



# NewsLine

A publication of the National Hospice and Palliative Care Organization

Vol. 15, No. 3 • MARCH 2004

ISSN 1081-5678

## Reaching Out: Hospices Educate Communities on Advance Care Planning

*“Some of the most difficult, desperate, and painful situations I’ve seen have occurred when somebody is dying and there are differing opinions about how they should be cared for among the family. The lack of advance directives can lead to unresolved grief among family members. By contrast, advance care planning can eradicate questions, eliminate problems, and ensure that the patient’s wishes are carried out.”* — J. DONALD SCHUMACHER, PSY.D., NHPCO PRESIDENT AND CEO

Within the hospice and palliative care community, it’s a commonly stated principle, at times almost a mantra: Hospice is about improving end-of-life care for all people with life-limiting illness and their loved ones. Part and parcel of this is ensuring that the wishes and desires of hospice patients are articulated, respected, and followed. Advance care planning (ACP) is one of the most important ways that hospice patients can outline—for the legal record and for their families—

how they want to die, who will act on their behalf, and how they feel about life-extending measures.

Helping patients who do not have advance directives is a standard part of the hospice admissions process. In recent years, many hospices have broadened their work with advance directives, becoming educators and advocates within their communities on this important subject. This month, *NewsLine* highlights the work that hospices are doing in this regard and provides tips for developing or enhancing advance care planning outreach. We talked with five hospices of different sizes and from different parts of the country to provide input for this article.

### INSIDE

Spreading the Message.....	1
Advance Care Planning Resources .....	2
▶ Publications	
▶ Web Sites	
Choosing Resources.....	2
Partnering at the State Level.....	2
Cultural Outreach .....	3
Media Coverage.....	3
Sticky Wickets .....	3
Conclusion .....	4
Developing an Advance Care Planning Education/Outreach Plan .....	4
State Resource At a Glance .....	5
▶ Arizona Hospice and Palliative Care Organization (AHPCO)	
▶ California Hospice and Palliative Care Association (CHAPCA)	
▶ Colorado Hospice Organization (CHO)	
▶ Florida Hospices and Palliative Care	
▶ Idaho State Hospice Organization	
▶ Illinois Hospice and Palliative Care Organization (IL-HPCO)	
▶ Indiana Hospice and Palliative Care Organization (IHPCO)	
▶ Kansas Hospice and Palliative Care Association	
▶ Kentucky Association of Hospice and Palliative Care (KAHPC)	
▶ Michigan Hospice and Palliative Care Organization (MHPCO)	
▶ Hospice Minnesota	
▶ Nebraska Hospice and Palliative Care Association	
▶ Carolinas Center for Hospice and Palliative Care	
▶ North Dakota Hospice Organization	
▶ Ohio Hospice and Palliative Care Organization (OHPCO)	
▶ Oregon Hospice Association (OHA)	
▶ The Hospice Organization and Palliative Experts of Wisconsin (HOPE)	
Advance Care Planning Glossary .....	8

### Spreading the Message

For many hospices, advance care planning outreach begins by considering the most effective ways to reach consumers. A direct approach takes advance care planning directly to consumers, often seniors, in settings such as senior recreation centers, public libraries, and churches. Hospice staff or volunteers often come into these venues and provide free educational seminars that explain advance directives, provide forms and literature, and sometimes even assist consumers in filling out their own directives. **Cedar Valley Hospice** (Waterloo, IA) proactively sends information to churches, senior centers, and other facilities outlining topics for presentations, including advance care planning, that it offers.

This spring, as part of its consumer outreach efforts, the **Center for Hospice and Palliative Care** (Cheektowaga, NY) will conduct a series of presentations on hospice and advance care planning at a Baptist Church on the lower east side of Buffalo with which it is collaborating on the development of a residential facility. Two years ago, the Center also successfully partnered with a local PBS station to get the word out. The hospice was able to have Bill Moyers tape a short PSA—aired following Moyers’ *On Our Own Terms* program—that referred viewers to the hospice for more information. More than 10,000 ACP brochures were sent out in response to the PSA.

