportive corporate cultures for employees who may be terminally ill or caring for someone with a critical illness. (This survey can be replicated locally. See "Resources" below.)

## Goals

- Increase the number of employers who are aware of how caregiving, grieving, and other end-of-life issues affect their employees and company productivity
- Spotlight model employers who are providing end-of-life-related services for their workers
- Encourage employers to provide benefits for grief counseling and bereavement, as well as time off when a loved one dies or is in need of special care
- Facilitate workplace seminars on topics such as:
  - The importance of advance directives, living wills, and healthcare proxies
  - Alternatives to nursing homes and the availability of long-term care and hospice care
  - How to have conversations with aging parents about finances and other tough issues

## Who Should Participate

- Human-resources managers
- CEOs of major corporations in the area
- Employee-assistance professionals
- Employees
- People who are having or recently had the caregiver experience

## When

Shortly before and after broadcast of ON OUR OWN TERMS

## Where

In the workplace:

- Employee lounges
- Cafeterias
- Conference rooms
- Auditoriums

## Suggested Outreach Activities

- **Get the word out.** Distribute statistics describing the current state of end-of-life care, information regarding model programs, and a Local Resource Directory to major employers in the region. Hold a one-day "summit" of business leaders to brief them on end-of-life issues and their impact in the workplace. Supply employers with information about ON OUR OWN TERMS, and ask them to post it where employees gather.
- **Recognize model programs.** Identify model employers and invite them to participate in a town meeting. Encourage all employers in the area to adopt the Last Acts Workplace Task Force Model Activities (see "Resources").

- **Promote training.** Encourage employers to offer training to managers, who often are the first people to hear about employee concerns about end-of-life issues and services.

## **Resources**

**(See “Resources for Further Learning and Training” for Details and Contacts)**

- *Last Acts Campaign Workplace Task Force Research Findings and Model Programs*  
Last Acts Workplace Task Force
- *Grief at Work: A Guide for Employees and Managers*  
American Hospice Foundation

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# Palliative-care Hotline for Physicians

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## Why

The Palliative-care Hotline for Physicians is staffed 24 hours a day, 365 days a year, by physicians who are board-certified in hospice and palliative medicine. Physicians calling the toll-free number speak to a staff member at an emergency medical service. The staff member then pages the palliative-care physician on call who will contact the initial doctor with advice on alleviating suffering. A backup physician is contacted if the on-call physician does not respond within 15 minutes.

## Goals

- Manage and reduce terminal patients' pain and other symptoms
- Provide healthcare professionals with the most up-to-date information on palliative care

## How to Establish a Palliative-care Hotline for Physicians

- **Secure financial support.** Identify a group interested in supporting the program — for example, the state medical society or Academy of Medicine. Identify a source of funding. Money will be needed for expenses such as outreach to physicians, mailings, and telephone costs.
- **Identify personnel.** Identify a source of volunteer doctors to handle the calls and establish an on-call schedule.
- **Create an operational plan.** Establish a system for answering calls.

- **Market the hotline.** Publicize the hotline with public-service announcements in medical-society newsletters and state licensing board newsletters. Distribute a flyer announcing the (easily memorized) hotline number for posting on staff bulletin boards on intensive-care units and in emergency rooms. Send a mailing to all medical-society members. Include a hotline sticker that can be posted on telephones or bulletin boards.

## Who Will Use the Hotline

- Physicians in general, especially:
  - Nursing-home medical directors
  - Intensive-care specialists
  - Emergency-medicine specialists
- Nurse Practitioners and other specially trained nurses

## When

Announce or launch the hotline at a meeting of a state or regional medical organization. Follow up with announcements and briefings at other medical meetings across the region covered by the hotline.

## Resources

### (See “Resources for Further Learning and Training” for Details and Contacts)

- Michael Gloth, M.D., hotline coordinator and chief of geriatrics at Union Memorial Hospital, Baltimore, MD, 410-554-2923; michael@helix.org
- *Last Acts Newsletter*  
Maryland Pioneers with Palliative Care Pain Hotline, Summer 1999

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# Supporting Bereavement Services in the Community

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## Why

To offer relevant bereavement information and support in a manner and time frame that fit individual needs and preferences.

Coping with the loss of a loved one or a coworker is a difficult and prolonged challenge. Grieving individuals, and their friends, colleagues, and professional caregivers can find help through community activities and support groups.

## Goals

- Raise awareness within the community about grieving and its impact on individuals, loved ones, family members, and colleagues
- Promote and encourage bereavement-support services within the community
- Provide information on and access to relevant reading materials, resource guides, training, conferences, and Web site addresses

## Who Should Participate

- Local volunteers and existing support groups
- Religious organizations
- Funeral-home directors
- School counselors
- Employee-assistance professionals
- Veterinarians who are often trained to help children deal with the loss of a pet

## When

On an ongoing basis, starting before or after broadcast of ON OUR OWN TERMS

## Where

- Places of worship
- Healthcare institutions
- Assisted-living complexes
- Workplaces
- Civic center
- Private homes
- Community-service organizations

## How to Initiate Bereavement Services

- Establish bereavement-support groups in a variety of settings (see Where above).
- Identify bereavement topics and share them with local discussion groups to encourage dialogue and generate interest in the bereavement process. Sample topics include:
  - How does one accept the death of a loved one and move forward?
  - How does one celebrate the life of a loved one?
  - When is the period of bereavement over?
- Mobilize end-of-life coalition members to facilitate training on grief counseling (see “Resources”).
- Encourage community groups to view the Hospice Foundation of America teleconference on grieving.
- National Bereavement Teleconference, April 26, 2000  
*Living with Grief: Children Adolescents and Loss*  
Hospice Foundation of America  
Considers child and adolescent loss, ways in which developmental level may affect responses to loss, and practical advice and intervention techniques that can be used to empower children and adolescents with effective coping skills.

Contact: 800-854-3402; [www.hospicefoundation.org](http://www.hospicefoundation.org)

- Create a support network for former caregivers to help them cope with their grief and move forward in their lives.

### Handout Materials

- ON OUR OWN TERMS Discussion Guide (see Discussion Guide Advance Request Form)
- ON OUR OWN TERMS Web companion piece at [www.thirteen.org/onourown/terms](http://www.thirteen.org/onourown/terms) or [www.pbs.org/onourown/terms](http://www.pbs.org/onourown/terms)
- Local Resource Directory

### Resources

#### (See “Resources for Further Learning and Training” for Details and Contacts)

- *Grief at Work: A Guide for Employees and Managers*  
*Grief at School, A Guide for Teachers and Counselors*  
*Grief and Faith: Spiritual Paths Through Loss*  
American Hospice Foundation. Contact: 202-223-0204; [www.americanhospice.org](http://www.americanhospice.org)

- Funeral Homes and Religious Organizations  
May provide not only services, burials and cremations, but also grief counseling. Bereavement and celebration of life services are offered up to one year after the burial or cremation.

- In Loving Memory National Conference, Labor Day week, September 2000  
Washington, DC  
A conference for bereaved parents who have suffered the death of their only child or all their children. In Loving Memory also publishes *In Bereavement*, a magazine of hope and healing as well as two newsletters: *Alice Alone*, for parents who are now childless, and *Largo*, for parents who have had more than one child die. Contact: In Loving Memory, 1416 Green Run Lane, Reston, VA 20190

- Journey of the Heart: A Healing Place in CyberSpace.

- *When the Caregiving Is Over: Helping Former Caregivers Move On*  
The National Family Caregivers Association  
A bereavement program for former caregivers. Contact: 800-896-2650; [www.nfcacares.org](http://www.nfcacares.org)

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# Healthcare Providers Training

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## Why

To assist professionals who regularly care for seriously ill patients in understanding the many issues involved in delivering quality care at the end of life.

Although many healthcare professionals are skilled in caring for the dying, most providers report that they have not received sufficient training on care at the end of life. Local institutions and other sponsors can assist them by offering continuing education courses and other vehicles for end-of-life training. Building end-of-life curricula into existing continuing education schedules is a logical place to start. In the spirit of communitywide learning, the sponsoring institutions will make courses available to healthcare providers from other institutions as well.