*(Cover story continues on page 2)*

(Continued from page 1)

## Reaching Out: Hospices Educate Communities on Advance Care Planning

Another common approach is to reach consumers through medical or legal professionals. Physicians, hospital social workers, and other medical professionals are well positioned to introduce the subject of advance care

directives because they interact with patients well before hospice does. Hospices working with these professionals hope to make advance directives a standard part of a doctor's or social worker's information sharing with patients. **Hospice Care** (Arthurdale, WV) conducts in-service education within hospitals and schools of social work, nursing, and medicine at local universities. "Our approach has been to actively engage those individuals who come into contact with consumers," says Ron Hicks, social services manager at Hospice Care. The hospice also was part of a pilot program to promote the state's Physician Orders for Scope of Treatment (POST) form, which is designed to complement advance directives.

Many hospices develop a combined approach through which they not only engage directly with consumers, but also educate and inform medical and legal professionals. For instance, when **Hospice of Iredell County** (Mooresville, NC) began its advance planning outreach, it organized a coalition that reflected the makeup and needs of the community.

The hospice targeted hospitals, nursing homes, libraries, community colleges, potential employees, and lawyer and physician groups. The hospice utilizes staff, as well as attorneys and physicians who volunteer their time, to do advance planning presentations in the community. The hospice makes sure that everyone on the ACP team uses the same resources and presentation, but each also is free to speak from their own discipline or expertise. Several of the doctors on the team have attended EPEC training, and the attorneys have worked with the hospice in the past, helping patients with legal paperwork.

### Choosing Resources

Hospices must decide whether to develop their own materials to guide people through the advance care planning process, use guides that already have been developed, or work with a combination of materials—recognizing that materials may resonate differently with various groups of people. There is no "right" approach.

Cedar Valley Hospice developed its own printed brochure, as well as a PowerPoint presentation that is used by speakers at presentations. The Center for Hospice and Palliative Care also uses its own materials and PowerPoint presentation, but, in addition, features advance directives prominently on its Web site. Included in the Center's Web guides are sections on appointing a health care proxy, creating a living will, understanding New York State law, and updating advance directives, as well as downloadable health care proxy and living will forms. Hospice Care uses its own guide, *Walking Through the Valley*, as well as another resource, *Hard Choices for Loving People: CPR, Artificial Feeding, Comfort Care, and the Patient with a Life-Threatening Illness*, a book by Hank Dunn.

Hospice of Iredell County has opted to use *Isn't It Time We Talk?*—a comprehensive guide to advance care planning developed by The Carolinas Center for Hospice and End-of-Life Care. The hospice's Web site also features a list of Web links to organizations that offer advance care planning guides or health care proxy and power of attorney forms. VITAS Innovative Hospice Care uses the *Five Wishes* guide, a tool developed by Aging With Dignity. Maureen Hamlinger, VITAS bereavement coordinator, likes the *Five Wishes* tool because it calls for a values statements and spells out interventions. "It's like giving someone a piece of your mind," she says.

### Partnering at the State Level

Many state hospice and palliative care organizations offer resources and guidance to hospices seeking to develop their advance care planning outreach (see sidebar, "State Resources At a Glance"). Additionally, the National Association of

## Advance Care Planning Resources

### PUBLICATIONS:

- ❖ **Caring Conversations**, Midwest Bioethics Center, [www.midbio.org](http://www.midbio.org)
- ❖ **Five Wishes**, Aging with Dignity, [www.agingwithdignity.org](http://www.agingwithdignity.org)
- ❖ **Isn't It Time We Talk?** The Carolinas Center for Hospice and End-of-Life Care, [www.carolinasendoflifecare.org](http://www.carolinasendoflifecare.org)
- ❖ **Respecting Choices**, Advance Care Planning Guide and Health Care Power of Attorney Form, Gundersen Lutheran Medical Foundation, [www.gundluth.org](http://www.gundluth.org)