## Goals

- Train physicians, nurses, and other members of the healthcare team in end-of-life care, and provide them with successful models and tools
- Disseminate information on palliative care more broadly among the professional healthcare community
- Encourage on-going continuing-education courses in local institutions on end-of-life topics
- Support the professional community with resources and information on palliative care

## Who Are Potential Sponsors of Continuing Education?

- Healthcare institutions
- Medical and/or nursing societies
- Chapters of voluntary health agencies

## Who Are Potential Learners?

- Physicians who care for terminally and chronically ill patients and their families (especially oncologists, cardiologists, intensive-care teams, etc.)
- Nurses who care for terminally or chronically ill patients and their families
- Social workers, pastoral counselors, chaplains, psychologists, home-health aides, and other members of the palliative care team
- Hospice workers and volunteers

## When

Continuing education programs can follow broadcast of ON OUR OWN TERMS

## Where

- Hospitals
- Medical centers
- Nursing homes and other long-term care facilities
- Hospices
- Clinics

## Potential End-of-Life Curriculum Topics

- Communication: breaking bad news; triggering conversations about advance care planning, and patient and family member wishes, decision-making, etc.
- Pain and symptom management: dyspnea, skin breakdown, fatigue, etc.
- Definition of end-of-life care: definition of death, goals of care

- Psychological issues: depression, anxiety, fear, loneliness, grief
- Spiritual issues: abandonment, completion of tasks, acceptance, religious tasks and choices
- Family issues: grief and bereavement, informal caregiving (role and support), education, economic issues
- Social/demographic issues: interpersonal relationships with spouses/partners, family, and friends; gender, race, cultural, and economic issues
- Epidemiology: vital statistics
- Natural history: prognosis, time course, mode of death, symptoms
- Context of care: advance directives, options for end-of-life care, setting of care, referral to hospice
- Ethics, law, and policies: individual vs. organizational ethics, patient self-determination, withdrawal and withholding of life support
- Physician end-of-life responsibilities: pronouncement, autopsy, organ donation
- Roles of physicians/nurses/other healthcare providers: communication with patient and family, personal grief and bereavement, avoiding burn-out while staying compassionate

## Organizing Continuing Education

- **Seek “buy in.”** Contact the person in charge of continuing education at the local hospital(s)/medical center(s)/hospice(s)/medical society(s) to discuss adding end-of-life issues to the training roster.
- **Design the course.** Determine curriculum—considering need, previous continuing-education offerings and target audience(s). Locate speakers or provide speaker lists to the person in charge of continuing education (see Resources). Local medical/nursing/specialty societies also may have speaker recommendations. Determine who locally has participated in the American Medical Association’s EPEC training program.

- **Market the course.** If appropriate, send notification of courses to the healthcare community at large. Include information on the ON OUR OWN TERMS series with course materials. Use this opportunity to share information on outreach efforts and to identify potential new members for the community coalition.
- **Extend the reach.** Talk to medical librarians to suggest end-of-life resources for their collections.

## Resources

(See “Resources for Further Learning and Training” for Details and Contacts)

### MODELS, PROGRAMS, AND CURRICULA

- Education for Physicians in End-of-Life Care (EPEC) Project  
American Medical Association
- Medical College of Wisconsin Palliative Medicine Program Web Site
- Missoula Demonstration Project  
Pain as Fifth Vital Sign
- 20 Improvements in End of Life Care-Changes Clinicians Could Do Next Week
- VA Faculty Leaders Project for Improved Care at the End of Life
- VA Pain Management Initiative

### JOURNALS

- *Innovations in End-of-Life Care*
- *Journal of Pain and Symptom Management*
- *Journal of Palliative Medicine*
- *Journal of the American Geriatric Society*

### BOOKS

- *Approaching Death: Improving Care at the End of Life*  
Institute of Medicine, 1997
- *Oxford Textbook of Palliative Medicine (Second Edition)*  
Edited by Derek Doyle, Geoffrey W.C. Hanks and Neil MacDonald  
Oxford University Press, 1997

## GUIDELINES

- *American Pain Society's Quality Improvement Guidelines for the Treatment of Acute Pain and Cancer Pain*
- *Peaceful Death: Recommended Competencies and Curricular Guidelines for End-of-Life Nursing Care*
- *Precepts of Palliative Care* (for professionals)
- *The Primer of Palliative Care*
- *Model Guidelines for the Use of Controlled Substances for the Treatment of Pain*

## CONTINUING EDUCATION

- *EPEC Compendium of Hospice and Palliative Care Experiences*
- EPEC Speakers Bureau
- Project on Death in America Faculty Scholars Program