### WEB SITES:

- ❖ **Aging with Dignity** – [www.agingwithdignity.org](http://www.agingwithdignity.org)
- ❖ **American Geriatrics Society** – [www.americangeriatrics.org](http://www.americangeriatrics.org)
- ❖ **Education for Physicians on End-of-Life Care (EPEC)** – [www.epec.net](http://www.epec.net)
- ❖ **End-of-Life Nursing Education Consortium Project (End of Life Care information for nurses)** – [www.aacn.nche.edu/elneec](http://www.aacn.nche.edu/elneec)
- ❖ **National Association of Attorneys General (NAAG)**– [www.naag.org](http://www.naag.org)
- ❖ **Midwest Bioethics Center** – [www.midbio.org](http://www.midbio.org)
- ❖ **Partnership for Caring** – [www.partnershipforcaring.org](http://www.partnershipforcaring.org)

(Cover story continues on next page)

Attorneys General (NAAG) has been working to bring end-of-life care to the fore. Through past president Drew Edmondson's *Improving End-of-Life Care* initiative, NAAG conducted a series of listening conferences (in which Don Schumacher participated—see July and October 2003 *NewsLines*), raised public awareness of end-of-life care and advance directives, and made NAAG's Web site ([www.naag.org](http://www.naag.org)) a resource on statewide end-of-life care initiatives. In some cases, these state initiatives are led by state hospice and palliative care organizations. In other cases, they are made up of health care, legal, and community groups working together to improve access to end-of-life care. Both the state hospice organizations and the state end-of-life initiatives are excellent resources for hospices embarking on—or seeking to improve—advance care planning outreach.

### Cultural Outreach

Because different cultures approach and plan for death differently, it's important for hospices to ensure that their advance directive outreach is tailored for different populations. Where there are language differences, it helps to have materials written in other languages. VITAS uses the *Five Wishes* guide in Spanish for its Hispanic patients and their families. They also have Spanish-speaking professionals on staff who can help those patients with the advance planning process.

Understanding how cultures approach dying also can help target advance care planning outreach. For instance, many hospices, like The Center for Hospice and Palliative Care, partner with church communities when educating African Americans about advance directives because that population places great store on the support received from their local congregations. In working with families in Appalachia, Hospice Care has had to widen the circle for information sharing because of the large extended families in these communities. Hospice staff often find themselves explaining hospice care and advance care planning to immediate family as well as nephews, nieces, and more distant relatives. *NewsLine* will address these cultural issues in greater depth in future stories on access and diversity.

### Media Coverage

In the last two decades, there have been several cases, most recently that of Terry Schiavo in Florida, where the lack of advance directives has led to a media frenzy, court orders, and anguish and strife for the patient's family. These unfortunate circumstances offer an opportunity for hospices to remind the public, through media and public outreach, that everyone

needs an advance directive. This has been NHPCO's approach at the national level in response to the Schiavo case, as well as others that have occurred over the years.

### Sticky Wickets

Even when a patient comes to hospice with an advance directive, sometimes there are situations that present a challenge with regard to ensuring the patient's wishes are carried out. "Advance directives are only a communication tool—sometimes inadequate to address a given situation not clearly covered in the document, sometimes an occasion of conflict among family members and interested parties, and sometimes ignored by care providers," says Kramlinger of VITAS. "The likelihood advance directives will be executed as the person intends is supported by clarity in the document, values context of the person, and the conviction and resourcefulness on the part of the person appointed to ensure they're executed." Kramlinger further recommends having the patient add a values statement—"a bit of the person's mind and heart and way of approaching things"—to provide guidance to the health care proxy in the event a situation arises not clearly covered by details of the advance directives.

Kramlinger encourages hospices to think through and be prepared to address the following situations:

- ◆ How to proceed in the face of family conflict—when one family member threatens to sue the physician if he or she executes the clear advance directives;
- ◆ How to deal with a doctor who forges ahead with his or her plan of care counter to contents of advance directives; and
- ◆ How to deal with care facility administration that accuses family of "killing the patient" if they withdraw hydration/nutrition.

Kramlinger also recommends that, in their advance directive training, hospices teach families how to ask for full disclosure of pros and cons if an intervention is proposed or initiated. She tells of one woman who described how a hospital called at 2 a.m. and said they wanted to put her husband on a ventilator to "help him rest and regain strength because he was struggling to breathe." "What the hospital staff didn't tell her was this wouldn't just be temporary," says Kramlinger. "The woman told me, 'My husband had very clear advance directives. He didn't want to be kept alive on a ventilator. They never told me that once he went on he would never be able to come off. I never would have agreed to start the ventilator if they told me that. I would have let him go without putting him through another ordeal.'"

*(Cover story continues on page 4)*

(Continued from page 3)

## Reaching Out: Hospices Educate Communities on Advance Care Planning

“Hospices, in their advance directive outreach, can play an important role in translating medical terminology and jargon so that the average person can understand both the definitions and the implications of certain decisions,” says Schumacher. Hicks of Hospice Care agrees: “It’s not uncommon to have someone say that he wants to have CPR but does not want to be placed on a ventilator, without realizing that one comes with the other.” Hicks says hospice staff do a line-by-line explanation, pointing out potential risks and benefits of each action. This helps patients see how a medical procedure that a patient may want can lead to other procedures they oppose.

### Conclusion

The benefits of today’s advance care planning outreach may not be seen in the near future. Nevertheless, hospices have recognized the value of reaching out to educate their communities on this important issue. Such outreach is an excellent community service, providing visibility for hospice and empowering consumers to begin thinking about an important, albeit difficult, topic. Hick sums it up: “Our goal in educating health care professionals and the public is to get patients to a place, where, after all is said and done, there are no ‘could haves,’ ‘would haves,’ or ‘should haves.’”

## Developing an Advance Care Planning Education/Outreach Plan

*The following are steps to creating an advance care planning education and outreach plan.*

*Please note these steps are not necessarily in order or all-inclusive.*

- 1. Determine your “target audience”** — Identify specific populations to educate or reach out to and places and opportunities to reach them. Identify partners in the community to support and promote your campaign and distribute materials. Examples include:
  - a. Faith communities
  - b. Workplaces
  - c. Community organizations
  - d. Senior living and other residential communities
  - e. Schools
  - f. Physician office and hospital staff.
- 2. Seek funding** to pay for your campaign. Funding sources include small, one-time grants; corporate or community sponsorship; underwriting from managed care companies, health systems or other health care organizations; and donations or reimbursement for forms, educational programming, or other community services.
- 3. Obtain or develop advance directive tools.** Determine whether or not to provide one or more different advance care planning tools/forms. Be sure to provide culturally appropriate tools and resources.
- 4. Develop or identify an educational presentation** that you can adapt based on length of presentation or the audience. Schedule presentations during or in conjunction with existing meetings.
- 5. Conduct a community presentation** on ethics at the end of life. Presenters or panelists can include an ethicist, physician, faith leader, and attorney.
- 6. Develop or modify existing outreach tools**, including:
  - a. Bulletin boards or posters to display information. Include business reply cards people can mail to request advance care planning materials.
  - b. Flyers promoting your educational sessions.
  - c. Bookmarks promoting the benefits of advance care planning and a phone number to receive more information. Bookmarks are relatively inexpensive, and many libraries and bookstores will help distribute them for you.
  - d. A “camera-ready” advertisement for community papers, employee newsletters, faith community bulletins, etc.
  - e. A family discussion guide that people can use to start conversations about advance care planning.
  - f. A resource to teach people how to talk to their physician about their end-of-life wishes.
- 7. Host events** such as informational sessions, lunch-and-learns, or town hall meetings where people can learn more about advance care planning, ask questions, and obtain advance care planning tools.
- 8. Train advance care planning volunteers** to be available in physician offices, clinics, and hospitals to answer basic questions about advance care planning.
- 9. Evaluate your outreach campaign.** Develop a system to track the number of calls, inquiries, and attendees at events or presentations to determine the number of lives you reached during your campaign.