## WEB SITES

- *American Academy of Hospice and Palliative Medicine*  
[www.aahpm.org](http://www.aahpm.org)
- *Center to Improve Care of the Dying*  
[www.gwu.edu/~cid](http://www.gwu.edu/~cid)
- *Innovations in End-of-Life Care*  
[www.edc.org/lastacts](http://www.edc.org/lastacts)
- *Last Acts*  
[www.lastacts.org](http://www.lastacts.org)
- *Medical College of Wisconsin Palliative Medicine Program*  
[www.mcw.edu/pallmed](http://www.mcw.edu/pallmed)
- *Painlink*  
[www.edc.org/PainLink](http://www.edc.org/PainLink)
- *Project on Death in America (PDIA)*  
[www.soros.org/death](http://www.soros.org/death)
- *University of Wisconsin Pain and Policy Studies Group*  
[www.medsch.wisc.edu/painpolicy](http://www.medsch.wisc.edu/painpolicy)
- *VA Faculty Leaders Project for Improved Care at the End of Life*  
[www.va.gov/oa/flp](http://www.va.gov/oa/flp)
- *Choice in Dying*  
[www.choices.org](http://www.choices.org)

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# Taking a Spiritual History

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## Why

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.

Conversations about spiritual aspects of dying help not only the dying person but also everyone who cares for that person. Talking with a dying person about his or her beliefs, hopes, fears, and dreams can touch a caregiver deeply. The experience creates a keen awareness of a shared truth—the realization that all of us must face our own mortality and recognition of the fact that all of us are living with dying.

## Goals

- Give all people a tool that can be used to talk with their loved ones, their patients, and their congregants about spiritual beliefs and issues
- Engage all caregivers to focus not only on the physical and emotional aspects of dying but also on the spiritual
- Re-focus care of the dying on the spiritual dimension
- Encourage our culture to look at dying as part of a larger, natural spiritual journey
- Create a greater awareness of mortality long before an actual diagnosis of terminal illness, so that everyone can search for meaning and purpose in life and, perhaps, become more at peace with dying

## Who Can Do a Spiritual History

- Everyone in the community
- Physicians and others involved in providing care as well as clergy, family, caregivers

## When

People who have these conversations before they or their loved ones become ill often experience less anxiety near the end of life. Care providers who have these conversations with patients early in the treatment/care plan will find patients generally more responsive and cooperative. Also, decision-making is facilitated when healthcare providers are aware of patients' and families' spiritual beliefs.

## Where

- Private homes
- Medical centers and clinics
- Hospitals
- Nursing homes and other longterm care facilities

- Hospices
- Places of worship

## How to Take a Spiritual History

Taking a spiritual history is having a conversation with someone about what gives meaning and purpose to his or her life, about who that person is deep inside, and about how that person uses spiritual beliefs and resources to cope with suffering. Healthcare institutions can offer continuing-education courses on the importance and techniques of spiritual-history taking. Individual healthcare professionals can incorporate spiritual-history taking into their everyday practice. Clergy can use it to understand individual congregant's spiritual needs. Family members can use the spiritual history as a tool for opening conversation about their loved one's fears about death and hopes for life.

Here is a simple guide for having this conversation:

### F — Faith (Meaning/Beliefs)

In planning your care (or acting as your pastor, physician, nurse, etc.), it would help me to know what gives your life meaning.

### I — Importance/Influence

Help me understand how important this belief is in your life, and how it influences what you do.

### C — Community

Do you have a community with whom you share this source of meaning and who supports you?

### A — Address/Application

How would you want me (your doctor, nurse, pastor, spouse, etc.) to apply this information as I care for you?

## Resources

### (See “Resources for Further Learning and Training” for Details and Contacts)

- Puchalski, C.M., et al. “FICA: A Spiritual Assessment.” *Journal of Palliative Care*, 1999. (in preparation)
- *Assessing Spiritual Needs: A Guide for Caregivers*
- *Handbook for Mortals: Guidance for People Facing Serious Illness*
- *The Healer's Calling: A Spirituality for Physicians and Other Health Care Professionals*
- *The Grace in Dying: How We Are Transformed Spiritually as We Die*

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## More Outreach Suggestions