(Cover story continues on next page)

## State Resource At A Glance

Here is an overview of what some state hospice organizations are doing in advance care planning outreach.



ARIZONA HOSPICE AND PALLIATIVE CARE ORGANIZATION (AHPCO)

WWW.ARIZONAHOSPICE.ORG

AHPCO has been very active in Caring Choices, Arizona's coalition to improve end-of-life care. The coalition has a task group specifically geared to getting the word out on advance directives and creating a single state repository for those directives. The state organization also gets the word out via public speaking and handing out samples of the attorney general's generic forms.



CALIFORNIA HOSPICE AND PALLIATIVE CARE ASSOCIATION (CHAPCA)

WWW.CALHOSPICE.ORG

CHAPCA has worked in three areas related to advance care planning, all of them directed toward consumers. First, the organization partnered with AARP two years ago to sponsor community forums. Second, as part of its yearlong partnership with Radio Bilingue, it did several radio programs last year in Spanish on advance care planning. Third, CHAPCA provides advance planning forms (in English and Spanish) to consumers upon request.



COLORADO HOSPICE ORGANIZATION (CHO)

WWW.COLORADOHOSPICE.ORG

CHO is the statewide representative for Rallying Points, and many of the local coalitions in Colorado are working on various projects to promote advance care planning. CHO collaborates with the coalitions to share what has worked well in one coalition with the others. CHO also is taking the lead in creating a new collaborative, inclusive, end-of-life care organization to fill many of the current gaps in Colorado's end-of-life care system. Advance care planning is one of the specific projects under discussion as work for this new organization.



FLORIDA HOSPICES AND PALLIATIVE CARE

WWW.FLORIDAHOSPICES.ORG

In September 1999, Florida Hospices and Palliative Care successfully lobbied the governor to declare a "Day of Decision" encouraging Floridians to talk about and document their end-of-life care wishes. Hospices in Florida were provided with a community presentation that could be used to educate consumers and providers about advance care planning. The Florida Partnership for End-of-Life Care in conjunction with the Florida Department of Elder Affairs (DOEA) developed a free resource on advance care planning and end-of-life issues entitled *Making Choices: Beginning to Plan for End-of-Life Care*. The document is available in English and Spanish on the DOEA Web site. <http://elderaffairs.state.fl.us/doea/english/LMD/EOL/EOL.pdf>



IDAHO STATE HOSPICE ORGANIZATION (ISHO)

WWW.HOSPICEIDAHO.ORG

The state organization has started an end-of-life coalition together with three other organizations, and one of the coalition's key projects is education on advance directives. The coalition also is working with the Idaho State Attorney General's office on these issues and will be part of the Idaho Governor's Conference on Aging in September.



ILLINOIS HOSPICE AND PALLIATIVE CARE ORGANIZATION (IL-HPCO)

WWW.ISHO.ORG

IL-HPCO has developed a public engagement campaign, *Say You Care: Start the Conversation*. This multi-element campaign includes a speakers bureau training manual, a video on starting the conversation, packets of information for consumers, a planning workshop, fact sheets on a variety of topics, wallet cards for advance directive information, conversation starter cards, and a brochure on family caregiving. IL-HPCO presented information on the campaign at the state conference.



INDIANA HOSPICE AND PALLIATIVE CARE ORGANIZATION (IHPCO)

WWW.IHPCO.ORG

IHPCO uses the same *Say You Care* campaign as IL-HPCO. In addition, they developed a Larry Bird public service announcement on "starting the conversation" and a special training manual and workshop, *Starting the Conversation with your Congregations*. IHPCO also uses a portable exhibit on *Say You Care* and have exhibited at aging conferences, health fairs, and state fairs. IHPCO presented information on the campaign at regional and state organization meetings.

(Cover story continues on page 6)

### State Resource At A Glance (cont.)

#### KANSAS HOSPICE AND PALLIATIVE CARE ASSOCIATION

The state association works with the other partners of the Kansas LIFE Project in a major campaign called *Advance Care Planning: Do it for those you love!* The state organization offers materials, a speaker's bureau, and workshops, as well as "train the trainer" sessions throughout the state.

#### KENTUCKY ASSOCIATION OF HOSPICE AND PALLIATIVE CARE (KAHPC)

[WWW.KAH.ORG](http://WWW.KAH.ORG)



KAHPC has added an educational offering at its spring symposium on advance care planning and is gaining input from the social worker peer group on interest for a two-day workshop. A workshop on this topic was held at Hospice of the Bluegrass in Lexington that social workers from around the state attended.



#### MICHIGAN HOSPICE AND PALLIATIVE CARE ORGANIZATION (MHPCO)

[WWW.MIHOSPICE.ORG](http://WWW.MIHOSPICE.ORG)

MHPCO has produced a booklet, *Caring Choices*, which describes advance directive in light of choices to be made. Every three years, MHPCO, in collaboration with the Department of Community Health, helps develop an end-of-life behavior risk factor survey, which provides information on how well people understand and utilize advance directives. The organization also has worked with the state Elder Law Association to encourage all attorneys who do estate planning to also do advance directives at the same time with their clients. MHPCO is developing a community tool kit for end-of-life decision making that will be rolled out to communities that are interested in educating their own people. This model is based on the research findings from MHPCO's study on educating underserved populations on end-of-life care.

#### HOSPICE MINNESOTA

[WWW.MNHOSPICE.ORG](http://WWW.MNHOSPICE.ORG)



In 2001, Hospice Minnesota developed a community education program, *Conversations That Matter*, part of which focuses on advance care planning. The organization gave *Conversations* training manuals to its 74 provider members and held regional training on how to present and market the program. The state organization also holds its own *Conversations* educational programs in libraries, senior centers, community education programs, and congregations at least once a month. It also offers a four-credit course for social workers on advance care planning each month at different locations around the state. Usually one of the state hospice provider members helps with the workshops.

#### NEBRASKA HOSPICE AND PALLIATIVE CARE ASSOCIATION

The Nebraska state organization currently is seeking funding to address advance care planning at the state level. In its recently released *2004 Nebraska End-of-Life Survey Report*, the top priority that emerged from the survey responses of Nebraskans was to "encourage end-of-life conversations and decision making in advance." Nebraska has been active in helping local end-of-life coalitions develop across the state and is working to provide training to the staffs of Nebraska's Area Agencies on Aging. Such training would include discussion of advance care planning and how those staff members can provide assistance in this area with those they serve.



#### CAROLINAS CENTER FOR HOSPICE AND END-OF-LIFE CARE

[WWW.CAROLINASENDOFLIFECARE.ORG](http://WWW.CAROLINASENDOFLIFECARE.ORG)

The Carolinas Center has a public engagement program for advance care planning using materials it developed called *Isn't It Time We Talk?* For the past three years, working with grant funding and The Carolinas Center resources, it has developed and implemented a two-state network of trained instructors in the *Respecting Choices*™ Advance Care Planning Training model. Currently, it has 105 certified instructors in North and South Carolina. These instructors, over the past three years, have conducted 93 training sessions for 1,236 advance care planning facilitators.

## State Resource At A Glance (cont.)

The facilitators now develop and produce programs locally for their communities in a wide variety of settings: faith-based, hospitals, other health care entities, local bar associations, industry, etc. Since the *Isn't It Time We Talk?* materials have been produced, 16,000 discussion guides, 42,000 advance care planning guides, and 27,000 brochures have been distributed in the two states. Other activities to support advance care planning and end-of-life discussions among citizens are conducted by its End-of-Life Coalition Program. The Carolinas Center has supported the development of 35 end-of-life coalitions in North Carolina and 14 end-of-life coalitions in South Carolina. These coalitions are a "grass roots" effort to bring together hospitals, hospice programs, and many other community stakeholders to engage in a cultural change around end-of-life care.