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- Distribute the ON OUR OWN TERMS Discussion Guide to coalition members to encourage older adults and their adult children to have face-to-face, values-laden, intra-family discussion about end-of-life care.
- Sponsor a completely online “town hall meeting,” conducted as a single live chat on your Web site about the broadcast of ON OUR OWN TERMS.
- Encourage study groups (religious or otherwise) to watch the series together and discuss it afterward. Urge them to develop a list of recommended activities that the study group might undertake to support dying members of their community.
- Distribute the Hospice Foundation of America’s publication *A Guide for Recalling and Telling Your Life Story* to use as a tool for getting older generations to talk about family values and how they wish to be remembered.
- Distribute *Five Wishes* or other state-specific advanced directives—a living will that includes not only one’s medical wishes but also one’s personal, emotional, and spiritual wishes—to members of the public, along with the *A Vision for Better Care at the End of Life* document.
- Contact senior centers and offer speakers to help encourage their members to discuss their roles as caregivers and the value of planning for their own and loved ones’ end-of-life care.
- Work with nursing homes and other longterm-care facilities to promote viewing of the series and to arrange discussions afterwards with either patients’ families or administrators.
- Work with your library: Ask the head librarian to post the American Library Association’s list of recommended readings on end-of-life issues. Sponsor a series of readings or discussions on great literature that has dealt with the many complexities of death.
- Encourage clergy to listen to the Hospice Foundation of America’s audiotape series *Clergy to*  
*Clergy: Helping You Minister to Help Those Confronting Illness, Death and Grief*. Urge them to bring up the issues identified in the audiotape series in their weekly sermons.
- Encourage faith communities to form discussion groups on information found about end-of-life issues in the Bible, Torah, Koran, Book of Mormon, and other traditions. Invite people of different religious perspectives.
- Encourage local employers to post information on the series in employee lunchrooms and on bulletin boards. Ask human-resource personnel to organize a brown-bag lunch with an invited speaker to discuss related work-life issues.
- Work with school administrators, the PTA, and school counselors to develop age-appropriate materials on the many end-of-life topics (e.g. losing a grandparent, a parent, a friend, or a pet) that affect children.
- Develop an intergenerational summit to discuss issues facing adults and children. Involve the schools and senior centers in your area.
- Organize and host reunions with community hospitals, hospices and nursing homes for the families of individuals who have died in their care. Ask them to write testimonials to share with others in your community.
- Set up a speaker’s bureau on end-of-life care in your community. Promote the speaker’s bureau to local civic groups and adult-education classes.
- Organize community associations, churches, and the local hospices to sign up volunteers to be on-call visitors to the sick and dying in their neighborhood. The goal might be to make sure no one dies alone in your community.

- Ask a community theater to produce a play like *Wit* that explores the topic of death and dying around the community outreach. Arrange for a post performance discussion with the actors to discuss their feelings portraying these scenes.
- Identify healthcare professionals to sit on panels in community meetings to discuss how to improve end-of-life care — e.g., have them develop a list of questions to ask one’s doctor, a check list for caregivers to monitor a patient’s pain control, when and how to ask for early referral to hospice, and how to talk with one’s doctor about one’s wishes.
- Join in urging governors or other state officials to proclaim the week of the broadcast as “ON OUR OWN TERMS Week.”
- Join in sponsoring a forum for policymakers — the forum could focus on the major public policy issues raised in the series — pain management, physician training, advance directives, reimbursement issues, longterm care, and other end-of-life topics.
- Join in asking the governor to publicly sign his/her advance directive — at a conference or press event.
- Help establish or join a work group to reform your state’s outside-the-hospital Do Not Resuscitate (DNR) policy by developing uniform physician orders, a uniform mechanism for identifying patients with DNR orders, and better protection for EMS providers, and educating physicians, EMS providers, and the public, so that people who do not want heroic measures are not subjected to them.
- Help organize briefing sessions with your governor, state-agency heads, and cabinet members on the status of end-of-life initiatives in your state, using your community assessment as a starting point.
- Help organize a “regulatory summit” convening state agencies and regulatory boards to discuss DNR and guardianship, advance-directive forms, coroner’s role, and definitions of palliative care.
- Help convene state medical, nursing, and pharmacy licensing-board executive directors to review regulatory consistency in end-of-life regulations. Work to enact a broad palliative-care policy that ensures protection for healthcare providers who follow accepted pain-management practices.