### NORTH DAKOTA HOSPICE ORGANIZATION

As part of the Robert Wood Johnson State Initiative Grant received in 1999, the North Dakota hospice organizations worked with the grant project steering committee to develop an advance care planning resource guide/advance directive document for use across the state. This document has helped to bring consistency across the state with use of the same advance care planning document by all hospice programs, as well as other health care providers.

### OHIO HOSPICE AND PALLIATIVE CARE ORGANIZATION (OHPCO)

[WWW.OHPCO.ORG](http://WWW.OHPCO.ORG)



OHPCO is the lead agency in the Light the Way Campaign, which strives to educate the public about advance directives. The state organization will release a new resource on ACP this spring as well as a companion document to its advance directives packet. The campaign has enabled OHPCO to provide templates, resources, and Web site access to agencies and to the general public. OHPCO also provides facilitator and educator training, through the *Respecting Choices* program, for end-of-life care coalitions across the state.



### OREGON HOSPICE ASSOCIATION (OHA)

[WWW.OREGONHOSPICE.ORG](http://WWW.OREGONHOSPICE.ORG)

OHA has been very involved in advance planning, participating, since its inception, in the Physician Orders for Life-Sustaining Treatment (POLST) task force, which converts advance directives into doctors orders for those who are nearing the end of life. Hospices throughout Oregon have been very involved in their communities in encouraging adoption of the POLST. The POLST is unique in that it gives patients options regarding DNRs, CPR, ventilators, antibiotics, comfort care only, and other topics, and is used and respected across all settings. OHA does many presentations on advance directives, directed primarily at those people (younger individuals) where a POLST would be inappropriate. Oregon's Death With Dignity Act has almost ensured that medical professionals are interested in end-of-life care, so anything addressing this topic generates interest.

### THE HOSPICE ORGANIZATION AND PALLIATIVE EXPERTS OF WISCONSIN (HOPE)

[WWW.WISCONSINHOSPICE.ORG](http://WWW.WISCONSINHOSPICE.ORG)



HOPE supported the development of end-of-life coalitions in the state as an offshoot of Bill Moyers *On Our Own Terms* series. Many Wisconsin hospices took the initiative in their areas to develop coalitions, and now there are now 14 in the state. In 2002, HOPE developed special materials to accompany a PBS special on caregiving, *And Thou Shalt Honor*, and the coalitions helped promote them. In June 2003, HOPE convened a meeting of all of the coalitions with Dr. Bud Hammes, founder of the *Respecting Choices* Advance Care Planning Model<sup>SM</sup>, and now about half of the coalitions are having people trained in that model. In October 2003, HOPE brought Bill Colby to Wisconsin to do presentations on advance care planning and his experience with the Nancy Cruzan case in Milwaukee, Madison, and at the UW Law School.

(Cover story continues on page 8)



## Advance Care Planning Glossary

Definitions were adapted from the National Hospice and Palliative Care Organization's Standards of Practice as well as other sources, such as National Association of Insurance Commissioners.

### Active Treatment

Potentially life-prolonging treatments.

### Advance Care Planning

The ongoing process of structured discussion and documentation of health care decision making that involves the patient, preferably with consultation with his or her physician and support of a family member or friend appointed by the patient as proxy decision-maker.

### Advance Directive

An instruction such as a durable power of attorney for health care, a directive pursuant to patient self-determination initiatives, a living will, or an oral directive that states either a person's choices for medical treatment or, in the event the person is unable to make treatment choices, designates who will make those decisions.

### Bereavement Care

Services provided to help patients, families, and caregivers cope with the losses occurring during the illness and death.

### Caregiver

Any person, compensated or uncompensated, designated to provide emotional support and/or physical care to a hospice patient.

### Chronic Illness

An illness with one or more of the following characteristics: permanency; residual disability; requires rehabilitation training; or requires a long period of supervision, observation, or care.

### Comfort Care

Care that relieves pain and suffering and controls debilitating symptoms but does not prevent dying. This includes:

- ◆ Administration of medications or other treatments such as radiation to relieve pain;
- ◆ Administration of medications for anxiety, constipation, breathing difficulty, and other symptoms;
- ◆ Provision of personal care such as bathing and turning;
- ◆ Provision of emotional and spiritual support to the dying person, family and friends; and
- ◆ Administration of other treatments that enhance comfort.

### Do Not Intubate (DNI)

A physician's order not to pass a tube into a patient's windpipe to facilitate breathing. Intubation includes use of an artificial breathing machine called a ventilator.

### Do Not Resuscitate (DNR) Orders

Orders written by the patient's physician which stipulate that cardiopulmonary resuscitation

will not be initiated or performed in the event the patient has a cardiac or respiratory arrest.

### End-of-life Care

Medical care and supportive services that an individual with an advanced disease receives in the last phase of life.

### Family

Individuals related by ties of blood, legal status, or affection and who consider themselves a family unit. For the purposes of these standards, this can include other inmates.

### Health Care Agent/Proxy

The person designated in a health care directive to make decisions for a patient if the patient lacks decision-making capacity.

### Holistic Care

Care that focuses on the individual's physical symptoms and the emotional and spiritual concerns of the patient and family.

### Hospice

A philosophy of care for people who are dying that emphasizes comfort over cure. Hospice care is available in a wide variety of settings including the home, hospitals, nursing homes, and residential hospices. Hospice care is provided by an interdisciplinary team of health care professionals who:

- ◆ *Attend to the physical, emotional, and spiritual needs of the patient and family;*
- ◆ *Have expertise in pain and symptom management; and*
- ◆ *Follow up with grief support services for the family.*

**Informed Consent**

A process in which information that specifies the type of care to be provided, and the potential and actual risks and benefits of a given type of care, is exchanged between the program and the patient. Based on this information, the patient agrees in writing to the care offered by the program.

**Interdisciplinary Team (IDT)**

Representatives of disciplines involved in the patient’s care, including physician, nurse, counselor, chaplain, and others as needed.

**Interdisciplinary Team Meetings**

Regularly scheduled, periodic meetings of specific members of the interdisciplinary team to review and confer about the most current patient and family assessment, evaluate care needs, and update the plan of care.

**Medical Power of Attorney**

Another name for a health care agent. A medical power of attorney has authority to make medical decisions. This is not the same as a power of attorney for property or financial matters.

**Mental Health Representative**

Social worker, counselor, psychologist or other professional with responsibility for mental health consultation or referrals.

**Palliative Care**

Physical, emotional, and spiritual treatment that enhances comfort and improves the quality of an individual’s life during the last phase of life.

**Patient**

A person receiving palliative care services.

**Patient/Family as Unit of Care**

A philosophy that asserts that the impact of terminal illness on both the patient and family is acknowledged and the patient’s and family’s needs are considered in developing the plan of care.

**Plan of Care**

An individualized plan, based on patient needs and preferences, that identifies services to be provided.

**Psychosocial Support**

Activities designed to meet the psychological and social needs of the patient.

**Program’s Leaders**

Individuals who are charged with the responsibility of implementing the end-of-life care program’s mission, vision, goals, and strategic plans.

**Qualified**

A person with the required education, training, and experience to meet job-specific legal and licensing requirements who demonstrates the sensitivity to address the unique needs of the patient and family.

**Respite Care**

Care provided by a third party that relieves family caregivers for a few hours to several days and gives them an occasional break from daily caregiving responsibilities.

**Team Coordinator**

A qualified health care professional responsible for coordination of assessment, planning, and implementation of the plan of care by the interdisciplinary team.

**Terminal Illness**

An illness that usually results in death within one year after diagnosis or as a progression in the course of the disease, in the opinion of a qualified medical professional.

**Volunteer**

A person trained by the program who provides services to the program or its patients without commensurate monetary compensation. Volunteers shall be carefully selected and screened. ■